

Assuring Quality of Care for Children With Special Needs in Managed Care Organizations: Roles for Pediatricians

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ABSTRACT. Increasing numbers of children with special health care needs are enrolling in managed care programs. Although managed care may improve service coordination and use of primary care, it may also threaten health outcomes for these children by potentially decreasing access to the range of needed services, eroding progress in developing community-based service systems, and failing to assure quality of care. To date, few frameworks have been proposed to assess quality of care for this population of children in managed care organizations. In this article, we adapt the Institute of Medicine's definition of quality and identify six key components: content of service delivery systems, the nature of desired health outcomes, risks associated with service delivery, constraints of care, interpersonal dimensions, and attention to developmental issues. These components can be assessed at three levels: the individual, the health plan, and the community. Pediatricians and other child health professionals have critical roles to play in assuring that policies and practices within managed care organizations promote a high quality of care for this vulnerable population of children. *Pediatrics* 1996;98:178-185; children with special needs, managed care, disabilities, chronic illness, quality of care.

ABBREVIATIONS. SSI, Supplemental Security Income; CSHCN, Children With Special Health Care Needs; HMO, health maintenance organization; IOM, Institute of Medicine.

As states implement health system reforms, new problems are emerging in the organization and financing of care for children with disabilities and chronic illnesses. Many families, pediatricians, and other health care professionals are concerned that managed care programs in both the public and private sectors will decrease access to needed subspecialty and supportive services and undermine recent efforts to develop community-based systems of care for these children and their families.^{1,2} Increased monitoring of medical costs and greater recognition of limited public resources will raise difficult questions about support for children who require long-term health and education services. Moreover, statewide implementation of Medicaid-managed care

programs and reductions in state Medicaid expenditures may affect this population disproportionately.

Little baseline data are available to assess the influence of these changes on health status and quality of life for these children and their families. As a result, pediatricians, other child health practitioners, families, and administrators of managed care programs will need to work together closely to balance cost-related concerns with assurances for a high quality of services for this population of children. Quality assessment for this population requires a broad strategy that encompasses physical health, mental health, social interaction, and family functioning. In this article, we aim to provide a framework for assessing quality of care for children with disabilities and chronic illnesses within the context of managed care programs and to identify key roles that pediatricians and other child health providers can play in assuring quality of care as health system reforms are implemented.

OVERVIEW OF POPULATION CHARACTERISTICS AND COSTS OF CARE

In the adult population, there are a limited number of major chronic diseases and disabilities, including stroke-related conditions, cardiovascular disorders, cancer, and orthopedic conditions. Each of them, however, occurs with comparatively high frequency. In the child population, the pattern is reversed: more than 200 chronic conditions and disabilities affect youth, including asthma, diabetes, sickle cell anemia, spina bifida, epilepsy, and autism. With the exception of asthma, most of these conditions are rare.

Analyses of data from the 1988 National Health Interview Survey suggest that 31% of children less than 18 years of age (about 20 million children) have one or more chronic health conditions, excluding chronic mental health problems and learning disabilities.³ Children with two or more chronic health conditions (2.2 million children) are at substantial risk for high rates of service use.⁴ Many of the challenges faced by the families of these children are similar, regardless of the child's particular diagnosis.⁵

Children with disabilities and chronic illnesses represent the high-cost segment of the childhood population; although few in number, they consume a vastly disproportionate amount of service dollars. Issues of cost pertain directly to the scope of benefit packages developed by managed care organizations for children with special health care needs, to referral practices, and to adjustments made in the cost of premiums.

