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SURGEON GENERAL'S SUMMARY

CAMPAIGN '87: COMMITMENT TO
FAMILY CENTERED COORDINATED CARE
FOR CHILDREN WITH SPECIAL
HEALTH CARE NEEDS

JUNE 16, 1987

HOUSTON, TEXAS

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AND

CHARGE TO THE GROUP

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June 14-16, 1987

Houston, Texas

Usually at the end of a conference like this while you are all winding down, I am getting more tense because I have to respond with unprepared remarks based upon things that have happened. This hasn't been the usual Surgeon General's Conference where I give a charge at the beginning and do this at the end. Instead I gave you the report at the beginning and foolishly I thought that that meant I could go home yesterday and that's not how it turned out. You all know that I was a pediatric surgeon and I was that for just a little more than thirty-five years. I guess the most frequent question that people ask me in this job is, "Do you miss surgery?" and I always answer in the same way, because it's the truth, I say, "No, I don't miss surgical procedures, per se; I've seen and listened to (remember that, listened to) all the hemorrhage that I wanted, and gullibly breathe faster! Secondly, I have to admit, I don't miss children, per se; but what I do miss is being able to find the sore point of anxiety of parents and set them on their way with the understanding that their problem has been or will be solved to the best of our ability as health professionals and I do miss that because I realize now, in retrospect, that that's why I got my kicks out of them for all years".

In meeting with you these last several days, puts me right back where I was, because many of you have come to me and you have revealed to me the sore point of your anxiety and the problems that I face today and yesterday are the same problems I've faced all those years - I can't solve all problems, but I want you to know that that doesn't mean I haven't heard them; that doesn't mean I don't care and it doesn't mean that I wouldn't like to do something about them.

I would like to start this afternoon by paying tribute to parents who have children of the type that we're concerned about here. These parents face very major adjustments to lifelong differences in a child, if not lifelong disabilities. Others face the prospect of knowing that they will lose a child and these people lose their children twice - once when they know the diagnosis and the prognosis and once when it really happens; and although there is a sense of relief and release when death does come to some children, there is no doubt about the

fact that you never get over the death of a child; and many of you know that I've been through that, too, and I speak with some authority on that subject. Most parents face their problems with what seems to me to be an extraordinary degree of equanimity. Even in their frustrations, they manage to do things that are important because they seem to be able to change the system to help others overcome the pitfalls that they encountered to somehow or other help others to cope. Some face family breakdown, which I think is perhaps the most tragic thing of all those things that we discuss around the care of these special children; and as I have pondered this question, I have sought to find what we could do in the way of preventive measures and I have to say that I've come back over and over again to the same thought that in marriage, especially when it is fraught with the kinds of problems that we understand so well, we have to ask people to center on the commitment to marriage and the commitment to family rather than on a commitment to a spouse. Now, that may sound queer to you, but think about it, and I think you'll recognize that the marriages that have endured through these tragic circumstances are indeed those marriages and I think that in addition to that, the generation that is now raising normal children owe to them the honesty that reveals what the human condition is all about, so that they can understand to some extent the quality and the nature of human relationships. I really believe that a realistic appraisal of the human condition is far preferable to what at the present time seems to me to be a cross between hypocrisy at some times and fantasy at other times, but parents, let me just say that my hat is off to you.

I'd like now to go over a few random thoughts that I've picked up from the meetings and also from conversations here in the corridors, how to teach physicians, nurses and other health care professionals, to be explicitly sensitive to the feelings of the family of the child with special needs. I used to face this problem, because in addition to being a pediatric surgeon I was also a trainer of pediatric surgeons. The law of residency programs limited me to training one man each year for two year periods so that they leapfrog up the ladder, so that I always had two people I was training to be pediatric surgeons. But, in

the course of the year, I had an additional sixteen to twenty surgeons that I really tried to train to be so afraid of me, I had to make sure that they wouldn't try it. Well, what I wanted them to do was to understand the problems of families and I did not ever have the time to sit down with each of the sixteen or twenty, because they came through peculiar rotations and tell them all the things that I have learned about parents, but I used to put it this way: I said, no matter what you see here in a child's problem, and no matter how mundane it might be to you, it is to that family an overwhelming burden and indeed, it might be an impending tragedy; and I would just ask you, Dr. Resident, to behave toward that family in such a way on every occasion, that even though we are unsuccessful and we lose this child, that the mother wants to come back to this hospital where it all happened and become a volunteer to help other parents.

