CHILDREN WITH CHRONIC CONDITIONS IN THE 21ST CENTURY

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ABSTRACT The care of children who have chronic conditions should focus on improving the lives of the children and their families. This is accomplished most effectively through community-based, family-centered care. Critical issues for these children and families in entering the next century include the level of insurance, content of benefits package, level of evidence required for health insurance reimbursement, preparation of and incentives for health care professionals, roles being demanded of families. As the richest country in the world, we should be able to (1) provide universal coverage, (2) guarantee a comprehensive benefits package that applies a child-specific standard of medical necessity, (3) establish criteria for requiring insurers to reimburse for new effective therapies, (4) develop strategies for overcoming professional barriers, and (5) create mechanisms for compensating family caretakers for their care.

KEY WORDS Benefits, Child Health, Chronic Conditions, Insurance.

Over the past few decades, a great deal of progress has been made in the care of infants, children, and adolescents with a wide range of chronic conditions. There is growing interest in how to improve the lives of the large number of children* who now live with considerable needs for long-term care. We have moved from an era of expected death for this group of children to one that focuses on trying to normalize their lives and their health care services within community settings, using a family-centered, community-based approach. The state of the art is the provision of care by interdisciplinary teams that balance the needs for health care services for the child with other needs of the social family unit and that work with families as full partners in providing care. These

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*Throughout this text, the term *children* is used to cover the full age range from birth through adolescence.

teams are designed to maximize quality of life, to provide long-term continuity, and to integrate and balance biomedical and psychosocial issues.

Such approaches, when they are successful, minimize hospitalization and institutionalization without compromising access to tertiary care management. They allow normalization of the child's social world to the maximal amount possible within the constraints of the child's health condition. We now have evidence that such programs are effective in improving child adjustment, increasing satisfaction, reducing maternal stress, and providing a more comprehensive set of services.¹⁻⁶ They also enlarge the role of families by increasing the responsibilities placed on family members for implementation of direct care and for coordination of the many details that go into the care plan. For some, this is a full-time job, at least during some phases of a serious chronic condition.

In addition, the new frontiers opened by our increasing understanding of the genetic basis of disease and the mapping of the human genome hold the promise of myriad new treatments and cures for the many rare diseases that account for the most devastating illnesses of childhood. It is difficult to anticipate the impact that these changes will have on the health of children in the future.

Against this backdrop, we must ask the question: What are the issues that these children and their families face in the 21st century? There are five central issues that I believe pose a major risk to the current state of care for children who have chronic health conditions and for their families:

1. Level of insurance
2. Content of the benefits package
3. Level of evidence required for health insurance reimbursement
4. Preparation of and incentives for health care professionals
5. Roles being demanded of families

Below, we examine the nature of these risks and some potential remedies that could go a long way to ameliorate the risks.

LEVEL OF INSURANCE

Children in the US, until recently, have been among the least-well-insured segment of our population and lag behind children in other Western societies in terms of their current level of insurance. Even with the proposed expansions of the State Child Health Insurance Plans, there still will be many children who will lack health insurance altogether. It should be self-evident that those with chronic illness who lack health insurance are in particular difficulty. This is especially the case because of the increasing financial squeeze that is being placed on not-for-profit health care providers and on academic medical centers, which

traditionally have been the mainstay of much of the care delivered to this segment of the population. Many of these sites have provided a great deal of free care to indigent children; in addition, academic medical centers have been the source of many of the scientific breakthroughs that have led to improved outcomes. The threats of closure or curtailed services at these sites are likely to have profound effects on children who have chronic conditions.