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Detailed estimates of the costs of care are unavailable for this population as a whole. However, general estimates have been made for some subgroups. For example, incremental costs (ie, costs for services beyond what healthy children require) of medical care for children who have limitations in their activities are estimated to have exceeded \$6.5 billion in 1992.⁶ On average, a child with a disability cost Medicaid approximately \$7100 in 1992, seven times more than a child with no disabilities.⁷ Blackman⁸ estimated that average hospital costs for the smallest surviving preterm infants exceeded \$100 000 in 1990 and that hospital costs for a very low birth weight infant (less than 1000 g) were three to four times higher than costs for infants weighing more than 1500 g at birth. Average health expenditures for children with mental retardation were \$4000 in the mid-1980s—four times the average expenditure for a healthy child.⁹

Studies also suggest that costs vary considerably within diagnostic categories. For example, a recent study found that incremental life-span economic costs for children with various heart defects ranged from \$69 000 to \$209 000.¹⁰ In the mid-1980s, per capita annual health care expenditures in a national sample of youth with severe mental retardation were found to range from less than \$100 to \$43 000.⁹ This variation typically results from the inclusion of a few children with extremely high medical care costs. Consequently, median expenditures are typically much lower than mean expenditures for most diagnostic groups within this population. Despite extensive within group variation in annual costs and mean expenditures, the majority of children with disabilities or chronic illnesses will not incur exorbitant medical expenditures within any given year. Predicting annual or lifetime costs for individual children in this population is difficult, however, because of the need to account for many demographic and health-related variables and the complex interactions among development, health status, and family environment.

CHILDREN WITH SPECIAL NEEDS IN MANAGED CARE PROGRAMS

Managed care programs are quickly becoming the dominant organizational form in the health care system of the United States. Unfortunately, early studies of the effects of managed care on health outcomes of children are generally inconclusive and shed little light on the population of children with special needs.^{11,12} The structural diversity and rapid development of these programs has far outpaced the knowledge needed to assess their impact on the health status of children with special health needs. Furthermore, the transition from a largely fee-for-service system to a managed care system poses special threats to existing relationships between families and health care practitioners. These relationships are often critical to effective management of the care of children.

To date, most managed care plans have not actively enrolled this population or developed special programs to address their needs. In the private sec-

tor, managed care plans have developed special patient education programs (eg, education around asthma management designed to reduce emergency department care or hospitalization). Overall, however, managed care programs have few incentives to extend coverage to children with disabilities or chronic illnesses. In the public sector, children with disabilities or chronic illnesses are usually exempted (or carved out) from many Medicaid-managed care plans.¹³ In 1993, for example, 50% of the states that had mandatory enrollment of Medicaid clients into managed care programs exempted certain categories of children with special health care needs; more than 50% of the states that had voluntary enrollment in managed care plans excluded disabled Supplemental Security Income (SSI) recipients from participation.² Some states, such as Tennessee, have implemented mandatory managed care programs for the Medicaid-eligible population, yet have made no special provisions for children with disabilities or chronic conditions.³

In a few sites, special efforts have been made to develop managed care programs specifically for children with special needs.¹⁴ Under the Section 1115 Medicaid managed care waiver in Kentucky, for example, children with special needs are assigned a case manager; special policies are being developed that will allow specialists and other providers to be the case managers and to maintain ongoing relationships with children currently under their care, assuming that these practitioners are willing to provide primary health care. In Michigan, the state Title V program for Children With Special Health Care Needs (CSHCN) has developed a physician case management model for this group of children in managed care programs.¹⁵ One of the major challenges is to understand the implications of structural variations that are emerging in managed care programs.¹⁶ A further challenge for managed care programs (and the field generally) involves defining the boundaries for this population. Definitional approaches have been discussed at length,^{17,18} but a standard approach has yet to be widely adopted by managed care organizations. This lack of a standard definition is inhibiting the development of managed care service delivery models for this population.

CRITICAL AREAS OF CONCERN

The adequacy of the current health service system for children with disabilities and chronic illnesses has been debated at length.⁵ From our perspective, major concerns tend to cluster around seven key issues: 1) access to care; 2) appropriateness of services; 3) comprehensiveness; 4) coordination; 5) continuity; 6) relation to community; and 7) the degree to which services and the service system are family-centered. All seven issues are relevant to the traditional indemnity insurance system. The increased inclusion of this population into managed care systems may exacerbate certain problems (eg, access to care), but also may bring new opportunities to address other longstanding problems in the current service system (eg, continuity of care). To make our discussion manageable, we focus on three cross-cut-

ting areas: access to services, gaps in the service system, and quality of care.

