MAKING CARE COORDINATION A CRITICAL COMPONENT OF THE PEDIATRIC HEALTH SYSTEM: A MULTIDISCIPLINARY FRAMEWORK

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ABSTRACT: It is widely acknowledged that the lack of care coordination within the U.S. health care system perpetuates the fragmentation of care, cost inefficiency, and poor health outcomes. This report proposes a framework for care coordination in a high-performing pediatric health care system. To develop this framework, the authors performed a literature review, held key informant interviews, and convened an expert panel. The framework includes a definition of care coordination; outlines its principal characteristics, competencies, and functions; and sets forth a detailed process for its delivery. It also describes a model to implement care coordination across all health care settings and related disciplines.

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May this effort inform the evolution of a high performance health care system that will enhance access, quality, and outcomes for all children, youth, and families.

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EXECUTIVE SUMMARY

Care coordination is described in a Commonwealth Fund report as one of seven elements needed to organize care around patients. The Institute of Medicine has explicitly stated that care coordination is needed to improve the quality of health care in the United States. Yet there is a lack of consensus regarding care coordination's competencies and core functions, who should provide them, the desired outcomes, and how to measure and pay for these services.

This report proposes a framework for pediatric care coordination. It includes a definition of care coordination; outlines its principal characteristics, competencies, and functions; and sets forth a detailed process for its delivery. It also describes a model to implement care coordination across all health care settings and related disciplines.

We employed multiple strategies to develop this framework, including a literature review and consultation with key informants representing families, public and commercial payers, pediatric nurses, pediatric and geriatric social workers, pediatric health care providers, and federal partners including the Maternal and Child Health Bureau and the Agency for Healthcare Research and Quality.

The proposed framework takes a family-centered approach and a health systems view with attention to interdisciplinary and environmental structures, processes, and outcomes (Figure 1). Effective care coordination is best provided in the context of a health care team, real or virtual, that has established working relationships with families, clinicians, community partners, and other professionals.

Figure 1. A Framework for High-Performing Pediatric Care Coordination

Care Coordination Definition:

Pediatric care coordination is 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 addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes.

Defining Characteristics of Care Coordination:

1. Patient- and family-centered
2. Proactive, planned, and comprehensive
3. Promotes self-care skills and independence
4. Emphasizes cross-organizational relationships

Care Coordination Competencies:

1. Develops partnerships
2. Communicates proficiently
3. Uses assessments for intervention
4. Is facile in care planning skills
5. Integrates all resource knowledge
6. Possesses goal/outcome orientation
7. Takes an adaptable and flexible approach
8. Desires continuous learning
9. Applies team-building skills
10. Is adept with information technology

Care Coordination Functions:

1. Provides separate visits and care coordination interactions
2. Manages continuous communications
3. Completes/analyzes assessments
4. Develops care plans with families
5. Manages/tracks tests, referrals, and outcomes
6. Coaches patients/families
7. Integrates critical care information
8. Supports/facilitates care transitions
9. Facilitates team meetings
10. Uses health information technology

Delivery of Family-Centered Care Coordination Services Includes:

We conclude that an integrated care coordination infrastructure is essential to create and sustain a high performance pediatric health care system. The success of this process will depend on multiple factors at all levels within the health care system and across multiple sectors of the community. Supporting this transformation will be the development of performance and outcome measures, as well as mechanisms for workforce development, education, policy support, and financing.

It is critical to note that the scope of services for care coordination for children and youth is markedly different from the scope of such services for typical adult populations. With the exception of geriatric services, care coordination for many adults is essentially management of chronic health conditions. While both adult and pediatric health care must focus on chronic conditions, care coordination that supports the comprehensive needs of children, youth, and families must be broader than this strictly medical view.

The effectiveness of a care coordination system can be measured by the experiences of the families that receive these services. Therefore, families must play a proactive role in informing the design of the infrastructure and policies that will support the development of care coordination as an integral part of the health care system.

MAKING CARE COORDINATION A CRITICAL COMPONENT OF THE PEDIATRIC HEALTH SYSTEM: A MULTIDISCIPLINARY FRAMEWORK

INTRODUCTION

Care coordination is a critical factor in a high performance health care system. It is described in a Commonwealth Fund report as one of seven elements needed to organize care and information around the patient.[1] The Institute of Medicine has explicitly stated that care coordination is paramount to improving the quality of health care in the United States.[2] Yet consensus is lacking regarding the competencies and core functions of care coordination, who should provide it, what the desired outcomes are, and how to measure and pay for care coordination services. In addition, the cost-effectiveness of care coordination has not yet been definitively demonstrated. There is also considerable variability in how care coordinators are hired, trained, and supported. In order to achieve a high performance health care system, it is essential and timely to define high-quality care coordination and outline the competencies and accountabilities required for community-based providers of care coordination.

