

POLICY STATEMENT

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of All Children

Council on Children With Disabilities

Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs

ABSTRACT. Care coordination is a process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health. Care coordination for children with special health care needs often is complicated because there is no single point of entry into the multiple systems of care, and complex criteria frequently determine the availability of funding and services among public and private payers. Economic and sociocultural barriers to coordination of care exist and affect families and health care professionals. In their important role of providing a medical home for all children, primary care physicians have a vital role in the process of care coordination, in concert with the family. *Pediatrics* 2005;116:1238–1244; care coordination, case management, children with special health care needs, medical home.

ABBREVIATION. AAP, American Academy of Pediatrics.

INTRODUCTION

As defined by the Maternal and Child Health Bureau and accepted by the American Academy of Pediatrics (AAP), “children with special health care needs are 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.”¹ It has become apparent that these more extensive health and related services require forethought in the development of their structure and coordination. *Healthy People 2010* calls for all children* with special health care needs to receive coordinated, ongoing, comprehensive care within a medical home.² The New Freedom Initiative announced in 2001 outlines goals to remove barriers to community living for people with disabilities.³ Care coordination plays an essential role in ongoing efforts to integrate health and related systems of care for children and youth with special health care needs.⁴ In a recent publication, the Institute of Medicine identified overly complex and uncoordinated care as a major reason for “a chasm...that exists between the health care that we

now have and the health care that we could have.”⁵ Although efforts to better define the population continue,⁶ data support the fact that children with special health care needs account for a substantial amount of health services utilization. Children with special health care needs are estimated to account for 13% of all children, yet they represent 70% of health care expenditures.^{7–9} Individuals with chronic illness need coordinated services to provide chronic care management. Recent research supports the benefits of professional care coordination in clinical and process improvements and in reducing health care costs and improving family satisfaction.^{10–13} The importance of these issues is reflected in the work of the National Center of Medical Home Initiatives for Children With Special Needs¹⁴ and in a recent AAP policy statement, “The Medical Home.”⁴

The medical home is an optimal setting for family-centered care coordination. Primary care physicians and other professionals caring for children with special health care needs generally acknowledge the importance of and the need for care coordination services. The increasing number of children with special health care needs, complexity of care, and outreach efforts necessary to educate about the medical home result in even greater responsibility for care coordination. Additionally, initiatives from health care reform and managed care have further expanded the role of the primary care physician in the areas of gatekeeper and coordination roles. New trends in the private health care market are reflected in consumer-driven health plans, a concept that has strong advocates and opponents. Arguments against the concept include biased selection of well members for the consumer-driven health plan, with resultant higher premiums for the chronically ill in traditional insurance programs, less preventive care, and a complicated system. Others argue that there will be cost benefits, more consumer choice, and support for health improvement. Another new trend is health savings accounts, which were created through the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (Pub L No. 108–173) and are designed to help individuals save for future qualified medical and retiree health expenses on a tax-free basis. However, these represent a significant potential negative effect on the concept of the medical home if parents are forced to seek low-cost

* In accordance with the policies of the AAP, references to “child” and “children” in this document include infants, children, adolescents, and young adults up to 21 years of age.
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health care professionals when their health plan requires significant out-of-pocket expenses. If this becomes the case, then the medical home is fragmented,, and quality care coordination services are put at risk. This transition to managed systems of care from traditional fee-for-service care has important implications for aspects of care coordination.

This policy statement reviews the importance of the primary care physician's role in care coordination in the context of the medical home.

MULTIPLE SYSTEMS OF CARE

Advances in medicine have resulted in more children surviving conditions that were once considered to be life threatening. This is often reflected in an increased demand for all levels of care, from primary care to community and educational services to special health care services required by children with chronic conditions.^{15,16} Great variability exists among programs with services for these children. The provision of care includes multiple organizations, often with different missions,¹⁷⁻²⁰ and consists of independent health care professionals, third-party payers, private organizations, and public agencies funded by a variety of sources. These entities, as currently arranged, do not often function collectively as a system of care. Care coordination is complicated by the lack of a single entry point to gain access to systems of health care, social services, education, public health services, and home services. Furthermore, complex eligibility criteria (ie, family income and the child's age and/or health condition) that determine the availability of funding and services often differ among organizations and agencies. Therefore, families may struggle to access needed services and would benefit from professional assistance.¹⁸ Few health plans offer risk-adjusted capitation or fee-for-service reimbursement rates that would justly compensate professionals for the additional time and effort invested in the provision of coordinated and comprehensive care for children with special health care needs.

