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ABBREVIATED STATEMENT OF

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BEFORE THE

SUBCOMMITTEE ON SELECT EDUCATION

UNITED STATES HOUSE OF REPRESENTATIVES

ON

DEAF/BLIND CHILDREN AND THE CENTERS SERVING THEM

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HIGHLIGHTS OF THE ABBREVIATED STATEMENT

Mr. Chairman and Members of the Subcommittee:

We are pleased to be here today to testify on what existing studies indicate about deaf/blind children and about the Deaf/Blind Centers and Services Program. In order to respond to the Subcommittee's time constraints and need for brevity, we are presenting only the highlights of the attached abbreviated statement of our findings.

In a nutshell, based on our review, we make the following 13 points:

(1) Information about the centers and the populations they serve is surprisingly incomplete and inconsistent, given the small number of centers and the small population sizes involved.

(2) This serious problem of information quality means that our numbers can best be considered and used as approximations.

(3) The number of deaf/blind children for the year 1982 ranges from about 2,600 (if one uses the State reports from Public Laws 94-142 and 89-313 combined), through about 3,500 (if the Registry for Deaf/Blind Children is consulted) to about 5,400 (using reports from Deaf/Blind Center directors to the Office of Special Education Programs).

(4) We do find that most rubella epidemic deaf/blind children appear to have been located by the centers.

(5) Rubella epidemic children will soon be ineligible for services, some in 1985, <u>all</u> by the end of 1988.

(6) Congenital rubella still results in deaf/blindness for approximately 15 to 110 children per birth year.

(7) Between approximately 100 and 140 children per birth year are born or become deaf/blind due to causes other than congenital rubella.

(8) Deaf/blindness exists in different degrees. In one State, for example, the degree of "blindness" for the deaf/blind children includes about 36 percent of the children "visually impaired," 21 percent "legally blind," 20 percent "with light perception only," and 23 percent "totally blind"; "deafness" includes about 50 percent with "mild or moderate" hearing loss and 50 percent with "severe or profound" hearing loss.

(9) Deaf/blind children are very often multiply handicapped.

(10) Center activities seem to be nominally well matched to center objectives with regard to direct services to children, counseling and consulting services, and training professionals in deaf/blind education; however, the lack of effectiveness evaluation precludes discussion of the quality of these services.

(11) Center activities do <u>not</u> seem to be well matched with the center objectives for demonstration and dissemination (that is, to develop new, better, and demonstrably effective ways to serve deaf/blind children).

(12) Most centers seem to allocate most of their funds to subcontracts. However, the distribution of center purchases is unclear with respect to direct service, indirect service, and/or technical assistance.

(13) Finally, <u>average</u> expenditures per child range from about $1,600 to about $5,600, depending on the center. The actual cost for each child, however, is unknown.

This concludes our discussion of highlights from our abbreviated statement. More detail is available in that attached statement, and of course, we would be pleased to explain any part of it and answer any questions you may have.

ABBREVIATED STATEMENT

Mr. Chairman and Members of the Subcommittee:

We are pleased to be here today to testify on what existing studies indicate about deaf/blind children and about the Deaf/Blind Centers and Services Program. As you know, these centers were authorized in 1968 in response to the rubella epidemic of 1963-1965 during which many children were believed to have been born deaf and blind as a result of their mothers having contracted rubella. The centers were also authorized, however, to serve deaf/blind children regardless of the cause of their deaf/blindness.

This January, the Subcommittee asked GAO to examine existing studies to determine what sound information is available on changes in the population of deaf/blind children since the rubella epidemic of 1963-1965, and on the services children have received through the centers. Today we are presenting what we have learned from our review of the findings of published evaluations and readily available data which we have supplemented by discussions with agency officials and with experts at the Center for Disease Control. For the published evaluations, we assessed the adequacy of the methods used, determined the soundness of the information they produced, and identified remaining gaps in the information needed by the Subcommittee. We also reviewed the completeness of readily available data and the logic of the analyses applied to them. In general, it's fair to say we found large gaps in the availability of sound information about deaf/blind children served, about the types of services provided to them, and about the costs of these services.

