
Introduction

Improving the Quality of Healthcare for Children: Implementing the Results of the AHSR Research Agenda Conference

Neal Halfon, Mark Schuster, Wendy Valentine, and Elizabeth McGlynn

Objective. To describe the rationale, development, content, and results of the AHSR-sponsored conference on developing a research agenda focused on improving the quality of care for children.

Data Sources and Methods. Planning documents, background papers, and conference proceedings.

Principal Findings. The conference developed the research agenda focused on (1) monitoring the health of children; (2) evaluating the efficacy and effectiveness of health services for children; (3) assessing the quality of healthcare provided to children; (4) improving the quality of healthcare within health systems; (5) assessing the performance of community systems for children; (6) exploring the impact of different financial incentives on the provision of pediatric healthcare; and (7) developing and disseminating clinical practice guidelines and other information to physicians, families, and consumers.

Specific issues and research questions in each area are also presented. Strategies for implementing the research agenda are presented and include: (1) expanding the child health services research workforce; (2) developing child healthcare quality improvement research centers; (3) conducting research in specific high-priority areas; (4) focusing research on improving the health of vulnerable populations; (5) improving child health data and collection systems at the national level; (6) developing better community health monitoring for children; (7) building and supporting research networks and a consortium of research users; and (8) developing a coordinated interagency federal effort to advance this agenda and to provide accountability for its completion.

Conclusion. The proposed research agenda should be a national priority so that all Americans can be assured that children are receiving the best quality of care that the United States can provide.

Key Words. Quality of care, children, quality improvement

Healthcare delivery in the United States is undergoing a dramatic and rapid transformation. In just the past few years, major changes have occurred in the ways in which consumers choose their physicians, in the benefits covered by their health insurance, in how their medical care is paid for, and in the economic incentives that influence their physicians' decisions. In light of these changes, concerns are being raised about the quality of care that is currently available to Americans and is going to be available in the future (Etheredge, Jones, and Lewin 1996). Concerns about the quality of healthcare are particularly acute for children (McGlynn, Halfon, and Leibowitz 1995).

As the healthcare system has changed, there has been a contemporaneous increase of interest in quality assessment, evidence-based medicine, and accountability. These approaches hold great promise as a means of protecting against a decline in quality of care and, more importantly, as a vehicle for its improvement. Many participants in the healthcare marketplace can make use of information on quality of care. (1) Consumers can use the information to choose among clinicians and health plans. (2) Private and public group purchasers of care can use it when deciding which plans to make available to employees or which health professionals to permit to provide publicly funded care. (3) Clinicians, hospitals, and health plans can use quality measures to improve the care they deliver; clinicians, as well as consumers, can use information on quality when making treatment decisions (e.g., for a particular condition, are local surgery success rates better or worse than medical management?). (4) Finally, policymakers can use quality assessment to measure the impact of new policies, such as the shift of many children into Medicaid managed care.

The growth in the field of quality assessment has been concentrated primarily in the area of adult health. Only limited work has addressed healthcare for children and adolescents (Bergman 1995; Finkelstein et al. 1995; Homer et al. 1996; McCormick 1997; Payne et al. 1995; Schuster et al. 1997; Starfield et al. 1994; Zenni and Robinson 1996). For example, a recent analysis of major health quality report cards showed that most quality measures focused

Address correspondence to Neal Halfon, M.D., M.P.H., Professor of Pediatrics and Public Health and Co-Director, UCLA Center for Healthier Children, Families, and Communities, School of Public Health, University of California, Box 951772, Los Angeles, CA 90095-1772. Mark Schuster, M.D., Ph.D. is Assistant Professor of Pediatrics, School of Medicine, UCLA and Senior Natural Scientist, RAND; Wendy Valentine, M.H.A. is Program Director, Association for Health Services Research; and Elizabeth McGlynn, Ph.D. is Director, Center for Research on Quality and Healthcare, RAND. This introduction was approved for publication in *Health Services Research* on June 4, 1998.

on adult health (McGlynn 1997). Quality assessment systems such as the National Committee for Quality Assurance's (NCQA) Health Plan Employer Data and Investigation Set (HEDIS) include many measures to monitor the quality of healthcare for adults, but few measures for children's healthcare quality (National Committee for Quality Assurance [NCQA] 1997).

Therefore, a national invitational conference—Improving Quality of Health Care for Children: An Agenda for Research—was convened to identify the key research issues and questions that should be addressed to achieve a delivery system that will ensure the continuous improvement of healthcare services for children. The major aims of the conference were (1) to develop a research agenda to improve our ability to assess quality of care for children in light of their unique healthcare needs, and (2) to determine how to develop the infrastructure needed to promote continued advancement of the field of children's health services research.

The conference was organized around seven major topics:

- Monitoring the health of children;
- Evaluating the efficacy and effectiveness of health services for children;
- Assessing quality of care;
- Improving quality of care;
- Assessing the performance of community systems for children;
- Aligning economic incentives to promote quality of care; and
- Developing and disseminating information to physicians, families, and purchasers of healthcare and health insurance.