This report defines care coordination; outlines its principal characteristics, competencies, and functions; and sets forth a detailed process for its delivery. It also describes a model to implement care coordination across all health care settings and related disciplines, with the goal of supporting the needs and enhancing the self-management skills of patients and families.

REVIEW OF CARE COORDINATION LITERATURE

Pediatric care coordination links children and their families with appropriate services and resources in a concentrated effort to achieve good health.[3] Patients and families want and deserve quality care in a medical home, defined as care that is family-centered, comprehensive, continuous, community-based, culturally effective, compassionate, and coordinated.[4] According to the professional literature, families and providers say that care coordination is often lacking in primary care. There is broad consensus with respect to the need for care coordination and the challenges health care systems and practices face when attempting to implement it. There is little research, however, on the steps necessary to overcome barriers to sustainable and successful care coordination.

A good deal of the relevant literature focuses on children and youth with special health care needs. According to the Maternal and Child Health Bureau, children and youth with special health care needs are defined as those who have or are at increased

risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.[5] Though children with special health care needs often require a variety of medical, social, and educational services, they frequently receive fragmented or duplicative services.[6] According to Nolan, Orlando, and Liptak, systems and services such as primary and specialty care and educational programs are often scattered and uncoordinated.[7] Mayer, Skinner, and Slifkin report that children and youth with disabilities or chronic health conditions typically have far more unmet needs related to important medical services than do the majority of children.[8] As a result, they likely receive less than optimal care. Additionally, Denboba et al. and Rosenberg et al. report that poor, uninsured, and minority children may be at a heightened risk for poor coordination of services.[9]

Delivering care coordination services is often described as complex, time-consuming, and frustrating, even though it is key to effectively managing care.[10] Relatively little has been written about the core functions and competencies that should be embedded within care coordination services in primary care practices. Furthermore, how care coordination operations should be structured and organized to foster efficient linkages to extramural health and community-based services is unclear. Additionally, minimal guidance is available for care coordination implementation and strategies for evaluation to ensure accountability of these services.

Care coordination services have the potential to provide multiple benefits to children, their families, and the health care system. Some research has attempted to capture rates of care coordination provided in primary care practices. For example, Gupta, O'Connor, and Quezda-Gomez surveyed members of the American Academy of Pediatrics and found that most pediatricians (71%) report that their practices have a designated care coordinator.[11] However, further inquiry about the types of care coordination services these practices provide indicated that important services for families (e.g., contacting schools or parents about findings or sharing referral information) are not occurring. Stille and Antonelli pointed out that the outcomes and efficacy of care coordination have not been demonstrated.[12]

Defining Care Coordination

A few articles attempt to define care coordination for children and youth with special health care needs. In a technical review funded by the Agency for Healthcare Research and Quality, Wise, Huffman, and Brat conclude that there is no consistent definition of care coordination.[13] Furthermore, many studies replace a formal definition with a list of

objectives or requirements. One reason cited for the lack of a standard definition is that care coordination does not have a strong theoretical foundation. Some of the literature recommends that families serve as the locus of care coordination, with physicians serving principally facilitative roles.[14] There is acknowledgement, however, that the degree of engagement in care coordination by families varies from case to case. The definition of the medical home emphasizes the role of primary care in coordination of services for children.[15] Furthermore, Cooley and McAllister suggest that designating a care coordinator within the physician's office is essential, as is family involvement in the development and implementation of the medical home.[16] To support the assessment of a primary care practice's performance, the Medical Home Index has been developed to examine performance on 25 quality indicators within six domains, one of which is care coordination.[17]

The National Quality Forum (NQF) has endorsed a definition of care coordination as a function that helps ensure patients' needs and preferences for health services and information are met.[18] This definition emphasizes the role that care coordination plays in delivering services to "patients by facilitating beneficial, efficient, safe, and high-quality patient experiences and improving healthcare outcomes." The NQF framework includes five domains: the health care or medical home; a proactive plan of care that includes follow-up monitoring of progress toward patient-specific goals; communication between and among all members of the health care team and the patient, emphasizing shared decision-making with families; use of standardized, electronic information systems; and an emphasis on the need for coordinated efforts to optimize safety and accuracy during handoffs, or transfers between health care settings. To date, the NQF has endorsed a single measure outlining the content for information transfer from the in-patient setting to home, rehabilitative care, nursing care, and community based primary care settings. Though this measure was not developed to ensure care coordination, it does focus on the preparedness of patients and their caregivers.[19]

Impact of Care Coordination

There is a dearth of empirical evidence regarding the impact of care coordination. Most studies have evaluated care coordination interventions for children and youth with special needs and the impact on health care utilization, costs, or health outcomes. Specifically, Criscione et al. found that individuals who were randomized into a coordinated care group had shorter average hospital stays and lower charges compared with a group receiving standard care.[20] In a retrospective design, Liptak et al. found that children receiving care at a hospital-based ambulatory care coordination program had shorter stays and lower costs than comparison groups.[21]

