

# Researches in the Field of Education and Welfare of Children with Multiple Disabilities in India

Dr. Neerja Shukla  
NCERT, New Delhi, India  
&  
Dr. Sidhhant Kamal Mishra  
RCI, New Delhi, India

**Abstract:** India has a large population and also population of persons with disabilities. As per survey conducted by the National Sample Survey Organization in 2002 a total of 1.8% population of the country suffers from one or the other disability. The population with multiple disabilities in India estimated to be of 10.63% of the total population with disabilities. This is one of the most difficult group for which the country is providing education as many of them find it difficult to attend mainstream education on a regular basis. The present paper is an attempt to collect information on researches done in the area of multiple disability in India and discuss their implications for welfare and education of children with multiple disabilities. These researches are few and the country needs to carry out more researches in this area so that persons with multiple disabilities could also be provided equal opportunity as others and are benefited by appropriate education.

India is the 2<sup>nd</sup> most populated country in the world after China with over one billion citizens. Despite only 50 years of its independence behind it, coupled with socio-economic and cultural diversities, India has made significant developments in the fields of health care, information and space technologies, agriculture, education etc. However, India is currently facing a number of challenges and one of them is to provide equal rights to its large population with disabilities.

According to the latest Census survey conducted in the year 2001, the population of persons with disabilities in India is 2.01 per cent of its total population. Therefore, in terms of numbers, the total population of persons with disabilities comes to 20 million. The Census did not record the population with multiple disabilities. The National Sample Survey (2002) has estimated this population to be 1.8% of the total population. Out of this population the prevalence of persons with multiple disabilities in India is estimated to be 10.63 per cent of the total population of persons with disabilities. Thus, over 2 million people in India have been estimated to have more than one type of disabilities.

Though Hindu mythological stories find mention of disabled characters with divine powers and extra ordinary intellectual capacity, traditionally the common belief has been that the disability is the result of sins of the past life. In the 18<sup>th</sup> century, Christian missionaries and other religious organizations started welfare activities for the persons with disabilities in India. However, the real boost came with the declaration of International Year of the Disabled by the United Nations in 1981. Since then, the disability movement has picked up due to the concerted efforts of the Government and Non-government Organisations. The rights of the persons with disabilities started getting recognition globally. India is among few countries to bring a comprehensive law on disabilities, namely, Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act in the year 1995. Besides, India has also developed a National Policy on Disabilities which has covered various aspects of disabilities to provide equal rights and opportunities to persons with disabilities in all spheres of life which is being discussed with stakeholders. The Ministry of Human Resource and

Development, Government of India is also preparing a comprehensive plan to provide free and compulsory education to all children and youth with disabilities. The National Curriculum Framework for School Education (2005) developed by NCERT is another significant step towards recognizing and planning for inclusive education for all children through mainstream schools. A shift from welfare oriented planning to right based approach is reflected in all the attempts of the Government and the country. India is also a signatory to all major UN resolutions on disabilities.

The National Trust Act for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities (1999) defines Multiple Disabilities as a combination of two or more disabilities. As per Encyclopedia of Special Education “Students with multiple handicapping conditions are persons with two or more disabilities that result in handicaps within functional living experiences” (Raynolde and Janzen, 2000).

Students with multiple handicapping conditions are persons with two or more disabilities that result in handicaps within functional living experiences. Persons with severe handicapping conditions, dual diagnosis, and orthopedic disabilities are also included under this category (Fewell and Cone, 1983)

The Government of India has enacted laws to provide free and compulsory education to all children including children with special needs and other disadvantaged children in the age group of 6 to 14 years. There is also a provision in the law which requires the Government to make efforts to provide early childhood care and education for all children until they complete the age of 6 years.

There is little indigenous research in the area of multiple disabilities. Much of this is due to lack of resources. However, some Government and Non-Government organizations have carried out exemplary research work. Compilation of such researches is not available at one place. However, one such recent attempt was made by the National Institute for the Mentally Handicapped, Secunderabad by publishing the proceedings National Conference on Multiple Disabilities in the country in 2005. This Conference paved the way for formulating policies for the establishment of the National Institute of Multiple Disabilities in the country.

The research studies reported in the proceedings have been classified into following seven categories:

1. Survey for the prevalence of multiple disabilities in a community
2. Early intervention programmes.
3. Home based training
4. Stress, need profile, burden and coping strategies of mothers of persons with multiple disabilities.
5. Behavioural problems and its management, social skills and social maturity of persons with multiple disabilities
6. Application of information technology in teaching the persons with multiple disabilities.
7. Vocational rehabilitation

These studies along with some other studies are briefly discussed in the following section.

---

## **Prevalence of multiple disabilities in a community**

Prabhu, (2004) reported a study on the profile of multiple disabilities in rural communities and rehabilitation needs of the impaired in Tamil Nadu State of South India. The objective of the study was to determine the prevalence of multiple disabilities among different age groups and gender and to look into their rehabilitation needs. One large and another small *Panchayat* (Countries) were randomly selected for the study. All the hamlets that were under these *Panchayats* (counties) were taken for data collection (N=7454). The Rapid Rural Appraisal (RRA) helped the investigators to identify the disabled in the community. This was followed by the post verification visits by the experts, which confirmed the disabilities by the professionals. In the RRA protocol, the participative village mapping and semi-structured interviews with a group of people residing in the locality were undertaken. The two *Panchayats* taken for the study were identical in all aspects like male and female, children, adult and old age population ratio. Results indicated prevalence of 4.8 per cent of disability of one type or the other. The prevalence of multiple disabilities was 1.26 percent. A marginally higher percentage of female (1.27%) than males (1.24%) suffered from multiple disabilities. Among the disabled, 26.47 per cent were found to be multiple disabled and 2.53% of them had 3 or more than 3 disabilities.

## **Early Interventions**

A study on 344 cases of infants and toddlers with disabilities attending early intervention programmes was conducted by Persha, A.J. (2004). Developmental checklists

were used for the study. The focus of study was on children with multiple delays that involved specific areas of child development. The case record used included information pertaining to demographic data, family history, presenting complaints, history of pre-natal and natal as well as post-natal factors. The data obtained has been analysed with focus on the areas such as demographic data, age of the sampled children etiology and severity.

In children below 3 years of age, early identification of the disability or delay will prevent the occurrence of other disabilities and thus improve the functional level. If children with multiple delays and disabilities are identified early in development appropriate intervention, strategies would help in minimizing the impact of these disabilities. The results indicate that the majority of the cases had motor and speech problem than vision and hearing. Most of the parents were aware of motor and speech problems compared to vision and hearing. This indicates necessity of parent training and awareness programmes on child development and early identification which will enable the parents to identify problems at an earlier age. Pre-natal history indicates that majority of the mothers (91%) had regular antenatal check ups. Some mothers had infections, poor nutrition and abnormal foetal movement. Most of the deliveries took place in the hospitals (86%). However, one fourth of the babies had delayed birth cry indicating lack of oxygen supply to the brain. Some babies had convulsions, low birth weight and pre-mature birth. Some children were not immunized leading to serious diseases finally resulting in developmental delays and multiple disabilities. Majority of the children had borderline development delays compared to very few with profound development delay. This shows that young infants and toddlers have a higher

incidence of borderline delays indicating that the impact of the delays and disabilities will increase with increase in age. Such studies help in gaining better understanding of the status of the child and in programming early interventions.

### **Home Based Training**

Narayan, (2004) in her study analyzed the effectiveness of home training through centre-based instruction. Children with more than one disability are doubly disadvantaged due to the complexity of the disability. Providing educational programmes for such children is a challenge as the combination of disabilities in such children varies requiring tailor-made programme to meet the individual needs of the child. In addition, incidence of such children is relatively low when compared to single disabilities thus making it difficult to organize educational facilities. Further, the combination of disabilities demands a team of professionals to train them.

Many special schools for children with mental retardation admit children with additional disabilities. A national survey conducted at National Institute for the Mentally Handicapped (NIMH) revealed (N=182) that 18.6% of children enrolled in special schools had additional disabilities. Among them 37% had Cerebral Palsy (CP), 28% had Autism Spectrum Disorders (ASD), 13% had Visual Impairment (VI), 18% had Hearing Impairment (HI) and 4% had VI and HI as informed by the principals of the schools. The principals also indicated that the teachers required additional training to educate such children (Narayan, J., 2003). There were a large number of children with mental retardation and additional disabilities who were unable to reach schools due to lack of schools for them or practical

difficulties in reaching a school.

One model to take care of such children is itinerant teaching, where the educator visits home periodically and trains the parent/care giver. Mobile services are also organized by special schools where the educators visit the clusters of geographically defined areas on prescribed day and time and provide services. The distance the parent has to travel is reduced by this effort. One other popular alternative model is home training through centre-based instruction. This is a model where the child and caregiver visit the Centre periodically, learn what and how to teach and carry out the training at home. In this background a study was carried out to analyze the effectiveness of home training through centre-based instruction for 3 to 15 years old male and female children. A pilot tested questionnaire was used to collect data from the parents of children with mental retardation and additional disabilities. A total of 21 parents responded to the questionnaire. All respondents were mothers and were educated. All the families preferred home training to regular admission to special school due to the complexity of the child's disabilities. Majority of the respondents felt that they were able to choose the timing of the training as per their convenience, child was more comfortable in home environment, transportation related problems are minimized, child learns better and home based training saves their time. Thus practical problems related to daily living activities are minimized through home based training. The mothers also indicated the role of siblings in teaching thus optimizing utilization of human resources at home.

The limitations of this training were inability of the parents to maintain time scheduling due to other pre-occupations and also their inability to discuss with the teacher when there was a need for clarification during

training. Lack of confidence on the part of parents was another difficulty. As rightly noted by Bailey and Wolery (1992) effective sharing of information with families require good communication skills, a recognition that parents and professionals have different perspectives on the child and therefore, being sensitive to parents' feelings.

