

Perspectives of Research and Service Activities Aiming at the Construction of a Support System for Deafblind Education in Japan

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Abstract: Due to the rare incidence of deafblindness, education for children with deafblindness is an area in which information, knowledge and skills are insufficient at both the local and prefectural levels. The National Institute of Special Education, being the sole national center of special education in Japan, is expected to provide various services and conduct research activities to support deafblind education. Aiming at the construction of comprehensive support system for deafblind education, the author ^(10,12,13,14,15,16,17,18,19) has been promoting over the past decade needs-driven research projects, educational consultation services, information services, networking among parents as well as developing international ties concerning deafblindness. Details of these research-linked service activities oriented toward establishing comprehensive support systems based at NISE are described and future perspectives are discussed.

Key Words : Deafblind education, support system, NISE, Japan

I Introduction

Since its establishment in 1971, The National Institute of Special Education (NISE) has taken a central role in Japan concerning practical and comprehensive research on special education, advanced in-service training for teachers, consultation to parents of children with disabilities referred to the Clinical Center for Children with Special Needs, overseas research exchanges and the dissemination of these research results through various means. The 30th anniversary in 2001 marked a fresh start for NISE being reorganized as an independent administrative agency instead of an institute directly affiliated to the Ministry of Education, Culture, Sports, Science and Technology (MEXT). As the national center of special education in Japan, greater demands are now being made on NISE to further tackle issues needing research at the national level and to pursue practical research and service activities accountable to the needs of society.

NISE is the only institute in Japan to carry out research on deafblind education. Consequently, it is expected to make a major contribution to the field of deafblindness with the dissemination of its research findings, the development of in-service teacher training programs and in the provision of educational consultation services for parents and related people.

This report provides an overview of the current status of deafblind education in Japan, the changes in social context over the past decade, the details of research and service activities of NISE that the author has been developing and the perspectives of future development of these activities to meet the expectations made of NISE described above.

II Current situation of deafblind education and changes in social context of deafblind persons

Several industrialized nations recognize deafblindness as a distinct disability category, such as the United States and Norway ^(1,6,12,18,25). However, as deafblindness was included into the category of "multiple disability" in Japan without any mention of its special needs, no system of support was developed. As a result, no pre- nor in-service training program for teachers of deafblind education had been developed. NISE had been the only institute in Japan to have provided consultation services on deafblindness. Currently, there are three researchers in the Department of Education for Children with Multiple Disabilities at NISE, including the author, who are engaged in deafblind education research.

1 A Population of deafblind students and children

The first survey on deafblind education was carried out in the 1993-94 school year by the Department of Education for Children with Multiple Disabilities ⁽¹¹⁾. The survey was done through questionnaires sent to all schools for the blind, schools for the deaf and day centers for preschool children with visual or hearing impairment. Three other types of special schools were not included in the first survey. The second survey carried out five years later in the 1998-99 school year covered all types of special schools and day centers for pre school children with visual or hearing impairment ⁽²²⁾. The two surveys defined deafblindness as a concomitant impairment of vision and hearing, with the following criteria for visual and hearing impairment: 1) "corrected visual acuity of less than 0.3" or "not measurable" and 2) "hearing threshold level of more

than 30dB" or "not measurable." For children and students identified as "not measurable," the result of the checklist on visual and auditory behavior was noted to determine eligibility. The criterion of "impairment in visual field and night blindness" was also added to screen progressive visual impairment such as retinitis pigmentosa. Those with severe problem with these two indices were included in the count even when they had visual acuity of more than 0.3, not only because they face potential deterioration of vision but also these two types of visual impairment themselves cause substantial problems in learning and social interaction as well. The number of children and students with deafblindness identified in the two surveys is shown on Table 1. The percentage of deafblind children and students in respective school types is also shown.

In these two surveys, the deafblind population in special education may not yet be fully ascertained. For example, there was a drastic fall in the deafblind population in schools for the deaf in the 1998 survey in comparison with 1993. As this result was not analyzed in the second survey, the author is not in the position to tell what caused this drastic decrease. However, as schools for the deaf in Japan have been increasingly adopting total communication and enrolling more children with multiple disabilities and deafblindness, it is difficult to find a reasonable cause within schools for the deaf that brought about this drastic fall. There is a day center for hearing impaired preschoolers in Japan which carries out an annual ophthalmological screening test ⁽³⁾. Each annual result since 1998 revealed visual problems in more than 25% of the children. Even though many of the children in this day center have additional disabilities which may partly contribute to the high prevalence, it is difficult to believe that only 0.8% of the students in schools for the deaf has

visual impairment.

One reason accounting for the identification of more deafblind population in the first survey might be the conscientious awareness raising done on schools for the blind and for the deaf during the survey through dissemination of information concerning deafblindness.

As there is no disability category of "deafblindness" in Japan, hard of hearing is easily overlooked in schools for the blind as well as low vision in schools for the deaf, particularly such progressive visual impairment caused by Usher syndrome. Usher syndrome is thought to be responsible for about half the adult deafblind population in Japan.

To get reliable results through surveys, awareness raising on deafblindness in all schools is needed. Accurate data on the deafblind population in schools provide the basis and orientation to research and service activities. For the time being, the analysis of referrals on deafblindness made to NISE and visits by researchers to schools where deafblind children are enrolled are necessary to supplement the data obtained through the survey.

Another method to make a reasonable calculation on the deafblind population Japan embraces is to apply the figures of other nations, which have had a long history of deafblind education. The federal definition of deafblindness, which is not medical but functional, in the United States is as follows.

