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Address

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This was the third occasion on which I had addressed an annual convention of the National Down Syndrome Congress. The last time I had met with them, we were in the midst of a profoundly significant debate that had been set off by the tragic circumstances surrounding the birth and untimely death, a week later, of "Baby Doe." "Baby Doe" in essence was the quintessential ethical problem: a Down's baby with a readily correctible surgical lesion. In summary, he was allowed to die at the family's request, because they had been presented with absolutely false information by an obstetrician who should have known better.

Early on I acknowledge my gratefulness to Madeleine Will, the Assistant Secretary for Education (special education).

I was introduced by a Down syndrome adolescent boy. I will never forget it. He walked to the front of the stage with that deliberate way that is typical of Down's children. He stood there and looked over the audience like a professional comedian. Then, with a straight face, he said: "You have forty-six chromosomes. I have forty-seven chromosomes, anyone want my extra chromosome?"

He took down the house and I never felt more upstaged in my life and I couldn't have been happier that it was by a Down syndrome child.

The theme of the meeting was "Access to Care" and I chose to address that subject, as well as a second challenge, -- "The Continuity of Care".

I referred to some of the things that had been accomplished by Surgeon General's Workshops and spoke first of 1982 meeting held at the Children's Hospital of Philadelphia entitled, "Surgeon General's Workshop on Children with Handicaps and Their Families". And then, an offshoot from that in 1987 where we codified the approach of family-centered, community-based, comprehensive, coordinated health care, with a "Surgeon General's Workshop on Children with Special Health Care Needs", which we held in Houston, in June of that year.

I also mentioned a third meeting convened on this same subject in Washington the previous September. At each of these meetings advocates for Down syndrome children and their families had been prominent and extremely helpful

In general, my talk expanded on the two concepts mentioned above, but illustrated by family-centered, community based, comprehensive health and social service.

Continuity of care which for children switching from the care of a pediatrician to a primary care physician, dealing with adults is always a time when some children can slip through the cracks. It's not addressed as often as other points of view, but if there is any point of disjunction in the health system for children with Down syndrome, or other developmental problems, it is when the child passes from a pediatrics to the care of another specialty.

This provided the opportunity to talk about the fact that we had set in motion plans to bring a group of people together to focus on the problem of transitional care and come up with some good suggestions for correcting it. For planning purposes we were calling it "Surgeon General's Workshop on the Transition of Health Care for Adolescents with Special Needs". We were looking forward to the spring of 1989, and I expanded on the people we would need to help us and what I hoped we would accomplish by it.

I felt very close to those who attended Down Syndrome Congresses, and reminded them that at the same time the next year, I would be out of uniform, but not out of touch.