All parents found training in self-help activities easier than the other educational programming. Training in communication skills was a major challenge for parents of mentally retarded children with autism and hearing impairment. Only 3 children were trained in functional reading and mathematics and showed progress. The rest were taught in concept training including size, distance, objects of daily use and colour (to sighted children) and they showed progress through minimum. In leisure skills, most parents (16) informed that the children spent time watching TV.

It is concluded that mothers are willing to train children at home and have identified strengths and needs. A detailed study on a large sample with both qualitative and quantitative analysis will throw light on the functional needs which will pave way for development of systematic and relevant curriculum for home training.

### **Stress, need profile, rehabilitation needs, burden and coping strategies of mothers**

Agarwal, and Nanda, (2004) conducted a study of stress on mothers' of children with mental retardation and autistic like features. Stress refers to a situation of frustration, conflict and threat that has adverse impact on the mind and body or psychological and physiological abilities of the individual. Birth of an autistic child creates a crisis situation in the entire family and the crisis leads to stress. Parental

stress affects the entire family relationship and at times it can damage marriage relationship among the parents.

Most research studies suggest that parents of handicapped children have significant stress than the non-handicapped children. Increasing age of the handicapped child is another dimension, which is related with the parents' stress. The sample of the present study comprised of 30 mothers of children with autistic like features, selected randomly. Family stress scale was used to assess mothers' stress. There were all together 24 statements in the scale. Each statement had four probable answers - severe, moderate and mild and no stress with scoring of 3,2,1 and 0 respectively. The results indicated that the mothers of children with autistic like features and mental retardation face much stress. An interesting feature that is observed from this research study is that very little percentage of mothers face severe stress due to the presence of multiply disabled child in the family. The incidence of severe emotional stress was highest. Again, 36% mothers did not face financial stress due to the child with multiple disabilities in the family. Parental stress can be reduced by early intervention services and parental counselling.

### **Needs profile of mothers**

A study was conducted by Kumar and Akbar (2004) on needs profile of mothers of children with multiple disability. The sample consisted of 30 mothers of children with multiple disabilities. Family Assessment Need Schedule was administered on the respondents. The study showed that the areas, which were sought the most by mothers for information were Government benefits (76%) followed by information on the condition of their child (72%). This indicates lack of awareness among

the parents of disabled children. Researches have indicated that mothers expressed significantly more needs than fathers in the areas of family and social support, explaining to others and child care (Peshawaria 1995). Addressing family needs leads to greater benefits for the child and thus, the fulfillment of mothers' needs while catering to the demands of nurturing a handicapped child can reap more benefits for the child and other family members than anything else.

Family Assessment Need Schedule (FANS) (Parents) by Peshawaria (1995) consists of 15 main areas and 45 items classified into areas of Government benefits/legislation, information condition, personal-social, child management, personal-emotional, services, vocational planning, future planning, hostel, support-physical and financial, facilitating interaction, family relationship, sexuality and marriage. The methodology included administration of FANS and semi-structured interview of 30 mothers of children with multiple disabilities individually. Descriptive statistics (percentages) were used to analyze and compare the needs. The results indicated that mothers reported needs in knowing about the benefits extended by the Government followed by information condition, personal-social and child management. The needs related to finances, facilitating interaction, family relationships, though given importance by some of the mothers, do not figure as front rank needs. Aspects of sexuality and marriage were given least priority by the mothers. Government policies was given utmost importance (77%), the second most referred need area was information condition, while vocational planning was ranked 7<sup>th</sup>. It indicated that mothers of multiple disabled children do not think much in terms of future employability of their disabled wards. They were more concerned about the present condition of the

child.

Prabhu (2004) in his study on prevalence of disability in rural community and rehabilitation needs as perceived by the parents of persons with disabilities found that among the rehabilitation needs of the persons with multiple disabilities, three fourth of them (78.2%) had physical well being requirements with mobility as their major concern (30.2%). Need for economic assistance came second (8.9%), psychological third (7.3%) and the last was the social aspects (5.6%).

Thus it was concluded that the persons with multiple disabilities and their family attach more importance to the physical well being concern that too especially for mobility. For example, if a Cerebral Palsy child with profound retardation, speech and hearing impairment and mobility problem can be helped towards mobility by means of exercises, adaptive methods and aids like wheel chair, then the child as well as his family will be satisfied and motivated towards other interventions like special education, speech therapy training etc. Thus, it was observed that improving physical status is more important for persons with multiple disabilities and their families, than anything else. Next comes an economic need for which most of them seek welfare schemes followed by psychological and social needs. Rajender (2002) in his study established that the rehabilitation needs of 80% of the people with disabilities could be satisfied at the community level, the remaining 20% require referral to some kind of specialist facilities.

### **Perceived burden and coping straggles in mothers**

Kishore, Behera and Verma (2004) studied the perceived burden and coping strategies of 28 mothers of children with multiple disabilities

using Disability Impact Scale (Peshawaria, R, et.al 2000) and a Coping Strategy Scale. In Disability Impact Scale, except on positive impact domain, high score means more adverse effect. For coping strategies, investigators compiled 15 statements related to coping and rated the responses on three points: 0=Never used, 1= Occasionally and 2= Predominantly used.

Through consensus among the investigators, the items were divided into proactive and negative strategies. Descriptive statistics and regression analysis were used with the help of SPSS for statistical analysis. Results showed that all individual domains of disability impact except positive impact had significant positive correlation with overall burden. Significant negative correlation ( $r = -0.53, p < .01$ ) was observed between burden in social relations and proactive coping. Significant correlation ( $r = 0.53; p < .01$ ) was observed between loss of social support and negative coping. Results also indicated that health state of mothers and social relations could predict proactive coping strategies. Regression analysis did not indicate any effect of the severity of the disability on burden and coping. It may imply that the presence of disability itself is enough to induce burden. Qualitative analysis also revealed that the mothers perceived some positive impact of disability such as becoming more tolerant, empathetic and sensitive etc. Lack of significant negative relationship between positive impact and overall burden may not guarantee absence of burden. The study revealed that among all areas that contribute to burden, problems with social relations, social support and health of the care givers seem to be associated with coping. This implies that the sense of strong social relations, social support and physical and mental health might reinforce proactive coping. Although, there can be

individual differences, it is well documented that the responsibilities associated with the care of children with disability may affect parents' psychological, physical and financial well being over the time (Seligman and Meyerson, 1982). The negative impact may also be seen in social relationships, self-esteem and thinking, thus affecting physical and mental health (Peshawaria et al, 1995). The study concluded that the caregiver's health and social support would enhance proactive coping strategies. Hence, appropriate medical and psychosocial interventions may routinely be offered to the parents.

### **Behaviour Problems, Social Skills and Social Maturity**

#### ***(i) Behaviour problems***

Chukkali and Pal studied the prevalence of problem behaviours among persons with multiple disabilities. Some previous studies had indicated that problem behaviours are more likely to be seen in those having additional impairments of vision or hearing (Maisto, Baumeiser and Maisto, 1978) and self-injurious behaviour is markedly more prevalent among persons with severe mental retardation who have significant impairments of mobility.

The need to study the impact of problems behaviours is due to the serious ramifications it has on the quality of life of persons with disabilities. The objective of the study was to identify the overall distribution of problem behaviours in different multiple disability groups (mental retardation with cerebral palsy, mental retardation with visual impairment and mental retardation with hearing impairment). Also to analyze the relationship of the different domains of problem behaviour with reference to client characteristics (age, gender and level of retardation) across the whole multiple disabled

population as well as across the types of multiple disability.

The sample consisted of 236 persons with multiple disabilities with problem behaviours. Behavioural Assessment Scale for Indian Children - Mental Retardation (Part B) and Behavioural Assessment Scale for Adult Living - Mental Retardation (Part B) checklists prepared by Peshawaria et al. (1992, 2000) were used to elicit information on current level of problematic behaviour. Case records of 236 persons with multiple disabilities having problem behaviours were analysed. The sample was divided into three groups - Mental Retardation with Cerebral Palsy (174), Mental Retardation with Visual Impairment (20), and Mental Retardation with Hearing Impairment (42). The sub-groups were further analysed for the client characteristics - age, gender and level of retardation. Mean, standard deviation and chi-square tests were used for statistical analysis. Majority of the subjects (79%) were in the school age group of 3 to 12 years of age and the rest were adolescents 10% and adult 11%. The moderate level of retardation was present in 33% and severe retardation was found in about 10% of the subjects. There were 64% male subjects. The results further revealed that persons with multiple disabilities exhibit higher percentage of repetitive behaviours (39%), violent/destructive (33%) and self-injurious behaviours (30%) when compared to fears (0%), antisocial (8%) and misbehaves (3%). Behaviours in the domains of temper tantrums, misbehaves and self-injurious behaviour are seen more in the mental retardation with cerebral palsy group than with other two groups. Behaviours in the domains of repetitive behaviour, odd behaviour and antisocial behaviour was observed more in the mental retardation with visual impairment group than in the others. The mental retardation with hearing impairment group scored higher on

the domain of violent/destructive behaviour and hyperactive and rebellious behaviour.

#### (ii) *Behaviour Management*

Sharma (1993) conducted a study of functional analysis of behaviour management of students with multiple disabilities. The study was an attempt to investigate the use of differential reinforcement in classroom situation for the management of problem behaviour. Relevance of functional analysis and its comparison with differential reinforcement in the classroom setup were also studied. The functional analysis model used in the study was ABC model, i.e. Antecedent-Behaviour-Consequence model. The sample comprised of four male students in the age range of 12 to 15 years having visual impairment with mental retardation / Cerebral Palsy. For identification of problem behaviour Part B of AAMD, Adaptive Behaviour Scale was used. Target problem behaviour and rewards were identified. Baseline behaviour was also recorded. Functions of problem behaviour in all the four students were determined using ABC model of functional analysis. Intervention in the present study was given in two phases – phase-I was for five days during which only the differential reinforcement (intervention I) was given and subjected to analysis. Phase-II was also for five days. Intervention was given in the form of behavioural techniques based on the functions identified for the problem behaviours along with differential reinforcement and subjected to analysis. Effectiveness of both the interventions was evaluated on the thirteenth day. The results showed that the problematic behaviours of all the four subjects were managed during both the phases of interventions but more effectively during the second phase except in one case. Problem behaviours such as flapping of hands, inability to sit at one place, abusing others etc.

were substantially reduced. It was concluded that the problem behaviour of children with multiple disabilities might be managed in classroom situation if the functions of behaviour are analysed correctly and significantly and also if behaviour techniques based on the functional analysis of target behaviour are used. Also functional analysis of problem behaviour may help in choosing appropriate techniques for behaviour management of students with multiple disabilities in the classroom situation. Small sample size was the limitation of the study. Matched sample would have been more useful for generalizing the findings of the study.