How do you overcome the problems of changes in doctors, the red tape, the delays in hospitals and clinics? I'm not sure that you can, but that doesn't mean that I don't think that you should try. I think one has to consider whether or not the benefits of a multi-disciplinary team of the kinds of specialist that a child needs under these circumstances, may outweigh all those other joint problems. One solution that I think could work in those communities that have a medical student is to assign a medical student as the manager, the advisor and the coordinator of the family with such a child. Now that wouldn't by any means cover all the children, but what it might do is raise a whole generation of physicians who understood this problem because they had dealt with and had the absolute grass roots level that they had put themselves in the position of the family; they understood the resources and the modes of access to them, but most important of all, they could train those that followed them to understand the same thing.

What aids can we provide for the support of such people until that day comes? I'll mention only two, although, of course there are more. Many of you have heard me speak of these before. One is a physician/health care worker-oriented database that can be queried by

a health professional who only has to know the diagnosis of this patient and the city in which that patient lives and he learns from the computer everything that is available to that child from a place where diagnosis and treatment can be carried out to a place where family support mechanisms can also be found. The second one is a patient-oriented system of the same type. Access by an '800' number, where a competent health professional, with the aid of a computer, can answer practically every question that a parent has after the parent has left the institution and is now out in that tremendous field where most people find they have to fend more often for themselves than with the help of others.

I might mention a project that is taking place that can feedback, I think, on some of the things that you are trying to accomplish in your own communities. Next September at UCLA, we will be having a three day conference on "Self-Help and Mutual Aid". There are enormous numbers of groups around the country that are engaged in self-help and mutual aid, usually based around a diagnostic problem, where parents get together and share their concerns and their triumphs but also teach others how to avoid their tragedies. Many of these overlap and duplicate each other and I was absolutely astounded when I began to look into this that in the State of New Jersey alone for example, there are 30,000 such self-help mutual aid organizations. They don't even know the others exist. They overlap and they duplicate. What we want to do in California next September, is to have a clearing house function, so we know who they all are and then have some kind of a networking procedure that will rid us of the duplication and the problems of overlap and provide for less money/better service for children. If you think about it, self-help and mutual aid causes every single initiative and every function of the Department of Health and Human Services and I am certain that some of these activities could actually be ancillary to the goals of this conference.

In the city where I practised for forty years, it was possible for a child with an orthopedic problem to be picked up by a yellow school bus, taken to a very special school for orthopedically handicapped children

and there the school was not only in a beautiful setting but its academic standards were extraordinary, their teaching was great and the equipment that they had for students was outstanding. The bus took the children to school, picked them up and took them to their homes and in the summertime it added other perks such as summer camps and everyday that bus passed many children en route to the school, children who had incontinence of urine and feces, children who were in the midst of a series of operations for hypospadias (for those of you who don't know what that is - the opening of the urethra in the male penis is not at the tip where it belongs but some place back towards the scrotum) - these youngsters have the terribly embarrassing problem going to school and instead of standing in front of a urinal like all the other boys, they have to sit down on the toilet like a girl. There are children who have a short bowel syndrome - they are not incontinent but because they have so little bowel and cannot absorb all of the moisture in their nutritional intake and, therefore, they have what amounts to the need to go to the toilet may be six, eight, ten, twelve times a day. There are other children who have colostomy, temporary or permanent. There are those who have an even more difficult similar situation, an ileostomy, and then there are the rare children who have the ureterostomy, where the ureters are joined together and empty onto the abdominal wall. Now these silent, invisible chronic or temporary long term difficulties must be addressed just as readily as we address the visible ones and care so well for children who have things that we understand rather than those which we never see.

Another thing that I have been reminded of during these past several days, is that we need to remind those of sound mind and body that hereditary and congenital disturbances can be mimicked in a flash by trauma. That the coordinated community-based care we seek for others today, may be their potential need tomorrow. For example, a spinal cord injury can result in the same orthopedic, gastrointestinal, neurological and urologic dysfunction exhibited by a youngster who was born with spina bifida; and as pediatric trauma becomes more successfully treated by advanced techniques, there are going to be an

increasing number of children who are presented to us who have the same special health care needs that we used to think were reserved for those with hereditary or congenital malfunctions. Because pediatric trauma is going to save more lives, but remember that with that improvement in result will come the intended heartache, the rehabilitation challenge, the need for comprehensive care, and of course the economic burden as well.

