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Case-Finding Criteria for Use in Identifying Deaf-Blind Children.

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CASE-FINDING CRITERIA FOR USE IN IDENTIFYING
DEAF-BLIND CHILDREN.**

**The Louisiana State University and Agricultural
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Education, special**

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CASE-FINDING CRITERIA FOR USE IN IDENTIFYING
DEAF-BLIND CHILDREN

A Dissertation

Submitted to the Graduate Faculty of the
Louisiana State University and
Agricultural and Mechanical College
in partial fulfillment of the
requirements for the degree of
Doctor of Philosophy

in

The Department of Education

by
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ABSTRACT

The purpose of this study was to develop case-finding criteria for use in identifying children who may be classified deaf-blind.

Items composed of referral sources and investigative potentials were devised from a demographic survey of 164 known cases of deaf-blind persons in Louisiana. The first inquiry sheets containing these possible sources of case-finding deaf-blind children were sent to a panel of 20 persons comprised of social workers, educators, physicians, administrators, a parent and rehabilitators with expertise in the field of deaf-blind. The items were ranked by the panel in order of importance for case-finding and write-ins were included. A matrix of frequencies table was used in the analysis of the panel's responses to determine rank order.

The second inquiry sheets containing the highest ranked items, write-ins, and combinations of both of these were returned to the same panel of experts to be ranked in order of importance for case-finding deaf-blind children. The responses were again analyzed on a matrix of frequencies table to determine the order of importance of the sources for case-finding. Based on these results a case-finding instrument was prepared for use in the field.

It was concluded that (1) all existing referral sources should continue to be utilized, (2) there is a national need for a more comprehensive method to obtain early identification and referral of all sensorially impaired and high risk infants, and (3) there is a need for the development of other new and unique programs to promote case-finding deaf-blind children.

Chapter 1

INTRODUCTION

Special education for the deaf-blind child began in 1837 when seven-year-old Laura Bridgman, who had been deaf-blind since age two, was admitted to what is now Perkins School for the Blind in Watertown, Massachusetts. Eight-year-old Helen Keller, who became deaf-blind from an illness at eighteen months of age, entered Perkins School for the Blind in 1888 (Spar, 1972).

The academic success of these two well-known deaf-blind persons is indicative of the potential educability of this type handicapped child.

The handicapping effects of deafness lie primarily in the area of communication; and the handicapping effects of blindness lie primarily in the area of physical orientation and independent mobility. . . . Consequently, the child who has major deficits in both hearing and seeing encounters problems in developing effective relationships with either blind children who hear or deaf children who can see (Spar, 1972).

These children, who may also have other physical or mental complications, have been a problem for all professions.

Deaf-blindness may occur at any time from neonatal stages to old age. It may have any number of known etiologies or may fall into the mysterious category of "etiology unknown." Too often no definitive assignment of singular

cause can be made for specific handicaps in multihandicapped persons because many of the various causes can result in either deafness, blindness, or both.

One example of a multihandicapping disease is retinitis pigmentosa. It is considered one of the major causes of blindness and represents 44% of the cases at the National Center for Deaf-Blind Youths and Adults. This disease frequently manifests itself in congenital deafness and gradually constricts the visual field over a period of years. The degeneration occurs during childhood and early adulthood, although it may continue beyond middle age (Spar, 1972).

Meningitis or encephalitis can attack children of all ages. Usher's syndrome can appear suddenly where normal conditions otherwise prevail. Oxygen can be administered in excess in an attempt to overcome oxygen deficiencies at birth. A physician must guess that imperceptible point where a frail neonate will live but not be handicapped by retrolental fibroplasia.

Relating to a less common cause, the National Foundation-March of Dimes recently warned pregnant women that eating rare or raw meat or handling cat feces could result in their contracting toxoplasmosis and passing it on to the fetus (New Outlook, 1972).

In 1941, the previous belief that few diseases were so benign as rubella was shattered by the observation in Sydney by Norman McAlister Gregg of

congenital defects in infants of mothers who had suffered rubella early in pregnancy (Forbes, 1969).

In 1947 Conrad Wesselhoeft's¹ paper on rubella drew world-wide attention by supporting Gregg's observations.

Rubella is possibly the only virus disease in which there is clear-cut evidence of an association between maternal infection and congenital malformation. Isolation of the virus became a reality in 1962 through the work of Parkman and his associates and Weller and Neva (Forbes, 1969).

Cooper, Ziring, Ockerse, Kiely, Fedun and Krugman (1969) report that pearly nuclear cataract is the most characteristic ocular anomaly in congenital rubella. The cataract may be unilateral or bilateral occurring in abnormally small eyes; it may be present at birth, or it may be too small to detect without a very careful ophthalmoscopic examination. The rubella cataract results from virus infection in the lens which may persist in cataractous lens for years after birth. The same medical team reported that congenital glaucoma due to rubella is clinically indistinguishable from hereditary infantile glaucoma. The cornea is enlarged and hazy, the anterior

¹C. Wesselhoeft, "Rubella (German Measles)," New England Journal of Medicine (236: June 19, 1947), pp. 943-950, cited by John A. Forbes, "Rubella: Historical Aspects," American Journal Diseases of Children (118: July, 1969), p. 7.

chamber is deep and ocular tension is increased in both conditions. It is important also to distinguish this problem from the transient corneal clouding which occurs occasionally in infants.

Fenelson (1968) stresses the need for the congenital rubella child to be evaluated as early as two months of age. At the same time Cooper and others (1969) point out that many rubella children may be born of mothers having had subclinical disease with no manifestations apparent at birth, but that handicaps may appear at a later time.

The year 1963 marked the beginning of a series of rubella epidemics which struck the United States with alarming consequences.

The rubella epidemic of 1964-65 stimulated the U.S. Congress [in 1967] to develop legislation to provide a continuum of services for deaf-blind persons. . . . (Dantona and Salmon, 1972)

The United States was confronted with a problem it had to solve.

In January 1968 Title VI of the Elementary and Secondary Education Act was amended by Public Law 90-247, Part C, later (April 1970) becoming Part C (Sec. 622) of Public Law 91-230, Title VI, the "Education of the Handicapped Act." Under this act ten regional centers are operated by the Bureau of Education for the Handicapped, Division of Educational Services, U.S. Office of Education to serve deaf-blind children throughout the United States (Spar, 1972). (Appendix A)

In addition to the responsibilities of parent counseling, program development, and child services and

training, the regional centers are responsible for finding deaf-blind children who are not now receiving services. In conversation Dr. Edwin K. Hammer, Project Director of the Southwest Regional Center for Services to Deaf-Blind Children stressed the need for a case-finding method.

In the spring of 1970, according to Guldager (1971), it was estimated that 2700 children throughout the United States were in need of services. By March 1972, Dantona and Salmon reported 3600 known cases and welcomed referrals and information on other possible cases of deaf-blind. In some states the handicap of mental retardation takes precedence over other handicapping conditions. It is difficult to determine the mental capacity of these children and many have been labelled mentally retarded. By March 1972, eight hundred of these children had been found in homes for mentally retarded (Dantona and Salmon, 1972).

It is not unusual to find state agency services regionalized. Guldager (1973) found that different agencies may have different regions for their services. It is a common practice for a young multihandicapped child to be served by as many as five agencies, each serving its own handicap, with no coordination of efforts. Such agencies may be departments of public health, mental health, public welfare, hospitals, blind, deaf or others. At the same time, not all children are

served. There is a recognized need for early identification programs and coordination of effort.

Statement of the Problem

The purpose of this study was to develop case-finding criteria for use in identifying children who may be classified as deaf-blind for referral to an appropriate agency.

Delimitations of the Study

This study neither attempted to establish programs for educating, evaluating and/or serving deaf-blind children nor to select a given central referral point.

THEORETICAL FRAMEWORK

Definitions of Terms

1. Blind: central visual acuity of 20/200 or less in the better eye, with correcting lens or a peripheral field so contracted that the widest diameter of such field subtends an angular distance no greater than 20 degrees.

Partially sighted: visual acuity is 20/70 or less in the better eye with treatment and correcting lens (Plan, 1964).

