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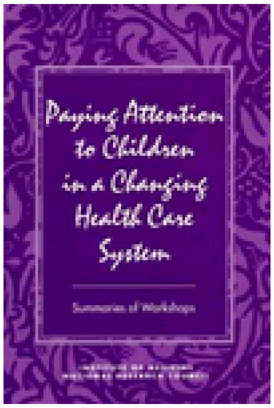

Paying Attention to Children in a Changing Health Care System

Summaries of Workshops

Paying Attention to Children in a Changing Health Care System

Board on Children, Youth, and Families, Institute of Medicine and the National Research Council

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THE NATIONAL ACADEMIES
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Paying Attention to Children in a Changing Health Care System

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Summaries of Workshops

Board on Children, Youth, and Families
Commission on Behavioral and Social Sciences and Education

Board on Health Promotion and Disease Prevention

National Research Council

Institute of Medicine

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Preface

Profound changes have occurred in America's health care system over the last few years. Although the 103rd Congress did not enact national health care reform in 1993-1994, the Kennedy-Kassebaum bill (P.L. 104-191) passed in August 1996 will have major implications for health insurance coverage for a number of Americans. Independent of the legislative agenda, the health care landscape is being reshaped by a convergence of rapid and major market-driven changes, including increasing pressures for cost containment, alterations in the organization and financing of Medicaid and other publicly funded health care systems, consolidation of health care delivery plans and insurers, and new divisions of responsibility among a wide range of health care professionals and organizations. Several states have moved to provide insurance coverage for all children up to age 18. In this context, states rather than the federal government are emerging as the major governmental influence on health policy development and reform. These changes are still under way in many places and must be systematically evaluated in terms of their impact on the quality of care that is provided to individuals, as well as on costs and access to care.

In the midst of these deep changes, the health and well-being of children can easily slip from view. Children are not simply small adults; with their mothers, they have special health needs related to their developmental status. Although most children are fundamentally healthy, they require health care that emphasizes preventive services such as immunizations and the continuous monitoring of physical and psychosocial growth and development, with particular attention to critical periods in which appropriate care is essential for sound development. Health interventions during adolescence, for example, provide an opportunity to prevent the onset of unhealthy behavior, as well as to establish healthy behavior patterns that may span a lifetime. Medical care can also mitigate the impact of socioeconomic and environmental health threats and help children gain access to additional services that can improve their health and well-being.

Acknowledging the importance of a child-based perspective, and based on a long-standing interest in the health and well-being of mothers and children, the Institute of Medicine (IOM) and the National Research Council (NRC) convened five workshops between 1991 and 1994 to explore various aspects of maternal and child health care in an era of health system change. In this volume, which is intended to inform reform efforts at all levels of government and in the private sector, we reprint the summaries of those workshops, based on the views presented and opinions discussed by those who attended the workshops.

Although some of the workshops whose summaries are reprinted in this volume were focused on national-level health care reform proposals, the goals and principles that they identify are enduring and apply at all levels of government, as well as in both public and private health care systems. The reports should also be considered by federal agencies reviewing waivers of federal laws necessary to implement state reforms.

Chapter 1, "Including Children and Pregnant Women in Health Care Reform," is based on two workshops held under the auspices of the NRC/IOM National Forum on the Future of Children and Families before the launch of the major Congressional health care reform debate. This chapter reviews 11 specific goals that emerged from the workshops that address access to and benefits of health insurance for children and pregnant women, resource development, administration, and cost management and quality assurance. These goals were intended to be a touchstone for evaluating specific legislative proposals from the standpoint of children and mothers, and remain valid for proposals on the table today and in the future. In the original report these goals were applied, in an illustrative way, to seven specific legislative proposals that were being considered in 1992; these sections are out of date and are not included in this volume.

The remainder of the volume deals with more specific issues. Chapters 2 and 3 ("Benefits and Systems of Care for Maternal and Child Health Under Health Care Reform" and "Protecting and Improving Quality of Care for Children Under Health Care Reform") summarize a two-day workshop held in July 1994 in the midst of Congressional consideration of health care reform legislation. The goal of this workshop, which was organized by the NRC/IOM Board on Children and Families and the IOM Board on Health Promotion and Disease Prevention, was to lay out principles to be considered in evaluating legislative health care reform proposals. The first day of the workshop focused on benefits and systems of care for mothers and children. The second day focused primarily on quality improvement and performance monitoring for children's health services.

Chapter 4, "Strategies for Assuring the Provision of Quality Services Through Managed Care Delivery Systems to Children with Special Health Care Needs," summarizes a workshop organized in December 1994 by the IOM Board on Health Care Services to address issues related to the delivery of high-quality health care services to special-needs children through managed care delivery systems.

Lists of committees and boards responsible for convening the workshops are in Appendix A. Lists of workshop participants are in Appendix B. In Appendix C, you will find acknowledgments of the foundations and individuals that contributed to the reports. Appendix D lists publications on related topics produced by the IOM and the NRC.

Since the original publication of the reports reproduced here, the Board on Children, Youth, and Families and the Board on Health Promotion and Disease Prevention have continued to address some of the implications for children of changes in America's health care system. One particular area of interest is the growth of managed care, especially for economically disadvantaged children and children with special needs. Along these lines, a recent joint meeting of the Board on Children, Youth, and Families and the Board on Health Promotion and Disease Prevention focused on the trend to use managed care organizations to provide care for populations formerly covered by Medicaid and other publicly funded programs.

One approach to ensuring quality health care that is receiving a lot of attention is the use of health-outcomes-based performance measures for managed care organizations and other organized health care delivery systems. The IOM is planning to address this issue through a new project that would summarize the state of the art regarding child health assessment and address the use of a child health standard in health care quality improvement activities.

In February 1996 the IOM began a three-year special initiative related to improving the quality of health care in the United States. Its purpose is to examine and report on the transition of health and health care in this nation, with a specific focus on maintaining and improving the health and well-being of the U.S. population and the quality of care delivered. America's evolving health care system, which often seems to be cost driven, creates a range of concerns about how prominently quality of care will be considered in decision making, particularly for vulnerable populations. At the same time, the changes taking place create unprecedented opportunities for new approaches to quality measurement and improvement tools. We expect that the material presented in this volume will contribute to this special initiative.

Thanks go to the Ford Foundation and the W.T. Grant Foundation for supporting the funding of this volume. Thanks also go to Deborah Phillips, director of the Board on Children, Youth, and Families; Mike Stoto, director of the Division on Health Promotion and Disease Prevention; Anne Bridgman, communications officer for the Board on Children, Youth, and Families; and all the volunteer participants in the projects presented in this volume.

Kenneth Shine, *President*
Institute of Medicine

Paying Attention to Children in a Changing Health Care System

Summaries of Workshops

CHAPTER

1

Including Children and Pregnant Women in Health Care Reform

Sarah S. Brown, Editor

National Forum on the Future of Children and Families
National Research Council
Institute of Medicine

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CONTENTS

INTRODUCTION

Not since the 1970s has there been such interest in restructuring the health care system. Building on the foundation of Medicare and Medicaid, enacted in 1965, four successive presidents—Lyndon Johnson, Richard Nixon, Gerald Ford, and Jimmy Carter—paid such significant attention to national health care issues that many believed broad-scale reform was imminent. No such millennium has arrived, of course. Instead, the intervening years have been characterized by incremental, marginal changes in health care policies rather than by fundamental realignment of the public-private system now in place.

In rapid succession over the last several years, however, many important national organizations and public policy leaders have introduced blueprints for reforming the health care system, some radically, some less so. The reasons for the current ferment include at least the following: a steady increase in the percent of gross national product (GNP) devoted to the health sector, leading to considerable anxiety about whether such growth will continue and whether it can be afforded; concern about the health and competence of the nation's work force at the turn of the century; substantial growth—by as many as 7 million people—-in the number of uninsured Americans between 1980 and 1990; higher levels of uncompensated hospital care because of increased numbers of patients without any form of third-party payment for health care; alarm among corporations and employed individuals about the continued escalation of private health insurance costs; fear among the currently insured that their coverage may be canceled if they become very ill or that preexisting conditions will limit their insurability; embarrassment over the poor international ranking of the United States on such basic measures of health as infant mortality and immunization rates among children; recognition that the aging of the population will lead to increased health care costs; the problems many states are encountering in meeting their share of growing Medicaid expenditures; and, finally, the steady erosion of the public health care system because of chronic underfinancing and the seriousness and intensity of problems brought to its doorstep, including AIDS, drug addiction, and violence.

Noting the renewed interest in health care reform and concerned that insufficient attention was being given to children and pregnant women in the debate, the National Forum on the Future of Children and Their Families (jointly sponsored by the Institute of Medicine and the National Research Council) arranged for a preliminary review in 1988 of current suggestions for national health care reform (Cislowski, 1988). The analysis revealed that most proposals focused primarily on ways to finance health care services for the over 30 million Americans without any form of health insurance. The complexity and enormity of the financing challenge, however, seemed to overshadow many subsidiary issues of special importance to pregnant women and to children. For example, the analysis noted the mismatch between traditional insurance coverage and many services important to child health; the absence of adequate strategies to meet the complex, multifaceted needs of technologically dependent children or seriously ill newborns; and a failure to address the increasingly limited number of obstetrical and pediatric care providers willing to serve low-income or high-risk women.

Since that analysis in 1988, the debate about reforming the health care system has intensified and deepened, and issues of maternal and child health have become more prominent. In 1990, for example, the Bipartisan Commission on Comprehensive Health Care—the Pepper Commission—issued a report that recommended greatly expanded access to health insurance, beginning with children and pregnant women. In 1991, the National Commission on Children made a similar call for revisions in the health care system for this population. Leaders in both the House and the Senate have introduced proposals for reform, some of which are confined entirely to children and pregnant women or give them special attention. In addition, several private associations, ranging from the American Academy of Pediatrics to the National Governors' Association, have offered blueprints for reform. All of these proposals share the view that improving health care for children and pregnant women is a top priority in health policy.

The Forum considered carefully its potential contribution to this debate and concluded that while "children's issues" now seem in vogue, the complexity and constantly changing dimensions of national discussions about health care reform hold the risk that the special problems of children and pregnant women will be overlooked. In particular, the health services needed by this group, which are frequently routine and predictable, are often not paid for in a risk-based health insurance model—the model that dominates current discussions of health system reform. Thus, the Forum decided to develop a monograph discussing the important health policy issues presented by children and pregnant women that should be addressed by any major proposal for health care reform. Such a document should be useful to policy makers considering ways to improve the nation's system of health care.

The Forum convened two workshops for this purpose. The individuals who participated in these sessions are listed on pp. 79-86, and several outside experts were drawn into the discussions as well. At the first session, participants outlined 11 goals central to maternal and child health that they agreed should form the foundation of any major reform. The goals are consistent with many major reports on maternal and child health that have been completed recently (see below). The participants also discussed examples of how each goal might be translated into the language of health policy and legislation. At the second workshop, the participants met with individuals associated with seven major proposals for health care reform—chosen from about 35 then in wide circulation—to learn more about why the authors settled on their particular approaches, the political forces that shaped their efforts, and how each of the proposals addresses the goals outlined by the participants at their first workshop. This discussion of specific proposals was undertaken primarily to explore ways in which the goals outlined earlier by the workshop participants could be reached through legislation, not to critique the plans themselves.

The seven proposals reviewed by the workshop participants were selected as representative of the major ideas for reform currently being considered by the U.S. Congress and by others interested in health system reform. The participants chose to review only proposals that were national in scope, although states have recently been very active and innovative in health care reform. Three proposals from private associations were studied along with four developed by members of Congress. Five of the seven are "multipayer" plans, that is, they retain a mix of private health insurance and one or more publicly financed programs. *[In the original report, each goal was applied, in an illustrative way, to seven specific legislative proposals that were being considered in 1992. These sections are out of date and are not included in this volume.]*

This monograph summarizes the two workshops and is organized around the 11 goals identified by the participants. The statement of each goal is followed by a brief section that amplifies the goal and offers examples of how it might be attained in a proposal for health care reform. The eleven goals presented in this monograph capture much that is important to the health of children and pregnant women. But the paper is only a beginning, and many details of implementation especially remain to be crafted. Hopefully, it will be a stimulus to deeper and more thorough consideration by other groups—particularly the U.S. Congress—of how best to meet the needs of this important population when reforming the nation's complicated system of health care.

UNDERLYING THEMES

Discussions among the workshop's participants were based on several shared values. First is the view that providing access to health care is a basic social obligation, equivalent to providing access to education, and that the ability to obtain health care should not rest on any particular attribute, especially income. Similarly, the participants believe that the long-term goal of health care reform should be to extend health care to all Americans, male and female, young and old, not just children and pregnant women. Indeed, the notion of a fundamental obligation to provide health services to all citizens has become a familiar refrain in discussions of health policy, and assertions of a basic right to health care appear in the preamble of virtually all proposals reviewed at the workshops.

The participants noted that their assigned focus on children and pregnant women was well justified by data documenting their substantial representation among the uninsured. In 1989, 29 percent of the U.S. population was under age 21, but they represented 36 percent of the uninsured—12.4 million children under the age of 21 were uninsured in that year (Foley, 1991). In addition, the National Commission on Children has estimated that in 1990, 433,000 pregnant women had no health insurance, representing 9 percent of all pregnant women (National

Commission on Children, 1991). Part of the explanation for such numbers is that many children and pregnant women are themselves not insured directly but are instead the indirect beneficiaries of a parent's or spouse's employment-based private insurance. Being one step removed from the source of insurance—that is, receiving coverage as a dependent—is an increasingly expensive and insecure basis upon which to receive health care coverage. Because of the increasing cost of dependent insurance, employers are ever more reluctant to meet the full cost of that coverage, asking instead that their employees pay a larger proportion of additional coverage. In 1980, for example, 40 percent of employers paid the full cost of dependent coverage; in 1990, only 33 percent did so (National Commission on Children, 1991). Such trends underlie the finding that 23 percent of uninsured children live in families with insured parents (Foley, 1991).

