

A New Pediatrics for a New Century

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ABBREVIATIONS

ACA—Affordable Care Act

CHIP—Children's Health Insurance Program

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abstract

Is the field of pediatrics doing all that it can for the health of children? Many think that the field has gone off track and that we could do better. These articles highlight some different ways of judging the successes and failures of pediatrics in the United States today. The choices that we face are stark. To change the system, we would need to recalibrate the balance between utilitarian approaches to resource allocation, such as might be dictated by cost-effectiveness analyses, and deontologic approaches that prioritize unbreakable commitments or promises to individuals. These changes would entail large-scale social engineering projects to reshape our health care system, our educational system, and our public health system. A failure to change, however, might perpetuate a system that is not doing all it can for the health of America's children and the society they will form. *Pediatrics* 2013;131:S121–S126

Is the field of pediatrics doing all that it can for the health of children? Or is the field drifting off track? Many people think that pediatrics today is caught up in models of disease and of care delivery that are outdated, inefficient, and more applicable to the diseases of the past than those of the future. That is, they think that we not only are failing to meet the needs of children but that these failures are deeply rooted in our ideas of what pediatrics ought to be and do and in the structures of the child health care system built upon those ideas. Others are more sanguine. They see the recent history of pediatrics as a great success story that is likely to continue.

There are clearly many narratives about pediatrics that suggest that we are at a crossroads. One way to tell the story of pediatrics in the 20th century is to present it as the quintessential preventive specialty. We pioneered immunizations, well-child screenings, folic acid supplementation to prevent neural tube defects, car seats to prevent motor vehicle injuries, and fluoridation of drinking water. And we have succeeded. Vaccines have nearly eliminated many infectious diseases.^{1,2} Simple public health interventions such as folic acid supplementation and changes in infant sleeping positions have led to dramatic decreases in neural tube defects³ and sudden infant death.⁴ Children today are less likely to be killed or injured in motor vehicle accidents than were children 20 years ago.⁵ Fewer children are hospitalized today than ever, and those hospitalizations are shorter.⁶ More children survive to adulthood than ever.⁷

The counter narrative to this success story is that we've developed a model of care that is ill-suited to address the new morbidities of childhood. More children are obese than ever, with consequent problems of diabetes, hypertension, and heart disease.⁸ Rates

of depression, autism, and learning problems have stayed stubbornly high for decades.⁹ Health disparities between poor and rich children are widening, not narrowing.¹⁰

Another heroic story that is told about pediatrics focuses on technology. Pediatrics has been a pioneer in the development of some of the most beneficial and cost-effective technologies in medicine today. Neonatal intensive care, newborn screening for metabolic disease, and new treatments for cancer, cystic fibrosis, and congenital heart disease have transformed diseases that were universally fatal a few decades ago into diseases that today we routinely treat successfully.

Here, too, there is a counter narrative. Are we doing too much, saving children who will be left permanently impaired, whose care will cost millions of dollars, and whose families will be destroyed by the challenge of keeping them alive? Shouldn't we be developing better palliative care programs and better ethical standards to decide which infants should be allowed to die peacefully?

One story of pediatrics is that we were on the right side (that is, the left) of politics. In the 1920s, pediatricians (but not the American Medical Association) were strong supporters of the Sheppard-Towner Act, which allocated federal funding to create 3000 child and maternal health centers across the United States. Pediatricians supported President Clinton's Health Security Act in the early 1990s and President Obama's Affordable Care Act (ACA) in 2010.

But there is a counter narrative here, too. For decades, leaders in pediatrics have been urging fundamental change in the way we think about the future of the field and design systems to care for children. Paul Wise noted that, "A growing mismatch has emerged between our current system of child health care and current threats to

children's health." As a result of the success of immunizations and antibiotics, acute illness is no longer the most serious problem facing American children. Instead, most are either healthy or else they suffer from chronic illnesses, and according to Wise, "current pediatric systems have become increasingly incapable of addressing chronic illness in childhood."¹¹

These narratives and counter narratives suggest the need for a critical reappraisal. Clearly, the world of health care delivery in the United States is changing. Providers, administrators, and policy makers must ask if we are spending our money wisely. Even if we were able to agree upon a set of metrics in reference to which we might even ask these questions, deriving an approximate figure for what the United States spends on child health care annually is difficult, in itself.

From the Bureau of the Census, we learn that our overall spending on health and health research in 2009 was ~\$2.4 trillion,¹² which places per capita expenditures for all Americans in 2009 at ~\$7600. Census Bureau figures do not break out a separate figure for children. But we can make estimates.

Each year, ~4 million children are born in the United States. Other children immigrate to the United States. So, we can estimate that there are ~80 million Americans under the age of 18 years. According to the Department of Health and Human Services, ~42 million children are covered by Medicaid and the Children's Health Insurance Program (CHIP).¹³ Per capita expenditures for children in CHIP are ~\$772 per year. We assume that expenditures on children with private insurance are higher than for children receiving public insurance, but we don't know exactly how much higher. The Kaiser Family Foundation estimates that, for all children under 5 years, average health spending is ~\$2500 per year and for older children,

those 5 to 17 years of age, it is ~\$1700 per year.¹⁴ For a general estimate, we could pick a number between the CHIP number of \$772 and the Kaiser number of \$2500. If the average annual expenditure on health for children in the United States is \$1500, then overall child health expenditures are about \$120 billion per year, or about 4–5% of overall national health expenditures (going to 24% of the population).