INFORMATION IS INCOMPLETE AND INCONSISTENT

There were five reasons to expect relatively complete information about deaf/blind children and the centers:

(1) The number of centers is small—15 at present—and many have been in operation for more than 10 years.

(2) The focal population also is small--that is, rubella epidemic children who are deaf and blind--and those children should have been located and served since 1969, when the first centers that the Congress authorized began operations.

(3) The entire eligible population--all children from 0 through 21 years of age suffering some degree of deaf/blindness regardless of cause--again is small and again should have been served since 1969.

(4) Existing regulations require an adequate system of records.

(5) Finally, a Registry for Deaf/Blind Children has been in operation since 1969.

Despite these factors, published or readily available information on the children and centers is, in fact, both incomplete and inconsistent. Here are four examples:

(1) Records at the Registry, despite the efforts of the staff, have so much missing information that the data have almost more holes than fabric. For example, two large States list about 650 children in the Registry but do not report the causes of deaf/blindness for 99 percent of them.

(2) The only nation-wide studies we located were carried out within the last few years. Two are surveys of the persons who serve the children on their views of met and unmet needs for service. The third study--assessing the match between objectives and operations in the centers--did not look at program effectiveness.

(3) There appear to be neither published national longitudinal studies of the progress of the children while they are eligible for center assistance nor of how they have fared after reaching 22 years of age. Thus, there is little empirical basis for (a) evaluating how well the program is meeting the children's needs, (b) examining whether the congressional intention that the children be helped to communicate with, adjust to, and participate meaningfully in society has been fulfilled, or (c) assessing what service they still need after reaching age 22.

(4) The data that do exist are elastic. Numbers in any given reporting period can differ by as much as 15 percent.

We present these concerns to emphasize the caution required in dealing with "factual" information about many aspects of the children's needs and services. Even for such a simple "fact" as the numbers of deaf/blind children in 1982, there are three different figures (with several possible reasons for the differences): about 2,600 from the combined Public Law 94-142 and 89-313 State reports, about 3,500 from the Registry, and about 5,400 from the center Directors' reports to the Office of Special Educational Programs. Thus the findings we report here todav are of necessity based on judgment calls at least to some degree. We signal them by our use of the word "about" in giving figures.

FINDINGS

1. MOST RUBELLA EPIDEMIC DEAF/BLIND CHILDREN APPEAR TO HAVE BEEN LOCATED BY THE CENTERS

In a 1969 report, the rubella epidemic of 1963-1965 was estimated as likely to have caused handicaps for about 20,000 children: 5,500 visually impaired, 12,000 hearing impaired, 1,250 retarded/crippled, and 1,250 deaf/blind. We estimate the deaf/blind centers have located about 1,640 rubella epidemic-age children. Of those, we believe about 1,360 are deaf/blind due to congenital rubella, a figure close to the 1969 projections.

2. SOME RUBELLA EPIDEMIC CHILDREN WILL BE INELIGIBLE FOR SERVICES BEGINNING IN 1985: ALL WILL BE INELIGIBLE BY THE END OF 1988

In 1985, the leading edge of rubella epidemic children who are deaf/blind to some degree will reach their 22nd birthday when they will be ineligible for service through the centers. By the end of 1988, all of the deaf/blind rubella epidemic age children will have reached 22 years of age.

3. CONGENITAL RUBELLA STILL MAKES SOME CHILDREN DEAF AND BLIND

Despite a developed vaccine and a vigorous immunization program, rubella is still with us. Local outbreaks occur on college campuses, in military barracks and other settings in which large numbers of people congregate. Among girls and young women of child-bearing age, those 15 to 19 years of age have the highest rates of rubella each year. The Center for Disease Control has joined some health associations in arguing for a national immunization effort for women of child-bearing age.