These data also supported a consensus among the participants that, over time, the health care needs of children and pregnant women will best be served by a policy that avoids pitting the relatively modest needs of this population against other populations and health care demands. The participants discussed, for example, the current practice in the Medicaid program of placing flat dollar and duration limits on coverage of ambulatory services but not on coverage of long-term care services—a practice that has led many state Medicaid programs to spend an ever larger share of their funds on the elderly, further reducing resources for children and pregnant women, who rely primarily on ambulatory services.

Another underlying theme of the workshops was the recognition that although financial barriers are a major—some say *the* major—obstacle to health care services, other important barriers can be defined for children and pregnant women (Institute of Medicine, 1988a). These obstacles include inadequate diversity, supply, and distribution of providers; poorly organized or even absent health care services in such areas as inner cities and rural communities; tangled relationships between public and private systems of care; and insufficient collection and evaluation of data to monitor the health of children and pregnant women. The latter creates a barrier to care by limiting the ability of providers and administrators to concentrate their efforts efficiently or to identify shortcomings. Although securing a reliable and adequate source of payment for health care is clearly a very important first step, and the major focus of most current proposals, it is only a first step, necessary but not sufficient. Accordingly, the goals begin with access to health insurance but then extend to other, equally important issues.

By presenting such a broad list of goals, however, the participants did not wish to imply that all problems of the nation's complicated health care system will necessarily be solved in one piece of reform legislation. In fact, it may be more realistic to urge that incentives for needed policies be enhanced and disincentives reduced, and to ask Congress to enact a series of laws over time, rather than to look for resolution of many long-standing problems in a single bill.

The workshop participants recognized explicitly that, in the great scheme of things, many determinants of maternal and child health status have little to do with access to or use of medical services, as traditionally defined. Poverty, education, housing, violence, and family environment often overshadow whatever impact health services are able to make, and parents remain potent influences on the health and development of their children. Even the outcomes of pregnancy, a major theme of this monograph, may have more to do with personal choices and behavior, with socioeconomic factors, and with the general health of women than with any of the particular health services detailed here. Thus, while the participants considered how to reform the health care system in ways that serve the needs of children and pregnant women, they agreed that achieving major improvements in health status may well require new personal choices, a deeper commitment by parents to enhancing their children's health, and social changes more far-reaching than even the most comprehensive proposal for health care reform envisions.

A final note. The workshop participants were not asked to construct their own proposal for health care reform, but instead to discuss those issues important to maternal and child health that they believed should be included in any reform bill. As a consequence, the participants identified the goals without having to meet a particular budget target or to identify financial offsets to support their ideas. Although the participants believed that the goals could be met with existing resources, or perhaps a modest increase in overall expenditures, no formal cost analysis was attempted. In addition, although one of the issues in health care reform is how best to finance the health care system—through government, employers or both, in varying combinations and structures, and with various tradeoffs—the participants' primary concern was the health services needed by children and pregnant women that must be addressed in any reform plan, regardless of the mechanism of financing. The participants took no position as to which financing approach is preferable and were neither asked to offer, nor offered on their own, a preferred model of reform. Indeed, the consensus was strong that there are many ways in this pluralistic, complicated country to achieve a given end and that the needs of children and pregnant women can be met well by a wide variety of systems to finance and deliver health care.

The goals of the workshop participants are consistent with numerous thoughtful and well-documented reports and books that have been completed in the last several years. These include Institute of Medicine, 1989b, 1988a, and 1985; Merkatz and Thompson, 1990; National Governors' Association, 1991 and 1989; the Alan Guttmacher Institute, 1991; U.S. Department of Health and Human Services, Public Health Service, 1991; and U.S. Preventive Services Task Force, 1989. Additional references are cited throughout the text.

HEALTH INSURANCE: ACCESS AND BENEFITS

Goal 1: All children and pregnant women have continuous access to health insurance.

Discussion

Access to a source of payment for health care—typically, health insurance—should be available regardless of employment status, family income, age, health or marital status, family composition, or geographic location. In addition, coverage should be continuous, despite changes in any one or more of these factors. In particular, a change in the employment status of an adult should not disrupt coverage of his or her dependents.

However straightforward this goal, it remains elusive under present arrangements. Coverage by private health insurance often requires individuals and families to meet such requirements as a minimum length of time employed, good health status, a particular degree of relationship to a covered person, lawful U.S. residence, and so forth. The Medicaid program also imposes a wide variety of preconditions centering on income, residence, age, family composition, and other factors. Failure to satisfy one or more requirements can cause pregnant women and children to be ineligible for coverage altogether or ineligible for coverage for a period of time or for certain conditions.

Principally for reasons of cost containment, health insurance plans may exclude certain groups with special relevance to maternal and child health; in some instances, legal concerns form the basis for exclusions (as when health insurance is not available to children in certain types of custodial arrangements). These groups include adolescents and young adults not yet insured on their own who have attained the age of majority as defined by their parent's insurer (and who do not receive coverage through one of the exceptions provided in the insurer's plan, such as enrollment in college); undocumented U.S. residents; adopted children; children who are not related closely enough to their caretakers to be covered by the caretaker's insurance plan (for example, children living with a grandparent or older sibling); and dependent adult children (such as a chronically ill adult living with his or her parents).

The exclusion of undocumented residents is of special relevance to maternal and child health because many of these persons are mothers, children, and pregnant women. Of the 2 to 4 million undocumented people in the United States at present, the majority are women. Women of reproductive age (15 to 44) are believed to comprise 30 to 40 percent of the total; 20 percent are believed to be children under 15 (Passel, 1991). More generally, the need to provide undocumented residents with a source of payment for health care is suggested by their significant contribution to the uncompensated care debt reported by hospitals in such states as Texas, California, Florida, New York, and Illinois, where there are large populations of such individuals.

In addition, and again for reasons of cost, some individuals *within* covered populations are denied health insurance because of medical underwriting practices (such as denying coverage because of preexisting conditions[1] or a history of large claims); provisions that exclude pregnant minor family members and their children; and waiting periods for coverage to begin. Similarly, groups of individuals may be effectively excluded from coverage by dramatic increases in premiums brought about by high costs incurred by one or two members of the group.

In multipayer systems—particularly those that incorporate employer-based private health insurance—problems of continuity in coverage are particularly salient. Continuous coverage may be interrupted when, for example: an insured worker changes jobs, interrupting coverage for the worker and his or her dependents; a public plan, such as Medicaid, fails to pick up immediately coverage of a family or individual when private coverage is lost; or a move to a different community or state results in loss of coverage (a liability of state residency tests).

To meet the goal of full and continuous health insurance coverage for children and pregnant women, all these excluded groups must be given access to health insurance and the specific barriers to continuous coverage eliminated. This might be accomplished by requiring all individuals in the United States to be covered by health insurance at all times as a matter of law or by trying to achieve this same end through the gradual elimination of all exclusions and gaps. It will be important under multipayer plans especially to separate the public portion of health insurance from the welfare system as much as possible. The stigma of welfare has been documented repeatedly as a deterrent to individuals' seeking Medicaid coverage or publicly subsidized health care, and there is obvious appeal to treating health programs differently from income supports (National Commission to Prevent Infant Mortality, 1988). If multipayer programs require means testing—for example, for individuals in the public insurance system to obtain premium subsidies—such determinations should be conducted in an environment less adversarial than a typical welfare office. In addition, if administratively possible, it would be useful to allow the paper work completed when applying for public health insurance to be used also for application to other social services such as food stamps and WIC (Special Supplemental Food Program for Women, Infants, and Children). Along these same lines, it may be wise, particularly in

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[1] Of great potential significance for insurance practices is the growing ability to detect conditions before the onset of symptoms. For example, the mapping of the human genome may eventually permit both prenatal and childhood diagnosis of genetic risk factors for diseases and conditions that may not manifest themselves until later in life. Whether such genetic information will be used as a basis for denying or limiting access to health insurance is not known, but the possibility of such exclusions merits vigilance and open discussion.

multipayer systems, to arrange the financing system in a way that leaves providers of care unable to determine a client's source of insurance coverage—that is, "blinding" the provider to whether an individual is covered by a public or private plan.

Reaching the goal of continuous access to health insurance also requires safeguarding the financial viability of the insurance plan or plans. For example, if a reform proposal relies on private insurance, such private plans should have to meet standards for reserve funds that are sufficient to pay all unpaid claims. Under current practices, insurance companies are regulated by the states, and self-insured plans are regulated in a general way by the U.S. Department of Labor under ERISA to ensure that they meet their fiduciary responsibilities. A reform proposal should extend these standards to new public plans, either by making them subject to these laws or by providing that their trust funds be managed according to sound actuarial standards if they are administered by a public entity.

[The section applying goal 1 to legislative proposals has been deleted.]

Goal 2: Personal expenditures for the health care of pregnant women and of children, including insurance premiums, deductibles, and other copayments, are affordable.

Discussion

Even if all the gaps and barriers to coverage outlined under goal 1 are eliminated, actual access to health insurance can be limited by cost-sharing provisions that individuals cannot afford. Cost sharing in health insurance can be burdensome in three principal ways. First, if the cost of premiums is too high for an individual or family to manage, coverage may be effectively denied. For example, even when coverage is initially affordable, groups of individuals may find themselves effectively excluded from coverage by dramatic increases in premiums due to the high costs incurred by one or two members within the group. Second, high cost-sharing requirements after coverage begins—through large deductibles and heavy coinsurance outlays—can result in major out-of-pocket payments. In particular, balance billing[2] can place a heavy financial obligation on consumers, particularly the poor. Third, the absence of reasonable stop-loss protections can mean that persons with catastrophic medical expenses will exhaust their coverage.

To give children and pregnant women genuine access to health insurance

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[2] Balance billing refers to the practice of demanding patient payments for services over and above what the patient's insurer's fee schedule will cover (minus applicable deductibles and coinsurance). The Medicaid program prohibits balance billing; it is an issue primarily in transactions involving private health insurance.

and, therefore, access to health care, personal expenditures for coverage and care must be affordable. Strategies that address affordability include, for example, establishing sliding fee scales for premiums, deductibles, and other copayments; waiving all out-of-pocket expenses for low-income individuals; and limiting, perhaps prohibiting, balance billing in certain circumstances.

[The section applying goal 2 to legislative proposals has been deleted.]

Goal 3: Coverage is provided for a continuum of services that emphasizes primary and preventive care and includes the diagnosis and management of a variety of diseases and conditions, as well as specialized care to handle complex health problems.

Discussion

Four overlapping issues related to covered benefits are taken up in this section: (1) defining the services that should be covered by health insurance; (2) ensuring access to important, medically necessary services that fall outside a benefits package; (3) addressing the problem of noncomparable benefits across insurance plans, especially public versus private ones; and (4) encouraging participation in preventive services.

Covered Benefits Deciding which services should be financed under a given health insurance scheme has proven to be one of the most contentious issues in health policy. This is especially true for maternal and child health, because many of the most important services do not fit well with a risk-based insurance model and many therapeutic interventions are as much educational, social, and behavioral as medical.

In a world of unlimited resources, agreement could probably be reached quickly about the health services that should be available to pregnant women and to children. Some arguments might arise about who should provide a particular service (such as assistance in stopping smoking), or whether a particular intervention is really a health service or a social service (for example, respite care). But in general, a consensus would be easy to develop. In the face of limited resources, however, disagreements arise about the definition of essential health services, what works (or, in current parlance, has been shown to be "effective"), and what should be included in a benefits package. In the midst of such complexity, the content and availability of services vary enormously from state to state, across insurance and managed care plans, and often from benefit period to benefit period, even in the same system. In particular, benefits packages in private insurance—and even in some publicly financed programs—may omit coverage of services important to children and pregnant women. For example, few, if any, private plans cover many of the benefits that children with chronic illnesses and handicapping conditions receive through state Medicaid plans, and immunizations offered as a part of well-child care are commonly not covered.

Listed below are the health services generally recognized as important *to children and pregnant women*, not all the health services needed by all populations. This list, an amalgam of lists constructed by numerous groups in recent years (Select Panel for the Promotion of Child Health, 1980; American Academy of Pediatrics, 1991; U.S. Department of Health and Human Services, 1989; American Academy of Pediatrics and American College of Obstetricians and Gynecologists, 1988; Health Policy Agenda for the American People, 1988) includes services that the workshop participants thought should be included for children and pregnant women in the benefits package of any proposal to reform the health care system. It assumes that all services are offered by licensed health care providers in settings that meet accepted standards of practice. The services are divided into three categories: preventive health services; major medical services; and special services and supplies for persons with extensive or complex health care needs. Although the precise content of these services is reasonably clear for some (such as immunizations), it is not so for others. Clearly, much work would need to be done to convert this general list into a detailed statement of health services to be covered. For example, information on amount, scope, and duration of services is not provided, and the specific content of some of the services (such as "nutritional services") is not presented. Nonetheless, the list is at the same level of specificity as most such lists in reform proposals now being developed, and the workshop participants believe that it is a useful basis on which to begin a more detailed discussion of benefit packages that meet the health care needs of children and pregnant women. Goal 4, which follows directly below, takes up these definitional issues in more detail and, in particular, discusses the need for a reform plan to include an explicit process for refining and updating a benefits package.

