

Symposium: Contributions of Governmental Agencies in Research, Treatment, and Teaching of the Oro-Facial-Speech Handicapped

III. Services for Children with Cleft Palates by State Crippled Children's Agencies

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Since all of you are the experts in cleft palate rehabilitation, I was told that my role was to speak briefly about the Children's Bureau, which I am representing on this panel, and then say something about services for cleft lip and cleft palate children in the crippled children's program. As we review the history of the Children's Bureau I think it will be obvious to all of us that the concern that the Bureau has for children with cleft palate had its origin in its concern for all disadvantaged children; for surely the cleft lip and cleft palate child with his disfigurement, his breathing and eating difficulties, his repeated infections, his problems of impaired hearing and speech, perhaps with the resulting social and emotional problems is truly a disadvantaged child—at least until he has received the expert care of one of today's excellent cleft palate teams.

The Children's Bureau is a federal agency devoted to improving the health and well-being of mothers and children, and is one of several federal agencies brought together in 1946 into what is now the Department of Health, Education, and Welfare. According to the basic act which created the Children's Bureau in 1912, the new agency was to 'investigate and report upon all matters pertaining to the welfare of children and child life among all classes of our people'. While having a concern for all children, it has more often than not presented the case for the disadvantaged child whether this disadvantage is social or cultural, physical or mental.

In 1935 with the passage of the Social Security Act, the activities of the Children's Bureau were extended to include the administration of three grant-in-aid programs, two in the health field and one in child welfare. The two federally-supported health programs are called maternal and

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child health and crippled children's programs. Each state and territory and the District of Columbia has an MCH and CC program.

The crippled children's program is a medical and rehabilitation program for handicapped children and young people to the age of 21. In the words of the Social Security Act, the Congress provides crippled children's funds

For the purpose of enabling each state to extend and improve . . . services for locating crippled children, and for providing medical, surgical, corrective, and other services and care, and facilities for diagnosis, hospitalization, and aftercare, for children who are crippled or who are suffering from conditions which lead to crippling . . .

State programs vary in the types of handicapping conditions which they accept for care, but all states include cleft lip and cleft palate in their definition of the crippled child. It was the cleft palate program more than any other which was responsible for first introducing the 'team' concept of care of a child.

Most of the funds for crippled children are used to purchase services which vary according to the individual needs of each handicapped child. Usually the funds are expended for medical and related professional and hospital services, including appliances. However, if transportation is a problem which cannot be solved in any other way, or if it is determined that boarding home care is necessary while the child is having diagnostic tests, or while he is receiving therapy on an ambulatory basis, these services may also be authorized by the state agency. No payments are made directly to the family.

The present appropriation for both the crippled children and maternal and child health programs is \$25 million each, which represents approximately one-fourth of the total expenditures by official state agencies for crippled children's services and for maternal and child health. Up to 12½% of the current federal appropriation for crippled children and a similar amount of the maternal and child health appropriation and a million dollars earmarked for mental retardation are set aside for special project grants. Special projects which are related to program interest in maternal and child health, crippled children, and mental retardation may be awarded to official state agencies or to institutions of higher learning. Projects may be for the purpose of demonstrating new or improved methods of giving care or may provide professional training or support clinical research. At present, the Children's Bureau supports 138 special projects, six of these are cleft palate or dentofacial projects. Several others are close to the interest of many of you here, for example, such projects as dental care for handicapped children and training in pedodontics, speech, and hearing.

In the beginning as the name implies, the crippled children's program served chiefly children with orthopedic handicaps. One of the early crippled children's statistical reports compiled by the Children's Bureau

records the fact that 97% of the crippled children's services were to children with 'orthopedic and plastic conditions'¹ a general term which included cleft lip and cleft palate.

Prior to the Social Security Act, there was very little information available on the number of crippled children in the United States and even less knowledge of the proportions of various crippling conditions. With the development of state-wide programs of medical care for handicapped children after the passage of the Act, it became desirable to obtain more complete data on the number and location of crippled children. States were required to build up and maintain registers of all children under 21 years who were suffering from a crippling condition diagnosed by a physician and to report these to the Children's Bureau. By the end of 1939, there were 248,627 crippled children listed on state registers². The diagnosis which accounted for the largest number of children on the registers was poliomyelitis, which represented 19.2% of the children reported. The second largest group was cerebral palsy, 10.2% of the total. The fifth largest group on the state rosters were children with cleft lip and cleft palate who constituted 4.4% of the crippled children on state registers. In the age group under one year, and one through four years, club foot led all other diagnoses, but cleft lip and cleft palate was second for both those age groups.