Palfrey et al. conducted a comprehensive evaluative study on care coordination for children and youth with special health care needs.[22] The authors used a pre/post design to assess an intervention using nurse practitioners as coordinators, based within a group of primary care centers. Findings indicated that parental satisfaction increased after care coordination was implemented in primary care practices. Parents report that, compared to before the intervention, they were able to speak with nurses more easily, were more efficiently connected to community resources and supports for prescriptions, and had an enhanced understanding of the goals for care. Most important, parents reported having a stronger relationship with their primary care providers. Parents also reported greater satisfaction with services (e.g., mental health and care coordination services) after implementation of the intervention. Additional findings indicated a reduction in family needs, caregiver strain, and children's school absences.

R. Antonelli and D. Antonelli reported the costs associated with care coordination for special needs children and youth in a primary care practice.[23] Clinic staff recorded all non-reimbursable care coordination activities occurring over a 95-day period. Notably, half of the encounters involved care for nonmedical issues (e.g., follow-through with referrals in managed care networks, conferencing with school officials, and overseeing psychosocial problems). Extrapolating from the cost of practice-based personnel from national benchmark data, the authors concluded that the total cost of non-reimbursable care coordination activities ranged between $22,809 and $33,048 per year for a practice of four full-time-equivalent (FTE) physicians and one FTE nurse practitioner. In a follow-up study, Antonelli, Stille, and Antonelli looked at time spent performing non-reimbursable care coordination activities and resulting outcomes in six practice models across the United States.[24] Practices representing a diversity of geographic, patient socioeconomic, and payer mix characteristics were selected. The practices used varying models of care coordination, from those with no designated care coordination staff to those with funded staff whose only tasks were related to care coordination. Significantly, care coordination activities delivered by nurses using non-billable telephone-based interventions often led to avoidance of billable office and emergency department visits.

Wise et al. concluded that there are relatively few well-executed studies looking at the impact of managed care on at-risk children.[25] Many of these studies have differing methodologies, contradictory findings, and no direct assessment of care coordination. Future work needs to address both programmatic and structural pathways of care coordination effectiveness.

In a recent review, Bodenheimer concludes that failures in the coordination of care are common and serious.[26] He highlights research suggesting that referrals to specialists often include inadequate information, and reports back to primary care physicians are likely to have insufficient information to sustain continuity of care. Additionally, he reviews several barriers to care coordination that have been documented in the literature. These include an overstressed primary care system, a low number of computerized records, dysfunctional payment systems, and a lack of integrated systems of care (e.g., between private physicians and emergency departments). Bodenheimer's review highlights several innovative models that may be excellent examples of systematic changes within the pediatric health care system. One that holds promise is the "teamlet" model, in which a primary care provider works proactively and collaboratively with a practice-based coach. The coach may be a nurse, medical assistant, or specially trained care coordinator. He or she works with families to implement a jointly created care plan, which ensures that information flows between primary care and other health system stakeholders. A critical outcome of this model is the development and support of activated patients and families.

Case Management Versus Care Coordination

There is confusion between the overlapping services of case management and care coordination. Case management is commonly defined as a process that addresses the health needs of patients. It tends to be focused on a limited set of predetermined diseases or conditions and guided by potential health care cost savings. The process can include assessment, planning, implementation of services, monitoring, and subsequent reassessment.[27] In many cases, targeted case management is one aspect of general disease management. Traditionally, case management services provide services in a benefits package, often supported by a health plan or managed care organization. Individuals who receive case management typically require services likely to result in high costs and have complex medical needs.[28] There are mixed results in the literature regarding the cost-effectiveness of case management and disease management. Specifically, Mattke suggests that more research is needed to determine whether there are improvements in quality of care and lower costs associated with disease management.[29]

In contrast, care coordination can be provided to any patient and includes a range of medical and social support services beyond medical case management. The goal of care coordination is to help link patients and families to services that optimize outcomes articulated in a patient-centered care plan. Care coordination may address the social, developmental, educational, and financial needs of patients and family. Care coordination often includes activities that may or may not be covered by defined benefit packages offered by managed care organizations.

FINDINGS FROM KEY INFORMANTS AND EXPERT PANELISTS

To inform the creation of a care coordination framework, we held teleconference interviews with 27 key informants; subsequently we convened an expert roundtable discussion with 19 panelists. Both groups were chosen for their experience in clinical practice, education, and research promoting the development and evaluation of care coordination for children and adults. Expert panelists specifically included those engaged in policy work related to health system design and delivery, payment for care coordination functions and services, and educational credentialing; others were consumer advocates, clinical experts with experience in practice-based care coordination, and leaders in academic medicine, nursing, and social work.

Twenty-five percent of those interviewed referred to the promise of the medical home model for health care reform. During interviews, the topic of care coordination was frequently associated with the successful implementation of the medical home model.

