ACCESS DENIED: TAKING ACTION FOR MEDICALLY UNDERSERVED CHILDREN

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Advocacy centered on access to health care for children is a straightforward business. The goal is clear: children need readily available, comprehensive, continuity-based, family-friendly, and child-friendly health services to meet a range of well-accepted objectives, including prevention, screening, acute care as needed, management of chronic conditions, and anticipatory guidance. Pediatricians refer to such a health care environment as a "medical home." Children who, for any reason, are unable to access such care are considered *medically underserved*. Although wide-ranging barriers interfere with access to medical homes for millions of children, particular populations remain at high risk for chronically poor access. These are precisely the groups that require focused and sustained attention from advocates and policymakers.

The fact is that serving vulnerable populations, such as homeless children, involves more than designing good programs, important as this may be. Often, the greater challenge is to understand and manage the barriers that keep such families from being able to utilize whatever services might be available.

This paper proposes a strategic approach for programs dealing with health care services for severely medically underserved children. Accordingly, it is important to begin by attempting to understand the functional or operational definition of "health care access" and to derive therefrom a clear sense of the specific barriers that impede access.

WHAT IS "ACCESS"?

What is "access"? Unfortunately, the answer to this question may very much depend on who is being asked. Many elected officials, health policy types, and

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even journalists hear “access” and think “insurance,” believing that if an individual has a decent health insurance and coverage package, she or he has access. Families struggling to secure health care for their children, and health care professionals working with vulnerable, disadvantaged populations, generally realize there are far more complex aspects to the question of finding a medical home for children than simply the finance issue. This is not meant to understate the importance of making sure that there is a way of establishing and paying for essential health services. Put another way, a “free” rail pass for an area not served by a train system is not useful.

The other perceptual problem that afflicts many lawmakers or members of the press has to do with a poor understanding of the *quality* and *array* of services actually available versus what is truly needed in a given community or for a particular population. The issue of access to emergency medical services is a case in point. If information is lacking regarding the need for a full range of pediatric screening, preventive, and health maintenance services, then the apparent availability of basic emergency care may be interpreted as representing full access for children. Of course, nothing could be farther from the truth. Other than true emergency care, emergency departments are not—and should not—be viewed as appropriate venues for delivery of comprehensive child health care.

Today, in fact, millions of children in the US have both health insurance and access to emergency services, but do not have access to health care that (1) meets current pediatric standards, (2) responds to their unique medical or social situations, or (3) provides the right levels of care at appropriate intervals. In addition, for 11 million uninsured and millions more only partially insured, proper care may simply be unaffordable.

THE CHILDREN'S HEALTH FUND'S EXPERIENCE

In 1987, the Children's Health Fund (CHF) initiated a mobile-based health care program for profoundly underserved and indigent children in New York City's homeless shelter system.¹ This flagship program, the New York Children's Health Project, now part of the Division of Community Pediatrics at Montefiore Medical Center, utilizes entirely self-contained pediatric “clinics on wheels.” Although clearly recognizing that, in an ideal world, children would be much better served in a “fixed-site,” stable, neighborhood-based clinical setting, that simply has not been possible for the majority of the 10,000 children residing in the system's squalid shelters and welfare hotels.

Although many of the facilities we visited in 1987 were in reasonable proximity to public or hospital-based clinics, substantial barriers to these services were a

constant problem for the homeless children. These were patients with multiple medical, behavioral, and social problems, who felt alienated in every hospital or health system they attempted to enter. There were no pre-existing medical records; the clinics were crowded and intimidating. Without financial resources, however, families had no other viable options, and, except in dire emergencies, they would stay away from the traditional health services for the poor, particularly if there was no sense of pressing need.

In this environment, then, mobile units have been bringing highly skilled, full-time health professionals *on a regular, weekly scheduled basis*, to see children residing with their families in the shelter system. A major challenge, however, was to create systems that compensated for some of the obvious shortcomings of a mobile-based service. The goal was to develop a medical home model that would be available to homeless families throughout the duration of their stay in the shelter system. For all intents and purposes, this continues to mean providing continuity and many features of the medical home as it might be manifested in other, more traditional health care settings.

Some of the elements of the New York Children's Health Project that are specifically designed to foster the notion of a comprehensive health care relationship for children are

- medical teams assigned to given shelters to encourage long-term provider/patient bonding
- 24-hour, seven-day coverage and triage by provider teams from the New York Children's Health Project
- computerized medical records systems available on mobile units
- ongoing case management and subspecialty referral management
- provision of car service to facilitate compliance with hospital-based subspecialties as needed

Since 1989, the Children's Health Fund has been "exporting" its model systems to other communities around the US. Well over 200 requests from community organizations, health care provider systems, and government bodies have sought CHF technical assistance and other support to establish local mobile-based programs. In reality, only a minority of communities meets criteria felt to justify the use, specifically, of a mobile pediatric system.