Because children spend a substantial amount of time in school and child care settings, the linkages between health care and educational and child care systems are especially important for many children and youth with special health care needs.^{18,20} However, each state's educational system uniquely interprets federal laws that mandate services for children with special health care needs, which creates variations in services among states. Although the laws are designed to provide special education and related services for all children with disabilities, some children with special health care needs are excluded from services because they do not meet the categorical definitions stated in these laws.²¹

THE ROLE OF HEALTH PLANS

Historically, public agencies and private organizations involved in human services have helped families determine the needs of their children and access appropriate services. This process is referred to as "case management." Case managers may assist with care coordination. Current payer systems often use

case managers in an attempt to control the costs of health care. These case managers work directly for the payer and may help families with access to services and resource utilization, especially less costly out-of-hospital care, but a major role of theirs has been to limit the financial risk of the payer.

During the past 10 to 20 years, children with special health care needs have had greater access to case management services. Families of children with special health care needs frequently demonstrate the ability to participate in the management of their child's care in a cooperative effort rather than as the subordinates in an authoritarian system.¹⁸ As a result, "care coordination" has replaced the term "case management." Care coordination occurs when care plans are implemented by a variety of service providers and programs in an organized fashion. Care coordination is multifaceted. It involves needs identification, assessment, prioritizing, and monitoring. A coordinator is required to communicate, network, and educate as well as advocate for resources.

THE ROLE OF THE PRIMARY CARE MEDICAL HOME

The role of the primary care medical home in care coordination is not fixed or determined by a defined set of tasks. Instead, it is a dynamic process driven by the health status and developmental progress of the child, the specific needs of the child and family, the primary care physician's expertise with children with special health care needs, and the ability of the family and/or other professionals to participate in care coordination. The primary care physician in the medical home should be aware of the array of available subspecialty services, know when these services are needed, know how to gain access to and advocate for subspecialty care within health plans, and know how to use subspecialists' recommendations and communicate the subspecialists' reports to the family.

The medical home is an important means for the primary care physician to provide care for children.⁴ Medical homes for children with special health care needs incorporate the same elements of health supervision, community-based preventive care, developmental surveillance, and anticipatory guidance used in the ongoing care of all children. Care should be accessible, comprehensive, continuous, compassionate, culturally effective, and family centered. The medical home reinforces care coordination activities by the primary care practice team: the primary care physicians in collaboration with nurses, families, and support staff.

The AAP policy statement "The Medical Home"⁴ lists the desirable characteristics of coordinated care within the medical home, including the following:

1. A plan of care is developed by the physician, practice care coordinator, child, and family in collaboration with other providers, agencies, and organizations involved with the care of the patient.
2. A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the prac-

tice. The record is accessible, but confidentiality is preserved.

3. The medical home physician shares information among the child, family, and consultant and provides a specific reason for referral to appropriate pediatric medical subspecialists, surgical specialists, and mental health/developmental professionals.
4. Families are linked to family support groups, parent-to-parent groups, and other family resources.
5. When a child is referred for a consultation or additional care, the medical home physician assists the child and family in understanding clinical issues.
6. The medical home physician evaluates and interprets the consultants' recommendations for the child and family and, in consultation with them and subspecialists, implements recommendations that are indicated and appropriate.
7. The plan of care is coordinated with educational and other community organizations to ensure that special health needs of the individual child are addressed.

"A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs"²² emphasizes the importance of developing a written transition plan by 14 years of age that will include what services need to be provided, who will provide them, and how they will be financed. Although the pediatrician continues to provide the medical home throughout adolescence, early development of an individualized transition plan that addresses transfer of care as well as educational, recreational, and vocational opportunities will facilitate a successful transition. The plan for transition is often difficult; thus, preparatory time is imperative.

Additional guidelines are outlined in the AAP policy statement "Role of the Physician in Care Coordination for Family-Centered Early Intervention Services,"²³ published in 2001. Training in care coordination and other aspects of the medical home are available through the Every Child Deserves a Medical Home training curriculum of the AAP.¹⁴ Additionally, tools have been developed through the AAP Committee on Coding and Nomenclature to help physicians with the complexities of reimbursement and the determination of the appropriate *Current Procedural Terminology* codes involved with the medical home.