Of those interviewed, 46 percent stated that care coordination must focus on more than just medical services. Care coordination is facilitated by and in turn supports team-based care. The experts emphasized the enormous amount of coordination needed across systems, agencies, organizations, schools, and Early Intervention programs. Partnering across communities and sharing responsibility for the future of children, with shared program objectives, funding, and accountability, is a priority. Fifty percent of the experts called for research and development to build evidence demonstrating the value of care coordination.

While 35 percent of the experts stress the need for a clear definition of care coordination, including specification of a standardized set of services, there is pervasive concern about the lack of capacity in primary and specialty care to provide such services. For example, communication is particularly weak during patient transitions across care settings and among varied “managers” of health care. Many experts expressed concern about primary care shouldering the burden of filling such gaps. Generally, how much the primary care system can take on to meet current and future needs for comprehensive care coordination is a looming question. Future investment will be necessary for coordination of care to be successfully placed within the hub of primary care. Health information technology has great potential to improve care coordination. A functional information technology infrastructure can enable health care teams to reach their potential in supporting care coordination processes.

Nearly all of the expert informants describe the primary care "hub," health care home, or medical home as the logical and effective center for care coordination. The critical role of families in care coordination was a common theme, including the notion that family leaders could effectively serve as care coordinators within a system of care. Health coaching to enable transference of knowledge and skills to parents and children needs to be a cornerstone of any care coordination framework. The role of coaches, as described by Bodenheimer and Laing, is a fundamental element of the enhanced primary care model known as a "teamlet."[30] Multiple perspectives and sources of information need to be coordinated to deliver proactive care coordination in partnership with parents, youth, health care teams, and community partners. Therefore, a well-functioning "hub" is needed and will require an investment in infrastructure development and adequate reimbursement for services.

The extent and quality of care coordination will depend on the skills, knowledge, and experience of the care coordinator. There is not yet consensus among the experts regarding the necessary or optimal educational level of professionals contributing to or performing care coordination. Recommended levels of preparation range from a coordinator with a doctorate to an array of other health professionals (e.g., medical assistants, social workers, or nurses) providing care coordination under a physician's leadership. Among the interviewees, most favored having registered nurses serve as care coordinators. Yet nurses are acknowledged as scarce and expensive, and current nursing curricula typically prepare graduates for hospital positions, which are better compensated than those in physician practices. One idealized model includes using a registered nurse who functions as a resource for a team of coordination "extenders," including social workers, medical assistants, licensed nursing assistants, and licensed practical nurses.

A MULTIDISCIPLINARY FRAMEWORK FOR PEDIATRIC CARE COORDINATION

Based on a review of the literature and input from key informants and expert panelists and relying on a family-centered approach and a health systems view, we developed a multidisciplinary framework for pediatric care coordination. The framework emphasizes cross-disciplinary and environmental structures, processes, and outcomes. It defines care coordination and outlines its core activities—detailing the essential competencies for those involved in the provision of care coordination and establishing the predicted outcomes.

Effective care coordination is best provided in the context of a health care team, real or virtual, that has established working relationships with one another and among families and children, other clinicians, community partners, and other professionals. Team relationships are characterized by mutual respect, trust, and transparency and are grounded in the needs, concerns, and priorities of families.[31]

The framework builds upon the six elements of the chronic care model developed by Wagner and colleagues.[32] These include the core components of self-management support (rearticulated in our work as care partnership support to reflect a more family-centered approach), delivery system design, decision support, clinical information systems, community, and health systems. The underlying assumption is that optimal patient- and family-centered outcomes are the result of relationships in which children, youth, and their families participate in a fully informed partnership with their primary care provider and a supportive, proactive health care team. Care coordination is the ingredient necessary to operationalize care processes leading to the achievement of these outcomes.

A Definition of High-Performing Pediatric Care Coordination

> *Pediatric care coordination is 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 addresses interrelated medical, social, developmental, behavioral, educational, and financial needs in order to achieve optimal health and wellness outcomes.*

To fulfill the standards set by this definition, care coordination must be connected to, or provided within, a clinician-led, proactive health care team. The team fosters partnerships with families and creates opportunities for them to express their needs. Care coordination is integrated within or strongly linked to a community-based primary care medical home setting, which has the resources and trained staff required to serve as a central hub for communication and information exchange among specialists and community partners across the continuum of care.

In its most robust state, care coordination provides linkages to systems of services available within health care, education, early child care, and family support sectors. An important component of care coordination is the creation of individualized care plans, informed by a comprehensive needs assessment and including a clear delineation of goals, roles, and responsibilities and expected outcomes.