In this article, we review the rationale for the conference, we report the research agenda developed during the conference, and we present a strategy for implementing the agenda.

RATIONALE FOR THE CONFERENCE: THE POLICY CONTEXT

In considering how to assure high-quality healthcare for children, it is important to keep in mind that most recent healthcare policies have been designed to minimize regulation and to improve how the healthcare market works. Even before recent changes, the market was not always an effective means of producing care for children. Since the major payment mechanism for healthcare is employer-based health insurance, parents who are not employed

or whose employer does not provide health insurance can have difficulty obtaining and paying for health insurance for their children. This problem led to the expansions in Medicaid funding and most recently to the creation of the State Child Health Insurance Program (SCHIP).

Because children account for only 15 percent of direct expenditures on healthcare, they appear to warrant less attention from the marketplace than do chronically ill adults (Lewit and Monheit 1992). Further, children do not have an independent political voice, and many children live in families whose poverty status has traditionally reduced the political clout of their parents.

The growing reliance of children on Medicaid means that nearly 25 percent of all children currently receive federal- or state-financed healthcare coverage (The Kaiser Commission on the Future of Medicaid 1997). With the enactment of SCHIP, the federal government could soon be paying for healthcare for 35 percent of American children. Increasing proportions of these federal funds are going to pay for capitated managed care plans. As the federal investment in children's health grows, concern for the accountability of billions of taxpayer dollars going to private managed care companies could create new interest on the part of many policymakers to know if they are receiving value for their investment.

For the competitive healthcare marketplace to work properly, parents as well as private and public purchasers of care need to be informed about the quality of the care that is provided. Otherwise, they will not be able to judge the value of the care they receive and purchase. To provide this critical information, we need better measures of the outcomes and quality of care, and we need to implement these measures.

RATIONALE FOR THE CONFERENCE: THE MEASUREMENT CONTEXT

Quality of healthcare has been defined 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" (Lohr 1990). High-quality care consists of several components: the person has the opportunity to obtain needed care; the care is appropriate and skillfully provided; the care is delivered in a humane manner consistent with patient (or parent) preferences; and the best possible outcomes are achieved (McGlynn 1997).

Although efforts to measure and improve quality for children can benefit from many of the methodological advances that have been developed in studying the quality of adult healthcare, adult measures cannot always simply

be used for children. Differences between children and adults not only affect children's health and healthcare but also the ways in which the quality of children's care should be assessed (Forrest, Simpson, and Clancy 1997; Jameson and Wehr 1993; McGlynn and Halfon 1998; Halfon et al. 1996). Childhood and adolescence are periods of rapid development characterized by physical, cognitive, and emotional changes. Illness, injury, and adverse social circumstances can have a negative effect on the developmental process, so quality measurement must take account of the importance of health services in affecting this process. Second, healthcare provided to children can have an impact that does not become apparent until adulthood. Diabetic care during childhood, for example, can prevent or slow the development of retinopathy and foot ulcers several decades later.

Third, the prevalence, pattern, and profile of childhood illness is quite different than that of adult illness, and the expression of the same disease can be quite different in a child than it is in an adult, so adult quality measures are not always relevant to children. Fourth, children's dependence on parents, other caregivers, and institutions like schools affects the way they receive healthcare. Therefore, quality measurement must account for the role these individuals and institutions play in children's health utilization and outcomes. Finally, the systems of care that exist for children differ fundamentally from those that exist for adults (Halfon, Inkelas, and Wood 1995). Healthcare services for children are often delivered not only in a medical care setting, but also in schools, day care centers, and other institutions where children spend time. Good care requires coordination and communication among the various clinicians and institutions providing care to children. Therefore, quality indicators must capture the degree of systematic efforts in a given community to promote children's health and development.

DEVELOPING THE AGENDA

Recognizing the need to develop better quality of care measures, the Association for Health Services Research (AHSR), in conjunction with several federal agencies and private institutions (listed earlier in this volume) sponsored a national conference to develop a research agenda for improving the quality of healthcare provided to children in the United States. AHSR, in consultation with co-sponsors of the conference, appointed a chairperson, two co-chairs, and a steering committee to plan the conference. The steering committee included representative consumers, clinicians, healthcare providers, health service researchers, healthcare purchasers, health plans, state and local agencies, and conference sponsors. The planning process was organized around

the development of a quality accountability continuum for children that included the determinants of children's health and the assessment of children's health status and quality of life; the effectiveness of health services for children (i.e., the evidence for what works); the standards and guidelines that have been developed to ensure that what works is what's actually provided; the assessment of quality of care; the development of strategies and mechanisms for improving the quality of care within the healthcare system; and disseminating information about each of these concepts (McGlynn and Halfon 1998).

The steering committee selected authors to write a background paper on the state of the art of each topic area and potential subjects for future research in the topic area. The committee also selected two reviewers per paper, one with an academic research perspective and one with a practitioner/delivery system perspective, to provide the authors with feedback prior to the conference.

