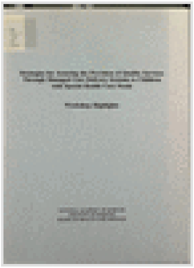

Strategies for Assuring the Provision of Quality Services Through Managed Care Delivery Systems to Children With Special Health Care Needs: Workshop Highlights (1995)

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Jo Harris-Wehling, Henry T. Ireys, and Margaret Heagarty, Editors; Board on Health Care Services; Institute of Medicine

Strategies for Assuring the Provision of Quality Services Through Managed Care Delivery Systems to Children with Special Health Care Needs

Workshop Highlights

Jo Harris-Wehling, Henry T. Ireys,
and Margaret Heagarty,
Editors

Board on Health Care Services

Institute of Medicine

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Preface

This report is based on presentations and discussions at an invitational workshop on strategies to promote quality services through managed care delivery systems to children with special health care needs; The workshop was held on December 12, 1994, in Washington, D.C. Its focus is compatible with broader attention that the Institute of Medicine (IOM) is giving to issues of quality of care in the face of major restructuring in the health care system. To that purpose, the IOM has recently embarked on a three-year special initiative—*America's Health in Transition: Protecting and Improving the Quality of Health and Health Care*—the intent of which is to maintain national attention on issues of quality as these uncoordinated changes in the health care system unfold. The transition now taking place is rapid and unpredictable, and it has a wide array of implications for the entire nation, not the least of which are major public programs such as Medicaid and state Children with Special Health Care Needs programs.

Members of the Board on Health Care Services (see roster, p. iii) oversaw the workshop planning. This report does not present formal recommendations. The Maternal and Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services, provided funding for the workshop. Participants included representatives of public and private sector involved in the fields of medicine, nursing, health care organization and financing, community-based systems of care, research, and quality assessment and assurance. Appendix A contains the participant list.

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Strategies for Assuring the Provision of Quality Services Through Managed Care Delivery Systems to Children with Special Health Care Needs

INTRODUCTION

All of America's children deserve to grow up as healthy as possible, including children with disabilities and chronic illnesses. In fact, during the last two decades, these children have benefited from impressive biomedical and technological advances. For most of this century, government and community institutions have made substantial contributions that enhance access to health care for this population of children. Increased monitoring of medical costs and greater recognition of limited public resources are raising difficult questions about supporting care for children and youth who require long-term health and education services. As states plan and implement health care reform and the private sector pursues major restructuring in health care delivery, new issues of concern are emerging regarding whether this population of children will be given opportunities to reach their full potential as adults.

Many families and health care professionals are concerned, for example, that managed care programs[1] in both the public and private sectors will decrease access to certain subspecialty and supportive services and undermine recent efforts to develop community-based systems of care for these children and their families. The principles of managed care are not antithetical to providing quality care to children and youth with special health needs. However, growth in private sector- and Medicaid-financed managed care programs may have negative consequences for the delivery of services to this group of children. Moreover, reductions in state Medicaid expenditures during the next several years are likely to affect this population disproportionate relative to other groups of children.

In response to interest in identifying strategies with potential for enhancing the provision of quality services by managed care programs for children and youth who have special health care needs, the Institute of Medicine (IOM) convened an invitational workshop on December 12, 1994.[2] Prior to the

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[1] In the context of the workshop discussion and this summary, managed care is used loosely to refer to health care systems, plans, and programs that are intentionally designed to integrate the financing of health care with its delivery. To date, most managed care systems provide acute and primary care; only a handful provide long-term care.

[2] The target population of this workshop and discussion—children with special health care needs—includes adolescents as well as younger children and infants.

workshop, participants received a background paper.[3] Throughout the workshop, several participants gave brief presentations on selected topics pertinent to the workshop theme. This brief report summarizes the major topics discussed by the participants.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS: DIMENSIONS OF THE POPULATION

Since the early 1960s, a wide range of legislative and judicial decisions have increased access to medical services for children with disabilities and chronic illnesses. Improvements in diagnostic procedures, surgical strategies, medication, medical technology, and symptom management have decreased morbidity and mortality for youth with cystic fibrosis, bronchopulmonary dysplasia, sickle cell anemia, spina bifida, cerebral palsy, and a host of other serious, ongoing physical conditions. Little baseline data are available, however, to assess the influence of these changes on health status and quality of life for these children and their families.

