

“Our commitment to the Disabled Child”
Presented to the
10th Anniversary Conference of the National Association for the Severely Handicapped
San Francisco, California
November 3, 1983

This was a natural and comfortable speech for me having spent all of my professional career at the Children’s Hospital of Philadelphia at the University of Pennsylvania, involved with handicapped children or as we came to call them later on, “Special Needs Children”. Now addressing an organization that has been on the cutting-edge of care for the severely handicapped seemed natural.

During the introduction, I mentioned Madeline Will, the Assistant Secretary for Education for Special Education, a personal friend and a long-time ally in fighting for the rights and privileges for severely handicapped youngsters.

This was the second time that I had the opportunity to speak about “Baby Doe” and the “Baby Doe Regulations” although some subsequent speeches will dissect the problems much more thoroughly than this rather superficial summary of some of the problems associated therewith.

In reference to “Baby Doe”, I’m speaking here after the first “Baby Doe” regulations had been written, after Health and Human Services had been challenged and taken to court, after Judge Gerhard Gesell had ruled against the governments procedure and we went back to revise what we had done in ~~the~~ more acceptable fashion to the courts.

Our second try with regulation was published on July 5th, and between then and September 6th the office of Civil Rights, which is the sponsor of this regulation, received 16,000 comments. Contrast that with the original “#504” regulation, the one that was the “host” so to speak, for the “Baby Doe Regulation”, which drew little more than 700 comments before it became final back in May of 1977.

Because the “Baby Doe Regulation #1” was still in the process of receiving comments, I could not talk about specifics, but rather use this occasion to talk about the philosophy behind the establishment of such regulations.

Many of the philosophical points made herein are part and parcel of my forty-year experience as a pediatric surgeon where I dealt with “Baby Does” probably as much as any physician in America ever had. My reference to “Baby Doe” here refers to infants having congenital defects ^{INCOMPATIBLE} recognizable with the life but amenable to surgical corrections.

Although this lecture expresses my sentiments, developed over a life-time in pediatric surgery and a part of public health experience since, I do believe it is excellent background for teaching not only the doctor/patient relationship, but especially in

handling their problems that the family, community, and profession face when dealing with a handicapped child.

Baby Doe Regulation #2
Burn out
Common sense
Compassion
Congenital birth defects rising
Competency in care
Dilemmas of the neonatal nursery
Every life uniquely important
Infant mortality declining without
rise in morbidity
Life as an entitlement in contrast to the
act of dying
Narrowing of the "Gray Area" in decision
making
Neural tube defects dropping
Professionalism
Profile of physicians & parents who
care for the handicapped
Restraining hopelessness vs. false hope
Self-determination of handicapped children
& young adults
Social services
Technology control
The appropriateness of saving every human
life
The effect of mere predictions of Baby Doe
Regulation #1 on the health
profession
The role of conscience in the care of the
handicapped
The rewards of caring for the handicapped
Training of physicians to deal with the
whole handicapped child