Family-Centered Care Coordination for Children and Youth With Special Health Care Needs

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Objective:

Identify effective methods for the practical application of concepts related to improving the delivery of services for persons with developmental disabilities at the level of the state.

Notes:
Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems
COUNCIL ON CHILDREN WITH DISABILITIES and MEDICAL HOME IMPLEMENTATION PROJECT ADVISORY COMMITTEE
Pediatrics 2014;133:e1451; originally published online April 28, 2014; DOI: 10.1542/peds.2014-0318

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://pediatrics.aappublications.org/content/133/5/e1451.full.html
POLICY STATEMENT

Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems

abstract

Understanding a care coordination framework, its functions, and its effects on children and families is critical for patients and families themselves, as well as for pediatricians, pediatric medical subspecialists/surgical specialists, and anyone providing services to children and families. Care coordination is an essential element of a transformed American health care delivery system that emphasizes optimal quality and cost outcomes, addresses family-centered care, and calls for partnership across various settings and communities. High-quality, cost-effective health care requires that the delivery system include elements for the provision of services supporting the coordination of care across settings and professionals. This requirement of supporting coordination of care is generally true for health systems providing care for all children and youth but especially for those with special health care needs. At the foundation of an efficient and effective system of care delivery is the patient-/family-centered medical home. From its inception, the medical home has had care coordination as a core element. In general, optimal outcomes for children and youth, especially those with special health care needs, require interfacing among multiple care systems and individuals, including the following: medical, social, and behavioral professionals; the educational system; payers; medical equipment providers; home care agencies; advocacy groups; needed supportive therapies/services; and families. Coordination of care across settings permits an integration of services that is centered on the comprehensive needs of the patient and family, leading to decreased health care costs, reduction in fragmented care, and improvement in the patient/family experience of care. Pediatrics 2014;133:e1451–e1460

The medical home is the standard of care for all children and adults.1–3 The patient-/family-centered medical home (PFCMH) is well positioned to provide coordinated, compassionate, family-centered health care by forming strong links among the primary care provider team, specialist team, nurses, social workers, educators, hospitals, and other health care facilities where patients access services with their family/caregivers and community providers.4
Care coordination is a “cross-cutting system intervention” that is the deliberate organization of patient care activities between ≥2 participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organizing care involves the marshaling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care. Within the context of a high-performing medical home model focused on addressing family-centered needs, care coordination is paramount in developing and fostering partnerships across various settings and communities.

Successful care coordination takes into consideration the continuum of health, education, early child care, early intervention, nutrition, mental/behavioral/emotional health, community partnerships, and social services (as well as payments for these services) needed to improve the quality of care for all children and youth including those with special health care needs, while acknowledging the importance of language and culture in achieving desired outcomes. It is to be distinguished from disease or case management, which primarily focuses on patients’ medical issues. Case managers work with and guide services intrinsic to their specific agency, often within the constraints of eligibility criteria. In contrast, care coordinators work with and guide the team process, which includes and is driven by the needs of patients and families for services across the community. These functions include care planning and building collaboration/partnerships with all medical and nonmedical providers working with a patient/family.

Rather than focusing on titles (eg, patient navigator, care coordinator, case manager), it is critical to focus on competencies, job descriptions, and functions in the physician-led team caring for the patient and his or her family in and outside the PFCMH.

**NEW INFORMATION AND POLICY DEVELOPMENTS**

The American health care system is being challenged to reduce costs of care while improving quality outcomes. A key component of recent legislative and regulatory efforts to achieve these savings includes the redesign of systems of care, building on robust medical and health care homes for both children and adults. One method of achieving these financial outcomes is the reduction in care fragmentation and inefficiency within and across health systems. Fragmentation of care can be addressed with care coordination: “a patient and family centered, assessment driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families.” Care coordination has been characterized as the set of activities that occurs in the space between providers, visits, and entities. Ultimately, coordination of care enables the achievement of the “triple aim” (better care, better health, and lower cost), a principal outcome for health system transformation.

Although adult and pediatric health care organizations underscore common elements of the medical home (which includes care coordination across systems), there are intrinsic differences in their respective systems. The “Five Ds” that distinguish pediatric from adult medical home models are as follows: developmental trajectory, dependency on adults, differential epidemiology of chronic disease, demographic patterns of poverty and diversity, and overall dollars spent on children versus adults.