A narrow focus on subspecialty medical care provided to this population ignores other essential services for quality health care; these include 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. For example, 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.

Definitional Framework

In the population of adults, a limited number of major chronic diseases and disabilities, including stroke-related conditions, cardiovascular disorders, cancer, and orthopedic conditions accounts for the vast majority of affected individuals, since each occurs with comparatively high frequency. In the child population, the pattern is different. 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 uncommon, but many of the challenges faced by families of these children are similar, regardless of the child's particular diagnosis.

From a nonclinical perspective, this group of children can be divided into three broad, overlapping subgroups:[4]

1. Children with developmental delays or disabilities, such as mental retardation, learning disabilities, and sensory impairments;

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[3] Ireys, H.T. Children with Special Health Care Needs: Evaluating Their Needs and Relevant Service Structures. A background paper commissioned by the Institute of Medicine. School of Hygiene and Public Health, The Johns Hopkins University, Baltimore, Md., 1994.

[4] For additional information on this typology and findings from recent surveys of Medicaid managed care plans pertinent to the workshop theme, see Fox, H.B., and McManus, M.A. *Preliminary Analysis of Issues and Options in Serving Children with Chronic Conditions Through Medicaid Managed Care Plans.* Portland, Me.: National Academy for State Health Policy, 1994.

2. Children with ongoing medical disorders and chronic illnesses, such as diabetes, asthma, sickle cell anemia, or AIDS; and
3. Children with emotional or behavioral problems, including attention deficit disorder, conduct disorders, or other psychiatric diagnoses.

The boundaries of these subgroups cannot be strictly drawn. Children with spina bifida, for example, might fit into all three categories depending on the exact nature of the condition in a particular child.

More specific definitions of the population have been developed for purposes of particular public programs or research efforts. Special education programs typically classify eligible children into one of 10 categories (e.g., learning disabled, mentally retarded, visually impaired, orthopedically impaired), based on evidence from a multidisciplinary evaluation. The Supplemental Security Income program now defines a child as disabled if the child has (1) a qualifying diagnosis or (2) a condition that produces or is likely to produce significant interference with age-appropriate major daily or personal care activities for at least one year. In addition to determining eligibility for targeted services, population definitions can have significant implications for rate setting by insurers in both indemnity and capitated plans.

Workshop participants did not take a consensus position on an optimal approach to defining the population of children with special health care needs.[5] Several discussants noted advantages to using a noncategorical approach based on the meaningful consequences of a condition rather than focusing solely on activity limitations or diagnosis. For such a noncategorical definition, a serious ongoing physical health condition is understood to be one that: (1) has a biological basis; (2) has lasted or is virtually certain to last for at least one year; and (3) produces limitations in function, activity, or social role; need for more than the usual amount of medical care; need for care at home or school; or dependency on medications, special diets, or assistive technologies.[6]

Such a condition-consequences definition provides the framework for identifying needed services of the population. Once a baseline is ascertained, public and private agencies are in a more informed position to discuss which services managed care providers will deliver and what critical needs of the population remain to be addressed by other sources such as the education system, parents, and public health agencies.

Epidemiology

Estimates of the prevalence of children with special health care needs vary from 2 to 31 percent of the nation's children, depending on the definition of "special needs," source of data, and analytic method. The current imprecision of prevalence estimates reflects the lack of a broadly accepted definition of children with special needs and the absence of a corresponding, validated set of survey questions to identify the defined group. Larger estimates typically include children with conditions that place few or no limitations on the child's functioning. Smaller estimates include children with conditions that have severe functional consequences.

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[5] At the time of the workshop, the Maternal and Child Health Bureau was considering adopting a definition of children with special health care needs and was reviewing options such as these with a special work group.