"Deaf-blindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness ⁽⁶⁾. "

Table 1 Survey of deafblind students in school years 1993 and 1998

TYPE OF SPECIAL SCHOOLS	DEAFBLIND CHILDREN in 1993/ TOTAL ENROLLMENT* = %	DEAFBLIND CHILDREN in 1998/ TOTAL ENROLLMENT** = %
BLIND	138 / 4,773 = 2.9%	96 / 4,199 = 2.3%
DEAF	128 / 7,842 = 1.6%	54 / 6,836 = 0.8%
INTELLECTUAL DISABILITY	Not surveyed	64 / 53,561 = 0.9%
PHYSICAL DISABILITY	Not surveyed	59 / 18,464 = 0.3%
HEALTH IMPAIRMENT	Not surveyed	39 / 4,395 = 0.9%
DAY CENTER for VISUALLY or for HEARING IMPAIRED CHILDREN	25 / data unavailable	22 / data unavailable
TOTAL NUMBER (DOUBLE ENROLLMENT)	291 (10)	353 (15)

* Ministry of Education. (1994). Special Education Statistics, School Year 1993.

** Ministry of Education. (1999). Special Education Statistics, School Year 1998.

The number of deafblind children differs greatly between the federal count and the census done by the state and the multi-state deafblind program. The former adopts a far more conservative figure. The number of deafblind students aged 6 to 21 in school year 1996-97 submitted to the Congress by the federal government was 1,453⁽³⁴⁾. As the population of Japan is about half that of the United States, we may roughly estimate about 700 deafblind students in Japan if the United States federal definition is applied.

Although the age group it covers does not overlap completely, this figure, however conservative it may be in the United States, is twice the number identified in the second survey in Japan. We would not be too short of the target if we assume a deafblind population of somewhere between 350 and 700 for whom "particular considerations on the disability conditions are needed for instruction"⁽²⁾. In the future, it is important to include regular schools to accurately determine the deafblind school population.

2 A brief history of deafblind education in Japan

Deafblind education in Japan started in 1949 at the Yamanashi Prefectural School for the Blind with two totally deafblind children^(7,33). This pioneering program continued for 20 years, and the Ministry of Education supported it in the last ten years through the Grant to Schools with Experimental Practices⁽⁷⁾. This successful long-term program laid the foundation for deafblind education in Japan as well as giving a lasting influence on the research approach concerning deafblind education.

When NISE was established in 1971, one of the many roles it was expected to play was the promotion of research on and the development of in-service training programs for deafblindness⁽⁷⁾. Nevertheless, when compulsory education system finally encompassed all school-age children in 1979, the School Education Act included deafblindness in the category of multiply disability. It was a time when a big population of children with severe and multiple disabilities who had been exempted from school education until that time flooded schools which had had little or no experience with such a population. To cope, the research and in-service training programs at NISE gave a priority to severe and multiple disabilities that far outnumbered deafblindness in population itself.

Research on deafblindness was barely sustained by the Department of Education for Children with Multiple Disabilities at NISE. Due to the practical influence of the Yamanashi Prefectural School for the Blind, research centered on case studies of a relatively small number of deafblind children who made periodic visits to NISE, employing methods used in schools for the blind. This tradition has been passed down to succeeding researchers and still exists to date.

The system and the contents of education for children with severe and multiple disabilities steadily developed by the early 1990's. It was a time when social context of deafblind adults was undergoing rapid change, stimulating the awareness of the parents with deafblind children. It was also a time when the author began investigating overseas practices and the delivery of education services to deafblind children^(9,10,18). The situation regarding deafblind research and service activities began to take on a new phase in the following. The first survey of deafblind education that was carried out in 1993 was one such manifestation of the new phase.

3 Changes in the social context of deafblind adults

The year 1983 saw the first deafblind person accepted into a university in Japan. He is adventitiously deafblind and has now been working as an associate professor at a university since 1997. Support service programs intended for deafblind consumers, such as interpreter-guide services, were all but nonexistent in both the public and private sectors at the time of his matriculation. A group of volunteers gradually gathered around him to support him in his studies and daily life. The number of volunteers grew and their activities began to draw other deafblind persons who were hitherto isolated in their homes. More and more deafblind persons were identified, the needs of deafblindness clarified and concrete support services were worked out by the volunteers.

In 1991, the volunteer group which had been supporting him served as the parent body to establish the Japan Deafblind Association (JDBA). It is a social welfare corporation dedicated to promoting independence and social participation of deafblind persons, and is run by government subsidies and private contributions. In the same year, parallel to this development, local deafblind clubs were organized in two major cities in Japan, Tokyo and Osaka, and these clubs now act as a focal point for the development of needs-related activities for deafblind persons. Big changes have taken place in the last decade concerning deafblind persons in Japan. At the time of its establishment, JDBA had identified only some tens of deafblind persons. However, as of March 2001, there were 560 deafblind persons registered with the JDBA. Interpreter-guide services which are essential in promoting the independence and social participation of deafblind persons expanded rapidly. The interpreter dispatching project which JDBA started with a minimal number of interpreters now numbers 1700 registered interpreters with an annual delivery load of more than 7000 calls⁽⁵⁾.

Local deafblind clubs are also spreading steadily, and 31 of 47 prefectures in Japan, that is, two third of the prefectures, now have a deafblind club. Parents of deafblind children, who could not hitherto identify