The assessment of community need from this perspective has become a principal function of the Children's Health Fund, and it is not simply a matter of being located in an identified area of substantial poverty. CHF programs are only

established in communities where existing patterns of care seem insufficient to provide the appropriate quantity and quality of service availability *and* where available data reflect insufficient access to adequate primary care for children. Particularly germane to this latter point would be low rates of up-to-date immunizations, as well as overutilization of hospital and subspecialty services. Also examined would be the distribution of public or hospital-based pediatric clinics with respect to where families with medically underserved children actually reside.

In addition, the Children's Health Fund does not go forward with the development of a new program until a local health care institution agrees to assume responsibility for ongoing project management. Typically, local institutions running CHF programs are departments of pediatrics at an academic medical center or federally funded community health centers. Connections to academic pediatric departments are essential to the "CHF model" because they can help ensure access to vital subspecialty care and special services and also, because the connection to health services research and clinical training programs helps to reinforce local credibility and quality.

Finally, the establishment of a local program requires a secure business plan. The Children's Health Fund always attempts to identify, in advance, likely sources of funding support to cover start-up needs (cost of initial assessment, design and purchase of mobile unit and computer systems, etc.), as well as ongoing expense budgets over the first 3 years of operation.

All of this said, CHF's mission is really *not* about mobile pediatric care. Rather, with a national network in 1998 consisting of 13 sites in severely underserved rural and urban communities, CHF focuses on access to appropriate health care for medically underserved populations. This perspective has led to three organizational strategies:

1. Sometimes, a community with serious access-to-care problems for children is better served by establishing a fixed-site satellite clinic or school-based health care program affiliated with an existing service.
2. Populations served by CHF projects go beyond the homeless. Currently, CHF's national network still provides services to homeless children in some urban areas (Dallas, Texas, and New York City), but also cares for housed poor children living in profoundly underserved inner-city neighborhoods (Washington, D.C.; Orlando, Florida; Los Angeles, California; East Palo Alto, California; Newark, New Jersey), migrant children, immigrant fami-

lies (southern Florida; Austin, Texas), and children living in remote, isolated, and impoverished rural communities (in Mississippi, Arkansas, West Virginia).

3. The Children's Health Fund recognizes the folly of trying to "solve" completely the problems of medically underserved and medically needy children in the US simply by providing more local programs, mobile units, or otherwise. Therefore, the organization has identified a major advocacy agenda. In this arena, CHF works to foster legislation and policy, particularly on the federal and state levels, that permit large-scale system changes or new funds to truly improve general conditions for children and their access to health services. The Fund's active and central participation in the efforts, which led to passage of the Children's Health Insurance Program as part of the 1997 federal budget, is an example of such activities.

CONSEQUENCES OF LACK OF ACCESS

Obviously, all children served by CHF programs are severely medically underserved. Interestingly, however, while the environment and set of specific barriers to care observed in each project site may vary considerably, the impact of being deprived of regular access to a comprehensive medical home system yields strikingly similar consequences. The immunization rates of homeless children in the shelter system in New York City, for example, are very similar to the immunization rates of similar-age children in areas such as rural southern Florida. Actually, the consequences of being medically underserved, irrespective of the conditions that led to the lack of access, are constant: underimmunization, missed opportunities for health screening and prevention, increased utilization of emergency rooms, excessive hospitalizations, and so on. Importantly, the absence of an ongoing relationship with one physician, one health care system—in other words, a medical home—ultimately leads to underdiagnosis and undermanagement of chronic conditions. Asthma is a particularly striking example of diseases that are virtually impossible to manage in the absence of a regular, accessible, and competent physician.

BARRIERS TO A MEDICAL HOME

The actual challenges that medically underserved children experience in attempting to gain access to a medical home fall under two categories: systemic barriers and local barriers.

SYSTEMIC BARRIERS

Systemic barriers are those not readily amenable to local actions and generally reflect issues that must be addressed by large-scale legislative, policy, or funding

initiatives. Thus, children without health insurance, children who do not have sufficient insurance, or children who have insurance but live in places where primary care capacity is insufficient all face important barriers to care, none of which are readily amenable to "local" solutions except on a case-by-case basis.