[6] See Stein, R.E.K., Bauman, L.J., Westbrook, L.E., et al. Framework for Identifying Children Who Have Chronic Conditions: The Case for a New Definition. *Journal of Pediatrics* 122:342–347, 1993.

Expenditures and Financing of Care

Some expenditures for the health care of children with special health care needs are like those for all children. Incremental costs of medical care for children who have limitations in their activities (i.e., costs for services beyond what healthy children require) were estimated to be more than $6.5 billion in 1992.[7] Most children, including those who have chronic conditions, have health insurance coverage through private plans. Medicaid is the primary source of medical insurance for poor children. On average, a child with a disability cost the Medicaid program approximately $7,000 in 1992, seven times more than a child with no disabilities.[8]

Within the group of children with special needs, a relatively small percentage of individuals accounts for most medical care costs. Few data are available to identify at any given point in time which children can be expected to use the most medical services or which children will account for the highest costs over their lifetime. The pattern of medical and health-related costs for a particular child can vary considerably from one year to the next. Available estimates of medical costs typically do not account for the family's indirect costs (i.e., income lost because a parent cannot work) or costs for nonmedical support services. Overall, studies suggest that despite the extremely high costs for a small percentage of children, the majority of children with disabilities or chronic illnesses have annual medical expenditures that are below the maximum expenditure limits of many private indemnity health insurance plans.

Nevertheless, because of the potentially high and unpredictable resource consumption, all but a small number of managed care companies have been reluctant to assume the significant financial risks that are associated with enrolling children with health care needs. Managed care systems that have large numbers of enrollees and mission statements that reflect commitments to serve community needs may be more likely to be responsive to the needs of this population compared with smaller managed care systems. Alternative funding mechanisms, including reinsurance programs (e.g. for stop-loss protection) and high-risk sharing pools to finance specialized services, are needed to overcome obstacles associated with the financial risk exposure. The sources of funds for such pools can include surcharges collected from private insurers, Medicaid, state general revenues, and federal grant funds such as those in Maternal and Child Health block grants.

QUALITY SERVICES AND MANAGED CARE PROGRAMS

A previous IOM meeting noted that, although some resources are available to guide and monitor children's care, assessing the quality of children's health care poses special challenges.[9] That discussion highlighted the importance of certain critical differences between children and adults, the contribution of many services beyond medical care to a child's healthy development, and conceptual and methodological considerations. Similar factors are pertinent and present even more engrossing challenges to providing

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[7] Newacheck, P.W., Hughes, D.C., McManus, M.M., et al. Meeting Children's Long-Term Care Needs Under the Health Security Act's Home and Community-Based Services Program. San Francisco, Calif.: Institute for Health Policy Studies, University of California, San Francisco. 1994.

[8] Regenstein, M., and Meyer, J.A. *Low Income Children with Disabilities: How Will They Fare Under Health Care Reform?* Portland, Me.: National Academy for State Health Policy. 1994.

[9] National Research Council and Institute of Medicine. *Protecting and Improving Quality of Care for Children Under Health Care Reform.* J.S. Durch, ed. Washington, D.C.: Institute of Medicine, 1994. A brief summary extracted from the report of that workshop is in Appendix B. A list of several related National Research Council and IOM publications is in Appendix C.

quality care to the subgroup of children who have special health care needs and who may receive health and health-related care, in part or in whole, through managed care systems.

Concerns about the welfare of children with special health care needs and their families that are relevant to issues of quality of care cluster around three general areas: access to service, gaps in community-based systems of care, and responsibility and methodology for monitoring and assessing quality. These issues were discussed by participants in this workshop both in general and in the context of managed care systems in particular.

Access to Service

For poor children with special needs, Medicaid has been a critical source of payment for medical and health-related services. In many states, the program has provided a benefit package that is much broader than the packages usually available to children with special needs who have private insurance. For example, Medicaid is likely to cover some services (such as physical therapy or home health care) to a greater extent than is covered under most private health insurance plans.

