



Recognition and Management of Medical Complexity

Dennis Z. Kuo, MD, MHS, FAAP, Amy J. Houtrow, MD, PhD, MPH, FAAP, COUNCIL ON CHILDREN WITH DISABILITIES

Children with medical complexity have extensive needs for health services, experience functional limitations, and are high resource utilizers. Addressing the needs of this population to achieve high-value health care requires optimizing care within the medical home and medical neighborhood. Opportunities exist for health care providers, payers, and policy makers to develop strategies to enhance care delivery and to decrease costs. Important outcomes include decreasing unplanned hospital admissions, decreasing emergency department use, ensuring access to health services, limiting out-of-pocket expenses for families, and improving patient and family experiences, quality of life, and satisfaction with care. This report describes the population of children with medical complexity and provides strategies to optimize medical and health outcomes.

INTRODUCTION

Children with medical complexity (CMC), who may also be known as “complex chronic”¹ or “medically complex,”² have multiple significant chronic health problems that affect multiple organ systems and result in functional limitations, high health care need or utilization, and often the need for or use of medical technology.^{3,4} An example of a child with medical complexity is one with a genetic syndrome with an associated congenital heart defect, difficulty with swallowing, cerebral palsy, and a urologic condition. This child would typically require the care of a primary care physician; multiple pediatric medical subspecialists or pediatric surgical specialists, home nurses, and rehabilitative and habilitative therapists; community-based services; extensive pharmaceutical therapies; special attention to his or her nutritional needs and growth; and durable medical equipment to maintain health, maximize development, and promote function.³

Children and youth with special health care needs (CYSHCN), who require health and related services for a chronic physical, developmental, behavioral, or emotional condition beyond what is typically required for children,⁵ have long been designated as a priority population of interest

abstract

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DOI: 10.1542/peds.2016-3021

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The authors have indicated they do not have a financial relationship relevant to this article to disclose.

FUNDED: No external funding.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

To cite: Kuo DZ, Houtrow AJ, AAP COUNCIL ON CHILDREN WITH DISABILITIES. Recognition and Management of Medical Complexity. *Pediatrics*. 2016;138(6):e20163021

for health care policy.⁶ CMC, a subset of CYSHCN because of their extensive and costly health care use, are increasingly recognized as requiring additional and specific consideration from physicians, payers, and policy makers. Approximately 1% of children, most of whom are CMC, account for up to one-third of overall health care spending for children,⁷⁻⁹ an increasing percentage of pediatric hospitalizations,¹⁰⁻¹² and recurrent hospital admissions.¹³ Evidence suggests that CMC have among the highest risk of all children for adverse medical, developmental, psychosocial, and family outcomes.¹⁴

The Department of Health and Human Services issued the “Strategic Framework on Multiple Chronic Conditions” in 2010,¹⁵ emphasizing health systems change, empowering individuals, equipping clinicians with best practices, and enhancing research. In the adult health care system, selected actions include the formation of new integrated care models, clinical practice guidelines, education and training initiatives, and additional funding mechanisms for patient-centered outcomes research focusing on multiple chronic conditions.¹⁶ Optimal care of CMC should be similarly framed, with the medical home as the foundation of an integrated care system. Most important, acknowledging and incorporating the life experiences of children, youth, and their families into the framework of understanding complexity strengthen its applicability and center the discussion on the child instead of the health care system that serves the child.

In this report, suggestions are provided for physicians, payers, and policy makers to address the growing population of CMC. The overarching goals for optimal health care for CMC are to (1) maximize health, function, development, and family functioning through coordinated patient- and family-centered care

(PFCC) and (2) provide proactive, rather than reactive, care so that critical medical and health events are averted to the extent possible. The prospective identification of CMC, proper and timely management of health care delivery, supports for self-management, and appropriate resource allocation are necessary to achieve a coordinated health care system that provides better health care, smarter use of health care dollars, higher family satisfaction, and healthier CMC.¹⁷

RECOGNIZING MEDICAL COMPLEXITY

Medical complexity is conceptually regarded as a combination of multiorgan system involvement from chronic health condition(s), functional limitations, ongoing use of medical technology, and high resource need/use.^{3,18} However, different constructs of complexity may exist at the individual as well as the population level, which makes consistent and reliable recognition of complexity difficult. Clinicians may subjectively identify complexity on the basis of consequences of medical and/or behavioral conditions, social context, or family stressors that influence health, relevant items that may not be available in population-level data sources.¹⁹ Because no consensus yet exists on recognizing complexity on the population level, multiple tools, such as a diagnosis classification scheme and a questionnaire, may be needed to recognize the multiple attributes of complexity.¹⁹ Limiting the construct of complexity to high health care resource use or multiple diagnosed medical conditions that are easily identified through administrative records, without considering associated social or functional issues, may hamper the development of resources and policies needed to address complexity. In addition, such an approach does not embrace PFCC principles of incorporating

the preferences, experiences, and psychosocial needs of the family.

CMC have functional limitations, specifically, limitations in their ability to do the things typically developing children of the same age can do in their day-to-day lives. The limitations experienced may be temporary or may result in permanent disability. Functional limitations are best understood by using the framework of the World Health Organization’s *International Classification of Functioning, Disability, and Health* (ICF).²⁰

According to the ICF framework, when a specific body system or body part’s functioning is affected, the person has an impairment; when the person’s total functioning is affected such that he or she has difficulty or is unable to perform tasks (eg, walking and dressing), the person has an activity limitation; and when the person is unable to fully engage in life events, he or she has a participation restriction.^{20,21} For example, CMC who are unable to attend school because of their health have participation restrictions. The experience of functional limitations (or in ICF language, disability) goes beyond health status and results from the interaction of specific health conditions with environmental and personal contextual factors, such as health service use, aspects of the home and community environments, and access to resources.^{21,22} Understanding the needs of CMC includes the consideration of such contextual factors.

CMC often rely on medical technology and/or ongoing supportive services for their health and well-being. This reliance on supportive care for vital functioning is why CMC, as a group, are sometimes referred to as medically fragile. The term “medically fragile” refers to continual needs for skilled services that support basic life functions necessary for survival.^{23,24} When designating complexity, it is important to recognize that parents

and extended family members often shoulder much of the responsibility for providing such skilled care because of the round-the-clock health care needs and limited resources from the health care financing system to support in-home services.²⁵ “Technology dependence” usually means that the child requires technology to compensate for the loss of a vital body function.²⁶ Examples of technologies include supplemental oxygen, ventilators, dialysis machines, and gastrostomy tubes. A child might also be “technology assisted” if he or she uses augmentative communication or assistive devices (eg, a wheelchair for mobility) that compensate for lost functions that are not essential for survival. “Technology assisted,” as opposed to “technology dependent,” is a more inclusive term and highlights the value of these technologies to help children function optimally in their day-to-day lives. The presence of either medical fragility or technology dependency/assistance alone does not constitute complexity, but both can be important components of complexity.

