

CLINICAL REPORT

Guidance for the Clinician in Rendering Pediatric Care

Theodore A. Kastner, MD; and the Committee on Children With Disabilities

Managed Care and Children With Special Health Care Needs

ABSTRACT. The implementation of managed care for children with special health care needs is often associated with apprehension regarding new barriers to health care services. At times, these barriers may overshadow opportunities for improvement. This statement discusses such opportunities, identifies challenges, and proposes active roles for pediatricians and families to improve managed care for children with special health care needs. *Pediatrics* 2004;114:1693–1698; managed care, children with special health care needs, chronic illness, disease management, Medicaid.

ABBREVIATIONS. MCO, managed care organization; SCHIP, State Children’s Health Insurance Program; AAP, American Academy of Pediatrics; CHCS, Center for Health Care Strategies.

INTRODUCTION

Managed care has been expanding to include coverage for children* with special health care needs, most of whom have previously received health services through a combination of fee-for-service plans and public programs including Medicaid and state and federal maternal and child health programs. Many managed care plans focus on the provision of efficient services to generally healthy populations and are not routinely designed to respond to the special needs of children who have disabilities and chronic illnesses. Managed care could benefit these children and their families by improving access and coordination of services. However, there is potential for the difficulties that families face in obtaining the full range of child and family services necessary to ensure the child’s good health and proper development to increase.^{1,2} Aspects of managed care are reviewed as they relate to children with special health care needs, and steps for improving managed care services for these children are suggested, including recommendations to assist pediatricians in improving their ability to be reimbursed for providing services to children with special health care needs who are enrolled in managed care organizations (MCOs).

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

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*In accordance with the policies of the American Academy of Pediatrics, references to “child” and “children” in this document include infants, children, adolescents, and young adults up to age 21.

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WHAT IS MANAGED CARE?

Freund and Lewit³ define managed care as a delivery system that integrates financing and delivery of specified health care services by means of 4 key elements:

1. Arrangement with selected clinicians to furnish health care services to members of the plan for preset fees.
2. Explicit standards for the selection of clinicians.
3. Formal programs of quality assurance and utilization review.
4. Substantial incentives for members to use clinicians associated with the plan.

Managed care aims to provide quality health services through utilization-control and cost-containment mechanisms. Achieving these goals for children with special health care needs requires special attention to several key issues. These concerns operate throughout the system of care, including the pediatrician, the family and child, the MCO, and the payor (parent’s employer, Medicaid, Medicare, etc). A more thorough discussion of managed care can be found in *The Pediatrician’s Guide to Managed Care*.⁴

WHO ARE CHILDREN WITH SPECIAL HEALTH CARE NEEDS?

Children with special health care needs represent a diverse population.^{5,6} Recently, the federal Maternal and Child Health Bureau’s Division of Services for Children With Special Health Care Needs convened a workgroup to develop a definition:

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.^{7(p138)}

Studies indicate that 6%³ to 35%⁸ (depending on what is included among the disabling conditions) of children have special health care needs and require special health care services. Children with special health care needs utilize significantly more health care services than other children.⁹ These children have more complicated disabilities (eg, multiple, life-long, and/or technology dependent) that compound their needs. Subspecialty and inpatient care, often at tertiary facilities, as well as ongoing complex outpatient management, community-based services, home nursing services, and medical supplies make it difficult to devise realistic strategies for cost containment.

This subset of the pediatric population, children with special health care needs and their families, faces an important challenge with the growth of managed care in being able to access all services described.

Children with special health care needs differ from adults with disabilities in a managed care environment in a variety of ways. Three major differences include: (1) the changing dynamics of child development affect the needs of these children at different developmental stages and alter their expected outcomes; illness and disability can delay, sometimes irreversibly, a child's normal development; (2) the epidemiology and prevalence of childhood disabilities, with many rare or low-incidence conditions and few common ones, differ markedly from those of adults, in which there are few rare conditions and several common ones; and (3) because of children's need for adult protection and guidance, their health and development depend greatly on their families' health and socioeconomic status.¹ Strategies that optimize child health outcomes, minimize the potential for developmental delay, and address these differences must be an integral part of any system that presumes to manage care for this special population.

PEDIATRICIANS, MANAGED CARE, AND THE MEDICAL HOME

The medical home is characterized as "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them."^{10(p184)}

Incentives of managed care that focus on primary care, care coordination, and community-based services based on the principles of the medical home are generally more effective than costly uncoordinated care, such as relying on episodic care in emergency departments. As a result, the pediatrician serving children with special health care needs in managed care must focus on preserving the medical home and enhancing the capacity of the family to care for the child in the community.