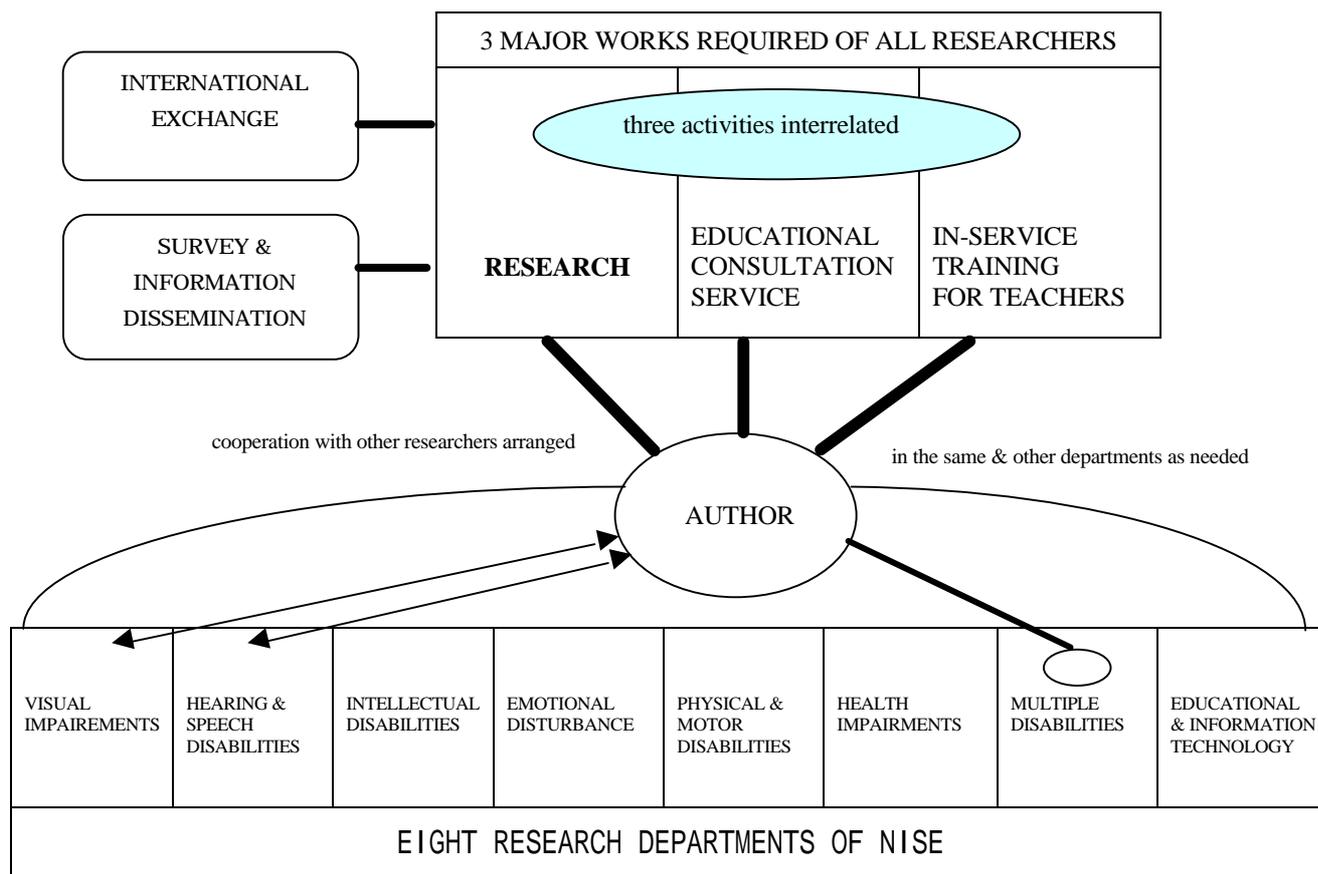


Fig.1 The eight research departments and the activities of NISE

themselves with other disability groups, gradually came to join local deafblind clubs to meet deafblind persons and other families in the same prefecture. Unlike many other countries with separate organizations for deafblind adults and for parents, the two parties in Japan collaborate closely to promote welfare and education for the deafblind.

As a result of continued lobbying, the national government included interpreter training services in 1998 and the interpreter dispatching services in 2000 to its list of subsidies to prefectural governments. As of 2001, 23 prefectural governments are subsidizing interpreter-training services and 11 provide interpreter-dispatching services. An increase in the prefectural governments initiating these services is anticipated, and all prefectures in Japan would most probably be providing these two services in about five to ten years⁽⁵⁾.

Currently, "deafblindness" is not legally recognized as a disability category in the welfare system of Japan. However, in 1999, the Ministry of Welfare and Labor entrusted the Research Institute of National Rehabilitation Center for the Disabled to launch a 3-year research project on "How Disability Policies Should be for Deafblind Persons^(23,24)." The result of this project will be used to orient welfare policies specifically geared toward deafblind persons in the near future.

There has not been a census on deafblind population in Japan. Calculated from statistics on overseas deafblind populations, it is estimated that Japan has a deafblind population of somewhere between 13,000 and 20,000⁽⁴⁾. Deafblind people are a diverse population, the diversity resulting from the combination of the differences in the degree of sensory impairments, the difference in the onset of impairment, the presence of additional disability and the quality of education provided. The majority of the deafblind population is adventitious, with Usher syndrome assumed to be the etiology accounting for the deafblindness of about half the population.

II The system of NISE and the support needs of deafblind education

In view of the drastic changes taking place in Japanese society as mentioned above, in early 1990's the author began to recognize the need to reevaluate the traditional research approach on deafblind research hitherto undertaken at the Department of Education for Children with Multiple Disabilities. Before going into details, an overview will be presented on the functions of NISE and the identification of support needs for deafblind education.

1 An overview of research and service system at NISE

NISE comprises of nine departments, eight of which are dedicated to research and one to administration. Seven of the eight research departments correspond with the disability categories used in Japan and one is specialized in educational information technology (Fig. 1).

The three major activities carried out at NISE are research, in-service training for special education teachers and consultation services for parents and other related persons.

The research projects at NISE can be divided into three types in accordance with the type of budget and project involved: 1) intra-departmental projects funded on a regular basis, 2) inter-departmental projects on themes of importance and urgency funded by an ad-hoc budget where researchers from multiple departments collaborate and 3) projects funded by grants researcher(s) obtain from outside NISE. Research projects on deafblindness have belonged to the first and the third types.

In-service training programs are offered for teachers throughout Japan who are expected to assume leadership roles in each locality after the program. There are 1-year and 2-month courses and a number of short-term programs lasting from one to four weeks. Each trainee on the 1-year course is assigned to a research department related to his/her interest and a program is tailored to each trainee under the supervision of a researcher. There are eight 2-month mainly lecture-based courses for visual impairment, hearing impairment, speech impairment, intellectual disability, emotional disability, health impairment, multiple disabilities and educational technology. Deafblindness is included minimally in the 2-month course for multiple disabilities, namely, half-a-day lecture and one-day workshop on simulation experience of deafblindness offered by the author.

