



The Surgeon General's seminar on ventilator-dependent children and adults captures the attention of the news media.

Surgeon General Appeals To Society To Share Problems Of The Handicapped

by **C. Everett Koop, MD**

This meeting is a natural follow-up to the Surgeon General's Workshop on Children with Handicaps and Their Families, which we held a year ago in Philadelphia. At that time, in my charge to the workshop participants I said, "The way we deal with problems like these reveals just what kind of society we are."

I think the record of the past 12 months is clear enough. It shows that we are still a caring and compassionate society — concerned about the health of children, sympathetic to the families who face enormous challenges in the course of accepting and raising a handicapped child, and innovative in the way we bend the political and economic environment to make it serve the human needs of our families, rather than the reverse.

But those are generalities. Actually, I have two specific reasons for being especially pleased to

open this conference this morning. First, I can't tell you how proud I am to be in the government, to have held a conference, and then, a year later, to be able to look back and see the results of that conference.

Even after two-plus years in this position, I still consider myself to be the new kid on the block in the Public Health Service. Many of my colleagues and friends in the Public Health Service have been fighting the battle of inertia for much longer than I. As the new kid, I haven't had the years of triumph and uncertainty that usually come with the territory of public service. But we've been very fortunate. In this highly complex and emotionally charged area of service to handicapped children and adults and their families, we've been able to make significant, measurable progress. I'm very proud of that — as a public servant and as your Surgeon General — and I hope you feel

the same way. In a single year, we may have made a difference in the lives of many hundreds of children and their families.

My second reason is a little different. Over the past year, we've been devoting our time to an issue that brooks no obstruction, that admits of no pettiness — an issue that inspires people to offer the best that is in them in order to plan and implement such a worthwhile program. The problems faced by ventilator-dependent patients and their families can be staggering. They are among the most complex problems to appear within the environment of medicine. They require innovative, careful relationships between medicine and community social services. These are also costly problems, requiring the help of accountants with the souls of saints. And the problems are also inextricably linked to a cluster of profound mys-

teries — the mystery of the human infant, the mystery of parenthood, the mystery of personal courage, and the mystery of family love.

As formidable a task as we set for ourselves, I have to nevertheless say that it was the right task. For too many years we had talked about this problem and we sympathized and commiserated and had come up with a number of steps to somehow lighten the burden for both the ventilator-dependent patient and his or her family. But clearly we were not doing enough.

Also, the way we were going about it said quite a bit about our intentions, generally in regard to the solving of many other serious socio-medical issues. The fact is, if we could pull together our resources in such a coherent and effective way that we could make good things happen for ventilator-dependent children, then we could do good things for many, many other disabled and handicapped children and adults.

You remember the words of Cassius to Brutus in Shakespeare's *Julius Caesar*. "The fault, dear Brutus, is not in our stars but in ourselves, that we are underlings." We so often defer to circumstance, as the Romans deferred to Caesar, and we become, in effect, the "underlings" of circumstance. That need not always be so. It is not written anywhere in the stars that disabled children, attached to machinery for the vital air of life, must go without any other help from their society. Nor is it written anywhere that other disabled and handicapped individuals, very young ones to very old ones, should be left outside the pale of assistance. That's just not the way we want our society to be.

So, with this project, addressing the needs of ventilator-dependent children and their families, we

declared our intention to blame the stars no longer, but rather to look to ourselves for what could be done. And I can tell you it worked.

At the close of last December's workshop, we affirmed our commitment to turn into reality as many of the workshop recommendations as possible. With us today are a number of the same people



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who had taken part in last year's program. And they have stories to tell us — stories of hope, professionalism, character, and I'm pleased to say, of success.

As an introduction to their contributions, let me briefly report on the status of the seven recommendations and how we're doing on them. As the top of the list last year was the need to get as clear a *definition of the problem* as we could. And by that, I don't mean to narrow down the problem and thus, in a sense, trivialize many of its aspects — quite the reverse. It was felt that the public as well as the medical and social service professions needed to appreciate the scope of the problem of care for

handicapped children and their families. We did not feel — and rightly so — that such appreciation was current.

I believe that the publication and distribution of the proceedings of the December workshop has contributed to this task of clarifying what the problem is. The workshop report does provide a common base of understanding for all persons with an interest in this problem.

