Carolyn S. Gleason
A Parent’s Perspective
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Many parents of children with special health care needs, myself included, have not embraced managed care as the best system of care for our children. For populations with special needs, managed care is new and unproven, and seems terribly risky when the stakes are so high. When our children’s health system fails, it wreaks havoc on our entire family structures and our daily lives. However, we know that managed care is here to stay, and that its principles offer opportunities for improving our children’s health care. We want and need to become partners with the other stakeholders who are developing managed care systems for children with special health care needs. Our goal is to take the best of the old fee-for-service system, combine it with the opportunities that managed care has to offer, and ensure that our children’s needs are met in the most effective way possible within the realities of today’s cost limitations. We realize what a daunting task this is, but developing managed care systems for children with special needs is at a critical stage, and how we proceed may determine the future for our most vulnerable children.

My perspective is based on my personal experiences with my medically fragile son, Aaron. I have seen the best and the worst of both the old fee-for-service system and managed care, in a capitated, staff-model health maintenance organization (HMO) that relies on in-plan providers to care for children with special needs. This journey left me with many unanswered concerns about managed care, and a determination to help find solutions. For years I have explored issues concerning children with special needs in managed care with other parents, with stakeholders, including providers, administrators, and health policy researchers; and with colleagues in Medicaid and public health. These issues include (1) the economic disincentives managed care organizations (MCOs) have to enroll children with special needs and to provide interdisciplinary team evaluations and monitoring for this population; (2) adequate training and expertise of primary care providers; (3) referral processes and access to appropriate specialty care; and (4) processes to promote good outcomes for children with special needs. While Aaron’s story is unique, it serves to illustrate many concerns, opportunities, and lessons for those who wish to develop quality care for children with special needs enrolled in managed care plans.

Aaron was born with natural charm, a wacky sense of humor, a superb memory, and a gift of compassion that surpasses most adults’. He was also born with several disabilities, including spina bifida, severe epilepsy, hydrocephaly, and Arnold Chiari Malformation. Taking care of Aaron was complicated when he was “healthy.” We knew that even one day of simply letting up on his personal care could result in pressure sores, urinary tract infections, or even grand mal seizures. Usual childhood illnesses or major changes in routine such as a new wheelchair could bring on these problems no matter what we did. At the time, our family was covered through employment by a large HMO, but its policy was to refer children with relatively rare, complex disabilities to the children’s specialty care facility in our city. Thus, Aaron was followed from birth in a neurodevelopmental specialty clinic, with yearly checkups by an interdisciplinary team that included a nurse case manager, a pediatrician who specializes in neural tube defects, a pediatric rehabilitation specialist, a pediatric urologist, a pediatric orthopedic specialist, occupational and physical therapists, and a social worker. These checkups served to catch problems early and
keep us informed of what to expect as Aaron grew and developed. Although Aaron did not have a separate primary care physician, the clinic nurses assisted with routine issues such as immunizations and typical childhood illnesses. Because common illnesses, injuries, or even growth spurts always posed the threat of more serious problems such as urinary tract infections, seizures, or digestive disorder complications, we often had direct contact with our nurse case manager or the pediatric specialist when Aaron was ill. Although this system may not be perfect for all families, it worked very well for us.

When Aaron was 16, the administration of our HMO decided to discontinue the policy of referring children with rare and complex conditions to the pediatric specialty referral center. This was a cost-cutting measure on the part of the HMO, and to my knowledge was not based on any study or consultation with experts in the care of children with special needs. Aaron’s care was abruptly changed. The generalist who was the primary care provider for the rest of our family became responsible for Aaron’s primary care and any necessary referrals. He made it clear that he would address Aaron’s acute illnesses and any apparent medical symptoms. He was not interested in reviewing Aaron’s history, gaining knowledge about his underlying disabilities, or working with us on preventive measures. I was not at all comfortable with this change, but we had no feasible alternatives since my husband’s employer selected our health plan. Unfortunately, it was at this time that Aaron began developing subtle symptoms that gradually worsened. Neither we nor the managed care system were ready for the challenges ahead. We began five years of struggling to understand Aaron’s medical problems and make the health care system work for him. There were barriers, allies, victories, and defeats. Ultimately, everyone lost, and Aaron died in January 1995 at the age of 21.