The steering committee also nominated potential conference participants to represent key stakeholder constituencies: researchers, providers, payers, health plans, quality assurance organizations, government agencies, and state and local administrators of community-based programs. The steering committee's executive committee chose the final list of 100 invited participants, whose names and affiliations appear at the end of this volume.

At the conference, participants were assigned to one of seven workgroups organized around the seven topic areas. Each workgroup reviewed the background paper and used the findings to stimulate the development of topics for a research agenda. At the end of the first day, each participant in a group was asked to vote for the top five priorities for a research agenda. AHSR staff and the conference co-chairs, in collaboration with the group leaders, prepared a list of the top-ranked priorities for each group. During the second day, the participants were assigned to a second group so that they could review and revise the proposed agendas. At the end of the second day, the final agenda in each area was presented to the full conference. The results are given in the next section.

THE AGENDA

A. Monitoring the Health of Children

To assess the quality of healthcare for children in the United States, a conceptual framework for monitoring children's health is needed that takes into

account the unique problems and requirements faced by children at all stages, from infancy through adolescence.

The work group discussed these critical issues:

- The need for a summary of the leading causes of death and functional limitations among children, along with estimates of the prevalence of various health problems among children, by age group;
- The need to identify the various tools that are used to measure different aspects of health, especially those used to assess health status among children;
- Gaps in current methods for assessing health and functioning among children, and strategies for eliminating those gaps;
- The need to define desirable health outcome measures specific to children;
- The need to identify the greatest health risks specific to children;
- The differences in perspectives from which health is assessed, including those of the healthcare provider, the parent, the child, and society; and
- The implications of different perspectives for measurement, and the methods needed to address various perspectives adequately.

Research Priorities

1. How well do existing health indicators assess health status and health needs at the individual, health plan, and community levels?
2. How can existing measures be expanded and new instruments be developed to assess the health of special populations (e.g., racial and ethnic minorities, economically disadvantaged groups, children with special healthcare needs, etc.)?
3. What are the relationships among different indicators of health (e.g., biological/physiological factors, symptoms, functional status, and perceived well-being) across multiple domains (e.g., physical, emotional, cognitive, and social)?
4. How can improved health measures be used routinely in practice and in community settings?
5. How can the child's perspective be incorporated into the measurement of health, and how does this perspective differ from the perspectives of parents and health professionals?
6. How can we enhance our capacity to track changes in the health of children over time?

B. Evaluating the Effectiveness and Efficacy of Health Services for Children

Better measures of health will enhance our ability to evaluate the effectiveness of interventions used for improving children's health. Effectiveness refers to results obtained in the "real world" through usual care, whereas efficacy refers to results achieved under ideal circumstances, generally in a randomized controlled trial. Because both of these types of research are difficult to conduct among children, scientific evidence that identifies the most promising health services interventions for children is often limited.

The work group agreed that effectiveness studies must include diverse patient populations and multifaceted interventions involving different systems (e.g., courts, schools, housing) to influence children's health. The work group also discussed these issues:

- Gaps in the knowledge base for effectiveness in selected areas, including preventive, acute, chronic, and urgent care;
- Ethical, logistical and technical problems in conducting research on children;
- The role of the family in influencing process and outcomes; and
- The lack of appropriate effectiveness measures and other methodological problems (e.g., sample size).

Research Priorities

1. What interventions are effective in reducing risky behaviors and promoting healthy behaviors in children and adolescents (e.g., smoking, alcohol and drug use, exercise, nutrition, sexual behavior)?
2. What is the nature and extent of influence that parents' behavior has on their children's health?
3. What is the impact of early identification and effective treatment of mental health and developmental problems on subsequent functioning and development among children and adolescents?
4. Do efforts to classify children by their vulnerability and treat them according to their presumed risk level improve or worsen health outcomes?
5. What are the effects of differences in preventive care, periodicity schedules, service delivery, sites of care, and practitioner types on health maintenance outcomes?
6. What are the most effective means of preventing violence and injury among children?

C. Assessing the Quality of Healthcare Provided to Children

Quality assessment measures are designed to evaluate whether healthcare services are delivered in a manner that is consistent with established standards. Three dimensions of the health service delivery system—structure, process, and outcomes—are commonly evaluated. Efforts to assess quality of care for children have been limited by the lack of reliable and valid health measures and scientific evidence regarding the efficacy and effectiveness of interventions.

The work group discussed these issues:

- The availability, breadth, and reliability of existing quality assessment measures;
- The evidence regarding the impact of those measures on healthcare delivery;
- Strategies for addressing the limitations of current measures for reporting performance across systems; and
- Key aspects of pediatric care about which more information on quality is needed, and methods for obtaining that information.

Research Priorities

1. What key pediatric processes and outcome measures should be refined, developed, and validated for quality measurement purposes?
2. What research is needed to develop quality measures that link processes and outcomes of pediatric care?
3. What are the cultural and developmental components of health, illness, and quality, and how can those factors be incorporated into future quality assessment systems for children?
4. How do various components of the healthcare system influence children's health, and how can that information be incorporated into the design of an accountability framework for pediatric care?
5. How can we measure the benefits and costs of different quality assessment measurement techniques or strategies?