There are increasing time and financial demands on health care professionals. The burdens become even more accentuated in small and rural practices and those dealing with special populations, such as immigrants, for which there is a limited range of available resources.

THE ROLE OF THE FAMILY

The family's role in the medical care of any child is vital. The AAP recognizes that "the family is the child's primary source of strength and support" in its policy statement on "Family-Centered Care and the Pediatrician's Role."²⁴ Additionally, the policy affirmed that the concept of the family as a primary

partner in care coordination is linked to improved health outcomes.

Family members who are knowledgeable about their child's condition often lead the care coordination activities effectively or are active participants in their children's care if they are given opportunities to further develop their skills and strengths.²⁵ The participation of adolescent patients in the decision-making process should be encouraged. Some families and adolescents require greater efforts to be empowered to function optimally as care coordinators.

There are clearly circumstances in which families may need more assistance with care coordination, reflecting factors such as language barriers, educational level, migrant or immigrant status, economic situation, and insurance benefits. In situations in which family members are unable to perform a leadership role and coordination of care has been insufficient, the only person available may be designated by default. This assigned or default care coordinator may not be qualified or prepared or have the needed support. For the treatment plan to be most effective, the individual in charge of taking the lead in care coordination should be designated before the treatment plan is determined.

Professionals who assume primary responsibility for care coordination are often physicians, nurses, and social workers. Alternatively, physical and occupational therapists and other professionals can lead and participate in the coordination process. Families and children themselves are important participants, advisors, and consultants throughout the process. This collaboration with family members is vital because they know the child's needs best.²⁶ Positive changes occur when families and professionals work together to support families in their central role as caregivers.²⁷ In contrast, when they do not work together, the cost of care may increase, patient and family satisfaction may decrease, and patient care may become fragmented and disorganized.^{28,29}

THE ROLE OF THE COMMUNITY

In the educational system, care coordination involves a written individual family service plan, individualized education program, 504 plan, or individual health service plan if individualized testing, special education, therapy, nursing services, psychosocial/emotional supports, appropriate transportation, or assistive technology devices are needed. Care coordination in the social service and public health systems may involve locating and accessing financial assistance programs and public health services. Care coordination in the home setting may mean organizing home nursing/therapy services and/or respite care and adapting the home environment to safely support special technology such as a ventilator or motorized wheelchair.

Many children with special health care needs, especially those who are medically fragile, have unique needs during an emergency that require care coordination and planning. Children who are technology dependent, such as those who require ventilator support or who have pacemakers, tracheostomies, gas-

trostomy tubes, or central venous catheters, have unique problems that often require care by emergency medical services personnel. For additional information, refer to the AAP policy statement "Emergency Preparedness for Children With Special Health Care Needs."³⁰ The primary care physician can facilitate coordination of services by ensuring appropriate communication and advocating for training of emergency medical services personnel. An emergency care form can be completed, including the family's wishes regarding advance directives for end-of-life issues.

BARRIERS TO EFFECTIVE CARE COORDINATION

Several barriers challenge the primary care physician in providing care coordination. These barriers include the following:

- a lack of knowledge and information about the chronic condition, community resources, and/or the coordination process;
- a lack of communication among health care professionals and organizations involved in the child's care;
- a lack of clearly defined roles for each of the members of the practice team, the specialty team, the community agencies, and the family;
- insufficient acknowledgment for the amount of time and work needed to provide quality care coordination services;
- inadequate reimbursement for care coordination because of the additional administrative tasks associated with care coordination, including extensive documentation and counseling;
- a lack of an organized system of care coordination with multiple service delivery systems with multiple care coordinators; and
- language and cultural barriers.

Published reports^{31,32} and families themselves¹⁷ have indicated that there is a greater need for involvement of primary care physicians in the care coordination process, in addition to the provision of primary care, for children with special health care needs. The absence of such involvement results in incomplete coordination and episodic, expensive, fragmented care.

The roles of the primary care physician as both gatekeeper and patient advocate may conflict with each other as physicians strive to manage limited economic resources while providing access to necessary subspecialty care and services.³³ Primary care physicians who provide a medical home for children with special health care needs are actively involved in care coordination, thereby improving quality of care.

CHARACTERISTICS OF SUCCESSFUL CARE COORDINATION MODELS

A number of studies have shown significant benefits related to implementation of care coordination models.¹⁰⁻¹³ Benefits include reduced hospital admissions, reduced length of hospital stay, reduced inpatient charges, reduced emergency department

visits, improved patient satisfaction, and enhanced opportunities for outcome-based clinical process improvement.