Consultation services are provided by the Clinical Center for Children with Special Needs upon requests from parents of children with disabilities. The Center assigns each case to the most appropriate research department(s). Educational consultation services were long restricted only to parents who could come to NISE in person, however, in 2001 NISE expanded the service to accept requests from both parents and teachers via e-mail, the telephone and the post, other than a direct visit.

There are currently 51 researchers at NISE, and each one is required to be actively involved in all three functions NISE; namely, research, in-service training and educational consultation. One unique aspect of NISE is that it has a system that enables the formation of a dynamic inter-relationship between these three functions. Another asset is that experts from different disability categories are all housed under the same roof, and multi-disciplinary cooperation may be formed easily if a researcher finds it

necessary. In this regard, the author has maintained close cooperation with experts on visual impairment and hearing impairment. Figure 1 illustrates the eight departments and the major functions of NISE as well as how a researcher is related to these functions, using the author as an example.

The results of these three activities are disseminated through various means. International research exchanges are also actively encouraged at NISE. All researchers take part in these two activities as well.

Under such circumstances, the author sought contributions one researcher could make in research and service provision in response to the needs identified in deafblind education.

2 Needs of research and service provisions in deafblind education

The results of the surveys of deafblind education mentioned earlier identified support needs from the perspective of teachers^(11,22). On the other hand, the analysis of requests for consultation to Clinical Center and direct contacts to the author through correspondence regarding deafblindness from across the country⁽¹⁶⁾ helped identify the support needs from the perspective of parents.

The variety of needs for support of teachers and parents found from these two sources of information were summed up in the following five areas to strategically address them in the research and service provision plan:

- 1) Consultation to parents concerning the raising of a deafblind child, adopting a total view of the life.
- 2) Consultation to teachers according to the type of deafblindness and the child's needs.
- 3) Parental needs to meet with other parents.
- 4) The need of parents and teachers for a variety of information about deafblindness.
- 5) Scarcity of information on deafblindness in Japan leading to the need for international investigation and information exchange.

In addition to the above-mentioned areas, the following points also were considered necessary in developing research and service plans.

- (1) Need to solve the problem of distance.

As deafblind children are widely spread across the country, the consultation service must not be restricted to a center-based system, but should include such means as correspondence, visits by researchers, a live-in workshop at NISE, and others.

- (2) Need to work with schools for the deaf as well as schools for the blind.

As mentioned earlier, the Department of Education for Children with Multiple Disabilities has traditionally had close ties with schools for the blind, but has had limited ties with schools for the deaf. The result of the first survey⁽¹¹⁾ identified almost the same number of deafblind students in

schools for the deaf and schools for the blind. Communication methods chosen by the teachers in two different types of schools differ greatly, particularly as regards sign language. Research and services should be planned with due regard to the difference in culture of different school types, thus promoting them to support each other to widen the communication opportunities for deafblind children. Naturally, special schools for other disabilities which usually lack expertise in both vision and hearing should also be considered.

(3) Need to cope with a variety of sub-groups of deafblind children.

Deafblindness is a rare disability which has its unique needs common to all deafblind children. However, as there is also a great diversity within this small population, research should be made to clarify the needs and support measures for a number of major sub-groups. The Department of Education for Children with Multiple Disabilities has traditionally focused on congenitally deafblind children with additional disabilities. Children

with high cognitive capacity, with progressive vision deterioration or infants with deafblindness have not been included in the research projects. However, parents and teachers have distinct needs in accordance with the different sub-groups. The following seven sub-groups were selected and research was planned in combination with consultation services to these groups.

- (I) Those with congenital rubella syndrome
 - (ii) Those with CHARGE association * and various medical needs
 - (iii) Those with Usher syndrome and other progressive deafblindness
 - (iv) Those with complexities due to premature birth
 - (v) Those with severe motor and intellectual disabilities
 - (vi) Families with deafblind infants and toddlers
 - (vii) Those with high cognitive capacity
- (4) Need to link "education plan" with "total personal plan."

The perspectives of teachers' needs and parents' needs differ greatly. Teachers' are usually restricted to tasks and a

