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Remarks

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This lecture is included in this archive because it concentrates on one of the most difficult aspects of my interest in and concern about special needs children and their families – the transition from pediatric care to adult medical supervision. This has always been a difficult aspect of the care of special needs children and even as late as this year – 2003 – I've been speaking publicly about the fact that we have to do more in this country to make this transition a safe one for children and a satisfactory one for their families.

I began the actual lecture by reminding the audience that we had established a National Agenda and I ticked off seven major initiatives that were moving forward and recalled that the previous year 1,200 participants from medicine, health, education, social service fields, and families joined us at the September Surgeon General's Conference in Washington.

The one area I felt had not been properly addressed in all that we had done about special needs children, was the barrier youngsters encounter and must surmount if they were to secure ongoing quality medical care as they made that transition from childhood to adulthood. Those present were invited by me as leaders in the major organizations and professions, which provided these services to help us solve that problem.

This was to be my last Surgeon General's Workshop and was sort of a personal effort to close the loop on the conference some of us had in June 1984 at Wayzata, Minnesota, a conference on youth with disabilities: "The Transition Years". That's when I first spoke on the subject that has been a favorite of mine ever since – "Who Are the Disabled Among Us." Although, I left the question unanswered, I think the implication was clear that some members of society were more handicapped than those we called disabled, but they were handicapped by attitude, prejudice and tunnel vision.

I then took an optimistic turn to talk about five major areas where I thought we were making progress and took this opportunity to do something I very infrequently did and that was to get something off my chest and castigate ASTHO – the Association of State and Territorial Health Officers for their behavior since my arrival in Washington. They believed the adverse publicity about me, when I arrived and never changed their minds.

ASTHO and the Surgeon General should be, for this country, a united front that initiates and sees follow-up come to fruition on the major health problems that affect the states and the territories. Nearing the time that I was about to leave my post, they invited me to their meeting the following month, but it was a half-hearted invitation, because they couldn't find the money for my airfare nor the will to meet me at the airport, so I did not plan to attend. I had hoped that in the future the leadership of ASTHO would try harder with my successor than they did with me. (They did not.)

I then went over what was wrong with available transitions services and concepts and summarized the basic underlying defect in the system as one that has to do with the lack of transition protocol for ordinary adolescents from pediatric to adult services. Strangely enough, part of that is because the population in general enjoys its healthiest years in the decade after adolescence. Not so for special needs children. I acknowledged that the pediatricians and internists that I was speaking to were not typical, but I had been involved for enough years with enough youngsters to know that they were having more trouble than they need growing up. An additional problem is that parents don't want to leave the familiarity, security, and expertise of what they have for the unknown – which usually turns out to make them suffer greatly in comparison with the known.

Pediatricians too – understandably – have a tremendous interest and investment that encourages them to cling to the patient longer than they know is necessary or even in the patient's best interest.

I was very blunt in saying that responsible adult care givers have lots of things to overcome: first, the idea that pediatricians play medical games with their patients and over indulge their patient's parents. Second, the truth that the parents know more about the child, and his problem, and the goals of his care than does the new practitioner. Third, the idea that it is not unreasonable for parents to be anxious, to expect satisfactory explanations, and to want to be part of any decision-making.

I have long accepted in my own mind that the adult caregiver will probably never have the same creative interest that was the priceless ingredient of the former situation, indeed may have been the adhesive that held it together.

Because I had been there, I said all these things. Some of the diagnoses I dealt with required 10 to 15 years of constant attention to ensure maximal rehabilitation of the infant who became a toddler, and then a child, and finally, an adolescent. I acknowledged that my interests were very proprietary. In our mobile society, I inherited lots of new patients – by referral – when they were halfway – or more or less – through their rehabilitation process. I know that my enthusiasm for them was not the same as it was for a child I had been caring for since birth. If that was the case with me, think how difficult it is for the reluctant physician.

One of the reasons that I called this workshop together was that even as I spoke, as hard as you might imagine it is for a stranger to beat his way through the bureaucracy and finally got to talk to me personally, not a month went by that an old patient eventually found me to ask me to intervene in a situation where one barrier or another had become insurmountable.

Everything I had been talking about was made more difficult by the fact that the care I wanted was labor intensive care, it was expensive, and reimbursement systems had not yet caught up with that fact.

Using my crystal ball based upon the previous almost 8 years of experience as Surgeon General, I realized that the two populations of greater risk of disenfranchisement were the elderly and the children. Each would fight harder than ever before for the funds to care for themselves and that would make it difficult for children with special needs.

I closed with a pessimistic note that I did not expect any administration or any Congress to address this issue on the clear merits of the situation. However, I felt in my heart that the day would come when the business community would cry for help as the cost of health care made us non-competitive in world markets. (That day has come!) What I don't see now in 2003 is any special plan being made for any special needs children so they are not short-changed as the health care delivery system is now being rebuilt.

(For the user who has been reading any of my positions on unintentional injury in children, please be aware that a lot of the special needs children I've been referring to here, started off life as normal healthy children, until they ran into an "accident" that we probably could have prevented and their lives and those of their families and communities have been unbelievably changed from that day and will remain so until the die.)