### *(iii) Social Skills*

Padmavathi (2004) conducted a comparative study of the perception of the parents and teachers on social skills in children with multiple disabilities. It is commonly observed that the social skills are significantly affected in children with multiple disabilities as their sensory impairments and motor deficits block their social interaction. Social skills are defined as socially acceptable learned behaviours that enable a person to interact with others in ways that elicit positive responses and avoid negative responses. Since, most of the social interaction of the children takes place in the presence of either parents or teachers as they are the key observers of their behaviour. Some times their perceptions may vary with each other's; hence a comparative study of perceptions of both teachers and parents was taken up. The objective of the study was to develop a questionnaire to assess and compare the perceptions of parents and teachers on social skills in persons with multiple disabilities. The sample of the study consisted of 25 parents and 25 teachers of children with multiple disabilities. An open ended questionnaire was developed with 12 questions containing the possibility of

training on social skills in children with multiple disabilities in different settings such as home, school, community with possible methods of training and demographic information of the parents, teachers, and child on age, diagnosis, education and schooling of the children. The results indicated that there was significant difference between parents and teachers on expressing basic needs by the children with multiple disabilities at home. As regards social competencies like wishing the relatives, playing with siblings and going to neighbourhood, no significant differences were observed in the perceptions of parents and teachers.

No significant difference was observed between the perception of teachers and parents regarding social competencies like playing with classmates, greeting teachers and participating in group activities in schools. However, in outdoor activities, there were significant differences in the perception of parents and teachers with regard to playing in groups. Similarity of responses was observed between the two groups on training the children on social skills like greeting, playing and sharing without much difficulty. Both parents and teachers indicated that it was difficult to train children in communication skills. There was some difference of opinion in the teaching methods, as the parents suggested 'giving more practice' is the effective method while teachers suggested 'modelling' to be more beneficial in teaching social skills to children with multiple disabilities. The study will prove to be useful in developing programme planning and intervention for training social skills to children with multiple disabilities. Similar skills revealed by parents and teachers will help in planning better interventions with coordinated efforts at home and school. The investigator has recommended that a similar study may be conducted on a larger sample for better

results. Also a checklist may be developed as a guide for professionals for implementation of interventions.

#### (iv) *Social Maturity*

A study was conducted on social maturity profile of persons with multiple disabilities: a comparative analysis by Thomas and Singh (2004). The study explored and analysed the pattern of social maturity of persons with multiple disabilities by using Indian adaptation of Vineland Social Maturity Scale (VSMS). A sample of 30 persons with multiple disabilities are collected and classified into three groups as per their nature of disability (10 persons with mental retardation and visual impairment, 10 persons with mental retardation and Hearing impairment and 10 persons with mental retardation and motor impairment). Assessment of social maturity and adaptive behaviour of the subjects was done on eight social areas of Indian adaptation of VSMS with the help of parents and teachers who have observed the individuals in many settings as well as their behaviour was observed during the assessment. Based on Social Age (SA) and Social Quotient (SQ), profile analysis was done for all the cases individually for eight areas - Self-Help General (SHG), Self Help Eating (SHE), Self Help Dressing (SHD), Self Direction (SD), Occupation (OCC), Communication (COM), Locomotion (LOC) and Socialization (SOC). Mean, SD, One way Analysis of Variance and Pearson Product Moment Correlation were used for statistical analysis. The results showed significant high correlation between Communication and Occupation (0.713) followed by Socialization and Self Help Dressing (0.71). It may be interpreted that the more the person has high social maturity in the reception, expression and comprehension of different concepts, the more the person

tend to experiment and apply them practically. The results further revealed that the group of mental retardation with hearing impairment was better than the other two groups in the area of locomotion. This may be due to the fact that their adequate motor skills and sharpened visual sensations help them to avail the cues for better mobility in their environment. This skill itself leads them to expose and explore many situations and thus maintain their development of adaptive skills. It was also found that the Social Quotient in Mental Retardation with Hearing Impairment Group was higher than the other two groups. Though their auditory sensation is handicapped, they receive, express and comprehend visual cues through non-verbal communication.

### **Application of Information and Communication Technology**

Basu et al (2004) in their paper on “Computer based education and communication systems for people with multiple disabilities” have discussed about the development of some systems by them for the persons with multiple disabilities for providing personalized education, speech enabled vernacular Alternative and Augmentative Communication (AAC) and an alternative mechanism to access computer. The need for developing these systems was felt due to the foreign accent of the speech systems, high costs, no local support as most of them are imported. The education system called “*Shikshak*” meaning Teacher is meant for students who are unable or are not fit for attending traditional classes. Using the system, a teacher can develop course materials for a class of students, including students with special needs. The system can then be used by individual students in a self-learning mode.

Based on the ability of the student (both

learning as well as physical ability), the system decides the study material to be used for the student. The system also takes test, when the student understands a concept then only the next concept is taught. The system is adaptive and flexible. The teacher can create any kind of materials, such as plain text, audio and video clips, slide shows, flash movies etc. The system also supports virtual books in which each page consists of grid of icons. The system can be interfaced with special access switches and techniques. This helps in making the system usable to the people with severe neuro-motor disorders, who are unable to use keyboards or mouse.

An Alternative and Augmentative Communication (AAC) System is also developed to help people with Severe Speech and Motor Impairment (SSMI) in as much a natural way as possible. For the neuro-motor disordered, special access switches are provided for selection of icons. On accepting the icons, the system can automatically form natural language sentences.

### **Vocational Rehabilitation**

A case study of a 20 year boy with multiple disability has been presented who was successfully employed in the laundry department of a hotel (Latha, 2004). Mohinish, a visually impaired and mentally challenged boy was trained using jigs of low cost made by using cardboard technology. Mohinish had receptive language for simple commands. He used both hands, initiated hand skills and finger movements. He had adequate hearing and he spoke in single words and phrases. The objective was to make him able to fold a towel using a jig. Reinforcers like attention and social praise were used. The baseline data on the date was 0%. Mohinish was given

individual instructions. The instructor stood behind the boy and jig was placed on the table and a towel was given. During acquisition stage, verbal cues were given as necessary. If he failed, physical assistance was provided. Ten trials were conducted from Monday to Friday. Initially the boy was praised for every correct response which later faded to randomly chosen response. The task analysis included spreading the towel over the jig, crease well all over the towel, lift the bottom flap with the towel, drop the flap with towel, lift the flap without the towel and so on and finally keep the folded towel aside. Altogether there were 23 steps involved. It is an example of training a child with multiple disabilities.

### **Deaf blindness**

The multiple disability of deaf blindness is a unique disability as it is more than just deafness and blindness. The incidence of deaf blindness is definitely low. Surveys of community-based projects have estimated the number of people affected by it to be around 450,000 in India. How many of them are congenitally affected and how many of them have acquired it afterwards in life is unknown. Sense International (India) is working through its regional partners in 17 States of India for persons with deaf blindness in India. Service delivery models that are common in India are CBR, Home Based Services, Center Based or Special School Based Services, Residential Schools, Mainstream Schools and Itinerant teacher support etc. The multi-disabled group is by no means homogeneous, with many of the needs of the children being quite different from one another. Most of the services for visually impaired multi-disabled (VIMD) are an extension of existing service delivery mechanism persons with one disability e.g.

blind, deaf, mentally retarded, Cerebral Palsy and so on. This is quite an advantage as children are benefited from already established resources and expertise. The philosophy of education for multi-disabled children especially with one or the other sensory loss is based on enhancing communication.

### **Summing up**

There is a wealth of good work happening in India but little knowledge of it is available. The need to have data base of existing services both educational and vocational in the field of multi-disability is essential and examples of good practices should be shared and be accessible to all those working with them.

There is a dearth of research studies on multi-disabled children in the country. Many of the larger NGOs like Spastic Societies at Kolkata, Mumbai, Chennai, Delhi and Bangalore have conducted exemplary work in this area in collaboration with national and international agencies. In the area of deafblindness Helen Keller Institute for the Deafblind, Mumbai has conducted pioneering research work in the country. Development of aids and appliances, assistive technology and development of indigenous communication devices are some of the crucial areas of research besides teaching and training strategies, classroom management, evaluation procedures and teacher preparation. These areas demand both fundamental and action researches to be made available to practitioners so as to help them address educational and welfare of these children.

### **References**

1. Aggarwal, R. and Nanda, B. (2004). A study on mothers' stress of children with mental retardation and artistic like features. Proceedings of the NIMH Conference on Multiple Disabilities, 2004 Secundrabad : NIMH.
2. Bailey, D.D. and Wolery, M. (1992). Teaching infants and preschoolers with disabilities, New York: Mc Millian Publishing Co.
3. Basu, A. et al (2004). Computer based education and communication systems for people with multiple disabilities. Proceedings of NIMH Conference on Multiple Disabilities, 2004 Secundrabad : NIMH.
4. Census of India (2001), Registrar General & Census Commissioner, India
5. Chatterjee, Ruma (2005). Government of India and Deaf blindness. 3<sup>rd</sup> National Expert Meet, New Delhi.
6. Fawell, D., and Cone, J. (1983). Identification and Placement of Severely Handicapped Children. In M.Snell ( Ed.) Systematic Instruction of the Moderately and Severely Handicapped (2<sup>nd</sup> Ed.) Columbus, OH: Merrill, pp. 46-73.
7. Government of India (1999). The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act. New Delhi: Ministry of Social Justice and Empowerment.
8. Government of India (1995). The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, New Delhi: Ministry of Social Justice & Empowerment.
9. Kishore, M. Thomas, Behera, P. and Verma, R.K. (2004). Perceived burden and coping strategies in mothers of children with multiple disabilities. Proceedings of NIMH Conference on Multiple Disabilities, 2004 Secundrabad : NIMH.
10. Kumar, Akbar, I.(2004). Needs profile of mothers of children with multiple disability.