Title V of the Social Security Act had its origin in 1935 but has undergone multiple revisions. The amendments of 1989 (42 USC Chapter 7, Subchapter V §§701-710) reinforced the development of case management services.³⁴ The initial goal of case management was to decrease overlapping of multiple services. Other recognized benefits that accrued were improved access to care and a resultant feeling that the care provided was superior.³⁵

Early intervention services were mandated in 1986 as an entitlement program when Congress passed the Education of the Handicapped Act Amendments (Pub L No. 99-457). They were reauthorized under the Individuals With Disabilities Education Act (Pub L No. 101-476 [1990]) as Part C. This legislation required the formation of the individual family service plan and defined community-based, family-centered, multidisciplinary intervention programs for infants and toddlers with developmental delays. Family training and counseling also were provided. New Jersey developed a unique model that combined the funding from Title V and the Individuals With Disabilities Education Act to provide county-based case management units, which provides a single point of entry into an otherwise very complex system when entry is based on need or funding. Many state Title V programs are implementing similar systems of care coordination.¹⁴

Successful models of care coordination have a number of common characteristics.^{10,36-38} Both the Center for Medical Home Improvement³⁵ and the Institute for Community Inclusion³⁸ have published guidelines for care coordination in primary care settings. Standardized criteria help to identify children in need of care coordination and should be used.^{6,36,38,39} Collaboration between insurers and professionals at the local and state level is critical. Each practice or community should have a designated care coordinator who provides a single point of entry. Nurses, nurse practitioners, physician assistants, and social workers have been successful in this role. One possible advantage for nurse practitioners and physician assistants in some settings is that their services may be reimbursed.³⁸ Ongoing assessment of the needs of each child and family is essential. The acuity and requirements of services fluctuate depending on the needs and wishes of the family. The process also may vary depending on the extent and multiplicity of the child's needs, family strengths, type of health care services available, limitation of benefits by the payer, and mission of the agency. Updated, standardized educational materials related to the care of children with special health care needs in general, as well as disease-specific information, should be available. The care coordination program should include an outcome-focused quality improvement component.

The care coordinator has the primary responsibility for the child's treatment plan and should document completion of tasks or, conversely, the need to vary from the original plan. The plan should include

the following components: a medical summary for use by emergency and hospital services as well as for medical care by physicians who are not familiar with the patient; patient- and family-centered short-term and long-term goals; role of the family and other supports; locus of implementation; methodology; intensity; and duration. The coordinator may need to communicate with payers such as Medicaid or health plans to obtain preapproval for services. The care coordinator should be knowledgeable about family and medical resources and insurance options, be able to identify and access resources for family support, and act as an advocate when necessary. Throughout the process, patient advocacy in the context of the family is important. High-intensity care coordination is needed at the time of medical diagnosis, hospital discharge, entrance into child care and school settings, transition to young adulthood, and when a change in health care status occurs. At these times, the primary care physician's special relationship with a child and the family can facilitate the appropriate support. At other times, coordination requirements may be less demanding and could be accomplished with a lesser degree of service, such as making a telephone call or forwarding records.

Generally, the goals of care coordination are to (1) develop an anticipatory/proactive plan for appropriate services for the child and family, integrating the recommendations of multiple professionals and service systems, (2) assist the family in accessing needed services and resources, (3) facilitate communication among multiple professionals, (4) avoid duplication of services and unnecessary costs, (5) optimize the physical and emotional health and well-being of the child, and (6) improve the child's and family's quality of life.

CONCLUSIONS

Although care coordination can be complex and time consuming and is always challenging, it is essential for efficient management of the many complex issues surrounding the care of children with special health care needs within the context of the medical home. Becoming aware of available resources, being involved in the care coordination process, and developing unique care coordination approaches within one's own practice and community and in relationship with existing tertiary care centers are essential for providing optimal care for children with special health care needs. Families, primary care physicians, and other professionals can collaborate meaningfully to provide effective coordinated care. Successful care coordination results in optimal outcomes for children with special health care needs and their families and provides an opportunity for professional fulfillment for physicians.