D. Improving the Quality of Healthcare Within Health Systems

Quality improvement refers to interventions that are designed to close the gap between desired processes and outcomes of care and what is actually delivered. Quality assessment measures are used to identify areas where care is substandard and requires improvement. Quality improvement interventions may be directed at any group of participants in the delivery

system: administrators, physicians, laboratory technicians, parents, children, employers, and others.

The work group agreed that all research in this area should consider issues of cost, research methodology, and the level of the system targeted for improvement. The work group also discussed these issues:

- The need to identify the current state of the art in healthcare quality improvement;
- The appropriateness of different quality improvement strategies for use in children's services;
- The effectiveness of different approaches to quality improvement for children's services; and
- The need to identify the most promising strategies for enhancing care delivery to children.

Research Priorities

1. How can research inform decisions about what elements of service delivery for children need to be improved?
2. How can individual decision making by clinicians, patients, and families best be changed?
3. How can the performance of pediatric healthcare systems be improved?
4. What organization or system characteristics promote or impede improvement?
5. How can industrial quality improvement techniques be applied to improve children's healthcare?
6. How can child, family, and other perspectives be incorporated into actions to improve services for children?
7. How might a systematic classification of current quality improvement programs enhance the diffusion and adoption of best practices?
8. How can sentinel events (e.g., deaths, complications) be used to motivate system improvement?

E. Assessing the Performance of Community Systems for Children

Children—especially those with special needs—often receive preventive, treatment, and rehabilitative services from other community-based institutions and providers outside the narrow confines of the medical care system.

Examples include special services for abused children at a regional child abuse assessment center and school-based rehabilitative services for children with cerebral palsy. Children with special healthcare needs often receive services from multiple providers at multiple sites, raising the importance of quality measurement across multiple systems of care. In addition, linkages between the healthcare system and other community support systems—such as child care, family support programs, schools, and others—may significantly affect the processes and outcomes of health services for children.

The work group discussed these issues:

- Identification of community systems that serve as critical linkages for healthcare delivery to healthy children and those with special needs;
- Methods for evaluating the quality of those linkages in a community; and
- Evidence about variations in the current levels of community performance on these key linkages.

Research Questions

1. What conceptual framework would facilitate research on community system performance?
2. What methodologies for performance measurement are most useful at the community level?
3. What system performance evaluation methodologies should be adapted from other fields?
4. How will the approach of systems research differ for discrete populations, services, and outcomes measures?
5. What are the critical features of model service systems for children?
6. What processes should be developed to enable communities to monitor system quality and change?

F. Getting the Incentives Right

Financial and other incentives can affect the quality of healthcare services delivered by a system or community. These include capitated payments, bonuses, withholds, and other incentives. Relatively few efforts have been made to evaluate the effect of such incentives, which are present at different levels within the system, on care delivery for children. Information on what interventions are most effective and how well delivery systems are performing can be used in designing incentives.

The work group noted that the role of risk adjustment in refining financial systems for children's services should be explored, particularly with respect to the willingness of systems to enroll and care for children with serious illnesses. In addition, the role of severity adjustment in ensuring that quality measures provide appropriate incentives should be addressed. The work group discussed these issues:

- The need to identify the major types of financial and other incentives that influence care delivery for children;
- How these incentives intentionally and unintentionally create barriers to the delivery of high-quality care; and
- The gaps in our current understanding of the use of incentives to enhance quality and cost-effectiveness.

Research Questions

1. How do financial and other incentives affect the quality of care delivered by health professionals?
2. How do separate funding streams for healthcare and other child services affect the ability of health plans to provide high-quality care?
3. How is quality of care affected by the scope of services for which providers are held responsible?
4. How can purchasers use payment mechanisms to encourage plans to enroll children who are expected to have high health costs and provide them with quality care?
5. How do purchaser decisions affect plan incentives to produce quality?

G. Developing and Disseminating Clinical Practice Guidelines and Other Information to Physicians, Families, and Consumers

Physicians, families, and consumers need a wide array of information on practice guidelines; treatment options, outcomes, risks and benefits; and best practices to help them reach appropriate healthcare decisions. Making this information broadly available to different audiences is critical for stimulating continuous improvement and assuring quality care.

The work group focused on the challenges in creating guidelines for pediatric conditions, strategies for developing these guidelines, and methods for providing guideline information to physicians, families, and consumers directly. The work group also discussed these issues:

- Selection of pediatric conditions for guideline development;
- Challenges for guideline development in a managed care environment;
- Various uses for guidelines, including quality measurement and improvement; and
- Transmission of guideline information to different users, including physicians, families, and consumers.

Research Questions

1. What and how much information do physicians, families, and consumers need to make decisions about healthcare?
2. How do the characteristics of guidelines or other information affect their use and impact?
3. How can patient preferences be integrated into guidelines and other quality-centered information products?
4. Does targeting parents with information result in increased empowerment, higher satisfaction with care, and better outcomes of care for children?
5. How can we match the information needs of different users with appropriate dissemination mechanisms to ensure the most effective use?
6. What effect does dissemination of information about quality have on decisions made by key stakeholders?