Given this need, it is particularly important to gather objective data to evaluate important process and outcome measures in managed care.^{11,12} Managed care, because it aggregates cost, utilization, and outcomes data, provides a unique opportunity to assess the quality of care received by children with special health care needs. Newacheck et al¹³ outlined the necessary attributes for such a system. Effective monitoring of managed care for children with special health care needs requires the capability to identify various categories of children with chronic conditions in the target population. Uniform definitions and coding mechanisms may also need to be established to retrieve data for these children. The system should be comprehensive enough to monitor a variety of factors pertinent to families with children with special health care needs, such as child health, family influences, access, utilization, expenditures, cost-effec-

tiveness, quality, satisfaction, and short- and long-term effects. "Managed Care and Children With Special Health Care Needs: Creating a Medical Home" is an excellent review of this topic and can be found at www.aap.org/advocacy/mcmdm.htm.

FOCUS ON THE FAMILY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

As families change from fee-for-service to managed care, long-term relationships may change abruptly. At times, the change is from physicians with whom the family feels familiarity and comfort based on common experience and understanding to physicians in another plan who may lack the experience or desire to care for children with special needs. Other factors such as unfamiliarity with the child and family, lack of resources available to families and children with special health care needs, or the inability to coordinate care may result in a decrease in the quality of care.¹⁴

Managed care may also pose other risks for children with special health care needs. First, "risk avoidance" may motivate health plans to "cherry pick," thereby leading to the exclusion of high-risk populations from many managed care initiatives. In addition, capitation contracts, particularly those that include financial risk, may create disincentives for primary care pediatricians to take on high-cost patients, especially without agreement as to what constitutes "fair" payment rates or adequate risk adjustment. Paradoxically, managed care can also lead to fragmentation of care. For example, the use of carve-outs for behavioral and other services often prevent pediatricians from being reimbursed for services, which can lead to difficulties in coordinating care between pediatricians and behavioral health care professionals. Finally, few data currently provide information on the relationship between managed care and other vitally important supports for the child and family. For example, states implementing Medicaid managed care for children with special health care needs need to ensure that "medically necessary services" include habilitative services, the goals of which are to improve function, including physical therapy, speech therapy, occupational therapy, durable medical equipment, specialized nursing services, telemedicine, and other similar services.¹⁵ These services need to be closely coordinated with additional guidance provided through the Individuals With Disabilities Education Act (Pub L No. 101-476 [1990]), the Home and Community Based Services Waiver (Pub L No. 97-35 §2176 §1915), the "Katie Beckett" Waiver, and Early and Periodic Screening, Diagnostic, and Treatment program services.

MAKING MANAGED CARE WORK

Pediatricians are in a unique position to have a significant role in ensuring the appropriate design and implementation of managed care for children with special health care needs, particularly when public programs such as Medicaid and the State Children's Health Insurance Program (SCHIP) are involved. The American Academy of Pediatrics

(AAP) offers a wealth of information to pediatricians interested in contracting with Medicaid MCOs. Particularly useful are "Medicaid Policy Statement," "Medicaid Managed Care Contracts: Key Issues for Pediatricians," (see "Resources") and "Guiding Principles for Managed Care Arrangements for the Health Care of Newborns, Infants, Children, Adolescents, and Young Adults."¹²

The following section is not a comprehensive review but represents a brief discussion of selected topics related to children with special health care needs.

At the state level, individual pediatricians can work closely with state agencies that contract with and/or regulate health plans. In many instances, pediatricians will find that their interests are aligned with those of other health care professionals, advocates, and consumers who see opportunities in the changing marketplace. For example, as states implement Medicaid managed care, pediatricians can play an important role at the state and plan levels in strengthening the capacity of MCOs to address special needs of children, including recruitment and retention of general and subspecialty pediatricians. They also can assist in establishing appropriate utilization review mechanisms and quality improvement activities. Finally, they can be important partners in ensuring cost-effective systems of care for children with special health care needs. The AAP has numerous policy statements and, along with state chapters, other resources available to states and plans. For example, the AAP is working with health plans to ensure that a definition of medical necessity be sensitive to the needs of children, particularly children with special health care needs.¹⁵

At the MCO level, pediatricians can support health plans by advocating for adequate capitation by payors. This may be an important step in building good will between pediatricians and health plans. Capitation systems that include managing the care of children with special health care needs should recognize the need for increased pediatrician time required for service coordination, an increased number of office visits, lengthy counseling, and the potential for increased communication associated with referral for community, subspecialty, and hospital services. If capitation is to be realistic in relation to the care of children with special health care needs, methods to determine fair and appropriate capitation rates need to be developed, including application of an empirically sound and methodologically valid risk-adjustment payment system based on health status. State AAP chapters and their member pediatricians can assist MCOs in negotiating with government or commercial payors.

