

# EARLY INTERVENTION OF THE BLIND AND VISUALLY IMPAIRED CHILDREN AND THEIR FAMILIES: A SLOVENIAN CASE

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**Abstract:** *This article is concerned with the problems of early intervention services in Slovenia. From the year 2000 onwards, also blind and visually impaired Slovenian children have legal basis for wider possibilities for integrated forms of education. The problem is that they formally still do not receive any kind of intervention by the special education teacher for visually impaired. The first step towards enabling equal opportunities for blind and visually impaired children and their families is thus in enabling their full early intervention, at which also special education teacher, qualified for work with the youngest blind and visually impaired children, will participate.*

**Keywords:** *early intervention, blind and visually impaired children, families, equal opportunities*

## INTRODUCTION

### 1.1. Definition of early intervention

Preschool period of a child's life is a decisive factor for his/her further development, for biological, physical, cognitive, and social development as well as for personality development (Hatwell, 1985; Leclerc et al., 2000; Vasta, Haith, & Scott, 1995; Warren, 1984, 1994). Almost all researches show clearly in each case the importance of this early period for the child's quality of life (Harris, 2008). A child with special needs requires a whole set of additional incentives in order to gradually compensate for his/her shortcoming from the time of birth onwards. Researches (Alexander, 1996; Beaty, 1991; Bigelow, 1995; Rodriguez, Sabucedo, & Arce, 1995) also warn that positive self-concept, which a child is developing from the earliest childhood onwards, is the very factor that is the most decisive on how a child will embrace his/her difference and live with it.

In 2005, *The European Agency for Development in Special Needs Education* (11) adopted the defi-

nition of early intervention that was the result of findings of different authors (Guralnick, 2001; Soriano, 2005). In this document, it is stated that early intervention is a set of services of different professions, intended to very young children and their parents. The services are available to the families at their request, that is, when they need them, and they encompass every type of help connected to special needs of a child. The intention of an early intervention is ensuring undisturbed personality development of children, empowerment of a family and social integration of children and their families into a wider social context.

### 1.2. The goal of early intervention of blind and visually impaired children and their families

According to the literature (Brambring, 1996), up until eighties there has been a lack of scientific knowledge about the impact of congenital blindness on early development. Researchers assumed that there were at least three reasons for that: (1) low incidence rates, (2) problem of access to young blind children, and (3) use of inadequate assess-

ment procedures (Koestler, 1976; Warren, 1984; 1994). Later on, research has become more precise (Brambring, 1996; Buultjens, 2002; Chen, 1999; Dote-Kwan, & Hughes; 1994; Dote-Kwan, Chen, & Hughes, 2001; Leyser, & Heinze, 2001; Rock, Head, Bradley, Whiteside, & Brisby, 1994), and in nineties, some excellent manuals for early intervention of blind and visually impaired children were published (Ferrell, 1994; 1996a; 1996b; Holbrook, 1996; Morgan, 1995; Pogrund, & Fazzi, 2002).

Early intervention of blind and visually impaired children and their families is a systematic interdisciplinary team and professional support to the blind or visually impaired child from the time of birth to the time he/she goes to school, and to his/her family (Brown, Simmons, & Methvin, 1991; Pogrund, & Fazzi, 2002; ). It is intended for a blind or visually impaired child and his/her family to get included into the narrow and wider social environment as equally and competitively as possible (Schneekloth, 1989; Skellenger & Hill, 1994; Troster & Brambring, 1994). It represents the first step on the path to inclusion, which signifies ensuring equal opportunities for the blind and visually impaired in education, at work, in partnership and life in general (Bishop, 1996; Kekelis, Sacks, 1988; MacCuspie, 1992; 1996 ).

Researches from the field of paediatrics and psychology (Bailey & Powell, 2005; Bruder, 2005; Guralnick, 2005a, 2005b) show that professional support received by children with special needs in the early period of their life as well as by their parents is fundamental for their later inclusion into social environment. Full early intervention of children with special needs and their families provides conditions for accomplishing the following goals:

- a) Children and their parents enjoy qualitative support,
- b) Institutions and experts act coherently and coordinated,
- c) Families are given a profound insight into the child's special needs, and
- d) Families acquire support, knowledge, and strategies for tackling their own individual needs.

Consequently, the families that enjoy full early intervention have bigger possibilities for establish-

ing and maintaining the quality of life and psychological well-being, while health and psychophysical development of their children progress.

Early intervention of the blind and visually impaired children should start immediately after birth of the child or immediately when risk factors are discovered, respectively (Ferrell, 2000; Ferrell, Shaw, & Dietz, 1998). In relation to the child's needs and his/her personality, different experts take part in early intervention: paediatricians, physiotherapists, play therapists, speech therapists, nurses, special education teachers, social workers etc. (Huebner, Merk-Adam, Stryker, & Wolffe, 2004) Early intervention is based on an integrated approach to the child and does not divide him/her into medical, psychological, social, pedagogical part etc. (Chen, 1999). In the European Union and the USA, the profile of the so-called care coordinator is established for early intervention, which takes care of an uninterrupted flow of implementation of early intervention and appropriate support to the child and parent. His/her post of employment is located either at certain departments in paediatric clinics or at the centres for early intervention, and it is financed by the state Ministry of Health and local communities (Gilliam, Meisels, & Mayes, 2005). In his /her basic education, he/she can be a physician, a certified teacher of the visually impaired, or a psychologist. It has to be emphasized that at early intervention, as soon as there is a suspicion of vision impairment, the key role is played by special education teacher for visually impaired. On the one hand, he/she teaches parents of efficient communication with blind or visually impaired children, and on the other hand, he/she works intensively on the integrated development of the child: in the field of cognitive development, gross and fine motor skills, speech, social development, self-concept development, on development of compensatory skills and efficient development of possible sight remained.

