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HOW IS THE NUMBER OF CHILDREN WITH SEVERE HANDICAPS  
LIKELY TO CHANGE OVER TIME?

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Testimony prepared for the Subcommittee  
on Select Education of the Committee on  
Education and Labor, U.S. House of  
Representatives, June 25, 1985.

We have heard a great deal this morning about exciting technological developments and research possibilities that might be used to train and assist individuals with serious disabilities to become productive members of society. In trying to evaluate the applications of these technologies, it is natural to ask how many young people in the foreseeable future will have handicaps that require these kinds of assistance. Unfortunately, the social science technology that can be used to make estimates of the size of particular human groups at specific points in the future is far from perfect. Indeed, the statistics that are available concerning the current numbers of persons with specific handicapping conditions leave a great deal to be desired. There are, however, some general considerations that may be used to help determine whether the number of handicapped persons is increasing or decreasing and by roughly how much. Among these considerations are: changes in the overall size of the child population; changes in the life expectancy of disabled persons; changes in infant mortality and morbidity that are being brought about by advances in medical technology and social programs. I have tried to summarize and evaluate some of these developments in the remarks that follow.

#### Growing Size of the Child Population

The first and perhaps the most important thing to realize when trying to project the size of the handicapped child population into the future is that the total population of young people in this country, which decreased in size during the 1970s

and early 1980s, is now on the rise again. Although the average number of children borne by each woman remains low, there are now so many women in their childbearing years (as a result of the post-World War II baby boom), that the total number of children produced is increasing. The Census Bureau has projected that there will be approximately 3.8 million births per year for the rest of this decade and into the early 1990s, and between 3.7 and 3.5 million per year during the late 1990s. This means that the total child population (ages 0-17) will rise from less than 63 million this year to nearly 65 million in 1990, and more than 67 million by 1995. The school-aged population (ages 5-17) will go from about 44 million this year to over 45 million by 1990, to more than 48 million by 1995, and nearly 50 million by the year 2000. Thus, unless the relative frequency of most seriously handicapping conditions were to drop significantly in the near future, it seems likely on the basis of population growth alone that the absolute numbers of handicapped young people in the U.S. will increase for the remainder of the century.

#### Increasing Life Expectancy of Disabled Persons

A second development that must be considered in trying to project the size of the population in need of rehabilitative services is that there have been significant increases in the life expectancy of individuals with serious handicaps. It is fairly well known that babies born in the 1980s with Down's syndrome, cerebral palsy, cystic fibrosis, and other disabling

conditions are much more likely to survive their first few hours, days, and months of life than children born with these conditions in previous decades. What is less widely realized is that today's handicapped children are also more likely to survive into young adulthood, middle age, and even beyond.

Increases in life expectancy have been true for a number of different disabling conditions, but the evidence is particularly dramatic in the case of Down's syndrome. Forty years ago, an individual with Down's syndrome could expect to live only to about 12-15 years of age on the average. Today, such an individual can expect to live into his late forties to mid-fifties. Indeed, persons with Down's syndrome are living long enough so that there is now concern about the high proportions of them who develop Alzheimer's disease in their later years.

There are a number of reasons for the increased survival of individuals with serious disabling conditions. Part of the story is better medical management of specific acute illnesses to which disabled individuals are susceptible. In the case of Down's syndrome, it is better treatment of pneumonia and other respiratory diseases that has made a difference. An important general change is that individuals with long-term disabilities are now less apt to be relegated to the back wards of large institutions and are more likely than in the past to receive adequate medical attention for their health problems.

There are several important implications of the trend toward longer life expectancies among disabled persons. To begin with,

if the incidence of a specific disability -- that is, the rate at which individuals are born with or otherwise develop the condition -- remains constant, but the life expectancy of victims of the disability goes up, then the prevalence of the disability will also go up. That is, there will be more people in the population at any given time who have the disability. Even if the incidence of a disability has decreased, as seems to be the case with Down's syndrome, increases in life expectancy may partially or completely offset the decline as far as prevalence is concerned.

Increases in the life expectancy of disabled young people make it all the more important to seek new and better ways to train these individuals to become economically productive members of society. If productivity is not achieved, each additional year of life means an extra year of economic burden for their families or for taxpayers in general. At the rate of \$85 a day, which is what it cost in 1982 to maintain a disabled individual in a state-run institution, the costs mount up at the rate of \$31,000 per year per person. On the other hand, if training and technological assistance make it possible for a disabled individual to become productive, then the economic return on the investment in research and training will be that much greater. In sum, the increases in life expectancy are likely to enlarge the number of handicapped young people in the population and make it more imperative to provide these young people with adequate training and assistance.

### Lower Death Rates for High-Risk Infants

Another development that is sometimes thought to be increasing the number of handicapped persons in the U.S. population is the advent of neonatal intensive care units and other medical and social changes that have dramatically improved the survival chances of premature, low birthweight, and other high-risk infants. Modern medical technology is succeeding in preserving the lives of tiny infants who would almost certainly have perished had they been born a decade or two earlier. Here are some figures that show just how much change has occurred in this area: Of the babies born in the United States in 1960 who weighted 1,500 grams (3 lbs., 4 ounces) or less, only about 28 percent lived to see their first birthdays. Of the babies born in the U.S. in 1980 with similar very low birthweights, more than half -- 52 percent -- were still alive at age one. Although up-to-date data are not available for the U.S. as a whole, Joseph Stockbauer of the Missouri Health Department has been good enough to provide me with some recent data from that State's vital statistics system. These data show that low birthweight mortality rates have continued to improve since 1980. For babies born weighing less than 1,500 grams in Missouri in 1984, 63 percent survived to age one.