BENEFITS PACKAGE

An issue that often is overlooked in the concern about extending some level of insurance to the maximum number of previously uninsured children is the nature and content of the benefits package available under their insurance plans. This is an area that is of special concern for children with chronic illness and disabling conditions. Under fee-for-service Medicaid, we have had a unique and hard-won benefits package, a package defined by a child-specific standard of medical necessity. Such a standard includes all services necessary to treat or prevent the development of problems or conditions. Childhood is a time of rapid development and critical periods, during which impaired function may have irreversible and long-term consequences. As a result, there is extreme urgency in providing remediation for deficits at a time when the remedy can be most beneficial. Adult standards tend to depend on the unequivocal demonstration of a deficit—something that delays treatment for children, decreasing their chance for full remediation. Further, adult standards are usually predicated on treating a diagnosis, not treating or preventing problems or conditions. Slow speech acquisition, nonspecific failure to thrive, and developmental delay are not treatable diagnoses. However, their prevention and treatment are critical.

Medicaid's child-specific standard also has been the basis for providing screening and early detection through the Early and Periodic Screening, Detection, and Treatment Program (EPSDT), as well as a number of services covered by the umbrella term, *wrap-around* services. These include enhanced health education to teach parents how to care for a child's medical needs; transportation and community outreach to ensure necessary follow-up; and access to prescription medications through pharmacy services and to supplies such as bandages, colostomy bags, or injectables other than for insulin,* as well as to durable medical equipment (braces or wheelchairs that need to be replaced as a child grows), special dietary supplementation, and a large array of other special needs that children with rare conditions present from time to time. Most, if not all, private

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*Only insulin injection supplies are currently covered in the New York State Child Health Insurance Plan.

insurance plans and the majority of state health insurance plans have strict limits on these benefits, and most do not use child-specific standards in their policies. Further, as Sara Rosenbaum points out, these broader benefits are also in jeopardy for Medicaid recipients who enter managed-care programs because many managed-care contracts do not refer specifically to the child-specific language in the EPSDT regulations.⁷ In the case of contract law, the benefit of the doubt is given to the insurer, rather than the consumer, whose interests are more likely to be protected under judicial interpretation of the EPSDT regulation.

If we have to make a choice between breadth and depth of insurance coverage—something that I do not believe we need to do—the long-term interests of children dictate that we should choose depth over breadth. This is because it is the more likely way to achieve the long-term goal of comprehensive coverage for all children: It is more probable that we can mount the constituency to support expansion of full coverage for everyone in the long run than it is that we will be able to expand a limited benefits package to include high-cost and infrequently used benefits that are so critical for the few who need them. Further, it is clear that a comprehensive package is what children need, especially when they have chronic conditions. Since serious chronic conditions can and do occur acutely in healthy children, a full package of services is the level of protection that every child ultimately needs. It is distressing to learn that there is new evidence that children with chronic conditions whose household incomes are *above* the level of poverty actually have more unmet health needs than those below poverty. Ostensibly, this paradoxical finding occurs because of the less-adequate benefit plans of children with private insurers that do not use the comprehensive, child-specific criteria of the Medicaid package.

STANDARD OF MEDICAL EVIDENCE

The third issue of concern is the standard of medical evidence required by insurance companies to approve reimbursement for new treatments for children with chronic conditions—that is, to be eligible for financial coverage by the plan. Documentation is growing that, to keep premiums down, many insurance plans limit coverage for treatment. Yet, many whose children have chronic conditions can derive considerable benefit from newly developed therapies. There is currently no system for evaluating the new, albeit expensive, breakthroughs that may change the lives of many children who have chronic conditions. This lack exists because the long-term, large-scale data that are usually required by insurers to establish the standard of care will not be available in time for most children to benefit. This is a particular problem for children with serious health conditions

that result from rare conditions. Many children will be denied the benefits of important therapies unless some mechanism is established for determining when the evidence of efficacy is adequate to deem that a therapy should be reimbursable.