2. Cataract: opacity of lens of eye or its capsule or both (Tabor, 1957).

3. Deaf: a chronic impairment of hearing so severe that most speech cannot be understood, even with optimum amplification (Spar, 1972).

Hard of hearing: hearing loss of 20 decibels or more in at least two frequencies in the speech range or a loss of 30 decibels in one frequency in the speech range in the better ear (Plan, 1964).

4. Deaf-blind: persons who have both auditory and visual impairments, the combination of which causes severe communications and other developmental and education problems that they cannot properly be accommodated in special education programs for the hearing handicapped child or for the visually handicapped child (Dantona and Salmon, 1972).

5. Encephalitis: inflammation of the brain. It may be a specific disease entity due to a virus, or it may occur as a sequella of influenza, measles, chicken pox, smallpox, vaccinia, or several other diseases (Tabor, 1957).

6. Glaucoma: the cornea becomes cloudy due to pressure in the eye (Stager, 1971).

7. Meningitis: inflammation of the membranes of the spinal cord or brain due to infectious disease (Tabor, 1957).

8. Mentally retarded: children with an I.Q. of 75 or less as measured by a standardized intelligence test administered individually (Plan, 1964).

9. Retinitis pigmentosa: gradual constricting of visual field due to degeneration of peripheral vision, may be manifested in deafness (Spar, 1972).

10. Retrolental fibroplasia: oxygen excess causes scarring of the retina resulting in damage which may be small affecting only part of the eye or complete loss of vision (Stager, 1971).

11. Rubella: an acute infectious disease, resembling both scarlet fever and measles, but of short duration and slight fever. Commonly referred to as German measles (Tabor, 1857).

12. Special education: the provision of services additional to or different from those provided in the regular school program by a systematic modification and adaptation of equipment, teaching materials and teaching methods to meet the needs of exceptional children (Plan, 1964).

13. Subclinical: lack of appearance of typical symptoms of a disease (Tabor, 1957).

14. Toxoplasmosis: parasitic infection affecting the macula of the eye resulting in peripheral vision only which also may eventually be lost (Stager, 1971).

15. Tumor: a swelling or enlargement which may grow from the connective tissues of nerve centers or affect tissues of other various types (Stager, 1971).

16. Usher's syndrome: an eruption of blisters which may appear suddenly on apparently normal skin. A progressive, chronic benign disease which attacks mucous membranes and connective tissues slowly causing scarring,

shrivelling and shrinking of the conjunctiva and eventual blindness; generally bilateral. Cause unknown, suspected to be of viral origin or caused by the development of an immunity to some part of the body. Occurs in infants and older people (Nelson and McCaffree, 1973).

Importance of the Study

This investigation is important for the following reasons:

1. The study developed a means of locating deaf-blind persons for referral to a state or other servicing agency.
2. An agency may use the information:
 - a. To develop a complete registry of children and families;
 - b. To provide early experiences and home programs;
 - c. To provide parent education and support;
 - d. To provide appropriate and necessary medical and/or surgical services;
 - e. To develop evaluative instruments of abilities and needs;
 - f. To determine school population of deaf-blind children; and
 - g. To provide transportation requirements.

3. There is a lack of standardized criteria for case-finding persons who may be classified as deaf-blind persons.

Method of Procedure

The following steps were taken to complete this study:

1. Data from the case histories of the entire population of 164 known cases of deaf-blind persons in Louisiana were tabulated to develop a demographic survey for analysis of relationship of etiology, age ranges of children, distribution pockets (if any), and referral sources. (Appendix B)

2. A panel of 20 experts on deaf-blind composed of social workers, educators, physicians, administrators, a parent and rehabilitators was selected from candidates recommended by the Coordinator of Centers and Services for Deaf-Blind Children, Bureau of Education for the Handicapped, U.S. Office of Education. (Appendix C)

3. A questionnaire concerning referrals based upon an analysis of the results of the demographic study was developed. It consisted of those items deemed necessary to aid in case-finding deaf-blind persons. The selected nationally known experts were asked to rank in order of importance the items on the questionnaire and to make recommendations to improve its applicability, universality and scope. (Appendix D) Their responses were

tabulated on a matrix of frequencies table to rank the importance of twenty case-finding factors listed in the questionnaire. (Table 1, pp. 25-26)

4. A revised questionnaire consisting of major elements determined from the table of matrix analysis was returned to the panel to be ranked in order of importance. (Appendix E) These responses were again tabulated on a matrix of frequencies table. (Table 2, pp. 32-33)

5. From this information a case-finding instrument was developed.

Sources of Data

Case history data was obtained from records of known cases of deaf-blind persons registered with the Southwest Regional Center for Services to Deaf-Blind Children in Dallas, Texas and/or Blind Services, Division of Income Maintenance of the Louisiana Health, Social and Rehabilitation Administration in Baton Rouge, Louisiana. Full cooperation was extended by the Louisiana State Department of Education, Bureau of Special Education; Blind Services, Division of Income Maintenance of the Louisiana Health, Social and Rehabilitation Administration; and the Southwest Regional Center for Services to Deaf-Blind Children.

Following analysis of initial data, information was obtained from questionnaires. In addition, both the

Regional Center and the Bureau of Handicapped, U.S. Office of Education were contacted for unpublished materials relevant to this topic which may have emanated from any Regional Center in the United States.

Chapter 2

SURVEY OF RELATED LITERATURE

In 1962 the Industrial Home for the Blind [New York] operated a federally funded research and demonstration project for developing national services for deaf-blind persons. This project's purpose was to demonstrate a need for regional rehabilitation programs. However, due to the sparse distribution of the deaf-blind population and the problems of case-finding, the study was inconclusive (Spar, 1972).

The problem served as a reminder when the 1967 amendments to the Vocational Rehabilitation Act authorized the establishment and operation of the National Center for Deaf-Blind Youths and Adults. This center continues to be operated by the Industrial Home for the Blind. Permanent facilities are scheduled to be completed by early 1975. Affiliations with colleges and universities will permit inclusion of orientation information on deaf-blind in courses for "social workers, public health nurses and other professional workers who are likely to find deaf-blind persons" (Spar, 1972)

Dr. Theodore F. Thurmon III, assistant professor of pediatrics and director of the genetics laboratory at Louisiana State University School of Medicine, New Orleans,

and Dr. Esther Anderson, hemotologist at Louisiana State University, are associate directors of the medical school's Heritage Disease Center working to develop genetic profiles of two areas of Louisiana which are termed a "genetic gold mine." The work, supported by the National Foundation-March of Dimes, is investigating the stable populations of Acadiana and the Florida Parishes where "extensive inbreeding has resulted in a greater incidence of genetic disease than would otherwise be the case." Twenty-three noted diseases included familial deafness and familial blindness. Drs. Thurmon and Anderson depend upon other physicians for referrals (Medical World News, 1972).

Lars Guldager (1973), executive director of the Community Group, Newton Centre, Massachusetts, and recent Coordinator of the New England Regional Center for Services to Deaf-Blind Children, has offered a six point macro-solution for handling the deaf-blind population under a regional center. Only two of the six points offered were relevant to this study. He suggested (1) there should be a central registry for all handicapped children from birth and (2) physicians and other professionals be required by law to report handicapped children to the registry.

Una Haynes (1967) prepared a developmental approach to case-finding of cerebral palsy, mental

retardation and related disorders for use by public health nurses in their work. The booklet made the nurse aware of steps in the normal child's development and signs which may indicate the presence of a problem. It did not develop a mode of seeking new referrals.

The only recorded systematic attempt at case-finding of deaf-blind was done by the Michigan School for the Blind in cooperation with the Michigan Department of Public Health and the Michigan State Medical Society in late 1968. Seven thousand six hundred questionnaires were sent to members of the Michigan State Medical Society. Thirty physicians returned the questionnaires, listing 580 cases. These referrals and follow-ups resulted in summer programs supported by federal grants to evaluate and make recommendations for each child and to instruct parents and family members in home training (Wiehn, 1970).