Workshop participants expressed concern that cost-centered policies within managed care will undermine the array of services that have been made available to children who have special health needs through Medicaid non-capitated arrangements and state public health agencies. Workshop participants expressed support for including in managed care plans a comprehensive array of pediatric medical and other specialty providers. If qualified specialists' services are not provided directly by the managed care plan, they should be made available with ease by referral. Several workshop participants voiced support for policy and funding directives that provide incentives for managed care plans to invest in prevention and early interventions.

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. Many families have invested much effort over several years to build ties with the community of care providers that now form a team with the family; such teams frequently include specialists who are sensitive to the developmental perspectives of caring for children and adolescents. Efforts should be made to the extent possible to maximize continuity in these relationships, including both specialty and primary care providers.

Who funds and who provides care management or care coordination is also of particular concern as managed care arrangements increasingly become the mode for delivering health care to children. Participants encouraged experimentation with a range of models, including the use of specialists as primary care providers and gatekeepers or care managers for children with certain types of conditions. The discussion noted that multidisciplinary teams can provide valuable expertise to care managers or gatekeepers.

Gaps in Community-Based Systems of Care

Until the recent increase in managed care initiatives, Medicaid programs paid comparatively little attention to the structure or organization of services. In contrast, state programs for children with special health care needs have long been concerned with organizational issues in the health care system for these children, including issues related to coordination of services and access to care.[10] Legislation passed in 1989 mandated programs for children with special health care needs at the state level to facilitate the development of comprehensive, coordinated systems of care for all children in this population, not just children in poor families. Funds provided through these state programs can be used in various ways, and this flexibility increases the likelihood that communities can tailor their use to meet local needs and priorities.

Some participants noted that jurisdictional confusion and conflicts exist now in many communities concerning delivery and payment of some community-based services to children with special health care needs. They speculated that such situations will likely increase with the growth of managed care systems unless special efforts are made by all parties to avoid duplication or gaps and to build comprehensive, coordinated systems. Confidentiality concerns are frequently seen as obstacles to coordination. Additionally, workshop participants observed that very few financial incentives exist to encourage coordination between and among (1) the public and private sectors' mechanisms for financing and delivering health care and (2) service systems of health, education, and other community programs such as housing, transportation, and social services. Several workshop participants commented that the state public health agencies that administer the children with special health care needs programs are in a good position to work effectively with both public and private sector managed care programs toward minimizing gaps in community-based systems of care. At this time, it is unclear who in a managed care environment will assume responsibility for this important role.

The rapid development of managed care programs and the diversity in organizational forms found in these programs in both the private and pubic sectors has far outpaced the knowledge needed to assess their impact on the health status of children with special health needs. One of the major challenges in this area is to understand the implications of the structural variations that are emerging in managed care programs, in particular in the context of subpopulations. Children with disabilities or chronic illnesses are usually exempted (or "carved out") from many Medicaid managed care plans, and they continue to receive health care services in the more traditional fee-for-service delivery systems. Other structural models are evolving, however, including managed care programs that enter into capitated subcontract arrangements with specialty managed care programs to serve selected subgroups of children (e.g., those who are disabled Supplemental Security Income recipients). Other managed care models might include provisions for tertiary care centers with strong records of serving children with special needs to be responsible for providing primary and specialty care to this population. Without more experience and data, no conclusions can be reached as to whether one particular structural model should become the standard across the country.

The presence of multiple managed care programs with diverse benefit packages and different mixes of public and private funding, each with their own accompanying mandates, may have extraordinarily confusing consequences for families. Parents may need to negotiate multiple systems if family members are associated with different managed care programs or if the care for a child with special needs is directed by multiple care managers. Workshop participants could see no advantage to a given child having multiple care managers; indeed given the information available to date, these experts supported consolidating care management and gatekeeping functions.

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[10] In 1985, amendments to the Social Security Act changed the name of the states' Crippled Children Services, which were established by the Social Security Act of 1935, to the Program for Children with Special Health Care Needs. For more information, see Ireys, H.T., and Nelson, R.P. New Federal Policy for Children With Special Health Care Needs: Implications for Pediatricians. *Pediatrics* 90(3):321–327, 1992.