PFCC AS THE FOUNDATION OF THE HEALTH CARE SYSTEM

PFCC is a fundamental component of a high-performing, coordinated health care system.²⁷ Given the intersection of family-identified needs, child functioning, and the framework of medical complexity, PFCC should be the foundation of the health care system for CMC. With PFCC, the family is understood to be the child’s primary strength and support,²⁸ and families are full and equal partners in shared decision-making.²⁹ PFCC has the potential to raise patient satisfaction and streamline care.³⁰ However, operationalizing PFCC in health care is frequently misinterpreted as patient education, patient engagement, or delegating excess responsibility and decision-making

to families.²⁹ The effective delivery of PFCC may require a shift in culture from the traditional physician-patient paradigm, leading to a collaborative partnership with shared decision-making that directly addresses family needs. In fact, such a shift has begun to take place. Ensuring that each person and family are engaged as partners in the care of CMC is 1 of 6 priorities on which the National Quality Strategy is focusing to improve health and health care quality.^{27,31}

Families of CMC describe the need for effective and timely medical care, assistance with care coordination among multiple providers to improve communication between providers, decreasing duplicative services and the need for unnecessary travel and appointments, the support of multiple community-based therapists, improved access to specialized community services, and assistance with significant financial and psychological burdens. Families know how complex their circumstances are, as articulated in the care map drawn by the mother of a child with medical complexity in Fig 1. Families also report feeling abandoned by providers with the expectation that they must navigate the health care delivery system by themselves, which many families perceive to be unrealistic.^{32–34} Caregivers of CMC report a median of 2 hours per week providing care coordination and >11 hours a week providing direct home care.⁴ Families report having to simultaneously manage the technical aspects of care, the additional parenting responsibilities, and the challenges of navigating the maze of health care services, all while having to juggle competing family needs.³⁴

The numerous and complex medical care services that CMC require lead to the highest unmet family-reported needs of all children, with nearly 50% of families reporting at least 1 unmet need.^{4, 35–38} Commonly reported

unmet needs include limited access to medical subspecialty, dental, and mental health care providers and a lack of help navigating the care system.^{32,39–43} More than half of families of CMC report having to stop working for pay, and 57% report having financial problems.⁴ In addition, 39.4% report being very dissatisfied with medical services.⁴ For CYSHCN in general, physicians already routinely underestimate the family needs for community referrals, access to care, psychological services, respite, and interpersonal communication^{44–46}; the situation is likely much worse for CMC.

THE MEDICAL HOME CONCEPT AS THE FOUNDATION FOR CARE OF CMC

The medical home, whose foundation lies in community-based care for CYSHCN, serves as the standard of care for all children, including CMC.⁴⁷ In 2002, the American Academy of Pediatrics reiterated that the medical home ensures that care is accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.⁴⁸ In 2007, multiple medical societies affirmed the principles of the patient-centered medical home (PCMH). The PCMH Joint Principles state that the PCMH is “an approach to providing comprehensive primary care for children, youth and adults” and emphasize the importance of quality, safety, and appropriate payments at the practice level. The PCMH has become a cornerstone for health care payment reforms within the Affordable Care Act by establishing financial incentives for expanded primary care–based services.⁴⁹

Effective care for CMC requires a comprehensive level of care that is seamless, accessible, and integrated for the child and family, with the medical home as the foundation. A comprehensive approach to care within a medical home may benefit

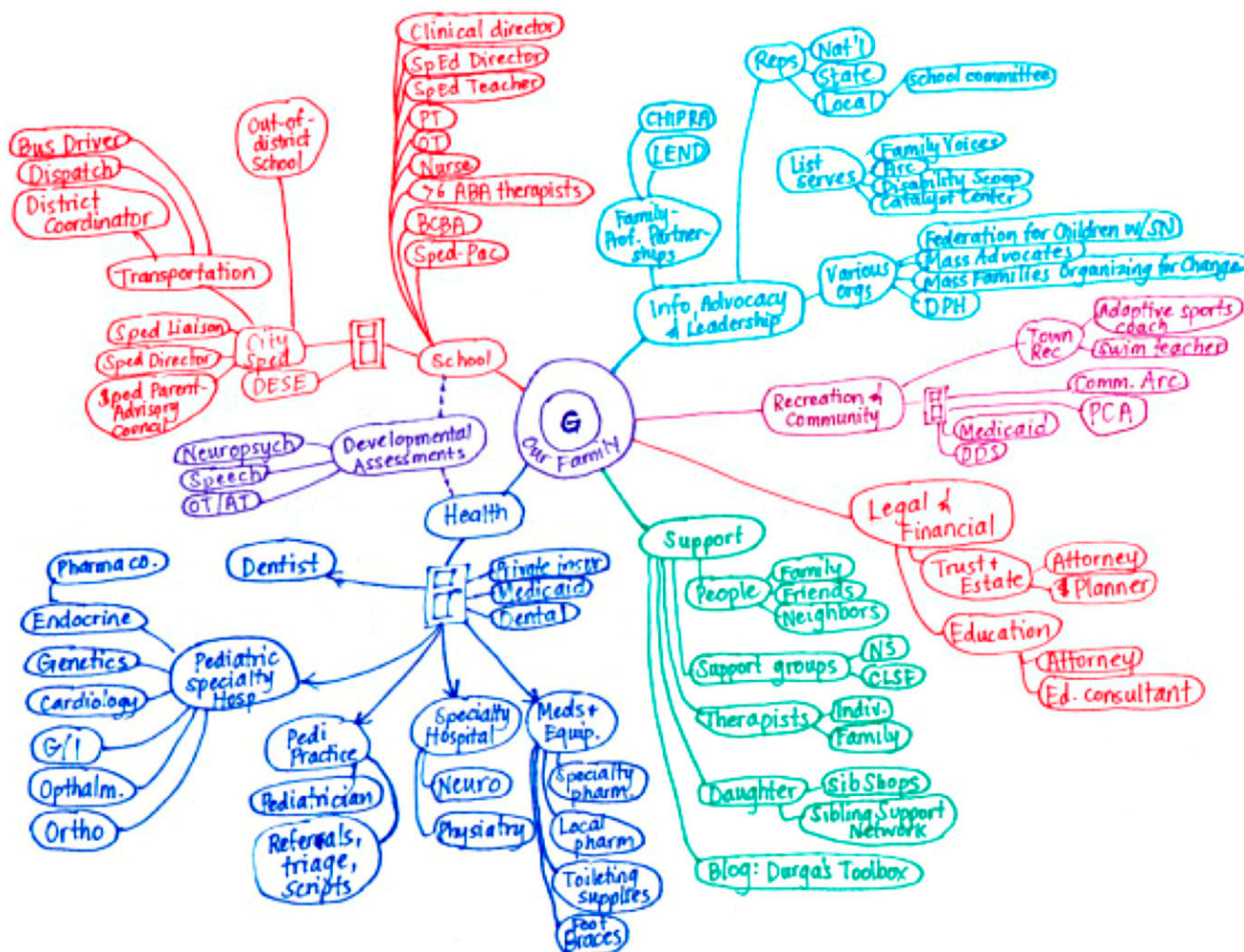


FIGURE 1

Care map created by the mother of a child with medical complexity to pictorially represent aspects of her child's life. Reprinted with permission by Cristin Lind.