IMPLEMENTING THE RESEARCH AGENDA

Several specific actions will be necessary to establish an infrastructure to support development of the quality measurement and improvement techniques that are part of the research agenda. These include:

Expanding the Child Health Services Research Workforce. The country needs a workforce capable of developing and implementing systems to measure quality for children, of interpreting the findings, and of using the results to improve care. This workforce can include both established researchers who retool for pediatric health services work as well as new researchers who are choosing an area in which to focus their work. Federally supported training programs at the doctoral, postdoctoral, and junior faculty levels are proved mechanisms for developing the person-power necessary to conduct research

on topics of national scientific significance. Such approaches have been used successfully by the National Institutes of Health, the National Science Foundation, and other federal agencies. At present, no federal agencies have child health services research training initiatives. Training new researchers is an investment in human capital that constitutes a long-term investment in improving children's health.

Developing Child Health Care Quality Improvement Research Centers. Health services is an interdisciplinary field in which clinicians, social and behavioral psychologists, sociologists, psychometricians, statisticians, economists, and others work together. In addition, many of the identified research questions and areas of focus demand sustained and complementary efforts by researchers. Therefore, the development of research centers is another important strategy to assure that a critical mass of individuals can work together to produce the greatest gains in knowledge. Again, NIH has used this strategy quite effectively to support advances in biomedical research. With investment by federal and state governments and private institutions, Child Health Care Quality Improvement Research Centers can become major contributors to research on children's health. The recent funding of ten Child Environmental Health Research Centers by the Environmental Protection Agency demonstrates recognition of the importance of concentrating expertise in such centers. There are several ongoing mechanisms in federal agencies to support such centers. These centers could be modeled after the National Institute for Child Health and Human Development-supported clinical research centers and could be operated by the AHCPR and/or the Maternal and Child Health Bureau.

Conducting Research in Specific High-Priority Areas. Dedicated funding is necessary to support the specific research projects outlined in the agenda. While funding for these high-priority areas could be allocated through existing grant-making programs in HRSA, AHCPR, and CDC, new grant programs based on the priority areas outlined earlier could also be used. Specific RFAs/RFPs, small start-up grants, and demonstration grants would be targeted to each of the areas designated. The effectiveness of such a targeted research effort would also benefit from coordination among the federal funding agencies involved. Greater oversight and coordination through the office of the Secretary of Health and Human Services could accomplish this.

Focusing Research on Improving the Health of Vulnerable Populations. Several sections of the agenda call for particular efforts to address the needs of groups of children who are especially vulnerable. These efforts include developing measures of the health status and quality of life for special populations,

and developing risk-assessment and risk-adjustment mechanisms that can be used for payment and quality measurement. Such groups include, for example, children with chronic conditions, children with severe emotional disturbances, and children in foster care. Research on improving the health of particularly vulnerable children should be encouraged.

Because many populations of vulnerable children currently receive services from multiple systems of care in addition to the standard healthcare sector, quality improvement will depend in part on improving communication and coordination across systems. For example, over half a million children are in foster care in the United States, and they have very high rates of chronic medical, mental health, and developmental problems. These children receive government-sponsored health services through the medical system, the mental health system, and the child welfare system (Halfon and Hochstein 1997). We need to determine how to make the current fragmented approach more organized, efficient, and rational. Similar considerations are important for children with chronic and disabling medical conditions, those with chronic severe emotional problems, and those who are homeless. The delivery of health services to each of these populations requires consideration of the particular risks that each of these populations face, the special circumstances under which their healthcare is delivered, and the multiple private and public agencies that are responsible for their well-being.

Improving Child Health Data and Developing Better Data Collection Systems. At present, the federal government collects considerable health information on the U.S. population through the National Center for Health Statistics and other federal agencies. Although important attempts have been made to monitor children's health through episodic supplemental surveys like the 1981 and 1988 National Health Interview Survey Supplement on Children's Health, more can be done to improve data systems to assess key determinants of children's health and health outcomes in a regular and consistent fashion. Improving our national data collection systems so that they are able to collect better data on the determinants of children's health could have an enormous bearing on our understanding of the prevalence, patterns, and trends in child health. This understanding is crucial for more efficient targeting of healthcare strategies at a population level. National data have already been used to show that there has been an increase in the number of children with asthma and in the severity of their disease. Better understanding about variations in prevalence and severity by community and region would allow better targeting of services. This sort of information would be useful for other conditions as well (Newacheck and Halfon in press).

Updating and improving our data collection and analysis procedures to focus on children's health could be accomplished by conducting periodic supplements (every two years) to the National Health Interview Survey (NHIS) and the Medical Expenditure Panel Survey (MEPS) in order to permit statistically valid estimates of healthcare expenditures for children, including policy-relevant groups such as uninsured children, poor and near-poor children, and children with special healthcare needs. The NHIS could also be used to conduct a longitudinal panel study of children to track health conditions, disabilities, and impairments as well as access, utilization, and expenditures over an extended period, such as five years. Such longitudinal data are crucial for measuring the effect of health system change on children's health and use of services. Augmenting the NHIS and MEPS would require a relatively modest increase in costs on top of the ongoing budget allocations for the existing core surveys.