Systemic access barriers are daunting. According to federal estimates and data published by the American Academy of Pediatrics, more than 11 million children are completely uninsured.² In addition, millions of other children are partially insured and covered, perhaps, for catastrophic illness, but not for preventive care, chronic illness management, and the like. They also face serious obstacles in obtaining ongoing health services that meet nationally accepted standards of pediatric care. Uninsured and inadequately insured children include those whose families earn too much to qualify for Medicaid or those who have parents who do not work for employers that provide dependent coverage. While the 1997 passage of the State Children's Health Insurance Program will permit millions of currently uninsured children to obtain subsidized coverage, these gains are undermined by employers who continue to drop dependent health care plans for their employees.

In addition, there is a major problem with respect to children who have adequate health insurance (Medicaid or commercial policies), but live in medical service shortage areas. The federal government identifies more than 2,600 so-called health professional shortage areas (HPSAs), where more than 45 million Americans reside in communities with less than 1 primary care doctor for every 3,500 people. Children with good insurance coverage who live in health professional shortage areas will have problems accessing comprehensive, timely health care simply because there is insufficient local capacity of the existing health care system. The Children's Health Fund believes that as many as 3–5 million insured children would fall in this category of "insured but underserved." Again, this is a challenge that requires large-scale policy and legislative strategies for the ultimate improvement of the distribution of health care capacity for all areas of the US.

LOCAL BARRIERS

Some barriers that interfere with appropriate access to health care for children can be addressed on a local level and do not necessitate large-scale governmental remedies. A local provider or clinic can institute changes that may greatly improve a family's ability to access needed health services. For instance, bringing bilingual signage and translation services into the environment where language barriers exist could make a substantial difference for families for whom English is not the primary language. Also, arranging for transportation for follow-up care or

special services may be needed for families living in communities without affordable public transportation. This effort can make the difference between a child making or missing a critical follow-up appointment.

Sometimes, the physical environment, administrative procedures, or even personnel attitudes in an ambulatory setting can be off-putting and intimidating for families and children. Such realities represent important barriers to care that we consider to be "local." However, nationally, the concept of "family-friendly care" is being incorporated gradually into child health facilities. Every office and clinic can address such issues by incorporating features or designing the ambience to make the health care encounter as comfortable and nonthreatening as possible.

AN AGENDA FOR ACTION: OUR GOALS

To develop an advocacy agenda that is appropriate to meet the challenges of ensuring access to health care for medically underserved children, it is helpful to be very clear about what is needed:

1. *Continuity and coordination of care* are absolutely critical for children who are medically underserved. For children facing multiple, complex problems, such as poverty, poor access to health care, educational problems, and multiple health-risk factors, it is necessary to coordinate and track care and provide extensive case management and support of all kinds.
2. There is also need for *appropriate providers*; that is, competent pediatric practitioners who understand not only the health issues, but also the social and economic environment of their patients.
3. Children need *innovative gateways into the system*. Innovation was essential in creating—and justifying—the mobile pediatric units of CHF's programs. The idea was to find a way to provide immediate, effective access to a health system by utilizing a nontraditional gateway that is, literally, brought to the doorstep of hard-to-reach patients and their families. Well-placed satellite clinics and school-based health services provide a similar approach.
4. Special attention must be given to *medical records for tracking and management*. The records of the New York Children's Health Project are totally computerized. Essential records on all children seen in the program are available in a custom-designed database accessible by providers in any of the mobile units or at headquarters.
5. *Twenty-four hour, seven-day coverage* is extremely important. A part-time health care system for medically underserved children, by definition, yields suboptimal care, leading to overutilization of hospital-based services and poor management of chronic diseases.

6. *One-stop shopping*, with the full range of health, social, and related services provided under one roof, greatly facilitates compliance and access. Health education, case management, and similar programs are also important to include.
7. Underserved children need the *connection to an integrated health system* in which secondary, tertiary, and subspecialty services can be obtained when needed. Many at-risk, access-deprived children need much more than primary care. Comprehensive backup and support services are necessary elements of the health system planning process for such children.

MAKING IT HAPPEN

As stated above, the more medically underserved and vulnerable the population, the more necessary it is that there be access to a fully functional, innovative medical home, a population-sensitive provider, extended services, and, finally, advocacy. Physicians who find themselves working in a Children's Health Fund project understand that their role is that of "doctor/advocate." They see themselves as working with families in a context that matters with respect to the understanding of health risk, the management of medical conditions, and the development of prevention strategies. These physicians—and other health professional colleagues—work actively with schools and social agencies, stay informed about relevant legislative and policy efforts that center around access to care for children, and, on occasion, even get involved with the political process.

In the end, designing programs that work and defining what true access to health care really means are essential goals for all advocates committed to the well-being of children. Medical professionals have a crucial role to play in this ongoing dynamic.

REFERENCES

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