The paucity of information on case-finding as applied to deaf-blind persons supported the need for this study. The review of literature graphically illustrated the frustrations of professionals, parents, and the deaf-blind in their efforts to locate coordinated services.

Chapter 3

PROCEDURES USED IN THE STUDY

Selected data from the case histories of 164 known cases of deaf-blind persons in Louisiana were tabulated on data sheets to develop a demographic survey for analysis and correlation of information considered relevant to case-finding deaf-blind children. (Appendix B) The data sheet was patterned after one used in gathering information considered essential to programming and action by Deaf-Blind Regional Centers.

The case history information was supplied by the Southwest Regional Center for Services to Deaf-Blind Children in Dallas, Texas, and Blind Services, Division of Income Maintenance of the Louisiana Health, Social and Rehabilitation Administration in Baton Rouge, Louisiana. As the study evolved, nine of the case histories were removed by Blind Services because there was no evidence either of blindness in some cases or of hearing disabilities in other cases. Therefore, the total case histories in this study were reduced to 155.

Complete confidentiality of case histories was required and was assured. For this reason, no formal statistical data analysis of the case histories will be

found in this writing. However, the information from the data sheets was analyzed by weight of occurrence and examined for interrelationships.

Robert Dantona, National Coordinator of Centers and Services for Deaf-Blind Children, Bureau of Education for the Handicapped, U.S. Office of Education was contacted and asked if he might both participate in the study as a panelist and recommend other recognized experts in the field who had demonstrated both proficiency and interest in deaf-blind activities. Mr. Dantona responded favorably and submitted a list of names and addresses of persons to be contacted for participation in the study. Members of the Advisory Committee for Centers and Services for Deaf-Blind Children, Bureau of Education for the Handicapped; regional and state coordinators of deaf-blind services; and physicians comprised this select panel of twenty experts. (Appendix C) Care was exercised to include at least one panelist from each Regional area in the United States. (Appendix A) The panelists were chosen to cover many contributing disciplines: social work, education, medicine, administration, rehabilitation and parenthood.

The results of the demographic survey were then compiled into the First Inquiry Sheet in two sub-categories randomly arranged. (Appendix D) The first sub-category,

Operating Agencies/Personal/Professional Referrals, listed all reporting sources found in the demographic survey. The second sub-category, Investigative Potentials, contained possible investigative potentials deemed important from the occurrence patterns noted in the same survey.

To increase applicability, universality and scope of the study, the respondents reacting to the listing of case-finding criteria were given the opportunity to write in other case-finding criteria deemed important by them from their experience. The instruction sheet encouraged them to rank such write-ins with the other criteria in their considered importance relative to those criteria presented. (Appendix D)

The First Inquiry Sheets and Instructions were forwarded with a letter of transmittal to the various respondents for their numeric ranking. (Appendix D) The responses were tabulated on a matrix of frequencies table to rank the importance of the twenty case-finding factors listed in the questionnaire. (Table 1, pp. 25-26) Each rank was assigned a numerical value ranging from one to eleven in the case of the first sub-category and from one to nine in the second sub-category. Those items not ranked were valued at zero. The products of the numerical value of each rank times the number of occurrences of that rank for each item were totalled. The item with the highest total was taken as the case-finding

criteria deemed most important by the panel; the successively lower totals established the descending order of importance. In addition, each write-in was tabulated for consideration of inclusion in the second inquiry.

The Second Inquiry Sheet was composed from the major elements determined from the first matrix of frequencies table, along with the panelists' suggested revisions, insertions, combinations of criteria, and/or other write-ins. (Appendix E) The twenty revised case-finding factors were randomly listed. The panel of twenty experts was requested to react to this Second Inquiry Sheet, again ranking the criteria in their considered order of importance.

The final responses were then tabulated on the Second Matrix of Frequencies Table for evaluation of rank of importance of the case-finding criteria. (Table 2, pp. 32-33) Each rank was assigned a numerical value ranging from one to twenty. Those items not ranked were valued at zero. The products of the numerical value of each rank times the number of occurrences of that rank for each item were totalled. The item with the highest of these totalled rank values was taken as the case-finding criteria deemed most important by the panel, and each successively lower total established the descending order of importance. From these rankings a case-finding instrument was developed.

Chapter 4

PRESENTATION AND ANALYSIS OF DATA

The tabulation of the initial case-finding data revealed a total of eleven different sources of referral, including both agencies and individuals. Because all of these were obvious sources for case-finding, none was omitted in the listing of initial case-finding criteria for use in identifying deaf-blind children. The listed sources were:

Department of Public Welfare

Statewide Services for the Blind

American Foundation for the Blind

Perkins School for the Blind

Executive referral from statistical audit

Hospital or clinic

Medical doctor

Parent

Mental Retardation Program

Public Health

Regional Center for Services to Deaf-Blind

Children.

In addition to these known referral sources, there seemed to evolve from the data patterns for

potential development of other referral sources. Analysis of high frequency of occurrence of some etiologies appeared to offer the greatest promise. Suggested programs or other investigative potentials were then devised, in general from consideration of the etiologies, and in specificity from correlative data and administrative concepts.

The most frequent cause of deaf-blindness proved to be maternal rubella, in an overwhelming proportion to all other etiologies. This was followed by retinitis pigmentosa; potential high risk of sensory impairment to neonate prior to, during or following birth; and meningitis/encephalitis. Investigative Potentials on the First Inquiry Sheet suggested the importance of these factors and offered mechanisms for developing case-finding methods:

Examination of birth records to identify children born in a given locality 5-9 months following a rubella epidemic

Identification of siblings and/or descendants of known deaf-blind with inherited disorders

Identification of high risk babies from hospital records

Examination of Public Health records for cases of meningitis/encephalitis

Development of programs to conduct hearing and vision screening of all school failures in grades 1-3

Development of programs to conduct hearing and vision screening of pre-school children in rural areas.

Evident in the data was the high incidence of mental retardation coincident with the multihandicapping condition of deaf-blindness. Likewise, many referrals came from mental retardation programs indicating a possible need for screening the children in these programs, hence the inclusion of the following Investigative Potential:

Development of programs to conduct hearing and vision screening of all children in special education (except the gifted).

Another area for case-finding indicated by the data was culture pockets. An Investigative Potential was provided to cover this aspect of investigation:

Development of multi-lingual public service advertisements of deaf-blind programs.

The great number of referrals by hospitals, clinics and medical doctors established the need for a referral program. Ease of referral and early identification of suspect infants seemed essential, hence the Investigative Potential:

Establishment of a referral program specifically to charity clinics, pediatricians and general practitioners using pre-addressed cards with nominal information for referral of a child to a central agency.

For the First Inquiry Sheet these total data were presented in two categories, each of which was randomly arranged. The first group comprised the known referral sources; the second group comprised investigative potentials as possible sources of referral.

The inquiry sheets were mailed to the twenty respondents for their expert evaluation for their considered importance. (Appendix D) A response level of 100 per cent of the panel was obtained.

Their responses were tabulated on a matrix of frequencies table resulting in the following order of significance from the composite of all respondents:

<u>Source</u>	<u>Total Rank Value</u>
1. Parent	166
2. Regional Centers for Services to Deaf-Blind Children	162
3. Statewide Services for the Blind	145
4. Public Health	137
5. Medical doctor	136
6. Hospital or clinic	127
7. Mental Retardation Program	127
8. Department of Public Welfare	105
9. American Foundation for the Blind	65

<u>Source</u>	<u>Total Rank Value</u>
10. Perkins School for the Blind	50
11. Executive referral from statistical audit	47

(Table 1, pp. 25-26)

The Investigative Potentials were also tabulated on a matrix of frequencies table to determine the composite value as assigned by the respondents. (Table 1, pp. 25-26) Those potential ranked as follows:

<u>Potential</u>	<u>Total Rank Value</u>
1. Examination of birth records to identify children born in a given locality 5-9 months following a rubella epidemic	123
2. Identification of high risk babies from hospital records	118
3. Establishment of a referral program specifically to charity clinics, pediatricians and general practitioners using pre-addressed cards with nominal information for referral	114
4. Development of programs to conduct hearing and vision screening of all children in special education (except the gifted)	103

