

AMERICAN ACADEMY OF PEDIATRICS

Committee on Children With Disabilities

Managed Care and Children With Special Health Care Needs: A Subject Review

ABSTRACT. Barriers to access to health care frequently overshadow the opportunities for improvement through managed care, especially regarding children with special health care needs. This statement discusses such opportunities, identifies challenges, and proposes active roles for pediatricians, and families of patients to improve some aspects of managed care for children with special health care needs.

ABBREVIATION. AAP, American Academy of Pediatrics.

Managed care has been expanding to include coverage for children and adolescents with chronic illnesses and disabilities, 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 relatively healthy populations without disabilities 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. The potential also exists, however, to increase the difficulties families face in obtaining the full range of child and family services necessary to ensure the child's good health and proper development. Aspects of managed care are reviewed as they relate to children with disabilities and steps to improve managed care services for these children are recommended.

Children with disabilities 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, differs markedly from that 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. These three characteristics distinguish children's needs as they increasingly enter managed care arrangements.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.

Freund and Lewit² define managed care as a delivery system that integrates financing and delivery of specified health care services by means of four key elements:

1. Arrangement with selected clinicians to furnish a comprehensive set of health care services to members of the plan for a preset fee in most cases.
2. Explicit standards for the selection of health care 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 while constraining costs. Achieving these goals for children with chronic illness and disabilities requires special attention to several key issues. Studies indicate 6%³ to 35%⁴ (depending on what is included among the disabling conditions) of children have disabilities and need special health care services. Although children with relatively minor special health care needs may require double or triple the expenditures made on average healthy children, an estimated 5% of children with special health care needs account for slightly more than 35% of the health care costs of all children and adolescents.⁵ These children have more complicated disabilities (eg, multiple, lifelong, and/or technology-dependent) that compound their needs. Subspecialized and inpatient care, often at tertiary facilities, as well as ongoing complex outpatient management, community-based services, home nursing services, and medical supplies, make realistic strategies for cost containment difficult. This subset of the pediatric population, children with special needs and their families, faces an important challenge with the growth of managed care in being able to access all these services described.

A potential benefit of managed care, which is growing in private and public markets, may be improved access to primary care with greater likelihood of establishing a medical home from which a broader array of services may be provided. Incen-

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 © 1998 by the American Academy of Pediatrics.

tives of managed care that focus on primary care and community-based services designed to provide continuity based on familiarity with the child and family are generally more effective than costly uncoordinated care, such as relying on episodic care in emergency departments.

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

Managed care may also pose other risks for children with chronic illness and disabilities. First, "risk avoidance" has motivated the exclusion of high-risk populations from many managed care initiatives. Many state Medicaid programs continued with fee-for-service in that segment of their population for whom eligibility was based on disability. Such strategies, called "carve outs," exclude persons from the managed care plan based on risk or need for ancillary services. Capitated programs create disincentives for primary care pediatricians to take on high-cost patients, especially without agreement as to what constitutes "fair" capitation rates or adequate risk adjustment.⁶ Furthermore, few data currently provide information on other key unanswered questions. What effect, for example, will managed care have on patient access to preventive services, physical therapy, speech therapy, occupational therapy, and other similar support services? What is the role of public health services (eg, Title V, Medicaid, or Early Periodic Screening, Diagnosis, and Treatment) in a managed care environment, and will children with disabilities continue to have access to these services if they are enrolled in a managed care plan?

Pediatricians who are enrolled as managed care clinicians face additional challenges, barriers,⁷ and quality issues. The absence of clear standards of care and clinical guidelines, especially for relatively rare conditions for which there may be a lack of consensus on what constitutes appropriate home or community care, makes it difficult for them to advocate for these services. Changing technologies and a paucity of outcomes data, particularly concerning habilitation and mental health services, often result in arbitrary caps on services provided by the managed care company.

Given these issues, it is particularly important to gather objective data, develop criteria, or measure outcomes in the managed care era. Monitoring care for groups of children with disabilities could provide those data. Beyond outcomes, monitoring should determine whether children with disabilities have access to plans and whether these plans provide appropriate quality services. Newacheck et al⁸ 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. There may also need to be the establishment of uniform definitions and coding mechanisms 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-effectiveness, quality, satisfaction, and short- and long-term effects.