CMC who have more severe needs compared with those who have less severe needs⁵⁰ but also may be harder to achieve. The medical home also is only 1 key component of care within a larger system of care for CMC.^{51,52} Extensive health care needs of CMC have led to calls for a "medical neighborhood" (or "health neighborhood") with service integration, through cooperative agreements, among health care providers.⁵³ The medical neighborhood is built on the "collaborative care agreement," which is a comanagement agreement that delineates roles and expectations for a child's health care across disciplines. The

medical neighborhood conceptually links the primary care setting with community-based services and medical subspecialists in tertiary care settings and emphasizes appropriate transfer of information and accountability.^{54,55} This arrangement between providers may be especially important as CMC transition home after an inpatient stay for surgery or illness. Some institutions have specialized transition services dedicated to this process.

Despite the surge of emphasis on the primary care-based medical home as part of health care reform, 1 recent study found that two-fifths of CMC with Medicaid insurance did not see their primary care physician in the

previous 12 months.⁵⁶ Primary care physicians have expressed limited desire to take on more children with special needs because of the time investment and limited capacity,^{57,58} and in a recent study, just under half of pediatricians surveyed across the United States reported that the subspecialty setting may be best equipped to provide a medical home to CMC.⁵⁹ Barriers to community-based primary care medical homes include a lack of care coordination skills, training, payment, time, adequate staffing, and system navigation. The primary care physician may need a higher level of medical expertise and staffing

support that is not readily available in many practice settings.

Primary care practices that serve as the medical home for CMC will often require practice transformation in staffing and clinical training, in addition to supportive changes at the system and payer level. Effective practice transformation requires the formation of practice-based quality-improvement teams, team-based care delivery that provides care coordination, and delivery of family-centered care with parents as improvement partners, all of which require substantial time and financial investment.^{60,61} Existing research on comprehensive care in the primary care setting has generally focused on a limited number of medical conditions instead of the multiple chronic conditions found in CMC,⁶² although the multiple studies of specific conditions do provide some guidance to the model of team-based care.

Ideally, the medical home concept would incorporate, in the medical neighborhood style, the extensive tertiary care services that CMC require, because CMC receive far more care in the tertiary care setting than in the primary care setting.⁵⁶ Tertiary care delivery settings range from individual specialty services, a service dedicated to a unifying condition such as cystic fibrosis, to “complex care” clinics dedicated to CMC that provide care coordinators, specific expertise to medically manage complex care, and team-based interdisciplinary services.⁶³ Compared with the traditional primary care setting, hospital-based complex care clinics may be better positioned to provide the care coordination and medical expertise that CMC require and, in some cases, may be the best option to be the medical home.^{64,65} Some complex care clinics may not assume the responsibility of primary care, but rather coordinate and collocate the most essential specialty services

related to the underlying conditions while comanaging with primary care. Three before-and-after studies of such services, 2 of which are comanagement consultative services and the third providing primary care, suggest overall financial savings through decreased emergency department and inpatient utilization,^{66–68} while acknowledging that payment models are insufficient to cover the costs of the services provided.⁶⁶ A randomized controlled trial of “enhanced” primary care, with collocation of specialty and comprehensive services, found significant reductions in serious illnesses, emergency department and inpatient admissions, and Medicaid payments.⁶⁹ Although these models are promising, they are limited to the enrolled population, and some families do not live close enough to the tertiary children’s hospital setting to take full advantage of available services. In such situations, many families also express a preference to have their care closer to home.⁷⁰ This preference underscores the important role of the community-based physician as part of an integrated care model for CMC.

BUILDING THE IDEAL MODEL OF CARE DELIVERY FOR CMC

The ideal family-centered model of care for CMC builds on the foundation of the medical home concept. The medical home, in turn, fosters family-provider-community partnerships that support an integrated, community-based system of care.⁷¹ The model of care should, first and foremost, identify and address the needs of the child and the family (including respite care, family support groups, educational support, and advocacy for resources) while simultaneously taking into account their strengths and assets. The provider should actively engage in shared decision-making with patients and families to define goals, solve problems, and plan

care.⁷² Families of CMC desire that the various parts of the health care system (primary and subspecialty care, dental care, emergency care, home-nursing services, and multiple supportive components such as physical therapy, community mental health, and school-based services) work as an integrated whole. The system of care for CMC would include components of the National Consensus Framework for Systems of Care for CYSHCN, published by the Association of Maternal and Child Health Programs. In this framework, the components of a unified system of care include the following: (1) family-professional partnerships, (2) medical home, (3) insurance and financing, (4) early and continuous screening and referral, (5) easy-to-use services and supports, (6) transition to adulthood, and (7) cultural competence.⁷³

Individual primary care practices should be supported, when desired, as the foundation of longitudinal, comprehensive care for CMC. Families are best supported when providers have high continuity and a thorough knowledge of the child and family, including their attitudes, beliefs, and values related to health and health care.⁷⁴ These care components are inherent to good primary care^{75,76} and may be best delivered from the communities where CMC reside. Adequate financial support, dedicated resources (eg, community health workers, interpreter services), staff training, and delineation of care roles within the broader integrated care system with seamless communication between providers are required to support primary care practices in this role of medical home provider. Key care aspects include a designated staff person who acts as a care coordinator who is the identified contact for CMC and their families, as well as a personal physician who is able to perform the medical functions of the medical

home. Staffing ideally accounts for adequate and appropriately trained personnel resources to support non-face-to-face care necessary in population management of CMC. Optimal care coordination requires enhancing the caregiving capabilities of families while addressing multiple domains of health care, psychosocial, and educational needs to achieve health and wellness.^{77,78} Effective care coordination, in turn, is associated with favorable family-provider relations and family-child outcomes.^{78,79}

The medical home is an ideal setting from which to address the educational needs of CMC who are at high risk of missed school days because of illness. Families often need the assistance of the medical home while they navigate the Individualized Education Program or 504 plans at school.⁸⁰ The medical home should provide medical information that will help the school develop programming, including physical, occupational, and speech therapy, to meet the child's needs in the least restrictive environment.^{81,82} Most CMC can attend school successfully with appropriate supports, but in circumstances in which the child is unable to attend school, the medical home should be highly engaged to ensure non-school-based instruction and a return to school when medically appropriate.⁸³