TABLE 1

MATRIX OF FREQUENCIES: FIRST INQUIRY

Operating Agencies/Personal/Professional Referrals

Rank	1	2	3	4	5	6	7	8	9	10	11	Not Ranked	Total Rank Value
Value	11	10	9	8	7	6	5	4	3	2	1	0	
Item													
1	0	1	2	0	3	4	2	2	4	1	0	1	105
	0	10	18	0	21	24	10	8	12	2	0	0	
2	2	2	5	1	2	3	3	0	1	0	0	1	145
	22	20	45	8	14	18	15	0	3	0	0	0	
3	0	0	0	1	2	0	1	3	4	7	0	2	65
	0	0	0	8	14	0	5	12	12	14	0	0	
4	0	0	0	0	1	2	1	1	3	3	7	2	50
	0	0	0	0	7	12	5	4	9	6	7	0	
5	0	0	0	1	0	1	2	2	1	3	6	4	47
	0	0	0	8	0	6	10	8	3	6	6	0	
6	0	2	6	3	0	1	2	1	3	0	0	2	127
	0	20	54	24	0	6	10	4	9	0	0	0	
7	3	5	1	0	3	2	1	1	0	0	2	2	136
	33	50	9	0	21	12	5	4	0	0	2	0	
8	4	4	3	3	2	3	1	0	0	0	0	0	166
	44	40	27	24	14	18	5	0	0	0	0	0	
9	1	2	2	4	3	2	1	1	1	0	1	2	127
	11	20	18	32	21	12	5	4	3	0	1	0	
10	1	2	0	5	5	2	1	3	0	1	0	0	137
	11	20	0	40	35	12	5	12	0	2	0	0	
11	9	2	1	2	0	1	0	2	0	2	0	1	162
	99	20	9	16	0	6	0	8	0	4	0	0	

TABLE 1 (continued)
Investigative Potentials

Rank	1	2	3	4	5	6	7	8	9	Not Ranked	Total Rank Value
Value	9	8	7	6	5	4	3	2	1	0	
Item											
1	5 45	2 16	3 21	2 12	3 15	1 4	2 6	2 4	0 0	0 0	123
2	2 18	2 16	1 7	1 6	1 5	3 12	2 6	3 6	3 3	2 0	79
3	4 36	6 48	1 7	1 6	1 5	2 8	2 6	1 2	0 0	2 0	118
4	0 0	2 16	1 7	3 18	3 15	3 12	1 3	3 6	2 1	2 0	79
5	6 54	2 16	0 0	4 24	1 5	1 4	3 9	1 2	0 0	2 0	114
6	0 0	1 8	5 35	3 18	1 5	4 16	0 0	2 4	3 3	1 0	89
7	0 0	0 0	3 21	1 6	3 15	0 0	4 12	1 2	5 5	3 0	61
8	1 9	1 8	4 28	4 24	3 15	3 12	1 3	2 4	0 0	1 0	103
9	2 18	4 32	2 14	0 0	2 10	1 4	2 6	2 4	4 4	1 0	92

	<u>Potential</u>	<u>Total Rank Value</u>
5. Development of programs to conduct hearing and vision screening of pre-school children in rural areas		92
6. Development of multi-lingual public service advertisements of deaf-blind programs		89
7. Identification of siblings and/or descendants of known deaf-blind with inherited disorders		79
8. Examination of Public Health records for cases of meningitis/encephalitis		79
9. Development of programs to conduct hearing and vision screening of all school failures grades 1-3		61

The write-ins included new items or suggestions for revision and/or inclusion in existing items. The write-ins and frequency of suggestion were summarized:

	<u>Write-in Suggestion</u>	<u>Frequency</u>
1.	Speech and Hearing Centers	2
2.	Headstart	1
3.	State Department of Education, Special Education	2
4.	Establishment of an early data bank of all sensorially impaired	2
5.	Establishment of a high risk registry in obstetric-gynecology offices	1

<u>Write-in Suggestion</u>	<u>Frequency</u>
6. Establishment of a high risk registry in pediatric and all baby clinics	1
7. Census reports	1
8. Survey of existing classes for deaf or blind	1
9. Screening of all children	2
10. Educate all deaf-blind related disciplines in the importance of early identification of cases	2
11. Public schools	1
12. Gear advertisements to parents and the general public as well as professionals	1

It was evident from the write-ins that a great deal of personal effort and thought went into the responses to increase the value of this study. Therefore, it was determined that in the second inquiry all write-ins should be considered, if possible, for cross evaluation by other members of the panel.

By visual inspection of the data a definite break in relative importance of existing referral sources was noted following the eighth-ranked source. In the Investigative Potentials the importance declined less abruptly at any single point. However, there was a fairly significant drop following the sixth-ranked Investigative Potential; and while Potentials 3 through 6 had some interlocking with write-ins, Potentials 7

through 9 had none. This formed the basis of the decision to hold the first six ranked Potentials for the Second Inquiry Sheet and to drop the last three.

These factors determined the weighting and shape of the Second Inquiry Sheet with the eight referral sources most heavily weighted at 40% of the twenty items to be presented and the six highest ranked Investigative Potentials and the write-ins weighted at 30% each. Those write-ins which seemed to be duplications or were suggested to improve the above-mentioned selected Potentials were used for revision of those Potentials; other write-ins were distinctive and were presented singularly. Only one write-in, census reports, was deemed not applicable as a case-finding potential in this study due to the considered time lag from collection of the census data to the availability of that data for public use.

The items for the Second Inquiry Sheet were prepared and randomly arranged in a single listing. (Appendix E) The eight selected sources of referral were revised to be grammatically consistent with the Investigative Potentials and appear on the Second Inquiry Sheet as "Referral from . . ." in each case: i.e., Referral from parent. The two top-ranked Investigative Potentials from the First Inquiry Sheet were not altered: (1) Examination of birth records to identify children born in a given locality 5-9 months following a rubella epidemic

and (2) Identification of high risk babies from hospital records. The Investigative Potentials which were revised to incorporate changes suggested by write-ins read:

1. Establishment of a referral program specifically . . . [for] charity clinics, [obstetricians,] pediatricians and general practitioners using pre-addressed cards with nominal information for referral of [high risk or sensorially impaired children] . . . to a central agency
2. Development of multi-lingual public service advertisements of deaf-blind programs [geared to parents and the general public]
3. Development of programs to conduct hearing and vision screening of all children . . . (except the gifted) [in special education]
4. Development of programs to conduct hearing and vision screening of pre-school children [, especially] in rural areas.

Other write-ins which were suggested as potential case-finding criteria for use in identifying deaf-blind children were either used as presented or combined with other write-ins:

1. Survey of all children in institutions for the retarded
2. Survey of existing classes for deaf or blind
3. Education of all deaf-blind related disciplines in the importance of early identification and referral of cases
4. Referral from public school screening programs
5. Referral from Headstart
6. Referral from Speech and Hearing Centers.

