1999 Survey of the Education of Children who are Deafblind in Japan

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Abstract: The aim of the 199 survey was to investigate educational provision for children and students who are deafblind in Japan. While there is no generally accepted definition of deafblindness, this survey, as with previous NISE surveys, used the criteria of "corrected visual acuity less than, or below 0.3" and "not measurable" for blindness," and a "hearing threshold level more than, or above 30dB, or not measurable" for deafness." The term, "deafblindness" was, thus, considered to be a condition where both existed. The total number of students who are deafblind enrolled in special schools is 334, the highest proportion (28.7% or 95) at schools for the blind, 19.2% (54) at schools for the intellectually disabled, 17.7% (59) at schools for the physically disabled, and 16.1% (54) at schools for the deaf. Deafblind students were enrolled at 10% of all special schools for the intellectually disabled (51), particularly at the elementary level, 59.1% (42) of all schools for the blind, and 35.5% (38) schools for the deaf. Deafblindness was found to have a multifaceted and diverse etiology. Other than "unknown" causes, 45 cases were attributed to premature birth related to complications of pregnancy such as Asphyxia delivery, pre-eclamptic toxemia and premature labour, 42 cases were attributed to congenital rubella syndrome, 31 cases to various CNS/brain damage, and eight cases to Usher syndrome. 85% of deafblind children and students identified had multiple disabilities, in particular, a high proportion had both intellectual and physical disabilities, or either intellectual or a physical disability. Some of these students were considered to be severely disabled. The survey also found that a variety of modes of communication, mainly at the elementary level were used. It also found that the majority of deafblind students were supported by a team of teachers, although a few were taught by only one teacher. Although most schools described the physical activity programmes they undertook, and the way in which they attempted to establish good relationships between teachers and students, schools for the physically disabled and for the health impaired placed the greatest emphasis on functional rehabilitation. Overall, the survey found that educational provision for these students is inconsistent, varying from school to school. It reveals the need to provide inservice training in the education of the multi-sensory impaired, including students who are deafblind, to enhance their professional skills. NISE has a role to play in this, in terms of providing consultation and gathering information from similar educational systems overseas.

Key Words: Deafblind, Deafblind education, National survey

The 1999 national survey of children and students who are deafblind is one of a series of nationwide surveys undertaken by the Department of Education for Children with Multiple Disabilities at the National Institute of Special Education (NISE). The objectives of the survey were to investigate educational provision and teaching methodology for children and students who are deafblind, and to gather information to improve support services.

The education of children and students who are deafblind has a long history in Europe and North America and, as a result, a solid foundation for special education of the multiply disabled has been established. Education for the multiply disabled in Japan has its origins in the education of students who are deafblind. A programme for these students was established as early as the 1950s at the Yamanashi Prefectural School for the Blind (Umezu, 1974), and provided a framework for the education of children and students with multiple disabilities. Following this, children and students with multiple disabilities were educated in the compulsory school system. However, since special education in Japan has developed on the just five main categorization of disability model, each category of disability may have been counted separately in previous surveys. Whereas relatively few children and students who are deafblind are considered to have gone to special schools, no survey to report accurate numbers in all special schools has been undertaken until the present. The Department has mainly targeted schools for the blind and for the deaf in previous surveys (Tsuchiya, Nakazawa & Takasugi, 1992; Nakazawa & Takasugi, 1995). In former survey, the data of other special schools were collected. But those were considered to be unreliable due to misunderstanding among respondents about the term "deafblind." This is because the concept of deafblind was not commonly used in
special schools and indicates that the needs of these students were not being adequately met. There has been little information on how children and students who are deafblind have been treated in the Japanese educational system. Considering these issues, the 1999 nationwide survey aimed to report on the quality and degree of educational provision made for these children and students in special schools.

Some difficulties were anticipated in conducting the survey. First, as mentioned above, children and students who are deafblind are not only enrolled in different types of special schools, but also the nature of their disability as defined by the term "deafblindness" was assumed to be not widely understood. It was possible that this could have invalidated many responses due to unreliable screening in special schools. Second, there was, and still is, no internationally standardized assessment available for deafblindness, so the survey had to rely on assessment at the operational level. Third, provided that deafblindness was to be assessed on the basis of visual acuity and hearing level, it was most likely that other disabilities contributed to the overall assessment.