The Center for Disease Control estimates that about 250 to 1,000 cases of newborns with the congenital rubella syndrome occur each year. If about 6 percent of these babies eventually develop some degree of deaf/blindness, then we have about 15 to 60 additional children deaf/blind due to rubella annually. If, however, we extrapolate from cases reported to the Registry, then about 110 new children annually suffer some degree of deaf/blindness due to congenital rubella. Thus, the number of new children swelling the ranks of the deaf/blind each year due to congenital rubella is likely to be between 15 and about 110.

4. RUBELLA IS NOT THE ONLY CAUSE OF DEAF/BLINDNESS

Some children not affected by rubella are born deaf and become blind for unrelated reasons such as child abuse and accident. Some are born blind and become deaf for unrelated reasons. Some suffer from a genetic disease called Usher's Syndrome in which a child born deaf becomes progressively blind during adolescence. The Registry has identified 55 causes other than rubella associated with some degree of deaf/blindness.

The number of children per birth year who are reported to have been born or to suffer some degree of deaf/blindness due to causes other than rubella has remained relatively steady. Extrapolating from Registry identification, we estimate about 110 per year prior to the epidemic, about 100 per year during the epidemic, about 140 per year in the 9 years after the epidemic, and about 110 per birth year in recent years.

In the absence of such changes as a highly successful immunization program, a redefinition of deaf/blindness or in statutorily mandated reporting, it is unlikely that there will be sudden increases or decreases nationally in the numbers of deaf/blind children reported.

5. CHILDREN HAVE DIFFERENT DEGREES OF DEAF/BLINDNESS

Children located by the centers have different degrees of deaf/blindness. We can see this through the use of indirect indicators such as the communication methods reported by a small sample of teachers of the deaf/blind children. These methods ranged from unaided speech to finger alphabets. More teachers reported using visual sign language than any other single method; the method reported by the next largest number of teachers was hand-on-hand sign language. This suggests that while many children may have some auditory or visual capacity, some also are almost wholly deaf and blind. The Registry's report form provides for degrees of blindness ranging from "visually impaired" to total blindness and for degrees of deafness ranging from "mild" to "profound." A State, which is said to have relatively complete and accurate data, reports that of children for whom degree of deafness is known, 50 percent have "mild" or "moderate" loss and 50 percent "severe" and "profound" hearing loss. Of the children for whom degree of vision is known, 36 percent are "visually impaired," 21 percent are "legally blind," 20 percent have "light perception only," and 23 percent are "totally blind."

6. THEY HAVE OTHER HANDICAPS TOO

Only about 24 percent of the approximately 2,000 children for whom the existence (or not) of additional handicaps is reported to the Registry, suffer some degree of deaf/blindness without additional handicaps. About 76 percent are deaf/blind to some degree with at least one additional handicap.

Diagnosis is often difficult. A deaf/blind child may appear to be mentally retarded, for example, due to sensory problems in communication. Lack of uniform diagnostic categories complicates things further.

We think it is reasonable, however, to characterize the population located by the centers as diverse both in degree of deaf/blindness and in the existence of other handicaps. We believe that the prevalence of other handicaps makes it as accurate to characterize the population as multiply handicapped as it is to characterize it as deaf/blind. We recognize, however, the complexities that deaf/blindness can add to these other conditions and the special implications involved for education and services.

7. CENTER PROGRAM OBJECTIVES AND CENTER ACTIVITIES MATCH WELL IN SERVICE TO CHILDREN

A 1982 study of the centers by the American Institutes of Research found a good match between objectives and activities in (1) direct educational services, (2) indirect counseling/consulting services, and (3) training professionals in deaf/blind education. Since the study did not evaluate program effectiveness, little is indicated about the quality of these services or how well they meet needs. Implementation also is uncertain. The report does suggest that services and technical assistance are concentrated within a fairly narrow geographic area close to the centers themselves. The reason may be partly the co-location of some centers with State Departments of Education, since travel freezes on State employees may affect the staff of such centers. This is of some significance in light of the change from 15 to 6 centers.