The Second Inquiry Sheets were then mailed to the same panel of twenty experts for their evaluation and the ranking of the case-finding criteria according to their considered order of importance. Again, 100 per cent of the panel responded. Their responses were tabulated on a matrix of frequencies table, and the total rank value of each criteria was determined. (Table 2, pp. 32-33) The order of importance assigned to each criteria according to the total rank value was:

<u>Criteria</u>	<u>Total Rank Value</u>
1. Referral from Statewide Services for the Blind	280
2. Referral from parent	278
3. Establishment of a referral program specifically for charity clinics, obstetricians, pediatricians and general practitioners using pre-addressed cards with nominal information for referral of high risk or sensorially impaired children to a central agency	258
4. Identification of high risk babies from hospital records	249
5. Referral from Regional Center for Services to Deaf-Blind Children	247
6. Referral from medical doctor	240
7. Referral from Speech and Hearing Centers	229
8. Referral from Mental Retardation Program	228

TABLE 2

MATRIX OF FREQUENCY FOR THE SECOND INQUIRY

Rank	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	Not Ranked	Total Rank Value	
Value	20	19	18	17	16	15	14	13	12	11	10	9	8	7	6	5	4	3	2	1	0		
Item																							
1	4 80	2 38	2 36	1 17	0 0	0 0	2 28	1 13	1 12	0 0	2 20	1 9	0 0	3 21	1 6	0 0	0 0	0 0	0 0	0 0	0 0	0 0	280
2	0 0	1 19	2 36	1 17	3 48	0 0	0 0	2 26	0 0	1 11	1 10	2 18	1 8	0 0	2 12	0 0	1 4	1 3	2 4	0 0	0 0	0 0	216
3	1 20	3 57	1 18	4 68	0 0	1 15	0 0	0 0	2 24	0 0	1 10	0 0	0 0	3 21	1 6	1 5	0 0	1 3	1 2	0 0	0 0	0 0	249
4	2 40	0 0	0 0	3 51	1 16	1 15	0 0	1 13	0 0	3 33	1 10	1 9	1 8	2 14	1 6	2 10	0 0	1 3	0 0	0 0	0 0	0 0	228
5	0 0	0 0	1 18	0 0	2 32	0 0	1 14	0 0	1 12	2 22	1 10	1 9	2 16	2 14	2 12	1 5	1 4	1 3	2 4	0 0	0 0	0 0	175
6	1 20	0 0	1 18	0 0	1 16	1 15	2 28	2 26	2 24	0 0	1 10	1 9	2 16	0 0	2 12	0 0	2 8	1 3	0 0	1 0	1 1	0 0	206
7	0 0	0 0	0 0	0 0	0 0	2 30	1 14	0 0	1 12	1 11	0 0	0 0	4 32	1 7	2 12	0 0	4 16	2 6	1 2	1 1	1 1	0 0	143
8	3 60	1 19	4 72	1 17	1 16	1 15	1 14	1 13	0 0	1 11	0 0	1 9	2 16	0 0	1 6	2 10	0 0	0 0	0 0	0 0	0 0	0 0	278
9	3 60	4 76	0 0	0 0	1 16	2 30	0 0	1 13	1 12	2 22	0 0	0 0	0 0	0 0	1 6	2 10	0 0	0 0	0 0	2 2	1 0	0 0	247
10	0 0	2 38	0 0	1 17	2 32	1 15	2 28	0 0	2 24	0 0	2 20	1 9	1 8	0 0	2 12	1 5	0 0	0 0	1 2	1 1	1 1	1 0	211

TABLE 2 (continued)

Rank	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	Not Ranked	Total Rank Value
Value	20	19	18	17	16	15	14	13	12	11	10	9	8	7	6	5	4	3	2	1	0	
Item																						
11	0	1	0	1	1	0	1	0	0	1	1	2	0	1	2	1	2	2	1	3	0	
	0	19	0	17	16	0	14	0	0	11	10	18	0	7	12	5	8	6	2	3	0	148
12	0	0	0	1	3	0	1	3	2	1	1	1	1	1	0	1	1	1	0	1	1	
	0	0	0	17	48	0	14	39	24	11	10	9	8	7	0	5	4	3	0	1	0	200
13	0	1	0	2	2	1	0	3	1	0	1	6	0	0	1	0	1	0	0	1	0	
	0	19	0	34	32	15	0	39	12	0	10	54	0	0	6	0	4	0	0	1	0	226
14	0	1	0	0	0	2	3	0	0	1	1	0	1	3	0	0	3	2	3	0	0	
	0	19	0	0	0	30	42	0	0	11	10	0	8	21	0	0	12	6	6	0	0	165
15	0	0	0	0	0	1	0	0	1	2	2	0	1	0	0	2	3	3	1	4	0	
	0	0	0	0	0	15	0	0	12	22	20	0	8	0	0	10	12	9	2	4	0	114
16	0	2	3	1	1	0	0	0	0	1	1	0	0	2	0	1	0	1	4	3	0	
	0	38	54	17	16	0	0	0	0	11	10	0	0	14	0	5	0	3	8	3	0	179
17	1	0	3	2	1	2	2	0	1	1	0	0	3	0	0	1	0	1	1	1	0	
	20	0	54	34	16	30	28	0	12	11	0	0	24	0	0	5	0	3	2	1	0	240
18	0	1	1	2	0	0	1	3	2	2	2	2	0	1	0	2	1	0	0	0	0	
	0	19	18	34	0	0	14	39	24	22	20	18	0	7	0	10	4	0	0	0	0	229
19	4	1	1	0	0	3	2	2	0	1	1	0	0	0	1	2	0	1	1	0	0	
	80	19	18	0	0	45	28	26	0	11	10	0	0	0	6	10	0	3	2	0	0	258
20	1	0	1	0	2	1	1	2	2	0	1	1	1	1	1	1	2	1	1	0	0	
	20	0	18	0	32	15	14	26	24	0	10	9	8	7	6	5	8	3	2	0	0	207

	<u>Criteria</u>	<u>Total Rank Value</u>
9.	Referral from hospital or clinic	226
10.	Survey of all children in institutions for the retarded	216
11.	Education of all deaf- blind related disciplines in the importance of early identification and referral of cases	211
12.	Referral from Public Health	207
13.	Survey of existing classes for deaf or blind	206
14.	Development of programs to conduct hearing and vision screening of pre-school children, especially in rural areas	200
15.	Development of multi- lingual public service advertisements of deaf-blind programs geared to parents and the general public	179
16.	Referral from Public Welfare	175
17.	Examination of birth records to identify children born in a given locality 5-9 months following a rubella epidemic	165
18.	Referral from public school screening programs	148
19.	Development of programs to conduct hearing and screening of all children (except the gifted) in special education	143
20.	Referral from Headstart	114

Chapter 5

SUMMARY

The total rank values of the case-finding criteria from the Second Inquiry Sheet were presented in Chapter 4. (Table 2, pp. 32-33) The two highest ranked criteria: (1) Referral from Statewide Services for the Blind and (2) Referral from parent had been previously ranked 3 and 1, respectively, by the panel from the referral sources listed on the First Inquiry Sheet.

The next two highest ranked criteria: (3) Establishment of a referral program specifically for charity clinics, obstetricians, pediatricians and general practitioners using pre-addressed cards with nominal information for referral of high risk or sensorially impaired children to a central agency and (4) Identification of high risk babies from hospital records had been previously ranked 3 and 2, respectively, by the panel from the investigative potentials listed on the First Inquiry Sheet.

Those referrals ranked fifth through ninth and twelfth on the Second Inquiry Sheet were existing referral sources which had been among the eight top-ranked referral sources on the First Inquiry Sheet. The seventh ranked item had been a write-in:

5. Referral from Regional Center for Services to Deaf-Blind Children
6. Referral from medical doctor
7. Referral from Speech and Hearing Centers
8. Referral from Mental Retardation Program
9. Referral from hospital or clinic
12. Referral from Public Health.

Case-finding criteria ranked tenth, eleventh and thirteenth had also been write-ins from the panel of experts' responses to the First Inquiry Sheet:

10. Survey of all children in institutions for the retarded
11. Education of all deaf-blind related disciplines in the importance of early identification and referral of cases
13. Survey of existing classes for deaf or blind.

The fourteenth-ranked case-finding criteria, Development of programs to conduct hearing and vision screening of pre-school children, especially in rural areas, and the fifteenth-ranked case-finding criteria, Development of multi-lingual public service advertisements of deaf-blind programs geared to parents and the general public, were combinations of (a) Investigative Potentials which had been ranked fifth and sixth, respectively, on the First Inquiry Sheet and (b) write-in suggestions. Although a sharp drop in value may be noted

between these two items, it should be pointed out that 35% of the panelists ranked item fifteen, dealing with multi-lingualism, among their top five sources.

The remaining five case-finding criteria were distinctly lower in value in the panel's expert judgement. However, it should be noted that in this group there were investigative potentials which had ranked first and fourth on the First Inquiry Sheet, items ranked 17 and 19, respectively:

17. Examination of birth records to identify children born in a given locality 5-9 months following a rubella epidemic
19. Development of programs to conduct hearing and vision screening of all children (except the gifted) in special education.