The survey addressed these problematic issues as follows. A brief description of deafblindness was provided in the questionnaire, further explaining possible misinterpretations and failures in judgement with paramedical screening methods. A contact address and telephone numbers were clearly indicated in the questionnaire in case respondents required further clarification. Respondents were also requested to provide personal details such as name, position held at the school and a contact telephone number in case they needed to be contacted for any clarification of their responses.

This paper reports on the educational provision of children and students who are deafblind at schools for the blind and for the deaf, and three other types of special schools. Information gathered included numbers enrolled (until now this has been unknown), degree of disability, and facilities available. The 1999 survey attempts to provide an overview of educational provision for children and students who are deafblind in Japan.

**Method**

The survey was conducted in 1998-99 school year and consisted of a preliminary survey (Stage 1) and a secondary survey (January 1999). Stage 1 aimed at identifying the numbers of students enrolled in special schools and Stage 2 collected information on the students identified in the previous stage.

**Questionnaire**

Information was collected on the following:

i. Student profile.

ii. Visual acuity and visual activity.

iii. Hearing level and hearing activity.


vi. Additional disabilities (other than deafblindness).

vii. Student curriculum.

viii. Student modes of communication.

ix. Teacher profile and educational experience.

x. Inservice training.

xi. Class management.

xii. Presence/availability of teachers who have experience in teaching children and students who are deafblind.

xiii. Cooperation with other institutions.

xiv. Activities most favoured by the student (detailed description).

xv. Difficulties judged by his/her teacher that need most work (detailed description).

xvi. Support available (detailed description).

The questionnaire as described above contains questions that are mainly concerned with the condition of the students' vision and hearing, the curriculum, educational setting and class management, the system of communication, teacher profiles, cooperation with other institutions, and educational difficulties.

**Definition of Deafblindness**

There is no generally accepted definition of the term deafblindness. However, this survey, as with previous surveys conducted by NISE, used the following criteria; measurement of "corrected visual acuity less than (below) 0.3." and not measurable for blindness, and a "hearing threshold level more than (above) 30 dB." or not measurable for deafness. The aim was to conduct a comparative study with other NISE surveys. The term deafblindness was taken to mean the condition where both disabilities coexist. As the term deafblindness was unfamiliar in the special school context, and there was a possibility of it being misunderstood as a condition that included both deafness and blindness, the 1999 survey employed the phrase "children with both visual and hearing impairment."

**Results**

**Questionnaire Return Ratio**

In Stage 1 of the survey, all schools for the deaf
and for the blind returned a completed questionnaire, and 84.1% of special schools (e.g., intellectually disabled, physically disabled, health impaired, and combined). In Stage 2, the return rate was 97.4% of schools for the blind, 92.7% of schools for the deaf, and 84.5% of special schools. Respondents beyond the scope of the survey were eliminated.

**Numbers of Deafblind Children and Students**

The numbers of deafblind children and students enrolled in special schools and kindergartens for the blind and hard of hearing is shown in Table 1a.

**Table 1a** The number of schools in which the students with DB are enrolled

<table>
<thead>
<tr>
<th>School Category</th>
<th>Institutions surveyed</th>
<th>Institutions with DB(%)*</th>
<th>Number of student with DB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blind</td>
<td>71</td>
<td>42 (59.1%)</td>
<td>96 (28.7%)</td>
</tr>
<tr>
<td>Deaf</td>
<td>107</td>
<td>38 (35.5%)</td>
<td>54 (16.1%)</td>
</tr>
<tr>
<td>Mentally Retarded</td>
<td>508</td>
<td>51 (10.0%)</td>
<td>64 (19.2%)</td>
</tr>
<tr>
<td>Physically Disabled</td>
<td>182</td>
<td>35 (19.2%)</td>
<td>59 (17.7%)</td>
</tr>
<tr>
<td>Health Impaired</td>
<td>96</td>
<td>14 (14.6%)</td>
<td>39 (11.7%)</td>
</tr>
<tr>
<td>Combined**</td>
<td>14</td>
<td>9 (64.3%)</td>
<td>22 (6.6%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>978</td>
<td>189 (19.3%)</td>
<td>334 (100%)</td>
</tr>
</tbody>
</table>

* Institution with DB / Institution surveyed
** special school for more than 2 categorized disabilities

Of 334 students identified in the total, 96 (28.7%) were enrolled at schools for the blind, 64 (19.2%) at schools for the intellectually disabled, 59 (17.7%) at schools for the physically disabled, and 54 (16.1%) at schools for the deaf. In special schools, deafblind students were enrolled at 51 schools for the intellectually disabled (10% of the total number of this type), 42 schools for the blind (59.1% of schools of this type), and at 38 schools for the deaf (35.5% of this type of school).