Now let me leave those rampant thoughts for a moment and turn to a look at the future and let me say that the call to action presented to you in the report delivered at your registration is a call to partnerships; it is a call to strengthen existing partnerships and a call to deal through partnerships; partnerships with families between families and states and among families, states and health care financing sector. I believe these partnerships will lead to the assurance of the family center community-based coordinated care we are all working so hard to achieve for our nation's families.

Therefore, I am calling on the Division of Maternal and Child Health to assist in the development of systems of care at the community level that demonstrate responsiveness to the strengths and needs of families that are developed through a partnership between parents and professionals.

I am calling on them also to insure that these systems of care are coordinated, flexible and sensitive to cultural differences in families. I am calling upon them to develop inter-disciplinary educational programs at the pre-service and in-service levels in which families participate in the development of curricula and in the preparation of providers to serve their essential role.

As many of you know, a major report is being prepared at the University of Iowa through the **Future Directions of Services for Children with Special Health Care Needs** project. It will be a landmark publication and will provide in-depth analysis and substantive information on the difficult and complex issues we have

dealt with over the past four years as we have struggled to improve and expand family-centered, community-based coordinated care. I would like to take this opportunity to recognize Dr. John MacQueen for his leadership throughout his distinguished career as a quiet architect in building systems truly responsive to family needs. A symposium on Thursday in Iowa for Dr. MacQueen recognizes these contributions as he retires from his position as director of the State program. Dr. Hutchins was to be a part of that symposium and I, for him, express our appreciation to John for his lifelong service and concern for children and their families.

The report will be completed this year and Maternal and Child Health and the University of Iowa will launch the report as a major milestone in furthering of family-centered, community-based coordinated care. The Division of Maternal and Child Health will, as a major priority for their discretionary Special Projects of Regional and National Significance funds, provide grants to states to assist them in developing "family centered, community-based coordinated care systems." These funds will help the States mobilize the coalitions--parents, providers and payers --and maximize all resources--public, private and voluntary. The information and knowledge you have gained at this conference will help you accomplish this task.

In order to facilitate a comprehensive approach to services, partnerships must continue to be developed with other Federal agencies I am particularly asking 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 our society and their families. Mrs. Madeleine Will, Assistant Secretary for Special Education, shares our concerns and has been totally supportive of strong Federal collaboration among families, health and education. On July 15 and 16, representative of all States are being invited to Washington for a meeting jointly sponsored by the Division of Maternal

and Child Health and OSERS to continue building partnerships and developing strategies for the implementation of this new law. A joint report to Congress on early intervention services is being prepared also by the two agencies. We are committed to working closely and collaboratively with parents, providers and States in implementing this legislation.

Also, I, with DMCH, will 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, Head Start, child care --in order to strengthen families rather than respond after crisis and disintegration have occurred.

On the issue of financing-- I am asking the Division of Maternal and Child Health, working with coalitions of parents, providers and payers -- to continue efforts to find solutions to the very complex problems of financing care for these children. For example, the leadership from Blue Cross/Blue Shield of Texas will be shared with other across the country and I, with the Division of Maternal and Child Health, will meet with Dr. Bill Roper, Director of the Health Care Financing Administration, to continue ongoing efforts to provide quality care in cost-effective ways. The American Academy of Pediatrics through its project on the underinsured and uninsured supports these efforts to finance the care of children with special health care needs.

As long as I am Surgeon General, parents, providers and payers will be a part of all of these deliberations. This meeting has been dedicated to the children ^{in whom} ~~in~~ this fund ^{must} ~~for~~ which special health care needs ~~and~~ ^{for children} and their families. ^{and} As I mentioned in my report, as a parent and a pediatric surgeon, I have felt a special commitment to these children and their families for over forty years.

Children are the future of our nation, our most precious resources. Let us join hands and forces today-- and go forward together-- dedicating ourselves at this very moment-- to improving the care and lives of these very special citizens and their families.