Access to services. Numerous concerns have been raised regarding reduced access to pediatric subspecialists in managed care programs, thereby leading to failures in detecting emerging problems, delays in using new medications or treatments, or applications of inappropriate treatments. Fox and colleagues report that benefit packages offered by health maintenance organizations (HMOs) that contract with state Medicaid programs are less comprehensive than packages provided under the standard Medicaid fee-for-service plans.¹⁹ A study of Aid to Families With Dependent Children recipients receiving Medicaid services in Wisconsin indicated that fewer than 50% of respondents who had requested a referral to an out-of-plan specialist were granted one.²⁰ Reporting on a survey of administrators of 22 managed care plans, Fox and McManus⁶ noted that with some exceptions, "few plans have made special efforts to assure the appropriate participation of pediatric specialists in their provider networks. This fact . . . often makes it difficult for families whose children have special health care needs to access appropriate pediatric specialists."

A study of barriers to pediatric referral found that managed care systems are successful in restricting referrals to pediatric subspecialists and to inpatient care. Pediatricians with patients covered under managed care and fee-for-service systems report making fewer referrals to subspecialists and to inpatient care for patients in managed care programs compared with those in fee-for-service programs.²¹ In the group of pediatricians who had made referrals to pediatric subspecialists for patients in managed care programs, one fifth indicated that at least one referral was denied; of those reporting at least one denial, about one third said they believed that the patient's health was compromised as a result of the denial.¹

Access to health-related services (eg, physical therapy) also may be limited by managed care programs through policies that restrict duration of services, limit total number of encounters, or establish special conditions under which services can be provided.⁶

Some studies suggest that managed care programs increase access to and use of primary care services and decrease use of emergency departments for non-Medicaid children in comparison to fee-for-service arrangements.^{23,24} Few investigations of this topic have controlled for children with special needs. However, a recent study of 1685 children receiving Medicaid who were randomly assigned to fee-for-service or HMO programs did account for the presence of major disabling conditions (blindness, diabetes, cerebral palsy, mental retardation, and amputations) and allergies (eczema, asthma, and hay fever). The investigators report that children with these conditions in the HMO had as many check-up and acute care visits as did children with these conditions in the fee-for-service system,²⁵ suggesting few differences in use of health services. Several factors, however, limit generalizability of these results: data were collected over a 2-month period, the number of

children with major disabling conditions was small, and only one HMO was studied.

Gaps in the service system. In theory, managed care systems will promote access to comprehensive primary care as a strategy to detect problems early and prevent secondary health conditions and may enhance service coordination by virtue of gatekeeping procedures. However, primary care physicians now vary widely in the nature and extent of their experience in providing services to children with special needs,^{26,27} and may be unfamiliar with new or emerging treatment protocols for children with particular diagnoses. Under some types of managed care programs, subspecialists may serve as gatekeepers and will manage their patients' primary care needs. How these different arrangements affect health outcomes is unknown.

Children with special health care needs are dependent on a wide range of community institutions to receive needed educational, social, recreational, and vocational services. Orchestrating the relevant agencies and programs into a coherent and nonduplicative set of services is essential for effective health care, but it also requires continuing effort in the face of ongoing changes in program staff, eligibility criteria, and enrollment procedures. To coordinate services, pediatricians and other child health providers must interact with numerous state and federal programs, including the Title V programs for CSHCN, local programs under the Individuals with Disabilities Education Act, the SSI program, and Head Start. Managed care organizations may have little experience or incentive to establish necessary linkages with these programs at the community level.

It is noteworthy also that in many states, education agencies bill Medicaid for health-related services rendered by school personnel to Medicaid-enrolled students in special education programs. As Medicaid includes more children with special needs in managed care programs, many issues will be raised concerning payment for these services. Available data suggest that managed care organizations have yet to incorporate provisions for negotiating financial and referral arrangements with special education programs.²⁸

Assessing quality. The growth in managed care programs has been accompanied by concerns that attention to limiting costs also will limit quality of services for children with disabilities and chronic illnesses.²⁹ In particular, few state Medicaid agencies have incorporated safeguards pertaining to these children into their contracts with managed care organizations. Although some efforts have been made to develop pertinent standards and quality indicators for this population of children,³⁰ little attention has been paid to conceptualizing quality as it relates to this population. Because issues of quality are critical to both pediatricians involved in the care of these children and administrators of managed care organizations, it is worth considering in depth how quality can be conceptualized for this population.

