

**F-26. Effect of Government Regulations on Death Rates of Severely Disabled, Cerebral Palsy Children**

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**OBJECTIVES:** An infant with Down syndrome, Baby Doe, was allowed to die without elective surgery. Strong public outcry resulted in U.S. federal laws and regulations (1982 and 1985) mandating medical care for all newborns. These laws should have resulted in increased medical care provided to disabled children, and in decreased death rates. We analyzed death rates of severely disabled CP children at a 98-bed, pediatric-skilled nursing facility from 1970 to 2002.

**STATISTICAL METHODS:** The  $\chi^2$  and PROC MULT-TEST.

**RESULTS:** During the 1970s, the overall death rate was 72%. In the 1980s it was 45%; in the 1990s, 26%. The 10-year death rates were significantly different (1970s vs. 1980s,  $p < 0.0005$ ; 1980s vs. 1990s,  $p < 0.001$ ). The 5-year death rate in 1980–1984 (35%) compared to the rate in 1985–1989 (20%) was also significantly different ( $p < 0.01$ ). After 1985, the death rate did not change. There was also an increase in the median age of death: 1970s: 1 year, 1 month; 1980s: 3 years, 8 months; 1990s: 4 years, 8 months; 2000–2002: 15 years, 6 months. Deaths in the 1970s were primarily due to pneumonia from aspiration of food. The first G-tube was placed in 1978. In 1982, 2% of residents were fed by G-tube; by 1985; 52%. Providing adequate nutrition without aspiration was a major factor in decreased death rates.

**CONCLUSION:** U.S. federal regulations of the early 1980s fostered an atmosphere of providing disabled children with full access to medical care. When these children's needs were met, there was a dramatic decrease in their death rates.