

# AMERICAN ACADEMY OF PEDIATRICS

Committee on Children With Disabilities

## Care Coordination: Integrating Health and Related Systems of Care for Children With Special Health Care Needs

**ABSTRACT.** *Care coordination* is a process that links children with special health care needs and their families to services and resources in a coordinated effort to maximize the potential of the children and provide them with optimal health care. Care coordination often is complicated because there is no single entry point to multiple systems of care, and complex criteria 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 pediatricians have a vital role in the process of care coordination, in concert with the family.

---

ABBREVIATIONS. MCHB, Maternal and Child Health Bureau; AAP, American Academy of Pediatrics.

---

According to the Maternal and Child Health Bureau (MCHB) definition, which was later adopted by the American Academy of Pediatrics (AAP), "children with special health care needs are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally."<sup>1</sup> Primary care pediatricians and other professionals caring for children with special health care needs generally acknowledge the importance of and the need for coordination of care. New initiatives from health care reform and managed care are reshaping the traditional direct clinical care role of the primary care pediatrician to include gatekeeper and coordination roles. This transition to managed systems of care from traditional fee-for-service care has important implications for aspects of care coordination. The primary care pediatrician may be required to assume even greater responsibility for providing care coordination for their patients under capitated arrangements. This policy statement reviews the importance of the primary care pediatrician's role in care coordination in the context of the medical home.

### MULTIPLE SYSTEMS OF CARE

Advances in medicine have resulted in increased survival of children with special health care needs

who require long-term services from a variety of health care professionals and organizations.<sup>2,3</sup> Great variability exists among programs with services for children with special health care needs and their families. Many systems of care include multiple organizations, often with different missions,<sup>4-7</sup> and consist of independent health care professionals, third-party payers, organizations, and agencies funded by a variety of sources. The lack of a single entry point linking systems of health care, social services, education, public health services, and home services makes coordination of care complicated. Furthermore, eligibility criteria (ie, family income and the child's age and/or health condition) that determine the availability of funding and services are often complex and differ among agencies. Families therefore often experience difficulty gaining access to some services and may request assistance.<sup>5</sup> Few health plans offer risk adjusted capitation or fee-for-service reimbursement rates that would more fully reflect the additional time and effort entailed in providing medical care for children who have 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 children with special health care needs.<sup>5,7</sup> However, each state educational system interprets the federal laws mandating services for children with special health care needs differently, which creates variations in services among states. Although the laws are designed to provide special education and related services for *all* children with disabilities, many children with special health care needs are excluded from services because they do not meet the categorical definitions stated in these laws.<sup>8</sup>

### HISTORY AND DEFINITION

Historically, public and private agencies involved in human services have helped families determine their needs and gain access to services. This process is referred to as "case management." Case managers may assist with care coordination. In contrast, insurance companies use "benefit managers" in an attempt to control the cost of health care. These benefit managers, because they work directly for the insurer, may help families gain access to services, especially less costly out-of-hospital care, but their major role, with few exceptions, has thus far been to limit the financial risk of the insurer. In such practice, these

---

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

PEDIATRICS (ISSN 0031 4005). Copyright © 1999 by the American Academy of Pediatrics.

benefit managers are involved in resource utilization.

During the past 10 to 20 years, children with special health care needs have had greater access to case-management services. Families of the children also have demonstrated that they are able to participate in the management of their child's care in a cooperative effort rather than as the subordinates in an authoritarian system.<sup>5</sup> As a result, they have advocated replacing the term *case management* with the term *care coordination*. Care coordination occurs when a specified care plan is implemented by a variety of service providers and programs in an organized fashion.

#### COMPONENTS AND TYPES OF CARE COORDINATION

In the *health care system*, care coordination may involve the following: planning treatment strategies; monitoring outcomes and resource use; coordinating visits with subspecialists; organizing care to avoid duplication of diagnostic tests and services; sharing information among health care professionals, other program personnel, and family; facilitating access to services; planning a hospital discharge; and notification, advanced planning, training of caregivers, education of local emergency medical services when a child with special health care needs lives in their community, and, finally, ongoing reassessment and refinement of the care plan.<sup>9</sup> In the *educational system*, care coordination may mean identifying the need for individualized testing, special education, and therapy and nursing services; clarifying plans as written in Individual Family Service Plans and Individual Education Plans; gaining access to appropriate transportation; and acquiring assistive technology devices. 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 and therapy services, respite care, and adapting the home to support special technology such as a ventilator or a motorized wheelchair. The process also may vary depending on the extent and multiplicity of the child's needs, family strengths, type of health care services available, limitations of the payer, and mission of the agency. 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: 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 maintenance organizations to obtain prior approval for services. Throughout the process, patient advocacy in the context of the family is important. High-intensity care coordination is needed at the time of hospital discharge, entrance into day care and school settings, transition to young adulthood, and when a change in health care status occurs. The primary care pediatrician may have established a special relationship with a child and the family over

many years, and therefore would most likely facilitate the appropriate support in such a time of need. During other times, coordination may require fewer services, such as making a phone call or forwarding records. Generally, the goals of care coordination are the following: 1) gain access to and integrate services and resources, 2) link service systems with the family, 3) avoid duplication and unnecessary cost, and 4) advocate for improved individual outcomes.