Concerns and Opportunities for Managed Health Care

Based on these experiences, my first concern is the role of the family in a managed health care system. Prior to having Aaron’s care turned over to HMO providers, my husband and I had spent years finding and building trust in providers we knew had training and experience in Aaron’s conditions, and learning from these experts. Once Aaron’s care was turned over to providers within our HMO, we had to start over by learning how to navigate an entirely new system and selecting new providers from the HMO’s limited network. Very few of the HMO administrators or Aaron’s providers had experience serving children with his particular conditions. Because they were not included among the HMO’s list of providers, however, we no longer had access to a specialty team of experts knowledgeable in Aaron’s disabilities. It became our responsibility to make sure everyone understood his unique needs. We also had to ensure that those needs were met in a health plan that focused primarily on serving healthy populations in a cost-efficient manner. This is a weighty responsibility for parents to assume, and through this experience I have seen an opportunity for managed care plans to hire and use special care coordinators. Some health plans make these specialists available to assist families in learning and navigating an unfamiliar managed care system, and to help ensure that the system works for children with special needs. Although we did not have access to a special care coordinator in our HMO, I often found myself longing for assistance from someone like this who had expertise in both childhood disabilities and the managed care system—someone who could advise us on what we needed to do to get Aaron the care he needed, and someone to help us overcome the barriers and problems we encountered.

Another major opportunity for managed care lies in the coordination role of the primary care provider, who functions as a case manager to ensure that preventive interventions occur and that coordinated referrals for specialty care are made. With Aaron, however, I was most concerned about whether our primary care provider was well trained, experienced, and knowledgeable about his condition. The nurse case managers and pediatric specialists who previously managed Aaron’s care in the neurodevelopmental clinic had years of training in pediatrics and developmental disabilities, and they served only children with these conditions. I worried that his providers within the HMO would not be so experienced. I also was concerned about whether the primary care provider in the HMO faced pressure by the MCO to contain costs by limiting expensive specialty referrals and procedures, thus compromising my son’s care.

Examples from our experience illustrate some of these issues. Our first primary care provider in the HMO was excellent at the “normal” preventive procedures such as immunizations and routine childhood illness management. However, he did not understand Aaron’s complex conditions and the need to identify potential problems early and intervene promptly. Consequently, Aaron’s subtle symptoms of progressive weakness and loss of voice volume went undiagnosed for more than 18 months, a highly significant delay when dealing with a degenerative condition. In desperation, I took
Aaron to his previous pediatric specialist, who agreed to see him on his own time. He recognized the complications of Arnold Chiari Malformation immediately and contacted the HMO with advice that Aaron needed neurosurgery as soon as possible.

Coincidentally, it was during this time that our first primary care provider left the MCO. Our second primary care provider, who was assigned by the plan, also was not very experienced in Aaron’s conditions. However, she took the time to establish mutual trust and respect with Aaron and our family, and while she could not resolve all of our concerns about managed care, she became an ally with us in seeking solutions. She also was willing to spend the extra time necessary to research Aaron’s various conditions and complications, consult with specialists in the HMO’s network, and become partners with us and several other key providers to address Aaron’s problems. These key providers included a pediatric neurologist who had never operated on a child with spina bifida, as well as a plastic surgeon, a physical therapist, and a visiting nurse—none of whom was experienced in Aaron’s conditions. Although this made me uneasy, our family could not afford to pay for the out-of-plan specialists who previously cared for Aaron in the neurodevelopmental clinic.