This list does not answer the important questions of how best to deliver and finance these services or how to ensure their quality and appropriate use. Historically, those services in category 1—preventive services—have been excluded from risk-based insurance for several reasons. For example, insurers (particularly profit-oriented ones) prefer not to pay for preventive services if the cost savings that stem from the service will not necessarily flow to them or if they believe that consumers will purchase the service directly without the assistance of insurance. Many of these preventive services have been provided to medically indigent children and pregnant women through the public health system. Similarly, the services in category 3—-special services and supplies—-have often been subject to increased cost sharing or, at a minimum, extensive prior authorization, because of their more specialized nature and the need to link most of them to other, ongoing care. These intertwined issues of financing, quality assurance, and services coordination are taken up in more detail elsewhere in this monograph (see goals 8, 10, and 11).

1. Preventive health services

—Comprehensive prenatal, delivery, and postpartum care, emphasizing continuous risk assessment in pregnancy, education, and intervention when problems are detected;

—Regular, routine preventive health care from birth through adolescence, including immunizations, anticipatory guidance and health education, and health screening (beginning with screening of newborns);

—Family planning services and supplies; postpartum care and counseling; and other related reproductive health services; and

—Preventive dental care.

2. Major medical services

—Services in hospitals and other licensed health facilities, including inpatient care for acute and chronic illnesses, emergency room care, surgery (including ambulatory surgery), and anesthesia;

—Services of physicians and of other licensed providers, such as certified nurse-midwives, obstetric-gynecologic and pediatric nurse practitioners, and physicians' assistants;

—Diagnostic services, including laboratory and radiology services;

—Mental health and substance (alcohol and drug) abuse treatment services;

—Prescription drugs, hearing aids, and corrective eyeglasses and lenses;

—Medical and surgical supplies and equipment; and

—Acute dental care and noncosmetic orthodontia.

3. Special services and supplies for persons with extensive or complex health care needs

—Durable medical equipment;

—Extended mental health and substance abuse services;

—Home health care and nursing in specialized day care for medically fragile children;

—Nutritional services;

—Recuperative stays in long-term care facilities;

—Hospice care;

—Home visiting;

—Respite care;

—Coordination of care for chronically ill or high-risk individuals with special health care needs; and

—Occupational, physical, and speech therapy and rehabilitation.

Uncovered Benefits Some proposals for health care reform present benefits packages that include only a portion of these health services. For example, some restrict provider payments to physicians only, fail to support family planning services, or omit coverage for coordination of care for children with special health care needs. In such instances, it is important that a reform plan describe how services that are important and useful, but not in the minimum benefits package, are to be provided and financed. Who is to decide when a patient may obtain services that are not in the basic package? How will financing for such services be arranged? And how is access to these services to be achieved without deepening the administrative and logistical complexity of the health care system (see goal 7)?

Strategies for financing important services that fall outside a minimum benefits package include:

—encouraging individuals or families to purchase supplemental coverage for services outside the basic package (an option that raises again the affordability issue covered in goal 2);
—retaining the Medicaid program for services not covered under the basic benefits package (an option, however, that does not help those who fail to qualify for Medicaid and cannot afford supplementary care; this approach also entails continued administrative complexities—see goal 7);
—funding services excluded from the benefits package directly through grants, an approach that can have the unfortunate effect of further fragmenting the health care system when separate systems are set up to deliver grant-supported services; and
—outlining a process of prior authorization, or similar gate-keeping device, that allows wider access to important health services not in the basic benefits package.

Noncomparable Benefits Reform proposals that retain a publicly financed program alongside a private system—the multipayer plans—present the additional problem of noncomparability of covered services between the public and private plans. There are, of course, differences in benefits among the hundreds of private plans now in existence, but the differences between public and private packages are generally more extreme. The importance of this issue is thrown into sharp relief when comparing the broad range of services that many Medicaid programs now support with the benefits packages typically offered through commercial insurers. For example, recognizing the special needs of low-income people, Medicaid often helps to pay for transportation to a health care facility, many home health care services, comprehensive dental care and eyeglasses for children, and extensive mental health services—services commonly excluded or highly limited in private plans. Similarly, Medicaid's Early and Periodic Screening, Diagnosis and Treatment program (EPSDT) has been used to finance such services as orthodontia for children with significant dentofacial problems and therapeutic day nurseries for developmentally disabled infants and toddlers.

In the case of multipayer plans, it may be desirable to require that benefits provided by public and private plans be essentially identical *if* the package is comprehensive. If not, it may be preferable to provide a more generous package under the public plan in order to accommodate the greater needs of the low-income individuals more likely to enroll in it. In particular, it is important to ensure that poor children and pregnant women are not worse off with regard to covered benefits under a new plan than under Medicaid. In the case of single-payer plans, which typically eliminate Medicaid and present a limited basic benefits package, the question of how existing Medicaid benefits are to be handled is pressing (see the section directly above on uncovered benefits).

Preventive Services Inadequate use of preventive services in maternal and child health has been well documented in recent years. For example, in the mid-1980s, one-third of pregnant women in the United States failed to receive the amount of prenatal care recommended by the American College of Obstetricians and Gynecologists (Hughes et al., 1988); and in 1990, only about 70 percent of two-year-olds were immunized against measles, mumps, and rubella—even fewer in inner cities. Not surprisingly, there have been major measles outbreaks in recent years; more than 26,000 cases of measles were reported in 1990 (100 of which resulted in death), mainly among poor, inner-city children, a major increase over the average of 3,000 cases a year between 1981 and 1988 (National Commission on Children, 1991). Such data reveal not only a health care system with important shortcomings, but also a health care system that is failing to take advantage of cost-effective services, of which prenatal care and immunizations are prime examples (U.S. House of Representatives, Select Committee on Children, Youth, and Families, 1990; U.S. Congress, Office of Technology Assessment, 1988).

These data also suggest that financing and reimbursement policies should be designed to encourage the use of the preventive services that are especially important to maternal and child health (category 1 in the list of services presented earlier). In practice, this goal might be met by eliminating co-payments, deductibles, and coinsurance for preventive services. It may also be possible to offer incentives for practitioners to provide, and for patients to receive, such care: for example, bonuses from insurers to providers, and perhaps even to patients, who complete the recommended immunization schedule; higher reimbursement rates for prenatal care begun in the first trimester of pregnancy; 100 percent payment for vaccine replacement and administrative costs; and so on.

[The section applying goal 3 to legislative proposals has been deleted.]

Goal 4: An objective process is established for refining and updating the benefits package to accommodate changes in the health care needs of children and pregnant women, in the ability of health care to address these needs, and in available funds.

Discussion

Whatever the final list of benefits adopted, many details will remain regarding amount, duration, and scope of benefits and about ways of adjusting the benefits package, within certain limits, to meet the needs of different individuals and groups. Accordingly, a proposal for reform should outline a process for well-informed, objective discussion of such specifics. The proposal should also explicitly consider how the benefits will be revised in response to changes in budgets and national needs, in the scientific base of medicine and health, in evidence of effectiveness, or in the burden of illness.

To perform these tasks, a publicly appointed commission or similar body charged with defining the benefits under the new plan (within broad parameters established by Congress) might be established. The commission could develop standards of actuarial equivalence to allow some flexibility within the overall package of benefits, while at the same time making certain that services for children and pregnant women remain comprehensive. It could periodically analyze services for children and pregnant women—and other populations as well—in light of new technologies, changing evidence of efficacy, new therapies, and emerging health problems. The DHHS's Agency for Health Care Policy and Research (AHCPR) may be able to fill these several roles.

Whatever the organizational approach chosen, the full involvement and direct assistance of the various medical specialty societies will be useful. Particularly in areas where evidence of effectiveness is incomplete, these organizations can provide guidance on accepted standards of practice. (See goal 11 for further discussion of practice guidelines, outcomes research, and related issues.)

[The section applying goal 4 to legislative proposals has been deleted.]

RESOURCE DEVELOPMENT: SERVICES AND PEOPLE

Goal 5: Health services are provided by qualified providers in a wide variety of settings that are effective in caring for children and pregnant women, especially the medically underserved.

Discussion

Several settings that are well suited to providing care to children and pregnant women are not routinely supported by private third-party payers, and grants to establish and maintain them are often inadequate and unreliable. For example, school-based health clinics serving adolescents (Lear et al., 1991), birthing centers (Rooks et al., 1989), comprehensive community-based health centers (Strobino et al., 1986; Peoples et al., 1984), and home-based health care for certain diseases and conditions (U.S. Congress Office of Technology Assessment, 1987) have proven both economical and effective, yet have limited support.

The importance of supporting multiservice centers for medically underserved populations deserves special comment. Extensive experience over the last two decades has demonstrated that meeting the health needs of high-risk pregnant women and children, particularly the very poor, is often accomplished through a mix of intensive medical and social services provided at a single site (Institute of Medicine, 1988a). Comprehensive community health centers (CHCs), migrant health centers (MHCs), maternal and child health services in local health departments, school-based clinics, and similar organizations can blend the various services needed by high-risk individuals into units understandable to both consumers and providers. Typically, these centers offer comprehensive medical, health, and social services; rely on the skills of a variety of health professionals; have adequate staff for assessment of community needs and for recruitment, tracking, and follow-up of patients; provide health education, transportation, and translation services; serve a clearly defined geographical area; offer care that spans the developmental sequence from pregnancy (including family planning and preconception care) through childhood, using the family as the basic unit of service; and provide the option of home visiting for high-risk individuals, particularly pregnant women and families with young children. Despite the proven value of such comprehensive centers for high-risk families, they have never had a secure base of funding, and their numbers have always been limited. For example, about 550 CHCs and MHCs are currently in operation; only 6 million of the 32 million Americans who are medically underserved receive care through these systems (National Commission on Children, 1991).

To ensure that these nontraditional practice arrangements are present in numbers sufficient to meet documented need, a reform plan might take one or more of at least three different approaches:

—the plan could require that all health and related social services provided through these settings be reimbursed by both public and private third-party payers and that the level of payment reflect the comprehensive, often intensive, nature of the services provided;

—special grants and public health monies could be earmarked to support additional nontraditional service settings at levels sufficient to meet documented need; and

—physicians, dentists, and other health care providers could be offered incentives through the reimbursement system to affiliate with such settings (accepting referrals from them and providing some services directly on site).

[The section applying goal 5 to legislative proposals has been deleted.]

Goal 6: The number and diversity of qualified providers caring for children and pregnant women is increased, particularly those who are poor, high-risk, or living in inner-city or isolated rural areas.

Discussion

There are not enough well-trained, licensed providers to care for children and pregnant women who are low-income, medically high-risk, or living in inner cities or rural areas. For example, over the last several years, the number of obstetricians serving these groups and these areas has declined, as has the number of family physicians practicing obstetrics; the latter provide over two-thirds of the obstetrical care in rural areas (Weiner and Engel, 1991). A slight decline in the number of pediatricians who take Medicaid patients has also been noted recently (Yudkowsky et al., 1990). Workshop participants did not discuss in detail whether these trends reflect provider distribution patterns that do not match need or, rather, an absolute deficit in numbers of providers. However, the consensus was strong that, with the exception of certain mid-level providers (see below), overall supply of health care providers is adequate, but that they are not always found in sufficient numbers in areas of greatest need.

This problem of "provider maldistribution" is exceedingly complicated, reflecting long-standing patterns of practice and payment. Although a single reform plan may not be able to solve this problem quickly and efficiently, it should nonetheless offer some constructive steps. One time-tested method of addressing the provider distribution problem is to fund special clinics in underserved areas, as described in goal 5. Five other strategies are taken up in more detail here: (1) the direct placement of health care providers in medically underserved areas through the National Health Service Corps and similar programs; (2) the use of midlevel practitioners in appropriate settings; (3) solutions to the medical liability situation; (4) encouraging private providers to accept more patients whose care is paid for by public funds; and (5) increased emphasis in graduate medical education for health professionals on primary and community-based care rather than on tertiary care.

Direct Placement In an earlier era, a partial solution to the provider maldistribution problem was the direct placement of health professionals in underserved areas, typically through the National Health Service Corps (NHSC). Despite its undisputed record of achievement (P.L. 101-597: The National Health Service Corps Revitalization Act, 1990), NHSC was virtually dismantled in the 1980s. Although it may now be on the mend (as a result of the 1990 rewrite of the NHSC authority, the Corps is now reauthorized through the year 2000), its role in increasing access to health care for children and pregnant women deserves emphasis. A reform plan that retains current health care structures could, for example, support the continued rebuilding of the Corps and its state-level analogues that place providers in medically underserved areas through a combination of education loans, loans in exchange for service, and other practices. A reform plan that proposes radically new systems of health care financing and delivery may still find some role for the NHSC or a similar entity in whatever remedies it offers to the maldistribution challenge.

Mid-Level Practitioners The second solution centers on the use of certified nurse-midwives, obstetric and gynecologic nurse-practitioners, and similar mid-level personnel in the health care system. Certified nurse-midwives (CNMs), for example, have been shown repeatedly to be especially well suited to providing many of the preventive and primary care services needed by pregnant women, and they have a long tradition of serving in low-income and rural communities (Rooks and Haas, 1986). Nonetheless, the use of CNMs in maternity care is constrained by, for example, the limited number of training opportunities for CNMs (too few to meet existing demand), the unstable availability of malpractice insurance for them, the continuing reluctance of some physicians to collaborate with nonphysicians, and the reluctance of some insurers to reimburse for health services provided by such practitioners. A proposal to reform the health care system should support the use of mid-level practitioners by encouraging wider use of them in organized settings (such as community health centers and hospital clinics) and in collaborative arrangements with physicians; making certain that adequate numbers of training slots are available; ensuring their access to malpractice insurance; and requiring adequate reimbursement for their services.