- Proceedings of the NIMH Conference on Multiple Disabilities, 2004 Secunderabad : NIMH.
11. Latha, S. (2004). Empowering persons with multiple handicaps. Proceeding of NIMH Conference on Multiple Disabilities, 2004 Secunderabad: NIMH.
  12. Maisto, C. R, Baumilister, A.A. Maisto A.A. (1978). Journal of Mental Deficiency Research - An analysis of variables related to SIB among institutionalized retarded persons, vol.22, pp.27-36.
  13. Mishra, S. (2005). A Majority within a Minority: Services for Visually Impaired Multi Disabled Children in India. ICEVI West Asia Conference, Delhi.
  14. National Sample Survey Organization (2002) 58<sup>th</sup> Round; Survey on Disabled Persons in India, New Delhi; NSSO
  15. Narayan, J. (2004). Educational status of children with mental retardation and additional disabilities. Proceedings of NIMH Conference on Multiple Disabilities, 2004, Secunderabad: NIMH.
  16. Padmavati, K. (2004). Perception of the parents and teachers on social skills in children with multiple disabilities - a comparative study. Dissertation submitted to Osmania University, Hyderabad for the partial fulfillment of M.Ed Special Education (Mental Retardation).
  17. Persha, A.J. (2004). A study of infants and toddlers with disabilities. Proceedings of the NIMH Conference on Multiple Disabilities. 2004, Secunderabad : NIMH.
  18. Peshawaria, R. et al (1995). Understanding Indian families having persons with mental retardation. Secunderabad : NIMH.
  19. Peshawaria, R. Menon. D.K., Bailey, D & Skinner, D. (2000). NIMH Disability Impact Scale. Secunderabad : NIMH.
  20. Peshawaria, R (2000). Behavioural Assessment Scale for Adult Living Mental Retardation. Secunderabad : NIMH.
  21. Peshawaria, R., Venkatesan, S. (1992). Behavioural Assessment Scale for Indian Children with MR. Secunderabad : NIMH.
  22. Prabhu, E.J. et al (2004). Profile of multiple disabilities in rural communities and the rehabilitation needs of the impaired. Proceeding of the NIMH Conference on Multiple Disabilities, 2004, Secunderabad : NIMH.
  23. Rajendra, K.R. (2002). Training needs in CBR in South Asia with special reference to severe disabilities, inclusiveness and the integrated approach. Asia Pacific Disability Rehabilitation Journal: Series 2, January 2002, 128-137.
  24. Rehabilitation Council of India (2003). Disability Status in India. New Delhi.
  25. Raynolds, C.R. and Fletches – Janzen, 6 (2000) Encyclopedia of Special Education (Vol. 2) New York: John Wiley and Sons, pp. 1222.
  26. Sharma, U (1993). A Study of Functional Analysis in the Behaviour Management of Students with Multiple Disabilities. Proceedings of the 7<sup>th</sup> National Seminar on Multi Disability. Madras: The Spastic Society of Tamil Nadu, India
  27. Thomas, T.M. and Singh, N. (2004). Social Maturity Profile of Persons with Multiple Disabilities: A Comparative Analysis. Proceedings of NIMH Conference on Multiple Disabilities, 2004, Secunderabad: NIMH.

# Educational supports for children with multiple disability in Korea

Hyun Jin Kim

(the Senior Education Researcher, Korea Institute for Special Education, Republic of Korea)

---

**Abstract:** Special education in Korea, in educating disabled children including with multiple disability, is aiming for inclusive education in nearby regular schools. Basic directions for special education policies are maximize educational efficiency among all students by sharing a sense of responsibility between general and special education. Based on this, Korea has educational supports for children with multiple disabilities as follow.

First, Korea provides guarantee free compulsory education for multiple disable students. Sometimes their severe and multiple disabilities prevent them to come to school. In that case, it provides education opportunity for disabled students through visitation services.

Second, it makes change of system in special education schools for multiple disable students. It makes the schools smaller, de-categorization of disability categories. De-categorization of the categories means that special education schools should be changed into one school for all range of disabilities instead of categorizing the disabilities and running separate schools for each.

Third, it builds a foundation for integrated education for them. The members of schools and societies need to accept the fact that schools and societies with disabled children are normal and are healthy school, classes, and societies. Students are to have some kind of education to understand disability once or more a semester. Teachers need to take 60 hours of special education at least once.

Fourth, it facilitates the regular schools with special equipments for the disabled. Schools need to have various facilities, equipments and learning materials and aides nor only for the regular students but also for the disabled students. It builds a basis for integrated education through improvements on general classroom environment and provides support for multiple disabled students to facilitate learning.

Fifth, it makes stronger special education support system and increase in support. In order to provide with appropriate special education services and related services for the multiple disabled students in special education classes and inclusive classes and also for those students who are neglecting their obligation to attend school, it has established and run special education support center in the district education hall unit. It builds a special education support system centered the around local communities. And it operates the special education assistant system. It hires 2,000 special education assistants.

---

**Key words:** Korea special education, multiple disability, inclusive education, education supports for disabilities, special school change, special equipment, integrated education

Special education in Korea, in educating disabled children including with multiple disability, is aiming for inclusive education

in nearby regular schools. The society is responsible for making sure all the members of the society get proper education regardless of

the conditions any member of the society could possibly be in. The worse the conditions are, the harder the society has to try to actively educate them and provide with opportunities. Disabled children surely are the ones in less opportunity. Therefore thoughtful considerations and support by the society is necessary. However, the society has been insisting on the logic of majority-centered system based on the average and standard, the government has rather been neglecting the education of disabled children and made it a norm to place them in separate institutions other than in the regular schools with other non-disabled children. Therefore, in order to make it possible for the disabled children to go to a regular school near home and get inclusive education, as it is stated in Act for elementary, middle high school. For the disabled children, the country and a district self-governing body are to provide with the adequate ways to admit and educate them from grade K to 12 or in regular schools or an institute equivalent to those.

In this paper I'll overview general situation of special education in Korea and to explain about educational supports for children with multiple disability.

### **I . General overview of special education in Korea**

According to the results of the 2001' Korea study on the Occurrence of special education children, the disability occurrence ration among school age children between 6-11years of age was 2.71% disabled, among which 61.25% or 150,712 students are able to receive general education. As of April 2004, 51,060 students receive education at 141 special school and 4,300 special education classrooms, 13,632 students are currently delaying their education and reside at homes, hospitals, and welfare.

### **1. Purpose of special education**

Basic directions for special education policies are maximize educational efficiency among all students by sharing a sense of responsibility between general and special education. First, the purpose of special education is guaranteeing equal opportunity for education for those in need of special education by the central and local governments, improving education methods and circumstances to cultivate ability to lead independent lives, accomplishing the goal of providing special education for all students in need as part of compulsory education free of charge. In order to accomplish the purpose, we should establish a diagnostic system for special education, build new special education schools, increase special education classrooms, cut the number of students per classrooms at special education schools and improve facilities for the disable

Second, the purpose is creating a school culture that respects the needs in other words it is improving education environment of general schools to build the basis for integrated education. We should improve school education curriculum management, expand the development of curriculum, teach materials and tools, strengthen the sense of responsibility for special education among general education teachers and raise the sense of professionalism among special education teachers.

Third is establishing an education support system that can expand the establishment and support for special education support system centered the around local community. We should expand the establishment and operation of special education support centers, increase the number of personnel for special education administration and support institutions, expand budget and investment for special education and strengthen ties among government ministries related to special education. Through these, we

will pursue high quality education that respects

## **2. Status of Multiple Disabilities**

According to the results of the 2001' Korea study on the occurrence of special education need children, the multiple disability occurrence among school age children between 6-11years of age was 0.01% disabled. But it is just estimated. In the National survey about the disabled children from the Ministry of Education, the multiple disabled children are not included. Because Multiple disabilities are not classified separately. We classify the disability into the seven categories which are 1) visual impairment, 2) Hearing impairment 3) Speech impairment 4) Physical impairment 5) Mental retardation 6) Learning disabilities 7) Emotional disturbance in Korea.

Therefore we don't have any data about that how many multiple disabled children are existed and where they are educated. Usually we guess they are in special education agency. Special education agencies are special schools, special classes in regular school. In Korea, we have the five categorized special schools. There are special schools for visual impairment, special schools for hearing impairment, special schools for physical handicapped, special schools for emotional disturbance. In case of multiple disabled children, they are usually placed into the special school according to their first and serious impairment. For example, if there is a child with blind-deaf , according to his disable condition, they are placed to blind special school or deaf special school.

## **II . How to support for children with multiple disabilities**

### **1. Guarantee Free Compulsory Education for multiple disable students**

Even though students have multiple

disabilities, from kindergarten to high school they have to be guaranteed balanced right to special education across the national and education level. For them, we establish and increase the number of special education institutions to provide free education. We provide and expand opportunities for special education adequate to the level and type of disability and guarantee a balanced opportunity for special education among all levels of education. Sometimes their severe and multiple disabilities prevent them to come to school. In that case, we provide education opportunity for disabled students through visitation services. We distribute the guidelines for visitation programs and conduct investigation of the current. In 2003, the number of students receiving visitation education services is 2,599. Visitation education is that special education provided to disabled students by special education teachers by making visits to homes and/or medical facilities. Compulsory education for special education includes primary and middle school curriculum, while kindergarten and high school education is provided free of charge.