8. PROGRAM OBJECTIVES AND ACTIVITIES DO NOT MATCH WELL IN DEVELOPMENT, DEMONSTRATION, AND DISSEMINATION

The same American Institutes of Research study found that objectives and activities do not match in (1) developing and demonstrating new and improved methods for educating deaf/blind children and (2) disseminating effective practices and information. The Office of Special Education Programs has been expanding and centralizing these functions since 1978. In 1978, $1,000,000 was allocated for competitive awards for demonstrating effective ways to mainstream deaf/blind and other severely-handicapped children into least restrictive environments. A total of $3.7 million is expected for FY 1983 for innovative program awards.

It is true that developing, demonstrating, and disseminating information on new, better, and effective ways to serve deaf/blind children is indeed an important function. And it is also true that many problems typically exist in planning, implementing, and evaluating demonstrations which have little to do with their locus or placement. That is, centralization and expansion of funds may not be panaceas for problems found in decentralized model or demonstration programs.

9. IT IS NOT CLEAR WHETHER THE CENTERS PURCHASE MOSTLY DIRECT SERVICE, INDIRECT SERVICE, OR TECHNICAL ASSISTANCE

According to the Office of Special Education Programs, direct or subcontracted expenditures include the costs of diagnosis and evaluation, weekend and summer programs, tuition in residential private schools, workshops for teachers of the deaf/blind and similar services. Ten of the 13 centers for which data are available allocate about 70 percent or more of their budgets to subcontracted service. The centers' operational costs include rent, staff salaries and benefits, telephones and supplies, and similar charges. These categories seem to blur, however, and the readily available data do not allow us to focus them. For example, some centers may provide technical assistance through their own staff in which case it is carried under center operations and others may purchase all or some technical assistance services in which case it is carried as direct services. According to State coordinators of deaf/blind programs surveyed in 1982, most direct instructional services for school-age deaf/blind children are provided by Public Laws 94-142 and 89-313 and by State or local funds. The center resources are said to be used to supplement and enrich services to school-age children in important ways, and in some centers, to provide direct services to the children who are too young or too old to be eligible for State supported education. We have not, however, been able to find an adequate empirical base for these statements.

10. THE EXPENDITURE ON SERVICES TO EACH CHILD IS UNCERTAIN

Per child expenditures are available as the total award to each center divided by the number of children located. The expenditure on services received by an individual child could be higher or lower by an unknown amount. A few children could have received services costing thousands of dollars while most children received relatively inexpensive services.

Centers vary considerably in "per child located costs." The highest is reported from the South Atlantic Center ($5,602 based on 252 children located with an award of $1,411,681). The lowest is from the South Central Center ($1,589 based on 694 children located with an award of $1,102,616). We are told that the national average cost of educational services to the deaf/blind child is about $11,000 with deaf/blind center funds paying for about 20 percent of the total. The variation in children's characteristics and other factors are likely to make the averages highly uninformative as a measure of allocation relative to need. The centers' budgets have remained relatively constant over the years, at about $15,600,000 for the total program and the numbers of children located have remained relatively constant, but inflation undoubtedly has increased considerably the costs of services. Most of a small sample of program directors and those serving deaf/blind children report that recent allocations have been "adequate" but express concern for the future.

Summary

Published or readily available information about the children and the centers is incomplete. What there is, can be inconsistent and useful only with caution as approximations.

We believe, however, that the centers are serving most of the 1963-1965 rubella epidemic children who are deaf/blind to some degree. We know that about a third of these children will be ineligible for service beginning in 1985 and that all will become ineligible by the end of 1988. Other children continue to be born or to become deaf/blind to some degree due to congenital rubella or to other causes. Their number annually is small, and we have no information indicating a dramatic decrease (or increase) in the near future. The centers seem to be providing direct and indirect service delivery and technical assistance corresponding reasonably to the congressional intent in these areas, but they do not seem to be meeting congressional intent with regard to development, demonstration, and dissemination functions.

This information suggests first, that there is a continuing need to provide services for a small, but severely handicapped group of young people and second, that there exists some uncertainty about the best ways to deliver services to them.

This concludes our statement. We would be pleased to explain any part of it or to answer any questions you may have.