Pediatric medical subspecialty care is vital to the care of CMC, and many pediatric medical subspecialists are located in tertiary care centers. Regardless of where CMC receive their care, all care should be coordinated through a single provider who acts as the designated care-coordinating entity. As described previously, care coordination may be through the primary care physician, although in certain situations, a complex care service located within the hospital setting may manage or comanage the child with medical complexity

and act as the designated medical home.⁶⁵ Such an agreement may be fluid, depending on immediate need. When feasible, dedicated support, education, and communication from the pediatric medical subspecialist and tertiary care center to the community-based provider can reduce the number of visits necessary to the tertiary care center, increase adherence to the care plan, raise satisfaction for families, and decrease costs through reduced tertiary care center utilization.^{50,84–87} Regardless of the setting, CMC should have periodic scheduled contact with the medical home as part of the care plan to prospectively address growth and nutrition, health maintenance and preventive care (including dental care), developmental and psychosocial needs, family functioning, medical management of underlying chronic conditions, long-term planning and palliative care (if appropriate), and early and timely intervention in the case of an adverse event. For children who receive home health services, the health maintenance visit is one of the best times to review the accuracy of home health orders, which must be signed at regular intervals.

The ideal medical home setting will have a registry of CMC to help the care team proactively identify CMC as well as support care coordination activities and functions for CMC care.^{78,88} Considerations for empanelment in a registry should include a combination of diagnoses and an assessment of functional needs and supports, family-identified needs, and risk factors putting the child/youth at risk of poor outcomes. Leeway should be provided for designation in the registry, given a lack of standardized methods to identify environmental and psychosocial determinants of complexity.¹⁹ Families should have continuous access to connect by phone, via telehealth, or through secure online

access to a knowledgeable provider to discuss health care needs of the child or be seen when an urgent situation arises. A key primary contact may be a care coordinator, in addition to the medical home provider, who is familiar with the child and family as well as the medical history and care needs. The key care team members are ideally available at all times on all days for consultations in case of emergencies and able to bridge communication between the primary care practice, specialty practice, and the emergency providers. In addition, the practice should be able to address the needs of and effectively communicate with families from diverse backgrounds. Care is negatively affected when language barriers exist⁸⁹; therefore, as the population becomes more diverse, extra efforts should be made to enhance communication with appropriate interpreter services.

Care templates and care plans (available in the report "Achieving a Shared Plan of Care With Children and Youth With Special Health Care Needs: An Implementation Guide" from the Lucile Packard Foundation at http://www.lpfch.org/sites/default/files/field/publications/achieving_a_shared_plan_of_care_implementation.pdf and the National Center for Medical Home Implementation site at <https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Practices.aspx>) are important adjuncts for effective comanagement.⁹⁰ The care plan should be jointly developed and maintained and implemented by the family and the provider responsible for overall coordination of care. The care plan may consist of a summary of medical needs, care providers, and goals outlined with families. A section of the care plan should address emergency care needs.⁹¹ Care plans can also provide all parties, but particularly parents and caregivers, with a level partner relationship.⁹² Electronic care plans integrated into

an electronic health record have the potential to facilitate sharing between providers and families, particularly when coupled with patient/family portals. The care plan should be available in real-time and across care settings electronically as an up-to-date document.

The 2001 Institute of Medicine report “Crossing the Quality Chasm” emphasizes the ongoing challenge of achieving the full potential of health care delivery and the systemic and organizational barriers that can impede consistent delivery of effective health care.²⁷ Accordingly, providers and practices caring for CMC should participate in quality-improvement initiatives to improve the consistency and quality of care that is provided to CMC. Quality measures for CMC can be obtained from a combination of chart review, patient surveys, and practice surveys and may include domains from primary care, PFCC, chronic care, care coordination, and health care transition.⁹³ Process measures specific to a care team may include the quality of care transitions between providers, reason for referral, the ongoing relationship between the referring primary care provider and pediatric medical subspecialist, and action steps incorporated into a collaborative care plan. Considerations for outcome measures include unplanned hospitalizations, readmissions, emergency department visits, and total costs of care. Other important outcomes include perceived ease of use of health care services, family experience of care, reduction in duplicate/unnecessary testing/laboratory tests, minimization of work loss for caregivers, and child functional status and quality of life. Some measures may rely on the achievement of specific health goals, such as improving respiratory function, optimizing nutrition, or maximizing community participation

through the use of adaptive technologies and equipment.

CMC are at particular risk of adverse outcomes during the transition from pediatric to adult health care.⁹⁴ Transition planning based on the unique needs of the individual child with medical complexity should be addressed beginning by the early adolescent years so that the process is seamless and the youth does not experience a gap in health care.⁹⁵ Areas of importance include self-management, to the extent possible; optimal health and functioning; and tools necessary to navigate the health care system. A handoff between pediatric and adult providers should be arranged at the appropriate time.⁹⁵ The high prevalence of neurodevelopmental disabilities, coupled with the myriad service needs, may restrict the opportunity for independent living and raise guardianship and service issues that should be addressed proactively. A transdisciplinary model approach may be needed to fully facilitate the transition process, which often takes longer for CMC than for children without medical complexity.⁹⁶

Pediatric residency training that focuses on caring for CMC may be helpful to prepare for the additional tasks required as the medical home provider for CMC.^{97,98} Residency and postgraduate training should focus on medical care issues that are common to many CMC, including growth, nutrition and feeding, respiratory health, technology management, home health order approvals, atypical development and disability, and psychosocial assessments.⁹⁸ Not only should training focus on the attributes of care that are condition specific, but it also should emphasize the whole-child approach with attention to how conditions interact with environmental and personal modifiers, as framed by the ICF and the medical home neighborhood.

PAYMENT AND POLICY CONSIDERATIONS

New and innovative systems of payment for CMC, if properly designed, may represent an important opportunity to support the ideal model of care, improve health, and address costs for this population and, because of their outsized effect on health care costs, for the pediatric population in general. Opportunities for health care system savings may be enhanced through reducing potentially preventable, costly emergency/hospital-based care.⁵⁶ Payment reform challenges also stem from the high level of services and payments that are incurred. Hospitals may see a loss in revenue if CMC use fewer inpatient services, even while health systems see savings. However, current payment models for CMC under a fee-for-service system for many outpatient-based physicians generally have not covered the cost of providing care, especially when care involves active care coordination and other nonbillable services.⁶⁶ Psychosocial assessment and management, care plan development, communication between providers, reconciliation of home health care plans and nursing/durable equipment orders, transition between settings, and 24/7 access by specific, knowledgeable providers are key labor-intensive activities that are crucial to effective health care management of CMC. These services require appropriate compensation under any payment model.

Appropriate compensation for delivered services may entail raising fee-for-service payments, compensation for non-face-to-face activities, and upfront payments for care management by clinical and nonclinical staff. Current Procedural Technology codes have set up the infrastructure for billing for a variety of non-face-to-face services. In recent years, this area has seen an expansion of codes and services covered under those codes. Refer to

coding resources from the American Academy of Pediatrics' "Coding for Medical Home Visits" and "Coding for Telehealth Services" for more details on what codes can be reported and associated values.