Another key differentiation is the inclusion and importance of family input in all aspects of coordinated pediatric care. A recent Institute of Medicine report provides 10 key recommendations for high-quality health care, including 1 emphasizing the integral role of the family: “involve patients and families in decisions regarding health and health care, tailored to fit their preferences.” Thus, it is essential that “family” is included in the “patient-centered care model.

As such, we refer to this model as the “patient/family-centered medical home” (PFCMH).

Payment for care coordination services has had limited success over the past decade. The American Medical Association added codes 99487–99489 to its Current Procedural Terminology (CPT) manual for care coordination for patients with complicated, ongoing health issues within a medical home, accountable care organization, or similar model. The inception of these codes allows physicians to document and bill for coordinating care between community service agencies, linking patients to resources, supporting the transition of patients from inpatient to other settings, and working to limit so-called preventable readmissions. Pediatricians need to advocate for recognition of the codes via third-party payers in their respective regions.

The multidisciplinary framework outlined in Fig 1 offers a definition of care coordination and articulates its essential activities and competencies. Pediatric care coordination highlights the role of the patient- and family-centered care and team-based activities designed to meet the needs of children and youth. Care coordination addresses interrelated medical, dental, social, developmental, mental health, educational, and financial needs.
to achieve optimal health and wellness outcomes.13

**BENEFITS OF AND EVIDENCE FOR CARE COORDINATION**

Simply put, care coordination improves outcomes (eg, health care utilization, family functioning/satisfaction, and finances). In a 2009–2010 National Survey of Children with Special Health Care Needs, 43% of parents reported receiving care coordination, as opposed to 47% in the 2005–2006 iteration of the survey.22 These data, which suggest a decrease in receipt of care coordination services over time, warrant further examination. Data analyses from the 2005–2006 National Survey of Children with Special Health Care Needs revealed positive associations between care coordination, family-provider relations, and family/child outcomes. Specifically, the provision of care coordination was positively associated with patient- and family-reported “receipt of family-centered care,” resulting in “partnerships with professionals, satisfaction with services, ease of getting referrals, lower out of pocket expenses and family financial burden, fewer hours per week spent coordinating care, less impact on parental employment, and fewer school absences and ED visits.”23

An Illinois study showed that children, youth, and their families had a higher need for care coordination when communication between health care providers was inadequate.24 Care coordination within primary care pediatric practices is associated with decreased unnecessary office and emergency department (ED) visits, enhanced family satisfaction, and reduced unplanned hospitalizations and ED visits.25–27 According to research in New Orleans, families of children and youth with special health care needs in an underserved population experienced enhanced services from nurse care coordinator support.28 In short, fewer unmet needs for services ensue when primary care clinicians are sensitive to the culture and needs of children and youth with special health care needs and their families and incorporate levels of care coordination in care delivery.29 Care coordination conducted as a standard of pediatric practice resulted in increased family satisfaction with the quality of care and also decreased barriers to care.30 Other data have suggested that the PFCMH represents a process of care that may help families manage the daily demands of caring for children with special health care needs through family-centered care, provider-to-provider communication, and provision of care coordination.31 A 2011 study in children and youth with special health care needs and their families who received care coordination and individualized care plans via a Medicaid managed care plan study reported improved satisfaction with mental health services and specialized therapies and participants were observed to have a decline in unmet needs, improved satisfaction with specialty care, and improved ratings of child health and family functioning.32 In a busy medical practice, care coordination fosters improved productivity and efficiency by transferring the mechanics of follow-up care,
referrals, equipment acquisition, letters of medical necessity, patient information, transition of care, and previous authorization to care coordinators rather than physicians. As such, efficiency ensues because physicians can spend less time on nonclinical issues for patients.

**IMPLEMENTING CARE COORDINATION IN TRANSFORMED SYSTEMS OF CARE**

Quality improvement processes are essential in the transformation to health care delivery models that support care coordination. However, it is critical to recognize that broad implementation of care coordination requires consideration of financing models, workforce development, and the development and implementation of tools supporting the provision of care coordination. The costs of care coordination are not directly reimbursable under many traditional payment models, such as fee-for-service, despite evidence of reductions in health care costs. The most recent CPT manual includes codes for care coordination and transition services.

