

Keynote Address

Development of Deafblind Education in Japan and Its Contribution to Education for the Multiply Disabled

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I. Deafblind education - the first education in Japan for the multiply disabled

The education for children with multiply disabilities was legally established 25 years ago in 1979. The first practice of education for children with multiple disabilities was done 55 years ago in 1949. It was begun by a pioneering principal of Yamanashi Prefectural School for the Blind for two children with deafblindness.

A few years after the initiation of the education, teaching method was sought in the literature on Helen Keller and was applied to the two children toward the acquisition of language. However, it lead to forcing tasks too difficult for the two deafblind children, resulting in the two children rejecting to touch the teaching materials. The "educability " of the children was suspected and the termination of the first educational trial was voiced.

When the first trial of education for the multiply disabled was about to be abandoned, a psychologist and a friend of the principal happened to join in the educational practice for the two deafblind children. Instead of looking for the causes of the difficulty in education in the disabilities of the children, causes were sought on the teachers' side, the lack of understanding in the behavior of children and the level of the tasks. Learning from the children, the teaching practice was reorganized.

Activities the children were motivated to participate were selected to expand their world with meaning. The foundation of communication was established using pre-lingual signs such as gestures. Tasks set at a level of difficulty that children could challenge were introduced step by step leading to the the acquisition of language using braille and manual alphabet. A systematic education continued for about 20 years till 1970. The educational practice was recorded on film and here are some scenes from the film.

II. Institutionalization of education for the multiply disabled and deafblind education

However, when education for all children became compulsory in 1979, deafblindness was included within the category of multiple disability. The distinct needs of deafblindness was not accommodated in the newly established system. The reason most responsible for this result was the low incidence of deafblindness. Unlike Japan, various countries including the United States recognized "deafblindness" as a unique disability. The difference came from the tragic situation that swept these countries in the mid-1960's - the rubella epidemic.

The United States saw the emergence of thousands of deafblind children due to congenital rubella within a short period of time. The government had to take measures to urgently cope with this situation on the federal level before these children would come into school education. Once the educational measures were taken systematically on a national level, the extensive impact of deafblindness and its unique needs were widely recognized and deafblindness established itself as a distinct category and continues to date.

Japan escaped the rubella epidemic. However, the small population of children with deafblindness were buried and obscured in the the far larger population of multiple disabilities.

Nevertheless, the basic concept of education and the teaching methods cultivated in the two decade of deafblind education contributed to the education of children with multiple disabilities by serving as its foundation, orienting its development and inspiring concrete measures. The following are the major five points applied to the education for the multiply disabled.

1) Disabling situation should be viewed as the result of interaction between the person with disability and the environment. The causes for difficulties that arise from such interaction should not be sought only in the person with disability nor should the solution be sought only by trying to change the person with disability.

Because every behavior is a function of:

- (1) the conditions of that particular person (subject)
- (2) the conditions of the persons who are interacting with the subject
- (3) the conditions of the physical environment surrounding the subject, and
- (4) the conditions of the larger society

2) The meaning of behavior.

No matter how "meaningless" or "problematic" the behavior of a person may seem, there

are meaning and reasons for that person in carrying out his/her life. Solution should be sought only after examining the meaning and reasons for such behavior.

3) Communication

Communication is the most essential issue in education.

Verbal language is not the only method of communication and there are communication methods fitted for each and everyone. There are logical steps toward developing different methods of communication.

It is best to start communication using the method and channel that the child can understand and use with greatest ease.

In the early stage of communication, its success depends on the sensitivity of teachers in reading and interpreting the behavior of children.

4) Assessment of children with multiple disabilities

Administering standardized test or a test devised for children with single disability would result in underestimation of the potential of children with multiple disabilities. A most reliable assessment is available through careful observation of children in their familiar settings by experienced practitioners accompanied by persons familiar to the child.