Monitoring care for children with special health care needs also functions at an emotional level. The term "gatekeeping," for many, implies overseeing access to health care services mainly to control costs. When health care plans monitor health services solely to control costs, the delivery of quality health care may be in jeopardy.⁹ As managed care seeks to impose a tight control over physician decisions, primary care pediatricians' frustration with the system may interfere with the process necessary to make managed care an effective tool in the delivery of care.

Partially or fully capitated reimbursement strategies can 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 subspecialists in addition to primary care pediatricians. Access and availability of pediatric subspecialty services must not be significantly impeded by managed care arrangements. Although it is ideal for the primary care physician to manage and coordinate the 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 of the needs of the child and family adequately without additional expertise. As presented in the American Academy of Pediatrics (AAP) policy statement, "Guiding Principles for Managed Care Arrangements for the Health Care of Infants, Children, Adolescents, and Young Adults,"¹⁰ access to pediatric subspecialty care should exist without burden of additional financial barriers and with appropriate referral processes and criteria in place. Adult-oriented physician subspecialists should not be substituted for more appropriate care by pediatric subspecialists. Furthermore, child-specific technological services should be accessible and affordable.

A February 1996 *AAP News* insert outlined components necessary to create a medical home for children with disabilities.⁹ In this model, managed care places the "keys" in the hands of the pediatrician to "open the door to a medical home and monitor the delivery of services through gatekeeping." The patient's family and primary care pediatrician work together to assure that services are "family centered, coordinated, and comprehensive."⁹, page 2

The concept of the medical home creates an active role for the pediatrician and other pediatric specialists, including the adaptation of their child advocacy

roles to a new delivery system. Pediatricians must be active in the negotiation of managed care contracts, ensuring that their patients have access to necessary programs and that the health plan is available to *all* the children. They must be sure that the contracts they negotiate provide a broad, comprehensive array of services within the plans, including appropriate periodic screening and diagnostic and treatment services.

Capitation systems that include managing the care of children with special health care needs should recognize the 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, the methods to determine fair and appropriate capitation rates need to be developed. Risk adjustment is an effective means for determining appropriate rates because of the time inequalities associated with caring for a child with special health care needs and reducing the barriers to enrollment or qualified pediatricians.

At state levels, active roles by AAP chapters can assist negotiating processes. Ongoing dialogues with state agencies, especially Medicaid and Title V programs, provide opportunities to discuss issues and perspectives from the physician-child-family interface. Cost-effectiveness may be enhanced by restructuring existing systems to function more efficiently rather than developing a completely new system.

All persons involved in managed care, including pediatricians and families, must address the issues. When plans for managed care are designed and implemented, planners and policymakers need to closely monitor them for unintended or unanticipated negative effects on children with special health care needs, their families, and their pediatricians. Flexibility and openness to prompt modifications in 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. Interagency communication and collaboration must exist within systems. The "end" of all our activity should reflect our advocacy role and in particular, should facilitate individual case management. Industry employers, from senior management to human resource directors, need to be responsible and informed agents for the benefits they provide. Information about what is included in various options and what is not must be made available to permit families to make informed decisions. If needed, employers should join families to have a positive impact on the contract for needed benefits to assist children with special health needs. Managed care checklists are available to provide needed guidelines.¹¹⁻¹³ Managed care physicians need to understand and accept flexibility and its unique role in the management of care for this very special population.

If managed care is to demonstrate the capacity and the flexibility to serve children with special health

care needs adequately, pediatricians and families must hold managed care organizations to standards of conduct and service that parallel their own obligations to children.¹¹

RECOMMENDATIONS

Opportunities exist for improving some aspects of care for children with chronic illness and disabilities in managed care systems. They can be facilitated by exercising the following strategies:

1. Creating understanding of major differences between adult and childhood disability and the resulting need for managed care models to be sufficiently flexible to serve children with special needs and their families.
2. Assuring access to care for all children through understanding and use of the medical home concept.
3. Establishing fair reimbursement to compensate for the increased time and complexity associated with providing and coordinating care for children and families of children with special health care needs. This translates into risk adjustment for capitated systems.
4. Ensuring access to and appropriate use of pediatric subspecialists with defined roles and open lines of communication between secondary and tertiary care and the medical home.
5. Creating viable systems of monitoring care capable of producing process and outcome data from which appropriate adjustments are made to refine care to benefit children and families.