Monitoring and Assuring Quality of Care

Roles for State Public Health Agencies As is the case in fee-for-service systems, monitoring and assuring the quality of care provided through managed care programs encompasses structure, process, and outcomes of care. Of particular concern to the participants at this workshop was the need for clarification of the appropriate and essential roles of state public health agencies in overall monitoring and assessment of the wide range of services needed by children with special health care needs. Some participants expressed interest in moving towards state-based legislation that explicitly designates state public health agencies that administer these programs as overseer of private sector managed care plans in terms of the care they provide to these children.

Others noted the importance of databases that inform providers and policymakers on the health status of the population and the critical link between good data and effective quality assurance and improvement systems. Discussion highlighted the fact that a necessary first step is to agree on the definitions of crucial and pertinent terms; only with these definitions in place will the data gathered provide meaningful information that can be used to assess changes in the population's health and functional status. "Information management" of this sort may be a legitimate responsibility for state public health agencies.

Empowering Families Quality assurance cannot occur in a meaningful way without accurate and timely information, and many different entities need a wide range of information. Families with children with special health care needs in particular need to be informed about how to work with the multiple service providers and systems they encounter. The advent of managed care programs will likely simplify, and perhaps improve, some situations by decreasing the number of individuals and entities involved in care planning and delivery. Nevertheless, other challenges may arise. For example, more information must be collected and analyzed to determine the best models of case or care management for these children. Additionally, families need to have adequate information to monitor the impact of decreased access to subspecialty care should such occur with enrollment in managed care. Available information technology can be better utilized to provide families with comprehensive, accurate, and timely information on services, quality measures, and performance reports.

The family is a key unit of analysis for evaluating the outcomes of health services for children with special health care needs. Families need to be given the opportunity to play significant roles in the development and implementation of treatment plans; as important, they need to be actively encouraged to do so. If family participation is to be of optimal benefit, all team members must be aware of the advantages of such involvement; some providers will need training in family-centered practices. Families whose children are served by managed care systems need to serve as members of policy-making, quality assurance, grievance, and other consumer-oriented boards. Several processes and mechanisms can facilitate family participation: family support groups at both the community and state level; state family training and information centers; and protection and advocacy systems to provide legal backup and technical assistance for health-related issues.

Roles for Other Parties Although the workshop discussion did not attempt to define an inclusive set of entities that contribute toward monitoring the quality of care for this population, participants noted that state insurance commissioners can and do carry out worthwhile oversight functions. Additionally, tertiary care institutions make valuable contributions to quality care for children with special health care needs through both caring for patients and providing medical education and research. The specific and perhaps unique roles such institutions can and should play in an environment oriented more toward managed care and cost containment needs further exploration.

Clinical Evaluation Workshop discussion highlighted the need to develop practice guidelines, performance standards, and clinical pathways pertinent to caring for children with special health care needs. Much variation exists in medical protocols for children, and the effectiveness of many technologies and procedures used is not known. Without sound evidence as to effectiveness, insurance companies and health care plans can question whether a given treatment or service such as home health care is medically necessary for a child with uncommon and complex conditions. Children-specific medical necessity criteria for use in making coverage decisions are needed; such criteria should take into account cognitive and emotional development concepts.[11]

Professional health care providers, not health plans, are responsible for managing the care of those they serve. The trend is shifting from a highly disintegrated and individualistic system of accountability to a type of practice that requires consensus building, team building, and adoption of clinical pathways. Families and public health agencies who are knowledgeable about the needs of this population can work with clinicians in identifying dimensions and elements of care that can guide the development of provisional practice guidelines pending further development of databases on outcomes.

CONCLUDING REMARKS

Technological advances are continuing to widen opportunities and lengthen survival rates and improve quality of life for children with special health care needs. In many instances these improvements will be associated with high costs and the need for multiple services for many years. That government and community institutions have some responsibility for these children and their families is generally accepted. The dimensions of that responsibility shift, however, as society redefines the role of government in health care and as the health care system itself takes on different characteristics. The public health system, the public and private health financing system, and the providers of health care are challenged to assure that widespread adoption of managed care programs does not erode the important achievements already accomplished for children with special health care needs and their families.