State Medicaid agencies are important providers of insurance coverage for many CMC. Payment initiatives, such as Health Homes from the Affordable Care Act,⁹⁹ and the rise of accountable care organizations offer the opportunity to design new care systems to meet the needs of CMC, potentially in collaboration with Medicaid agencies. CMC may be considered separately in payment models from children without medical complexity because of differing utilization patterns, such as significantly higher specialty care and mental health, and inpatient care needs.^{56,100} In some cases, CMC may remain in traditional fee-for-service programs; in other cases, they are considered for managed-care models that may include bundled payments or fully capitated plans with assumption of risk. This movement has occurred because of outsized costs of care for CMC and the perceived difficulty for primary care physicians to be responsible for overall care. The assumption is that making an organization responsible for the totality of care for a given population will result in appropriate spending, reduced overall costs, and improved quality.^{101,102} A national demonstration project across multiple children's hospitals is testing care planning and coordination interventions while developing a population-based payment model to support the interventions.¹⁰³ Proposed national legislation would create a national care model and accompanying payment reforms for CMC that would be centered in tertiary care children's hospitals.¹⁰⁴ On the state level, Texas is rolling out the STAR Kids program, a Medicaid managed-care program that enrolls children with disabilities

identified by Supplemental Security Income, with individual service assessments, plans, and accompanying benefits.¹⁰⁵ Challenges include the accurate identification of CMC, risk stratification, and setting appropriate payment rates that may underestimate actual need on the basis of previous outpatient claims. The longitudinal cost trajectory of CMC or the rate of return on investment remains poorly defined, along with approaches of care management that may result in improved health and cost savings for CMC as a whole or for specific subgroups of CMC.^{56,106}

CONCLUSIONS AND RECOMMENDATIONS

To support the movement for additional health care reform and service delivery enhancements specifically for CMC, the following recommendations are offered.

Pediatricians and Other Pediatric Health Care Providers

- Pediatricians are encouraged to be familiar with the concepts of the medical home, particularly as they apply to CMC, including practice-based patient registries, interdisciplinary team-based care, care planning, care coordination, and care templates, and to have a familiarity with common clinical challenges such as nutrition and respiratory and technology needs.
- Pediatricians may strive to ensure that CMC have a medical home that provides team-based comprehensive care. Ideally, there would be a clearly identified provider who will be the "go to" person for comprehensive care needs who, unless otherwise stated, should be the primary care physician, as per the family's expectation.
- Pediatricians can consider assessing their practice's willingness and capability to support care for CMC.
- Pediatricians may consider prospectively identifying CMC and including them in a practice registry for comprehensive management of health care needs. Pediatricians may use a combination of methods, such as review of billing data, resource use, family survey, or chart review. Identifying criteria may consider administrative data, survey data, and/or clinical assessments.¹⁹
- Pediatricians who deliver primary care in the community setting may consider augmenting their care through comanagement with providers within the tertiary care setting who may provide additional medical home/neighborhood supports. It is advised to explicitly define the locus of management and specific care roles.⁶⁵
- Pediatricians should document and bill appropriately for complexity management and both face-to-face and non-face-to-face time for medical management and care-coordination services.
- Pediatricians are encouraged to recognize, identify, advocate for, and partner with community-based services, such as schools, therapists, and home health and family-support services, with appropriate referrals. Communication tools available may include a written or electronic care plan and the use of a dedicated care coordinator who serves as the point of contact for home nursing, school feeding, or other supportive services.
- When possible, pediatricians across the care setting, including hospitalists and pediatric medical subspecialists, can use appropriate tools to facilitate care planning, real-time communication with families and all providers, and transitions between hospital and home, community resources, and

pediatric to adult settings. Such tools and mechanisms may include electronic care plans, secure messaging, electronic registries, or telehealth mechanisms, with defined electronic interoperability and communication mechanisms with the child's identified care team members.

- Pediatricians may consider the use of quality-improvement process and outcome measures and value capture tools to evaluate and improve care coordination and care management.

Payer

- Payers should provide adequate incentives for community-based providers to accept and manage CMC. Such methods may be tied to emerging quality metrics and financial incentives specific to CMC who are identified in panels of primary care providers.
- Payers should recognize the value of non-face-to-face encounters and care management that are crucial to health outcomes for CMC. For CMC in particular, payers should pay at appropriate levels for care coordination, including telephone management, telehealth, home-health and equipment documentation, population registry formation, and comanagement of CMC. In some cases, payers may consider providing the care coordination for CMC that works in partnership with the community-based medical home.
- Payers need to recognize current care management codes for CMC to allow all CMC to receive care that can be paid to all primary care physicians, without the potentially financially burdensome technology requirements.
- Payers should account for the presence and management of CMC under different payment models. Under fee-for-service models, non-face-to-face encounters

should be adequately reimbursed; under a capitated plan, appropriate care management fees should be provided with appropriate risk-adjustment strategies that account for varying levels of severity and need. Care should be taken to avoid narrow provider networks that may discriminate against patients with complex care needs.¹⁰⁷

- Given the current levels of evidence, population-based payment models that support integrated care systems for CMC, incorporating a range of community-based, primary care, and hospital services, should be developed and implemented in partnership with provider and community stakeholders that continually monitor and evaluate payment levels and outcomes.

Policy

- CMC should be recognized as a distinct population of interest for policy, research, and payment reform agendas. Policy strategies applied to adults with complex conditions may not adequately service CMC who need specific attention to their unique needs.
- Residency, postgraduate, and continuing education may consider standardized learning modules and curricula specific to the management of CMC, including nutrition, development and function, care coordination, technology management, telehealth, coordinated handoffs, and PFCC. Similar considerations can be made for interprofessional training (eg, nursing, social work, community health worker, behavioral health professionals) that is essential for care coordination and integration.
- Quality measures relevant and specific to CMC should be developed and applied across systems. Such measures should be specific to children. Quality metrics

should consider child functioning, utilization (preventable emergency department and hospital encounters), and patient- and family-centered metrics (growth, parent stress, employment).

- National and state policies should require adequate health insurance and payment for medically necessary services for CMC while minimizing out-of-pocket costs, which are often barriers to needed care.
- Research agendas should drive a consensus definition of which children constitute the cohort of CMC and then address the accurate identification of CMC for population management, development and assessment of evidence-based models of care, the impact value of PFCC, the impact on health status of CMC, and the financial effect of the previous factors. Metrics should focus on health care quality, psychosocial needs, and investments in outpatient care delivery to assess the value of care delivery provided, managed, or coordinated in the medical home that may mitigate potentially preventable inpatient and emergency department use for nonurgent care.