Critical Characteristics of High-Performing Pediatric Care Coordination

Organizations and individuals delivering care coordination services should explicitly endorse the principles of high performance pediatric care coordination and implement strategies to support the provision of these services. The foundational characteristics and attributes of excellent pediatric care coordination include the following:

1. Patient- and Family-Centered

- Links patients and families to an accessible, community-based primary care medical home

2. Proactive, Planned, and Comprehensive

- Supports anticipatory, proactive, continuous, and longitudinal care
- Builds on family strengths and is guided by a comprehensive, standardized assessment of needs
- Supports and relies on team care
- Facilitates the care-planning process including consultation, referral, testing, goals (jointly developed and shared), monitoring, and follow-up
- Plans for the transition of youth from pediatric to adult systems of care

3. Promotes Self-Care Skills and Independence

- Ensures the provision of patient/family education to build self-management skills
- Equips families with the skills needed to navigate a complex health care system

4. Emphasizes Cross-Organizational Relationships

- Builds strategic relationships across a community that support integration of care and patient/youth/family self-management skills
- Ensures effective communication and collaboration along the continuum of care

Essential Competencies for Providing Pediatric Care Coordination

A core care coordination skill is the ability to develop and sustain caring relationships among children, youth, and families, as well as members of the community-wide support system. These competencies need to be held individually or collectively by all clinicians, nurses, social workers, and allied health care professionals who are engaged as a team supporting families. Additional competencies include:

1. Building partnerships that foster family-centered, culturally effective care;
2. Proficiency in interpersonal communication and cross-sector and interdisciplinary communication;

3. Use of team-based, patient- and family-centered assessments that identify strengths and needs of the families;
4. Care-planning skills promoting shared decision-making and patient/family self-management, with thorough follow-up;
5. Integration and shared use of accumulated medical, educational, and community resource information;
6. Efforts and attitudes that are goal- and outcome-oriented;
7. Flexibility and adaptability to the fluctuating needs of children, youth, and families in the context of a changing health care environment;
8. Continuous learning skills and team leadership sharing new knowledge;
9. Capacity to participate in organizational quality improvement activities; and
10. Resourcefulness in the use of information technologies (e.g., tracking and monitoring functions, electronic care plan development and oversight) for optimal care coordination.

Since many patients and their families execute care coordination activities to support their own needs, they should be assisted in developing these competencies. In addition, these competencies should extend to non-health professionals who may provide care coordination services.

The Functions of Care Coordination

Many practices and community-based organizations are looking for clear steps for integrating care coordination services into their fast-paced work environments. The following steps help clarify the roles of coordinators, clinicians, other team members, and families and offer ideas relevant to the testing and implementation of care coordination services.

1. Establish relationships with children, youth, and families through introductory visits dedicated to setting expectations for care coordination.
2. Promote communication with families and among professional partners, and define minimal intervals between communications.
3. Complete a child/youth and family assessment.
4. Working with the family, develop a written care plan, including a medical summary, action plan, and, if needed, an emergency plan, that reflects mutual goals.

5. Arrange for, set up, and coordinate referrals, and track referrals and test results.
6. Provide condition-specific and related medical, financial, educational, and social supportive resource information, while coaching for the transfer of skills supportive of partnerships with families to care for their children and youth.
7. Ensure the health care team integrates multiple sources of health care information; communicate this summary, thereby building caregiver skills and fostering relationships between the health care team and families.
8. Support and facilitate all care transitions from practice to practice and from the pediatric to adult systems of care.
9. Coordinate family-centered team meetings (across organizations as needed).
10. Use health information technology to effectively deliver and continually monitor care coordination and the effectiveness of service delivery.

High-quality care coordination will enable children, youth, and families to access services that support their health, developmental, behavioral, and wellness needs—to get the right care, at the right time, in the right place. Delivery of care coordination must therefore be flexible and responsive to these needs.

Assessment

Care coordination begins with a comprehensive, systematic, and structured assessment of needs, strengths, and assets. Assessment may occur in the primary care medical home or in a community-based, regional health, family support, or educational center linked to the health care system. Under certain circumstances, subspecialty providers may serve as a medical home. Using a co-management model, specialists and primary care providers communicate about care protocols and are explicit about roles and responsibilities for parents. Care coordinators can help with these communications to support integration of care across the health care system.[33] The pediatric care coordination assessment includes the following elements:

- Family Status and Home Environment
    - Medical/behavioral/dental health status
    - Social supports of family and friends
    - Financial needs
    - Family demands, relationships, and functioning
    - Cultural beliefs and values of family

    - Strengths/assets of child, youth, family/caregivers
    - Current goals of child, youth, and family
- Growth and Development
    - Child/youth developmental progress/status
    - Child/youth strengths/assets
    - School performance/needs
    - Emotional/behavioral strengths and needs

Flexibility in Care Coordination Approach

The delivery of care coordination services needs to be flexible, varying by location, encounter type, timing, intensity, and duration. Care providers must take into account the cultural preferences of each family and strive for effectiveness in different circumstances and environments. Innovative approaches to care are essential, from face-to-face visits to nontraditional encounters that optimize use of resources and maximize value for families and providers. These may include the use of:

- Telephone and/or video conferencing;
- E-mail, texting, or instant messaging;
- Group visits for children/youth/families with common conditions or concerns;
- Interactive Web sites;
- School-based visits; and
- Meetings held offsite such as team meetings that "wrap around" the child/youth and family, include a cross organizational representation of professionals involved, and may be held in a variety of community or home settings. These are established collaboratively with youth and families.