To Guarantee Free Compulsory Education for multiple disable students, we increase the number of special education classes. In Korea, the special education classes are the practical unit that supports inclusion. In special education promotion Act, Article 2, Paragraph 4 characterizes special education class as the full time, part time classes run by schools according to their capability. Therefore the government is making classes for the disabled to be part time rather than full time in the inclusive education. They are planning to increase the special education classes in number.

### **2. Change of system in Special education schools**

Students with multiple disabilities get

inclusive education in nearby regular school, the government of Korea is demanding the following three things to be done. First, to make the schools smaller, dispersion of schools and de-categorization of disability categories, making the schools smaller in size and dispersing means that for students who want to choose a school, small size schools should be available in every region. Although in the future when inclusion becomes more common, there will always be students who are in need of special education schools for the disabled only. Therefore special education schools need to be dispersed evenly throughout the region and be increased in number. De-categorization of the categories means that special education schools which are now separated by the categories of disabilities should be changed into one school for all range of disabilities instead of categorizing the disabilities and running separate schools for each. Category of the impairment is the first thing to consider in educating the disabled student because special quality and educational needs differ from one kind to another. However, when majority of disabled students move to regular schools, in special education school, the only ones left will be students with severe and multiple disabilities. Those are students with severe cerebral palsy, severe mental retardation, severe emotional, behavioral disorders and the ones with two or more disabled perceptive functions. However, even students with two or more disabled perceptive functions can perform adequately in regular schools while receiving support services. Therefore in order to reinforce inclusion, Korea is encouraging students with mild disabilities to be moved to regular schools if possible and schools for the disabled to be run without separating students by categories of impairment for the students with severe, multiple disorders.

### **3. Build a foundation for integrated education for them**

Recently regular classroom teachers and parents of non-disabled children agree with the fact that schools and organizations they are concerned about their children having disabled friends or their classes having disabled students. Unless this kind of prejudice against disabled students is lessened, both inclusive and regular educations could not be carried out properly. Therefore the members of schools and societies need to accept the fact that schools and societies with disabled children are normal and are healthy school, classes, and societies. In order to make this kind of social and psychological environment, the government is reinforcing the following politics. Students from grade K to 12 are to have some kind of education to understand disability once or more a semester such as volunteering at an organization for disabled people, having to experience disability, or campaigning to change the prejudice against the disabled people. Teachers need to take 60 hours of special education at least once and those who did, take charge of the inclusive class.

It is important to abolish prejudice of non-disabled students and teachers at general schools against disabled students. We build a foundation for integrated education through improvements on the physical environment of general schools. We strengthen education for awareness towards the disabled for teachers and students at general schools. Kindergarten, primary, middle, and high schools are encouraged to provide education on the disabled at least once a semester. Teachers at general schools (kindergarten, primary, middle, and high schools) are encouraged to receive training on special education. Standards for assigning teachers at integrated classrooms and management/operation guidelines have been delivered. Priority shall be given to special

education majors and those who have completed training. We appoint and operate pilot school for integrated education. At least one school has recommended to be established as an integrated education pilot school for each metropolitan/provincial education office for the widespread implementation of integrated education. The metropolitan/provincial education offices have held a conference on success cases of integrated education at pilot schools.

It is important to establish special education responsibility of regular classroom teachers. Some regular teachers consider special education as the duty of special education teachers, but it is also duty of regular teachers. In order to establish special education responsibility, Korea is reinforcing these policies to make it mandatory to take special education in the curriculum for kindergarten, elementary, middle school teachers, and in the practical training of teaching and thereby take special education curriculum and the teachers in charge of inclusive classroom from grade k to 12, to take the test of the ability to operate inclusive education. Special education is reinforcing policies that extend to provide special programs for the disabled putting into the evaluation category.

#### **4. Provide special equipments for the disabled.**

In a society that considers disability as a pathological condition, unless we get rid of the physical barriers, it is impossible to educate both the disabled and non-disabled students. There are two physical barriers that keep the disabled students from learning in regular schools. The first one is the facilities and equipments that schools have that are not at all suitable for the disabled students and therefore limiting the right to move around. The other one is the lack of special learning materials and aide who ends up limiting the

right to learn. Schools need to have various facilities, equipments and learning materials and aides not only for the regular students but also for the disabled students. We build a basis for integrated education through improvements on general classroom environment. We improve education environment at special education classrooms and provide support for disabled students to facilitate learning. We establish the 「Comprehensive plans for improving facilities for disable students at general schools」. Plans are underway to complete the installment of facilities for the disable at schools with special education classrooms within three years beginning 2004. Schools without special education classes shall undergo establishment starting with primary schools.

#### **5. Stronger Special Education Support System and Increase in Support**

In current special education system in Korea, the local community institutes for supporting the disabled students are special education schools, special education classes and inclusive classes, however, the students in special education classes or in inclusive classes are not getting the proper education or the related services compared to the ones in special education schools. And for the multiple disabled children under school ages or for the ones not selected to receive special education, there are no counseling services or support available. Therefore in order to provide with appropriate special education services and related services for the multiple disabled students in special education classes and inclusive classes and also for those students who are neglecting their obligation to attend school, Korea has established and run special education support center in the district education hall unit. However now the areas with personnel from special education center

are very limited and the financial support has not been well received therefore resulting in difficulties. Therefore Korea is reinforcing policies to establish special education center in all 180 district education hall in the country and place worker in charge, financially support these and therefore make the system more effective and substantial. We establish a decentralized special education support system around local communities and enhance education welfare for special education students through expansion of support for special education. We build a special education support system centered the around local communities. Special education support centers are established and operated at each metropolitan/provincial office of education. In “Special Education Support Center” treatment and counseling services are provided to special education students attending general kindergartens and schools. We enhance professional capabilities of special education teachers. We expand the assignment of special education teachers and enhance their level of professional capacity. Educational efficiency has been improved through the consolidation of occupational education for special education students. We expand education welfare for special education students.

Due to multiple disable students, the importance of therapeutic education has increased along with the professional capability of teaching staff multiple. The excessive numbers of student assigned to therapeutic education teachers and the multiple nature of the disability have made it difficult to provide professional therapeutic services. We provide a basis for assigning therapeutic education teachers by disability type and education environment.

We operate the special education assistant system. In 2004, we hire 2,000 special education assistants. The government has set aside about

55 billion won for this purpose.

To help multiple disable students with visual impairment, we supply “Large-print books” for the visually disabled students. It is first trial among OECD nations. The entire set of primary school textbooks has been produced in large-print in 2002. National textbooks in the middle school and high school curriculum have been produced in large print in 2003. Large-print textbook means 150% enlargement of the textbook for students with vision lower than 0.4. In addition to that we improve teaching materials and tools for special education curriculum for multiple disable students. For physically disabled students we improved transportation. It has been provided for the purchase of school buses for the disabled, electrical wheelchairs at special schools.

### III. Conclusion

Recently special education in Korea has made tremendous progress. However it is also true that special education in Korea needs to be developed quantity and quality.

The educational rights of all children with special needs including who have multiple disabilities are protected by the Korea Special Education Promotion Law and Education regulation. The Korea has to survey about the multiple disabilities over the country. Through survey, we have to collect the status of the multiple disabilities. With the basic information the Nation has to supply properly devised planning and educational interventions for the multiple disabilities. Also it is required special support in education services and curriculum for them. Since it is very difficult for them to integrate, there is a need to devise a plan for them and open schools.

In order to reach the quantitative and qualitative progress of special education, the

first thing to do is creating the atmosphere that classes, schools and society. In order to teach them appropriately, teacher training is an important. We should prepare resource materials for teacher and the multiple disabilities to promote. Planning, material development, research support, teacher training, classroom organization, parental and community support are needed. Based on this improvement, we have to provide vast range of support for multiple disabled students to study with regular student. Therefore carrying out the policies now being reinforced will be the way to improve not only the special education but also education itself. To do special education, we have to consider proper education for students with multiple disabilities.

## References

- Kim, H. J. (2004a). Political directions of Special Education in Korea. The first certification workshop. Ansan : Korea Institution for Special Education
- Kim, H. J. (2004b). Special Education policy and Law. The workshop for general teachers. Ansan : Korea
- Ministry of Education & Human Resources Development (2004a). The Statistics on Special Education
- Ministry of Education & Human Resources Development (2004b). Special Education Annual Report to National Assembly
- Ministry of Education & Human Resources Development (2004c). The Special Education Master Plan in 2004
- The Education Law Compliation committee(2004). The Education Law. Seoul : Kyou-Hak-Sa Institution for Special Education

# The Study of Problems, Needs and Planning in Counseling & Guidance of Deafblind Cases in the Rehabilitation Institute

SAOWARUK SUKONTHARUNGSEE

Faculty of Graduate studies Mahidol University, Thailand

**Abstract:** This research on deafblindness is the first official research done in Thailand. The first collection was 130 cases, selected from 14 deaf and blind institutions. Later, 35 cases from 8 places, age ranging from 7-60 years old, were used in this study. The survey was done by questionnaire, consisting of 37 questions constructed by the researcher. Questions were asked directly to the clients by the researcher, using one sign language interpreter throughout the study. In case the communication failed, collection of data was obtained from parents; teachers or caregivers of the clients. Clinical examination and findings were obtained from eye and ear specialists. Results on their needs and their problems were obtained after the clinical examination was finished. Data analysis was calculated in percentage. Later, results were used for counseling guidelines.

Most cases were selected from schools for the deaf(62.86%) with age ranging 11-20 years (60.0%). Sex ratio between male and female is 1.9 and 1.0. Cases who had congenital deafness-adventitious blindness (CD-AB) were 17 (48.58%), congenital deafblindness (CDB) were 16 (45.71%), and congenital blindness-adventitious deafness (CB-AD) were 2 (5.71%). According to the research the causes of deafblindness, were Maternal Rubella 9 cases (25.71%), Usher syndrome 6 cases (17.14%), and premature birth 1 case (2.86%). Cases that were able to orally communicate were only 2 (5.71%), using sign language were 20 (57.14%), and using only gestures and body language were 16 (45.71%).