CONCEPTS OF QUALITY

The Institute of Medicine (IOM) defines quality of care as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."³¹ Harris-Wehling³² provides a useful review of the components underlying this definition. Somewhat adapted and expanded, these components provide a conceptual framework for assessing quality of care for children with special needs and their families.

Content of care. The term **health services** was deliberately included in the IOM's definition of quality of care because it refers to a wide range of elements of care, extending beyond more narrow terms such as **medical services**. This approach is especially relevant for children with special needs. A narrow focus on subspecialty medical care ignores other essential services such as primary care, developmentally appropriate assistive technology, or community-based family support programs. These services can have important direct and indirect effects on health status by influencing quality of family life, adherence to medical treatments, and capacity to cope with stresses commonly associated with childhood disability or chronic illness. The outcome of even the most brilliant surgical procedure to correct an infant's birth defect can be undermined by inadequate resources for the family to provide postsurgical care at home. This fact requires us to take a broader perspective on the essential components of care for these children and their families.

Goals of care. What are **desired health outcomes**? Pediatricians, parents, and children themselves may answer these questions differently. For health care practitioners, answers often involve measurable technical or biomedical achievements (eg, increasing range of motion in a particular limb). For parents, treatment goals may be developmental in nature (eg, not restricting an active child with orthopedic interventions or invasive treatments). For the youth themselves, goals may involve quality-of-life issues that are inconsistent with certain medical interventions. Moreover, different goals may be relevant depending on whether the child is in the hospital or at home. Trade-offs between costs of providing care and potential benefits almost always shape the process of setting treatment goals. These potential complexities in defining **desirable** health outcomes imply that quality of care is **inherently** relativistic and relational; assessments of quality depend on the person making the judgment, the relationship between that person and the child, and the setting in which judgments are made.

Risk of care. Outcomes of health services can not be guaranteed because every health service has some risk for poor or unintended outcomes. The IOM's definition of quality of care accounts for this observation by noting that health services can only increase the **likelihood** of desired outcomes. This concept is especially pertinent to this population of children because new medical treatments for this population emerge routinely. Long-term risks of

some treatments may not be completely known before widespread adoption. Knowledge of risk and benefit ratios may alter the availability of financing, which in turn may shape the diffusion of treatment innovations for this group of children. One dimension of assessing quality within managed care programs must involve questions of how new treatments are diffused into standard benefit packages as well as the broader question of how treatment decisions balance estimates of risk and benefit within an environment highly conscious of cost implications.

Constraints on care. The IOM definition explicitly recognizes that quality of care is limited by **current professional knowledge**. The effectiveness of many technologies and procedures is not known, and this is especially true for many services related to the population of children with disabilities and chronic illnesses. Medical protocols vary from clinic to clinic, with little comparative evidence to favor one method over another. Variance is especially extreme with respect to generally accepted standards for providing family support services, in part because knowledge about their effectiveness is sparse. It is difficult to judge quality of a procedure if the underlying research base on its effectiveness is absent or inconclusive. Moreover, if a treatment has not been shown to be efficacious, then it is less likely to be considered medically necessary. Knowledge about effectiveness of medical procedures shapes definitions of **medical necessity**, which in turn influence availability of insurance coverage.³³

Other types of constraints can be placed on care as well, including financial constraints. For example, some services may be technically feasible but financially exorbitant, either to society or to the family. In fact, many families have had to confront the difficult questions of paying for expensive care or modifications to the home at the expense of resources for other family members. To what extent should providers and health care institutions account for these economic constraints in assessing quality of care? This issue also arises when providers and families differ regarding judgments in the overuse of certain technologies. For example, repetition of expensive lab tests that involve invasive procedures may be perceived as important by providers but financially burdensome by families or health plan administrators.

