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# Practice-Based Care Coordination: A Medical Home Essential

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## ABSTRACT

Families who raise children and youth with special health care needs deserve a medical home. They expect a team approach to health care, with coordination across multiple services and settings. Children, youth, and families benefit from the organization of critical information into written care summaries and action plans. If primary care pediatricians, family physicians, and internists are to achieve optimal health care quality and improvement of existing health care delivery, care coordination will be an essential contributing process to their team approach. Several national health policy recommendations identify care coordination as a cross-cutting intervention to fill the gap between what exists and what is needed in health care today. A practice-based care-coordination model, including a definition and vision for care, a framework of structures and processes, and a position description with specific competencies, is needed. Improvement methodology provides an effective means for health care teams to implement and evaluate practice-based care coordination within their medical home. The improvement approach and model must be flexibly applied to have utility across diverse health care organizations. A medical home team approach, with fully developed practice-based care-coordination services, will enhance health and cost outcomes for children, youth, and families and heighten the professional satisfaction of those delivering health care.

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### Key Words

children with special health care needs, care coordination, access to health care, quality of life, medical home, quality improvement, primary care

### Abbreviations

CYSHCN—children and youth with special health care needs

CSHCN—children with special health care needs

CMHI—Center for Medical Home Improvement

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**P**ATIENTS AND FAMILIES want and deserve quality care found in a relationship-based, continuous, coordinated, and compassionate context.<sup>1</sup> The primary care medical home addresses these needs through culturally effective partnerships with patients and families. A medical home is a community-based primary care setting that provides and coordinates planned, family/youth-centered, high-quality health promotion and chronic-condition management.<sup>2</sup> "Team practice" in primary care is widespread.<sup>3</sup> A medical home must have the capacity to offer practice-based care coordination as a function of its team practice or teamwork. Care received in a medical home can be good, better, or great depending on openness to change and commitment to partner with families/consumers to improve. Practice-based care coordination is a primary care service with the potential to lift a medical home from a conceptual ideal to a more fully implemented array of family-centered services. Small community practices, midsized multispecialty groups, and larger health care organizations need informative models to help them develop and sustain effective care coordination and achieve quality services and outcomes that warrant enhanced reimbursement.<sup>4,5</sup> New Hampshire's Center for Medical Home Improvement (CMHI) facilitates primary care teams and leaders of their respective health networks to engage in a consistent, family-centered improvement process to develop comprehensive services, including a fully developed care-coordination capacity.<sup>6</sup> In this article we describe methods and tools for successfully achieving a care-coordination service as part of team-based care within the medical home. Once fully developed, tested, and evaluated, additional research will be necessary to further demonstrate the quality and business case for care coordination. First, the focus must be on the establishment of care-coordination competencies and the team-based service systems in which they are implemented.

## BACKGROUND AND HISTORY

The American Academy of Pediatrics describes care in a medical home as accessible, family-centered, compassionate, continuous, comprehensive, coordinated, and culturally effective.<sup>7</sup> This definition is endorsed by the American Academy of Family Physicians and the National Association of Pediatric Nurse Practitioners<sup>8-10</sup> and embraced by the American College of Physicians.<sup>10</sup> The availability of an effective medical home is of particular value for children and youth with special health care needs (CYSHCN) and their families. According to the US Maternal and Children Health Bureau, CYSHCN have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required by children generally.<sup>11,12</sup> Families raising and caring for a child with special health and developmental needs would like to work in partnership with

their primary care providers (M. W. Krauss, PhD, *The Family Partners Project: Summary of Findings and Conclusions*, unpublished manuscript, 2000). Families want interactions with health care professionals that are characterized by compassion and that demonstrate respect for their expertise as their child/youth's parent/guardian and primary caregiver.<sup>13</sup>

An excellent medical home effectively combines place, process, and people, which includes families, youth, and health care professionals.<sup>14,15</sup> Horst et al<sup>16</sup> found care coordination to be an essential element for ensuring quality and continuity of care for CYSHCN and their families. Many agree that care coordination plays a critical role in an effective medical home.<sup>6-8,17-21</sup> A comprehensive or "great" medical home will need staff with fundamental care-coordination skills including the ability to ensure planned care and secure needed information to help families link with community-based care and resources.<sup>21</sup>