As the health care system changes during the next three to five years, families, providers, staff in state agencies, and decision-makers in managed care programs should consider several strategies to assure quality of care for children with special needs.

First, despite an historical neglect of the service delivery and financing issues associated with this population of children, managed care programs will increasingly need to enroll these children under an appropriate benefits package. The expertise in evaluating quality of care that is characteristic of many managed care programs must be focused now on this population. State-administered Programs for Children with Special Health Care Needs have critical leadership roles to play in assuring that their own experience in facilitating systems of services for these children helps to shape quality of care procedures within managed care programs.

Second, standards of care are needed that will define the goals of care for this population beyond strictly medical considerations. These standards and associated clinical practice guidelines will help link costs and financing with desired outcomes of care, and they may provide a foundation for defining value of services.

Third, traditional measures of quality of medical care are insufficient to assess quality of health care for children with special needs and their families. State agencies managing the Programs for Children

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[11] Jameson, E.J., and Wehr, E. Drafting National Health Care Reform Legislation to Protect the Health Interests of Children. *Stanford Law and Policy Review* Fall:152–176, 1993.

with Special Health Care Needs, managed care programs, and academic health care centers must work together to develop relevant, useful, and comprehensive indices of quality that are family-centered.

Fourth, there is an urgent need to define the relative capacities and roles of families, government agencies, providers, and plan administrators in the decisionmaking process that determines (1) which services will be provided to which children under what conditions, and (2) how services will be monitored for purposes of policy reform and outcomes research. Consensus on these points is likely to evolve slowly. However, the public sector, especially the state agencies administering the Programs for Children with Special Health Care Needs, might appropriately take the lead in organizing the forums within which this consensus can evolve.

Finally, more experimentation is needed to identify how managed care plans can be crafted to manage financial risk, prevent long-range morbidity, and enhance quality of life in this population of children.

Appendix A

Workshop Participants

PANELISTS AND DISCUSSANTS

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Appendix B

Protecting and Improving the Quality of Care for Children Under Health Care Reform: Workshop Highlights[1]

SUMMARY

Changes in the financing and delivery of health care across the United States make it particularly important to ensure that the quality of care is both protected and improved. The Institute of Medicine (IOM) has defined 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."[2] A workshop organized by the National Research Council and IOM identified several critical factors that affect our ability to protect and improve the quality of health care for children in particular.

Valuable, but still limited, techniques and tools are available to evaluate certain aspects of care for adults. Some resources are available to guide and monitor children's care, but assessing the quality of children's health care poses special challenges. The workshop highlighted the importance of certain critical differences between children and adults, the contribution of many services beyond medical care to a child's healthy development, and conceptual and methodological issues.

Critical differences between children and adults include the complex and continuing ***developmental changes*** that occur between birth and adulthood. Care for children emphasizes protecting and promoting healthy physical and psychosocial development whereas much adult care responds to illness. To assess children's care, ways must be developed to identify the separate effects of health care and developmental changes.

Children also are ***dependent*** on adults and community institutions (e.g., schools) to protect and promote their health and well-being. Assessments of their health status cannot, therefore, rely on the criterion used for adults of "independent functioning." Assessments also often rely on adult perceptions of a child's condition, which may differ from the child's perceptions or from those of other adults.

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[1] This Appendix contains the summary from *Protecting and Improving Quality of Care for Children Under Health Care Reform: Workshop Highlights*. J.S. Durch, ed. Washington, D.C.: National Research Council and Institute of Medicine, 1994.

[2] Institute of Medicine. 1990. *Medicare: A Strategy for Quality Assurance*. K.N. Lohr, ed. Vol. I. Washington, D.C.: National Academy Press, p. 21.

Children's ***patterns of illness and injury*** differ from those of adults. Overall, children are healthier than adults, and therefore, assessments of children's care must focus more on preventive care than assessments for adults. The small proportion of children who have chronic illnesses have a more varied array of illnesses than do adults.