As tenuous a hold as that figure has on any statistical basis, tracking exactly how those funds are dedicated is even more challenging. We have no single system for tracking health expenditures for children or for deciding what our priorities should be. What we do have is thousands of health insurance companies and hundreds of children's hospitals incurring costs and generating invoices, as well as the National Institutes of Health and drug companies sponsoring research and drawing on still different funding systems.

Halfon et al¹⁵ recently described the federal system of support for child health as a “cat’s cradle of federal funding streams.” They highlighted Title IV (Child Welfare); Title V (Maternal and Child Health); Title XIX (Medicaid); Title XXI (the State Children’s Health Insurance Program, or SCHIP); Head Start; the Women, Infants, and Children program; and funds from No Child Left Behind, the Individuals with Disabilities Education Act, and other programs in the Department of Education. Even within the Department of Health and Human Services, there are many agencies that fund maternal and child health. The acronyms alone suggest the complexity of the funding models: AHRQ (Agency for Healthcare Research and Quality), CMS (Centers for Medicare and Medicaid Services), CDC (Centers for Disease Control and Prevention), FDA (Food and Drug Administration), HRSA (Health Resources and Services Administration), IHS (Indian

Health Service), NIH (National Institutes of Health), SAMHSA (Substance Abuse and Mental Health Services Administration), and OPHS (Office of the Public Health Service). Some funding also comes from the Departments of Defense, Education, Agriculture, and Housing and Urban Development and the Environmental Protection Agency. (As an example, the US military runs 65 hospitals in the United States and provides health care to nearly 2 million children.)

In 2010, an American Academy of Pediatrics task force looked to the future and predicted which “megatrends” would shape the field.¹⁶ The task force identified 8 such megatrends and imagined best-case and worst-case scenarios for what would happen if the field of pediatrics were to get ahead of those trends and shape them or to fall behind them and fail to change in response to them. For example, one of the megatrends is that the demographic and clinical characteristics of children and families are changing. The best-case scenario is that “rapid expansion and adoption of medical home models lead to lower costs, more providers, and improved outcomes. Physicians, nurses, and allied health professionals work together seamlessly to provide high-quality cost-effective care.” The worst-case scenario is that “children with chronic conditions and mental health needs lack coordinated, accessible care.” Other megatrends include burgeoning health information technology, alterations in health care delivery systems, growth of consumer-driven health care, and the changing dynamics of the pediatric workforce.

How can we find some order in this tangled mess? And what neglected areas of pediatrics ought to receive more attention and more funding in the future? With these considerations in mind, we are pleased to publish the first in a

series of special supplements to *Pediatrics* that will focus on bioethical issues in child health and health care. Our first supplement addresses questions about the overall goal and design of the child health care system in the United States. Is pediatrics working the way it should? Are we investing our child health dollars most efficiently?¹⁷ If not, then what should the field be doing that it is not doing now to take better care of children in the United States? We asked leading economists, social scientists, pediatricians, and policy makers to reflect on these questions.

Conti and Heckman summarize a growing body of research on the ways that various interventions, or “investments,” in a child’s developmental environment can produce large benefits for the child, the adult that child will become, and the society in which he or she lives. They note that the opposite is true as well: childhood and even prenatal privations have measurable, deleterious impacts.

On the basis of these important research findings, they propose that child health expenditures should be guided by a “life cycle framework.” This framework helps select optimal points for introducing those “investments.” More and better research will allow even better selection of such investment points. It will allow researchers to demonstrate accumulating or concatenating effects of such investments as the child grows.

The authors review long-term outcomes from projects that invested in early education, health care, and social services for disadvantaged children in Michigan and North Carolina. They observe that the subjects not only benefited, as one would expect, but that the benefits may be measured and even indexed statistically against selected success criteria, which augurs well for an economic model of the effects of their developmental approach’s investments.

They recommend that pediatric services in the United States be conceptualized as a way of designing these interventions, in the whole childhood environment. They emphasize that the payoff is greatest when the investments are made earliest. Starting before birth is best! They caution that without a broad-based policy supporting such investments, the current divide between rich and poor is likely to widen, because wealthy families presently have greater access not only to conventional pediatric care but to interventions that promote cognition and socialization in ways that developmentally prepare their children for success.

Coker, Thomas, and Chung's article takes a similar approach. They review the proposition that failure to intervene effectively in childhood health care is an immense driver of the costs, to say nothing of suffering and other quality-of-life indices, of adult morbidity, early death, and, it might be added, associated socioeconomic outcomes. Pediatrics thus need not be ethically driven merely by a duty to promote the welfare of a vulnerable and conventionally protected population (children) but by its potential influence on outcomes in the general population, which may not be apparent in specific terms until decades in the future.