Stimulated by this first recommendation regarding the definition of the problem, the Crippled Children's Program at the University of Illinois surveyed the status of ventilator therapy and support among children in Illinois. This makes Illinois the second state to obtain this kind of information. Pennsylvania was the first and has been updating its information base.

A similar study was also begun at the University of California at San Francisco. The health policy program at the university is investigating, for example, the increase in the last 25 years of the number of days of limited activity among children.

Additional efforts have included a "National Conference on Chronic Illnesses in Children," conducted last April by Vanderbilt University. This conference has helped us in a number of ways, but I'll mention in particular the attention it paid to the issue of research priorities regarding chronic illness among children.

Then, just this past October in Kalamazoo, MI, a three-day "Invitational Symposium on Ventilator-Dependent Children" was held. I understand it was quite a success. A full report of that symposium will soon be published in *Pediatrics* magazine, and I urge you all to watch for it. The Kalamazoo Symposium dealt with a num-

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ber of issues such as the need for better data, the problems associated with the financing of care from both public and private sources, the research needs of this field, and the major task of education that has to be done among parents, patients, health and social service professionals, and our communities in general.

The second recommendation of the workshop last December concerned the need for *model standards*. The workshop participants felt we needed to spend much more time and effort in developing standards that reflected the needs of the family as well as the concern for the quality of life of each disabled child. To get this work started, our division of Maternal and Child Health awarded two grants for special projects of regional and national significance now known as “Sprans” grants. One of these is the project at the University of Iowa. It will explore the relationships that develop between disabled children and the health professionals who take care of them.

The other, at the University of Michigan, is looking at standards of care that may be applied to regionalized community health services for children with diabetes. Such a regionalized support network would involve health and social service professionals, private professional and voluntary organizations, and local and state governmental agencies. It's an ambitious and very worthwhile project.

And that brings up the third recommendation which was to develop *regionalized systems of*

care for ventilator-dependent children.

Three “Sprans” grants have been awarded for the development of regionalized systems that deal specifically with ventilator-dependent children. The accent is on ways to help move children out of institutional settings and get them back home, or at least to a home-like setting. Naturally, the role played by effective community-based support systems is crucial.

Six other “Sprans” grants have been awarded for the development of model systems to serve children with arthritis. In all, the Public Health Service has awarded close to \$750,000 for the development of regionalized systems of care for disabled children.

Among the most exciting efforts in this area is the contract awarded by the Office of Human Development Services to the John F. Kennedy Institute in Baltimore. What we hope to accomplish here is a model for a working nationwide referral network for the developmentally disabled. Using today's sophisticated technology, it should be possible for a developmentally disabled individual, or the physician, parents, or care-takers of such an individual, to query a single source for information about that disability and pinpoint the best or most appropriate places to get help for the person so disabled — help anywhere in the country or possibly even the world.

This is no longer the “blue-sky” thinking of visionaries. We know it can be done because it is being done here and there, albeit in piece-meal fashion. But we look to

the Kennedy Institute to pull some of these things together.

Under the terms of this award, the strong features of two important information systems are to be combined and regionalized. One is a data retrieval system for the particular use of practicing physicians, and the other is accessible by the general public.

The database for the physician-oriented system was developed by the Kennedy Institute in Baltimore, using data supplied by the 38 university-affiliated facilities around the country. As a matter of fact the American Medical Association itself has a contract with Kennedy to bring the institute's data in as the fifth offering of the AMA's Nationwide Medical Information Network, or “Minet.” It is available to every “Minet” subscriber who has a desk-top computer and a telephone.

This enterprise nicely pulls together government, the private non-profit sector, and organized medicine — in this case, the AMA — to make information available to physicians concerning access to specialized care for their patients and the presence of community support services.

The other and more consumer-oriented data system is now functioning out of the University of South Carolina to benefit citizens of that state. The system carries information on access to care and community support services within the state. However, any individual or family member can get into the system merely by dialing a toll free “800” number. It isn't open only to physicians, for ex-

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ample.

The Kennedy Institute has an excellent concept of just how such a network will function. By means of the Kennedy Award, we hope to expand the South Carolina model to cover all the states in federal Region IV, and they are, in addition to South Carolina, Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, and Tennessee. If that works — and I am very optimistic that it will — then the next step is to "go national" as it were, and thus make available to all our citizens the best information and the most appropriate resources relative to handicapping conditions.