Medical Liability High malpractice insurance fees, fear of lawsuits, and the erroneous impression that poor women (especially those enrolled in Medicaid) are more likely to sue than other women represent serious disincentives to practicing obstetrics in low-income communities or caring for poor or high-risk women and children generally (Institute of Medicine, 1989a). There is increasing sentiment that the current liability system does not effectively deter negligent medical care, that it reduces access to needed services while increasing the use of costly, inappropriate care, and that it resolves claims in an inefficient and inequitable manner.

To improve access to care for pregnant women, therefore, a proposal for health care reform should take up the malpractice challenge. A proposal could, for example:

—earmark funds to study the effects of various state remedies to the medical malpractice problem, including, for example: subsidizing the liability premiums of obstetric care providers; establishing publicly funded indemnity insurance for obstetric providers caring for low-income or medically high-risk women; and such alternatives to the tort system as no-fault compensation for certain events, a fault-based administrative system, and the use of private contracts; or

—provide funds to support alternative systems for the resolution of medical malpractice disputes—that is, fund some new systems, not just studies of new systems—and extend Federal Tort Claims Act coverage to community and migrant health centers (Institute of Medicine, 1989a).

Provider Acceptance of Public-Pay Patients Because many current proposals for health care reform retain Medicaid or include a public insurance plan of some sort for those who are not covered by private insurance, it is important to consider that Medicaid has failed to attract a sufficient number of qualified providers to deliver health care to all children and pregnant women eligible for the program. The poor participation of providers in Medicaid has been repeatedly linked to the program's low reimbursement rates, cumbersome administration, and other factors (the Alan Guttmacher Institute, 1989). Easing such problems in the Medicaid program—or in whatever public-pay programs are offered by various reform plans—will require a detailed review of Medicaid policies and procedures, with the goal in mind of increasing provider participation. A large literature exists about the strengths and shortcomings of the Medicaid program, and a national commission is presently considering ways to improve it. Steps that have been suggested to increase provider participation in Medicaid include: requiring that, in all areas of the Medicaid program, compensation to providers be roughly equivalent to Medicare or private market rates; raising the Medicaid reimbursement rates for health services provided by practitioners in medically underserved areas; and simplifying program administration. It has even been suggested that providers be required to accept patients enrolled in Medicaid (or whatever new public insurance plan replaces or supplements it).

Graduate Medical Education of Health Professionals Historically, the nation's policies supporting graduate education in the medical and health professions have been strong in inpatient and tertiary care training and weak in primary care, preventive medicine and community health—all areas particularly important to maternal and child health (Institute of Medicine, 1989b). Grants from the Public Health Service have been used to support primary care training for nurses and physicians, but undergraduate and postgraduate education continues to be dominated by nonprimary care—specialist and subspecialist interests. The vast bulk of funds spent for the training of medical professionals is in the form of Medicare, Medicaid, and private third-party reimbursement to cover the direct and indirect costs of hospital-based graduate training programs. Financing graduate medical education in this fashion skews funding toward inpatient and emergency care and away from primary ambulatory care. Primary health care training programs operate on shoestring budgets and cannot afford to expose health care practitioners to an adequate array of patient needs, particularly those seen in ambulatory settings.

No single remedy will alleviate this imbalance, but any major proposal for health care reform should explicitly address the education of health professionals, with particular attention to the support of education in primary care, preventive medicine, and community health, which form the cornerstone of care for children and pregnant women, including those who are most disadvantaged.

[The section applying goal 6 to legislative proposals has been deleted.]

ADMINISTRATION

Goal 7: The administrative complexity of the health care system is substantially reduced from the perspective of both providers and consumers.

Discussion

Frustration with the complexity of the current U.S. health care system is one of the strongest forces pushing the reform debate (Himmelstein and Woolhandler, 1986). The administrative tangle of multiple programs and sources of funding creates its own barrier to care and contributes to costly inefficiency. This is a problem for all populations, but particularly for children and pregnant women. Children must depend on adults to arrange for their health care; but if these adults cannot or will not arrange for needed services, children have few tools available to them to secure the care they need or to advocate on their own behalf. And because pregnancy is a ticking clock, requiring concentrated care in a relatively brief time, care delayed by administrative complexity is care denied.

Plans offered to consumers in the private sector are often difficult to comprehend; Medicaid can be even worse. The long-standing association of the Medicaid program with the stigma and complexity of welfare and AFDC offices has alienated consumers for years, as noted earlier. Similarly, providers report that the intricacy and cumbersome procedures of some private insurance plans, and of Medicaid in particular, discourage their participation in them. Even the most socially organized and well-educated consumers and providers have difficulty understanding available programs and assembling needed care.

A reform plan should therefore define specific steps to simplify enrollment, participation, and payment procedures, particularly in multipayer models that, by definition, are complicated and often retain the cumbersome Medicaid program. For example:

—for private plans offered through the workplace, the reform proposal should require that materials be developed that clearly describe the nature and content of each plan, including the precise out-of-pocket costs to the employee or family,

and the method for participating in the plan. Assistance should be offered employees in completing claims forms and other documents;
—for a publicly financed program, the reform proposal should require that enrollment forms be brief, available in other languages as well as English, require minimum documentation, and be available in a wide variety of easily accessible locations (including the point of service), such as private physicians' offices, WIC clinics, hospital outpatient clinics, and Head Start programs. It should also be possible to submit the application by mail, and employees should be able to pay premiums for the public plan through payroll deductions. Materials should be made available to enrollees in the public plan describing its coverage, how to use it, and any important administrative limitations that a consumer should understand;
—the reform plan should set up an on-going forum or administrative body to assess and improve the administrative and reimbursement problems experienced by providers under both private and public plans (especially Medicaid). These problems include difficulty in determining whether a particular patient is eligible for coverage under a particular plan, unreasonable restrictions on the types of services covered, extensive delays in paying claims, delays in receiving pre-certification approvals, and unwieldy claims processing. State-level experience in this area will be particularly helpful: for example, some states have been developing specific training programs, hotlines to resolve reimbursement problems, visits to providers by representatives of various payment plans to explain procedures, and so on).

Because it is more difficult for individuals to secure continuous health insurance coverage under multipayer models, reform proposals that retain a complicated mix of public and private financing should devise some means of moving between plans—especially between public and private plans—that is swift and easy. It may also be important to create additional mechanisms for "special needs" children and their families to coordinate benefits, providers, and other resources across multiple insurers.

[The section applying goal 7 to legislative proposals has been deleted.]

Goal 8: Cooperative, complementary administrative structures are established spanning public and private sectors to monitor and improve the health care system used by children and pregnant women.

Discussion

Increasing access to health insurance should be accompanied by a careful reconsideration of the administrative structures that govern the U.S. health care system, especially that portion used by children and pregnant women. Many of the reports referenced earlier in this monograph discuss the need to improve the ways in which health care is administered in the United States. They urge, in particular, that means be found to blend the efforts of the public and private sectors in a more coherent fashion, and that financing agencies be brought into closer alignment with programs that actually provide services. They also point out the need for administrative structures to monitor overall performance in the health care system according to a set of standards; to fill gaps in care as they appear, particularly for more vulnerable groups; and to be understandable to both providers and consumers.

Several administrative structures might move matters in these general directions. Whatever the construct chosen, important administrative functions that the proposal should address include the following (Select Panel for the Promotion of Child Health, 1980):

—monitoring the overall health status of children and pregnant women in relationship to such standards as the "Year 2000" goals that is, immunization levels, trimester of enrollment into prenatal care, rates of cesarian section, and so on);

—monitoring health care expenditures *in both public and private* health sectors to ensure that the monies are spent as intended and relating those expenditures to the health outcomes achieved (this monitoring will require, among other things, assembling and analyzing uniform claims data from both public and private payers and postaudit functions sensitive to the needs of children and pregnant women);

—filling gaps in care as they emerge (that is, placing and financing services in areas that remain without necessary providers, if all other remedies fail);

—monitoring provider behavior and qualifications;

—providing public information and education services, and professional training;

—developing approaches to cost management and quality control that emphasize health outcomes (see goals 10 and 11 below); and

—supporting research important to children and pregnant women either by direct funding or by encouraging other public and private groups to study key topics (see goal 11).

Since these responsibilities require financial resources, a proposal for health care reform must not only clarify the administrative framework for these functions, but also ensure that enough money—and legislative authority—is available to perform assigned tasks. Some existing structures at the state level that could be used as a basis for meeting these responsibilities are the maternal and child health authorities, funded in large part by the Maternal and Child Health Services Block Grant.

One particularly important task that blends administrative issues and issues of direct service delivery merits emphasis: developing networks of care for expensive or relatively rare diseases and conditions of childhood. Some such networks already exist. Regionalized systems of perinatal care are perhaps the most widely recognized, but networks of specialty care also exist for cystic fibrosis and other low-prevalence disabling conditions and for pediatric emergency services. These networks are especially important in rural areas which do not have the critical mass of people needed to attract a full range of specialty services. The private indemnity and managed care industries are also rapidly developing contract networks of special centers (often called "centers of excellence") to provide care that requires high-cost technology, specialized procedures, and medical interventions on the cutting edge of research (Behrman, 1991).

In any reform of the health care system, the usefulness, function, and future of these networks should be considered. For children with diseases or conditions such as spina bifida and cerebral palsy, particular attention should be paid to the relationship between community-based services and services orchestrated through specialty networks. Some services—such as primary care, some types of therapy, and coordination of care—should perhaps be offered at the community level, whereas others are more properly provided at the hub of a regionalized network (Hobbs et al., 1985).

To address these interrelated issues, a reform plan might:

—charge the governance entity (or entities) described above with responsibility for reviewing the role and performance of various maternal and child health networks, for recommending areas in which they should be expanded or diminished, and for working with states and communities to accomplish needed changes. In some instances, it may be important to finance networks directly or to increase support of those already receiving some assistance. The agency or agencies should specifically consider the relationship between networks of care and managed care plans (see goal 10 below for additional discussion of this issue);

—require that third-party payers reimburse services provided through these networks; or

—finance such services directly through grants.

[The section applying goal 8 to legislative proposals has been deleted.]

Goal 9: The future role of existing government grant programs in maternal and child health is explicitly considered in reforming the health care system, with regard to both the personal health services supported by these grant programs and to their planning, evaluation, and training functions.

Discussion

Expanding the availability and affordability of health insurance intensifies the ongoing debate about the future role and structure of the public health system in providing personal health services, and it raises specific questions about the fate of many grant programs funded through the Public Health Service (PHS), the Social Security Administration, and other authorities. Examples of such programs that are especially important to children and pregnant women include:

—Title V, the Maternal and Child Health Services Block Grant,
—the Preventive Health Services Block Grant,
—Childhood immunization grants to states,
—Health services that are part of special education programs,
—Pediatric emergency medical services,
—Title X family planning services,
—Pediatric AIDS health care demonstration program,
—Injury control grants,
—Grants for lead poisoning prevention and abatement, and
—Poison control activities.

Many of these programs provide health services to those with no source of payment for health care, serving in some instances as providers of last resort. Some of these programs serve special populations or provide important health services that third-party reimbursement does not cover. Many of them address such community-level problems as prevention of lead poisoning and traumatic injury, not easily handled through one-on-one health services financed by traditional insurance. These grant programs can be innovators in systems that provide few incentives for coordinated, interdisciplinary care (for example, special services for children with multiple handicaps), and have the capacity to move easily across traditional boundaries between health and other human service and educational areas. In addition, they often carry out community-level planning, needs assessment, data collection and analysis, and training—tasks that cannot easily be assumed by individual providers of care.

Given the importance of these public health grant programs, their future role should be considered in reform proposals. Are they to be eliminated? Folded into the new public system? Retained as is? If the intent is to fund all, or most, personal health services through insurance, what is to be the fate of the functions that public health grant programs often encompass? Are some services best financed and regulated through public health systems but provided by private institutions and individuals? Answers to these questions pertain directly to the future course of the public health system, of which maternal and child health services are only a part (Institute of Medicine, 1988b). In practical terms, bringing some order to all these programs and defining their relationship to a new financing system will be exceedingly difficult, not only because each has its own bureaucracy and constituency, but also because not all are under the jurisdiction of the same congressional committees.

Deciding the future role of special grant programs will require that policy makers carefully consider ways to manage some of the most serious health and social problems that infants, children and adolescents bear, such as pediatric HIV disease, child abuse, teenage pregnancy, youth violence, and substance abuse. Clearly, universal access to health insurance is likely to make only a small impact on these issues, because they involve a complex array of socioeconomic and behavioral issues in addition to medical concerns. Managing them effectively may well require a series of intensive categorical programs, well integrated into others systems of health and social services.

Despite these complexities, the future of the grant programs requires attention. A proposal could, for example, suggest in the bill's accompanying report that all the grant programs at issue remain intact for a significant period of time to see how the new insurance and payment provisions affect need and demand for the grant-supported personal health services. It is important to stress, however, that even if such an inquiry reveals that grant programs are no longer required to finance personal health services, the need to continue—and even strengthen—the monitoring, administering, and training tasks now supported by these programs will remain. These functions need to be given a permanent home and adequate support.