COMMITTEE ON CHILDREN WITH DISABILITIES, 1997-1998

Philip R. Ziring, MD, Chairperson
Dana Brazdziunas, MD
W. Carl Cooley, MD
Theodore A. Kastner, MD
Marian E. Kummer, MD
Lilliam González 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
United States Department of Education
Merle McPherson, MD
Maternal and Child Health Bureau
Marshalyn Yeargin-Allsopp, MD
Centers for Disease Control and Prevention

SECTION LIAISONS

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

CONSULTANTS

James Perrin, MD
John Poncher, MD

REFERENCES

1. Jameson EJ, Wehr E. Drafting national health care reform legislation to protect the health interests of children. *Stanford Law Policy Rev.* 1993;51:152-176
2. Freund DA, Lewit EM. Managed care for children and pregnant women: promises and pitfalls. *Future Child.* 1993;3:92-122
3. Newacheck PW, Hughes DC, Stoddard JJ, Halfon N. Children with chronic illness and Medicaid managed care. *Pediatrics.* 1994;93:497-500
4. Weitzman M, Walker DK, Gortmaker S. Chronic illness, psychosocial problems, and school absences: results of a survey of one county. *Clin Pediatr.* 1986;25:137-144
5. Lewit EM, Monheit AC. Expenditures on health care for children and pregnant women. *Future Child.* 1992;2:95-114
6. Halfon N, Inkelas M, Wood DL, Schuster MA. Health care reform for children and families: refinancing and restructuring the US child health system. In: Anderson RM, Rice TH, Kominski GF, eds. *Changing the US Health Care System: Key Issues in Health Services, Policy, and Management.* San Francisco, CA: Jossey-Bass Publishers; 1996:227-254
7. Cartland JD, Yudkowsky BK. Barriers to pediatric referral in managed care systems. *Pediatrics.* 1992;89:183-192
8. Newacheck PW, Stein RE, Walker DK, Gortmaker SL, Kuhlthau K, Perrin JM. Monitoring and evaluating managed care for children with chronic illnesses and disabilities. *Pediatrics.* 1996;98:952-958
9. Palfrey J, Haynie M. Managed care and children with special health care needs: creating a medical home. *Strategies for Managed Care: An Update From the Committee on Child Health Financing. AAP News.* (insert); February 1996
10. American Academy of Pediatrics, Committee on Child Health Financing. Guiding principles for managed care arrangements for the health care of infants, children, adolescents, and young adults. *Pediatrics.* 1995; 95:613-615
11. Family Voices. *Children With Special Health Care Needs: How Will They Fare in Managed Care? Questions to Ask and to Answer.* Algodones, NM: Voices; November 1995
12. American Academy of Pediatrics. *Managed Care for Children With Special Needs: Are Medical Homes Provided? A Self-Evaluation Tool for Managed Care Companies.* AAP News. (insert); March 1998
13. *Evaluating Managed Care Plans for Children With Special Care Needs: A Purchaser's Tool.* Gainesville, FL: Institute for Child Health Policy; March 1998

ERRATUM

In the policy statement entitled "Neonatal Drug Withdrawal" (June 1998;101:1079-1088), an incorrect dosage for clonidine was inadvertently published. On page 1084, under the heading "Clonidine," line 9, the sentence should read as follows:

"In an open trial, six of seven infants with neonatal narcotic withdrawal signs were treated effectively with oral clonidine (0.5 to 1.0 $\mu\text{g}/\text{kg}$ [not mg/kg] in a single dose, followed by a maintenance dose of 3 to 5 $\mu\text{g}/\text{kg}/\text{day}$ [not $\text{mg}/\text{kg}/\text{day}$], divided every 4 to 6 hours).⁸³"

As stated in this AAP policy statement in reference to the treatment for neonatal drug withdrawal: "Larger controlled trials and pharmacokinetic data are needed before clonidine can be advocated as routine treatment."

We regret any confusion this error has caused.