Interpersonal dimensions of care. Many definitions of quality stress both the technical competence of providers and the interpersonal **art** of applying technical skills in the context of human relationships. No amount of interpersonal skill should overshadow technical shoddiness, nor should lack of interpersonal skill undermine technical brilliance. For most health care providers, competencies are needed in both the technical and interpersonal aspects of care. This is particularly true for health care professionals who will be involved with families over a long period of time.

Harris-Wehling³² extends this notion further by invoking the concept of a practitioner's "fidelity to a community of patients." This concept suggests that

pediatricians have an obligation to be technically proficient, interpersonally skilled, and committed to integrating family-centered practices and policies that will foster the health of all patients and families.^{34,35} Especially important are skills related to the inclusion of families in decision-making and in managing the issues of informed choice when treatment goals are established. Issues of choice are particularly germane to professionals in managed care settings, when fidelity to the institution may conflict with the need to share information with families in an unbiased manner and to discuss the broadest range of choices possible.

Developmental perspective. For most children with chronic illnesses or disabilities, development and health status interact in a complex fashion. For example, a wheelchair that is suitable for a 5-year-old can become ill-fitting before age 6; for adolescents with physical disabilities, normative developmental anxieties around body image may contribute to serious secondary conditions such as eating disorders or depression. Moreover, as children progress through childhood to adolescence, it is expected that they will take increasing responsibility for self-care such as administering their own medication, reporting changes in symptoms, and interacting more directly with health professionals. To assist this process, health professionals need sufficient training in the application of developmental concepts to children and youth with chronic health problems. During the last two decades greater focus has been directed to conceptualizing and understanding how children actively use their own dispositional strengths and interpersonal skills to achieve positive developmental outcomes. Renewed concerns with concepts such as effacement motivation,³⁶ social competence,^{37,38} and resilience³⁹ have begun to correct a disproportionate attraction to deficit-related concepts. This perspective emphasizes that many individuals with disabilities have considerable strengths and that an important goal of the health care system should be the promotion of competencies and prevention of secondary conditions. A focus on health promotion is consistent with the premise of managed care, but the development of effective health promotion efforts for children with special needs may require new strategies and programs particularly suited to this population.

ROLES FOR PEDIATRICIANS

Over the last two decades, ambulatory care pediatricians and other primary care professionals have been encouraged to play active roles in the care of children with chronic health conditions by assisting families in managing the child's condition, by coordinating medical and health services, and by becoming a trusted source of guidance and advice for the family.^{26,27,40} Most of these recommendations are based on the belief that by playing such active roles, pediatricians can improve the child's medical outcomes, avoid unnecessary interventions, and support the family in its role as primary caregiver. In many instances, however, the actual capacity of pe-

diatricians to play these roles is limited by constraints on time, the lack of reimbursement for these activities, and limited training.⁴⁰ These limitations may persist in an environment dominated by managed care organizations. However, managed care organizations also have the opportunities to provide a **medical home** for these children while continuing to monitor costs. The infrastructure of many large managed care organizations has the potential to support programs of comprehensive care that will increase satisfaction and improve outcomes of care. Furthermore, some managed care organizations have advanced information systems; the potential for these systems to assist in measuring and tracking quality of care in relation to outcomes is largely untapped. The challenge for pediatricians and other child health professionals is to work with the leadership of managed care organizations to assist in developing resource-constrained but appropriate service models⁴¹ and to explore how information can be collected and used to improve quality of care.

Assessments of quality must extend beyond the level of the individual encounter between patient and practitioner to include also the health plan and the community-based system of care.⁴² The six components of quality noted previously can be mapped against these three levels (individual, health plan, community) to suggest key activities that pediatricians and other child health practitioners can undertake in the process of assuring quality of care for these children.

The Individual Level

At the individual level, these six components reflect the elements of good patient care. The importance of attending to a wide range of needs, negotiating clear treatment goals with the family, acknowledging levels of risk and constraints of knowledge, and incorporating good interpersonal skills within a family-centered and developmental framework are tasks usually associated with high quality clinical care for this population of children. In addition, many families of children with special health care needs (even those who are already in capitated systems) are unfamiliar with the general concept of managed care or the specific implications of any single program. When questions arise, these families will turn to pediatricians who have provided medical care, guidance, and support. Thus, pediatricians also will need to play critical roles in educating families regarding new choices and challenges, and assisting them in negotiating the transition to managed care.