The questionnaire is divided into 4 groups based on deafblind people's needs. In the medical area (1) they wanted to have annual eye and ear examinations once a year (40.0%). (2) They needed low vision devices 14.29%, (3) and they needed hearing aids 8.57%. In the area of education, they needed (1) education and training to be an independent person 40:0%, (2) they wanted to study in an informal education program 1 1.43%, (3) they wanted to extend their college education at Ratchasuda College 5.71%, and they felt they had no need for further education beyond grade 6th 2.86%. In the area of social needs, they wanted to be well accepted by non-disabled people 80.0%, needed budget for training and education 51.43%. According to vocational training, they needed job training 17.14%, and to have their own private job 14.29%.

The report of their problems state that they are (1) lacking a deafblind interpreter 100%, (2) and have problems in communicating with non-disabled people 85.71%, (3) the problem with poor attitudes of non-disabled toward the deafblind group was 91.43%. They felt there was an attitude and belief that deafblind cases are unable to be an independent person 57.14%. There was a problem and misconception that the deafblind are mentally retarded people 31.43%. Other problems mentioned were a lack of specialized teachers for the deafblind 71.43%, and that the Thai government have never had a policy on deafblind rehabilitation 28.27%.

Suggestions for further studies are, (1) to increase surveys on deafblindness. (2) A preparation on the rehabilitation process and services as well as the Individualized Education Program (IEP) for

the deafblind. Last but not least is to set up a counseling procedure for this group in Thailand.

---

**Key Word :** Deafblind

## **Introduction**

Moment to moment, our vision and hearing give us the information we need to continuously expand our knowledge and to interact with the world around us. Vision and hearing provide individuals with a wealth of learning experiences. Difficulties in either seeing or hearing alone have a great impact. An individual with a hearing loss must use vision to help compensate for the lack of available auditory information. Deafness hinders individuals' abilities to hear sound: voices and conversation, music and environmental sounds, and sounds that provide awareness of immediate events. Similarly, an individual with a vision loss must use hearing to help compensate for the lack of available visual information. Blindness hinders individuals' abilities to experience every day things such as independent movement, color, shape, and **symmetry; and the activities** that vision normally facilitates. When both vision and **hearing are affected, this type of compensation cannot occur, and adequate and consistent amounts of sensory information are not available.** This results in varying **degrees** of sensory deprivation, which occurs on a continuous basis, day after day, year after year.

Individuals, who have combined vision and hearing loss or deafblindness creates unique problems of communication, mobility, and learning that often result in intense isolation and loneliness for many individuals. Because 95% of what we learn about the world comes through our vision and hearing (Sense, 2002: 1). The child with deafblindness misses much essential information, and incidental learning is greatly limited.

The word deafblind is written in a connected way and not as two separate words "deaf blind", because a unique condition is at stake here, one not merely caused by a combination of deafness and blindness (van Dijk, et al., 2002:1).

Deafblindness is a low-prevalence disability that creates serious barriers to inclusion and full participation of the individual in community, social, and work life. Critically, the individual with deafblindness will have limited opportunity to communicate with a variety of people, access information, develop meaningful social relationships, orient to, and move about the environment. Individuals with deafblindness are a diverse group with a continuum of needs, which vary depending upon the age of onset of deafblindness, degree of sensory loss, presence of concurrent disabilities, and environmental conditions.

In the United States, the 1992 census report estimated 7,839 children and other youth who are under age twenty-two years who meet the federal definition of deafblindness (Bagley, 1992 cited in Orto & Marinelli, 1995: 234). It is estimated that there are 30,000 to 45,000 individuals in the United States who are deafblind (Watson, 1993). In addition, a study by Teaching Research Division at Western Oregon State College has identified over 5,000 children and youth. It is estimated that this number could be as high as 11,000. It is generally believed that dual sensory impairment occurs in 3 of 100,000 births (JCA Unlimited Design Studios, 2000: 1). In the year 2001 we found statistic from Los Angeles Time newspaper stated that

the population of the United States was 248.7 million but failed to report number of people with disability. If we use the above ratio of deafblind 3:100000, it should be estimated that in the year 2001 there should be at least 7,461 cases of deafblind all over USA.

In the UK, it is estimated over 21,000 deafblind people (The Nation Deafblind and Rubella Association, 1988 cited in RNIB challenging blindness, 2000: 1). Statistical analysis in Thailand for deafblind case still not available till today.

With question on causes of deafblindness; rubella, CHARGE association, Usher syndrome, genetic disorders, accident, and illness are some of the common causes (The Arizona Deafblind Project, 2001 : I ). The main causes of deafblindness are premature birth, birth trauma, and host of genetic conditions including Usher syndrome, where a child is born deaf and loses their vision in their teenage years of life (Sense The National Deafblind and Rubella Association, 1999: 1).

Four critical factors which effect the severity of deafblindness on the child and his development are:

- degree and type of vision and hearing loss
- stability of each sensory loss
- educational intervention provided (The Arizona Deafblind Project, 2001 : 1-2).

Deafblindness is defined by The Individuals with Disabilities Education Act (IDEA of United States) as, "concomitant hearing and visual impairments, the combination of which creates 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" (Federal Register, 1999 cited in Alsop, et al., 2000: 1).

Planning services for this unique group of people requires sensitivity by the service delivery system to the individual issues specific to deafblindness, and the creation of alternatives to services that have been traditionally provided for individuals with other disabilities.

With in the deafblind population, there are many variables that must be taken into consideration in order to provide individuals with services and supports best suited to their needs. Not all individuals who are deafblind are both totally deaf and totally blind. Many have varying degrees of useful residual vision or residual hearing. They vary greatly in their degree of education and experience, their skills in communication, and their understanding and potential.

In conclusion, deafblind children and adults require services specially designed to meet their needs. In seeking to enhance the quality of life for deafblind people and help them become as independent as possible.

### **Picture of Deafblindness in Thailand**

In the developing countries there is very little awareness about deafblindness and virtually no appropriate services. Hundreds of deafblind children therefore remain in isolation at home or institutions (Sense The National Deafblind and Rubella Association, 1999: 1).

Before the year 1989 (B.E.2532), deafblind cases in Thailand have not been mentioned at all in the educational rehabilitation services. There are small number of case found in the eye and ear clinics where doctors would followed up the case and helped them to get some medical rehabilitation such as the use of hearing device and the fundamental visual aids. It may be said that those cases were left at home and

some institutions without chance to receive an official training toward the independent living. Dr.Poonpit Amatyakul (2000) said from his clinical experience that, he found several cases of congenital deafness in the school for the deaf whom later became severe low vision, those kids had dropped and went out of school after the they could not read from the blackboard and the medical treatment were not satisfied by the patient as well as the family needs.

As a matter, of fact, several deafblind cases are commonly complicated with mental retardation and other disabilities such as microcephaly, thus, those case were kept in the back of the house or they were admitted in a lifetime institutes of people disabilities which was under the control of the government department of welfare.

Presently in Thailand, some considerable attention is being directed towards the development of educational and vocational programs and services to meet the needs of deaf people and blind people. But in the field of deafblindness (however), there has not yet been any significant development for services to children and young adults who are deafblind. There are only a few schools have provision to cater for those children as a multiple disabilities. Unfortunately, the Ministry of Education of Thailand has no record of having ever provided special educational services to students with deafblindness. Since 1989 (B.E.2532), the Hilton/Perkins Program has supported Thailand by sending teaching specialists to some schools and villages in the northeast and some institutions taking care of multiple disability in Bangkok areas. Recently, there has been some movement to develop deafblind and multihandicapped children in the northern school in Chiang Mai. And later in Lampang and Lop Buri provinces. As a

matter of fact there are very few services for children with multiple disabilities in Thailand as well as services for deafblind children and the multisensory impairment (Suwimon Udompiriyasak, 2000: 1 ).

Since Thailand is now in the beginning era of deafblind service, the researcher is interested in the study of deafblindness. First, we wanted to find out how many deafblind cases that are available for the study and where are they living at moment. Second, what are their medical, and social problems and their needs. Thirdly is concerned with the rehabilitation counseling.

With this study we hope to bring the better understanding with the deafblindness, their independent living, human rights and services for them.

### **Objectives of the Study**

For this research study, the researcher will work with the deafblind cases that can be found in some institutions where deafblindness are reported and lived in such institutes. The objective of this study are as followed:

1. Medical findings of the deafblind cases.
2. Their needs and problems.
3. The guidelines for rehabilitation counseling.

### **Scope of the Study**

1. The selected case for this study must be the registered case that defined with the law as described in the Rehabilitation of Disabled Persons Act B.E. 2534 (A.D.1991).
2. Cases will be selected from institutions (government and non-government) whom the director of the institute reported cases with problems of seeing and hearing difficulties. The institutions are among schools of special education such as schools for the blind, school for the deaf, institution of children with multiple disabilities and etc.

3. Cases in this study must be completed examined and reported by medical and paramedical specialists. They are ophthalmologist, otologist, optometrist, and audiologist (speech pathologist may be consulted in some case).

### **Definitions and Terms used in this Study**

- 1. Communication:** Any means by which an individual relates experiences, ideas, knowledge, and feelings to another, including speech, sign language, gestures, braille, and writing.
- 2. Daily living skills:** Skills that enable a person to perform routine activities necessary to live independently. An example feeding and eating, dressing, grooming and hygiene, and toileting.
- 3. Deafblindness:** Concomitant hearing and visual impairments, the combination of which can create unique communication, development, social, emotional, physical, and learning needs.
- 4. Gestures:** Movement of any part of the body to express or emphasize an idea, emotion, or function; does not include formalized symbolic methods of communication, such as fingerspelling, signed English, or American Sign Language.
- 5. IEP (Individualized Education Program):** A written plan of instruction by a transdisciplinary educational team for a child who receives special education services that includes the student's present level of educational performance, annual goals, short-term objectives, specific services needed, duration of services, evaluation, and related information.
- 6. Independent living:** Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday

activities (Frieden, Richards, Cole, & Bailey, 1979 cited in Parker & Szymanski, Eds., 1992: 103).