Table 1b shows the number of students who are deafblind by level of schooling. 145 students (43.4%) were enrolled at the elementary level (aged between six and 12), 58 (17.4%) at the lower secondary level (aged between 13 and 15), and 74 (22.2%) at the upper secondary level (aged between 16 and 18).

In summary, the survey revealed that schools for the blind had the highest numbers of students who were deafblind enrolled, followed by the elementary division of schools for the intellectually disabled.

**Visual Acuity and Hearing Levels**

To observe the distribution of visual acuity and hearing levels among students with deafblindness, analyses were conducted using the following definitions (These levels are based on a previous survey conducted by NISEB):

- Blind level visual acuity <0.01
- Low vision level visual acuity 0.01 & above
- Deaf level hearing level 100dB & above
- Hard of hearing level hearing level 30dB & above, <100dB

**Table 2** Distribution among different combinations (Unit : Number of Student)

<table>
<thead>
<tr>
<th>School Category</th>
<th>Blind</th>
<th>Low vision</th>
<th>Others</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaf</td>
<td>15</td>
<td>20</td>
<td>23</td>
<td>58</td>
</tr>
<tr>
<td>Hard of Hearing</td>
<td>62</td>
<td>18</td>
<td>33</td>
<td>113</td>
</tr>
<tr>
<td>Others</td>
<td>16</td>
<td>1</td>
<td>146</td>
<td>163</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>93</td>
<td>39</td>
<td>202</td>
<td>334</td>
</tr>
</tbody>
</table>

Table 2 shows the results of the analysis using the levels described above. Deafblindness with unknown medical aetiology, but identified as deafblind by behavioural observation, were classified as "Others (unknown or unmeasurable)." The highest distribution (62) was found at the blind plus hard of hearing level. 15 students were totally deafblind.

The number of students medically assessed with difficulties in visual acuity was 95, and 158 were assessed as having difficulties in hearing.
Table 3  Distribution of Visual Acuity and Hearing Level

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Visual Acuity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual Acuity 1 (less than 0.01)</td>
<td>22</td>
<td>23.2</td>
</tr>
<tr>
<td>Visual Acuity 2 (0.01 or more, less than 0.04)</td>
<td>14</td>
<td>14.7</td>
</tr>
<tr>
<td>Visual Acuity 3 (0.04 or more, less than 0.3)</td>
<td>59</td>
<td>62.1</td>
</tr>
<tr>
<td>Total</td>
<td>95</td>
<td>100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>b. Hearing Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing Level 1 (100dB or more)</td>
<td>28</td>
<td>17.7</td>
</tr>
<tr>
<td>Hearing Level 2 (70dB or more, less than 100dB)</td>
<td>56</td>
<td>35.4</td>
</tr>
<tr>
<td>Hearing Level 3 (50dB or more, less than 70dB)</td>
<td>72</td>
<td>45.6</td>
</tr>
<tr>
<td>Hearing Level 4 (50dB or more, less than 50dB)</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td>Total</td>
<td>158</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 3 shows the distribution of visual acuity and hearing level. As shown in the table, three levels were then applied to visual acuity in the case of Braille and printed type (Harada, 1988), and four levels to hearing in the use of hearing aids (Washio, 1996). The highest of the visual acuity levels was 59 cases in visual acuity 3 (0.04 or >0.04; <0.3). The highest of the hearing levels was 72 cases in hearing level 2 (50dB or >50dB; <70dB). In terms of type, there were 167 hard of hearing and sensori-neuronal hearing loss cases who replied “unknown” (94% of the total).

Visual field loss and night blindness was also investigated. 13 students were reported to have visual field loss, 67 no visual field loss, and 273 "unknown". 14 students had night blindness, 53 no night blindness and 286 "unknown." Many students (70-80%) were reported as "unknown" in both conditions. It is suggested that this is a very high ratio and clearly indicates that standard assessment methods for visual field loss and night blindness are not yet widely recognized in Japan.

