

STATEMENT OF
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before

THE LABOR AND HUMAN RESOURCES COMMITTEE OF THE UNITED STATES SENATE

concerning

THE CONFIRMATION HEARINGS OF

C. EVERETT KOOP, M.D.

for

SURGEON GENERAL OF THE
UNITED STATES PUBLIC HEALTH SERVICE

Senator Hatch, members of the Committee, I am pleased to appear before this Committee supporting the nomination of Dr. C. Everett Koop as Surgeon General of the United States.

I am appearing before you as the mother of a severely disabled young man and as a concerned citizen. As my son ages, I have come to realize that the Surgeon General can have a direct impact on my son's life, probably more than any other

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physician. The Surgeon General has the responsibility to report and track the trends of America's health. However in the past, problems of people like my son have been overlooked. The health care needs of the disabled as they relate to information dissemination on chronic disease management have been seriously neglected.

It is important for you to understand my reason for supporting Dr. Koop, for the position of Surgeon General. As the parent of a severely disabled person, I have great concerns for my son's future and the future of those persons who have diseases that must be managed medically. There has been no Surgeon General, to my knowledge, who has advocated for disabled people and whose professional experience gives insight into the problems of the aging disabled.

My son Paul became severely disabled at 14 months. From the moment my husband and I were told that our first born would be permanently disabled, our lives, our hopes for the future, our plans were totally altered. Physicians told us that our son might have to be institutionalized. The reasons varied - total physical and mental disability, possibly an infectious disease or even a progressive degenerative disease. They offered us no diagnosis.

Today Paul is at home and in a wheelchair. He is the victim of a disease that has yet to be diagnosed, after fourteen years of medical testing. He cannot go to the bathroom or feed himself. In spite of this, he has a keen mind and he takes a vital interest in life. He goes to a public high school where he maintains a "B"

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average even though he cannot hold a pencil.

Recently, I read in a Mid-western newspaper that one in every seven Americans has a medical condition which severely limits his or her activity. In the past, one thought of a disabled child as a rarity. Although Paul is the only child in his public school in a wheelchair, he is not the only one who is disabled. The unfortunate truth is that many other children have not been integrated into the public school system. It was reported by the New York Times that 12,684 disabled children had to be placed on a waiting list in order to enter New York public schools because there were not enough teachers and schools to accommodate the children. This was one week before school started. As the rates of functional disability are increasing and as the rates of medical conditions resulting in disability are also increasing, who then is looking after the health care needs of all these people? The Surgeon General of the United States should be. Frankly, I want someone as Surgeon General who has the professional background, interest, insight and drive to look to the future health care needs for all American citizens, including the disabled. This is why I am supporting Dr. Koop's nomination as Surgeon General.

Senators, children who are disabled and denied access to services are second class citizens in the country of their birth. For how long will we continue to abuse them? Barriers to human potential are destructive and humiliating, whether they are architectural or attitudinal. My son is part of a large and forgotten minority. To his family and friends he is a person, a human being with dreams, talents and rights. What is he to

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the nation? What is his future?

My family came to the United States in 1631. It is a family which prides itself on self-accomplishment. My ancestors fought and worked to secure the basic human rights that Americans have come to take for granted - those same rights that are now being denied my own son. My family finds itself in the unaccustomed position of being a "beggar", begging for the very rights that my ancestors fought to ensure him. I resent having to justify my son's rights as if those rights were a privilege.

Everyone reaches a point in his or her life when he needs help. Removing architectural barriers is not something that one person or one family can do alone. Many of the devastating situations we have experienced could have been mitigated had there been parents groups or understanding "professionals" sharing information on how to fight for our son. The emotional, physical and financial strain that a family with a disabled child endures is incaluable - it is small wonder so many families break under the pressure.

Do not misunderstand me, my family is willing to carry its share, to work to pay for the enormous expenses, to volunteer to help other disabled so as to bring about changes. My husband and I are on many boards as volunteers and I serve as the Volunteer Director of an Office for the Disabled in New York State. However, contrary to current beliefs, we cannot do it alone. The disabled and parents of the disabled need leadership, guidance, but above all we need commitment and someone who is involved in public policy that believes our fight is worth fighting. When we are isolated in our local communities, we need to know someone is

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working for our interests. That gives us hope. We need hope, more than ever, that Section 504 of the Rehabilitation Act of 1973, as amended, will not be gutted; hope, that the government programs will reach those for whom they were intended; hope that the horrible regulatory morass is made more flexible; and hope that someone is concerned about the health care needs of the disabled person as he or she ages. Although there are historical reasons why programs for the disabled are fragmented, chaos reigns for the disabled person in accessing comprehensive care. The incidence rates for disability are so high this nation can no longer postpone a comprehensive look at disability policy, but to do so means people must understand the problems.

During the past months, I have participated with Dr. Koop on panel discussions surrounding the issues of disability. I must say he is the first person I have met in such a government position that I did not have to go "begging" to for understanding. He asks my opinion for ways to affect the health and well-being of the disabled. I have observed also that Dr. Koop has tapped the expertise within the Public Health Service to broaden his own understanding - he has disabled staff persons who bring an even different perspective.

I do not expect Dr. Koop to correct all the problems of the disabled but he, as Surgeon General, could influence research, acquaint the nation of the medical/health care problems as well as suggest approaches to these problems. Illustrative of one such approach is an information system for providers and parents which would access information on places for diagnosis, treatment centers

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and specialized agencies, public and private, which serve the disabled. In our discussions he has advocated another idea which would establish a nation wide network of parents groups who could share their experiences as well as their failures. To have had either one of these resources as my child was growing would have lessened the trauma.

My husband is a physician who specializes in treating chronic disabling conditions. One might think that having a physician in the family would somehow lessen the anguish and frustration of having a severely disabled child- it does not. After our family went through a period of adjustment, we realized that dealing with the system and trying to get information on health and education services was nearly as traumatizing as the realization that our son was disabled. I believe that the nation needs in these times of limited resources, a compassionate and competent chief physician who understands how the system works. Dr. Koop's more than thirty years of experience in caring for children from childhood to adulthood, his work with underdeveloped nations and his understanding of the frustrations faced by parents, as well as the disabled person are the reasons why this Committee should vote to support his nomination as Surgeon General of the United States.

Thank you for allowing me to appear before this Committee.