Finally, because of major recent federal policy changes, including the enactment of the State Child Health Insurance Plan (SCHIP), it would be very useful to develop a 50-state survey to provide a national profile of standardized state-level data to monitor changes in the organization, finance, and delivery of healthcare to children. This would provide policymakers and researchers with essential information to analyze the impact of SCHIP and the different ways in which it will be implemented at the state level.

Developing Better Community Health Monitoring. Community Child Health Report Cards are increasingly being used to monitor both children's health at the local level and the capacity of local communities to meet children's health needs. These efforts are being developed as part of community-wide health improvement initiatives like those that have been created in cities like Los Angeles, Minneapolis, Rochester, NY, and Seattle (Los Angeles County Children's Planning Council 1996; Seattle-King County Department of Public Health 1992; Weitzman and Doniger 1994). These measurement efforts are often linked to local efforts to develop immunization and other health registries. Ultimately, it would be useful to have communities throughout a region or a state, or across the country, use a core set of indicators, to facilitate benchmarking and so that comparisons can be made.

Coordination of these efforts nationally is important so that each community that decides to monitor the health of its children does not have to invent a whole new process. Therefore, the development of software and standard data collection procedures for local communities to create community-wide child health report cards would make it easier for them to initiate such data collection efforts and to facilitate comparisons across communities.

At present, there is no funding mechanism or support for communities to improve their capacity for data collection, analysis, and presentation or to use these data to improve child health in the community. The Public Health Practice Program Office (PHPPPO) of the Centers for Disease Control and Prevention has supported some small initial efforts to develop this capacity. The MCH Bureau has also supported community efforts to integrate systems of care and to monitor their impact. Additional funds are necessary to support the development of both software and local technical capacity to allow communities to carry out these important functions, and to coordinate these efforts and share information at the national level.

Building and Supporting Research Networks and a Consortium of Research Users. Provider-based research networks are needed to address the full continuum of child healthcare quality and outcomes research, to link this research to practice improvement, and to speed the dissemination of research to practice settings. Research networks can link the expertise that exists at different institutions. Networks can provide a large enough number of patients with uncommon conditions for research studies, and they can provide multiple settings in which to compare different clinical strategies.

Research agenda questions such as those that focus on improving the measurement of health and risk states in practice settings, or that are concerned with the provision of different service packages by different providers and services locations, are particularly well suited for this approach. Research focused on the development, testing, and implementation of quality measures, and research focused on the comparison of different quality improvement strategies, would also benefit from this approach. The work of the privately supported HMO Quality of Care Consortium has demonstrated that this is an effective strategy for conducting research, especially in a real-world setting (Siu et al. 1992). Research networks (office-based, hospital, health plan) can also serve as learning laboratories where shared learning about the rapid implementation of new procedures, measures, and innovations can take place. An example of such a network is the Pediatric Research in Office Settings (PROS) (Wasserman 1997).

Because many research questions regarding the quality and outcomes of care require the participation of children with specific conditions across institutions and communities, it is important to develop research consortia that can facilitate this process. For example, many hospitals and treatment centers would be needed to include enough children to measure changes in quality in a statistically valid manner, to conduct studies on improving the quality of care for children with end-stage kidney disease, or to determine whether a

new outpatient asthma treatment protocol would be effective in a real-world setting. A network of geographically and organizationally diverse practices would be particularly advantageous to address many of the questions that were developed as part of this agenda-setting process. Networks that cover hospital-based care and ambulatory care are both needed. A considerable investment of time is required to establish such networks and to make them function effectively. Once networks are established, there will be multiple opportunities for ongoing research and for the implementation of findings. Ambulatory (primary care) research networks provide the opportunity both to address important questions that can result in fewer hospitalizations for common conditions like asthma, and to develop more effective preventive interventions. Other research agenda questions focused on evaluating the effectiveness of care—such as considering the best interventions to reduce risky behaviors in adolescents, to measure the influence of parental behavior on children's health, or to understand the impact of early identification of mental health and developmental problems—would all be answered best through some type of consortium approach.

THE RESPONSIBILITY FOR MOVING THIS AGENDA FORWARD

Although nearly 30–35 percent of all children in the United States are expected to receive health services through publicly financed health insurance programs by the year 2000, the majority of children will continue to receive their care through private, employer-based insurance coverage. Thus, the responsibility for the delivery of services to children is shared by both public and private institutions. In order to improve the quality of care provided to children and, hence, the value of services paid for by both public and private payers, the private sector must share the responsibility for moving this agenda forward. While the federal government can support training activities, research centers, and specific project grants, private industry (including healthcare plans and hospitals) can play a substantial role in helping to develop the networks necessary to support and conduct such research activities.