The Center for Health Care Strategies (CHCS) offers a number of resources for pediatricians. The CHCS works with state officials, health plan leaders, and consumer organizations across the country to improve health services for low-income families and for people with severe illnesses and disabilities whose needs cross over from the routine to the highly specialized. These resources include training

and technical assistance to help states, health plans, and consumer organizations effectively use managed care to improve the quality of services for beneficiaries, reduce racial and ethnic health disparities, and increase community options for people with disabilities. CHCS recently concluded a program titled "Improving Managed Care for Children With Special Needs" to develop and pilot strategies to improve the quality of care for children with special needs enrolled in Medicaid and SCHIP. The workgroup, consisting of chief medical officers and decision makers from leading Medicaid health plans across the country, identified and piloted best practices for children with special needs. Plans focused on creating a "Medical Home," cultural competency, risk adjustment, and consumer relations. A toolkit summarizing best practices learned by workgroup plans is available online at www.chcs.org.

PEDIATRICIANS CAN ADVOCATE FOR THEMSELVES IN THIS PROCESS

As noted above, pediatricians contracting with health plans are paid through a variety of means such as fee-for-service reimbursement, capitation, and/or administrative fees. It is certain that providing care to children with special health care needs is more expensive than providing care to average healthy children. As a result, it is most important that pediatricians contracting with health care plans have specific knowledge about how much it costs their practices to provide care to specific types of patients. Pediatricians who contract with MCOs at rates that are below cost will ultimately shortchange themselves, their patients, and their patients' families and be frustrated by what they perceive as a poor relationship with their MCO partners. As a result, all negotiations for reimbursement must be guided by and based on knowledge of the practice's internal cost structure. Fee-for-service options are most appropriate for pediatricians in smaller practices that have small numbers of children with special health care needs. In this scenario, the practice is protected against cost overruns associated with unexpected patterns of utilization (adverse events). In contrast, pediatricians in larger practices may consider capitation as a means of reimbursement. When appropriate, capitation can improve cash flow, thereby enabling pediatricians to make investments in necessary support services. More importantly, capitation may allow pediatricians to negotiate to provide an expanded array of services that may include mental health and care management services. For example, reimbursement through capitation may be used to pay for care coordination services that may not be paid for in a fee-for-service system. In addition, capitation that includes primary care and behavioral services may protect pediatricians and their patients from the negative effects of aforementioned behavioral carve-outs, which may be particularly useful for pediatricians whose practices are focused on neurodevelopmental disabilities or developmental and behavioral pediatrics.

Finally, pediatricians should seek opportunities to

work with utilization management and quality improvement committees of MCOs. Pediatricians may be assisted in this effort by their AAP chapters. Many chapters operate practice-management committees that work closely with pediatricians to monitor contracting issues between pediatricians and MCOs. These forums provide opportunities for pediatricians to educate MCO personnel about standards of care for children with and without special health care needs and to address issues including Early and Periodic Screening, Diagnostic, and Treatment program services, clinical practice, and transition planning.

CARE COORDINATION

Care coordination has emerged as a vitally important part of successful managed care for children with special health care needs.¹⁶ In this regard, care coordination is not focused solely on utilization management but rather represents a collaborative process that assesses, plans, implements, coordinates, and monitors and evaluates available services that may be required to meet an individual's health needs. Care coordination can occur at several levels including state systems such as Title V. Care coordination can occur within the MCO through models such as those used in Oregon or New Jersey. For example, New Jersey requires that all contracting MCOs provide care management services to persons with "special needs." These individuals receive a comprehensive needs assessment, an individual care plan, and monthly case management support. In addition, case management can occur through carve-out organizations, including disease management companies or behavioral health care organizations, or at the level of the individual physician. The best known carve-out models relate to the provision of mental health services. Most pediatricians find these arrangements uncomfortable because they encourage fragmentation in contracting and service delivery.

MCOs recently began to explore the role of care management programs targeted at special-needs populations. These programs are generally modeled after disease management programs demonstrated to have been successful in addressing issues related to chronic illness (eg, asthma, diabetes, depression, congestive heart failure) in managed care. Programs include Community Medical Alliance (Neighborhood Health Plan), which focuses on human immunodeficiency virus infection and physical disabilities; Independent Care (Humana), serving all persons with special health care needs; and Developmental Disabilities Health Alliance Inc (University Health Plan),¹⁷ addressing children and adults with developmental disabilities. Care management takes time and requires financial support. Pediatricians should advocate for adequate funding of care management. For pediatricians who want to provide these services, reimbursement for care management is occasionally available in the form of enhanced fee-for-service reimbursement, capitation, and/or administrative fees.