Health information technology can play a pivotal role in care coordination. Electronic tools can facilitate information sharing among patients/families and their health care teams, and subsequently, health care teams, community partners, and medical and nonmedical providers. For example, previsit summaries, comprehensive health care plans, medical summaries, and personal health records can be shared with, among, and between partners and health care teams caring for patients. Tracking and monitoring patients via the use of patient registries can support care coordination activities and functions and improve patient safety.

These registries can be incorporated and supported via electronic health records (EHRs) and other software tools with some adaptation. This technology is still evolving with “meaningful use” criteria of EHRs. Meaningful use is intended to use certified EHR technology to improve quality, safety, efficiency, and accountability; reduce health disparities; engage patients and families as partners; improve care coordination and population and public health; and maintain privacy and security of patient health information. Ultimately, it is hoped that meaningful use compliance will result in better clinical outcomes, improved population health outcomes, increased transparency and efficiency, empowered patients/families, and more robust research data on health systems. Interoperability of registry functionality and care plans with team members outside of the medical arena, but still in the medical and community “neighborhood” caring for a child, is critical. Care planning includes the use of an “actionable” care plan with assigned tasks/roles, a care plan document, an emergency information form, and/or a medical summary, including past medical history and salient specialist information. These care plans are developed and implemented with input from members of the team caring for a child, including community partners, educational specialists, primary care providers, dental providers, medical subspecialists and surgical specialists, and, most importantly, the family and patient themselves. Coordinated care plans are used across the continuum of care by including medical, educational, mental health, community, and home care provider input. These plans should explicitly state goals with therapeutic (including early intervention) educational/vocational and family interventions to maximize outcomes for children and youth with special health care needs and to drive successful transitions to adult systems of care. It is essential that care plans are maintained and updated with timely and salient information from all partners to avoid duplication of services and to optimize care for patients.

Health care teams are essential to the provision of coordinated care. Teams include, but are not limited to, the patient/family, primary care providers, community partners/agencies, mental health care providers, educational systems, medical subspecialists and surgical specialists, urgent care/ED centers, nurse practitioners, physician assistants, dietitians, child care centers, nursing staff, social workers, therapists, home visitors, and other medical staff. Team building starts with establishing teams of physicians and ancillary staff and working with patients, families, and communities to coach patients/families to optimize their health care and chronic condition management.

“Relational coordination” is an emerging topic highlighting the fact that coordination is not merely management of the interdependence between tasks but addresses management of the people who are performing tasks. It is defined as “a mutually reinforcing process of interaction between communication and relationships carried out for the purpose of task integration.” This concept is particularly relevant to care coordination for children and youth, because care coordination “activities” are as important as the team (eg, families, community partners, physicians, nurses, mental health providers, social workers) performing those activities. Relational coordination values the quality of communication (eg, care plans and meetings) and the quality of relationships between families, patients, providers, and partners.
Internet-based tools can optimize communication between families and providers, provide information, support skills training, allow networking among families, facilitate connections between health care providers and community partners, and elicit patient feedback about care. Comanagement with specialists ensures high quality of care and fosters communication across disciplines for patients with multiple diagnoses.40 Also, care coordination augments reciprocity of patient information with transfer across settings (eg, from inpatient to outpatient settings). As health care system redesign evolves, it is critical that practitioners are cognizant of tools and organizations providing resources for care coordination. Several national organizations incorporate standards on care coordination structure, process, and outcomes. Table 1 shows a variety of such organizations and tools.