5) Educational program for children with multiple disabilities

Instead of fitting a child into a program, fit the program to each child. An effective program is one which is grounded on what the child can do now, what she/he is motivated and what makes sense to her/him.

When introducing any activity, allow her/him to explore fully, and give enough time to process the information she/he gathers.

It should be noted that it is not only in Japan that the principles and methods established in deafblind education were applied to education for the multiply disabled. We have once had the opportunity to invite a researcher in the field of multiply disability from Norway. Prof. Miriam Skjorten of Oslo University mentioned in her presentation that the same has happened in Norway, the applicability of deafblind education to the multiple disabled.

II. Number of deafblind persons in Japan

Deafblindness is a disability with very low incidence. The population of Japan is approximately 120million, and the deafblind population is estimated to be somewhere

between 13,000 and 24,000; that is, one out of 5,000 to 10,000. The great majority of this population is those who became deafblind adventitiously in adulthood.

In 1991, Japan Deafblind Association (JDBA) was established. It is a social welfare corporation dedicated to promoting independence and social participation of deafblind persons, run by government subsidies and private contributions. There are about 600 deafblind persons currently registered to JDBA. The services for deafblind persons, particularly the training for and provision of interpreter-guides, has been developing since the establishment of JDBA. In addition, the local deafblind clubs which serve as the prefectural center for deafblind persons and supporters were gradually organized, and currently about 80% of 47 prefectures in Japan have such clubs. Annual conventions on national and regional levels are held.

The number of deafblind children is even smaller. In the survey of special schools carried out in 1998 by NISE, about 350 deafblind students were identified. They were scattered in all five types of special schools - for the blind, the deaf, the intellectually disabled, the physically disabled and for the health impaired.

Deafblind population is at the same time a very diverse population. Though sharing major needs of deafblindness, some sub-groups need to be distinguished in order to fully address their specific needs. Examples of such sub-groups are children with congenital rubella syndrome, with CHARGE who have a variety of medical issues, with profound and multiple disabilities, with high cognitive function or with Usher syndrome having progressive visual impairment.

Low incidence, scattered across the country, diversity within the group - it means that the accumulation of expertise, training resources and research is hard to maintain on the prefectural or local level, calling for a support system on a national level.

V. Constructing support system for the deafblind with NISE as its core

The NISE has taken a central role in Japan concerning practical and comprehensive research on special education, advanced in-service training for teachers and consultation to parents of children with disabilities referred to the Clinical Center for Children with Special Needs. The mission of NISE is to tackle issues which cannot be fully coped with on the prefectural level or by universities. One such issue is the research and services for disabilities with very low incidence, and deafblindness is its major example. At NISE, following the research tradition of the first deafblind education, the longitudinal study of a restricted number of congenitally deafblind cases at schools for the blind has been pursued.

However, in order to meet the needs of entire deafblind student population in Japan, I

found it crucial to dedicate to developing a comprehensive support system, with NISE working as a catalyst. Therefore, I adopted a different strategy to develop research and service activities over the past decade. The goal was, and still is, to construct a comprehensive support system to support parents, to have training programs for teachers who are in charge of deafblind student, to have a forum of information exchange among different disciplines involved with deafblindness and to have a clearinghouse of information on deafblindness.

What I would like to share with you now is the aforementioned service and research activities I have developed over the past decade with NISE as its core, and their outcome. It is still an on-going process. I believe that the results of this research may be used as a research model to develop support system for other disabilities with very low incidence which NISE may need to consider in the future.

The three major activities carried out at NISE are research (including survey), in-service training for special education teachers and consultation services for parents and other related persons. All researchers engage in the three activities. Using this system I have collected and analyzed the information on the current needs of deafblind education. In addition, I travelled throughout the country as much as possible to visit deafblind children at schools and at home and participated in the conventions of deafblind people and families to gather information at the grass-root.