Levels of Care Coordination: Needs and Activities

Care coordinators use a comprehensive, systematic assessment to identify and stratify families' needs, taking into account the requirements for carrying out care plans and the resources available to the family. Care coordinators must also have a thorough knowledge of the various health, education, and family support services in the community.

The designation of care coordination levels is critical to the evolution of an integrated system of care coordination. The complexity and intensity of care coordination is a continuum, and the level of care coordination services a family receives will reflect their needs and choices, as well as available resources.

For this framework, we stratified care coordination into three levels, depending on the intensity of services: basic, moderate, or extensive. Children, youth, and families may require different levels of services at different times.

Level 1: Basic. At this level, families are informed of care coordination opportunities and services and are assisted in how and when they choose to take advantage of them. Level 1 can be viewed as an "information and referral" transaction, but the services rendered should still be integrated into a comprehensive care plan.

Example: *The parents of a 2-year-old child wonder what resources are available for child care in their community. The family is given contact information for a community agency, which provides a listing of potential child care providers.*

Level 2: Moderate. At this level, a care coordination plan is developed with families. It details needs, short- and long-term goals, and related strategies and clarifies how care coordination services will be delivered. Skills, knowledge, and increasing responsibility for care coordination are transferred to children and families, as appropriate. Transactions at this level involve communication among various stakeholders; integration of information into a care plan is essential.

Example: *A 30-month-old child presents with possible expressive language delay. The medical home team, in conjunction with the family, creates a care plan that includes referrals to audiology, Early Intervention, and a community-based family-to-family support center. These referrals include sufficient information to optimize the contribution of the consultative services to the child's health and developmental outcomes.*

The family is referred to an Early Intervention program. It is learned that they have no access to transportation other than the city buses. The care plan includes a referral for transportation services. A follow-up phone call in one week is arranged between the family and the care coordinator to review scheduling of appointments. An appointment in four to six weeks with the medical home team (including the primary care physician and care coordinator) is scheduled to review diagnostic assessments and propose future interventions. At that visit, assessment will be made to

determine whether active care coordination needs to continue for this family or the family members are able to maintain principal responsibility for follow-up, with supportive care coordination available on an as-needed basis.

Level 3: Extensive. At this level, care coordination needs to be longitudinal and far-reaching. The members of the care team and family determine methods of communication and intervals for the coordination of care, as well as assessments of progress and outcomes.

- Eligible families require the commitment of significant time and the services of appropriately trained personnel.
- Patients and families are often identified by health insurers as being eligible for case management services. Indeed, the balance of resources between case management and care coordination providers may work together to serve families—if activities are well coordinated.
- Care coordination at this level may also involve co-management among primary and subspecialty providers and community partners. To be effective, this process requires active definition and communication of the roles and responsibilities of all parties with precise documentation in a shared care plan.

Example: *A 17-year-old female has cerebral palsy, a seizure disorder, and nutritional issues including dependence on a G-tube for nighttime feedings, as well as developmental and educational needs. Her care plan is multifaceted to meet her various needs for medical care (neurologic, nutritional, surgical, and gastrointestinal) as well as developmental and educational support. She will require referrals to specialists at community-based agencies and tertiary care settings. In addition, there will be issues related to her transition from pediatric to adult systems of care. Longitudinal, proactive, anticipatory, participatory, and multidisciplinary engagement of the youth with her family and care coordinator will be essential.*

Evaluation: Measurement Strategies

For use in the development of a measurement strategy, Batalden and Nelson offer a four-point compass as guide, called the Clinical Values Compass. North, south, east, and west on the compass represent functional, cost, satisfaction, and clinical outcomes respectively.[34] Table 1 uses this compass as an organizing structure to articulate the desired and anticipated outcomes resulting from excellent care coordination. For example, we hypothesize that there will be enhanced child/youth clinical outcomes and child, youth, and family functional outcomes; greater patient, family, and professional satisfaction; and a reduction in costs with an increase in efficiency and effectiveness. There are few measures available to gauge predicted and desired care coordination outcomes; it is anticipated that Figure 1 will provide a map from which to prioritize and develop this future work.

Table 1. Measuring Care Coordination: Outcomes and Needed Measures

Clinical, cost, functional, and satisfaction outcomes to be measured at the child and family/caregiver levels, the primary care level, at all specialty care points, and from the perspective of critical community partners.