LEAD AUTHORS

Dennis Z. Kuo, MD, MHS, FAAP

Amy J. Houtrow, MD, PhD, MPH, FAAP

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STAFF

Stephanie Mucha, MPH

ABBREVIATIONS

CMC: children with medical complexity
CYSHCN: children and youth with special health care needs
ICF: *International Classification of Functioning, Disability, and Health*
PCMH: patient-centered medical home
PFCC: patient- and family-centered care

REFERENCES

1. Feudtner C, Christakis DA, Connell FA. Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington State, 1980-1997. *Pediatrics*. 2000;106(1 pt 2):205-209
2. Srivastava R, Stone BL, Murphy NA. Hospitalist care of the medically complex child. *Pediatr Clin North Am*. 2005;52(4):1165-1187
3. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529-538
4. Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. *Arch Pediatr Adolesc Med*. 2011;165(11):1020-1026
5. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1 pt 1):137-140
6. US Department of Health and Human Services. *Children with special health care needs. Campaign '87. Surgeon General's Report. Commitment to: Family-Centered, Community-Based, Coordinated Care*. Rockville, MD: US Department of Health and Human Services; 1987
7. Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttman A. Patterns and costs of health care use of children with medical complexity. *Pediatrics*. 2012;130(6). Available at: www.pediatrics.org/cgi/content/full/130/6/e1463
8. Neff JM, Sharp VL, Muldoon J, Graham J, Myers K. Profile of medical charges for children by health status group and severity level in a Washington State Health Plan. *Health Serv Res*. 2004;39(1):73-89
9. Kuo DZ, Melguizo-Castro M, Goudie A, Nick TG, Robbins JM, Casey PH. Variation in child health care utilization by medical complexity. *Matern Child Health J*. 2015;19(1):40-48
10. Burns KH, Casey PH, Lyle RE, Bird TM, Fussell JJ, Robbins JM. Increasing prevalence of medically complex children in US hospitals. *Pediatrics*. 2010;126(4):638-646
11. Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics*. 2010;126(4):647-655
12. Berry JG, Hall M, Hall DE, et al. Inpatient growth and resource use in 28 children's hospitals: a longitudinal, multi-institutional study. *JAMA Pediatr*. 2013;167(2):170-177
13. Berry JG, Hall DE, Kuo DZ, et al. Hospital utilization and characteristics of patients experiencing recurrent readmissions within children's hospitals. *JAMA*. 2011;305(7):682-690
14. Bramlett MD, Read D, Bethell C, Blumberg SJ. Differentiating subgroups of children with special health care needs by health status and complexity of health care needs. *Matern Child Health J*. 2009;13(2):151-163
15. US Department of Health and Human Services. *Multiple Chronic Conditions — A Strategic Framework: Optimum Health and Quality of Life for Individuals With Multiple Chronic Conditions*. Washington, DC: Department of Health and Human Services; 2010
16. Parekh AK, Kronick R, Tavenner M. Optimizing health for persons with multiple chronic conditions. *JAMA*. 2014;312(12):1199-1200
17. Burwell SM. Setting value-based payment goals—HHS efforts to improve U.S. health care. *N Engl J Med*. 2015;372(10):897-899
18. Berry JG, Agrawal RK, Cohen E, Kuo DZ. *The Landscape of Medical Care for Children With Medical Complexity*. Overland Park, KS: Children's Hospital Association; 2013
19. Berry JG, Hall M, Cohen E, O'Neill M, Feudtner C. Ways to identify children with medical complexity and the importance of why. *J Pediatr*. 2015;167(2):229-237
20. World Health Organization. Towards a common language for functioning, disability and health. 2002. Available at: www.who.int/classifications/icf/training/icfbeginnersguide.pdf. Accessed February 8, 2016
21. Jette AM. Toward a common language for function, disability, and health. *Phys Ther*. 2006;86(5):726-734
22. Lollar DJ, Simeonsson RJ. Diagnosis to function: classification for children and youths. *J Dev Behav Pediatr*. 2005;26(4):323-330
23. Rehm RS, Bradley JF. Normalization in families raising a child who is medically fragile/technology dependent and developmentally delayed. *Qual Health Res*. 2005;15(6):807-820
24. Rehm RS, Bradley JF. The search for social safety and comfort in families raising children with complex chronic conditions. *J Fam Nurs*. 2005;11(1):59-78
25. Wells N, Krauss MW, Anderson B, et al. *What Do Families Say About Health Care for Children With Special Health Care Needs? Your Voice Counts!! The Family Partners Project report to families*. Boston, MA: Family Voices at the Federation for Children With Special Health Care Needs; 2000