One special aspect of this issue merits emphasis—the fate of state and local monies currently invested in maternal and child health services. Not including Medicaid expenditures, state health agencies spent $8.3 billion in fiscal year 1988 on public health programs; although some of these funds came from federal grants and contract funds, more than half were raised at the state and local levels (Public Health Foundation, 1990). An important proportion of these expenditures was on maternal and child health and played a vital role in the support of local health clinics, public hospitals, and specialized medical and health care in schools, institutions, and other settings. A major revision of health care financing would undoubtedly cause states and localities to rethink and possibly reconfigure their own expenditures in this area, but whatever the realignments, it is important that a proposal for reform not interfere with the ability of states and localities to create and support their own health services and systems.

[The section applying goal 9 to legislative proposals has been deleted.]

COST MANAGEMENT AND QUALITY ASSURANCE

Goal 10: Cost management measures accommodate the special needs of children and pregnant women.

Discussion

With the relentless escalation of health care costs, cost containment has become a major force driving the discussion of health care reform. Accordingly, any reform proposal must include specific measures for keeping national health expenditures, whether tax-supported, direct, or out-of-pocket, at some reasonable, acceptable proportion of national income. Clearly, containing the growth of health sector costs is vital to preserving scarce national resources for other competing needs. Two principal approaches to overall cost management and containment are in current proposals for health care reform: managed care and global budgeting.

Managed care deserves special comment because of its growing popularity as a tool for managing costs for privately insured as well as Medicaid-insured children and pregnant women. Managed care systems have developed largely in response to various problems in the fee-for-service system, including the steady rise in health care costs. These new practice arrangements include various payment and provider networks designed to contain costs by negotiating reduced fees with providers enrolled in the system, limiting consumers' freedom of choice, and, in theory, improving the care of patients through increased access to private physicians (in the case of Medicaid) and increased monitoring of provider behavior. These systems usually incorporate continuous quality improvement mechanisms and incentives to provide only appropriate and necessary care, and are accountable to purchasers and patients on the basis of cost, quality, and outcomes. It is important to add, however, that despite their growing popularity, managed care systems have yet to demonstrate conclusively that they contain costs.

From the maternal and child health perspective, the critical issue is whether managed care arrangements meet the health care needs of this population. Limited data and anecdotal experience with managed care for children and pregnant women identify several concerns (Cartland and Yudkowsky, 1992). First, there remain some questions about the proper role of the "gatekeeper" function for a pediatric population. In some instances it may be helpful, as for children with chronic illnesses whose access to primary care services may be facilitated by health maintenance organizations (HMOs); in others instances, the result may be less favorable, as when managed care networks conflict with existing systems for triaging and transporting seriously ill newborns. Second, managed care networks may place strict limits on access to providers who are not enrolled in the plan, even when their skills are not available from plan providers; although such limits may be appropriate for essentially well children, they can pose major obstacles to needed care for children with more serious and rare diseases and conditions. And third, managed care can generate conflicts between the fundamentals of good medical care and the pressures of cost containment (as exemplified by the growing practice among managed care plans of denying more than 24 hours of hospitalization after a normal vaginal delivery and limiting coverage of postpartum home-based nursing care for early discharge patients).

It is important to add, nonetheless, that as managed care becomes a more common administrative arrangement, and experience with it increases, it is possible that many of the actual or imagined problems that it presents will be resolved. Moreover, the pros and cons of managed care need to be weighed not in isolation but in comparison with the fee-for-service system it often replaces, which itself has significant liabilities, such as contributing to health care cost inflation, overuse of physician services, tests and procedures, and poor coordination across individual providers. This suggests that, over time, all forms of medical practice—fee-for-service, managed care and other arrangements—require careful oversight from the perspective of both cost and quality (see goal 11).

If a reform proposal incorporates systems of managed care, the concept should be clearly defined to include not only the goal of cost containment, but also the provision of high-quality care that is appropriate to the level of need. In addition, the proposal should specify that, over time, managed care will be evaluated not only on the extent to which it limits costs, but also on the extent to which it ensures access to needed services and achieves positive health outcomes.

The other major approach to cost containment—global budgeting—is the cornerstone of most single-payer proposals and raises a different set of concerns. This approach requires, in essence, that a single sum of money be allocated for all health expenditures nationally and that all providers function within prearranged, fixed budgets. In a system that relies on global budgeting, it is important that explicit steps be taken to ensure that children and pregnant women be provided with adequate health care resources—that some process be established to ensure that the aging of the population (with its increasing demands for health care services) not erode the resources available to children and pregnant women (Fuchs, 1990; Sugarman, 1991). For example, a global budgeting system can set its benefit, eligibility, and administrative requirements in such a way that the needs of children and pregnant women are well attended. Alternatively, or additionally, a mechanism can be used to set a minimum level of expenditures for this population.

Moreover, if the nation does adopt global budgeting, it is reasonable to predict that, particularly at the outset, expenditure targets would mirror existing patterns of expenditures—in effect freezing all current inequities for several years at least. This possibility suggests that plans based on global budgeting should devise some means at the outset for better meeting the needs of children and pregnant women, and correcting some of the problems noted elsewhere in this monograph.

[The section applying goal 10 to legislative proposals has been deleted.]

Goal 11: Vigorous, well-financed systems of quality assurance and research are supported.

Discussion

As noted above, quality assurance must be a major part of cost management. No matter what the health care system's mix of managed care, fee-for-service, or other payment arrangements, several dimensions of quality assurance are particularly important to children and pregnant women and should be encompassed in any comprehensive reform of the health care system. They include:

—supporting long-term, continuous relationships between providers and consumers (for example, continuity of care), especially for children with special needs and for other high-risk individuals;

—ensuring adequate provider credentialling with regular reviews;

—supporting partnerships between parents and providers around the care of children;

—ensuring the confidentiality of health care, particularly for adolescents;

—providing both providers and consumers with grievance procedures to resolve disputes over charges, reimbursement, and related issues; and

—helping to ensure that health care services are provided in a timely fashion without excessive waits for appointments, in convenient locations and settings, in culturally sensitive environments, and with adequate systems in place for patient monitoring and follow-up.

Research is essential to quality assurance. Policy makers and the public alike understand the need for a strong national commitment to a broad program of research in the overlapping fields of biomedicine and clinical practice, health services, epidemiology, and related fields. Accordingly, any major proposal for reshaping the health care system should be accompanied (in companion legislation or in clear congressional intent) by generous and stable support for health-related research, broadly defined. It might even be wise to peg overall health-related research expenditures to some minimum fixed percentage of health care expenditures. In particular, strong ties between the clinical research community and those who design the benefits package of a health care financing plan should be fostered. That is, the benefits package should be continually revised in light of new research findings, and those who provide and pay for services should be able to let researchers know what issues merit investigation from their point of view. Similarly, the complexity of the health care system, the large sums of money it consumes, and the prospect that it might be significantly altered by major national legislation underscore the need for research on health systems, on financing, and on other aspects of health services delivery.

Two aspects of research pertinent to quality assurance deserve special comment: the development of practice guidelines and the growing interest in outcomes research, both of which are closely related to the general field of technology assessment. Two federal agencies very active in this type of investigation include the Office of Technology Assessment (OTA) and DHHS's Agency for Health Care Policy and Research (AHCPR), neither of which has focused intently on maternal and child health for a variety of reasons. In the case of the OTA, for example, the research portfolio of the agency is determined largely by Congress, which asks OTA to pursue certain specific issues; and in recent years, most of those requests have not emphasized maternal and child health. It is important that these agencies and related research institutions pay adequate attention to the many unresolved issues in health care for children and pregnant women, in part because some clinical issues have major cost implications (such as resolving issues in the management of otitis media) and because some of the procedures needing further definition and refinement are performed frequently on large numbers of children (for example, well-child care).

With regard to outcomes research especially, the results of clinical interventions should be assessed in part by their overall impact on public health (using such measures as rates of infant mortality and adolescent suicide), not just on a single individual or a small, atypical population. In addition, outcomes research should distinguish carefully between results obtained in adults and those obtained in children.

[The section applying goal 11 to legislative proposals has been deleted.]

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CHAPTER

2

Benefits and Systems of Care for Maternal and Child Health Under Health Care Reform

Workshop Highlights

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Maternal and Child Health Under Health Care Reform

Board on Health Promotion and Disease Prevention
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Board on Children and Families
Commission on Behavioral and Social Sciences and Education
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CONTENTS

SUMMARY

In the summer of 1994, Congress was in the midst of debating legislation to reform the health care system. Congress chose not to pursue health care reform legislation this year, but plans to consider it again next year. If Congress does enact health care reform legislation next year, it could change the way health care is financed and delivered in the United States. All Americans have health care needs that will have to be met, but the current interest in health care reform, coupled with the long-standing interest of the Institute of Medicine (IOM) and the National Research Council (NRC) in the well-being of women and children, presented a special opportunity to address the unique health care requirements of women in their childbearing years, children, and adolescents. This report is based on a July 1994 workshop organized by the IOM and the NRC, which focused on health care benefits and systems of care for maternal and child health under health care reform.

Because women and children are disproportionately represented among the uninsured, expanding health insurance coverage to this group will also increase their access to necessary health services more than other groups. Workshop discussions emphasized, however, that neither health insurance coverage nor better benefits will meet all of the health care needs of women and children. Adequate support is also needed for the public health and community services that many maternal and child health programs promote. The public health system (comprising federal, state, and local health departments) provides essential, population-based public health services such as surveillance and vital statistics, epidemic control, and environmental monitoring. In addition, state and local public health departments often provide personal health services such as prenatal care and well-child care, and enabling services such as case management, transportation, and home visiting.

Workshop discussions highlighted the need that women in their childbearing years (and especially women who are pregnant) have for a wide variety of reproductive health services in addition to routine medical care and mental health services. Participants agreed that health care services for women should include contraceptive services and supplies; diagnosis and treatment of sexually transmitted diseases; prenatal, intrapartum, and postpartum care; regular breast and pelvic exams (including Pap tests), in accordance with well-recognized periodicity schedules; risk assessment; and adequate education and counselling to support all of these interventions. Participants also outlined children's health care needs, which vary at different ages. Although most children are fundamentally healthy, they require health care that emphasizes preventive services, such as immunizations, and the monitoring of physical and psychosocial growth and development, with particular attention to critical periods in which appropriate care is essential for sound development and progress. Adolescents require access not only to medical care for illness and injury but also to family planning services, mental

health services, substance abuse treatment, anticipatory guidance, and various informational and educational activities that are oriented toward the development of positive health behaviors. Some of their health problems arise from health-damaging behaviors that increase their risks for sexually transmitted diseases, unintended pregnancy, substance abuse, injuries, and violence. Intervening during adolescence provides an opportunity to prevent the onset of health-damaging behavior as well as to introduce and establish healthy new behavior patterns that may span a lifetime.

Workshop participants pointed out that there should be continued efforts to design a comprehensive benefits package for women and children in the context of health care reform. The discussion of health care benefits for women and children emphasized a need for more attention to family planning services, mental health and substance abuse services, and services for children with special health care needs. Several approaches to benefit design were addressed by workshop participants, including benefit packages from several congressional health care reform proposals, without attempting to reach consensus.

Neither the current system for delivering traditional personal health services nor the public health system alone can effectively provide the full range of health services needed by women and children. Consequently, many people feel that a collaboration between the public health system and providers of personal health services is necessary to ensure access to comprehensive health care for these groups. Participants in the workshop agreed that many old models for health care delivery are no longer adequate and that health care reform needs to promote a coordinated and collaborative approach, especially to improving the health of women and children.

INTRODUCTION

In 1994, Congress was considering legislation to reform the U.S. health care system, but chose to defer action on it until next year. If Congress does enact health care reform legislation next year, it could change the way health care is financed and delivered. A critical concern for many people is how a reformed system will balance issues of cost-containment and quality of care, particularly for women and children. The risk that cost-containment programs may create incentives for underservice touches everyone, but may be especially worrisome for those disadvantaged by their economic status or special health care requirements.

Because of a long-standing interest in the health and well-being of women and children, the IOM and the NRC held an invitational workshop on July 7–8, 1994, to address the unique health care requirements of women and children in the context of health care reform. This brief report, prepared under the guidance of the workshop steering committee, highlights the major points raised in presentations and discussions during the first day of the workshop. Issues associated with assessing the quality of children's health care were addressed at length during the second day of the workshop (NRC and IOM, 1994).

Women and children[1] have a great deal at stake in the outcome of health care reform. Workshop participants noted that the report *Including Children and Pregnant Women in Health Care Reform* (NRC and IOM, 1992) continues to be a valuable guide for efforts to achieve adequate health care for women and children. They expressed concern, however, that federal legislation may not ensure universal coverage, that its benefits package may not meet the needs of women and children—particularly those with disabilities—and that key public health and community services have received little attention and funding (Perrin et al., 1994). The public health system (comprising federal, state, and local health departments) provides essential, population-based public health services such as surveillance and vital statistics, epidemic control, and environmental monitoring. In addition, state and local public health departments often provide personal health services such as prenatal care and well-child care, and enabling services such as case management, transportation, and home visiting.

Expanding health insurance coverage is important because women and children are disproportionately represented among the uninsured. Even with recent federally mandated expansions in Medicaid coverage that have offset some of the decreases in private coverage, during 1992, 15 percent of children in the United States (nearly 10 million children) had no health insurance from any source (Employee Benefit Research Institute, 1993; Teitelbaum, 1994). Currently, 40 percent of children are not covered under their parents' employment-based health insurance (Teitelbaum, 1994). In 1991, 6.2 million employed women of childbearing age (ages 18–44) had no health insurance (March of Dimes, 1993).