Given this rapidly changing and innovative landscape, it is imperative to continue education on care coordination, the PFCMH, accountable care organizations (ACOs), and family-centered and -driven health care for practicing physicians, medical students, resident trainees, nurses, nurse practitioners, physician assistants, mental/behavioral health practitioners, and social workers. This workforce training goal can be accomplished through maintenance of certification, continuing medical education, continuing education units, and curricula/competency changes in training. Education of the workforce is critically important, because care coordination functions and family-centered principles must be learned and cultivated. The training of current and future physicians on the value and pragmatic adoption and implementation of care coordination is paramount in ensuring its success in practice. The Accreditation Council for Graduate Medical Education has selected a care coordination milestone as a key competency in the semiannual assessment of residents in its “Next Accreditation System,” which shows a fundamental commitment to training the next generation of physicians in care coordination. In addition, a Care Coordination Curriculum (funded by the US Maternal and Child Health Bureau) is now available to support the education of care coordination providers. This care coordination curriculum is designed to help fill the void of inadequate training opportunities for care coordinators presently. The target audience for this curriculum includes families and patients as well as physicians, nurses, social workers, and administrative staff. Essentially, it provides a framework for the evolution of team-based patient- and family-centered care coordination. It is currently being used in several state programs and delivery systems working to create care coordination capacity.

**CARE COORDINATION AND ACCOUNTABLE CARE**

ACOs are expected to play a key role in achieving the outcomes of the “triple aim.” The Medicare Payment Advisory Commission has defined ACOs as “a set of providers associated with a defined population of patients, accountable for the quality and cost of care delivered to that population.”43 ACO providers could include a hospital, a group of primary care providers, specialists, and possibly other health professionals who share responsibility for the delivery of the highest quality care at the lowest appropriate cost. Key elements of accountable care include payment reform, performance measurement and accountability, and coordinated continuum of care. In the ACO model, there are incentives to manage health care utilization and improve quality with shared savings to control cost. The PFCMH model can be enhanced through the ACO model with greater organization, coordination, and integration throughout the care system; yet, defining accountability within and across systems will be a formidable challenge.44 One must begin with the premise that, from the perspective of the patient and family, care integration means that seamless and coordinated health care services are delivered across the entire care continuum, irrespective of institutional and departmental boundaries.45 Implementing the activities of care coordination, with explicitly articulated roles and responsibilities for all members of the care team, will be foundational to the success of ACOs. The recommendations of a national expert panel tasked with defining the core elements of accountable care for children are presented in Table 2. These elements emphasize the unique needs of children and the role of care coordination in their health care delivery system.