Acute, preventive, and chronic care are integrated within a medical home as distinctly and explicitly defined care processes.<sup>14</sup> The chronic-care model calls for practice improvements in 6 domains including patient activation, delivery system design, decision support, clinical information systems, community linkages, and health policy.<sup>22</sup> In a fully implemented medical home, this means learning to engage families in the redesign of care, addressing complex multisystem issues around transition to adulthood and accessing adult services, providing planned care, comanaging care with multiple specialists who draw from appropriate evidence-based guidelines, and developing and using patient registries. Collaborative relationship building initiated by primary care practices enables productive interactions with community partners and health policy makers around continuity, quality, and fair reimbursement. These proactive, all-inclusive activities represent functions that are not typically performed in traditional acute and preventive care models.<sup>14,23</sup>

## DIMENSIONS OF EFFECTIVE PRACTICE-BASED CARE COORDINATION

The literature suggests a broad consensus with respect to the need for coordination of care and the challenges that primary care practices face when attempting to implement this service. However, relatively little has been written on the core functions that should be embedded in the care-coordinator professional role and the core competencies needed, requisite training, and methods for implementing and evaluating this service.

An Illinois statewide study demonstrated that children, youth, and their families substantially benefit from care-coordination services offered by registered nurses within primary care offices or health centers.<sup>4</sup> Of note, this research has also suggested that communication among providers is often poor and that problems in this

area correlate strongly with a parent's/caregiver's increased need for care coordination. In "A Ten-Point Strategy to Achieve Better Health Care for All," Davis cites care coordination as 1 of 10 key components needed to organize care and information around the patient.<sup>24</sup> A health policy article by the same author and her colleagues calls for care coordination as 1 of 7 attributes of patient-centered primary care with promotion of the medical home as an important first step toward creating such a care system.<sup>25</sup> Presler<sup>26</sup> recommended that care coordination be delivered from a child and family strengths-based model rather than an approach built on deficit- or problem-based thinking. Presler acknowledged that such coordination of care is labor intensive and time consuming, whether accomplished by parents or in the context of a parent-professional partnership.

Effective care coordination enhances access to services and resources, promotes optimal health and functioning of children and youth, and supports improved quality of life.<sup>15,19,27-29</sup> Data show that primary care pediatricians struggle to fulfill the care-coordination needs of children, youth, and families.<sup>30</sup> An American Academy of Pediatrics policy statement described the functions of care coordination as complex, time consuming, and frustrating while stressing care coordination as key to the effective management of complex care issues.<sup>31</sup> Their policy statement recommends a designated care coordinator/individual to facilitate optimal outcomes and prevent confusion for children, youth, and families.

An Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*,<sup>32</sup> outlined a vision for the redesign of the health care system. Although it included 6 characteristics of optimal health care (safe, effective, patient centered, timely, efficient, and equitable), it did not offer practical strategies for change and improvement. A follow-up Institute of Medicine report, *The First Annual Crossing the Quality Chasm Summit: A Focus on Communities*,<sup>33</sup> offered a strategic plan and included care coordination as 1 of 6 overarching needs that transcend 20 priority areas. The population of children with special health care needs (CSHCN) is among the 20 priorities named in the report. The need to define and measure good care coordination was underscored as an important preliminary step toward the establishment of and reimbursement for care-coordination services. Care coordination takes time and resources. A primary care practice that is willing to assess its quality with family-centered measurements and improve its care accordingly must be reimbursed for care coordination or have a means of financing this labor-intensive team role.<sup>18</sup>

The US Maternal and Child Health Bureau defined 6 core outcome measures in "Achieving and Measuring Success: A National Agenda for Children With Special Health Care Needs."<sup>34</sup> Every state and territory must

address these outcomes, which include the areas of (1) medical home, (2) insurance coverage, (3) screening and identification, (4) family-friendly organization of services, (5) family and professional partnerships, and (6) transition to adulthood and adult services. Outcome measures 2 through 6 depend greatly on the presence of a primary care medical home, one with the capacity to offer practice-based care coordination. Care coordination can operationalize medical home behaviors and characteristics. Antonelli and Antonelli<sup>17</sup> predicted that without the ability to support care coordination at the level of the primary care medical home, significant barriers to achieving the other 5 performance measures will remain.