Those students who had visual field loss and night blindness were also likely to have retinitis pigmentosa, and some of those with hereditary deafblindness were likely to have Usher syndrome. It is, therefore, of critical importance that these assessments are used more widely in the field of special education in Japan.

Aetiology of Impairment

Among the responses concerning the aetiology of visual and hearing impairment, 162 cases (45.9%) answered "unknown." One of the causes specified was premature birth (45 cases), related to complications of pregnancy (viz., Asphyxia delivery, pre-eclamptic toxemia and premature labour). 42 cases related to rubella were reported, 31 cases of a range of CNS injury, and eight cases of Usher syndrome. In addition, there were a number of unspecified causes indicating that the aetiology of deafblindness is multifaceted.

The aetiology of cases with both deafness and blindness and where there was more than one case is as follows:

- CHARGE syndrome 10
- Cokayne's syndrome 5
- Down syndrome 3
- Cytomegalovirus 2
- 4P monosomy 2
- Mirror Deck syndrome 2
- Cornelia de Lange syndrome 2
- Other aetiologies Unspecified

Impairments other than Deafblindness

Impairments other than deafblindness are shown in Table 4. Additional impairments were reported in 85% of students who were deafblind in the survey. A high proportion of students had both intellectual and physical disability, with fewer students with either intellectual disability only, or physical disability only.

Educational Provision

Table 5 shows the educational service provision for students who are deafblind in all types of special schools in Japan.

220 respondents answered "interaction with another person," 196 answered "enjoying movement activity," 137 answered "self help," 106 answered "functional re-

Table 4  Additional Disabilities of Students with DB

<table>
<thead>
<tr>
<th>Additional Disabilities</th>
<th>Blind</th>
<th>Deaf</th>
<th>Intellectually Disabled</th>
<th>Physically Disabled</th>
<th>Health Impaired</th>
<th>Combined*</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>35</td>
<td>17</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mental Retardation</td>
<td>29</td>
<td>22</td>
<td>20</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Multiple Disability**</td>
<td>22</td>
<td>18</td>
<td>44</td>
<td>52</td>
<td>36</td>
<td>17</td>
</tr>
</tbody>
</table>

* special school for more than 2 categorized disabilities
** Mental Retardation + Physical Disability (+ Other Disabilities)
habilitation," 86 answered "exploration," and 54 answered "academic subjects." Most schools responded to "interaction with another person" and "enjoying movement activity."

However, "vocational training" had a higher response rate in schools for the blind. It is suggested that schools for the blind in Japan have traditionally provided vocational training courses for traditional Japanese massage, acupuncture, and moxibustion, and have been functioning as vocational training centres for the blind.

**Communication System**

Communication is considered to be a most important feature for students who are deafblind. Modes used by the students to communicate with teachers-in-charge and those by teachers-in-charge to communicate with their students were determined using a multiple-choice questionnaire (see Table 6a).

210 (43.5%) deafblind students used the communication system of gross signs (e.g., touch, cry, and objects), 68 used gesture, and 62 voice. 223 (32.6%) teachers-in-charge used gross signs (e.g., touch, cry, and objects). 153 (22.3%) used voice, and 90 (13.1%) used gesture. With the exception of finger Braille, teachers-in-charge initiated more communication and used a wider variety of receptive than expressive methods. This indicates that, with the exception of communicating modes of an initial level of such as physical contact and pointing to objects, a diverse range of communicating modes were used both by students who are deafblind and by teachers-in-charge. A considerable number of respondents said they used more than one mode of communication.

Table 6b shows the total number of each mode of
communication chosen in the questionnaire. More than half of the total number of cases used combined communication modes. More than one mode was used by teachers-in-charge of the deafblind.

**Student-Teacher Ratio**

Table 7 shows the numbers of teachers assigned to take charge of children and students who are deafblind for different school types.

195 respondents answered "a teacher is assigned and other teachers are also involved." 81 answered that "a teacher is assigned in principle," and 42 replied that "several teachers are assigned, and other teachers have no involvement." Nine respondents answered "other" describing, for example, that "all teachers are involved," or "no teacher is assigned."