For these authors, poverty is not just poverty and educational failure is not just a predictor of future socioeconomic status. Instead, both are strong predictors of future health problems that will impose huge and, perhaps, quantifiable costs on society. Our currently constrained concept of "well-child care" and the small investment we make in it deprive us (or "society") of demonstrable realizations of value we might reap down the road from a larger investment now. Conventional vaccinations and disease-screening are the easy part, and not nearly

enough. Although reiterating that the costs to society of adult chronic illness are much greater than the foreseeable costs of implementing the reforms in child care delivery they propose, the authors acknowledge that this value-relationship, with the "lengthy time horizons involved," does not readily fit conventional budgeting models, to say nothing of demand-based economics, although they propose that "some type of integration with adult care payment systems might be necessary."

The authors propose several possible models for reforming the well-child care system. Some are speculative whereas others are partially validated by pilot programs in the United States or national programs in other countries. Each proposal presumes both a broader and a more penetrating reach into the universe of families' life options. For example, they suggest that pediatricians should be concerned with how families eat and educate their children, and even how the parents seek employment.

Goldstein and Rosenbaum examine the pediatric care provisions of the ACA, insofar as regulatory decisions to date reveal them, with a look back at the history of federally subsidized health care programs. They highlight how, over the years, the political philosophy behind federally subsidized health care programs for children has changed.

Medicaid's 1967 "Early and Periodic Screening, Diagnosis, and Treatment" program defined a specific package of services to be provided. The program was expanded in 1989. The authors view the Children's Health Insurance Program of 1997 as a qualitative shift backward in that it "emphasized alignment with the commercial insurance market and its coverage norms," and moved away from the earlier norms that were developed by expert physicians who determined

which specific services were best for children.

They point out, with misgivings, that the ACA's approach, essentially an insurance subsidy within a framework that stipulates a baseline (or "decent minimum") of "essential health benefits," follows the norms of CHIP more closely than it does those of the Early and Periodic Screening, Diagnosis, and Treatment program. In addition, they fear that the implementation of the ACA may allow politically influential interests to manipulate coverage priorities at the state level.

One theme runs through many of these articles. The problems facing children today are unlikely to be solved within the context of traditional, office-based, or hospital-based clinical practice. Child health care needs to get out of the pediatrician's office and to be integrated into a larger system of social and psychological support for children and families. Such a system would offer early childhood intervention, school-based services, and complex behavioral interventions. The efficacy of such systems of care needs to be studied by using large data sets that analyze not just medical factors but also environmental and social factors.

These authors raise a fundamental underlying question: how should we evaluate any changes in the organization of child health care? With that question in mind, Janet Currie proposes changing the way we use new capabilities in data analysis to analyze features of society or of our health care system that have subtle but pervasive effects on the health of children. Such analyses will only be possible, she argues, if we modify the rules governing epidemiologic research. She acknowledges possible conflicts with prevailing "privacy" protocols.

Finally, O'Donnell and Nichols examine the current system of health care from the perspective of children's hospital

administrators. Children's hospitals are a linchpin of child health care. They provide individually expensive interventions to critically ill children. They provide care for the smaller and smaller proportion of the overall population of children who need tertiary or quaternary inpatient care. Children's hospitals must change, too. O'Donnell and Nichols suggest some changes likely to be necessary as chronic disease replaces acute illness as the most common cause of hospitalization for children.

Taken together, these articles propose possible future directions while highlighting some of the obstacles and challenges that stand in the way of moving in those directions. The \$120 billion per year child health care system is complicated. Redesigning it would be a vast social engineering project, especially if that redesign required complementary changes in the educational system and even in the ways that families would be asked to behave. One of the central questions inherent in child health policy is implied rather than articulated in these articles:

assuming that the utilitarian benefits of the reforms can be achieved, what is the unacknowledged cost in challenging traditional societal arrangements? Will it deepen an existing culture of dependency in which the government and the pediatrics profession assume a larger and larger role in telling parents and teachers how children ought to be raised? Or are the problems so serious and the potential benefit so large and obvious that some erosion in today's consensus about professional and family autonomy is worth risking? It seems reasonable to define children's health as the extent to which individual children or groups of children are able or enabled to (1) develop and realize their potential, (2) satisfy their needs, and (3) develop the capacities to allow them to interact successfully with their biological, physical, and social environments.¹⁸

Although we believe that definition will not be disputed, proposals to reshape pediatrics raise ethical questions. First, they raise questions about justice and

resource allocation. We allocate resources in ways that are neither straightforwardly utilitarian nor straightforwardly egalitarian. We don't treat all children equally or all lives as of equal value. Generally, we seek a balance between a utilitarian approach to resource allocation, such as might be dictated by cost-effectiveness analyses, and a deontologic approach that would be dictated by a strong sense of our unbreakable commitments and moral principles. And sometimes those principles dictate that we should do things that make no sense from a utilitarian perspective.

To propose a new system is to place the tension between utilitarian, deontologic, and egalitarian values in the spotlight. It is to invite a broad and complex conflict among those who adhere to differing but defensible ethical baselines. Our hope is that it is possible to facilitate a dialog that might recognize, respect, and possibly even reconcile these conflicts in ways that lead to practical solutions that enable us to do better by our children.

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