Dimension of Value	Source for Measure	Process	Outcome
Satisfaction:			
1.Achieve patient/family goals	1.Patient, family, caregiver	1.Parent report	1. Goals achieved
2.Reduce unmet needs	2.Patient, family, caregiver	2.Parent report	2. Reduced percentage of unmet needs
3.Increase provider & staff satisfaction	3. Provider (staff)	3.Provider/staff report	3. Increased satisfaction
Function:			
1. Ease of access to resource information 2. Achieve self-management skills 3. Enhance communication among providers/family/community partners 4. Increase functional abilities 5. Support achievement of optimal developmental trajectory	1. Patient, family, and primary care physician (PCP), specialist 2. Patient, family, PCP, specialist 3. Patient, family, community partner, PCP, specialist 4. Family, clinician, school 5. Developmental surveillance/ screening tools	1. Patient, family, PCP, and specialist report 2. Patient, family, PCP, and specialist report 3. Care plans 4. Functional assessments 5. Standardized screening	1. Increased family and professional access to information about available resources 2. Increased positive patient/family "teach-back" skills demonstrated 3.Increased documentation of care plan/medical summary use and oversight 4. Increased functional assessment, school attendance/success, ability to perform activities of daily living 5. Optimal levels achieved; milestones marked
Clinical:			
1. Enhance communication among providers/family/community partners 2.Increase measures of health 3. Increase activity: developmental screening and health promotion (Early and Periodic Screening, Diagnosis, and Treatment)	1. Patient, family/caregiver, PCP, specialist, team 2. Child/family 3. PCP/medical home	1.Shared care plans; co-management agreements 2. Family survey, clinical measures/outcomes 3. Measure screenings, milestone checks, community-focused measures 4. PCP/care team document screening, results, and next steps if necessary.	1. Reduced percentage of children seen by specialists without info from PCP; reduced percentage of children seen by PCP without information from consultants/specialists 2. Clinical goals reached; family perception of child/youth's health increased 3. Increased percentage of all children screened for developmental delays and sensory deficits by select periodic well-child visits and/or school entry
Costs of care:			
1. Reduce emergency department visits	1. Health plan/family	1. Plan and family report	1. Reduced utilization
2. Reduce hospitalizations/hospital days	2. Health plan/family	2. Plan and family report	2. Reduced utilization
3.Reduce duplication of tests, services	3. Health plan, PCP, specialist, community partners	3. Plan, practice, specialist, and community partner report	3. Reduced utilization, redundancy
4. Reduce repeat data gathering by service providers	4. PCP, specialist	4. Practice report of efficiency	4. Increased care team efficiency
5.Reduce caregiver work days lost	5. Family/caregiver	5. Family/caregiver report	5. Reduced lost work days

INTEGRATING CARE COORDINATION ACROSS THE HEALTH SYSTEM

Many recent policy discussions focus on care coordination almost exclusively at the level of the primary care pediatric practice. Yet, a multidisciplinary, multi-stakeholder approach is the only effective way to integrate care coordination into the broader system of care. A high-performing health care system will require clearly defined roles and responsibilities for providing and supporting care coordination at multiple levels: national organizations, federal and state governments, regional and community organizations, practices, and family (Table 2). The stakeholders at each level must play a role in ensuring the development, implementation, and monitoring of well-defined functions of care coordination.

Creating a sustainable approach to care coordination will require policy, financing, operational, regulatory, clinical, and infrastructural elements. Since the ultimate measure of effectiveness of a system of health care is how patients and families themselves experience it, process and outcome measures must be tracked at all levels, including key metrics from the perspectives of families and youth.

Table 2. System-Level Framework for Care Coordination in Pediatric Health Care

Level	Functions of Care Coordination	Enabling Factors for Care Coordination	Family Experience of Care
National Organizations	Well-defined standards for care coordination are declared/disseminated Standards for care coordination financing are adopted	• Quality-focused organizations define and endorse care coordination functions at national, federal, state, regional, practice, and family levels • Professional organizations (family advocacy, providers, allied health, payers) adopt and endorse standards for care coordination across continuum of care • Public–private partnerships seek to jointly fund aligned care coordination demonstration projects • Commercial and public payers support principles to enable equitable access to care coordination services	Opportunities are created for family and consumer groups to articulate their needs and expectations for care coordination
Federal Government	Monitoring system-level care coordination performance	• Medicaid policies support care coordination framework • Link care coordination to EPSDT efforts • Public and commercial payers support unified care coordination principles • Fiscal support promotes system-level care coordination with quality improvement efforts • Interagency collaborations to align care coordination efforts are identified and supported including Title V, Early Intervention, Education, CMS, AHRQ, HRSA, Bureau of Primary Care, MCHB, and others	Opportunities are created for families to provide input into federal policies on care coordination and include measures of quality, safety, equity, finance, and transparency
State Government	Tracking system performance: - quality and cost outcomes - service provision to families - education and training for practices Evaluation includes satisfaction, clinical, functional, and cost outcomes	• Policies promote care coordination competencies and include best-practice guidelines/standards. • Interagency collaborations to align care coordination efforts are identified and supported including Title V, Early Intervention, Education, CMS, AHRQ, HRSA Bureau of Primary Care, MCHB, and others • Regulatory standards for safety and quality include care coordination competencies and responsibilities	Families are involved in developing education and training for care coordination target audiences (other families, agency staff, CBOs, medical personnel) System performance is transparent to families (e.g., care coordination outcomes are measured and publicly available) Family leaders are supported as advisors in developing regulatory standards for care coordination provision