Items ranked 16, 18 and 20 were existing referral sources which ranked of least importance in the panel's judgement:

16. Referral from Public Welfare
18. Referral from public school screening programs
20. Referral from Headstart.

Conclusions

The panel of experts exhibited strong support of existing referral sources and remarkable consistency in the relative order of importance assigned to the sources

in the two inquiry sheets. Seven of the first nine highest ranked criteria were existing referral sources.

It is significant that the panel valued two of the investigative potentials derived initially from evaluation of the original case history data used in this study as more important case-finding criteria than even nine of the existing referral sources evaluated. If only one conclusion were drawn from this study, it must be that there is a nationally recognized need for a more comprehensive effort to obtain early reporting of sensorially impaired or of suspect infants from doctors, hospitals and clinics to some central agency.

However, there is also a recognition of the need for development of other new and unique programs to conduct case-finding of deaf-blind persons. The following instrument was therefore developed to guide case-finding of deaf-blind persons:

<u>S</u>	*	<u>E</u>	*	<u>A</u>	*	<u>R</u>	*	<u>C</u>	*	<u>H</u>
<u>Survey</u>		<u>Advertise</u>				<u>Coordinate</u>				
		<u>Educate</u>		<u>Register</u>				<u>Habilitate</u>		

A national panel with varied expertise in deaf-blind related disciplines ranked a group of known and potential case-finding sources in the sequence shown on the attached Target Instrument.

Prime Target Areas

1. Your efforts are probably already coordinated with some of the referral sources listed. Maintain them as prime sources. Develop the use of other sources as soon as possible.
2. Persuade hospitals, clinics and doctors to participate in a program of early identification of sensorially impaired or suspect infants, providing referral to a central agency. Facilitate the mechanics of referral, i.e., use pre-addressed checklist cards similar to the attached sample, to enhance the acceptability of such programs. Further, in continued contact with these medical sources, request limited access to records, sufficient to identify high risk babies not previously reported.
3. Conduct surveys of all children in institutions for the mentally retarded on a planned basis to afford as near complete coverage as possible.

Other:

4. Prepare and make available slide or film presentations for loan to training

SEARCH Target Instrument

Top 10 - Prime Target Areas

1. Statewide Services for the Blind
2. Parent
3. Establish a referral program specifically for charity clinics, obstetricians, pediatricians and general practitioners using pre-addressed cards with nominal information for referral of high risk or sensorially impaired children to a central agency
4. Identify high risk babies from hospital records
5. Regional Centers for Services to Deaf-Blind Children
6. Medical doctor
7. Speech and Hearing Centers
8. Mental Retardation Program
9. Hospital or clinic
10. Survey all children in institutions for the retarded

Other Sources Ranked in Final Evaluation

11. Educate all deaf-blind related disciplines in the importance of early identification and referral of cases
12. Public Health
13. Survey existing classes for deaf or blind
14. Develop programs to conduct hearing and vision screening of pre-school children, especially in rural areas
15. Develop multi-lingual public service advertisements geared to parents and the general public
16. Department of Public Welfare

17. Examine birth records to identify children born in a given locality 5-9 months following a rubella epidemic
18. Public school screening programs
19. Develop programs to conduct hearing and vision screening of all children (except the gifted) in special education
20. Headstart

Additional Sources Considered

- ___ American Foundation for the Blind
- ___ Census reports
- ___ Develop programs to conduct hearing and vision screening of all school failures in grades 1-3
- ___ Examine Public Health records for cases of meningitis/encephalitis
- ___ Identify siblings and/or descendants of known deaf-blind with inherited disorders
- ___ Other professional individuals
- ___ Perkins School for the Blind

The complete and enthusiastic response of the panelists and the effort shown by each has reinforced the awareness that there is a desire for more research directed toward case-finding. As previously indicated in the review of literature, there are neither prior studies of possible sources of case-finding nor prior studies concerning case-finding the deaf-blind. There is a paucity of information concerning case-finding in any form.

Recommendations

The panel has endorsed the need for an expanded and continuing approach to case-finding through the development of workable modes of referral. At the same time, they have not underestimated the continuing need for cooperation of agencies and professionals already contributing. It is not, therefore, the intent of this study to suggest the supplanting of any existing referral source. Rather, it is to recommend the following additional potential case-finding criteria:

1. Develop a mode to implement a referral program specifically for charity clinics, obstetricians, pediatricians and general practitioners using pre-addressed cards with nominal information for referral of high risk or sensorially impaired children to a central agency. In conjunction with this development, explore the potential for searching hospital records to identify existing high risk babies.

2. Conduct surveys of children in programs and institutions for the mentally retarded and in existing classes for deaf or blind.

3. Prepare and make available slide or film presentations for loan to training institutions for use in training programs and to agencies for use in workshops or in-service training sessions.

4. In applicable areas develop multi-lingual public service advertisements of deaf-blind programs and services geared to parents and the general public for use by local media. In other areas use similar programs in English alone.

5. Conduct a pilot study using the case-finding instrument to determine its value. (Appendix F)

6. Continue to encourage further research in case-finding.

BIBLIOGRAPHY

A. Single-Volume Works

Tabor, Clarence W. Tabor's Cyclopedic Medical Dictionary.
Philadelphia: F. A. David Co., 1957.

B. Government Documents

Hammer, Edwin K. Deaf-Blind Children: A List of
References. U.S., Office of Education Publication
No. O40 520. Bethesda, Md.: Eric Reproduction
Service, 1969.

Haynes, Una. A Developmental Approach to Casefinding.
U.S., Children's Bureau Publication No. 449.
Washington: Government Printing Office, 1967.

C. Periodicals

Cooper, Louis Z., and others. "Rubella, Clinical
Manifestations and Management," American Journal
Diseases of Children, 118 (July, 1969), 18-29.

Dantona, Robert, and Peter J. Salmon. "The Current
Status of Services for Deaf-Blind Persons," The New
Outlook, 66 (March, 1972), 65-70.

Fenalson, Judith T. "An Occupational Therapy Program
for the Developmental Habilitation of Congenital
Rubella Children," The American Journal of
Occupational Therapy, 22 (November-December, 1968),
525-529.

Forbes, John A. "Rubella: Historical Aspects,"
American Journal Diseases of Children, 118 (July,
1969), 5-11.

Guldager, Lars. "Progress in Education for Deaf-Blind
Children," Education of the Visually Handicapped,
3 (March, 1971), 18-21.

Guldager, Lars. "A Macro-Solution in Special Education," The New Outlook, 67 (February, 1973), 72-78.

Medical World News Staff Reporter. "Louisiana: A Genetic Gold Mine," Medical World News, 13 (February, 1972), 73-77.

New Outlook Reporter. "News Notes," The New Outlook, 66 (May, 1972), 155.

Spar, Harry J. "What the Future May Hold for the Deaf-Blind Child," The New Outlook, 66 (December, 1972), 349-355, 360.

Wiehn, Virginia. "An Early Childhood Education Program for Deaf-Blind Children," The New Outlook, 64 (December, 1970), 313-314.