Szilagui<sup>35</sup> asserted that care coordination requires available personnel and dedicated time, both of which are scarce within typical primary care settings.<sup>30</sup> In a national Family Voices survey, parents reported that physicians have the skill to coordinate care, but they are difficult to access and have limited time.<sup>13</sup> Daily pressures and productivity quotas undoubtedly contribute to this dilemma. A survey of the directors of state divisions of CSHCN programs detailed the existing barriers to care coordination in the medical home, including lack of time, inadequate reimbursement for care-coordination services, lack of physician preparation, and limited ability to offer culturally effective care.<sup>36</sup>

#### **DEVELOPING AND IMPLEMENTING CARE COORDINATION BY USING A QUALITY IMPROVEMENT PROCESS**

Care coordination is a complex set of functions that can be difficult to define and measure and harder still to develop, implement, and sustain in a busy practice setting. US Maternal and Child Health Bureau medical home grants and learning-collaborative efforts have supported improved primary care for CYSHCN through implementation of the medical home model. In these initiatives, primary care medical home-improvement teams focus on the (1) identification of CYSHCN and their enrollment in a registry, (2) involvement of families in the redesign of care, and (3) systematic implementation of care-coordination activities as a critical primary care service.<sup>37</sup> As a part of these efforts, care coordination is developed through a quality improvement process and implemented gradually while allocating time for dedicated staff members to take on the role of a practice-based care coordinator. During protected time, typically a staff nurse or social worker develops, implements, documents, and evaluates care-coordination activities. Alternatively, some states promote access to care coordination by providing accessible assistance from outside the office, such as by assigning state or county nurse coordinators to primary care practices.<sup>38</sup> This process relieves the primary care office of the burden of recruiting personnel and funding care coordina-

tion; it also has the advantage of providing them with a well-prepared and supervised coordinator.

It is the experience of the CMHI, from 13 years of interventions and interviews with >60 primary care sites, that an internal practice-based coordinator is crucial for both medical home improvement and maximizing the value of all available external resources and sources of coordination external to the practice. Physicians, care coordinators, and other staff members who partner with patients/families to form care and improvement teams should be reimbursed for their quality efforts. Such teams measure quality and strive continuously to redesign care and improve outcomes.

Others have supported models of team care that are supported and made possible with care coordination. The Massachusetts Consortium for Children With Special Health Care Needs 3-year study report recommended a system of care coordination housed in the medical home of CYSHCN.<sup>38</sup> According to the workgroup, this creates a model within an existing service system rather than creating a freestanding system. It builds on the family's organic relationship to the medical home and enhances the team's ability to provide effective primary care. Being on-site enables ease of use for families with continuous "real-time" availability for busy clinicians. It is important that primary care practices have a clearly defined set of team-based care-coordination processes for their staff.

### **Planning and Implementing a System of Practice-Based Care Coordination**

Health care teams and their respective umbrella organizations must choose a framework and model for practice-based coordination as a step in strengthening their medical home. The model and framework should include a detailed care-coordination position description and core practice competencies. The following steps guide the establishment of practice-based care-coordination services:

1. Articulate a care-coordination definition and vision.
2. Use a framework for practice-based care coordination.
3. Declare a facilitative, team-based care-coordination-model approach.
4. Develop, test, and implement a care-coordination-service capacity.
5. Strategically integrate care-coordination services into team-based primary care.
6. Evaluate care coordination.

#### *Articulate a Care-Coordination Definition and Vision*

The literature offers various definitions of coordinated care that have been designed for application across

health care environments such as hospitals, specialty care centers, or community and home health care agencies.<sup>26</sup> Many definitions focus on case or care management rather than care coordination.<sup>39,40</sup> Lindeke et al<sup>36</sup> described case management as a process that matches client health care needs with available services and resources to improve quality, continuity, and cost-effectiveness. Presler<sup>26</sup> described care coordination as a process of assessment, planning, implementation, evaluation, monitoring, support, and advocacy to facilitate timely access to services, promote continuity of care, and enhance family well-being. Presler's articulation is a more family-centered one; it is relationship based and includes patients and families as active learners and participants in their care. Few definitions focus exclusively on the circumstances found within the primary care medical home. Fewer still involve the activities that are essential to the continuous delivery of relationship-centered health promotion and chronic-condition management for a distinct population over time. Practice-based care coordination in a medical home goes farther than the resource matching of case management; it facilitates care partnerships and an uptake of new skills and knowledge by youth/families and by health care teams. Care coordination builds relationships that foster integration and coordination of services and information across multiple organizations. Care coordination has the potential to greatly increase the overall value of primary health care for CYSHCN and their families in that it impacts clinical, functional, satisfaction, and cost or resource outcomes. Because primary care coordination is crucial to an improved health care system, a distinct, comprehensive definition of practice-based care coordination is needed.<sup>33</sup> The following definition of care coordination in a medical home builds on that developed by Presler<sup>26</sup> and colleagues as part of the Children's Healthcare Options Improved Through Collaborative Efforts and Services (CHOICES) project.