Level	Functions of Care Coordination	Enabling Factors for Care Coordination	Family Experience of Care
Regional/ Community	Tracking system performance: - outcomes, costs - service provision to families - technical assistance to support care coordination in and across practices - family-to-family support system is at community level Evaluation includes satisfaction, clinical, functional, and cost outcomes	• Real-time analysis of community resources for provision of care coordination • Ongoing assessment of care coordination in meeting needs of patients, families, and practices • Support regional system of protected, secure communication	Families receive equitable, timely care coordination services and information that supports their ability to better care for their children and to navigate the system of care Family-to-family support (if desired) is integrated into care plans and easily accessible Accurate information is transferable and shared across all components of the care system (both medical and nonmedical)
Practice	Colocate care coordinators if hired by outside entity or practice hires/leases trained care coordinators Practice-based quality improvement to include: - care plan developed, used, and monitored - family and/or youth advisory - integrate care coordination information across systems of care Evaluation includes satisfaction, clinical, functional, and cost outcomes	Educational resources available to practices for care coordination Educational resources to support quality improvement Educational resources to support family–professional partnerships Health information technology supports care coordination and electronic medical records/electronic health records and is interoperable with external systems Absent fully developed interoperable health information technology system, secure, asynchronous communication mechanism must exist	Well-defined team is apparent to family at point of care Access to team clearly defined Patient/family responsibility as partners in care established Receipt of care plan is standard of care for health care interaction Care plan is developed and informed by all members of care team (including families) Care plan is routinely assessed for accuracy and timeliness, and updating it is a standard part of each care interaction Families and youth have access to health information technology for their care (e.g., via a patient portal)
Family	Receives ongoing, on time assistance as needed; enables family and care coordination skill development Skill development is appropriately focused on youth in transition stages Care coordination is culturally and linguistically competent	Availability of training curriculum for family-centered care coordination Resources for youth preparing for transition are readily available Systems of care and standard-setting organizations endorse the expectation by families that they are entitled to equitable, effective care coordination	Input and feedback from families regarding functional, satisfaction, cost, and clinical aspects of care Education and support are provided to youth on routine basis to support transition to adult systems of care

Notes: CBO = community-based organization; EI = Early Intervention; AHRQ = Agency for Healthcare Research and Quality; CMS = Centers for Medicare and Medicaid Services; MCHB = Maternal and Child Health Bureau; HRSA = Health Resources and Services Administration; EPSDT = Early and Periodic Screening Diagnosis and Treatment.

RECOMMENDATIONS

Much work remains to be done for care coordination to become a regular feature of health care. The contributions of many sectors, both public and private, will be necessary to achieve this goal. These include:

- identifying promising models, tools, and best practices for care coordination based in medical homes;
- identifying promising community-based models to support care coordination;
- developing consensus standards for care coordination services;
- developing measures of care coordination quality;
- evaluating the effectiveness of various care coordination models and systems;
- assessing the value of care coordination for different patient populations;
- integrating care coordination capacity into electronic medical records and health information systems;
- creating a rigorous, cross-disciplinary, and family-centered curriculum for the education and preparation of care coordinators;
- creating training materials for referral from medical homes to community partners and care coordination collaborators;
- identifying policy frameworks to support the provision of care coordination services by all public and private payers; and
- transferring care coordination practices and policies for pediatric care to the care of other patient populations.

CONCLUSION

To achieve a high performance pediatric health care system, it is essential to create and sustain an integrated care coordination infrastructure. The success of this process will depend upon the design and implementation of multiple elements and promoting factors at all levels within the health care system and across multiple sectors of the community. Supporting this transformation will be the development of performance and outcome measures, as well as strategies for workforce development, education, policy support, and financing.

It is critical to point out that the scope of services that comprises comprehensive care coordination for children and youth is markedly different from the scope of care coordination services that comprises care coordination for many adult populations. With

the notable exception of geriatric services, care coordination for many adult patients is essentially management of chronic illnesses. While both adult and pediatric health care must focus on chronic conditions, care coordination that supports the comprehensive needs of children, youth, and families must be broader than this strictly medical view.

The key components of a high-performing care coordination system are most effectively assessed by how the families that receive those services experience the provision of care. To that end, family input is essential to the design of the infrastructure and policies that will support the development of care coordination as an integral part of the health care system.

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