TRADITIONAL APPROACH

NEED- DRIVEN APPROACH

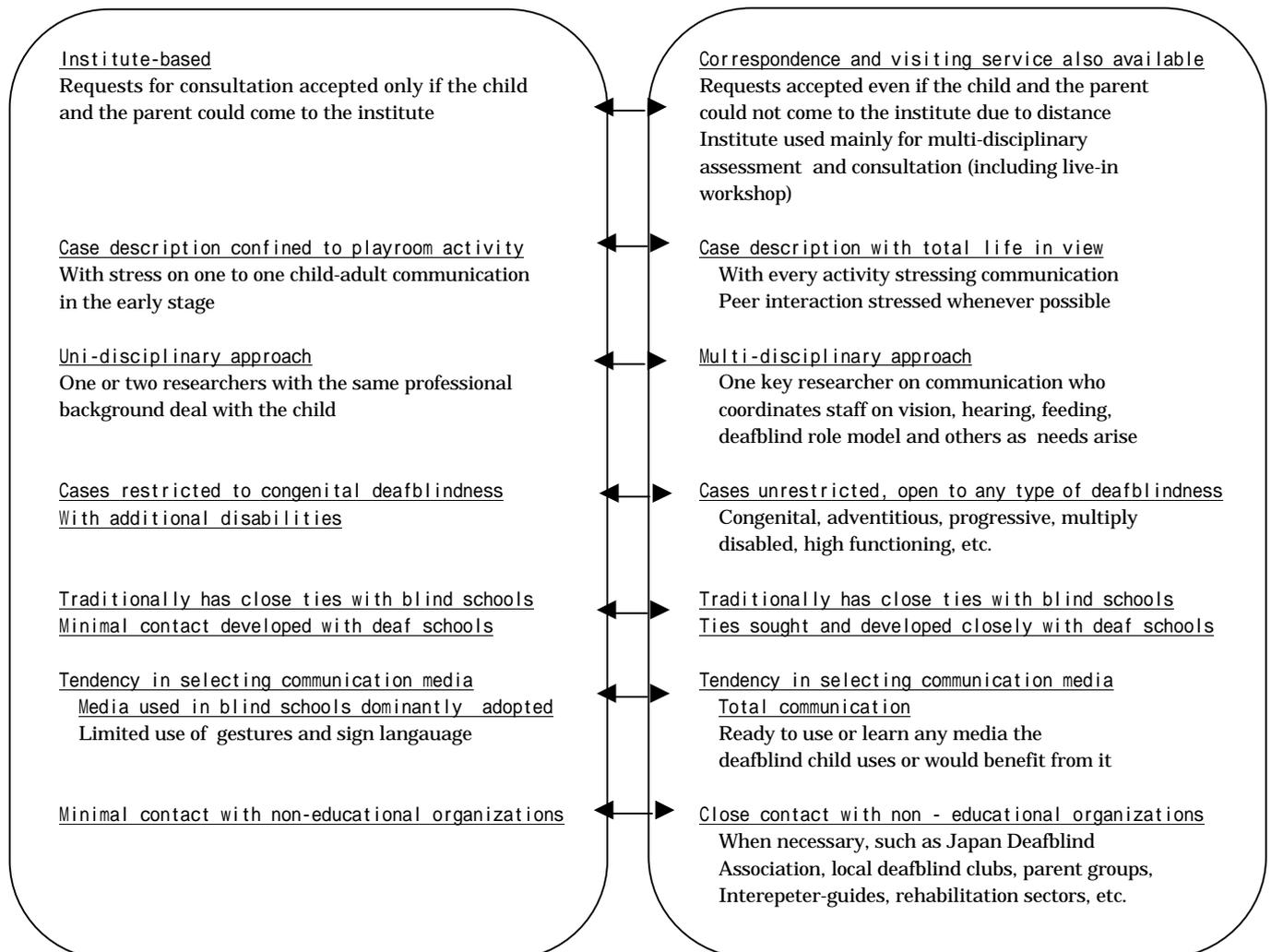


Fig.2 Two approaches for research/support services for deafblindness

activities at school whereas parents have the entire life of the child in view - before and after school, during weekends and vacations as well as life in the community. When both distant senses of a child are impaired, leisure activities, for instance, may be extremely limited, leading him/her easily into self-stimulatory behavior when left alone. Incidental learning through distant senses that takes place without effort in most children is also extremely limited in a deafblind child, and unless a practical and feasible intervention is planned for all the waking hours ⁽⁶⁾, the development of a deafblind child could easily be hampered. The education plan should be dynamically linked with the personal plan and priorities carefully selected to be of benefit to the deafblind child. For teachers and families who have difficulty understanding this special need of deafblindness, a training program to promote empathetic understanding of deafblindness should be developed as well.

(5) Need for multi-disciplinary teamwork and collaboration with different organizations

The needs of a deafblind child covers a wide span - functional assessment of vision and hearing, selection of communication system, adjustment of environment, orientation and mobility, medical needs if any, eating, establishment of regular patterns in sleep and meals, toileting, development of enjoyable leisure activities, formation of sibling and peer relationships, participation in community activities and many more. To cope with these needs in the community, the consultation services provided by schools for the blind and for the deaf, such as support of a multi-disciplinary team at special education centers and welfare organizations in the prefecture or at NISE, contacts with deafblind organizations and parent groups, support of interpreter-guides and volunteers, and other relevant resources must be identified and coordinated. The Department of Education for Children with Multiple Disabilities has traditionally been promoting case studies with uni-disciplinary researcher(s), but the large variety of needs found in deafblind children requires a variety of services to be coordinated by a key person.

3 Change in the approach to research and service activities

The case studies focusing on communication development of congenitally deafblind children based on traditional approach has been actively promoted to date ^(21,26,27,28,29,30,31,32). However, the reevaluation of the traditional approach and recognition of the vast range of needs in deafblind education that are left unattended has driven the author to adopt a different strategic approach to tackle them. The differences in the two approaches are illustrated in Figure 2.

III Strategic development of research and service activities from 1993 to 2001

Based on the five major areas of needs identified in the previous section, and utilizing the resources at NISE to the full, the author strategically developed various research-linked service activities.

1 Responding to the needs of consultation through various methods

Through consultation at NISE, by telephone, fax, e-mail (after 1997), receiving videos from parents and teachers, home and school visits and others, the author made contact with approximately 160 deafblind cases spread throughout Japan since 1993. About one sixth of these cases were catered for in live-in consultation workshops held at NISE for a period of 3-4 days. A combination of assessment, consultation, guidance and in-service training are carried out in the workshops. Each workshop is coordinated in such a way so that a group of 2-5 children with similar needs were invited together with their parents, siblings, teachers and other related staff. The number and the types of participants over the past decade is shown on Table 2.

Researchers from the Departments of Education for Children with Multiple Disabilities, with Visual Impairments, and with Speech and Hearing Disabilities worked closely during the workshop. Ad hoc collaborators to meet the various needs of the children were invited to join the workshop, such as teachers of the National Kurihama School for Children with Disabilities involved with deafblind education (the school is adjacent to NISE). Figure 3 illustrates a multi-disciplinary team organized for a certain workshop.

These workshops were one method of educational consultation service provided for deafblind referrals, but they were also directly linked to research to deepen understanding of the seven sub-groups and to clarify the needs and necessary support for these groups ^(12,13,17,20).