PREPARATION OF PROVIDERS AND THE INCENTIVES UNDER WHICH THEY WORK

As we begin the next century, the fourth issue of concern in providing care to children with chronic conditions is the level of preparation of health care providers for assuming responsibility for their care and the factors influencing their motivation. Recent residency graduates of most pediatrics training programs have been trained in an era in which medical education has been dominated entirely by subspecialties and in which they have been taught to defer a great deal of decision making to subspecialists. Much of the art of medicine has given way to the notion that there is a scientific answer for everything. This has diminished the average pediatrician's understanding of how to deal with uncertainty that is inherent in treating many children who have chronic conditions. It also has tended to de-emphasize the importance of providing support.

When this deficit in training is combined with the current pressure for managing large caseloads and the disincentives in a capitated system of caring for individuals who need extra attention, it becomes very clear why many physicians will steer away from the care of children who have chronic conditions. Add to these factors the profiling by managed-care companies of pediatricians who use excess resources or are less efficient than average (sometimes because of the high concentration of patients with chronic conditions whom they serve) and the current concerns about malpractice litigation, and we have a situation that severely threatens to undermine the availability of community-based care.

FAMILY ROLES

The fifth issue is the change in the nature of our expectation about the responsibilities of family to provide care for children who have chronic conditions. While all of us favor the movement away from prolonged hospitalization (which had its own associated morbidity), we need to recognize that deinstitutionalization substantially increases responsibilities of families to provide 24-hour-a-day care for children with chronic conditions. This movement was brought about by pioneers, who legitimately led a crusade to return their children to more-natural environments. They paved the way for a change that some of us predicted might become a requirement or standard for all families—even those who did not have the strength and resources of the initial pioneers. This has in fact happened, and

the pressures have escalated under the current drive to decrease the cost of the formal health care system. These pressures are beyond what is tolerable for many families, and there is reason to worry about what will happen when the child support offered by the welfare system evaporates. Given the difficulty of surviving on the wages of one employee per family, the number of single-parent households, and the incentives not to miss work because of the threat of losing employment, this shift may become unbearable for some families. Further, as we cut back on the services provided through the education system, the need to provide some therapies outside of the school day that have previously been school based may well intensify and add to parental burdens. We can only hope that this extra strain does not magnify the already high rate of mistreatment and medical neglect of children with chronic conditions.

REMEDIES

What, then, are the potential remedies for which we need to advocate?

1. There must be advocacy for universal health insurance, certainly for children, and, it is hoped, for all the members of society. The time has come for the US to join the rest of the industrialized nations that have made this transition. Failure to ensure universal coverage for children is a shortsighted and misguided economy that will cost our society a great deal in the future productivity of our nation.

2. All children must have a comprehensive benefits package based on a child-specific standard. Making such a benefit package available to all children is rational because of the high proportion of children who develop chronic conditions *de novo* in any given period of time, because it reflects a habilitative rather than antihabilitative philosophy, and because it eliminates the high bureaucratic and administrative costs of determining eligibility. It also makes eminent sense because it does not cost much except for the small percentage of high-end users, whom most would agree need coverage anyway.

3. Criteria are needed for the adoption of reimbursement responsibilities for new therapies. This must rely on a process that will consider what is reasonable against what is feasible and will establish guidelines that can direct the insurance industry. It should not require families to spend all their energies fighting for legitimate services that their children need.

4. Strategies need to be developed for overcoming professional issues. These might include the establishment of (1) centers that specialize in the care of medically complex children; (2) community-based networks coordinated by health maintenance organizations, integrated delivery systems, or tertiary care

centers; and (3) intensive continuing education and intensified postdoctoral training for health care professionals so that they can increase their comfort level in providing care for children who have chronic conditions. In addition, it must be accompanied by less-punitive incentives.

5. A policy is needed that will compensate family caretakers in instances in which substantial or full-time care is required. Many European countries have acknowledged this important activity as a legitimate type of work effort and have provided stipends for parental caretakers. This is a policy we ought to develop as well.

While the points outlined above delineate a substantial agenda, it is not one that is beyond the reach of the richest country in the world. Without our commitment to such an agenda, children who are unlucky enough to have chronic health conditions and their families will face a very uncertain future in the 21st century.

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