Practice-based care coordination within the medical home is a direct, family/youth-centered, team-oriented, and outcomes-focused service. It is designed to:

- facilitate the provision of comprehensive health promotion and chronic-condition care;
- ensure a locus of ongoing, proactive, planned care activities;
- build and use effective communication strategies among family, the medical home, schools, specialists, and community professionals; and
- help improve, measure, monitor, and sustain quality outcomes (clinical, functional, satisfaction, and cost).

Outcomes should show improved quality of life for children/youth and families and improved quality of care within the medical home. This definition implies that care coordination is best provided in a team context.

Effective teamwork directly results from relationships among the family/youth, clinicians, and other medical home staff. These team relationships should be characterized by mutual respect, trust, and transparency and be grounded on the needs, concerns, and priorities of families. The caregiving process fosters the family's health management and system-negotiation skills and improves communication overall. An appropriate goal for practice-based care coordination is for children, youth, and families to have seamless access to their team, enhanced by the availability of a designated care coordinator who facilitates a team approach to family-centered care-coordination services.

#### Use a Framework for Practice-Based Care Coordination

A framework for practiced-based care coordination (see Table 1) provides the backdrop for understanding, defining, and implementing care-coordination services. Using and implementing a framework for care coordination draws on 2 fundamental structures and 2 fundamental processes. Structures need to be in place to make certain that every child receives quality care. Processes are needed to ensure maximum value around every patient/family interaction with the team at their medical home.

#### Framework: Care-Coordination Structures

Care-coordination structures must ensure access to health care and resources within the medical home and allow for personnel to coordinate external sources of care, building community connections. This includes relationships among the medical home staff, the family, and essential external partners (eg, subspecialists, early intervention programs, schools, other community agencies, state Title V CYSHCN programs, insurers, and others).

Practice-based care coordinators contribute to the design and implementation of office policies and practices, which fosters access to a medical home. A registry of CYSHCN enables a practice team to know who needs and receives care-coordination services. Care coordinators can facilitate family participation and feedback through the establishment of partnerships with parents/youth and through the use of family surveys, focus groups, and advisory boards to inform the practice/health care team. Care coordinators also facilitate the process of translating family input into practice changes. Coordinators help to establish effective ways for families to access and communicate with their doctor and other team members. Although the family is central to the medical home model, a care coordinator can be an ef-

**TABLE 1 A Framework for Practice-Based Care Coordination as Part of the Health Care Team in the Medical Home**

	Medical Home Interventions
Fundamental structures	
Access to medical home, health care teams, and other resources	Identify and register the CYSHCN population. Establish with families effective means for medical home/office access. Provide accessible office contact for family and community agencies. Catalog resources to link families to appropriate educational, informational, and referral sources. Promote and "market" practice-based care coordination to families and others (eg, brochure, poster, outreach).
Community connections	Establish alliances with community partners. Facilitate practice and family linkages with agencies (eg, family support, schools, early intervention, home care, day care, and agencies offering respite, housing, and transportation). Align transition support activities with schools and other groups. Collaborate with families, payors, providers, and community agencies to improve systems of care for CYSHCN.
Fundamental processes	
Proactive team care and care planning	Help to maintain health and wellness and prevent secondary disease complications. Maximize outcomes (eg, alleviation of the burden of illness, effective communication across organizations, enrollment in needed services, and school attendance/success). Listen, counsel, educate, and foster family skill building. Screen for unmet family needs. Develop written care plans, and implement, monitor, and update them regularly. Plan for future transition needs, and incorporate them into a plan of care. Facilitate subspecialty referrals and communication, and help family integrate the recommendations of specialists. Link family and staff to educational/financial resources.
Improving and sustaining quality	Contribute to family-centered quality improvement team process, helping in the redesign of care and improvement of the medical home. Provide a contact person for family partners and quality improvement team members. Coordinate implementation of medical home improvements (eg, identification and registry, care planning, data, and tracking of outcomes). Broaden strategies for gaining family feedback for the organization. Document context of care-coordination activities (what is promoted/prevented). Help to measure, collect, and share quality data. Implement consistent medical home standards of care for all CYSHCN and their families.