RECOMMENDATIONS

1. Primary care physicians, medical subspecialists and surgical specialists, physician's staff, families, community agencies, educators, early intervention professionals, allied health professionals, tertiary care centers, state Title V agencies, and in-

2. Families of children with special health care needs should have the opportunity to lead the care coordination team and/or be proactive participants. To do so, the parents (or adolescent patients themselves) must have information about the condition, proper education in care coordination, and access to necessary resources.
3. Primary care physicians caring for children with special health care needs should facilitate access to community-based services through use of the medical home strategies. The AAP National Center of Medical Home Initiatives for Children With Special Needs (www.medicalhomeinfo.org) is a resource that can assist the pediatrician.
4. The primary care physician's role in care coordination should be flexible to meet the dynamic needs of the child and family. The primary care physician, a member of the physician's staff, a family member, or another member of the child's medical home may be designated the leader of the care coordination team. The Center for Medical Home Improvement³⁶ and the Institute for Community Inclusion³⁸ have developed kits that provide tools to identify needs and areas for improvement.
5. Successful provision of care coordination is contingent on adequate reimbursement for efforts. Health care professionals should be financially reimbursed by third-party payers for the time spent on care coordination and care plan development and oversight; otherwise, the efforts will fail. *Current Procedural Terminology* codes for telephone calls, prolonged service, team conferences, and care plan oversight and management should be reimbursed in all benefit packages.
6. Research efforts should continue to develop new approaches in care coordination and to investigate the outcomes and benefits of care coordination, especially within the context of the medical home.
7. Interdisciplinary training opportunities in the medical home philosophy and care coordination are available through the National Center of Medical Home Initiatives for Children With Special Needs.⁷ Medical students and residents in training should incorporate care coordination skills so that they are better prepared to coordinate care when they begin community practice. (For additional information, refer to the AAP policy statement "The Pediatrician's Role in Community Pediatrics."⁴⁰)
8. Barriers to care coordination should be addressed and overcome. These barriers for the family often include cultural/language status, educational level, economic situation, and transportation resources.

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ADDITIONAL RESOURCE

Center for Infants and Children With Special Needs, Cincinnati Children's Hospital Medical Center and The National Center of Medical Home Initiatives for Children With Special Needs. *Care Coordination Toolkit: Proper Use of Coordination of Care Codes With Children With Special Health Care Needs (CSHCN)*. Elk Grove Village, IL: American Academy of Pediatrics; 2004. Available at: www.medicalhomeinfo.org/tools/continuous.html

This toolkit provides information on billing for the coordination of care with descriptions of individual codes and proper documentation and an easy-to-follow billing slip. The appendices include:

- Identification of Children and Youth With Special Health Care Needs: Tools and Strategies
- How to Label/Flag the Chart: Tools and Strategies
- Forms
- How to Negotiate With Public and Private Insurers: Tools and Strategies
- Selected Vignettes

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13. Publication Title Pediatrics	14. Issue Date for Circulation Data Below September 2005	
15. Extent and Nature of Circulation	Average No. Copies Each Issue During Preceding 12 Months	No. Copies of Single Issue Published Nearest to Filing Date
a. Total Number of Copies (Net press run)	66,249	68,100
(1) Paid/Requested Outside-County Mail Subscriptions Stated on Form 3541 (Include advertiser's proof and exchange copies)	61,020	60,781
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c. Total Paid and/or Requested Circulation (Sum of 15b (1), (2), (3), and (4))	63,320	65,146
d. Free Distribution by Mail (Samples, complimentary, and other free)		
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(3) Other Classes Mailed Through the USPS		
e. Free Distribution Outside the Mail (Carriers or other means)		
f. Total Free Distribution (Sum of 15d. and 15e.)		
g. Total Distribution (Sum of 15c. and 15f.)	63,320	65,146
h. Copies not Distributed	2,929	2,954
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j. Percent Paid and/or Requested Circulation (15c. divided by 15g. times 100)	100%	100%
16. Publication of Statement of Ownership <input checked="" type="checkbox"/> Publication required. Will be printed in the <u>November</u> issue of this publication. <input type="checkbox"/> Publication not required.	17. Signature and Title of Editor, Publisher, Business Manager, or Owner <i>Bridget A. Donohue</i> Date 9/23/05	

I certify that all information furnished on this form is true and complete. I understand that anyone who furnishes false or misleading information on this form or who omits material or information requested on the form may be subject to criminal sanctions (including fines and imprisonment) and/or civil sanctions (including civil penalties).

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Pediatrics 2005;116;1238

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