At the same time, these workshops provided opportunities for parents to meet other parents sharing similar needs and anxieties who had often been isolated in the locality. The encouragement and relief gained by the families through these encounters constituted one of the most important aspects of the workshop. As for teachers, the workshop served as an on-site training program covering the total life activities of the child. Also, the encounter with other teachers working with similar children in different types of special schools (particularly schools for the blind and for the deaf) gave them the chance to share respective experiences and to have insight into the advantages and disadvantages each school culture possesses regarding deafblind education.

Tabel 2. Live-in workshops between 1993 and 2001

*CRS: congenital rubella syndrome

year	target sub-group, number of children sex, age or school dept., type of school	who came with the child
1993	<u>usher syndrome</u> , 2boys, elementary dept., blind school & deaf school	mother, father, siblings of 1child, 4 teachers
1994	<u>CRS*</u> , 2girls, elementary dept., blind school & deaf school	mother, siblings of 1 child, 4 teachers
1995	<u>usher syndrome</u> , 3boys, elementary & lower secondary dept., blind school & deaf school	mothers, siblings of 1boy, 7teachers and 2 dorm staff
1996	<u>CRS*</u> , 5boys, pre-schools & elementary dept., blind school, deaf school, day center for hearing impaired	mothers, siblings of 2 boy, 6 teachers, 1 day center director
1997	<u>premature birth</u> , 2girls & 1boy lower & upper secondary dept., blind school & deaf school	father, 2 parent surrogates, 3 teachers
1998	<u>high cognitive function</u> , 2boys, elementary dept., deaf school	mothers, 3 teachers
1999	<u>CHARGE</u> , 3girls, 2-year ord, elementary & lower secondary dept., deaf school & consultation at blind school	mothers, sibling of one girl, 4 teachers
2000	<u>severe multiple disabilities</u> , 3boys, cockayne, cerebral palsy & premature birth, pre-school & elementary dept., school for physically disabled	mother, father, sibling of one boy, 5 teachers
2001	<u>early intervention</u> , 1girl & 1boy, premature birth & etiology unknown, 2year-old & 3year-old, regular nursery school & blind school kindergaten	mothers, 3 teachers
	<u>high cognitive function</u> , 3boys, elementary dept., deaf school	mothers, fathers, 8 teachers
	<u>CHARGE</u> , 1boy & 1girl, 3year-ord & 4year-old, regular kindergaten & day center for disabled children	mothers, fathers

Furthermore, when families and teachers live together a few days with the deafblind children in focus, the needs of each deafblind child over the total life scene and the hardships of the families involved were more easily shared by the teachers, leading to a better cooperative relationship between the two parties. Shared understanding of deafblind children by families and teachers were further enhanced by the simulation experience of deafblindness to be described in the following section. The insight of families and teachers into the needs of deafblindness around the clock facilitated the linkage of the "educational" and the "total personal" plans.

2 Research on simulation experience and its use in a training program

As a method of promoting empathetic understanding of deafblindness and low vision in teachers working with deafblind children, the author collaborated with the Department of Education for Children with Visual Impairment between 1993-95 to develop a program of simulation experiences in a research project. Four-day workshops to deepen the

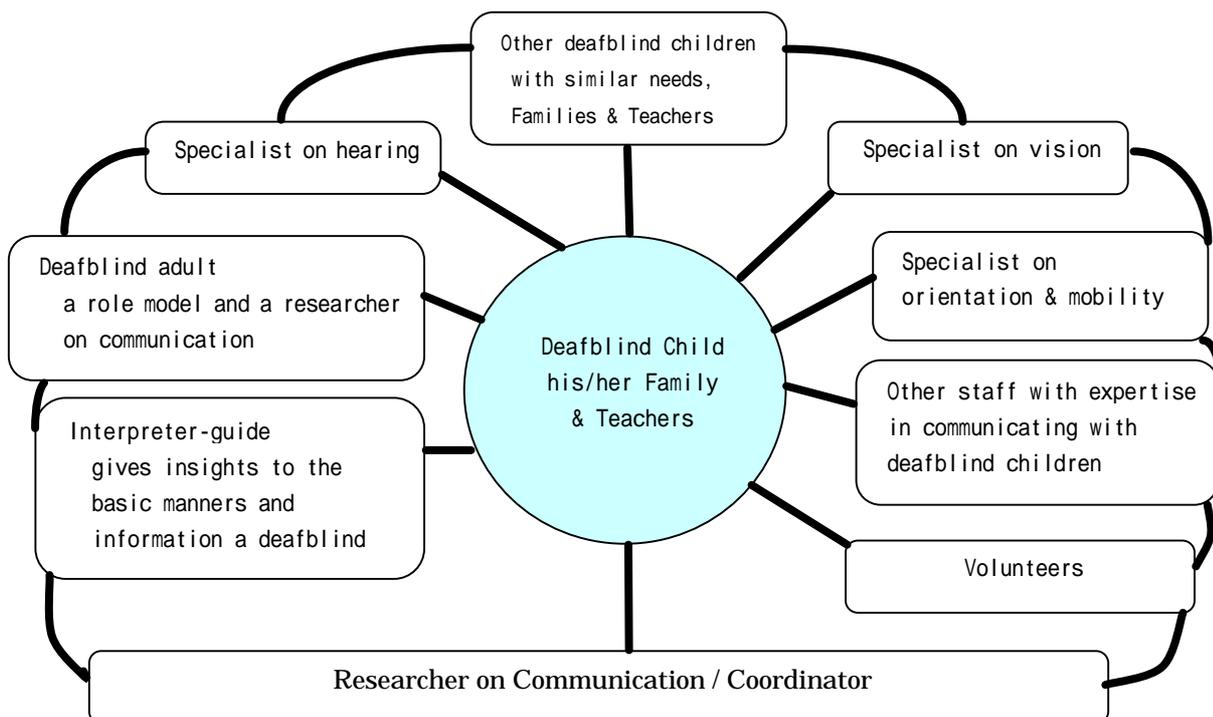


Fig. 3 Example of a multi-disciplinary team at a live-in consultation workshop

understanding of low vision and deafblindness were held six times between 1994 and 1996. A total of 223 teachers, welfare and medical staff from around the country participated in the workshops ⁽⁸⁾. After the workshop, many of these participants carried out simulation experience sessions in their locality when necessary. The simulation experience kits were lent to them upon request.