Much of what the proposed research agenda calls for is, in fact, basic child health services research, but the agenda also includes items that are more applied and are likely to enhance the value of the care delivered. For this reason, in forging this new agenda it will be important to involve both the private and public sectors and to maximize new and fruitful collaborations.

ORGANIZATION

In developing a set of new programs and funding initiatives, some attempt must be made to coordinate efforts within DHHS at the Secretary's level so that programs work effectively together. To maximize coordination efforts, an interagency coordination committee should be set up with AHCPR and MCHB playing the lead roles. This coordinating committee would also include the CDC, HCFA, NIH, NIMH, the National Center for Health Statistics, and the Administration for Children and Families. An external advisory committee should include representatives of consumers, payers, providers, health plans, and insurers. These two committees should work closely together. We believe the Secretary should also assign oversight of this process to the Assistant Secretary for Health. In keeping with the Government Efficiency and Performance Act, the Secretary should be required to report to Congress on the progress made in the development of evidence-based measures of children's healthcare and the type and extent of ongoing need in this area.

States may also have an interest in the agenda. With the passage of Title XXI, states will be contracting through Medicaid or private healthcare providers for a package of services for newly enrolled children. These contracts represent important new opportunities to include appropriate quality measurement and accountability requirements. This agenda would also benefit from partnerships between the federal and state governments, foundations, and the private sector.

CONCLUSIONS

We believe that the proposed research agenda should be a national priority so that all Americans can be assured that children are receiving the best quality of care that the United States can provide. We also believe that the strategy that we have presented to carry out this agenda represents a sound investment that will have a great pay-off in both the knowledge that is generated and the tools that can be applied to solve very important problems.

Given that both the public and Congress are interested in improving the quality of healthcare, the time is right to make a difference in children's healthcare delivery systems. We need to improve our ability to determine the most effective interventions for children and our ability to assure that the healthcare system is providing quality care for children in various settings. While children's health and quality of care concerns have not commanded

much attention from private payers and insurers, federal and state governments are increasingly becoming the majority payers for children's health services. This creates prevailing public interest in guaranteeing that these public dollars are well spent on services that truly make a difference in a child's health and well-being. Moreover, if the government wishes to minimize its regulatory role, better information about the quality of healthcare is needed by consumers and payers to inform their choices in the marketplace. The government also has an interest in making sure that children's health problems are caught early and cared for effectively because a growing body of evidence suggests the persistence of child health problems into adult life.

By addressing this agenda and implementing the strategies put forth in this article, we can make an investment in the future of our healthcare system. By helping our healthcare system to perform in a more equitable, effective, and efficient manner, we will go a long way toward assuring that children have the opportunity to receive the care that will improve and maintain their health. In both the short and long run, this agenda, and the resources required to carry it out, represent an investment in our future.

REFERENCES

- Bauchner, H., and L. Simpson. 1998. "Developing and Disseminating Practice Guidelines and Other Information to Physicians, Consumers, and Families." *Health Services Research* 33 (4, Part II): 1161-78.
- Bergman, D. A. 1995. "Thriving in the 21st Century: Outcome Assessment, Practice Parameters, and Accountability." *Pediatrics* 96 (Supplement): 831-35.
- DuPlessis, H., M. Inkelas, and N. Halfon. "Assessing the Performance of Community Systems for Children." *Health Services Research* 33 (4, Part II): 1111-1142.
- Etheredge, L., S. B. Jones, and L. Lewin. 1996. "What Is Driving Health System Change?" *Health Affairs* 15 (4): 93-104.
- Finkelstein, J. A., R. W. Brown, L. C. Schneider, S. T. Weiss, J. M. Quintana, D. A. Goldmann, and C. J. Homer. 1995. "Quality of Care for Preschool Children with Asthma: The Role of Social Factors and Practice Settings." *Pediatrics* 95 (3): 389-94.
- Forrest, C. B., L. Simpson, and C. Clancy. 1997. "Child Health Services Research, Challenges and Opportunities." *Journal of the American Medical Association* 277 (22): 1787-93.
- Glied, S. 1998. "Getting the Incentives Right for Children." *Health Services Research* 33 (4, Part II): 1143-60.
- Halfon, N., and M. Hochstein. 1997. "Developing a System of Care for All: How the Needs of Vulnerable Children Inform the Debate." In *Health Care for Children: What's Right, What's Wrong, What's Next*, edited by R. Stein, pp. 303-38. New York: United Hospital Fund.