**IMPLEMENTATION**

Pediatricians are encouraged to provide and partner with the PFCMH team in the office setting to manage patients and work with families and community partners across systems. The Care Coordination Measures Atlas, developed by the Agency for Healthcare Research and Quality, provides a list of activities proposed as a means of achieving coordinated care that are organized by domains and perspectives (patient/family, health care professional, system representative) and can be a useful tool in achieving these aims.46 There are several organizations that promote medical home and care coordination resources and tools. Table 1 summarizes several organizations, Web sites, and tools available to support those providing
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<th>Tool/ Organization</th>
<th>Developer(s)</th>
<th>Description</th>
<th>Link(s)</th>
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<tr>
<td>Patient-Centered Medical Home (PCMH) Recognition Program</td>
<td>The National Committee for Quality Assurance (NCQA) with input from the 4 primary care specialties</td>
<td>&quot;Gives practices information about organizing care around patients, working in teams and coordinating and tracking care over time,&quot; specific elements covered including &quot;Tracking and coordinating care&quot; in the patient-centered medical home</td>
<td><a href="http://www.ncqa.org/Programs/Recognition/PatientCenteredMedicalHomePCMH.aspx">http://www.ncqa.org/Programs/Recognition/PatientCenteredMedicalHomePCMH.aspx</a></td>
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<td>Medical Home System Survey (MHSS)</td>
<td>National Quality Forum (NQF)</td>
<td>Focuses on improved patient care and addresses communication, transitions, health care home/PCMH proactive plan of care and follow-up, and information systems</td>
<td>Requires log-in</td>
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<tr>
<td>TransforMED</td>
<td>American Academy of Family Physicians (AAFP)</td>
<td>Adult and pediatric medical home; TransforMED provides ongoing consultation, support, tools, and resources to physicians and practice leaders looking to transform their practices to a new model of care based on the concept of the PCMH</td>
<td><a href="http://www.transformed.com/resources/Continuity_of_Care.cfm">http://www.transformed.com/resources/Continuity_of_Care.cfm</a></td>
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<td>Medical Home Builder</td>
<td>American College of Physicians (ACP)</td>
<td>Adult medical home. Medical Home Builder is divided into self-paced modules on a variety of operational and clinical areas. Each of the modules contains background information, the ACP Practice Biopsy (a practice assessment tool), and links to the Resource Library, which includes relevant references and informative guides in a variety of formats including downloadable guides and policy templates.</td>
<td><a href="https://www.practiceadvisor.org/home">https://www.practiceadvisor.org/home</a></td>
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<td>Care Coordination Accountability Measures for Primary Care Practice</td>
<td>Agency for Healthcare Research and Quality (AHRQ)</td>
<td>This report presents selected measures from the Care Coordination Measures Atlas that are well suited for primary care practice. The selected measures are divided into 2 sets: Care Coordination Accountability Measures (from the patient/family perspective) and Companion Measures (from the health care professional and system perspectives, ie, self-assessment).</td>
<td><a href="http://www.ahrq.gov/qual/pcpaccountability/pcpaccountability.pdf">http://www.ahrq.gov/qual/pcpaccountability/pcpaccountability.pdf</a></td>
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<td>Other National Medical Home recognition/accreditation programs</td>
<td>Provided by National Center for Medical Home Implementation (NCMHI)</td>
<td>Provides a list of additional programs offering medical home recognition, accreditation, and standards for interested practices and organizations.</td>
<td><a href="http://www.medicalhomeinfo.org/national/recognition_programs.aspx">http://www.medicalhomeinfo.org/national/recognition_programs.aspx</a></td>
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<td>Care Coordination Curriculum</td>
<td>Boston Children’s Medical Center; Maternal and Child Health Bureau</td>
<td>This curriculum, funded by the US Maternal Child Health Bureau can be used in training programs at the levels of local, state, national, delivery systems, and pediatric practices.</td>
<td><a href="http://www.bostonchildrens.org/CareCoordinationCurriculum">www.bostonchildrens.org/CareCoordinationCurriculum</a></td>
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services to children and families. As health care reform implementation continues with delivery system changes and ACO evolution, pediatricians can work via their state and ACO evolution, pediatricians can continue with delivery system changes and health care reform implementation to ensure that system changes support improved care coordination opportunities for meeting the needs of children and youth. Care coordination activities for implementation include the following:

- establishing formal responsibilities among team members and with the patient and family to comprehensively address patient needs;
- fostering strength-based relationships with families and children while building on existing strengths of patients and their family support systems;
- collaborating with all team members and providers involved in caring for a patient and family, including (but not limited to) medical subspecialists and surgical specialists, nurse practitioners, nurses, mental health care providers, social workers, dietitians, educators, community partners, child care centers, home visitors, and family networks;
- communicating across all systems (medical and nonmedical) involved in a child’s care while adhering to Health Insurance Portability and Accountability Act rules and Family Educational Rights and Privacy Act regulations and consent driven by families and patients;
- facilitating transitions between entities (eg, pediatric/adult providers, community partners, hospitals, urgent/emergency care facilities, offices, specialists) and across time;
- assessing needs and establishing clear goals for the patient, family, health care team, and system;
- creating, implementing, and updating a formal written plan of care with family/patient input that is sensitive to their language, values, and culture; examples can be found at the National Center for Medical Home Implementation Web site (http://www.medicalhomeinfo.org/how/care_delivery/#care);
- monitoring, following, and responding to needs and changes over time;
- supporting self-management goals as outlined by the team and patient/family;
- linking and collaborating with community resources and partners, including state Title V Children and Youth with Special Health Care Needs programs (eg, formal meetings, education collaborations, task forces, policy development meetings);
- fostering knowledge about community resources and linking families/patients to those resources commensurate with the needs of the patient, family, and population;
- using quality improvement strategies to facilitate implementation for the medical home team, staff, and partners (eg, EQIPP medical home course, APEX-AAP digital navigator) (see Table 1);
- visiting the National Center for Medical Home Implementation Web site (www.medicalhomeinfo.org)

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**TABLE 2** Summary of Core Principles for Creating Accountable Child Health Outcomes

1. Child health care delivery has the potential to deliver both short- and long-term cost savings.
2. The epidemiology and treatment of chronic conditions in children are different than they are in adults.
3. Families are the drivers of child health.
4. Implementation of life-course approaches is essential for optimal child, adult, and population health outcomes.
5. Children’s health care requires a diverse and complex network of nonmedical and medical stakeholders.
6. There is a strong need for well-defined care coordination and integration in children’s health care.
7. Children represent a disproportionate segment of the population living in poverty, with large disparities among different subgroups.
8. Child health care quality measures require further development and specialized methods.
9. Payment for child health must incentivize stakeholders to provide elements of accountable care.