Another opportunity for managed care is motivation and flexibility to create special ancillary or supportive services for children with complex needs. For managed care plans, offering these services—such as interdisciplinary care planning, access to a consulting nurse with expertise in childhood disabilities, and parent training in preventive home care—requires a commitment to appropriately train additional staff and to provide institutional supports such as supervision, continuing education, and adequate time for outside consultation. Our family benefitted from such services by being assigned a visiting nurse after Aaron’s neurosurgery. She came to our home regularly to teach us how best to care for Aaron and to monitor his recovery. When Aaron’s condition began to deteriorate, she also helped us obtain necessary diagnostic services with neurologists. Finally, once we found out about Aaron’s poor prognosis, this visiting nurse helped our family deal with the reality of his degenerative condition.

I am concerned that as pressures to contain costs within managed care become more intense, decision makers in health plans may not support adequate funding and/or appropriate allocation of these services to meet the unique needs of families with special needs children. Our family, for example, was assigned a visiting nurse only after Aaron’s condition was determined to be debilitating and he had undergone neurosurgery. If she had been involved from the time Aaron’s case was taken over by the HMO providers, it would have been far less stressful for our family, and I believe the care he received would have been better. Ironically, families often know about services for their children that can help prevent complications and illness—such as home care assistance, equipment and supplies to avoid infection, nutritional services, and occupational, physical, and speech therapy—but many of these services are not covered in managed care contracts.

Managed care plans have yet another opportunity to improve care for children with special needs by coordinating care with other systems that help keep this population healthy (such as special education, social services, and home providers). I know that families often are overwhelmed by the need to coordinate fragmented services across these systems. For example, our family often battled rigid school policies related to issues such as safe transportation, after-school care, special dietary needs, and bowel and bladder care. On occasion, our health care providers in the HMO wrote letters to school administrators explaining how Aaron’s unique needs related to his conditions. When it was available, this assistance was crucial in our negotiations with the educational system. I am concerned that decision makers within managed care plans often do not recognize the preventive value of supporting and encouraging providers to actively coordinate care across other systems that work with special needs children and their families.

Yet another opportunity for managed care lies in making available a network of providers that includes appropriate pediatric specialists, as well as a mechanism for out-of-plan referrals when warranted. Although most managed care contracts require this, many health plans still build in disincentives for referrals, particularly to out-of-plan specialists. This occurs when the primary care provider is at financial risk through capitation. Under capitation, the primary care provider may be responsible for the cost of a patient’s care beyond the predetermined level of reimbursement, or coverage for out-of-plan providers may be denied altogether. Consequently, referrals may be delayed at the onset of symptoms in a “wait and see” approach, or to ensure that the referrals will be deemed medically necessary under a utilization review. If the appropriate pediatric specialist is not available within the plan’s provider network, there may be pressure to use a specialist who primarily serves adults or a pediatric specialist without experience in the complex disabilities of a specific child. For our family, the “wait and see” approach adopted by Aaron’s first primary care provider was devastating. When Aaron’s life-threatening condition was finally recognized by the specialist I sought outside of our plan’s network, we were denied access to a pediatric neurosurgeon who was internationally recognized for expertise specific to Aaron’s problems. Instead, our HMO provided specialists who were not experienced in working with Aaron’s neurodevelopmental conditions. Only after tragic complications of surgeries left Aaron with a terminal condition were we referred to the specialist we had originally requested. He was to advise us whether heroic measures would be warranted. Unfortunately, it was too late to initiate any reasonable treatment. Over a period of three years,
Aaron’s body gradually lost the strength to fight even minor illnesses and infections, and one of these eventually caused his death.