The needs were narrowed down to the following:

- 1) Advisory services for parents.
- 2) Keen wish of parents to meet other parents.
- 3) In-service training and advices for teachers who will be in charge of deafblind students.
- 4) Development of teaching material (text and videos) for in-service training
- 5) Information on deafblindness over a wide variety of topics
- 6) Exchange of information and experience among various disciplines and professions.

V. What were done and what were achieved

To approach the goal, the following were undertaken.

1 Responding to the advisory needs of parents and teachers through various media

Until three years ago, the consultation services at NISE were center based. However, since a decade ago, I have resorted to all possible media such as telephone, fax, videos, home

and school visits, and e-mails since late 90's to respond to the needs of parents and teachers. The number of cases summed to about 200, from various parts of Japan on various issues. Of these, about 1/6 of the cases were invited to NISE for a 3 to 4-day lodge-in workshop. In each workshop, a small group of deafblind children sharing similar needs, their parents, siblings, teachers and researchers stayed together in the lodging facility at NISE .

These workshops served to deepen understanding of the needs of different sub-groups of deafblind children. They were also invaluable opportunities for families to meet other families to share experience and encouragement. For teachers, they were hand-on training session as well as a forum to meet other teachers in charge of students with similar needs. The encounter of teachers from different educational culture (schools for the blind and for the deaf) served to broaden the perspective of teachers.

2 Research and service activities to provide information

In order that a wider range of people could access information on deafblindness, "Deafblind Library" and a web site was constructed. There had not been a systematic collection of literature and information on deafblindness by any library in Japan or by any researcher. There were various needs of information from parents, teachers, researchers, welfare and medical professionals, but the needs were not met. Over the past decade, I have collected about 1,000 items of information (literature, manuals, journals, proceedings, papers, videos and others) and the database has been uploaded on the web site, "Deafblind Information Network."

To provide information in print form, I have worked on the editorial board for "Deafblind Education Research", a bi-annual journal published by JDBA. The six issues published so far mainly focused the different sub-groups of deafblindness: congenital rubella syndrome, Usher syndrome, deafblind children with additional severe disabilities, CHARGE syndrome and transition issues of deafblind children. The journals are distributed free of charge to all special schools with deafblind children and to the families.

3 Networking and empowering parents

As the lodge-in workshop could network only a limited number of families, the internet bulletin board was constructed to network families scattered throughout Japan. The bulletin board was introduced in April of 1999 and have enjoyed an average of 2000 accesses a month. Messages are written by parents, teachers, institution staff, interpreter-guides, deafblind persons and others for exchange of information and experience. Many parents contact NISE after they hit upon this bulletin board and web-site.

I have also actively participated in national and regional meetings held annually by

deafblind people and have offered consultation and information to parents attending the meeting.

In August of 2003, the "Association of Deafblind Children and Families" was finally organized in Japan. Parents throughout Japan has now an association to discuss the issues they face and to voice their opinions. Annual meeting, publication of newsletters and an active exchange of opinions though mailing list are the major activities at the moment. Parents of children with CHARGE syndrome have another association, and I serve as an adviser on education.

4 Information exchange among different organizations and professions

In order to respond to the variegated needs of parents and teachers, I have contacted various organizations and came to know the different works they have been carrying out with deafblind children. Different special schools, day centers for pre-schoolers with disabilities, JDBA, local deafblind clubs, rehabilitation center, medical institute, interpreter-guides, volunteers, researchers, public administrators and others. Deafblind consumers and parents of deafblind children have begun to voice their needs and opinions. The time was ripening to prepare a forum where a variety of people involved with deafblindness come together to share their experience and insights. With a group of comitted teachers and professionals, the National Association of Deafblind Research was established in July of 2003. In August 2004, annual conference was held at NISE where deafblind persons, parents and professionals involved with deafblind services have gathered from across the country for three days to share presentations and to participate in workshops. It was the first research conference in Japan focused solely on deafblindness. This research association created access to works and research being done hitherto in isolation, a forum to share and to inspire each other.