Monitoring the quality of children's care needs to include the contributions of medical care plus other services that help promote optimal physical and psychosocial development. Medical care can mitigate some of the impact of socioeconomic and environmental health threats and can help children gain access to additional services that can improve their health and well-being. Successful integration of health care with educational and social services appears valuable but techniques are needed to assess the quality of those integrated services.

Additional indicators are needed to assess the quality of children's health care. The few that are commonly used touch on only limited aspects of the care given to children. ***Health status measures*** suitable for guiding policy and assessing the outcomes of care also require further development. In addition, important ***methodological problems need to be resolved***, including measuring the impact of prevention, developing statistically reliable measures to assess the care of small numbers of children with specific chronic illnesses or other special health care needs, and developing techniques for risk adjustment that are appropriate for all aspects of pediatric care.

Assessments of health and health care can be made from three perspectives: the individual patient and provider, health plan performance, and systems of services for entire communities and states. Further development of ***measures and tools for all three forms of assessment*** is still needed.

Establishing accountability for the quality of the care that children receive is a special concern. Simply measuring performance does not ensure that problems will be corrected. Well-established criteria to define "medically necessary" or clinically appropriate care for children are not available, and administrative and legal remedies may not offer adequate protection for children in low-income families or other vulnerable populations. The array of public and private services that contribute to children's health and development need coordination and oversight. Workshop participants felt that federal and state health care reforms need to include ***mechanisms that will lead to action by health plans, public health agencies, or other entities to respond to identified problems.***

Discussions throughout the workshop emphasized the need for ***further research*** to develop better techniques and tools to support assessments of the quality of children's health care. The workshop discussions also drew attention to the need to ***develop better data, data collection, and data systems*** to support efforts to monitor and improve children's care.

Appendix C

Recent Publications from the Institute of Medicine and the National Research Council Related to Quality of Care Issues

INSTITUTE OF MEDICINE

The Future of Public Health. Washington, D.C.: National Academy Press. 1988.

Clinical Practice Guidelines: Directions for a New Program. M.J. Field and K.N. Lohr, eds. Washington, D.C.: National Academy Press. 1990.

Medicare: A Strategy for Quality Assurance. K.N. Lohr, ed. Vols. I and II. Washington, D.C.: National Academy Press. 1990.

Guidelines for Clinical Practice: From Development to Use. M.J. Field and K.N. Lohr, eds. Washington, D.C.: National Academy Press. 1992.

Access to Health Care in America. M. Millman, ed. Washington, D.C.: National Academy Press. 1993.

Assessing Health Care Reform. M.J. Field, K.N. Lohr, and K.D. Yordy, eds. Washington, D.C.: National Academy Press. 1993.

Emergency Medical Services for Children. J.S. Durch and K.N. Lohr, eds. Washington, D.C.: National Academy Press. 1993.

America's Health in Transition: Protecting and Improving Quality. A Statement of the IOM Council. Washington, D.C.: National Academy Press. 1994.

Health Data in the Information Age: Use, Disclosure, and Privacy. M.S. Donaldson and K.N. Lohr, eds. Washington, D.C.: National Academy Press. 1994.

Protecting and Improving Quality of Care for Children Under Health Care Reform. J.S. Durch, ed. Washington, D.C.: Institute of Medicine. 1994.

NATIONAL RESEARCH COUNCIL AND INSTITUTE OF MEDICINE

Including Children and Pregnant Women in Health Care Reform: Summary of Two Workshops. S.S. Brown, ed. Washington, D.C.: National Academy Press. 1992.

Toward a National Health Care Survey: A Data System for the 21st Century. G.S. Wunderlich, ed. Washington, D.C.: National Academy Press. 1992.

OTHER PUBLICATIONS

Advances in Health Status Assessment: Proceedings of a Conference. 1989. K.N. Lohr, ed. *Medical Care* 27(March Suppl.):S1–S294.

Advances in Health Status Assessment: Proceedings of a Conference. 1992. K.N. Lohr, ed. *Medical Care* 30(May Suppl.):MS1–MS293.