The final opportunity for managed care that comes to mind is perhaps the most crucial to evolving managed care systems in this era of cost containment: reducing runaway costs and unnecessary care. Obviously, in the fee-for-service system, providers face incentives that encourage the overutilization of services and expensive procedures. Perhaps not well recognized, however, is the adverse impact of overtreatment and unnecessary services on families with special needs children. Our family became overwhelmed by many invasive and painful medical tests Aaron underwent; numerous office visits during our work hours; specialty care that was available only with extensive travel; hospitalizations that disrupted our lives and terrified Aaron; medical equipment that required our training and the training of others in our child’s life; and medications that caused frightful side effects such as mood swings, diarrhea, and an inability to eat. These were extremely difficult aspects of parenting a child with special needs. They cost our family enormous dollars, time, energy, and stress. My husband changed jobs at one point, to allow more free time during doctors’ office hours to take Aaron to his appointments. Stress associated with family disagreements over major medical decisions for Aaron, and our experiences with the HMO, eventually contributed to our divorce. Nonetheless, I recognize the precious nature of these health care resources when they are necessary to keep children like Aaron alive and as healthy and functional as possible. The key is to provide these services in a cost-efficient way that does not promote overutilization or unnecessary treatment. Parents of children with special needs can be the managed care system’s greatest advocates to achieve this goal.

I worry that capitation and fierce competition in the managed care arena make children with special needs unwelcome and unwanted enrollees. Plans and providers that rely on capitation may lose money when they enroll more than their fair share of special needs children, especially if reimbursement rates are not adjusted for the expensive and time-consuming services these children need. Those that are qualified and willing to care for this population may end up enrolling the majority of special needs children in a given community, and may go out of business as a result. As an example, the first criteria I originally looked for when selecting a provider for Aaron were experience and a good reputation in caring for children with my son’s conditions. All of the families I knew who had children with significant neurodevelopmental disorders took their children to the same clinic. Consequently, word of mouth among families in our community identified providers with the greatest skill and expertise, and each of us wanted our child to be cared for by these providers. In a capitated managed care system in which physicians’ reimbursement rates are not appropriately adjusted for high costs related to children with special needs, it seems logical that the most skilled providers, who attract a disproportionate number of high-cost patients like Aaron, will be at a huge financial disadvantage. This creates an enormous disincentive for managed care plans to attract and enroll children with special needs and their families.

What is to keep plans and providers from providing poor-quality care so that families of high-cost children will avoid them? Personally, I never saw adequate measures taken by our HMO to have safeguarded my son from substandard care aimed at saving money. Data that were available during Aaron’s illness—and are available now—do not address children with disabilities and multiple diagnoses. For example, I could not look at available data for outcomes of childhood asthma and determine whether our plan was prepared and willing to appropriately deal with my son’s pressure sores, grand mal seizures, and neurological impairments. I could review a list of providers available within my health plan, but I could not determine whether I would have access to skilled providers with the necessary expertise and flexibility to deal with Aaron’s unique needs. For some families, results from patient-satisfaction surveys provide promise, but the relatively small number of special needs families in large managed care plans like ours often preclude accurate information about issues pertinent to children with special needs. Moreover, issues faced by different children with special health care needs may vary substantially. A child with severe orthopedic problems, for example, may have very different needs from those of my son.

Finally, although we had access to complaint and grievance procedures aimed at protecting consumers, these relied on bad things happening before an issue would be addressed. What our family really needed instead was some type of anticipatory process that would have addressed our concerns early to avoid later complaints. At the time Aaron’s care was moved into the HMO, however, I did not have the benefit of the experience and understanding of managed care that I have today. I was unprepared for the task of taking on the managed care system at the same time that my son’s health was failing and my family was under tremendous stress. Frankly, I was intimidated by the sophisticated world of managed care and legal processes, and feared being branded a troublemaker. Once Aaron’s prognosis was a slow, progressive decline until death, all of my attention and strength became dedicated to his care and preparing for the inevitable. I had no stomach or time for filing grievances and felt it would be useless at that point.