Source: unpublished data from SA Londhe, MHA, MA; N Sachedina, MBBS, MBA, MPP; M Mann, MD, MPH; S Wegner, JD, MD, RC Antonelli, MD, MS, March 12, 2012.
for assistance and examples of support, resources, and templates in transforming clinical practice into a PFCMH;

- using health information technology and tools to facilitate care coordination;2–9,40;

- advocating for adequate payment mechanisms for supporting care coordination (using CPT codes)20,21,26;

- ensuring ACOs and integrated delivery systems address and promote the integrity of the care coordination model (see Table 2)44–46;

- engaging with national organizations dedicated to quality measurement to ensure care coordination metrics and standards are appropriate to advance child health outcomes47; and

- supporting efforts to develop practical implementation of care coordination algorithms in practice, practice management, and team development.

SUMMARY AND CONCLUSIONS

Care coordination should be a team- and family-driven process that improves family and health care practitioner satisfaction, facilitates health care outcomes, and reduces costs associated with health care fragmentation, which can lead to under- and overutilization of care. It is imperative that well-defined care coordination is integrated into children’s health care. Tools for care coordination include health information technology, integrated health care teams, and Internet-based resources. Because of their foundational reliance on PFCMH, ACOs may support the delivery of high-quality, lower-cost care but only if explicit elements of care coordination are included in delivery system design and training and resources are provided for care coordination.

RECOMMENDATIONS

1. Use and create mechanisms for patients/families to learn the skills they may need to be partners in their own care and in decision-making for optimal care coordination.49

2. Ensure that the patient’s and family’s needs for services and information sharing (eg, care planning) across people, systems, and functions are met via (a) formal assessments, (b) infrastructure (eg, teams), and (c) tracking (eg, registries); this is crucial in operationalizing care coordination.46

3. Continually involve the patient/family (eg, families as partners/advisors), build on the strengths of the patient/family, clearly delineate responsibilities of team members, and create careful handoffs when transitioning across settings (eg, between inpatient and outpatient settings and between pediatric and adult care providers or settings).46,49–51

4. Use and develop efficient and accredited health information systems and information technology advances to foster successful transfer of information; to support collaborative communications between patients, families, and the care team; and to facilitate shared decision-making (eg, developing and using care plans).

5. Use care coordination across transitions between entities of the health care system (ie, between and among patient care teams, across settings, between caregivers, and between health care organizations) and with transitions over time (ie, across the life span, between episodes of care, across trajectory of illnesses).49–51

6. Ensure that comanagement and communication occur among specialists and primary care providers. This care model requires reciprocal and bidirectional communication (ie, secure e-mail, phone call, note, fax), which can be augmented, but not replaced, with health information technology.7,37

7. Ensure ongoing education of elements of care coordination and the medical home for practicing physicians, nurse practitioners, physician assistants, nurses, medical students, resident trainees (across disciplines), mental/behavioral health care practitioners, social workers, and other health care professionals via specific training/curricula, continuing medical education programs, and publications.41,42

8. Understand the landscape of the PFCMH and care coordination as they relate to national organizations and certification/standards, such as ACOs, the National Committee for Quality Assurance, the Patient-Centered Primary Care Collaborative, the National Quality Forum, quality metrics broadly, and health care reform, including financing of care coordination as well as remote collaborative services (eg, phone, e-mail consults with specialists, phone/e-mail encounters with families) that maximize the potential of children, youth, and families.47

9. Collaborate with state Title V agencies and Maternal Child Health Block Grant applications ensuring that care coordination is incorporated and addressed and that best practices of care coordination models are emulated.
10. Understand and use new care coordination codes (99487–99489)^20 and advocate for payment of these care coordination services by payers.

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