D. Other Sources

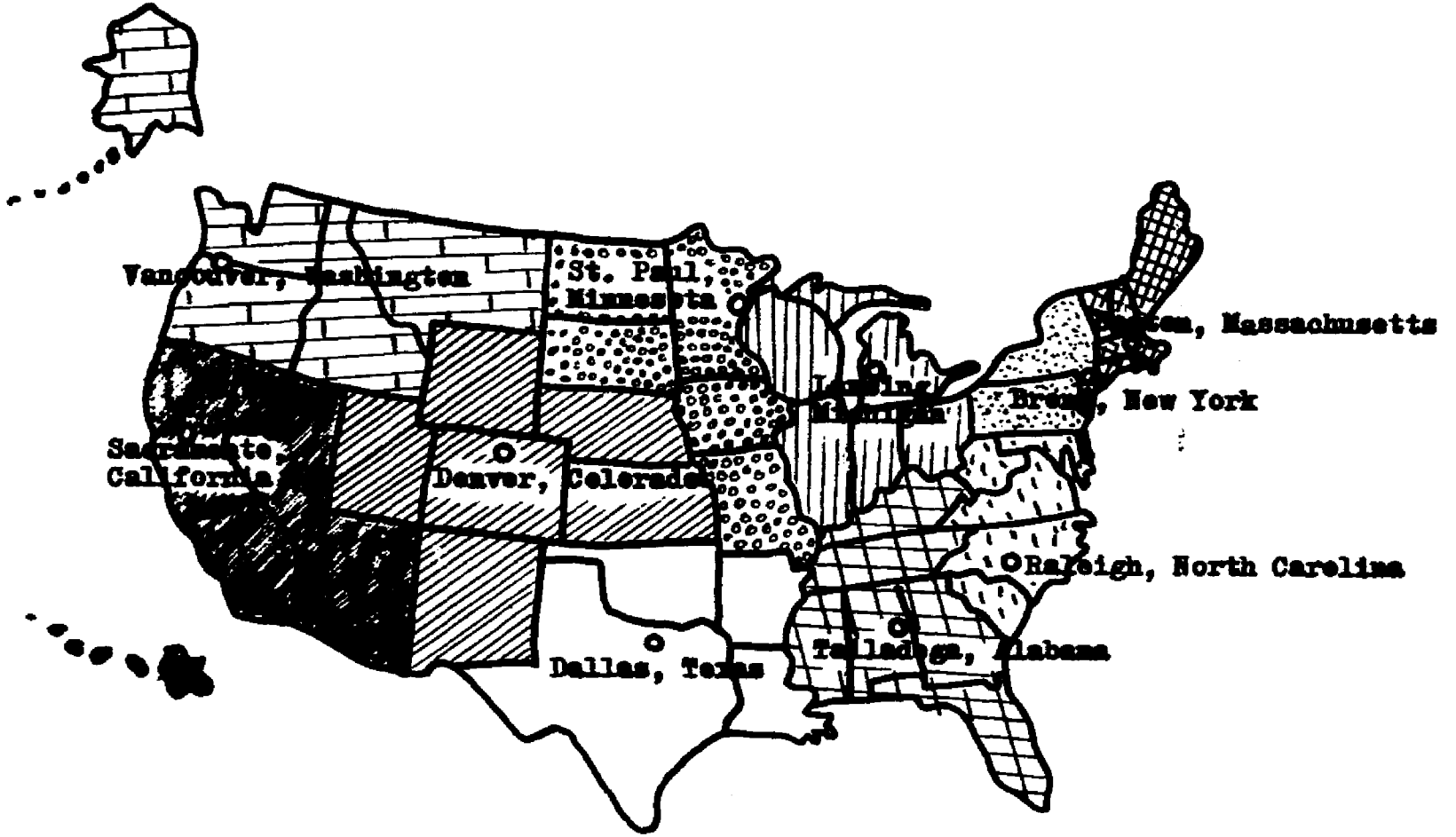
Nelson, Frank L., and David L. McCaffree. Telephone consultation. July, 1973.

"Plan for Implementation of Act 487." Regular Session of the Louisiana State Legislature. 1964.

Stager, David. University of Texas Summer Institute, Callier Hearing and Speech Center. August, 1971.

APPENDIX A

MAP OF DEAF-BLIND REGIONAL CENTERS



AREA CENTERS FOR SERVICES TO DEAF-BLIND CHILDREN

APPENDIX B

DATA SHEET

APPENDIX C

PANEL OF EXPERTS

APPENDIX C

PANEL OF EXPERTS

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APPENDIX D

FIRST INQUIRY

LOUISIANA STATE UNIVERSITY
AND AGRICULTURAL AND MECHANICAL COLLEGE

BATON ROUGE · LOUISIANA · 70803

College of Education

SPECIAL EDUCATION SERVICES
TELEPHONE 388-5282



HUEY P. LONG FIELD HOUSE
ROOM 85

November 26, 1973

The ever-increasing effectiveness of deaf-blind programs is well-known and attested in technical literature. However, in conversation with leaders in deaf-blind services I have been impressed by the dearth of casefinding criteria and the need for establishing and refining these capabilities for professionals. It is for this purpose that my doctoral investigation is being conducted under the direction of Dr. James L. McDuffie at Louisiana State University.

Only the most knowledgeable and experienced leaders in the area of deaf-blind can effectively evaluate patterns for casefinding. For this reason I am seeking your valued opinion, as a member of a panel of twenty experts, to establish a set of casefinding criteria.

Based upon criteria derived from case histories in the State of Louisiana this first request seeks your judgment of their relative importance. Space has been designated for comments and additional recommended criteria. The second, and final, inquiry will seek your judgment of the statistically screened criteria evaluated as most important from the first questionnaire including the supplementary recommendations.

Your cooperation represents an essential part of this investigation. The difficulty of obtaining valid and competent appraisal need not be impressed upon you. Realizing the number of requests which must cross your desk, the two inquiries are designed for maximal use, but minimal time requirement on your part.

I shall be most grateful for your participation as a member of this panel.

Sincerely yours,

Catherine E. Nelson
Doctoral Fellow

James L. McDuffie
Director of Dissertation

An Equal Employment Employer

/fhl

DIRECTIONS FOR THE FIRST INQUIRY

The attached inquiry sheet consists of twenty potential casefinding criteria for use in identifying deaf-blind children. These criteria have been separated into two categories, each in random order: 1) group or individual referrals and 2) investigative potentials.

Space is provided for any comment you care to make and/or any additional criteria you wish to recommend.

Without regard for the sub-categories, please rank your choices, including your own additional recommendations, in order of importance from the most important as number 1 down through the remainder.

CASEFINDING CRITERIA FOR IDENTIFYING DEAF-BLIND CHILDREN

CriteriaOperating Agencies/Personal/Professional Referrals

- ___ Department of Public Welfare
- ___ Statewide Services for the Blind
- ___ American Foundation for the Blind
- ___ Perkins School for the Blind
- ___ Executive referral from statistical audit
- ___ Hospital or clinic
- ___ Medical doctor
- ___ Parent
- ___ Mental Retardation Program
- ___ Public Health
- ___ Regional Center for Services to Deaf-Blind Children

Investigative Potentials

- ___ Examination of birth records to identify children born in a given locality 5 - 9 months following a rubella epidemic
- ___ Identification of siblings and/or descendants of known deaf-blind with inherited disorders
- ___ Identification of high risk babies from hospital records
- ___ Examination of Public Health records for cases of meningitis/encephalitis
- ___ Establishment of a referral program specifically to charity clinics, pediatricians and general practitioners using pre-addressed cards with nominal information for referral of a child to a central agency
- ___ Development of multi-lingual public service advertisements of deaf-blind programs
- ___ Development of programs to conduct hearing and vision screening of all school failures in grades 1-3
- ___ Development of programs to conduct hearing and vision screening of all children in special education (except the gifted)
- ___ Development of programs to conduct hearing and vision screening of pre-school children in rural areas

Write-ins:

PLEASE RETURN THIS SHEET IN THE ENCLOSED STAMPED ADDRESSED ENVELOPE

APPENDIX E
SECOND INQUIRY

LOUISIANA STATE UNIVERSITY
AND AGRICULTURAL AND MECHANICAL COLLEGE

BATON ROUGE · LOUISIANA · 70803

College of Education

SPECIAL EDUCATION SERVICES
TELEPHONE 388-8282



HUEY P. LONG FIELD HOUSE
ROOM 68

January 8, 1974

Thank you for your prompt response to my previous letter and for your personal effort to improve the scope and effectiveness of this research to develop casefinding criteria for deaf-blind children.

In the initial inquiry you ranked the relative importance of a listing of sources of referrals, investigative potentials and your individual write-ins.

This second and final inquiry is a listing of the aforementioned criteria as developed through an evaluation of your combined responses. The listing is in random order; I would appreciate your ranking them in consecutive order from 1 - 20 in accordance with your concept of their relative importance to casefinding with the most important as number 1.

As previously stated, only the most knowledgeable and experienced leaders in the area of deaf-blind can effectively evaluate patterns for casefinding. Without complete cooperation such as yours, this type of research would be non-existent and inaccessible to workers in the field. I am most grateful for your participation.