Lack of health insurance coverage limits access to necessary health services, but workshop discussions emphasized that neither full health insurance coverage nor better benefit packages will meet all of the health care needs of women and children. Adequate support is also needed for the public health and community services that many maternal and child health programs promote. For example, women may need transportation or child care services that enable them to use available prenatal care and reproductive health care services. For children and adolescents, optimal physical and psychosocial development may be encouraged by services such as nutrition programs, protection from intentional and unintentional injuries, mental health programs, health education, and family planning programs. As lawmakers develop legislation for health care reform, they need to be adequately informed not only about the medical care that women and children need, but also about a broad range of beneficial health promotion activities.

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[1] This report refers to women in their childbearing years, especially pregnant women, and children of all ages, from infancy through adolescence.

HEALTH CARE NEEDS OF WOMEN, CHILDREN, AND ADOLESCENTS

All Americans have health care requirements that should be met under a reformed health care system. The current national interest in health care reform presents a special opportunity to address the unique health care requirements of women in their childbearing years, children, and adolescents.

Health Care Needs of Women

A growing interest in protecting and promoting the health of women is reflected in such activities as the new women's health research agenda of the National Institutes of Health and the creation of numerous advocacy groups promoting women's health, broadly defined to include medical, psychological, and social dimensions. Workshop discussions highlighted the need that women in their childbearing years, and especially women who are pregnant, have for a wide variety of reproductive health care services in addition to routine medical care and mental health services. Participants indicated that these reproductive health services should include, at a minimum: contraceptive services and supplies; diagnosis and treatment of sexually transmitted diseases; prenatal, intrapartum, and postpartum care; regular breast and pelvic exams (including Pap tests), in accordance with well-recognized periodicity schedules; risk assessment; and adequate education and counselling to support all of these interventions (Klein, 1994).

Many workshop participants supported the view that reproductive health services should also include access to sterilization and abortion without excessive delay. In the case of abortion, delay into the second trimester greatly increases the risk of medical complications. Despite the continuing political controversy that surrounds the inclusion of abortion in a mandated national benefits package, workshop presentations noted that the majority of current commercial indemnity plans already cover both abortion and sterilization as surgical services.

Workshop participants contended that many barriers help to explain the relatively poor pattern of contraceptive use in the United States as compared to several other developed countries. Some people pointed out that many private insurance companies do not provide full coverage for family planning services. For example, cost-sharing requirements—deductibles and co-payments by which a patient and an insurance plan share the cost of services and contraceptives—may, for some women, constitute an important barrier to contraception. Understanding and decreasing barriers to contraceptive use are especially important inasmuch as over half of all pregnancies in the United States are unintended at the time of conception (Forrest, 1994), which contributes to unnecessarily high rates of abortion, as well as to late entry into prenatal care and various poor pregnancy outcomes. Accordingly, workshop participants noted that insurance policies—

public or private—should avoid significant co-payments for contraceptive services and supplies.

Barriers to health care for women, especially high-risk women, are not limited to the fields of contraception or reproductive health. Workshop participants noted that a variety of cultural, financial, and other barriers may impede women's access to health service generally. For example, women (especially young women, who are in their prime childbearing years) are more likely to be un- or underinsured than men because many of them work at jobs that do not provide health insurance benefits, and this affects their ability to secure needed care. Moreover, some recent studies on cardiovascular disease suggest that women are not always provided the same quality of medical care offered to men with the same diagnosis (Wenger et al., 1993).

Health Care Needs of Children

Although most children are fundamentally healthy, they require health care that emphasizes preventive services, such as immunizations, and the monitoring of physical and psychosocial growth and development, with particular attention to sensitive periods in which appropriate care is essential for sound development and progress. In 1991, only 6 percent of children under 18 years of age (3.8 million children) were limited by chronic health conditions in their ability to perform regular activities such as attending school or playing (Newacheck et al., 1994).

Workshop participants noted that even subtle shifts from a child's normal developmental track may have a life-long impact. For example, recurrent otitis media with fluctuating hearing loss has been postulated to be associated with speech and language difficulties during the toddler years. Delays in identifying a problem or in receiving proper treatment can have irreversible consequences that may increase morbidity, mortality, and cost over both the short and long term. For protection of their health and well-being, children depend on their parents and other adults as well as community institutions (including schools) to both detect and manage emerging health problems. The degree of dependency decreases over time, but in large measure children must rely on adults both to provide care that promotes normal development and to recognize disorders and obtain treatment.

Workshop participants noted that optimal health and development for many children requires both medical care and other health and social services to prevent problems and counter the effects of conditions that have an adverse impact on children. Many important health threats to children lie in socioeconomic and environmental factors, such as poverty and community violence, that are not the traditional targets of clinical preventive services. The health care system must often provide acute or chronic care for conditions that stem from injuries, exposure to toxic substances (e.g., lead), or emotional disturbances; these conditions are all highly influenced by social and environmental factors. The design of effective health promotion or primary prevention programs will often require broad environmental and social interventions, along with more traditional medical approaches. For instance, a range of social services may be needed to provide comprehensive care for children with chronic illnesses, to promote a safe home environment or response to certain behavior problems that may not typically be viewed as health related.

Health Care Needs of Adolescents

Adolescence is a unique developmental period that encompasses the biological changes of puberty, along with other psychological, cognitive, and behavioral changes (Irwin, 1993). Adolescents require access not only to medical care for illness and injury but also to family planning services, substance abuse treatment, mental health services, anticipatory guidance, and various informational and educational activities oriented toward the development of positive health behaviors. Some of their health problems arise from risky health behaviors, which increase rates of sexually transmitted diseases, unintended pregnancy, substance abuse, injuries, and violence. Workshop participants noted that many teenagers receive health care at community clinics or through school-based services, which work to promote healthful behavior and to ensure access to health care for all adolescents. Intervening during adolescence provides an opportunity to prevent the onset of health-damaging behavior as well as to introduce and establish healthy new behavior patterns that may span a lifetime.

Adolescents overall use health care services infrequently and are the age group least likely to seek care through office-based settings. They can face numerous barriers to health care: Often teenagers are no longer comfortable seeking care alongside of babies or small children; they may not want to involve their parents in their care; or their care may not be covered by their parents' insurance. Workshop participants noted that because teens face numerous barriers to health care, they need ways to obtain care independently and with a guarantee of confidentiality such that their parents would be notified only when appropriate. They should not be denied care because of an inability to meet cost-sharing obligations, especially in areas such as reproductive health (including contraception and sexually transmitted disease diagnosis and treatment), substance abuse, or mental health, where family support may be particularly difficult to obtain.

HEALTH CARE BENEFITS FOR WOMEN AND CHILDREN

Workshop participants pointed out that there should be continued efforts to design a comprehensive benefits package for women and children in the context of universal health insurance. The discussion of health care benefits for women and children emphasized the need for more attention to family planning services, mental health and substance abuse care, health education and counselling, and services for children with special health care needs such as care coordination, long-term care or home- and community-based therapeutic services. Several approaches to benefit design were examined by workshop participants, including benefit packages from several pending congressional health care reform proposals.

The term *benefit* refers to "the amount payable for a loss under specific insurance coverage (indemnity benefits) or as the guarantee that certain services will be paid for (service benefits)" (IOM, 1993b). The United States relies on a system of voluntary employment-based health benefits (private insurance) and government-funded insurance programs (e.g., Medicare and Medicaid). Currently, neither government- nor employment-based coverage reaches certain vulnerable populations, such as families whose income exceeds Medicaid limits but who cannot afford private insurance (IOM, 1993b). Moreover, coverage under private insurance in particular may be less comprehensive than government-funded insurance for certain types of services, such as preventive care, mental health, and family planning services.

Workshop participants agreed that a national benefits package will need to be comprehensive in order for women and children to receive optimal health care. However, it was emphasized that neither broadening access to health insurance nor improving benefits will meet all health care needs of women and children. In particular, participants emphasized that the need for adequate benefits for long-term care and ancillary services such as care coordination is especially important for children with chronic health problems. Several people also noted the importance of having benefits for mental health and substance abuse services.

Legislative proposals for health care reform address coverage of specific health care services (or benefits) in two ways. One approach defines specific services (including the amount, scope, and duration of coverage) in health care reform legislation. Another approach defines a set of covered services or categories in legislation at a general level and identifies an organization or agency, such as a national health benefits board, which will define the amount, scope, and duration of coverage, as well as co-payments for individual services. For example, services covered in some legislative proposals are listed in general categories such as physician and hospital services, prescription drugs, family planning and prenatal care, preventive medicine, mental health and substance abuse services, hospice and home health services, and vision, hearing, and dental care.

An alternative to designing a benefits package was described at the workshop in which benefits are provided to meet individual needs on a case-by-case basis resulting in a clinically-determined benefit, rather than the traditional benefit-driven treatment. For example, some large corporations have negotiated with health maintenance organizations (HMOs) to provide mental health and substance abuse services using this approach. Arbitrary limits on these services were deemed unnecessary and all treatment is managed according to clinical protocols and criteria so that patients are placed in appropriate levels of care according to their specific needs (Abrams, 1993; Digital Equipment Corporation, 1994).

Defining Medical Necessity

Workshop participants stated that the inclusion or exclusion of specific health services from health insurance plans often depends on whether they are designated "medically necessary." Some argued that this term is unclear and can be interpreted in different ways. The IOM (1993a) defines medical necessity as the need for a specific medical service based on clinical expectations that the health benefits of it will outweigh the health risks; the term is sometimes used interchangeably with medical appropriateness. As noted at the workshop, however, the term *medical necessity*, in a legal context, often serves to limit a health plan's contractual obligation to a beneficiary. Standard clauses in health insurance contracts do not state the decision-making criteria that health plans use to determine medical necessity. Some insurers and health plans may narrowly interpret medical necessity and possibly limit or exclude certain services that could have broader health benefits (Jameson and Wehr, 1993).

Care for all people, not just women and children, may be particularly constrained by narrow interpretation of the concept of medical necessity. Establishment of a pediatric standard of care could possibly ease this problem with regard to children. Three major differences between adults and children provide the rationale for a separate, pediatric standard: (1) developmental vulnerability, (2) dependency, and (3) patterns of illness and injury (see the section on the Health Care Needs of Children). As described at the workshop, a pediatric coverage standard should allow for a balanced determination between the expense of a service and what is medically necessary. The standard of care would include a list of health care services that plans should provide for children and would require that the scope and duration of those services be consistent with children's growth and development, their dependent status, their risk status, and good clinical practice (Jameson and Wehr, 1993).

COORDINATED HEALTH CARE SERVICES FOR WOMEN AND CHILDREN

Participants in the workshop agreed that many old models for health care delivery are no longer adequate and that health care reform needs to promote a coordinated and collaborative approach, especially for maternal and child health programs. Neither the current system for delivering traditional personal health services nor the public health system alone can effectively provide the full range of health services needed by women and children. For example, personal health services are limited in their ability to manage socioeconomic threats to health, violence, or homelessness, and public health services have not traditionally focused on personal health services, including the diagnosis and treatment of most medical illnesses. Workshop participants suggested that effective systems of care ensure collaboration between medical services and education, nutrition, welfare, and public health programs to prevent and monitor health problems. Ensuring optimal pregnancy outcomes, for example, requires a combination of community-based education and nutritional programs prior to and early in pregnancy, medical and monitoring services during pregnancy, adequate social support during and after pregnancy, and access to specialized technologically sophisticated services for high-risk pregnancies and community-based services for normal and high-risk pregnancies. Consequently, many people feel that collaboration between the public health system and providers of personal health services will be necessary to ensure comprehensive health care (Perrin et al., 1992; IOM, 1994a). For example, the effectiveness of traditional pediatric care offered in a doctor's office may be enhanced when combined with school health services and counseling and enabling services such as case management, and periodic home visits.

Access to Health Care

Although access to health care is often equated with insurance coverage, having insurance does not guarantee that people who need services will get them. As defined by the IOM (1993a), "Access is a shorthand term for a broad set of concerns that center on the degree to which individuals and groups are able to obtain needed services from the medical care system." Even though the number of physicians has grown in recent years, relatively few serve rural or inner city populations and many have been reluctant to accept Medicaid patients. This has created barriers to care for many low-income and uninsured women and children, which in turn has increased their reliance on community health care providers such as hospital clinics, public health clinics, and community and migrant health centers.

Managed-Care Organizations

Cost containment for health care services provided the initial impetus for reforming health care in the United States. In this context, managed care[2] has been suggested as a mechanism to slow the growth of health care costs while

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[2] The term *managed care* as defined by the IOM (1993b) is used (a) broadly to describe health care plans that add utilization management features to indemnity-style coverage or (b) more narrowly to identify group or network-based health plans that have explicit criteria for selecting providers and financial incentives for members to use network providers, who generally must cooperate with some form of utilization management. Managed care includes preferred provider organizations (PPOs), individual practice associations (IPAs), and health maintenance organizations (HMOs).

improving access and maintaining the quality of health care. Participation in managed care plans has increased tremendously in both the private and public sectors over the past several years, and many states have mandated enrollment of Medicaid recipients in managed care plans.

Workshop participants noted that managed care is here to stay, regardless of the progress of health care reform, and that its presence has implications for access to appropriate health care services, especially for vulnerable populations. Managed care programs—public or private—are not likely to develop community-based preventive services such as social work or to provide comprehensive treatment services for high-risk populations beyond those enrolled in the health plan. Participants stressed the important role of the public health sector to ensure that women and children in general have access to a broad range of programs that will help to promote their appropriate growth, development, and health. Major concerns were raised about the consequences of managed care for Medicaid recipients. Some workshop participants noted that managed care may limit Medicaid patients' access to health care services, particularly as referrals are restricted. Workshop participants suggested that these issues be considered by the federal government when decisions are made regarding Medicaid waivers.