- 7. Night blindness:** A condition in which visual acuity is diminished at night and in dim light.
- 8. Nystagmus:** Involuntary, usually rapid, movement of the eyeball: horizontal, vertical, rotary, or mixed.
- 9. Orientation and mobility (O&M):** The field dealing with systematic techniques by which blind and visually impaired persons orient themselves to their environments and move about independently.
- 10. Problems and needs of deafblind people:** Problems and needs in daily living and service of deafblind people in 4 parts as those:
  - 10.1 Medical:** Service in medical to cure disability, rehabilitation, prevention or complication from disability, equipment or supporting machine for disabled people, and instrument disability.
  - 10.2 Education:** Service in education characteristics of department and lesson appropriate the disabled people. Although the opportunity of care get from another service etc.
  - 10.3 Vocation:** Service in practice/ rehabilitation vocation depend on department of practice vocation, characteristics of working is appropriate the disabled people, service of counseling, cost and money for working etc.
  - 10.4 Social:** Service in taking care, solving problems, daily living skills, and adaptation to other persons. Although the social accept the ability of disabled people etc.
- 1 1. The deafblind person:** Individuals, who have combined vision and hearing loss under the Law "Rehabilitation of Disabled

Persons Act B.E. 2534 (A.D.1991)".

12. **Retina:** The innermost layer of the eye, containing light-sensitive nerve cells and fibers connecting with the brain through the optic nerve.
13. **Rehabilitation institutes:** Department for rehabilitation of disabled persons about medical, education, social, and vocation. Each department may not give rehabilitation cover 4 parts as the Nakhon Pathom Special School, Ram-Intra Home of Children with Multiple Disability. Pattaya Redemptorist School for the Blind, Songkhla School for the Deaf. Anusan Suthon School for the Deaf, Tak School for the Deaf, Mukdahan School for the Deaf, and Roi Et Center of Education and Rehabilitation for the Blind.
14. **Retinitis :** an inflammation of the retina.
15. **Retinitis pigmentosa (RP):** Hereditary degeneration and atrophy of the retina. Symptoms include night blindness and progressive contraction of the visual field.
16. **Retinopathy of prematurity (ROP):** A common cause of blindness in premature infants, caused by exposure to high

concentrations of oxygen at birth and leading to retinal detachment and various degrees of vision loss.

17. **Syndrome:** A group of symptoms that together are characteristics of a specific disease (Webster's Desk Dictionary of the English Language, 1990: 909).
18. **Visual field :** The area of physical space that is visible when the body, head, and eyes are in a stationary position.

#### **Expected Outcomes**

1. The understanding of characteristic of deafblindness.
2. The understanding of severity and complication of deafblindness.
3. The understanding of problems and needs of deafblindness.
4. The use of research result as suggestion and guidelines for individuals involved in providing services and counseling for deafblind people.
5. To provide public understanding with deafblindness in Thailand.

# Home/Hospital-Bound Education in Japan – From a Survey on Home/Hospital-Bound Education

Hirofumi Osaki

Researcher, Department for Policy and Planning, National Institute of Special Education (NISE) JAPAN

**Key Word:** Home/Hospital-Bound Education. Severe and multiple disabilities.

## I. Preface

In “Home/Hospital-Bound Education education”, teachers visit homes, child welfare facilities, medical institutions etc. to provide education to children who have severe or multiple disabilities for which they cannot attend special schools (Reference 1).

Home/Hospital-Bound Education was started around 1965. In the outset, local boards of education provided this type of education by dispatching teachers to facilities for disabled children, hospitals etc. Later, upon implementation of the system to oblige disabled children to attend special schools (1979), Home/Hospital-Bound Education covering disabled children who ought to enroll in elementary and lower secondary schools came to be implemented nationwide.

The Course of Study revised in 1999 stipulated Home/Hospital-Bound Education covering disabled children enrolled in upper secondary schools. Such education covering such children came to be carried out full-scale nationwide since 2000.

As of May 1, 2004, the numbers of children enrolled in schools for the blind, deaf and other disabled children are as follows: 30,921 in elementary school departments, 21,884 in lower secondary school departments and 44,303 in upper secondary school departments for a total of 97,108. Among these, the numbers of children covered by Home/Hospital Bound education are elementary school departments

1,444, lower secondary school departments 816 and upper secondary school departments 936 for a total of 3,196 (Reference 2).

The children covered by Home/Hospital-Bound education today are not restricted to those with severe and multiple disabilities. Home/Hospital- Bound education also covers children who cannot attend schools for diverse reasons which include illnesses and home circumstances.

This paper focuses on the state of Home/Hospital-Bound Education in Japan based on the results of “Survey on Home/Hospital-Bound Education” conducted by the NISE in 2003 (Reference 3).

## II. Survey method

The “Survey on Home/Hospital-Bound Education” was conducted as follows.

From the list of association of principals of schools for the blind, deaf and other disabled children nationwide, 446 schools (including branch schools and classes) that were implementing Home/Hospital-Bound education were selected. Questionnaires (“A” and “B”) were mailed to these schools, which were asked to fill them out and return.

Questionnaire A was for schools that were implementing Home/Hospital Bound Education. Questionnaire B was for teachers who were actually providing Home/Hospital-Bound Education.

**Survey period, questionnaires returned, recovery rate**

The survey period was from January 31 to February 28, 2003, for both Questionnaires A and B.

388 schools returned Questionnaire A for a recovery rate of 87%. 1,503 teachers (who were providing Home/Hospital Bound Education) returned Questionnaire B.

The breakdown of the 388 schools that returned Questionnaire A was as follows: 197 schools for intellectually disabled children, 103 schools for physically disabled children, 49 schools for health impaired children, 34 schools for intellectually and physically disabled children, and 5 “other” schools. The survey showed that the schools for the blind and deaf were not providing Home/Hospital- Bound education. (Table 1)

**Table 1. Schools Providing Home/hospital Bound Education**

Schools for the blind	0 (0%)
Schools for the deaf	0 (0%)
Schools for intellectually disabled	197 (50.8%)
Schools for physically disabled	103 (26.5%)
Schools for health impaired	49 (12.6%)
Schools for intellectually & physically disabled	34 (8.8%)
“Other” schools	5 (1.3%)
Total	388

### III. Findings

#### 1) Number of teachers providing Home/Hospital-Bound education by gender

The findings are limited to those teachers who returned the questionnaires. With that in mind, the gender breakdown was 406 males and 1,076 females. Thus, there were more than two times more female teachers than male teachers.

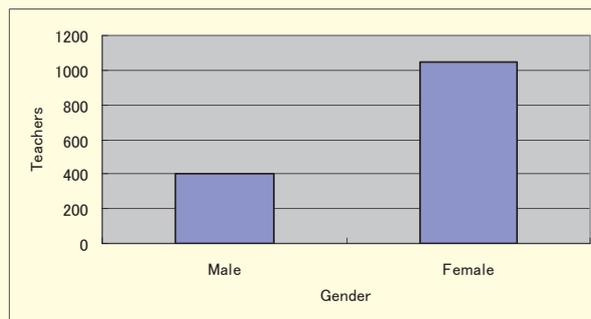


Figure 1. Number of Teachers Providing Home/Hospital-Bound Education by Gender

#### (2) Number of children under charge

1,485 teachers responded to this question (N = 1,503). This means that a teacher was in charge of an average of 2.09 children. (Figure 2)

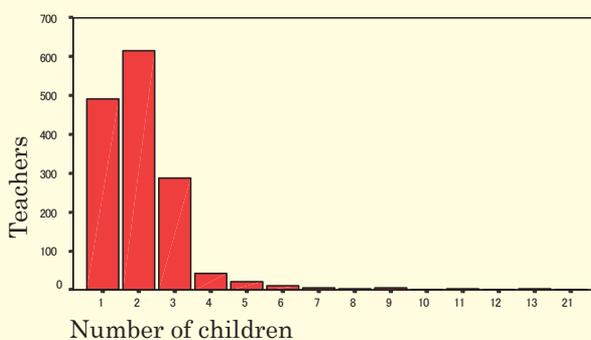


Figure 2. Number of Children per Teacher

#### 3) Places visited

1,471 teachers responded to this question. The places they visited were homes (1,490 teachers), children's facilities (812) and hospitals (594). (The total number of teachers who provided Home/Hospital Bound Education was 2,086 which exceeds the number of teachers who responded to the previous question (1,485). This is because one teacher is in charge of about two children and some teachers visited more than one places such as homes and children's facilities.)