- Halfon, N., M. Inkelas, and D. Wood. 1995. "Nonfinancial Barriers to Care for Children and Youth." *Annual Review of Public Health* 16: 447-72.
- Halfon, N., M. Inkelas, D. L. Wood, and M. A. Schuster. 1996. "Health Care Reform for Children and Families: Refinancing and Restructuring the U.S. Child Health System." In *Changing the U.S. Health Care System: Key Issues in Health Services, Policy, and Management*, edited by R. M. Anderson, T. H. Rice, and G. F. Kominski, pp. 227-54. San Francisco: Jossey-Bass Publishers.
- Homer, C., D. Goldman, and L. Kleinman. 1998. "Improving the Quality of Healthcare in Health Systems." *Health Services Research* 33 (4, Part II): 1091-1110.
- Homer, C. J., P. Szilagyi, L. Rodewald, S. R. Bloom, P. Greenspan, S. Yazdgerd, J. M. Leventhal, D. Finkelstein, and J. M. Perrin. 1996. "Does Quality of Care Affect Rates of Hospitalization for Childhood Asthma?" *Pediatrics* 98 (1): 18-23.
- Jameson, E., and E. Wehr. 1993. "Drafting National Health Care Reform Legislation to Protect the Health Interests of Children." *Stanford Law and Policy Review* 5: 152-74.
- The Kaiser Commission on the Future of Medicaid. 1997. *Medicaid Facts*. Washington, DC: The Henry J. Kaiser Foundation.
- Lewit, E. M., and A. C. Monheit. 1992. "Expenditures on Health Care for Children and Pregnant Women." *The Future of Children* 2 (2): 95-114.
- Lieu, T. 1998. "Effectiveness of Health Services for Children." *Health Services Research* 33 (4, Part II): 1041-58.
- Lohr, K. N. 1990. *Medicare: A Strategy for Quality Assurance*, Vol. I. Washington, DC: National Academy Press.
- Los Angeles County Children's Planning Council 1996. *Profiles of Los Angeles County*. Los Angeles: Children's Planning Council.
- Mangione-Smith, R., and E. A. McGlynn. 1998. "Assessing the Quality of Healthcare Provided for Children." *Health Services Research* 33 (4, Part II): 1059-90.
- McCormick, M. C. 1997. "Quality of Care: An Overdue Agenda." *Pediatrics* 99 (2): 249-50.
- McGlynn, E. A. 1997. "Six Challenges in Measuring the Quality of Health Care." *Health Affairs* 16 (3): 7-21.
- McGlynn, E. A., and N. Halfon. 1998. "Improving Quality of Care for Children: Overview of Issues for a Research Agenda." *Health Services Research* 33 (4, Part II): 977-1000.
- McGlynn, E. A., N. Halfon, and A. Leibowitz. "Assessing the Quality of Care for Children: Prospects Under Health Reform." *Archives of Pediatrics and Adolescent Medicine* 149 (4): 359-68.
- National Committee for Quality Assurance. 1997. *HEDIS 3.0 Narrative: What's in It and Why It Matters*. Washington, DC: NCQA.
- Newacheck, P. W., and N. Halfon. 1998. "Prevalence and Impact of Disabling Chronic Conditions in Childhood." *American Journal of Public Health* 88 (4): 610-17.
- Payne, S. M. C., C. Donahue, P. Rappo, J. J. McNamara, J. Bass, L. First, J. Kulig, S. Palfrey, B. Siegel, and C. Homer. 1995. "Variations in Pediatric Pneumonia and Bronchitis/Asthma Admission Rates: Is Appropriateness a Factor?" *Archives of Pediatrics and Adolescent Medicine* 149 (2): 162-69.

- Schuster, M. A., S. M. Asch, E. A. McGlynn, E. A. Kerr, A. M. Hardy, and D. S. Gifford. 1997. "Development of a Quality of Care Measurement System for Children and Adolescents: Methodological Considerations and Comparisons with a System for Adult Women." *Archives of Pediatrics and Adolescent Medicine* 151 (11): 1080-81.
- Seattle-King County Department of Public Health. 1992. *The Health of King County's Children 1990*. Seattle, WA: Robert Wood Johnson Foundation.
- Siu, A. L., E. A. McGlynn, H. Morgenstern, M. H. Beers, D. M. Carlisle, E. B. Keeler, J. Beloff, K. Curtin, J. Learning, B. C. Perry, H. P. Selker, W. Weiswasser, A. Wiesenthal, and R. H. Brook. 1992. "Choosing Quality of Care Measures Based on the Expected Impact of Improved Care on Health." *Health Services Research* 27 (5): 619-50.
- Starfield, B., N. R. Powe, J. R. Weiner, M. Stuart, D. Steinwachs, S. H. Scholle, and A. Gerstenberger. 1994. "Costs vs. Quality in Different Types of Primary Care Settings." *Journal of the American Medical Association* 272 (24): 1903-908.
- Szilagy, P., and E. Schor. 1998. "The Health of Children." *Health Services Research* 33 (4, Part II): 1001-1040.
- Wasserman, R. C. 1997. "Research in Private Practice and the Challenge of Network Research." *Current Opinion in Pediatrics* 9 (5): 483-86.
- Weitzman, M., and A. Doniger. 1994. *Pathways to a Coordinated System of Health Care and Human Services for Children and Families in Rochester, New York*. Rochester, NY: Monroe County Health Department.
- Zenni, E. A., and T. N. Robinson. 1996. "Effects of Structured Encounter Forms in Pediatric House Staff Knowledge, Parent Satisfaction, and Quality of Care." *Archives of Pediatrics and Adolescent Medicine* 150 (9): 975-80.