Public Programs for Maternal and Child Health

Federal and state public health programs that serve women and children include Medicaid; the maternal and child health programs of Title V of the Social Security Act (which provides services to low income women and children, including children with special health care needs); the Supplemental Food Program for Women, Infants, and Children; and the federal family planning program of Title X of the Public Health Service Act (Perrin et al., 1994). Other relevant public health programs include community and migrant health centers and community-based preventive care programs (i.e., immunization programs and lead poisoning prevention programs) sponsored by the Centers for Disease Control (Perrin et al., 1994). Workshop participants expressed deep concern that health care reform should not be allowed to compromise the services currently provided by maternal and child health programs.

Many established public health programs will change appreciably under the current proposals to reshape the health care system. It is not at all clear, however, what the long-term effects of the proposed changes will be on these programs and the populations they serve. In particular, it is very uncertain what relationship the public health programs will have to the managed care organizations that many reform plans propose. Some effort clearly needs to be devoted to understanding how these many disparate pieces will relate to each other under a reformed system and whether or not this new system of programs will be adequately responsive to the needs of women and children.

Workshop participants articulated an important role for maternal and child health programs in the context of comprehensive health care reform. Participants also attempted to define the elements and structures necessary for maternal and child health programs to complement services available through managed care programs or other sources of direct medical care.

Workshop participants suggested that the design of effective health promotion or primary prevention programs will often require broad environmental and social interventions, along with more traditional medical approaches. Even though medical care cannot "cure" social and environmental problems, it can lessen some of the adverse health effects and facilitate access to a variety of other services that can promote better health and development for children. Some services may be available from health care providers, whereas others may be provided by public health agencies, often with federal support such as Maternal and Child Health Block Grant funds. Education and school-based services also make important contributions to a child's health and developmental progress. Community-wide prevention programs extend beyond the clinical setting, such as injury prevention, family violence prevention, or prevention of environmental toxic effects (i.e., lead). Care that involves the family may help to ensure that children have adequate access to preventive health services.

Participants suggested that one way to ensure that children have adequate access to preventive care is through home visiting programs, which provide care that involves the entire family. A home visiting program usually begins during a woman's pregnancy and continues through the first 2 years of her child's life. Home visiting programs have been proven effective in delivering some preventive health services to children and their families, such as infant health and development programs, and in providing mental health and social services (IOM, 1994b; Olds and Kitzman, 1993). These programs have been used primarily for "at-risk" parents, such as those who are poor, young, single, and have little education (NRC, 1993) and for children with developmental delays and chronic health care needs.

A few states are developing integrated approaches to better serve the health care needs of women and children. Workshop participants reported that some states have combined sources of care and funding to create better mental health programs for children and adolescents. For instance, Minnesota recently passed an integrated funding law that allows local agencies to pool local public funds, which are then matched by Medicaid monies to develop children's mental health programs. Ohio has created a program called Ohio Care, in which they are redesigning their Medicaid program to extend health benefits to underserved populations.

Workshop participants agreed that the existing public health system can facilitate the integration and coordination of maternal and child health programs and that collaboration between public health and personal health services providers will be necessary to ensure the availability of comprehensive health care for women and children. Under health care reform, the public health system could monitor providers' compliance with standards of care, investigate circumstances of untoward morbidity, and collect and analyze data on population-based outcomes in maternal and child health. The public health system could also recommend priorities for services to families and facilitate and support outreach and community interactions among health care, education, and social support agencies.

One perspective presented at the workshop is that the public health system should be responsible for ensuring that all women and children have access to primary and preventive health care services (Miller, 1994; IOM, 1988). Although the public health system need not always provide these services directly, it may need to continue to offer health care to those children and families who are not accommodated by the private health care system. Some workshop participants felt that the federal maternal and child health program could be strengthened by providing it with greater administrative visibility and assistance in policy development through the creation of a national advisory board (Miller, 1994).

CONCLUSION

As the U.S. health care system changes, the parts of the system designed for women and children will need to be reorganized before it can operate effectively. Workshop participants agreed that a priority for the maternal and child health community is to set forth a new vision that values programs for children and women and to define a strategy to carry out this vision to improve and advance their health care. Once the national debate over the financing of health insurance is concluded, federal leadership can help define clinical standards for the entire maternal and child health community. Federal leadership could also support creative improvements and redesign efforts that would integrate public and private health programs to provide the best care possible for women and children.

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CHAPTER
3

Protecting and Improving Quality of Care for Children Under Health Care Reform

Workshop Highlights

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Committee on
Maternal and Child Health Under Health Care Reform

Board on Children and Families
Commission on Behavioral and Social Sciences and Education
National Research Council / Institute of Medicine
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Board on Health Promotion and Disease Prevention
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CONTENTS

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 (Institute of Medicine, 1990). 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.

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.

INTRODUCTION

As actions at the state and local levels and in the public and private sectors change the financing and delivery of health care across the United States, there is concern that the quality of care must be protected and enhanced.[1] Anticipated federal health care reform legislation offers the possibility of important changes in health care financing and increased access to care; it also offers a greater opportunity than in the past to ensure that the essential function of monitoring quality of care is explicitly addressed. Successful monitoring of care for adults will not be simple, but monitoring the quality of health care for children[2] poses

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[1] The Institute of Medicine has addressed concerns about quality in all aspects of health care in a white paper issued by the IOM Council in July 1994 (Institute of Medicine, 1994).

[2] As used in this report, the term "children" encompasses infants through adolescents.

special challenges. Measures are needed to assess not only treatment of illness but also preventive care and promotion of optimal physical and psychosocial development over the roughly 20-year period from birth to adulthood.

In response to concern that important aspects of children's health and health care require greater attention as federal health care reform proposals take final shape and as other aspects of federal health programs are developed, the National Academy of Sciences' National Research Council (NRC) and Institute of Medicine (IOM) held an invitational workshop on July 7–8, 1994. At the request of the Office of the Assistant Secretary for Health in the U.S. Department of Health and Human Services, the second day of the workshop focused on protecting and improving the quality of care for children. This brief report, prepared under the guidance of the workshop steering committee, summarizes the major points raised in presentations and discussion.

ASSESSING THE QUALITY OF CARE

As defined by the IOM, "quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge. This definition reflects several important points: the process of care (health services) can be linked to the outcome of care (health or health status), quality assessments should consider care for individuals and that received by defined groups (e.g., members of a health plan or an entire community), and care should be guided by accepted professional standards and by preferences expressed by patients (or their families). The definition applies to health services to meet physical or psychosocial needs and to services offered by many kinds of health care providers.

Assessments of care can identify problems in the form of poor health outcomes or inappropriate health services (use of unnecessary or ineffective care, lack of needed care, or shortcomings in technical and interpersonal aspects of care). Identifying poor health outcomes is critical for evaluating the effectiveness of care and shaping policy. To improve outcomes, however, policy makers and health care providers must have information about the processes of care that produced those outcomes.

Work over the past 30 years has led to the development of valuable but still limited techniques and tools for assessing and improving the quality of health care. Presentations at the workshop reviewed some of the measures that have been developed for children and pointed out that less progress has been made than for adults, in part because of factors such as limited funding for research on children's health and special ethical concerns that arise for research involving children.

Increasing interest in monitoring quality and in reporting measures of health care performance (e.g., with health plan report cards) is helping to draw greater attention to the need to develop better quality assessment techniques and tools for both adults and children. Workshop participants emphasized, however, that efforts to monitor and improve the quality of care should move ahead using the available tools, even though perfect measures are not yet available.

ASSESSING CHILDREN'S HEALTH AND HEALTH CARE

Workshop discussions highlighted several factors that contribute to the complexity of assessing children's health and health care: certain critical differences between children and adults; the impact on a child's healthy development of services beyond the scope of traditional medical care; and conceptual and methodological issues in developing quality measures for children.

Critical Differences Between Children and Adults

Three differences between children and adults were cited as particularly significant for assessing health status and health care:

1. *Developmental changes.* Between birth and adulthood, children experience a complex and continuing process of physical and psychosocial development, with certain vulnerable periods in which appropriate care is essential for optimal developmental progress. Even subtle shifts from what would have been a child's "normal" developmental track may have a life-long impact.

Because some of the criteria for healthy functioning and for appropriate care change as children move through this developmental process, techniques for assessing their health status and quality of care need to reflect those changes. Among adults, adverse effects of illness and the compensatory effect of health care can often be assessed against a relatively stable level of functioning immediately before the illness. Among children, however, the effects of an illness and of health care can be much harder to judge against the background of developmental changes that occur within a wide range of normal functioning. For some children, a long-term assessment process may be needed to determine the full impact of either health care or illness.

2. *Dependency.* Children are inherently dependent on their parents and other adults as well as community institutions (including schools) to protect and promote their health and well-being. Therefore, the element of "independent functioning," which is a critical factor in judging adult health status, does not apply to children. The degree of dependency decreases over time, but in large measure children must rely on adults, as individuals or through society's various institutional structures, to provide care that promotes normal development, to recognize disorders and obtain treatment, and to define pre- and posttreatment functioning. Some workshop participants pointed out, however, that adults' perceptions of a child's condition may not match the child's perceptions; even

among adults, the judgments of parents and health professionals may differ from each other.

3. *Patterns of illness and injury*. Children have a characteristic epidemiology of health and illness. Most children are fundamentally healthy and require care that emphasizes preventive services, such as immunizations and monitoring of physical and psychosocial growth and development. By comparison, adult care is based much more on response to illness. Patterns of serious illness in children, especially chronic illness, also differ from those in adults. Relatively small numbers of children experience a diverse array of conditions in contrast to the larger number of adults who, in general, experience a more limited and more predictable range of disorders. The diversity of children's conditions means that few health professionals have the expertise or resources to provide the full range of care for all such conditions and that families may need help gaining access to specialized support services. Furthermore, these children need care not only for the illness itself but also to minimize possible adverse effects of the illness on overall development.

More than Medical Care for Children's Health

Workshop participants emphasized that optimal health and development for many children requires not only medical care but also other health and social services both to prevent problems and to ameliorate the effects of conditions that do have an adverse impact on children. The discussions pointed to the need to consider the contribution of those services in addition to medical care in at least some assessments of the quality of children's care.

Many important health threats lie in socioeconomic and environmental factors, such as poverty and community violence, that are not the traditional targets of clinical preventive services. If these risk factors are not addressed, however, the health care system must often provide acute or chronic care for conditions such as injuries, exposure to toxic substances (e.g., lead), or emotional disturbances. For some children, a range of social services may be needed to provide comprehensive care for a chronic illness, to ensure adequate nutrition, to promote a safe home environment, or to respond successfully to certain "behavior" problems that may not typically be viewed as health related.

Even though medical care cannot "cure" social and environmental problems, it can mitigate some of the adverse health effects and facilitate access to the variety of other services that can promote better health and development for children. Some of the services may be available from health plans or other health care providers, while others may be provided by public health agencies, often with federal support such as Maternal and Child Health Block Grant funds. Education and school-based services, which often are more removed from the realm of medical care, also make important contributions to a child's health and developmental progress.

The problem of injury, a leading cause of death among children, clearly illustrates the need to combine personal health services with broader public health and community efforts. The health care system provides acute, and sometimes rehabilitative and chronic, care for injured children, but its contribution to prevention is primarily counseling for parents and children about avoidable risks. Effective prevention also depends on activities such as public education, enacting and enforcing safety laws (e.g., for bicycle helmets, pool fencing, or sale of alcohol to minors), and special programs such as school-based violence prevention training for children.

Many workshop participants felt that successful integration of health care, education, and social services is particularly valuable in meeting children's unique health and developmental needs. The diversity of these services, however, makes it less clear how to monitor the quality of the care that they provide. Health plans may have an interest in assessing how well such services are meeting the needs of member children, but public health agencies have a broader perspective that can enable them, in collaboration with providers in the private sector, to make overall assessments of these services for all children in a state or community.

Conceptual and Methodological Considerations

Rates of immunization, low birth weight, and hospitalization for asthma are among the handful of indicators used to monitor children's health care. These measures touch on only a few aspects of the care given to children, but there is little consensus about the merits of other measures. An informal survey of pediatricians, which was described at the workshop, has produced suggestions that the process of routine preventive care be monitored on the basis of procedures such as vision screening, assessment of language development, or measurement of weight, height, and head circumference.

Although monitoring the quality of care focuses on process, the outcomes of care—usually assessed with health status measures—must also be considered. Workshop participants emphasized that, for children, the concepts of health and health outcomes are not easily defined but must be broader than the presence or absence of disease. The elements of developmental change and dependency, which were discussed above, contribute to the complexity of assessing children's health status and functional outcomes. Strong support was voiced at the workshop for the development of generic measures, but some participants saw merit in disease-specific measures as well. Some tools for health status assessment are less appropriate for clinical evaluation and are intended for community-based assessments and policy guidance. Many national assessments rely on the National Health Interview Survey, but the sample size is too small to provide data for state-level or condition-specific assessments.

Developing reliable and valid process measures poses several methodological problems. An assessment of preventive care, for example, must contend with two issues: how to measure events that do *not* occur (or occur very rarely) because that care was given, and how to evaluate effects of care over a very long time span. Some measures may be useful but not appropriate for children of all ages: for example, immunization rates for 2-year-olds reflect care being given to infants and toddlers but do not provide information about care that adolescents are receiving. Children with chronic illnesses or other special health care needs receive substantial amounts of care, but the small numbers of such children make it hard to develop measures with adequate statistical power to detect meaningful differences over time or among health plans.