Table 2. Places Visited, Numbers of Children and Teachers

	Department				
Place visited	Elementary	Lower secondary	Upper secondary	Total	Teachers
Homes	758	361	448	1,567	1,066
Facilities	368	215	427	1,010	614
Hospitals	316	177	39	532	406
Total	1,442	753	914	3,109	2,086

**4) Reasons why children were home-visited**

Teachers provided answers for a total of 1,855 children who were visited at their homes. The main reasons that they provided for the home visit were “Severe illnesses and disabilities” (898 children), “Require medical care” (395), “Home circumstances / parents’ request” (352) and “Can not commute / no special school nearby” (162). (Figure 3) It can be seen that teachers are often visiting homes for reasons other than children's health conditions.

that the amount was “More than appropriate” (90 teachers), “Appropriate” (1,720) and “Less than appropriate” (1,036). Thus, the survey showed that the overwhelming number of teachers felt the amount was either “Appropriate” or “Less than appropriate”. (Figure 4)

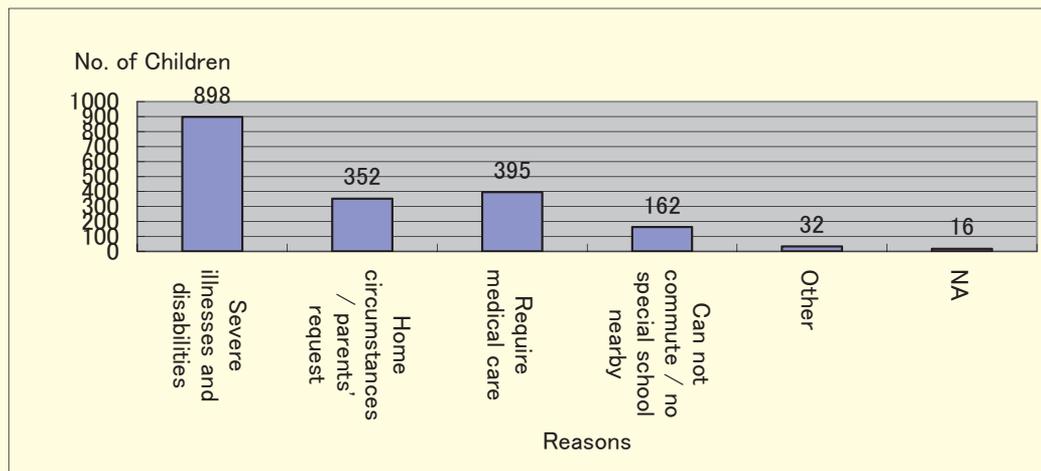


Figure 3. Reasons for Home Visit

**5) Amount of lessons**

When providing education by dispatching teachers, the Course of Study provides for prescription, if necessary, of appropriate amounts of lessons (or number of classes) in meeting with the target children’s situations. Regarding this matter, the teachers who were providing Home/Hospital-Bound education said

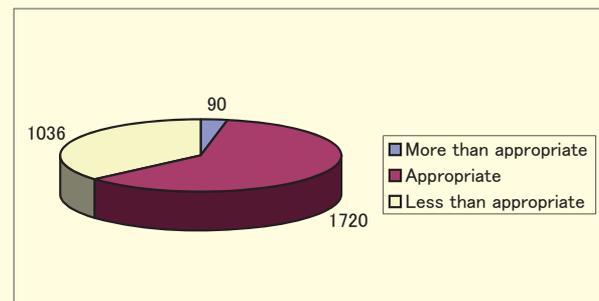


Figure 4. Is the Amount of Home/Hospital-Bound Education Appropriate for the Children?

## 6) Length (years) in charge

The questionnaire asked teachers how many years they were in charge of the children. 1,873 were in charge less than one year, 895 one year to less than three years and 177 three years or more. Hence, an overwhelming number of teachers were in charge less than one year. This is indicative of the fact that in Home/Hospital-bound education, the teachers change in one year. (Figure 5)

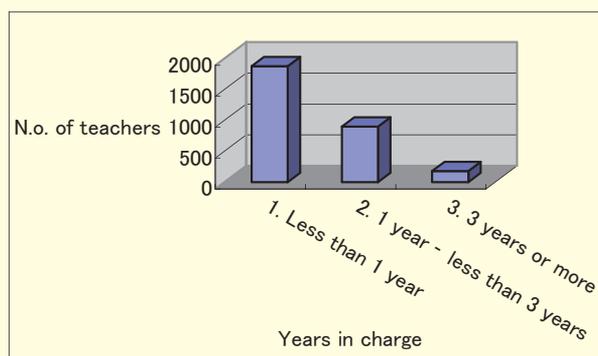


Figure 5. Length (Years) in Charge

## 7) Curriculum

The curricula covered by the children were those centered on “jiritsukatsudou(activities for independence)” (2,040 children), those corresponding to their grades (350), those corresponding to lower grades (115) and those taught at schools for intellectually disabled (160). It can be seen that in Home/Hospital-Bound education, many children are undergoing curricula centered on “jiritsukatsudou(activities for independence)”. (Figure 6)

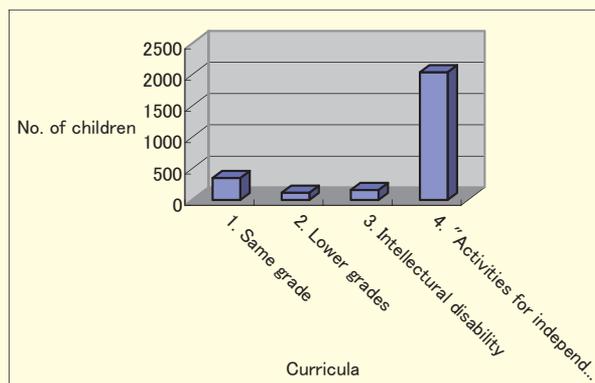


Figure 6. Curricula of Children

## 8) Problems encountered

Open answers to this question were diverse, including “Difficulty collaborating with family members”, “Children cannot stabilize the rhythm of their living, sometimes dozing off while being taught” and “Mental care for hospitalized children”.

## 9) Hopes and suggestions for better education

The open answers to this question included “Increase of opportunities for group study and real-life experiences”, “Better education by cooperating with other teachers and medical staff in the absence of parents”, “Formation of teams of teachers so that different teachers can see and think about the same children” and “Institutionalized children often spend their entire life in institutions. Provision of education of the kind that would make their life more meaningful”.

## IV. Discussion and Summary

In Japan, all children are guaranteed the right to receive education. This is so, even if the child may be severely disabled, require extended hospitalization for illnesses, or have difficulty coming to schools. (Reference 4)

Home/Hospital-Bound education is an important form of education in examining the educational systems in Japan which guarantees all children the right to receive education. Teachers of schools for the blind, deaf and other disabled children who have high expertise concerning education for children with disabilities visit and provide education to children who cannot come to schools.

In Home/Hospital-Bound education, teachers provide education by visiting places where children actually live. Such places mainly consist of homes, welfare facilities such as for severely mentally or physically

disabled children, and medical institutions such as hospitals. These are called “home bound education”, “facility bound education” and “hospital bound education” respectively.

In Home-bound education, teachers provide education by visiting the homes of children who cannot come to schools for diverse reasons. Examples include children who are not necessarily sick, but require constant medical care and attention (for instance, children who are easily infected, require suction of phlegm or rely on artificial respirators) and physically disabled children who cannot rise from their beds.

In Facility-bound education, teachers provide education by visiting welfare facilities where children are for similar reasons and cannot come to schools.

In Hospital-bound education, teachers provide education by visiting hospitals and other medical institutions where children are for diverse illnesses which sometimes include pediatric cancer.

The actual amount of lessons can be determined in accordance with the actual condition of these children. The most frequent case nationally seems to be 35 weeks a year, thrice a week, and two hours per lesson for one child.

It must be noted that it is not so easy for teachers to provide Home/Hospital-bound education.

The means of transportation available in reaching the destinations consist of public transportation systems (trains, busses and subways) and public vehicles and private cars. This poses restrictions on the type and quantity of teaching aids that teachers can bring.

On the average, one teacher is in charge of two children. To use the example of Hokkaido where I used to provide Home/Hospital-bound education, there were cases that the child to

teach in the morning and the one to teach in the afternoon lived more than 40 kilometers apart. I had to keep in mind the transportation time all the time. For instance, there was only one bus service an hour which I could not miss. Or, I prayed it wouldn't snowstorm or fog or be stuck in traffic backup.

In home bound education, teachers provide education by going into other people's homes. They must find out and respect the rules and what not of such homes. The visited families also show concern such as by cleaning the room. In addition to teaching children, teachers sometimes wind up listening to the parents and other family members who are exhausted from caring. In providing the lessons, the teacher must also think about how to effectively use the limited space of the room available.

In facility and hospital bund education, the key point is how to collaborate with the facility personnel and medical staff. It is also necessary to let them know what kind of education you are providing.

Teachers can bear with these problems and tasks. The saddest thing in providing Home/Hospital Bound Education is that teachers must sometimes face the death of their pupils, as many of the children covered by Home/Hospital-Bound education have physical problems. Children who were smiling joyously until just yesterday suddenly die. If children have pediatric cancer for instance, teachers must teach them with full knowledge that they are soon to die. In such cases, they must behave “normally” so that children wouldn't know what's coming. Very often, teachers who provide Home/Hospital-Bound education must accept the fact that even in this day and age when medicine has progressed so much, there are children who die.

Yet of course, sadness is not all that Home/Hospital-Bound education is about. Or, for that

reason, Home/Hospital-Bound education is a kind of education that is worth doing. Children do want to learn things, and if possible, to go to schools. When such children show happy faces when we visit them, perhaps such happy faces are the mental support for the teachers who provide Home/Hospital-Bound education.

The survey shed light on the state of Home/Hospital -Bound education in Japan. It also revealed many hopes and suggestions entertained and made by teachers actually providing Home/Hospital -Bound education for the betterment of such education. These hopes and suggestions show the sincere and enthusiastic feelings of the teachers about the children. I sincerely hope that such hopes and suggestions would be achieved, by starting from what can be done no matter how small they may be. Such would be to realize dreams and create better life for children.

## **References**

- (1) “Examples in Home/Hospita- Bound Education”, Special Education Division, Elementary and Secondary Education Bureau, Ministry of Education, Science and Culture, 1978.
- (2) “Materials for Special Support Education”, Special Support Education Division, Ministry of Education, Sport, Science and Technology, 2005.
- (3) Report of “Survey on Home/Hospital-Bound Education” in Japan, Department for Educational Support Research, Dept. of Education for Children with Multiple Disabilities, National Institute of Special Education, 2004.
- (4) “Home/Hospital-Bound Education in Japan” (report presented in “The Japan-OECD International workshop on the education of student with disabilities, learning, difficulties and disadvantages in OECD countries ”), Hirofumi Oosaki, 2005.