I'd like to add one additional point. The Kennedy Grant is for \$95,000. It is probably the greatest bargain today in the entire field of health care and social service R & D. But it also illustrates that the size of the problem may not always determine the costliness of the solution. As professionals in this field, we need to keep our minds open to what can be done and then pay what's necessary.

I agree that such a sentiment is easier to say than to live, and for that reason, we have been moving on the fourth recommendation, the one that deals with the *financing of care* for children with disabilities. Last May, we held another kind of workshop in Washington, D.C. on this problem.

The cost of care is an important and continuing concern of the administration. I can tell you that the May workshop and a subsequent meeting in June with officials of the Health Care Financing Admin-

istration have served to throw some light on more and better ways — within existing law and regulation — to help pay for more and better service to handicapped children.

But the problem will not go away with the conduct of one workshop or the scheduling of one meeting. For that reason, I am setting as a personal objective the need to keep track of all developments in the financing of care so that the potential for increased support is fully realized and every child who needs care will get it. I know that is clearly the feeling here in our host state of Missouri, and I want to recognize the leadership given to this complex issue by Governor Bond.

Three other recommendations are worth mentioning, although I would rather not take the time to comment on them right now. They are: *Identifying areas of potential abuse*. That is, controlling costs, eliminating duplicative services, monitoring care according to model standards, and so on. Another is *incorporating principles of care for children with disabilities into training programs for health professionals and parents* which is a straightforward enough recommendation. I can report that an Ad Hoc Committee dedicated to following up this training recommendation met last June, with representation from across a broad spectrum of health, social service and educational specialties.

The seventh recommendation from our first workshop has to do with *supporting research in the care of children with disabilities*. The Vanderbilt study that I men-

tioned earlier, has been helpful in giving us some direction in our research strategy.

I hope you feel as good as I do about this record of achievement over the past 12 months. It does demonstrate that concerned citizens — health and social service professionals, government officials, and lay citizens — can focus their interests and energies on a particular issue and make a difference in the outcome of the public debate, and that disabled children and adults will benefit.

In these remarks I have measured progress according to what's been accomplished on the recommendations of last year's workshop. But many other things have happened over the past year, and I would be remiss if I did not recognize that. In fact, I would like to pay special attention to an event that took place in Washington, D.C. on November 29.

On that day, representatives of nine national organizations came together at a press conference. They convened to announce their agreement on a joint statement entitled, "Principles of Treatment of Disabled Infants." The nine participants included:

- The American Academy of Pediatrics
- The American Association of University-Affiliated Programs
- The American Association of Mental Deficiency
- The American Coalition of Citizens with Disabilities
- The Association for the Severely Handicapped

- The National Association of Children's Hospitals and Related Institutions
- The Association for Retarded Citizens — United States
- The National Down's Syndrome Congress
- The Spina Bifida Association of America

The first statement of their statement reflects a great deal of social, legal, and medical history of the past few decades. It says, "Discrimination of any type against any individual with a disability/disabilities, regardless of the nature or severity of the disability, is morally and legally indefensible."

The statement goes on to highlight the "need for information" which will "improve decision-making about disabled individuals,

especially newborns." Medical care and the role of both government and the community are also dealt with in this statement. If you have not read it, I urge you to get a copy by writing directly to any of the nine signatories.

At the beginning of this year, I doubt that more than two or three of these nine groups could have agreed on such a broad statement, although they all believe deeply in the issues as well as in the need to keep moving forward. As the debate over the "Baby Doe" cases unfolded, I think the need for accommodation and consensus became increasingly clear to everyone. Yes, principles are at stake, but they are not at risk.

Events have made this past year both hectic and crowded, but it

has been a gratifying year as well. I've not been gone that long from the Children's Hospital of Philadelphia that I've forgotten the enormous personal and family problems faced by a number of my former patients — little children who had to be hooked up to a ventilator to get through the first few months of life with a disability.

So the hard work of the past year does have its very precious rewards. More children and more adults are going to get a better break in life, as a result of what we've accomplished and what we intend to accomplish. It seems to me that getting deeply involved in this kind of issue is precisely what an office such as mine ought to do — or else — what are Surgeon Generals for? ●