26. Spratling R. Defining technology dependence in children and adolescents. *West J Nurs Res*. 2015;37(5):634–651
27. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: The National Academies Press; 2001
28. Committee on Hospital Care; Institute for Patient- and Family-Centered Care. Patient- and family-centered care and the pediatrician's role. *Pediatrics*. 2012;129(2):394–404
29. Kuo DZ, Houtrow AJ, Arango P, Kuhlthau KA, Simmons JM, Neff JM. Family-centered care: current applications and future directions in pediatric health care. *Matern Child Health J*. 2012;16(2):297–305
30. Kuhlthau KA, Bloom S, Van Cleave J, et al. Evidence for family-centered care for children with special health care needs: a systematic review. *Acad Pediatr*. 2011;11(2):136–143
31. Agency for Healthcare Research and Quality. About the National Quality Strategy. Available at: www.ahrq.gov/workingforquality/about.htm. Accessed February 9, 2016
32. MacKean GL, Thurston WE, Scott CM. Bridging the divide between families and health professionals' perspectives on family-centered care. *Health Expect*. 2005;8(1):74–85
33. Leiter V. Dilemmas in sharing care: maternal provision of professionally driven therapy for children with disabilities. *Soc Sci Med*. 2004;58(4):837–849
34. Ray LD. Parenting and childhood chronicity: making visible the invisible work. *J Pediatr Nurs*. 2002;17(6):424–438
35. Bitsko RH, Visser SN, Schieve LA, Ross DS, Thurman DJ, Perou R. Unmet health care needs among CSHCN with neurologic conditions. *Pediatrics*. 2009;124(suppl 4):S343–S351
36. Singh GK, Strickland BB, Ghandour RM, van Dyck PC. Geographic disparities in access to the medical home among US CSHCN. *Pediatrics*. 2009;124(suppl 4):S352–S360
37. Kane DJ, Kasehagen L, Punyko J, Carle AC, Penziner A, Thorson S. What factors are associated with state performance on provision of transition services to CSHCN? *Pediatrics*. 2009;124(suppl 4):S375–S383
38. Kenney MK. Oral health care in CSHCN: state Medicaid policy considerations. *Pediatrics*. 2009;124(suppl 4):S384–S391
39. Dusing SC, Skinner AC, Mayer ML. Unmet need for therapy services, assistive devices, and related services: data from the national survey of children with special health care needs. *Ambul Pediatr*. 2004;4(5):448–454
40. Warfield ME, Gulley S. Unmet need and problems accessing specialty medical and related services among children with special health care needs. *Matern Child Health J*. 2006;10(2):201–216
41. Mayer ML, Skinner AC, Slifkin RT; National Survey of Children With Special Health Care Needs. Unmet need for routine and specialty care: data from the National Survey of Children With Special Health Care Needs. *Pediatrics*. 2004;113(2). Available at: www.pediatrics.org/cgi/content/full/113/2/e109
42. McPherson M, Weissman G, Strickland BB, van Dyck PC, Blumberg SJ, Newacheck PW. Implementing community-based systems of services for children and youths with special health care needs: how well are we doing? *Pediatrics*. 2004;113(suppl 5):1538–1544
43. Lewis C, Robertson AS, Phelps S. Unmet dental care needs among children with special health care needs: implications for the medical home. *Pediatrics*. 2005;116(3). Available at: www.pediatrics.org/cgi/content/full/116/3/e426
44. Nolan KW, Orlando M, Liptak GS. Care coordination services for children with special health care needs: are we family-centered yet? *Fam Syst Health*. 2007;25(3):293–306
45. Liptak GS, Revell GM. Community physician's role in case management of children with chronic illnesses. *Pediatrics*. 1989;84(3):465–471
46. Houtrow AJ, Okumura MJ, Hilton JF, Rehm RS. Profiling health and health-related services for children with special health care needs with and without disabilities. *Acad Pediatr*. 2011;11(6):508–516
47. Sia C, Tonniges TF, Osterhus E, Taba S. History of the medical home concept. *Pediatrics*. 2004;113(suppl 5):1473–1478
48. American Academy of Pediatrics; Medical Home Initiatives for Children With Special Needs Project Advisory Committee. The medical home [reaffirmed May 2008]. *Pediatrics*. 2002;110(1 pt 1):184–186
49. Edwards ST, Abrams MK, Baron RJ, et al. Structuring payment to medical homes after the affordable care act. *J Gen Intern Med*. 2014;29(10):1410–1413
50. Palfrey JS, Sofis LA, Davidson EJ, Liu J, Freeman L, Ganz ML; Pediatric Alliance for Coordinated Care. The Pediatric Alliance for Coordinated Care: evaluation of a medical home model. *Pediatrics*. 2004;113(suppl 5):1507–1516
51. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA*. 2002;288(14):1775–1779
52. Antonelli R, Stille C, Freeman L. *Enhancing Collaboration Between Primary and Subspecialty Care Providers for Children and Youth With Special Health Care Needs*. Washington, DC: Georgetown University Center for Children and Human Development; 2005
53. Greenberg JO, Barnett ML, Spinks MA, Dudley JC, Frolkis JP. The “medical neighborhood”: integrating primary and specialty care for ambulatory patients. *JAMA Intern Med*. 2014;174(3):454–457
54. Garg A, Sandel M, Dworkin PH, Kahn RS, Zuckerman B. From medical home to health neighborhood: transforming the medical home into a community-based health neighborhood. *J Pediatr*. 2012;160(4):535–536.e1
55. Meyers D, Peikes D, Genevro J, et al. *The roles of patient-centered medical homes and accountable care organizations in coordinating patient care*. Rockville, MD: Agency for Healthcare Research and Quality; 2010. AHRQ Publication No.: 11-M005-EF

56. Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. *Health Aff (Millwood)*. 2014;33(12):2199–2206
57. Kuo DZ, Robbins JM, Burns KH, Casey PH. Individual and practice characteristics associated with physician provision of recommended care for children with special health care needs. *Clin Pediatr (Phila)*. 2011;50(8):704–711
58. Agrawal R, Shah P, Zebracki K, Sanabria K, Kohrman C, Kohrman AF. Barriers to care for children and youth with special health care needs: perceptions of Illinois pediatricians. *Clin Pediatr (Phila)*. 2012;51(1):39–45
59. Van Cleave J, Okumura MJ, Swigonski N, O'Connor KG, Mann M, Lail JL. Medical homes for children with special health care needs: primary care or subspecialty service [published online ahead of print October 30, 2015]? *Acad Pediatr*. doi: 10.1016/j.acap.2015.10.009
60. McAllister JW, Sherrieb K, Cooley WC. Improvement in the family-centered medical home enhances outcomes for children and youth with special healthcare needs. *J Ambul Care Manage*. 2009;32(3):188–196
61. McAllister JW, Cooley WC, Van Cleave J, Boudreau AA, Kuhlthau K. Medical home transformation in pediatric primary care—what drives change? *Ann Fam Med*. 2013;11(suppl 1):S90–S98
62. Homer CJ, Klatka K, Romm D, et al. A review of the evidence for the medical home for children with special health care needs. *Pediatrics*. 2008;122(4). Available at: www.pediatrics.org/cgi/content/full/122/4/e922
63. Berry JG, Agrawal R, Kuo DZ, et al. Characteristics of hospitalizations for patients who use a structured clinical care program for children with medical complexity. *J Pediatr*. 2011;159(2):284–290
64. Cohen E, Jovcevska V, Kuo DZ, Mahant S. Hospital-based comprehensive care programs for children with special health care needs: a systematic review. *Arch Pediatr Adolesc Med*. 2011;165(6):554–561
65. Cooley WC, Kemper AR; Medical Home Workgroup of the National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives. An approach to family-centered coordinated co-management for individuals with conditions identified through newborn screening. *Genet Med*. 2013;15(3):174–177
66. Gordon JB, Colby HH, Bartelt T, Jablonski D, Krauthoefer ML, Havens P. A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs. *Arch Pediatr Adolesc Med*. 2007;161(10):937–944
67. Casey PH, Lyle RE, Bird TM, et al. Effect of hospital-based comprehensive care clinic on health costs for Medicaid-insured medically complex children. *Arch Pediatr Adolesc Med*. 2011;165(5):392–398
68. Klitzner TS, Rabbitt LA, Chang RK. Benefits of care coordination for children with complex disease: a pilot medical home project in a resident teaching clinic. *J Pediatr*. 2010;156(6):1006–1010
69. Mosquera RA, Avritscher EB, Samuels CL, et al. Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: a randomized clinical trial. *JAMA*. 2014;312(24):2640–2648
70. Miller MR, Forrest CB, Kan JS. Parental preferences for primary and specialty care collaboration in the management of teenagers with congenital heart disease. *Pediatrics*. 2000;106(2 pt 1):264–269
71. Murphy NA, Carbone PS; American Academy of Pediatrics Council on Children With Disabilities. Parent-provider-community partnerships: optimizing outcomes for children with disabilities. *Pediatrics*. 2011;128(4):795–802
72. Godolphin W. Shared decision-making. *Healthc Q*. 2009;12 Spec:e186–e190
73. Association of Maternal and Child Health Programs. *Standards for Systems of Care for Children and Youth With Special Health Care Needs*. Washington, DC: Association of Maternal and Child Health Programs; 2014
74. Miller AR, Condin CJ, McKellin WH, Shaw N, Klassen AF, Sheps S. Continuity of care for children with complex chronic health conditions: parents' perspectives. *BMC Health Serv Res*. 2009;9:242
75. Starfield B, Simpson L. Primary care as part of US health services reform. *JAMA*. 1993;269(24):3136–3139
76. Donaldson MS, Yordy KD, Lohr KN, Vanselow NA. *Primary Care: America's Health in a New Era*. Washington, DC: Institute of Medicine; 1996
77. Antonelli RC, McAllister JW, Popp J. *Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework*. New York, NY: The Commonwealth Fund; 2009
78. Council on Children With Disabilities; Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014;133(5). Available at: www.pediatrics.org/cgi/content/full/133/5/e1451
79. Turchi RM, Berhane Z, Bethell C, Pomponio A, Antonelli R, Minkovitz CS. Care coordination for CSHCN: associations with family-provider relations and family/child outcomes. *Pediatrics*. 2009;124(suppl 4):S428–S434
80. Adams RC, Tapia C; Council on Children With Disabilities. Early intervention, IDEA Part C services, and the medical home: collaboration for best practice and best outcomes. *Pediatrics*. 2013;132(4). Available at: www.pediatrics.org/cgi/content/full/132/4/e1073
81. American Academy of Pediatrics Committee on Children with Disabilities. The pediatrician's role in development and implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP). *Pediatrics*. 1999;104(1 pt 1):124–127
82. Lipkin PH, Okamoto J; Council on Children with Disabilities; Council on School Health. The Individuals With Disabilities Education Act (IDEA) for children with special educational needs. *Pediatrics*. 2015;136(6).

