SUMMARY AND NEXT STEPS IN ACHIEVING UNIVERSAL ACCESS

ROBERT J. HAGGERTY, MD

At the Margaret E. Mahoney Symposium, the participants and attendees heard from Dr. Marian Wright Edelman, President of the Children's Defense Fund, an eloquent call to improve child health services. She outlined ways in which we all can assist in that effort. We also heard important data presented on the steps that have been taken, and those not taken, to implement the new State Child Health Insurance Program. With the infusion of this new and significant amount of money into the system, we are challenged to use it effectively and to enroll as many children as possible in the new programs. For the current session of the New York State Legislature, the issue is clearly to advocate for passage of some bill to utilize the money effectively.

That is our first step. What, however, should be the next steps? What should be our goal? I have a dream, a vision, of what an equitable and effective child health service for all Americans would look like.

Such a child health service, of course, would offer access for all children to health services, both curative and preventive, without a means test and would probably be a single-payer system. Some say that is not practical, but my task is not to be practical, it is to dream. Providing a ticket of admission, or universal access, to the health care system is only a beginning. (It is a beginning, by the way, that I thought was so close to reality in 1975 that, with colleagues at the Center for Advanced Study of Behavioral Sciences at Stanford University, I wrote a paper called "After National Health Insurance.")

While progress has been made in increasing access since the 1970s, it has been agonizingly slow. However, had it been rapid, or even complete, I should like to emphasize that access is only the first step toward the type of child health

Dr. Haggerty is Professor of Pediatrics, Emeritus, University of Rochester School of Medicine and Dentistry, 601 Elmwood Avenue, Rochester, NY 14642-8777.

service that I dream about. An effective service must begin with defining *what* is accessed, not only whether it has been accessed.

Access to *what* is usually concerned with the so-called benefit package. The fairly broad Medicaid definition, with full Early Periodic Screening, Diagnosis, and Treatment, is a good start. That *what* includes availability, 24 hours a day, of a culturally sensitive physician and other members of the health care team, all skilled in both traditional biomedical diseases and the psychosocial problems, and all committed to serve all children in the community.

Even that dream, however, is not enough. One must demonstrate *how* it can be accomplished. Even with the ticket to admission, we must ensure that the patient can get to the clinician who is prepared to provide the services needed. These services may include transportation, translators, and outreach; will provide primary care, preventive services, and care for children with special needs or problem behaviors; and will link the rest of the family to the health care system.

I would like to identify a problem that is increasingly prevalent, namely, the existence of far too many fragmented programs, all of them begun with good intentions, but often with different eligibility rules and different staffs providing services at different sites. A few years ago, the Robert Wood Johnson Foundation supported nine communities in the development of several programs that were subsumed collectively under the Foundation's "Reducing Categorical Barriers to Care" initiative. Each of these programs had three components: a community report card, a care coordination plan, and a decategorization of funding streams, that is, a blending of categorical, separate funding streams. Not surprisingly, all communities did a fairly good job in developing report cards; they were able to outline, with some painful precision, the health problems of children in their communities. Most made some progress in care coordination, but few made any progress in decategorization of the many fragmented existing funding streams.

One of the Foundation-supported programs was in Rochester, in western New York State. The project in Rochester was considered one of the most successful because it brought together six previously categorical state-funded programs through the health department (Fig. 1). All of these programs had been funded previously by the New York State Health Department, but as separate programs with separate staff and separate eligibility criteria. The Rochester program was able to bring these categorical programs together with a single set of eligibility rules. That success may seem minor, but it took well over a year to obtain all of the waivers necessary to accomplish it, and it is still not integrated at the point of service for the family. Nevertheless, the dream in Rochester has been to bring together many of the social services programs and these health programs. In

FIG. 1 Components of an integrated child health system, as integrated in Monroe County, New York (WIC: Women, Infants, Children program; EPSDT: Early Periodic Screening, Diagnosis, and Treatment).

spite of the fact that, in Rochester, both the social services department and the health department share offices in the same building and are led by committed people who have the best will in the world to bring their programs together, this has not occurred yet. Decategorization of all of these programs has never happened.

The next step that I would like to dream about is to bring together some of the health programs with nonmedical programs, such as programs of social services and juvenile justice (Fig. 2). My vision of an equitable and effective child health service includes nonmedical programs as well as medical, because my dream is broader than I have described thus far. My definition of child health starts with the World Health Organization's definition: "Health is the optimal state of physical, social, and emotional well-being." Our new surgeon general has articulated that the most prevalent and destructive disorders among young people today are violence, injuries, homicides, suicides, drug abuse, new infections such as human immunodeficiency virus, chronic disease, and resistant tuberculosis. Behind all these problems lies social disadvantage, which includes poverty, racism, social isolation, stresses of living, poor housing, and, perhaps most important of all, lack of meaningful jobs. The health professions alone cannot solve these problems, but we can demonstrate their relation to the profoundly destructive health problems of children and join as partners with others to create advocacy for a more equitable society and, in the process, reduce these destructive disorders.

INTERAGENCY STRUCTURE

FIG. 2 An illustration of how current categorical services might pool resources so that, at the point of service, they are integrated for the family (MR: mental retardation; MH: mental health; CW: child welfare; SP ED: special education; JJ: juvenile justice; SUB AB: substance abuse).

There are several ways to approach decategorization (Table I). Not all programs need to be decategorized at once. There can be a "5% solution," with a small number of programs targeted, or the targets can be special populations. Other approaches can be tried. The important point is to begin the decategorization program.

My final dream goes beyond our own shores. We, who are most fortunate to live in this land, its problems notwithstanding, must recognize the interdependence of the world today. We live in a truly global village. In my role as Executive Director of the International Pediatric Association, I was privileged to visit over 50 countries throughout the world. As a result, I believe that we must have increasing health relations with the nations of the world.

TABLE I Categorical Versus Decategorical Programs: Policy Options

Challenge grants
Waiver strategy
Statewide versions of decategorization
The 5% solution (go slowly)
Targeted on high-needs communities
Selective decategorization programs
Negotiated decategorization programs
Wrap-around funding

TABLE II Reasons for a Global Perspective

Environmental factors have no boundaries.
Infections have no boundaries.
Many US pediatricians have worked or will work abroad.
We can learn from others.
War and ethnic violence are moral issues for us.
Western medicine has much to offer others.
Research opportunities are available.

There are many reasons for including an international perspective in our dream (Table II). Many diseases no longer halt at national boundaries. We, in the developed world, have much to offer in the way of knowledge about scientific medicine, but we also must recognize that we have much to learn from other cultures. The oral rehydration effort for diarrhea, the Doula for women in labor, and the community child development programs in Thailand are all examples of successful programs initiated in the developing world that have much relevance to us in this country. Perhaps most important of all is the commitment of many countries, with far fewer resources than we have, to the idea of universal access to the health care systems of their countries.

Finally, let me close my dream with two quotes. The first is from the second inaugural address of President Franklin Roosevelt: "The test of our programs is not whether we add to the abundance of those who have much; it is whether we provide enough for those who have too little."*

I conclude with a remark that I learned from Dr. Gilbert Forbes, who believed that service itself is an important, rewarding aspect of life and must not be denigrated: "Service is the rent we pay for living."

*January 20, 1937.