These results suggest that in the majority of cases one teacher is assigned to take charge of a student, and only 15% answered that "no teacher is assigned." In addition, more than 50% of each type of special school, with the exception of schools for the health impaired, answered that "a teacher is assigned, and other teachers are also involved." On the other hand, 43.6% of teachers at schools for the health impaired answered that "a teacher is assigned in principle," which was the highest proportion of all items among different types of special schools. The proportion of "a teacher is assigned, and other teachers are also involved," was more than twice that of "a teacher is assigned in principle," at schools for the blind, for the deaf and for the intellectually disabled.

**Teachers-in-charge and Inservice Training**

The period in which a teacher is "in charge" ranged from 0 to 15 years. The highest proportion was 139 (47.7%) who answered "being in charge for the first time - 0 years." This was followed by "for one year," and then "for two years."

The ratio of respondents less than two years was 89.1%. This indicates that a teacher is generally in charge from one to two years and it is unusual for teachers to be in charge longer than three years. 58 of 289 cases answered "no experience - 0 years," to the question whether or not they had had any prior experience in the special education of children or students with multiple disabilities. It was found that years of experience in this category ranged from 0.1 to 29.0 years. The highest number of years of experience (50) taught at schools for the physically disabled, 46 at schools for the blind, 45 at schools for the intellectually disabled, 36 at schools for the deaf, and 24 at schools for the health impaired. 18 respondents taught at other types of special schools with a combined curriculum for more than two categories of disabilities.

The question also asked whether or not teachers had any specific training for communicating with the deafblind. 61(18%) of 339 respondents answered "yes," 256 answered "no," and 22 replied "other." Comparison by type of school found that 16 schools for the deaf, 14 schools for the physically disabled and 10 schools for the blind provided inservice training. Concerning the ideal model of teacher inservice training, 97 respondents answered "visits to schools and other institutions for the deafblind," and 95 answered "inservice training dealing with the communication system." Other answers focussed more on individual students such as "training in the use of educational materials and learning aids," and "seminars and discussions with specialists at work." This outnumbered items such as "lectures by specialists," "training at specialized institutions," and "talking with other deafblind people."

**Discussion**

The 1999 national survey identified the number of deafblind students enrolled at special schools in Japan and collected information on the educational provision and educational setting of these students. It also identified 334 students who were deafblind at
special schools and found that, although schools for the blind had the highest number of these students, schools for the intellectually disabled and for the physically disabled also had high numbers.

The visual acuity and hearing levels of deafblind students were in a wide range and many students (85%) were multiply disabled. It was also found that both the degree of and level of disability were diverse. It was found that there were a variety of communication modes, and most students were on basic level of communication. Concerning the degree and level of disability, some students were categorized a "(very) severely and profoundly disabled."

In many cases, a deafblind student was placed under the care of a teacher-in-charge with support from other teachers. However, there were also a few cases in which a student was cared for by only one teacher. Although most schools reported on the kind of physical activities they engaged in and how they attempted to build a good relationship with their students, schools for the physically impaired and for the health impaired were found to have placed greater emphasis on functional rehabilitation. Further, it was found that educational provision varies from school-to-school.

From these findings, it has become dearer that the deafblind are likely to have disabilities, other than deafblindness, and to be cared for by a single teacher-in-charge with the support of other teachers with the aim of establishing communication. On the other hand, it is also the case that many students experience differing levels of educational provision and are placed in various educational settings. This leads to differences in actual service provision.

It was found that teachers rarely take charge of a particular student for more than three years, and in most cases, ceased to care for the child after periods ranging from one to two years. This arrangement is considered to be problematic, especially for those students with only basic communication skills since one of the primary objectives of this form of special education is to establish communication. In the survey, it was also found that only 18% of respondents had any inservice training dealing with modes of communication. There is no system of pre-service or inservice training available for teachers of students who are deafblind, but it was found that there was a demand for such training, especially in the form of visits to other institutions and for learning modes of communication.

It is believed that it is important to provide teachers with inservice training in the education of the multi-sensory impaired, including deafblindness to enhance knowledge in the field, to develop links with related fields, to increase knowledge and experience, and to improve teaching skills. In this, the Department of Education for Children with Multiple Disabilities (NISE) is available to provide specialized support and consultation. It is considered vital that a solid foundation should be laid for a teacher-training scheme, and also it is considered essential that we learn from models operating in other countries and broaden the base of cooperation between schools.

References