Sincerely yours,

Catherine E. Nelson
Doctoral Fellow

James L. McDuffie
Director of Dissertation

/fhl

DIRECTIONS FOR THE SECOND INQUIRY

The attached inquiry sheet is a random listing of twenty potential casefinding criteria for use in identifying deaf-blind children. These criteria were developed from an evaluation of responses to the first inquiry, including write-ins.

Please rank the items according to your concept of their relative importance, from the most important as number 1 through the least important as number 20.

CASEFINDING CRITERIA FOR IDENTIFYING DEAF-BLIND CHILDREN

- ___ Referral from Statewide Services for the Blind
- ___ Survey of all children in institutions for the retarded
- ___ Identification of high risk babies from hospital records
- ___ Referral from Mental Retardation Program
- ___ Referral from Department of Public Welfare
- ___ Survey of existing classes for deaf or blind
- ___ Development of programs to conduct hearing and vision screening of all children (except the gifted) in special education
- ___ Referral from parent
- ___ Referral from Regional Center for Services to Deaf-Blind Children
- ___ Education of all deaf-blind related disciplines in the importance of early identification and referral of cases
- ___ Referral from public school screening programs
- ___ Development of programs to conduct hearing and vision screening of pre-school children, especially in rural areas
- ___ Referral from hospital or clinic
- ___ Examination of birth records to identify children born in a given locality 5 - 9 months following a rubella epidemic
- ___ Referral from Headstart
- ___ Development of multi-lingual public service advertisements of deaf-blind programs geared to parents and the general public
- ___ Referral from medical doctor
- ___ Referral from Speech and Hearing Centers
- ___ Establishment of a referral program specifically for charity clinics, obstetricians, pediatricians and general practitioners using preaddressed cards with nominal information for referral of high risk or sensorially impaired children to a central agency
- ___ Referral from Public Health

PLEASE RETURN THIS SHEET IN THE ENCLOSED STAMPED ADDRESSED ENVELOPE

APPENDIX F

SEARCH DOCUMENT

S * E * A * R * C * H
Survey Advertise Coordinate
Educate Register Habilitate

A national panel with varied expertise in deaf-blind related disciplines ranked a group of known and potential case-finding sources in the sequence shown on the attached Target Instrument.

Prime Target Areas

1. Your efforts are probably already coordinated with some of the referral sources listed. Maintain them as prime sources. Develop the use of other sources as soon as possible.
2. Persuade hospitals, clinics and doctors to participate in a program of early identification of sensorially impaired or suspect infants, providing referral to a central agency. Facilitate the mechanics of referral, i.e., use pre-addressed checklist cards similar to the attached sample, to enhance the acceptability of such programs. Further, in continued contact with these medical sources, request limited access to records, sufficient to identify high risk babies not previously reported.

3. Conduct surveys of all children in institutions for the mentally retarded on a planned basis to afford as near complete coverage as possible.

Other

4. Prepare and make available slide or film presentations for loan to training institutions for use in training programs and to agencies for use in workshops and/or in-service training sessions.
5. In applicable areas develop multi-lingual public service advertisements of deaf-blind programs and services geared to parents and the general public for use by local media. In other areas use similar programs in English alone. It is important to pursue this development to improve information flow from prime referral sources which are not operating agencies, i.e., Parent.
6. At all times consider local needs in the utilization of the attached listed sources, recognizing that each is a possible source of referral of a deaf-blind person.

SAMPLE REFERRAL CARD

Child's Name _____
 Last First Middle

Parent(s) _____

Address _____

Birth Date _____ M ___ F ___

Sensorially Impaired ___ High Risk ___

Referred by _____

SEARCH Target Instrument

Top 10 - Prime Target Areas

1. Statewide Services for the Blind
2. Parent
3. Establish a referral program specifically for charity clinics, obstetricians, pediatricians and general practitioners using pre-addressed cards with nominal information for referral of high risk or sensorially impaired children to a central agency
4. Identify high risk babies from hospital records
5. Regional Centers for Services to Deaf-Blind Children
6. Medical doctor
7. Speech and Hearing Centers
8. Mental Retardation Program
9. Hospital or clinic
10. Survey all children in institutions for the retarded

Other Sources Ranked in Final Evaluation

11. Educate all deaf-blind related disciplines in the importance of early identification and referral of cases
12. Public Health
13. Survey existing classes for deaf or blind
14. Develop programs to conduct hearing and vision screening of pre-school children, especially in rural areas
15. Develop multi-lingual public service advertisements geared to parents and the general public

16. Department of Public Welfare
17. Examine birth records to identify children born in a given locality 5-9 months following a rubella epidemic
18. Public school screening programs
19. Develop programs to conduct hearing and vision screening of all children (except the gifted) in special education
20. Headstart

Additional Sources Considered

- ___ American Foundation for the Blind
- ___ Census reports
- ___ Develop programs to conduct hearing and vision screening of all school failures in grades 1-3
- ___ Examine Public Health records for cases of meningitis/encephalitis
- ___ Identify siblings and/or descendants of known deaf-blind with inherited disorders
- ___ Other professional individuals
- ___ Perkins School for the Blind

VITA

Catherine Epps Nelson, the daughter of Frank Andrew and Viola Hills Epps was born in New London, Connecticut June 13, 1925. She completed her elementary and secondary education in Norfolk, Virginia where she attended the College of William and Mary - Virginia Polytechnic Institute. She also attended the Richmond Professional Institute of the College of William and Mary and the University of Virginia. She received a Bachelor of Science degree in Elementary Education from Louisiana State University and Agricultural and Mechanical College in 1969 and a Master of Education degree in Special Education, Mental Retardation from the same institution in 1970. At the present time, she is completing requirements for the Doctor of Philosophy degree in Elementary Education at Louisiana State University and Agricultural and Mechanical College.

Her professional experiences include two years as an elementary substitute teacher, five years as a teacher of educable mentally retarded, one summer session as a teacher of emotionally disturbed, four semesters as a college teacher, and three years as a teacher of elementary deaf, the position she now holds.

She is married to Lawrence Earl Nelson. They are the parents of three children: Donald Earl Nelson, J.D., Frank Lawrence Nelson, D.D.S., and Catherine Nelson Atkinson, M.Ed.

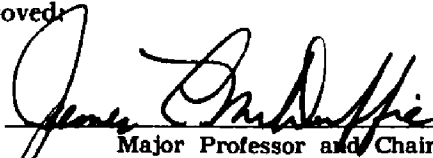
EXAMINATION AND THESIS REPORT

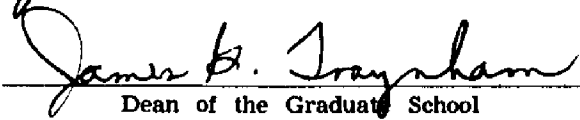
Candidate: Catherine Epps Nelson

Major Field: Education

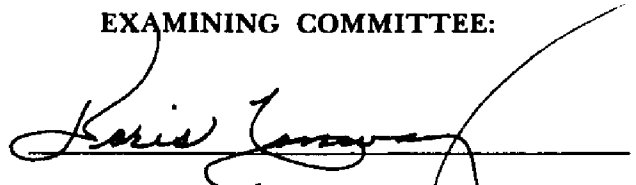
Title of Thesis: CASE-FINDING CRITERIA FOR USE IN IDENTIFYING DEAF-BLIND CHILDREN

Approved:

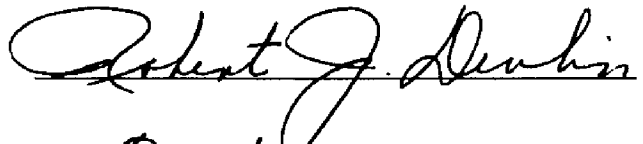

Major Professor and Chairman

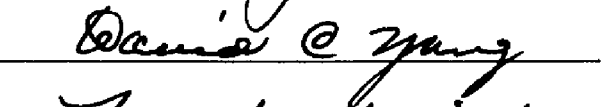

Dean of the Graduate School

EXAMINING COMMITTEE:











Date of Examination:

March 29, 1974