**Critical Next Steps for Managed Health Care**

What are the critical next steps for ensuring quality managed care systems for children with special health care needs? First, we all need to speak the same language. We must learn how to identify the group of children we are so concerned about, recognize their diverse needs, and articulate these needs so that policymakers and managed care administrators can build appropriate systems and safeguards with adequate financing and support.
Second, education, information, and communication are crucial at all levels. Providers must obtain the knowledge, skills, and abilities to serve children with special needs and to recognize the necessity for appropriate specialty referrals. Families must understand the costs and financial issues of designing and delivering health services, learn to weigh costs and benefits, and learn to advocate and negotiate reasonably for high-quality care. Administrators and other decision makers in managed care systems need adequate understanding of special needs children and their great diversity, and accurate information to make the system responsive to the unique needs of each child.

Third, financial disincentives need to be resolved, either by adjusting reimbursement rates for the high-cost care required by children with special needs or by creating alternative financing systems. Purchasers such as Medicaid and employers need to ensure that contracts with managed care plans adequately address the needs of these children, and clearly define the services to be provided. If purchasers are unable to afford all the services our children require, this must be made clear to families, so that we can explore other resources and not waste time and energy trying to get managed care plans to provide services that are not in their contracts.

Finally, more research and expertise are needed to develop mechanisms to ensure quality of care in MCOs. We need to identify special needs children within managed care plans, identify and communicate cost-effective care models to providers and administrators, collect and evaluate data on both cost and quality measures, and effectively communicate results to all relevant stakeholders, including families.

Conclusion
After my experiences with Aaron and careful consideration of the issues, I have come to the conclusion that there is no perfect system of care for children with special health care needs. However, if managed health care is to succeed for children with special needs and their families, we have a great deal of work ahead to resolve troublesome problems associated with managed care, and to build on potential opportunities. Families such as mine are willing and able to join forces with others to ensure the highest quality of care for our children within the economic realities of our times. We have the most at stake here: the lives of our precious children.

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A Pediatrician’s Perspective
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In this period of rapid change in the American health care system, it is critical that special attention be paid to care for children; otherwise, we are unlikely to create systems that will meet the needs of this special, and potentially vulnerable, population. The term “managed care” is often used as a shorthand to refer to virtually any part of our health system that is not the same as it was a decade ago. As such, managed care serves as a lightning rod for public and physician opinion about all that is right and wrong with health care today. Professional organizations, such as the American Academy of Pediatrics (AAP), have already weighed in with guiding principles that urge caution in implementing managed care for children. The contributions in this journal issue extend this conversation for all of us by grappling with the complex issues of health care for children as we enter the next century.

Attributes of an Ideal Health Care System
Focus on Individual and Population Health
The most fundamental question for pediatricians and families is not whether systems should manage care. Rather, we should start by defining the attributes of a health care system that would maximize the health of children. As a pediatrician, I accept a broad definition of health for children that includes a state of well-being and not just the absence of disease. Such health is dependent on many social and economic factors outside of health care, but without access to high-quality health care, health will not be achieved for many children. The AAP has suggested that children benefit from a consistent source of medical care, which has been conceptualized as a “medical home.” To complement this focus on individual children, advocates for child health consistently place a high priority on health promotion for communities. In many ways, pediatrics has led the way in breaking down the very American barriers between public health interventions and health care for individuals. We do this through immunization programs, bicycle helmet giveaways, and school health programs, to name but a few ways. With these goals in mind—health for individual children and communities—we can begin to explore the attributes of managed care that could contribute to reaching them.

The Dilemma of Managed Health Care and Cost Containment
Discussions about managed care often suffer from a lack of a clear definition. Here, I will use a broad definition of managed care as health care for a defined population within a predetermined budget. Moore has made the helpful distinction between managed care as an insurance product and managed care as the process of medical care experienced by patients. The part of the definition that evokes the angst and ire of many is the notion that care must be delivered with attention to cost. First, I will argue that while cost consciousness is integral to managed care, cost cutting is not. One could imagine a parallel universe where care was managed under a budget that was increasing at 20% per year. Like many readers of this commentary, I would move there in a minute. One of the primary reasons for the rapid expansion of managed care in this universe is the problem of rapidly increasing healthcare costs in a country that has rejected the idea of nation-
ally coordinated health care reform. Therefore, modern managed care systems have operated in largely “free” markets that have forced cost containment to be a high priority. However, if managed care were abolished by decree tomorrow, pressure from industry and the public would not allow the issue of cost to disappear. We would still be advocating for more resources to promote child health; and we would still be right.