CHARACTERISTICS OF SUCCESSFUL PEDIATRIC PRACTICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Satisfaction for pediatricians working with MCOs to provide care to children with special health care needs can be enhanced. Negotiating for adequate compensation is strengthened if pediatricians can demonstrate that primary care and preventive health interventions decrease hospitalizations, emergency department utilization, and pharmaceutical costs. For the individual clinician, collection of utilization data on all patients with special health care needs in the practice is useful. For example, Developmental Disabilities Health Alliance Inc has demonstrated that appropriate outpatient care and care management services can decrease inpatient utilization and costs by ~25% for persons with developmental disabilities,¹⁸⁻²⁰ and Children's Hospital at Strong in Rochester, New York, demonstrated an eightfold decrease in length of stay for selected children.^{21,22} In general, it is more efficient for a practice to serve a larger volume of patients through a smaller number of payors. Once a practice has chosen to work with a specific payor, it should also discuss methods of ensuring that an adequate volume of patients be referred for care.

It should be cautioned that partially or fully capitated reimbursement strategies could also create disincentives for appropriate subspecialty referral. In fully capitated plans, the primary care physician assumes financial risk for all care. Consequently, the reimbursement to the primary care physician decreases with increasing need for subspecialty care and hospital services. Children with disabilities and other chronic conditions that may lead to disability require the services of pediatric medical subspecialists and pediatric surgical specialists in addition to primary care pediatricians. Access to and availability of pediatric medical subspecialty and pediatric surgical services must not be significantly impeded by managed care arrangements. Although it is ideal for the primary care physician to manage and coordinate care for a child's health needs, the complex or rare nature of a particular child's condition may make it difficult for the primary care physician to meet all the needs of the child and family adequately without the expertise of pediatric medical and surgical consultants. As presented in the AAP policy statement "Guiding Principles for Managed Care Arrangements for the Health Care of Newborns, Infants, Children, Adolescents, and Young Adults,"¹² access to pediatric medical subspecialty and pediatric surgical specialty care should exist without the burden of additional financial barriers and with appropriate referral processes and criteria in place. Adult-oriented physician medical subspecialists and surgeons should not be expected to have the expertise necessary to care for children with special health care needs. Likewise, pediatric therapy providers (physical therapy, occupational therapy, speech-language pathology, etc) should have significant pediatric specialty training and experience. Furthermore, child-specific technologic services

should be accessible and affordable. Finally, pediatricians may also benefit from education guidelines related to specific conditions, such as those published by the Center for Health Improvement (available at www.ddhealthinfo.org).

All persons involved in managed care, including pediatricians and families, must fully understand how managed care works and how to advocate effectively for services. When plans for managed care are designed and implemented, planners and policy makers need to monitor them closely for unintended or unanticipated negative effects on children with special health care needs, their families, and their pediatricians. Flexibility and openness to promptly modifying these plans is called for when significant ineffectiveness, unnecessary costs, or a reduction in the quality of patient care is evident. Effective systems management and the use of predictable points of intervention can facilitate management in an already complex delivery system. If managed care is to demonstrate the capacity and flexibility to serve children with special health care needs adequately, pediatricians and families must hold MCOs to standards of conduct and service that parallel their own obligations to children.¹⁴

In conclusion, it is possible to make managed care work for children with special health care needs, their families, and their pediatricians. Successful models of managed care can be adapted to meet local market conditions. Partnerships among children with special health care needs, their families, and their pediatricians can be successful in creating a medical home for children with special health care needs in managed care.

IMPORTANT POINTS FOR THE PEDIATRICIAN

Opportunities exist for improving care for children with special health care needs in managed care systems. They can be facilitated by exercising the following strategies:

1. Creating partnerships among pediatricians, families of children with special health care needs, advocates, and payors, particularly state Medicaid and SCHIP programs, to address the needs of children with special health care needs in managed care.
2. Creating an understanding of major differences in disabilities between adults and children and the resulting need for managed care models to be sufficiently flexible to serve children with special health care needs and their families.
3. Ensuring access to care for all children through understanding and use of the medical home concept.
4. Adapting successful models of managed care to meet local market conditions through negotiation with payors and regulatory and licensing agencies.
5. Establishing fair reimbursement rates to compensate the physician for the increased time and complexity associated with providing health care services to children with special health care needs

and their families. At the MCO level, this translates into risk adjustment for capitated systems.

6. Obtaining additional funding for care coordination functions required by children with special health care needs and their families. These funds could be used to support social workers, nurses, or nurse practitioners in pediatric care settings.
7. Ensuring access to and appropriate use of pediatric medical subspecialists and pediatric surgical specialists with defined roles and open lines of communication between secondary and tertiary care and the medical home.
8. Creating viable systems of quality improvement capable of evaluating process and outcome data from which appropriate adjustments in the system are made to refine care to benefit children with special health care needs and their families.
9. Advocating at the federal level to protect children with special health care needs by ensuring access to adequate benefits, appropriate specialty services, and habilitative care.

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