5 International exchange

The population of deafblind people is small in any country, and this rarity has promoted an active international exchange. "Deafblind International" is a world association to promote services for the deafblind. World conference is held every four years. I have reported on the construction of deafblind information network in Japan at the World Conference in Portugal in 1999. At the World Conference held in Canada last year, I have had the opportunity to come to know Dr. Jude Nicholas, the keynote lecturer from Norway. The Asian Conferenced scheduled to be held in Nepal this year was unfortunately cancelled, but I wish to join again with many of the delegates here at the World Conference to be held in Australia in 2007.

Concerning CHARGE syndrome on which Japan lacks both medical and educational information, two experts from the United States were invited in March of 2003 for open lectures for families and for educational and medical professionals. These open lectures gave momentum to many medical institutions to diagnose CHARGE syndrome. The membership of CHARGE families in the Association of CHARGE Families which was 25 last year more than doubled within one year.

6 Discovering practices of excellence, research cooperation, linking to training

Through the many direct visits to special schools and day centers throughout Japan, I have discovered many practices of excellence. Collaborative research on case studies are currently being done with these schools, focusing on the sub-groups of deafblind children mentioned earlier. Manuals and videos are scheduled to be produced next year from these case studies.

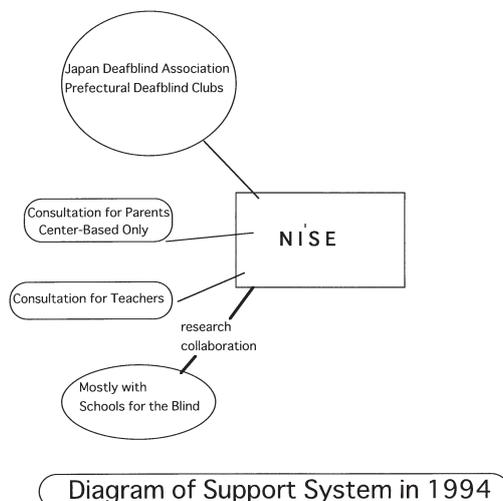
Using the research results accumulated so far, an internet training program combined with hands-on workshop will be carried out on a trial basis this year.

Another new research cooperation has also begun this year with a university to support a deaf student with progressive visual impairment.

VI. Outlook

Support system for deafblind education in Japan has made a gradual but steady progress over the past decade.

This is a simplified figure of the system 10 years ago.



This is the system we have now.

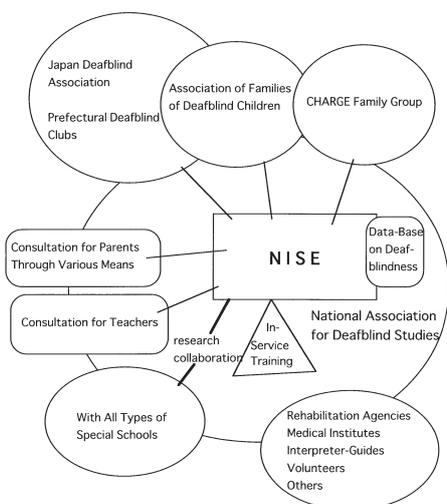


Diagram of Support System in 2004

The high-priority target now is to implement training programs on deafblindness for teachers. The further empowerment of parents is another important target and there is a need to develop programs focused on parents and families.

A new step should be toward the development of key professionals who could provide advisory and consultative services on a regional basis. Finding a way into the regional educational system to place such professionals should also be sought in conjunction.

VII. Encounter with different culture, turning deficits into assets and breaking down the limit

I have had the opportunity to make visits to many sites of education this past decade. There, I have encountered stimulating practices and cultures different from what I had been used to. They helped me break down the limits which I left unquestioned and confined myself in a small world. They provided me with inspiration to think of deafblind education in new lights and the courage to keep working on. I would like to share with you three such examples to conclude this lecture.