Simulation experience of deafblindness and low vision are now effectively used in live-in consultation workshops and in-service training programs at NISE, training programs for interpreter-guides for deafblind persons and, Naturally, in schools where deafblind children are enrolled.

3 Research and service activities on information provision

Requests for various information on deafblindness have been coming from parents, teachers, welfare and medical staff. However, no library or any researcher in Japan has collected enough literature on deafblindness to cope with these various requests. The author has been providing whatever information possible on deafblindness upon request from parents and teachers on an individual basis.

In 1997, the author received an outside grant to collect information on deafblindness. Between 1997 and 1999, the author collected a little more than 700 books, manuals, periodical, proceedings of deafblind conferences, academic papers, videos and other materials on deafblindness in Japan and from overseas, made a database and started to build up the "Deafblind Library" in response to the need for information. The list of titles of the literature and videos collected are given on the web site.

The web site "Deafblind Information Network in Japan" was set up in 1999 to provide information on various sites related to deafblindness in Japan, on some etiologies of deafblindness, introducing international sites on deafblindness and reports of international conferences attended. Hits between May 2000 and December 2001 numbered 10,100.

Dissemination of deafblind information in print form has been done by "Deafblind Education and Research," a biennial publication of the Japan Deafblind Association to which the author has been working as an editor. A thousand copies are distributed free of charge to all schools for the blind and for the deaf in Japan, special education centers in all prefectures, teacher training colleges, families with deafblind children registered with the Japan Deafblind Association and others. The themes taken up in the past five publications are "Congenital Rubella Syndrome," "Usher Syndrome," "Children with Additional Severe Disabilities" and "Transition." "CHARGE Association" is the theme for the sixth volume to be published in August 2002. The uniqueness of this publication is that the contributors of the papers are mainly deafblind consumers,

parents and teachers. Each publication also includes information from other countries concerning the theme.

4 Service activities for the formation of parental networks

In addition to arranging encounters for a limited number of families in live-in consultation workshops, the author started a bulletin board on the web site to promote parental networking. The bulletin board was set up in April 1999, and there have been approximately 2,000 postings by parents, teachers, volunteers, interpreters, deafblind persons and many others. The majority are postings of parents and they came from 26 of the 47 prefectures in Japan.

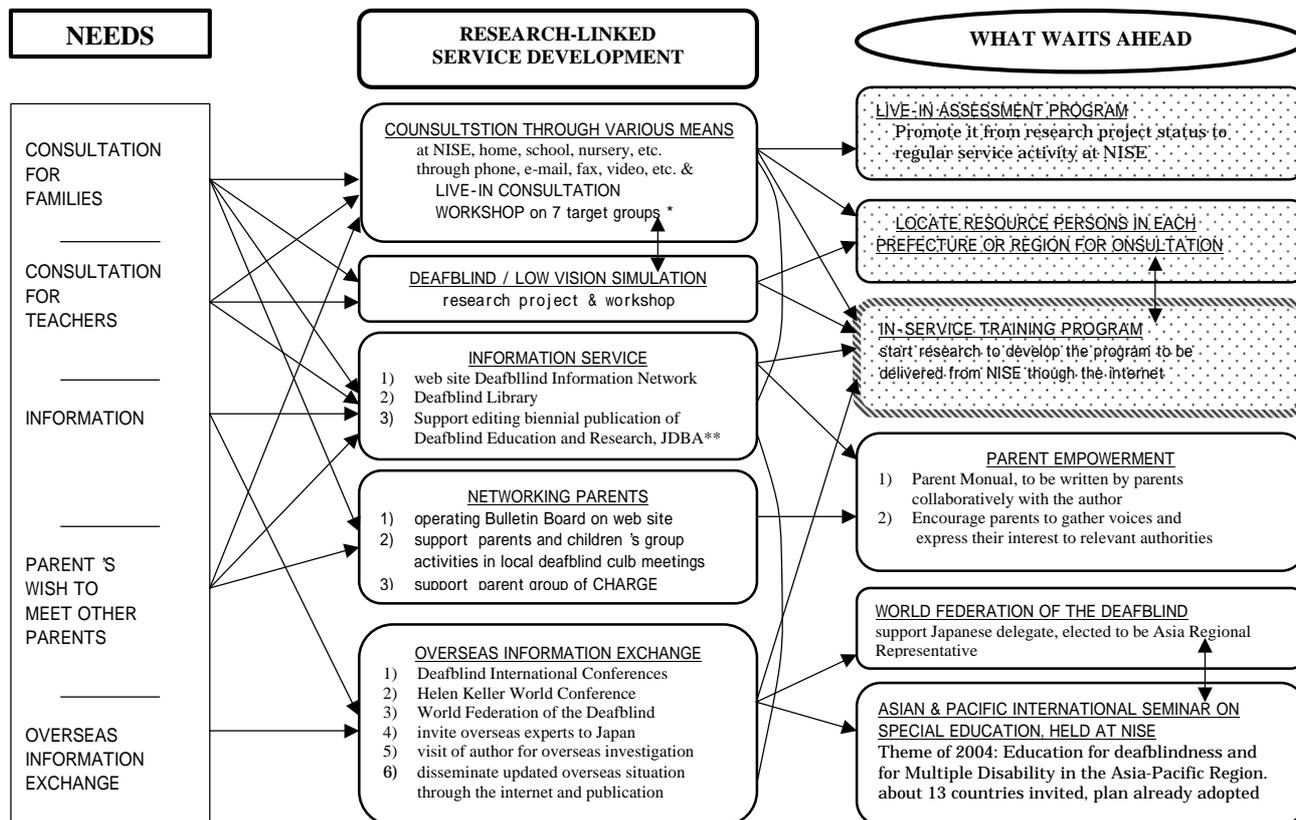
The author also participates whenever possible in the annual convention of local deafblind clubs or multi-prefectural deafblind clubs in which workshops on deafblind children are sometimes organized by parents. The author shares the information with parents living in various areas of Japan as well as encouraging these parental initiatives.