One of the anticipated uses of quality measures is to facilitate comparisons of the care provided by health plans. For such comparisons to be fair, adjustments must be made for significant differences in the underlying health of the populations served by plans or for other factors outside of the control of health plans (e.g., members' socioeconomic characteristics or differences in benefit packages selected by employers) that might lead to entirely appropriate differences in care or outcomes of care. Available adult-based adjustment techniques may not be satisfactory for children and should not be used unless they can be validated for a pediatric population. Work done in pediatric populations has largely focused on mortality risks among critically ill or injured children. Because such methods apply to only a small number of children, more broadly based approaches are needed as well.

ASSESSING QUALITY AT SEVERAL LEVELS

Assessments of the quality of health and health care for children (or adults) can be made from at least three perspectives: the individual patient and provider, health plan performance, and systems of services for entire communities and states. Workshop participants emphasized the importance of the broad perspective of population-based assessments, which make it possible to examine patterns of care and identify gaps in services.

Health plans, which can examine the care provided to the population represented by their members, can use assessments to obtain information to support their internal quality improvement programs. Those assessments can also help purchasers and consumers of health services select among competing plans. Individual health plans are not, however, in a position to assess whether a community's entire population has health insurance coverage, and they may not accept responsibility for assessing how well plan services mesh with those that children may receive (or need) from other sources.

Communities and states seem to be the levels at which overall assessments should be made. Public health agencies can work with health plans and other private providers to make assessments, but they will need adequate financial and technical resources to do so. The tools (appropriate measures and survey instruments or other data collection systems) needed for all but the most basic assessments require further development. Reliable national-level data also need to be collected to monitor the overall health of children and families.

ACCOUNTABILITY FOR CHILDREN'S CARE

Assessing quality of care does not by itself ensure that problems that are identified will be corrected. Workshop participants expressed concern that without adequate means to monitor children's care, a particularly vulnerable population could be put at even greater risk in the midst of a changing health care system that tends to focus on adult needs and may face stronger incentives to control costs than to improve care.

To the extent that quality assessments are possible, they will promote correction of some problems. For example, given the appropriate information, many health care providers will take what steps they can to make improvements. Publication of performance measures for health plans may encourage those with lower ratings to make improvements so that they can compete successfully with other plans. If children's unique needs are considered, accreditation standards established by private, voluntary groups can also promote improvements in quality of care provided by hospitals, health plans, or other providers that want to achieve accredited status. Since it is not possible to monitor all aspects of care, accreditation standards may also promote good quality of care through attention to the structural aspects of health care (e.g., numbers and qualifications of providers, availability of beds, and proper equipment).

Many workshop participants felt, however, that these mechanisms would not be sufficient to protect and improve the quality of children's care. They saw a need for federal and state health care reforms to establish other means to ensure that health plans or other responsible parties take action to correct any deficiencies in the care they are providing to children.

Discussions pointed to two particularly important motivations for public sector involvement in establishing accountability for the quality of children's care. The first factor is a need for a recognized standard of care for children that can be used to establish appropriate criteria for "medically necessary" care. The currently limited amount of science-based evidence for formulating pediatric practice guidelines may lead health plans to rely on adult-oriented standards for medical necessity. Those standards may result in care that is not in the best interests of children by, for example, offering access to adult rather than pediatric specialists or limiting coverage for home-based care, which could avoid the adverse developmental effects of prolonged hospitalization. There was also concern that children in low-income families and other vulnerable groups (including adolescents who may be alienated from their families) could have difficulty taking advantage of administrative and legal mechanisms to challenge health plan judgments on the medical necessity of specific kinds of care.

The second motivation for public sector involvement in monitoring quality of care is the need for coordination and oversight of the full array of public and private services that contribute to children's health and development. Unless a public health department or other entity is given explicit responsibility for monitoring and improving this package of services, the separate components may not mesh effectively and children may not benefit as they should from those services. Some at the workshop felt that authority for all quality oversight should rest with state public health agencies. They noted that the IOM has identified as core public health functions assessing health status and health needs and assuring that high quality services are available to meet those needs.[3]

DEVELOPING AND ENHANCING RESOURCES FOR ASSESSING CHILDREN'S CARE

Throughout the workshop, presentations and discussions pointed to the need for federal assistance to support research to develop appropriate techniques and tools for assessing the quality of children's health care. Some of these research needs are noted here. Research is needed to develop measures of health status and functional outcomes that are suited to monitoring the impact of health care on children as well as measures that can meet other clinical and policy needs. Studies must continue to examine the effectiveness of various kinds of preventive, curative, and rehabilitative care across the pediatric age range. More and better clinical practice guidelines for pediatric care are needed. Work is also needed to develop ways to promote the integration of the broad range of services that contribute to the health and well-being of children and to assess and improve the quality of this system and the services it is providing.

A second theme that emerged from the workshop was the need to develop better data, data collection, and data systems to support efforts to monitor and improve care. Some states (e.g., Massachusetts and Washington) are already taking steps to ensure that they have statewide data systems and data reporting requirements that will allow them to monitor health care. Other states and communities may need technical assistance to establish assessment and improvement programs. Better use of existing public and private data sources and data systems may make it possible to develop needed information in a particularly cost-effective manner. Relevant federal and state data, for example, could be made more readily available to communities. National guidelines will be needed to promote comparability of quality data across the country.

Several specific suggestions were made for improving the usefulness of national surveys and data systems (e.g., vital statistics) for monitoring children's

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[3] These functions were first identified in *The Future of Public Health* (Institute of Medicine, 1988). They were recently reaffirmed in the IOM Council's July 1994 white paper, *America's Health in Transition: Protecting and Improving Quality* (Institute of Medicine, 1994).

health status and the impact of health care reform: evaluating and improving measures of child health, developing the capability to assess both short- and long-term effects of illness and health care on children's health status, instituting longitudinal data collection (e.g., through panel surveys), expanding national surveys so that they can produce state-level estimates, and developing the capability specifically to monitor vulnerable child populations.

CONCLUSIONS

As changes are made in the health care system to control costs and improve access to services, changes should also ensure that the quality of care is protected and improved. To ensure that children receive appropriate care, the available, but still limited, tools for assessing their health status and health care need to be used as effectively as possible. Development of a more comprehensive set of quality indicators will require rigorous studies that examine the effectiveness of various elements of children's care. Programs to monitor quality of care will need to establish accountability for correcting problems that may be found and mechanisms to ensure that improvements are made.

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CHAPTER
4

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

Workshop Highlights

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Board on Health Care Services

Institute of Medicine

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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 workshop, participants received a background paper (Ireys, 1994). 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.

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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.

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:[3]

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

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[3] For additional information on this typology and findings from recent surveys of Medicaid managed care plans pertinent to the workshop theme, see Fox and McManus (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.[4] 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.[5]

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.

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[4] 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.

[5] See Stein et al. (1993).

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.

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 (Newacheck et al., 1994). 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 (Regenstein and Meyer, 1994).

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 (National Research Council and Institute of Medicine, 1994). 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 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.[6] 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

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[6] 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 and Nelson (1992).

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 public 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.

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 policy makers 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 (Jameson and Wehr, 1993).

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 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.

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APPENDIX

A

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APPENDIX

B

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APPENDIX

C

Acknowledgments

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women is deep and well informed, and the workshop participants learned a great deal from each of them.

Funding for the workshops that produced the reports "Benefits and Systems of Care for Maternal and Child Health Under Health Care Reform" and "Protecting and Improving Quality of Care for Children Under Health Care Reform" was provided by the March of Dimes Birth Defects Foundation, the National Foundation for Public Health Policy, and the U.S. Department of Health and Human Services through the Office of the Assistant Secretary for Health (Cooperative Agreement Number ASU-000002-01) and the Maternal and Child Health Bureau. The following individuals were particularly helpful to the staff in formulating the workshop agenda and identifying possible speakers: Donald Berwick, Institute for Health Care Improvement; Amy Fine, Association of Maternal and Child Health Programs; Neal Halfon, UCLA School of Public Health; Kay Johnson, March of Dimes Birth Defects Foundation; Woodie Kessel, Maternal and Child Health Bureau; Jonathan Kotch, National Foundation for Public Health Policy; Kristen Langlykke and Pamela Mangu, National Center for Education in Maternal and Child Health; Sara Rosenbaum and Elizabeth Wehr, the George Washington University Center for Health Policy Research; and Lisa Simpson and Robert Valdez, Office of the Assistant Secretary for Health. Numerous staff members in addition to those listed with the workshop steering committee contributed to the success of the workshop and the preparation of this report: Brenda Buchbinder, Claudia Carl, Nancy Crowell, Molla Donaldson, Judith Doody, Michael Edington, Marilyn Field, Eugenia Grohman, Carrie Ingalls, Amanda Klekowski, Kathleen Lohr, Philomina Mammen, Alison Smith, and Mary Thomas. For both the workshop and this report, Kathleen Lohr, then director of IOM's Division of Health Care Services, provided particularly valuable advice on quality-of-care issues.

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The views presented in the four reports reprinted in this volume are those of the workshop participants and are not necessarily those of the funding organizations.

APPENDIX

D

Other Publications

Other reports from the Board on Children, Youth, and Families

Beyond the Blueprint: Directions for Research on Head Start's Families: Report of Three Roundtable Meetings (1996)

Child Care for Low-Income Families: Directions for Research: Summary of a Workshop (1996)

Service Provider Perspectives on Family Violence Interventions: Proceedings of a Workshop (1995)

"Immigrant Children and Their Families: Issues for Research and Policy" in *The Future of Children* (1995)

Integrating Federal Statistics on Children (with the Committee on National Statistics of the National Research Council) (1995)

Child Care for Low-Income Families: Summary of Two Workshops (1995)

New Findings on Children, Families, and Economic Self-Sufficiency: Summary of a Research Briefing (1995)

The Impact of War on Child Health in the Countries of the Former Yugoslavia: A Workshop Summary (with the Institute of Medicine and the Office of International Affairs of the National Research Council) (1995)

Cultural Diversity and Early Education: Report of a Workshop (1994)

Benefits and Systems of Care for Maternal and Child Health: Workshop Highlights (with the Board on Health Promotion and Disease Prevention of the Institute of Medicine) (1994)

Protecting and Improving the Quality of Children Under Health Care Reform: Workshop Highlights (with the Board on Health Promotion and Disease Prevention of the Institute of Medicine) (1994)
America's Fathers and Public Policy: Report of a Workshop (1994)
Violence and the American Family: Report of a Workshop (1994)

Other reports from the Board on Health Promotion and Disease Prevention

Maternal and Child Health

Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment (with the Board on Behavioral Sciences and Mental Disorders) (1996)
The Best Intentions: Unintended Pregnancy and the Well-Being of Children and Families (1995)

Immunizations

Vaccines Against Malaria: Hope in a Gathering Storm (1996)
Options for Poliomyelitis Vaccination: Summary of a Workshop (1996)
The Children's Vaccine Initiative: Continuing Activities (1995)
Overcoming Barriers to Immunization: A Workshop Summary (1994)
DPT Vaccine and Chronic Nervous System Dysfunction: A New Analysis (1994)
Research Strategies for Assessing Adverse Events Associated with Vaccines (1994)

AIDS and Sexually Transmitted Diseases

Changing Demographics of the HIV Epidemic: Implications for Clinical Research (1995)
Preventing HIV Transmission: The Role of Sterile Needles and Bleach (with the Commission on Behavioral and Social Sciences and Education, National Research Council) (1995)
HIV and the Blood Supply: An Analysis of Crisis Decisionmaking (1995)
Assessing the Social and Behavioral Science Base for HIV/AIDS Prevention and Intervention: Workshop Summary (with the Board on Behavioral Sciences and Mental Disorders) (1995)

Environmental and Occupational Health

Evaluation of the Department of Defense Persian Gulf Comprehensive Clinical Evaluation Program (1996)

Medical Research in Cold War Alaska: Radioactive Iodine-131 Studies of Thyroid Function and Cold Adaptation in Alaska Natives and Military Personnel (with the Commission on Geosciences, Environment and Resources and the Commission on Life Sciences, National Research Council) (1996)
Veterans and Agent Orange: Update 1996 (1996)
Enhancing Environmental Health in Nursing Practice (1995)
Lead: A Public Health Policy Case Study (planning meeting summary, 1995)
Environmental Medicine: Integrating a Missing Element Into Medical Education (1995)
Veterans and Agent Orange: Health Effects of Herbicides Used in Vietnam (1994)

Public Health Infrastructure

Using Performance Monitoring to Improve Community Health: Exploring the Issues (1996)
Using Performance Monitoring to Improve Community Health: Conceptual Framework (1996)
Social Marketing of Health Promotion and Disease Prevention to Minorities and Adolescents (1995)

Other reports from the Board on Health Care Services

America's Health in Transition: Protecting and Improving Quality (1994)
Health Data in the Information Age: Use, Disclosure, and Privacy (1994)
Access to Health Care in America (1993)
Assessing Health Care Reform (1993)
Emergency Medical Services for Children (1993)
Toward a National Health Care Survey: A Data System for the 21st Century (with the Committee on National Statistics of the National Research Council) (1992)
Guidelines for Clinical Practice: From Development to Use (1992)
Clinical Practice Guidelines: Directions for a New Program (1990)
Medicare: A Strategy for Quality Assurance (1990)