fective link for both the family and medical home staff by providing a communications interface with multiple external partners, resources, and vendors. Making these community connections through alliances, outreach, relationship building, and collaboration lays the foundation for continuity of care, an essential factor that is associated with improved health outcomes.<sup>41</sup>

#### *Framework: Care-Coordination Processes*

Built on these structures are fundamental care-coordination processes that enable the provision of proactive care, including screening, assessment, planned visits, and care planning with ongoing monitoring and management. The care coordinator assists families and youth to fulfill the goals that they have personally determined and those developed in consultation with their team at their medical home and others. The team orientation of care coordination must involve the family/youth as full and equal members. The team should be linked with other key professionals within specialty medical centers, school systems, and community agencies. The care coordinator helps improve and carry out medical home systems that are designed to offer:

- ease of access to the office and services;
- identification of special populations and development and use of special population registries;
- previsit assessments of patient concerns with a record of any emergency department use, hospitalizations, specialty visits, or other events that occurred since the previous visit;
- chronic-condition-management appointments with ample time for care plan development, use, and monitoring;
- office visits with enhanced value resulting from accessible and clear records of test results and letters and with recommendations appropriately assembled and synthesized (thus reducing duplication); and
- successful follow-up and communication with the family and all involved community agencies, school staffs, and specialists.

In their direct role with patients, all team members should emphasize the independence, self-determination, and personal choices of children, youth, and their families.

Children, youth, and families may benefit from periodic, planned chronic-condition-management visits that are scheduled independently (if possible) of well-child care and acute illness visits.<sup>14</sup> This goes beyond the typical primary care offered. According to Christakis et al,<sup>42</sup> clinic visits are both more efficient and more rewarding for families and professionals when they are held in a setting where there are established relationships. Such rapport contributes to continuity of care, which is asso-

ciated with parental reports of higher quality of care and families viewing clinical interactions much more favorably. Identifying a patient with a chronic condition who has an upcoming appointment (or need for an appointment), preparing key information, and readying test results and consultative information can increase the value of the face-to-face encounter. Planned visits include roles for the coordinator of listening, counseling, educating, and transferring essential skills to families and youth when needed. Facilitation of referrals to subspecialists and other providers and services, working to achieve clear communication so that subspecialty expertise can be drawn on at the next office visit, and working to improve staff preparedness for these visits can positively impact child and family outcomes. At these planned visits, needs are anticipated, information and interventions are prepared for, and encounters are concluded with specific follow-up plans. Care coordinators enable a proactive approach to care by facilitating future planned visits and following up with linked resources (eg, specialty clinics, home health agencies, equipment and service vendors, hospice, school, and other resources). Coordinators establish themselves as an identifiable contact for families and others. The team functions together, but the care coordinator ensures that plans are thoroughly implemented and evaluated. Care coordinators help keep medical home efforts moving continuously forward. Ideally, a coordinator is present during the office visit; however, his or her role is especially important between visits to ensure these continuous relationships.

An assessment of the needs and strengths of children and youth allows for the development of individualized care plans. The coordinator supports youth and family involvement in the completion and use of a care plan or medical summary. At the discretion of the family, the care plan can be available to all team members and to other professionals such as school staff or emergency responders. Care plans provide documentation of history, needs, services, corresponding therapeutic and educational interventions, and contact information that are helpful to the integration of multiple recommendations.<sup>43</sup> Care plans prevent duplication of services and confusion about goals, treatments, and responsibilities. They may also be used to show the relationship between medical home and care-coordination processes and key health outcomes such as reduced school absences and reduced acute clinical episodes with commonly set and shared goals among the family, medical home, school, and community agencies. Examples of care plans can be found on the CMHI Web site ([www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org)) and the American Academy of Pediatrics National Center for Medical Home Initiatives Web site ([www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)).