Opportunities for Promoting Child Health in Managed Care

I believe that certain attributes of managed care hold great opportunity for promoting the goals for a pediatric health care system outlined above. Some managed care systems already promote these goals; others may present barriers to them. What is most striking, though, is the diversity of the systems that are lumped under the umbrella of managed care in the 1990s. They vary dramatically in size, ties to local communities and academic centers, and for-profit status. While confusing, this diversity gives us a unique opportunity to see which aspects of these systems promote optimal care for children.

The first attribute of care systems that promote child health is the assignment to a specific provider (or group) of the responsibility to provide complete care for a population of children. This responsibility includes not just the treatment of disease when a sick child is brought to the office, but monitoring, outreach, and disease prevention activities. I believe that managed care has made us confront the real challenges in operationalizing the concept of a medical home. It is always much easier to treat the child in front of you than to develop effective outreach for those families who do not seek care.

Second, a system must align the incentives for physicians and other care providers to promote the health of children, in a way that is both ethical and measurable. Much has been written about the ethical dilemmas that physicians working in managed care systems must navigate to fulfill their responsibility to each patient, while simultaneously considering the needs of a larger population of children and the resources available to meet them. This balance between individuals and populations is not so different from the one we confront when we give the polio vaccine, with some small risk for individuals but an overall benefit to the community. The issue is not that we have to weigh both the individual and the general good, but that we do it with the right reasons in mind: for the promotion of overall health and not for individual profit. If resources for health care are limited (and they are), using them for the greatest good may itself be an ethical imperative. However, physicians should not be put in the position where they are torn between providing high-quality care for individual patients and an imperative to cut costs. Rather, incentive systems should promote wise use of resources across many patients. This means that personal financial risk should be limited (though not necessarily eliminated), and should be based on meeting the goals of health, not just on spending less money. Finally, incentives should promote high-quality care for the minority of pediatric patients with chronic diseases, so that providers are not punished for providing comprehensive care for these children. For their part, providers must be willing to be accountable for the quality of the care they provide and the resources they use. The development of effective measures of quality will be critical to making this feel like more than just empty regulation.

The third attribute of a care system that would maximize health is access—on several levels. Managed care, by itself, will not solve the problem of access to health insurance and medical care for currently uninsured children. Likewise, managed care cannot solve the problems of economic deprivation and the other complex social problems that afflict children disproportionately. We should demand of government that all children have health insurance that allows access to care. If health insurance can get a child in the door, we must demand of managed care systems that children have access to their primary providers and to specialty care that will enhance health. Since the majority of children are healthy, we must ensure that systems meet the needs of children with a wide range of less common chronic illnesses and disabilities. Promoting health for all children includes access to multidisciplinary teams for children with attention deficit hyperactivity disorder (ADHD), and access to tertiary centers for children with complex medical problems more effectively handled by regional centers of excellence.

The fourth attribute of an optimal health system is that it has a focus on improvement and innovation. In previous decades, advances in basic sciences and medical technology made substantial improvements in specific areas of health. As physicians, we accepted these changes, while ironically letting other aspects of our work—like inefficient documentation and communication methods—inhibit our ability to provide care. Managed care organizations have been at the forefront of bringing quality-improvement efforts into medicine. Though there is some resistance, many of us are now reaping the benefits of improved processes of care, in addition to improved medical knowledge and technology.