In 1961, the latest year for which complete data are available, a total of 372,024 children received services under official crippled children's programs; of these children, 18,383 had cleft lip and cleft palate and an additional 3,760 children had a variety of dentofacial problems. Since 1950 when comparable figures have been available, not only has the number of children with cleft lip and cleft palate in crippled children's programs been increasing, but the rate per 100,000 children has been increasing. In 1950 the rate was 14.5, in 1961, 24.7. The entire group of children with congenital malformations who are cared for under the crippled children's program has been increasing at a more rapid rate than other categories of children, so that for the year 1961 they constituted about 30% of all children served and numbered 106,975; in 1950 they represented 20.6% of the total children served by official crippled children's agencies. As is thus evident from the crippled children's programs, the problem of congenital malformations is one of great magnitude. On the basis of numbers alone, can we say that the overall incidence of congenital defects, including cleft lip and cleft palate is increasing? Such a conclusion cannot be drawn from crippled children's data as presently reported to the Children's Bureau. However, it is hoped under the new reporting system now being tested in several states, much more useful information regarding handicapping conditions in children will be avail-

¹ Social Statistics Supplement No. 3, March, 1939 to *The Child*, Vol. 3, No. 9, published by the Children's Bureau, U. S. Department of Labor, Washington, D. C.

² Social Statistics Supplement No. 4, June, 1940, to *The Child*, Vol. 4, No. 12, published by the Children's Bureau, U. S. Department of Labor, Washington, D. C.

able. Even though the numbers reported for any given condition do not represent incidence or prevalence, an unmistakable trend upward or downward in crippled children's cases may be significant. For example, there has been a marked decline in such infectious conditions as osteomyelitis, tuberculosis of bone, mastoiditis, and acute poliomyelitis under the crippled children's program which undoubtedly reflects the progress made in the prevention and treatment of these conditions.

There are probably several reasons for the rapid increase in the number of children with congenital defects under the crippled children's program. For one, many infants who formerly died now live as a result of new surgical and other procedures. As scientific advances in medical research open up new ways of benefiting children, the state crippled children's agencies respond by expansion of their programs. Another reason for the growing number of children with congenital defects is that many congenital conditions are extremely complex; the treatment usually is of long duration and may require the skills of many professional disciplines. Since more than one member of the family may be affected or the child may have multiple defects, the cost may be too great for a family of modest means to bear without assistance. Therefore, an increasingly higher proportion of families, whose children are born with severe congenital defects, must seek the help of crippled children's agencies in the provision of medical, hospital, and related services for their children.

Coincident with progress in the medical sciences, an even higher standard of patient care continues to evolve and a broader concept of care is more generally accepted, described by such terms as 'complete,' 'total,' 'comprehensive'.

The treatment and rehabilitation of the cleft lip and cleft palate child is a good illustration of this progressively higher goal of care. In the first years of the crippled children's program the principal service given to the child with cleft lip and cleft palate was surgical. Orthodontic and prosthodontic dentistry were usually not a part of the care; speech and hearing problems, though noted, received attention rather infrequently. Seldom were emotional difficulties dealt with. Since the child with a cleft lip and cleft palate has a multifaceted problem, it is not surprising that many disappointing results of this early treatment were observed and that the goal of treatment changed from surgical closure of abnormal clefts to the restoration of the child to as nearly normal appearance and functioning as possible. To achieve this goal many more professional disciplines were gradually added to the 'team' not as individuals to promote their respective professions (which your President warned against in his presidential address), but as contributing members of a group whose purpose is to develop a coordinated, dynamic treatment plan for a child—a plan which is re-evaluated at appropriate intervals to meet the changing needs of the infant as he grows into childhood and finally into adolescence and prepares for a useful role in society as an adult.

It has seemed to me that the value of membership on a professional team extends beyond the immediate benefits, however great, to the child and his family. One value to the team member is the opportunity for professional growth. Since a good team attracts large numbers of patients, members of teams have the advantage of accumulating a wealth of clinical experience. A team usually becomes the nucleus of a center for cleft palate research and training. The role of the crippled children's program in helping to stimulate the development of the cleft palate teams has been a useful one.

Since the beginning of the crippled children's program much progress has been made in the care of the cleft palate child on a number of fronts. For example, some states report they seldom see a missed or neglected case now, or that 85% of their babies were registered in the crippled children's program at birth, as one rural state reported as evidence of early casefinding. The impact of the birth of a defective child on the parents and the professional role in supporting them at this critical time and in preparing them for what lies ahead for them and their child is much better understood than formerly. The parents are indeed important members of the team.

Though our present goal is to rehabilitate the cleft palate child and help him develop his highest possible potential, our ultimate goal is prevention. Prevention of disability from congenital defects may seem far from attainment now, but progress is being made. The fact that several maternal and child health programs have added genetic counseling services and that crippled children's agencies are also moving in this direction with plans for 'genetic' service laboratories, reflects both the rapid strides which have been made in our knowledge of genetics and also the great eagerness there is to apply this knowledge for the benefit of children.

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