The parent group of the CHARGE association was organized through the initiative of a parent a few years ago and its membership now is 25. Exchange of information in this group is very active. The publication of the coming 'Deafblind Education and Research' focusing on CHARGE association includes a large section dedicated to the first parental get-together held in 2001 and case reports written by two parents. It is hoped that this publication will not only provide information on the CHARGE association to those who need it, but in addition offer an opportunity to parents who did not know of this group.

5 International exchange

Being a rare disability, international exchanges of research and current practices in deafblind education is very active. Deafblind International is the international organization of persons involved with the support of deafblind children and adults. The author has participated in the World Conference held in 1999 and the Asia Conference in 2000 ⁽¹⁹⁾ making a presentation at the former conference on the current situation of deafblind education in Japan ⁽¹⁵⁾. Exchange of information and development of international ties are essential aspects of these conferences. To grasp the global trend concerning deafblind consumers, the author also participated in the Helen Keller World Conference held in 1997 ⁽¹⁹⁾ and the Founding Assembly of World Federation of the Deafblind (WFDdb) held in 2001.

Also, the author coordinated the invitation of an expert on deafblindness from the United States ⁽¹⁾ as well as made overseas investigation on the support system of deafblind education ⁽¹⁸⁾.



* Following 6 major target groups need to be researched to identify distinct needs and provisions: 1)congenital rubella syndrome, 2)CHARGE association, 3)jusher syndrome, 4)complications of prematurely, 5)children with severe cognitive and physical disabilities, 6)high functioning deafblind children, 7)family-centered early intervention.
** Japan Deafblind Association

Fig. 4 Needs, research-linked service and future perspectives

Needs-driven research and service provision are closely related (see Figure 4).

IV Future perspectives

Based on the results obtained from the research and service activities over the past decade and on the expectation of and available resources at NISE, the following research and service activities seem necessary as well as feasible. (Refer to right column of Figure 4.)

1 Research on the development of distant in-service training program on deafblind education using the Internet

This issue should have top priority in future research. The results of the research over the past decade were enjoyed by a limited number of teachers participating in the project. Based on these results, further research should be designed on the development of training programs to be used for in-service training programs for all teachers involved with deafblind education (those currently identified number approximately 350). "New Perspectives of Special Education in the 21st Century" ⁽²⁾

published by the Ministry of Education recommends the development of distant training programs by NISE. Distant training programs using the Internet are actually suitable and feasible for a rare disability like deafblindness. When all teachers involved with deafblind education were linked through the Internet in the training program, teachers working with deafblind children having similar needs may also form sub-groups using mailing lists and build a support system among themselves.

2 Establishment of a live-in comprehensive assessment program

This has been done over the past decade as a "research project." However, in view of the rarity of deafblindness and of the effectiveness of this method, the author finds it one of the ideal service activities a national center could provide to population with a rare disability. Possibilities should be sought toward this end in the future.

3 Identification and maintenance of human resources on deafblindness in each prefecture

Through live-in consultation workshops and simulation experience workshops, teachers in different prefectures

who are both able and eager to support deafblind education are being identified. Also, there are a number of schools for the blind and schools for the deaf, which have developed an excellent cooperative relationship in supporting deafblind students. It is crucial in the future to identify, develop and maintain key persons or organizations in each prefecture that can provide consultation, advice and guidance on deafblind education which has until now been concentrated solely on the NISE.

4 Empowerment of parents

The long isolated parents and families are now beginning to unite across the country through the widespread use of the Internet and the development of local deafblind clubs.

One important aspect the postings on the bulletin board revealed was the countless measures parents have devised when bringing up deafblind children. These measures are both practical and readily available. Also, the deep insight into deafblindness born out of love and years of child raising has the wisdom and power with which no professional can compete. Parents' manual on raising a deafblind child is not yet written in Japan, and the author has been discussing with a number of parents the possibility of compiling a manual written mainly by parents. The activity to utilize one's personal experiences and to have its value acknowledged by others would contribute to the further empowerment of parents. The voice of the parents gathered through such endeavor could also provide an important orientation to research and policy concerning deafblind education.

5 International exchange

Research exchange on deafblind education has been and will be promoted in the future as well, particularly on distant teacher training programs in the near future. Another aspect needing development is exchange with Japan's neighbors in Asian and Pacific countries. At the founding assembly of the World Federation of the Deafblind, the Japanese delegate was elected as the regional representative of Asia. He was asked to gather information in Asia concerning welfare for deafblind people and to contribute to the international exchange in this region of the world. The Asian and Pacific International Seminar on Special Education which NISE hosts annually is planning to hold the seminar in 2004 on the theme of "multiple disabilities and deafblindness." This requires a further exchange with Asian and Pacific countries on deafblindness from the perspective of education.

The above are some of the necessary and feasible propositions for future development concerning research and service activities on deafblind education in Japan. It is going to take much more effort and time before a

comprehensive support system for deafblind education will be fully constructed in Japan. Nevertheless, the results of the past decade show that the development of needs-driven research and services in feasible areas, with a comprehensive system always in mind, guide the way to the next step that will eventually lead to the construction of such a system.

*CHARGE association:

CHARGE association refers to children with a specific set of birth defects. It is one of the etiologies that may cause deafblindness. The acronym 'CHARGE' originally came from the first letter of some of the most common features seen in these children:

- C** - Coloboma of the eye
 - Cranial nerve anomalies
- H** - Heart malformation
- A** - Atresia of choanae
- R** - Retardation of growth and/or development
- G** - Genital and/or urinary abnormalities
- E** - Ear abnormalities/hearing loss

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