### *Care-Coordination Training and Education*

Several different groups have reported on the training and education of care coordinators working within their model efforts. The Pediatric Alliance for Coordinated Care uses the services of a designated practice-based pediatric nurse practitioner.<sup>28</sup> The Shriners Hospitals for Children use both nurses and social workers, working either alone or as a team, as care coordinators.<sup>44</sup> Jackson and Vessy<sup>45</sup> cite nursing frameworks that include care coordination for CSHCN and detail the care-coordination roles of bachelor's degree-prepared nurses as case managers. Presler<sup>26</sup> based her care-coordination descriptions on the 1994 standards for CSHCN nursing practices of the Maternal and Child Health Bureau. Betz and Redcay<sup>46</sup> reported that nurses and medical social workers have been the traditional service coordinators of specialized health care teams. These teams are responsible for integrating input into care plans as they coordinate services and make referrals. A screening and developmental assessment model in South Carolina calls for nurse practitioners with at least 3 years' experience as a requirement to skillfully interview and dialogue with parents.<sup>47</sup> A Commonwealth Fund special article on the medical home for all patients described the central role that nurses would play when working with primary care physicians to develop chronic-condition management and health promotion support programs.<sup>48</sup> A model program in Kansas uses bachelor's degree-prepared early childhood experts with 3 years' experience, or the equivalent, in the role of "healthy steps" specialists.<sup>47</sup> There is no comparative evidence that distinguishes among these programs. Neither is there a set of practice-based care-coordination parameters that outline appropriate education and experience. Those who create programs seem to make their own judgments with regards to prescribed requirements for care coordinators and case managers.

Reflecting different views about the role of the care coordinator, some recommendations call for a "nurse, social worker or the equivalent" rather than requiring a specific discipline,<sup>3,19,36</sup> or they suggest care-coordination competencies that draw from multiple disciplines. For example, the Massachusetts Consortium for Children With Special Health Care Needs has suggested that several disciplines bring different skill sets that might complement each other and that this allows coordinators to learn from one another about the strengths and limitations that various disciplines, approaches, and resources have to offer.<sup>38</sup> Such a call for a cross-fertilization of skills and knowledge highlights the need for a set of care-coordination competencies.<sup>38,40</sup> To aide primary care practices with care-coordination development, the CMHI has developed a sample position description (see Table 2). This description was designed to guide flexible care-coordination implementation at the improvement-team level in the medical home.

### **"Declare" a Facilitative Team-Based Care-Coordination Model Approach**

Care-coordination services in many settings are delivered in a rather ad hoc manner in response to pressing clinical needs.<sup>21</sup> An urgent, rather than strategic, approach characterizes the coordinating role of physicians and staff. Clinicians often describe staff as providing reactive "clean up" after a complex visit. A variety of approaches to care coordination have evolved within primary care and can generally be categorized as either designated or delegated. In the designated approach, all care needs that emerge during a time-limited office visit are distributed across a group of available staff. In a delegated approach to care coordination, care needs are assigned to a specific coordinator or staff person who is designated to provide some care-coordination services. All needs that cannot be addressed in a typical visit are referred to the care coordinator. Insufficient priority setting can weaken the potential for using the care coordinator's time effectively and efficiently, which puts successful care coordination in jeopardy.

A more effective and sustainable model of care coordination is best described as facilitative. Facilitative care coordination is a more team-based approach to the interventions and services needed to effectively care for children and youth with complex needs.<sup>15</sup> In a facilitative model, tasks are shared across the team of family, clinicians, and the person or persons with the special responsibility for ensuring coordination of care. The advantage to taking a facilitative approach is that coordination tasks are viewed by the practice as everyone's responsibility. Team efforts are supported, but the team has the assurance of added capacity represented by the care coordinator(s). A facilitative approach works for families needing a true team approach.<sup>15</sup> Families perform many daily tasks of coordination; they benefit from help of fluctuating intensity at different points in time.<sup>13</sup> A coordinator assesses this need and performs in a fluid and flexible manner.

### **Develop, Test, and Implement a Care-Coordination Service Capacity**

A high-quality medical home has an improvement process in place.<sup>21</sup> The care coordinator plays a key role on its family-centered improvement team. This team will need to address the development of the care-coordination role as a part of their improvement process. The care coordinator adds the necessary "glue" to hold the pieces together and the "oil" or "elbow grease" to do what it takes to accomplish team goals. The team should determine what is needed and what will work in its own practice environment. The Medical Home Index is used as a practice self-assessment tool that can help a team review their current care-coordination structures and processes and decide where to focus needed improve-