Available at: www.pediatrics.org/cgi/content/full/136/6/e1650

83. American Academy of Pediatrics Committee on School Health. Home, hospital, and other non-school-based instruction for children and adolescents who are medically unable to attend school. *Pediatrics*. 2000;106(5):1154–1155
84. Stille CJ. Communication, comanagement, and collaborative care for children and youth with special healthcare needs. *Pediatr Ann*. 2009;38(9):498–504
85. Stiles AD, Tayloe DT Jr, Wegner SE. Comanagement of medically complex children by subspecialists, generalists, and care coordinators. *Pediatrics*. 2014;134(2):203–205
86. Cohen E, Lacombe-Duncan A, Spalding K, et al. Integrated complex care coordination for children with medical complexity: a mixed-methods evaluation of tertiary care-community collaboration. *BMC Health Serv Res*. 2012;12:366
87. Van Cleave J, Le TT, Perrin JM. Point-of-care child psychiatry expertise: the Massachusetts Child Psychiatry Access Project. *Pediatrics*. 2015;135(5):834–841
88. Wagner E. Transforming safety net clinics into patient-centered medical homes: empanelment. The Safety Net Medical Home Initiative; March 2010
89. Arthur KC, Mangione-Smith R, Meischke H, et al. Impact of English proficiency on care experiences in a pediatric emergency department. *Acad Pediatr*. 2015;15(2):218–224
90. Van Cleave J, Boudreau AA, McAllister J, Cooley WC, Maxwell A, Kuhlthau K. Care coordination over time in medical homes for children with special health care needs. *Pediatrics*. 2015;135(6):1018–1026
91. American Academy of Pediatrics Committee on Pediatric Emergency Medicine and Council on Clinical Information Technology; American College of Emergency Physicians; Pediatric Emergency Medicine Committee. Policy statement—emergency information forms and emergency preparedness for children with special health care needs. *Pediatrics*. 2010;125(4):829–837
92. Adams S, Cohen E, Mahant S, Friedman JN, Macculloch R, Nicholas DB. Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): a qualitative study. *BMC Pediatr*. 2013;13:10
93. Chen AY, Schraeger SM, Mangione-Smith R. Quality measures for primary care of complex pediatric patients. *Pediatrics*. 2012;129(3):433–445
94. Bloom SR, Kuhlthau K, Van Cleave J, Knapp AA, Newacheck P, Perrin JM. Health care transition for youth with special health care needs. *J Adolesc Health*. 2012;51(3):213–219
95. Cooley WC, Sagerman PJ; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182–200
96. Ciccarelli MR, Gladstone EB, Armstrong Richardson EA. Implementation of a transdisciplinary team for the transition support of medically and socially complex youth. *J Pediatr Nurs*. 2015;30(5):661–667
97. Sadof M, Gortakowski M, Stechenberg B, Carlin S. The “HEADS AT” training tool for residents: a roadmap for caring for children with medical complexity. *Clin Pediatr (Phila)*. 2015;54(12):1210–1214
98. Bogetz JF, Bogetz AL, Rassbach CE, Gabhart JM, Blankenburg RL. Caring for children with medical complexity: challenges and educational opportunities identified by pediatric residents. *Acad Pediatr*. 2015;15(6):621–625
99. Centers for Medicare and Medicaid Services. Health homes. Available at: <https://www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Integrating-Care/Health-Homes/Health-Homes.html>. Accessed February 28, 2016
100. Kuo DZ, Berry JG, Glader L, Morin MJ, Johaningsmeier S, Gordon J. Health services and health care needs fulfilled by structured clinical programs for children with medical complexity. *J Pediatr*. 2016;169:291–296.e1
101. Homer CJ, Patel KK. Accountable care organizations in pediatrics: irrelevant or a game changer for children? *JAMA Pediatr*. 2013;167(6):507–508
102. Kelleher KJ, Cooper J, Deans K, et al. Cost saving and quality of care in a pediatric accountable care organization. *Pediatrics*. 2015;135(3). Available at: www.pediatrics.org/cgi/content/full/135/3/e582
103. Children’s Hospital Association. CARE award. Available at: <https://www.childrenshospitals.org/Programs-and-Services/Quality-Improvement-and-Measurement/CARE-Award>. Accessed January 14, 2016
104. O’Donnell R. Reforming Medicaid for medically complex children. *Pediatrics*. 2013;131(suppl 2):S160–S162
105. Texas Health and Human Services Commission. STAR Kids. Available at: www.hhsc.state.tx.us/medicaid/managed-care/mmc/star-kids.shtml. Accessed January 14, 2016
106. Collier RJ, Lerner CF, Eickhoff JC, et al. Medical complexity among children with special health care needs: a two-dimensional view [published online ahead of print November 30, 2015]. *Health Serv Res*. 2016;51(4):1644–1659
107. Summer L. *Health Plan Features: Implications of Narrow Networks and the Trade-off Between Price and Choice*. Washington, DC: Academy Health; 2014

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DISABILITIES

Pediatrics 2016;138;

DOI: 10.1542/peds.2016-3021 originally published online November 21, 2016;

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Pediatrics 2016;138;

DOI: 10.1542/peds.2016-3021 originally published online November 21, 2016;

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