Challenges for Managed Health Care

What are the challenges that prevent managed care arrangements of today from contributing to improvements in child health? Again, we must begin with calling attention to the diversity across systems from which we can learn; it is crucial that we, as child health advocates, recognize positive attributes of care systems and nurture their growth. This being said, the current pressures of the free market make competition on price so intense that it is a challenge for many managed care plans to see past it. It is beyond the scope of this commentary to grapple with the issues of for-profit managed care. In the end, it is how the mission of an organization is carried out, not in words, but in actions, that determines its contribution to child health. I remain concerned that the requirement to focus on the needs of investors will cloud that mission, but am prepared to be surprised by some investor-owned entities that will be able to meet both the needs of communities and those of investors. Finally, the structure of managed care systems will be only a minor determinant of health. The serious external challenges that have always created barriers to providing high-quality medical care for children remain in an era of managed care. For managed care, as well as the health care world in general, child health is never the
biggest piece of the pie. As long as we have an employer-based system of health care, children will be an add-on in the minds of many.

Medicaid managed care has its own important opportunities and challenges to consider. Managed care systems must develop new and effective modes of outreach and delivery to optimize the health of vulnerable populations. And we must learn from those systems that are already doing it well. The good news is that for the first time, states can measure which systems are meeting the goals of care and hold them accountable. The current frenzy of expansion of Medicaid managed care must be followed by a period of learning from one another and of demanding excellence in these programs.

The last challenge for managed care organizations to meet in order to contribute to the goals of child health will be to enhance ties outside the walls of their own organizations. Child health happens in schools and communities, much more than in physicians’ offices. A challenge for managed care organizations will be to cooperate for the benefit of children in a community, especially in markets that are intensely competitive. Managed care organizations could cooperate with communities to promote injury prevention, childhood immunization, and other preventive strategies that can be effective only at a community level. One recent report describes a program of school-based health clinics, and suggests that this may be cost effective for health plans as well as being of benefit to the children served. Managed care organizations will see some of these programs as being to their immediate advantage and will be willing to make substantive contributions, while for other programs more encouragement (and funding) from community sources will be required.

Showstack and colleagues have recently described a vision of what a socially responsible managed care organization would look like. It includes responding to community needs, representing a cross section of the population, and making links with others whose aim is improved health for the community. At the core of this vision is the idea that to achieve maximum health for a community, the organizations that deliver health care cannot be isolated. Academic medical centers could take the lead as neutral parties in organizing such interrelated activities. New opportunities for partnerships in education and research are being explored by a growing number, though still a minority, of managed care organizations.9

Conclusion

I believe the single biggest danger we face is allowing managed care to evolve subject only to market forces. Health care, especially for children, must be driven by core values and a focus on a mission by both direct providers and the organizations in which they work. We have a tendency in this country to assume that the free-market system is value neutral. In fact, allowing health care to be driven only by the laws of supply and demand would be a great mistake. The worst outcome of the current evolution of managed care would be a devolution to a system in which providers acted as completely independent entities (without the opportunity for accountability, shared learning, and disease management of specific illnesses), but in which independent physicians were at financial risk for the costs of the care they delivered. This would be tantamount to the old fee-for-service model except that now physicians would have replaced insurance companies as the onesshouldering the financial risks of health care.

I believe that advocacy for child health, which today is often framed as protecting children from managed care, must focus on promoting child health through managed care. In fact, completely unmanaged care would likely be less effective in allowing us to achieve the goals of child health. All who work on behalf of children must take the lead in identifying and demanding the attributes of a health system that will be most effective in caring for children. Managed care organizations must live in, and sometimes be regulated by, the communities they serve. This is an appropriate role for government working in cooperation with those who provide and finance medical care, but we must get beyond the current ad hoc atmosphere in which legislators respond to the public outcry of the day. Right now, managed care looks to many like a train barreling down a track. Rather than throwing ourselves in front of it, we should be at the switches making sure it gets us where we want to go.