Quality of care at the individual level will also depend on how successfully individual pediatricians in managed care organizations balance the ethical conflicts inherent in the gatekeeping role. Primary care pediatricians may feel pressure to **stretch their competence** and not refer patients to specialists to conserve either their own or an organization's resources. This practice conflicts with their primary obligation to serve the needs of their patients.⁴³ Although some **bedside rationing** is inevitable in any health care financing system, managed care organi-

zations have an obligation to develop fair practice guidelines for primary care pediatricians and other health professionals to assure that children who require specialty care are not placed at a disadvantage. Pediatricians need to be actively involved in the development of such guidelines.⁴⁰

The Health Plan Level

Strategies for assuring quality of care at the health plan level involve some activities that are familiar to most pediatricians. Other tasks, however, may lead pediatricians into new territory. Table 1 lists potential tasks associated with the six components of quality at the health plan level. It illustrates, for example, the need to define an appropriately broad benefit package as a means for defining the content of care within health plans for this population of children. Furthermore, pediatricians and other child health professionals can play important roles in assisting administrators in managed care organizations to develop measures or indices of satisfaction and developmental appropriateness. One large managed care organization completed over 50 000 satisfaction surveys in 1994; few, however, were focused on this population.⁴⁴ Pediatricians, families, and research staff in managed care organizations will need to work together to develop satisfaction surveys that will contribute to family-centered policies and practices.^{4,3,45} Furthermore, as professionals who are knowledgeable about the interactions between development and health status, pediatricians will be responsible for examining the developmental implications of the policies and procedures of managed care programs.

For other components, many pediatricians and child health professionals will face concepts that have not been part of traditional service delivery systems. For example, much like the corporate sector's concern with new product development, managed care organizations place considerable emphasis on defining the value of an intervention, where value is viewed as the cost of a service balanced against its health benefits. From this perspective, costly interventions may be supported if they are known to have substantial benefits. Even inexpensive interventions, however, may be excluded from coverage unless there is evidence of their positive impact on health status. Defining the value of an intervention intersects with the task of defining the goals of care and therefore requires a careful integration of the diverse perspectives of the child, family, physician, and plan administrator. Some services may be of considerable value to families but have not been shown to have cost benefits to the plan. "Value to whom?" will be a

difficult question to resolve and the answer may be found only through a combination of expert judgment and family participation.

Related to the concept of defining an intervention's value is the concept of defining risk. Most managed care organizations are **risk-averse**, meaning that interventions whose outcomes are uncertain will be less likely to be covered in a benefit package. Yet, parents of many children with chronic illnesses or disabilities are willing to take risks on new treatments even if there is only a small possibility for positive outcomes. How will these opposing perspectives be resolved? At what point will new technologies be integrated into benefit packages offered by a managed care organization? How will current knowledge about the rapidly-changing treatment picture for many chronic illnesses and disabilities be made available to the decision-makers in managed care organizations? Pediatricians will necessarily be key participants in decision-making around these matters.

The issue of adoption of new treatments is an example of the larger task of identifying the boundaries of professional knowledge. Health status varies widely across children with the same chronic illness or disability, reflecting differences in both the phenotypic expression of the disease process and the child's family and socioeconomic environment. At this point in time, knowledge is insufficient to define a rigid treatment protocol for all children with a given chronic condition. For the foreseeable future, clinical judgment will play an extremely important role in establishing treatment protocols for individual children. At the level of the health plan, how much room will be made for the role of clinical judgment? Too narrow a role (ie, standard protocols that fail to account for individual differences) will yield a poor quality of care; too wide a role may conflict with the goal of cost containment. Where is the right balance and how is this to be determined and monitored? Answers to these questions will require considerable input by a broad range of pediatricians and other child health professionals.