Although nearly everyone would agree that preserving the lives of vulnerable infants is a good thing, a number of commentators have expressed concern that an unintended consequence of these advances may be a sharp rise in the number of young people with physical and mental deficiencies. There is

disagreement among public health experts, however, over the issue of whether such a rise in handicap really is an inevitable consequence of the improvements in neonatal care.

There is no question but that children born with very low birthweights show a higher rate of physical defect and retarded development than children born at higher birthweights. For example, in one study of a random sample of one-year-old children in several different areas of the U.S., it was found that of those who weighed 1,500 grams or less at birth, 39 percent had some form of at least mild congenital abnormality or developmental delay at age one. Among children of normal birthweight (more than 2,500 grams), less than 13 percent were found to have some form of abnormality or significant delay. If we focus only on severe defects or delays, 12 percent of the very low birthweight children had such problems, compared with less than 2 percent of the normal birthweight children.

On the other hand, it is important to realize that the majority of very low birthweight children do not show congenital defects or developmental delays, at least not by age one. Moreover, the vast majority of children who do exhibit such defects and delays are born at normal birthweights. Thus, the potential increase in the number of handicapped children that might be produced by saving the lives of a high proportion of low birthweight infants is not as great as is often assumed. I have calculated, for example, that the changes in birthweight-specific mortality rates in the U.S. between 1960 and 1980 would, when applied to 1980 birth numbers, produce at worst a 3

percent increase in the number of severely handicapped children. Now a 3 percent increase is not nothing. It represents about 2,000 more seriously handicapped children produced from one year's births. It is, however, a far cry from the epidemic of unintended disability that is sometimes envisioned as a necessary byproduct of the reduction in infant mortality.

A number of public health experts would question whether even the relatively modest increase in disability that I have just described is really taking place. They would argue that the improvement in neonatal technology is actually producing a net reduction in later handicap because difficulties that may arise during pregnancy and delivery are being picked up earlier and complications such as respiratory distress and jaundice in newborns are being treated more effectively. The avoidance of childhood disability that results from these advances more than offsets the increase in disability that comes from preserving the lives of more infants with congenital abnormalities, or so it is argued.

There are data that seem to support this contention. Regional surveys of one-year-olds sponsored by the Robert Wood Johnson Foundation and conducted by investigators from The Johns Hopkins School of Public Health in 1976 and 1978/79 found that the overall risk of congenital anomalies or developmental delay decrease significantly between the two surveys. On the other hand, the same studies found that the proportions of children with severe or moderate congenital anomalies or developmental

delay did not change over time. I believe that a prudent reading of these results does not rule out the possibility that the number of severely handicapped children may be increasing as more high-risk infants survive.

To reiterate and try to integrate the considerations discussed above: I project that there will be increases in the number of seriously handicapped young people in the U.S. population between now and the end of the century, but that these increases will be more modest in scope than is sometimes feared. For example, I would hazard a guess that ten years from now, in 1995 there will be about 6 million young people in the public schools who will be receiving various forms of special educational assistance for handicapping conditions that range from mild to severe. And I would estimate that in the same year there will be a total of perhaps 1.3 million to 2.7 million young people between the ages of 3 and 21 with handicaps severe enough to warrant use of the kinds of technological assistance that has been described here today. Given the higher expectations that we have today for the quality of life of seriously handicapped persons, the economic implications of these increases will be far from trivial. On the other hand, the payoff from successful attempts to train handicapped persons for productive activity will also be sizable.

# 85-06

TWO MILLION MORE HANDICAPPED STUDENTS BY 1995, RESEARCHER PREDICTS

By 1995 there could be nearly 2 million more special education students in public schools than there are now, a researcher predicted in testimony before a House subcommittee on June 25.

Nicholas Zill, president of Child Trends Inc. a Washington, D.C., research firm specializing in data on children and families, told the House Select Education Subcommittee, "I would hazard a guess that 10 years from now ... there will be about 6 million young people in the public schools who will be receiving various forms of special education assistance for handicapping conditions that range from mild to severe."

Zill, testifying at a reauthorization hearing for the 1973 Rehabilitation Act, said the increase in children needing special education will result from an increase in the total population of children, the increased life expectancy for disabled children and the improved survival rates of high-risk infants.

Baby Boom The total population of children, which decreased in size during the 1970s and the early 1980s, is now rising, Zill said. "It seems likely on the basis of population growth alone that the absolute numbers of handicapped young people in the U.S. will increase for the remainder of the century," Zill told the panel.

Zill also pointed out that today's handicapped children are more likely to survive into young adulthood and middle age than were handicapped children born in past years.

For example, Zill said, "Forty years ago, an individual with Down's syndrome could expect to live only to about 12-15 years of age on the average. Today, such an individual with Down's syndrome could expect to live into his late 40s to mid-50s." The increased life expectancy of handicapped children can be explained, Zill said, by the better medical care they are receiving.

Intensive Care Nurseries The advent of neonatal intensive care hospital units is also partly responsible for the increased numbers of handicapped children, Zill said, because they improve the survival rates of premature, low birth weight and other high-risk infants.

But Zill said there would not be an epidemic of disability accompanying this reduction in infant mortality and, he added, some public health experts argue that improved neonatal technology is producing a net reduction in later handicaps because difficulties and complications during pregnancy and delivery are being picked up earlier.

"The avoidance of childhood disability that results from these advances," Zill said, "more than offsets the increase in disability that comes from preserving the lives of more infants with congenital abnormalities."

The increased life expectancy of disabled children makes it all the more important, Zill told the panel, "to seek new and better ways to train these individuals to become economically productive members of society."

It can cost up to \$31,000 per year, Zill said, to maintain a disabled person in a state-run institution. But, if training and technology make it possible for a disabled person to become productive, "then the economic return on the investment in research and training will be that much greater." ###