1 Learning from deaf education - rich emotional expression

As I have mentioned, the case studies on deafblind children were traditionally carried out at schools for the blind. The visit ten years ago to a day center doing outstanding works for hearing impaired pre-schoolers taught me what was lacking in the culture of schools for the blind. It is the importance placed on clear expression of emotions using

active body movement. This realization motivated me to collaborate with schools for the deaf in my research.

There were 4 deafblind toddlers surrounded by people with different roles. There were staff who took gentle and responsive mother-like role, those who took active father-like role such as introducing daring games and peers who took roles like siblings. In these interactions, both positive and negative emotions were naturally aroused, and bodily movement, gestures, signs were attached to name these emotions. This formed the foundation for sharing emotions, the basis for lively communication. Here, I would like to share in a video clip, a scene I have seen ten years ago.

2 Importance of after-school support and various volunteers

After-school hours are far longer than the time spent at school. Deafblind children cannot enjoy TV or radio. They are readily left alone in a small family and are deprived of the chance to be exposed to verbal language. It can be hours of boredom as well as hours of obstructing language development. Unfortunately, there is no service for after school hours yet. However, here is an example where a deficit was turned into an asset and developed into a unique after-school support for a deafblind boy.

The boy and his mother moved into an apartment house without bath. In order to use a public bath (Sentou), the boy needed a guide of the same sex. To cope with this problem, a coordinator gathered Sentou volunteers. Volunteers who did not know about his communication method were also accepted as long as they were interested in the boy.

Japan has a long tradition of taking bath together for socialization. This boy began to fully enjoy this tradition. Here is the video of the boy and volunteer at Sentou. In addition to the original function, the Sentou support brought along with it two happy hours of conversation at the bathhouse. This natural after-school support greatly expanded the vocabulary and usage of Japanese language. Also, it gave him the chance to cope wisely with people who could not understand his communication method, a situation he would encounter in the future.

3 A day center and group home for adults with profound and multiple disabilities - realizing the ideal

For persons with profound and multiple disabilities in Japan, it is a dream to have one-on-one support during the waking hours. It is a dream shared by deafblind persons. It

is partly available in schools, but not at all available at home after graduation. When they have to live in institution after parents aged, they would have to stay alone in bed for the majority of their day.

Here are pioneering people who turned this dream into reality. Determined to support the dignity and quality of life of persons with profound and multiple disability, they have cultivated close ties with the community with careful planning. One important key was the extensive use of housewives in the community as part-time supporters and the minimum use of permanent staff who would require much higher wages. Much wisdom is poured in to maintaining the quality of support. Housewives' experiences in child rearing and caring the family were most helpful in the work to support persons with profound and multiple disabilities. The part-time employment here is coveted among housewives in the community and the work is regarded with respect in the community.

How the building of the day center is made is itself a proof of how much they respect the needs of persons with multiple disability. Anytime, anywhere, they can roll or crawl on the floor. The floor is flat and carpeted, even up to the rim of the toilet basin! Everybody is asked to walk without slippers in the building to keep awareness on the cleanliness of the floor.

There are four persons now in the group home, including one who needs special health care. Every morning, there is one person who always makes a visit to the person in the next room to give a good morning pat. Support is provided on one-on-one basis during all waking hours.

Encounter with different culture, turning deficits into assets, thoughts and wisdom to break down the limits. These give us new perspective and courage. They inspire us to broaden the possibilities for social participation of persons with multiple disabilities.

The next keynote lecture focuses on neuroscience and deafblind education. For many of us here at the seminar, this must be an innovative subject, a new culture. I am excited to listening to the latest research in this field.

Starting from tomorrow, we will listening to the different systems and practices of the Asia Pacific region. Each report, I am sure, will be an exciting encounter with different culture. Let us share ideas and practices and make this seminar a chance to break down the limits found in any system.