The Community Level

At the community level, attention to these six components of quality involves core public health principles of needs assessment, monitoring of health status, and assurances of quality of care. Numerous strategies are available to accomplish these goals. For example, periodic population-based surveys can assess access to an appropriate set of services and satisfaction with the interpersonal and developmental dimensions of services received. Public health

TABLE. Components of Quality and Associated Activities at the Health Plan Level

Components	Activities
Content	Identifying an appropriate benefits package
Interpersonal dimensions	Addressing family/child satisfaction with policies and procedures
Growth and development	Examining developmental implications of policies and procedures
Goals	Defining the value of interventions
Risk	Predicting outcomes and consequences of new treatments
Constraints	Determining the role of clinical judgment

agencies, such as state programs for CSHCN, can play active roles in disseminating information about managed care organizations in general and results of performance reviews of specific managed care plans. These agencies also can serve to advance the knowledge of new treatments and the value of interventions by hosting consensus-building conferences and by developing and disseminating standards of care and best practice manuals. Some state agencies have begun to implement projects related to these goals (M. McPherson, personal communication).

To promote quality of care for the population of children with special needs in managed care programs, both internal and external reviews will be needed.⁴⁶ Managed care programs (as well as fee-for-service programs) must continue to conduct internal audits of service quality through a variety of review procedures, performance measures, and consumer satisfaction surveys. Established managed care organizations that have a large enrollment and substantial experience may have the resources to conduct these reviews successfully. But even careful audits by the large managed care organizations may not address: 1) those children who lack insurance altogether; 2) children who are enrolled in smaller health plans that lack adequate resources for assessing or assuring quality of care; 3) the special circumstances and needs of Medicaid-enrolled children with chronic illnesses and disabilities who may require special services (eg, transportation to service sites) that managed care programs have little experience in providing;¹⁴ and 4) services (eg, day care for children with special needs) that lay outside of traditional medical treatments but which are essential components to a comprehensive community-based service system. Pediatricians will need to play an active role in seeking ways of assuring that these services are accessible and of assuring quality of care for disenfranchised or at-risk subgroups within this population.

One strategy for pediatricians involves participating in local interagency coordination councils established under PL 99-457 (Part H of the Individuals with Disabilities Education Act that mandates early intervention for infants or toddlers with or at risk for disabilities) or becoming knowledgeable about and serving as advisors to state programs for CSHCN, many of which have a long history of involving pediatricians in policy-setting and implementation.⁴⁷ For example, in some states, directors of state CSHCN programs have begun to assume active leadership by working with families to define models of managed care and schedules for rate-setting that are appropriate to this population.^{6,48}

Far more effort will be needed as the diversity of managed care organizations increases and as diverse health system reforms are implemented among the states. Although many state CSHCN programs have met difficult challenges in linking with managed care organizations,¹⁴ these state programs have played leadership roles in implementing reforms in previous decades and many programs have considerable experience in managing contracts with specialty providers. As a result, many of the state CSHCN pro-

grams are likely to become the primary vehicle for assuring quality of care for this population at the community level. Their success will depend heavily on partnerships with both specialty and general pediatricians.

CONCLUSIONS

Pediatricians, including those within and outside of the public health system, have played and will continue to play an important role in assessing services for children with special health care needs and their families, assuring access to an appropriately broad range of services of high quality, and developing tools and strategies for promoting quality of care. Reforms in the structure and financing of health care are unlikely to diminish the importance of these roles. The specific activities associated with each of these roles, however, will need to evolve in response to the implementation of reforms. Selected communities and projects have demonstrated that effective, coordinated service systems for children with special needs can be developed using a family-centered framework based on developmental concepts, functional considerations, and the promotion of competencies.^{45,49} With sustained advocacy and practical assistance from families, pediatricians, and other health providers, this progress will continue as health system reforms are implemented.

The current challenges are: 1) to assure that expansion of managed care programs does not erode the important achievements already accomplished and 2) to assist managed care programs in meeting the goal of providing a set of comprehensive services of high quality in the context of cost containment. Some of the key issues that must be resolved include: 1) using incentives to assure that quality of care, broadly defined, will be given sufficient attention within managed care programs and in a fashion that will promote fidelity to a community of these children and families, 2) resolving technical, measurement problems in relation to assessment of quality at various levels, and 3) revising or expanding the concept of **medical necessity** to account for the wide range of services needed by this population of children.

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