#### THE FAMILY'S ROLE

Family members are able to lead the care coordination team effectively and/or be active participants when they are knowledgeable about their child's condition and their skills and strengths are supported.<sup>10</sup> The participation of adolescent patients in the decision-making process should be encouraged and supported. Some families and adolescents require greater efforts and support to be empowered to function most optimally as care coordinators. In situations in which family members are unable to perform a leadership role, and treatment planning has been insufficient, the care coordinator may be chosen by default as the only person available and may not be qualified, prepared, or have the needed support. Pediatricians, through the AAP Medical Home Training program, may assist and educate the care coordinator. For the treatment plan to be most effective, the care coordinator should be designated before the treatment plan is determined.

When care coordination for children with medically complex needs is assumed primarily by professionals, it is commonly accomplished by nurses and social workers, but primary care pediatricians, physical and occupational therapists, and other professionals can lead or participate in the coordination process. Nevertheless, families and adolescents themselves are important participants, advisors, and consultants throughout the process. This collaboration with family members is vital because they know their needs best,<sup>11</sup> usually better than the health care professional. Very positive changes occur when families and professionals work together to support the families in their central role as caregivers.<sup>12</sup> In contrast, when they do not work together, the cost of care may increase, patient satisfaction may decrease, and patient care may become fragmented and disorganized.<sup>13,14</sup>

#### THE PRIMARY CARE PEDIATRICIAN'S ROLE

The primary care pediatrician's role in care coordination within the medical home concept is not fixed or determined by a defined set of tasks but 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 pediatrician's expertise with children with special health care needs, and the availability of other professionals to provide care coordination. Several barriers challenge the primary care pediatrician in providing care coordination. These barriers include the following:

- Lack of knowledge and information about the

- chronic condition, community resources, and/or the coordination process;
- lack of communication among the health care professionals and organizations involved in the child's care;
  - the extra time and effort necessary to provide coordination services;
  - the lack of adequate reimbursement for care coordination; and
  - the existence of multiple care coordinators.

Published reports<sup>15,16</sup> and families themselves<sup>4</sup> have indicated that there is a greater need for involvement of primary care pediatricians in the care coordination process, in addition to the provision of primary care to children with special health care needs. The absence of such involvement results in incomplete coordination and episodic, expensive, fragmented care. The primary care pediatrician should be aware of the array of available subspecialty services, know when they are needed, know how to gain access and advocate for them with managed care organizations, and know how to communicate the subspecialist reports to the family.

The concept of the medical home is an important way for the primary care pediatrician to provide care for children.<sup>17</sup> The medical home for children with special health care needs incorporates the same elements of well-child care, community-based preventive care, developmental surveillance, and anticipatory guidance used in the ongoing care of children who do not have special needs. Care should be accessible, comprehensive, continuous, compassionate, culturally competent, and family-centered. The concept of the medical home reinforces care coordination activities of primary care pediatricians, in collaboration with nurses and support staff. A designated care coordinator is necessary to facilitate optimal outcomes and to prevent confusion.

Many children with special health care needs, especially the medically fragile child, have unique needs during an emergency that require care coordination and planning. Complex problems often must be addressed by unprepared professionals during an emergency. Children who require ventilator support or who have pacemakers, tracheostomies, gastrostomy tubes, and central venous catheters have unique problems that often require care by emergency medical services personnel. (For additional information, refer to the AAP's statement "Emergency Preparedness for Children with Special Health Care Needs."<sup>18</sup>) The primary care pediatrician can facilitate coordination of services by assuring availability of information related to anticipated emergency problems.

The roles of the primary care pediatrician as both gatekeeper and patient advocate may conflict with each other, as physicians strive to reduce costs while providing access to necessary subspecialty care and services.<sup>19</sup> Primary care pediatricians who provide a medical home for children with special health care needs are actively involved in care coordination, thereby improving quality of care.

## CONCLUSION

Although care coordination can be complex, time-consuming, and even frustrating, it is the key to 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 community and tertiary care centers are essential to provide optimal care for children with special health care needs. Families, primary care pediatricians, and other professionals need to collaborate meaningfully to provide effective coordination of care. Successful care coordination resulting in optimal outcomes for children with special health care needs and their families provides an opportunity for professional fulfillment for pediatricians.