**TABLE 2 Medical Home: Practice-Based Care-Coordination—Position Description**

Care-coordination qualifications: the care coordinator<sup>a</sup> shall have

- Bachelor's degree preparation as a nurse, social worker, or the equivalent with appropriate past experience in health care
- 3 years relevant experience, or the equivalent, in community-based pediatrics or primary care, particularly in the care and service of vulnerable populations such as CYSHCN
- Essential leadership, advocacy, communication, education and counseling, and resource-research skills
- Core philosophy or values consistent with a family-centered approach to care
- Culturally effective capabilities demonstrating a sensitivity and responsiveness to varying cultural characteristics and beliefs

Medical home care-coordination responsibilities: the care coordinator will

- Demonstrate and apply knowledge of the philosophy/principles of comprehensive, community-based, family-centered, developmentally appropriate, culturally sensitive care-coordination services
- Facilitate family access to medical home providers, staff, and resources
- Assist with or promote the identification of patients in the practice with special health care needs (such as CYSHCN); add them to registry and use it to plan and monitor care
- Assess child/patient and family needs and unmet needs, strengths, and assets
- Initiate family contacts; create ongoing processes for families to determine and request the level of care-coordination support they desire for their child/youth or family member at any given point in time
- Build care relationships among family and team; support the primary caregiving role of the family
- Develop care plan with family/youth/team (emergency plan, medical summary, and action plan as appropriate)
- Carry out care plans, evaluate effectiveness, monitor in a timely way, and make changes as needed; use age-appropriate transition timetables for interventions within care plans
- Serve as the contact point, advocate, and informational resource for family and community partners/payors
- Research, find, and link resources, services, and supports with/for the family
- Educate, counsel, and support; provide developmentally appropriate anticipatory guidance; in a crisis, intervene or facilitate referrals appropriately
- Cultivate and support primary care and subspecialty comanagement with timely communication, inquiry, follow-up, and integration of information into the care plan
- Coordinate interorganizationally among family, the medical home, and involved agencies; facilitate "wrap-around" meetings or team conferences and attend community/school meetings with family as needed and prudent; offer outreach to the community related to the population of CYSHCN
- Serve as a medical home quality improvement team member; help to measure quality and to identify, test, refine, and implement practice improvements
- Coordinate efforts to gain family/youth feedback regarding their experiences with health care (focus groups, surveys, other means); participate in interventions that address family/youth-articulated needs

<sup>a</sup> The care coordinator works within the context of a primary care medical home, from a team approach, and in continuous partnership with families and physicians to promote timely access to needed care, comprehension and continuity of care, and the enhancement of child and family well-being.

ments.<sup>21</sup> The Medical Home Index guides a team's improvement steps and helps them to measure progress.

Guidance for health care organizations developing care-coordination services can be drawn from the model for improvement described by Langley et al.<sup>49</sup> The model for improvement poses 3 basic questions (see Table 3): (1) What are you trying to improve? (2) How will you know that a change is an improvement? (3) What changes can you make that will result in improvement? In this context, the answer to question 1 is "practice-based care coordination within the medical home." The answer to the second question relates to the measurement of whether care coordination leads to improved outcomes for patients, families, primary care providers,

and other community partners. A list of care-coordination outcomes are detailed in Table 4. There are strong indications that coordinated care results in a reduction of unnecessary or redundant services.<sup>27-29</sup> Additional research is needed to demonstrate enhanced outcomes for children/youth, families, and primary care practices/networks. Finally, the answer to the third question involves the development or identification of change ideas for care-coordination improvement: ideas that are ready for testing, refinement, and ultimately implementation. In

**TABLE 3 Applying the Model for Improvement**

Model for Improvement Questions	Medical Home-Improvement Responses
What are we trying to accomplish?	Practice and team-based care coordination in the medical home
How will we know that a change is an improvement?	Measures: Medical Home Index, Medical Home Family Index and Survey
What changes can we make that will result in an improvement?	Care-coordination good ideas: ready for use (eg, care-coordination definition, position description, framework and activities, and "plan, do, study, act" examples)

**TABLE 4 Projected Outcomes of Care Coordination**

Family satisfaction	Decreased worry and frustration
	Increased sense of partnership with professionals
	Improved satisfaction with team communication
Staff satisfaction	Improved communication and coordination of care
	Improved efficiency of care
	Elevated challenge and professional role
Improved child/youth outcomes	Decreased emergency department visits, hospitalizations, and school absences
	Increased access to needed resources
	Enhanced self-management skills
Improved systems outcomes	Decreased duplication
	Decreased fragmentation
	Improved communication and coordination

this article (and a companion workbook, *Medical Home Practice-Based Care Coordination Workbook*, which is available at [www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org)), we include specific ideas that are ready for adoption or adaptation by primary care. Flexibility in approach and model is crucial for tools and supports to utility across diverse health care organizations.

