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Surgeon General's Summary and
Charge to the Group

Campaign '87: Commitment to
"Family Centered Coordinated Care
For Children with Health Care Needs"
Houston, Texas
June 14-16, 1987

The previous address was given at the opening at that conference. This was given at the close.

All of my speeches and other addresses are prepared in advance and I tried to stick pretty close to that text or a corrected text that I prepare on the way to the venue in question. This address was given off the cuff; it wasn't planned this way. As I said in the previous lecture's introduction, this is not a Surgeon General's Workshop, it is a Conference and therefore, I skipped the charge and instead, at the beginning brought them a report on what had been going on since 1982. During the meeting, those who organized it prevailed upon me to close the meeting with my observations and recommendations. That is the substance of this talk. For that reason, this is a very personal account and it lacks the polish that comes with having the luxury of doing several drafts.

My opening remarks were general about a lot of things: my pediatric surgical background, my concern about the questions I'd heard over the previous two days, the problems that parents face, the death of children, the vicissitudes of marriage, the way chronic illness threatens marriages, training of pediatric surgeons, the nature of my surgical practice, and the development of a surgical group, the extra surgical problems of being a surgeon, the care and feeding of parents by resident physicians, the use of a medical student as the manager of a child's family in time of crisis, the use of 800 numbers and computers in the care of a child, and so on.

I mentioned the Surgeon General's Workshop I would have the following September at UCLA on "Self-help and Mutual Aid", and talked about the tremendous advantageous that such a program could have for the families of children with handicaps or special problems.

I then talked about the disabilities that one can see from the outside and those that children can hide from the passer-by. That was a favorite subject of mine throughout my years as a pediatric surgical trainer and this seemed a good place to talk about it as a philosophical problem. The kids on crutches that were picked up by a yellow-school bus and taken to a special school for handicapped children had it ever so much easier in the long run than the kids who had an inborn error of metabolism and who, in a sense, fought the problems on their own.

I then approached another problem, which was a subject of many of my seminars, and that is how easy it is when one is of sound mind and body to forget that heredity and congenital disturbances can be mimicked in a flash by trauma. That means that the coordinated community-based care we seek for others today may be our own potential need tomorrow.

Then I found myself slipping off into believing that I had the opportunity to leave a charge with that group, and I started by calling on the Division of Maternal and Child Health to assist in the development of systems of care at the community level. I also asked them to insure that these systems were coordinated, flexible, and sensitive to cultural differences and families. I also asked that they develop interdisciplinary educational programs at the pre-service and in-service levels in which families could participate.

A major report was being prepared, at that time at the University of Iowa, through the "Future Directions of Services for Children with Special Health Care Needs" project. That gave me the opportunity to recognize an old and valued friend, Dr. John MacQueen, who provided leadership throughout his distinguished career on such matters and was a quite architect in building systems that were truly responsive to family needs.

I asked the Division of Maternal and Child Health to work with the Department of Education on the implementation of Public Law 99-457 in order to coordinate services to the youngest and smallest members of society and their families. Here I had the opportunity to mention, Mrs. Madeleine Will, Assistant Secretary for Special Education with whom I shared concerns many times and for whom I had great respect. A joint report to Congress on early intervention services is indeed now being prepared by the two agencies.

I also promised that I, with the Department of Maternal and Child Health would meet with Dr. Jean Elder, Assistant Secretary Designee, Office of Human Development services to look at ways to use the Social Services system to improve support to families through respite care.

In reference to financing, I asked that division to work with coalitions of parents, providers, and payers to continue efforts to find solutions to the very complex problems of financing care for these children.

Here I mentioned the cooperation we always had had with Dr. Bill Roper, Director of the Health care Financing Administration at that time, who has remained involved in public health matters with me ever since I left the office of Surgeon General.

I closed with the reminder that children are the future of our nation, our most precious resources and made the final plea that we join hands and forces today and go forward together dedicating ourselves to improving the care and lives of these very special citizens and their families