## RECOMMENDATIONS

1. Primary care pediatricians and tertiary care centers should work cooperatively to develop health care models that include care coordination to link families and to help patients be accommodated with a full spectrum of needed health, education, and social services in an effort to improve the quality of care.
2. Ideally, families of children with special health care needs should lead the care coordination team and/or be proactive participants. To do so, the parents (or adolescent patients themselves) must have access to information about the child's (their own) condition, proper education in care coordination, and other necessary resources.
3. Primary care pediatricians caring for children with special health care needs should facilitate access to community-based services through use of the medical home concept.
4. Primary care pediatricians should have an important role in care coordination. This role should be flexible to meet the dynamic needs of the child and family. If neither the primary care pediatrician nor the family is able to become the care coordinator, another member of the child's medical home should be designated.
5. Barriers to care coordination should be addressed. Successful provision of care coordination is contingent on adequate reimbursement for efforts. Time expended in care coordination by primary care pediatricians and other health care professionals should be financially reimbursed by third-party payers; otherwise the efforts will fail.
6. Research should be done to develop new approaches to coordinating care 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 being developed. These curricula are already available to physicians and families in some parts of the country. However, they should be expanded and made available to all medical students and residents so that they are better

prepared to coordinate care when they *begin* community practice. (For additional information refer to the AAP's policy statement "The Pediatrician's Role in Community Pediatrics."<sup>20</sup>)

COMMITTEE ON CHILDREN WITH DISABILITIES,  
1998–1999

Philip R. Ziring, MD, Chairperson  
Dana Brazdziunas, MD  
W. Carl Cooley, MD  
Theodore A. Kastner, MD  
Marian E. Kummer, MD  
Lilliam Gonzalez de Pijem, MD  
Richard D. Quint, MD, MPH  
Elizabeth S. Ruppert, MD  
Adrian D. Sandler, MD

LIAISON REPRESENTATIVES

William C. Anderson  
Social Security Administration  
Polly Arango  
Family Voices  
Paul Burgan, MD, PhD  
Social Security Administration  
Connie Garner, RN, MSN, EdD  
US Department of Education  
Merle McPherson, MD  
Maternal and Child Health Bureau  
Linda Michaud, MD  
American Academy of Physical  
Medicine/Rehabilitation  
Marshalyn Yeargin-Allsopp, MD  
Centers for Disease Control and Prevention

SECTION LIAISONS

Chris P. Johnson, MEd, MD  
Section on Children With Disabilities  
Lani S. M. Wheeler, MD  
Section on School Health

CONSULTANTS

John Nackashi, MD  
James M. Perrin, MD

REFERENCES

1. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102:137–140
2. Boyle CA, Decoufle P, Yeargin-Allsopp M. Prevalence and health impact of developmental disabilities in US children. *Pediatrics*. 1994;93:339–403
3. Newacheck PW, Taylor WR. Childhood chronic illness: prevalence, severity, and impact. *Am J Public Health*. 1992;82:364–371
4. Stein REK. Introduction. In: Stein REK, ed. *Caring for Children With Chronic Illness: Issues and Strategies*. New York, NY: Springer; 1989:23
5. Bruininks RH, Frenzel M, Kelly A. Integrating services: the case for better links to schools. *J Sch Health*. 1994;64:242–248
6. Ireys HT, Nelson RP. New federal policy for children with special health care needs: implications for pediatricians. *Pediatrics*. 1992;90:321–327
7. Kelly A. The primary care provider's role in caring for young people with chronic illness. *J Adolesc Health*. 1995;17:32–36
8. Walker DK. Public education: new commitments and consequences. In: Stein REK, ed. *Caring for Children With Chronic Illness: Issues and Strategies*. New York, NY: Springer; 1989:41–62
9. Liptak GS, Revell GM. Community physician's role in case management of children with chronic illnesses. *Pediatrics*. 1989;84:465–471
10. Bishop KK, Woll J, Arango P. *Family/Professional Collaboration for Children With Special Health Care Needs*. Burlington, VT: University of Vermont, Dept of Social Work; 1993
11. Jeppson ES, Thomas J. *Essential Allies: Families as Advisors*. Bethesda, MD: Institute for Family-Centered Care; 1994
12. Bailey DB, Buysse V, Elam J, Smith T. The effects and perceptions of family involvement in program decisions about family-centered practices. *Eval Program Plann*. 1992;15:23–32
13. Pierce PM, Freedman SA. The REACH project: an innovative health delivery model for medically dependent children. *Child Health Care*. 1983;12:86–89
14. Fields AI, Coble DH, Pollack MM, Kaufman J. Outcome of home care for technology-dependent children: success of an independent, community-based case management model. *Pediatr Pulmonol*. 1991;11:310–317
15. Kanthor H, Pless B, Satterwhite B, Myers G. Areas of responsibility in the health care of multiply handicapped children. *Pediatrics*. 1974;54:779–785
16. Palfrey JS, Levy JC, Gilbert KL. Use of primary care facilities by patients attending specialty clinics. *Pediatrics*. 1980;65:567–572
17. American Academy of Pediatrics, Ad Hoc Task Force on Definition of the Medical Home. The medical home. *Pediatrics*. 1992;90:774
18. American Academy of Pediatrics, Committee on Pediatric Emergency Medicine. Emergency preparedness for children with special health care needs. *Pediatrics*. 1999;104(4). URL: <http://www.pediatrics.org/cgi/content/full/104/4/e53>
19. Azevedo D. Are we asking too much of gatekeepers? *Med Econ*. 1994;71:126–138
20. American Academy of Pediatrics, Committee on Community Health Services. The pediatrician's role in community pediatrics. *Pediatrics*. 1999;103:1304–1306