In addition to addressing the 3 questions of the model for improvement, the change process involves establishing an aim statement and developing a “plan, do, study, act” sequenced approach for testing change.<sup>49</sup> When an improvement team knows what it is trying to improve and for whom, a sound aim statement readily emerges. A good aim statement includes the target population (who are we trying to help?), the intent (what does the team want to do and why?), and a time frame for change to happen with measurable goals within the team’s designated time frame (how will we know it is working?). Using a plan, do, study, act approach leads the team to develop, test, examine, and refine changes within their medical home.

### **Strategically Integrate Care-Coordination Services Into Team-Based Primary Care**

Once a definition, vision, framework, and model for care coordination are identified, organizations must decide about their allocation of human resources. How care coordination will be integrated within other primary care services must be considered. If the coordinator is selected or acknowledged from among existing staff and already carries multiple responsibilities, strategies to protect his or her time for these new functions will become necessary.

Protecting time for the fulfillment of the care-coordination role requires a purposeful administrative shift from the urgent to the important, from the reactive to the proactive. The care coordinator must be free to focus on the important and develop his or her role on the basis of the needs of children, youth, families, and medical home staff. Reorganizing roles and reallocating resources are difficult in the absence of supportive leadership. A care coordinator must have the time to participate fully in the quality improvement–team process described earlier. Time must also be available to learn about services and systems and to build relationships with professionals in the broader community. Time is required for the care coordinator to help educate other practice staff about the needs of CYSHCN and their families, the role of care coordination, and the many needed medical home–system improvements. Practice-based care coordination may be beyond the expectations that families have previously had of their child’s medical home. When care-coordination services are made available, practice teams need to effectively communicate this developed service to families. Families will need to know how to access

particular care-coordination services and whether there is any additional cost.

### **Evaluate Care Coordination**

An investment in care coordination has value for families as they perform their role as primary caregivers and coordinators of their children’s care. Care coordination lends vitality to primary care clinicians in pediatrics, family medicine, and internal medicine who struggle to meet the complex and ongoing priorities of CSHCN. Care coordination, emanating from an effective team process, can lead to enhanced clinical and functional health outcomes and increased satisfaction with more accessible, coordinated care. An organization/primary care practice needs to set definitive care-coordination service objectives and use these objectives to select care-coordination quality measures. Consumers, clinicians, coordinators, community partners, and payors should each be offered the opportunity to evaluate the effectiveness of this service and to redesign the focus of care coordination accordingly.

Payors or insurers will want evidence that care coordination is cost-effective. This evidence is difficult to obtain for many reasons but most importantly because there are so few fully implemented examples of practice-based care coordination. It has been demonstrated that care coordination at the practice level enhanced family satisfaction and improved cost outcomes in a small sample of primary care practices.<sup>28</sup> Evidence supports the extent that care coordination contributes to continuity of care. Continuity of care is a predictor of enhanced cost, satisfaction, and clinical outcomes.<sup>3,27,41</sup> Some evidence exists that specialty-based care-coordination programs reduce hospitalizations and emergency department use that lead to hospitalizations.<sup>29</sup> Future research investigating health and cost outcomes of practice-based care coordination is needed.

### **CONCLUSIONS**

The development of a specific practice-based care-coordination service requires the use of tested tools and strategies. Approaches have been designed to assist health care organizations to develop effective models of team-based care coordination. With a focus on the formulation of a vision, definition, framework, model, and a process for improving practice-based care coordination, organizations or individual practices have a suitable beginning. Evaluation and research of established care-coordination systems must follow. Kelly et al<sup>15</sup> stated that families want a medical home that (1) develops a written summary of critical information, (2) offers a collaborative family-centered team approach, and (3) has a developed process to integrate and coordinate multiple services. A well-developed program of practice-based care coordination, offered in a team context within a medical home, increases the potential to meet

each of these important family goals. Designating a care coordinator to act in a facilitative model with adequately protected time is critical. Evaluation of practice-based care-coordination services that link distinct care processes with outcomes promoted and/or prevented must then be carefully completed to secure future payment for these valuable services. Practice-based care coordination, delivered in a family-centered team context, is essential to the medical home.

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## Practice-Based Care Coordination: A Medical Home Essential

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