Early intervention is not intended for professional support and empowerment of the child only, but also for his/her entire family, since the child is a part of the latter. The parents are also in need of suitable professional help and support, since they find themselves in a new, unexpected role, at which they need professional guidance (Soriano, 2005). The necessary support is usually provided by experts

who take part in full intervention of a child, and psychologists or psychiatrists – psychotherapists, who see to mental health or psychological well-being of parents, especially the mother. Researches (Moore, 1984; van Doesum, 2007; van Doesum, Hosman, Riksen-Walraven, & Hoefnagels, 2007; Warren, 1984; 1994) from the field of interaction between the mother and the child with severe visual impairment namely show that negative mood, especially depression of mothers, that comes about as a consequence of the child's discovered blindness, can strongly inhibit the qualitative psychosocial development of the child, lead to inappropriate forms of attachment between the mother and the child and deepen retracting of a child into his/her own world, which can lead to different forms of anti-social behaviour, deficiency in development of the child's cognitive, motor and verbal functions. Personality disorders can also appear. Even an excellent professional support, that the child would later enjoy, cannot substitute for deficiencies that he/she experienced in his/her early period of life, as a whole set of secondary and tertiary health, psychological and social impairments is attached to his/her primary impairment.

Since ophthalmologist is usually the one who has to communicate to the parents the news on blindness of their child, abroad a lot of attention is given to the very education of paediatricians – ophthalmologists and other medical staff in the field of communication, interpersonal relationships and empathy development towards the child's parents and their siblings (Buckman, 1992; Dickinson, Huels, & Murphy, 1983; Dube et al., 2003; Maguire, 1997).

Certified teacher of the visually impaired teaches parents effective ways of communication with their blind or visually impaired child and advises them on creation of physical, psychological, and social conditions that will enable to the child the most positive incentives from the outside world. A psychologist with intensive knowledge from the field of motivation of incentives offers the parents the opportunity to give meaning to this type of incentives for optimal development of their blind or visually impaired child (Ferrell, 1994; 1996a; 1996b).

Indispensable is also the social support network, that the families with a blind or visually impaired

child weave from their family outwards, among relations, friends, colleagues and superiors at their post of employment, and later also representatives of pedagogic and educational institutions to which that their child is going to be entrusted. An important role is played also by the so-called self-help groups.

In addition, the siblings of visually impaired child are in need of help and support (McHugh, 2003) that is in the first place provided by their parents. This fact thus only certifies the finding that appropriate full early intervention is only the one that offers help, support, and empowerment of all family members: the child with special needs, father, mother and brother/s and sister/s. When grandparents or other relations of the child with special needs are at least partly involved in education, also they should be included in full early intervention (Chapius, 2000).

In many authors' opinion (Guralnick, 1997; Nicaise, 2000), early intervention is crucial also from the point of prevention of further possible social and economic exclusion of children and later adults with special needs.

On the basis of stated above, it is unequivocal that the full early intervention of all family members is the most urgent approach to a blind or visually impaired child and his/her family. However, in order to actually contribute to optimal psycho-physical development of the child and to establishment of psychological well-being of his/her family members, constant, continual and consistent interdisciplinary cooperation of all experts that work on intervention and equal inclusion of parents to team work is needed.

### **1.3. Early intervention in the world – emphasis on teamwork**

#### **1.3.1. The USA**

Most of democratic countries also have a regulatory decree on implementation of full early intervention. In the USA, for example, an exact individual and later individualized approach to a child and his family is stipulated by law. The Act on full early intervention adopted in 1984 (Bailey & Powell, 2005) enabled support to children as well as their parents and emphasized the main reasons for its implementation:

- a) child: encouragement of the development of infants and toddlers with special needs in order to decrease their potential developmental setback,
- b) financial cost: reducing the cost of their upbringing and education, paid by the taxpayers; with effective early intervention the cost of special education and similar activities are being reduced when these children reach the age for going to school; the costs of maintaining positions of employment in closed institutions get reduced, since the need of this staff is lessened,
- c) The policy of independent life: the necessity for institutionalization of persons with special needs is reduced,
- d) Family: the capability of a family in facing special needs of a family member is increased and,
- e) The state and local communities: the capability of state and local communities and services that enable recognition, evaluation and the needs of children with special needs get increased (IDEA, 1997).

### **1.3.2. European countries**

In 2005, "The European Agency for Development in Special Needs Education" published on its website the findings of the project Full Early Intervention. The research encompassed 18 European countries, namely: Austria, Check Republic, Denmark, Estonia, Finland, France, Greece, Iceland, Latvia, Luxemburg, Germany (Bavaria), the Netherlands, Norway, Portugal, Spain, Sweden, Switzerland and the UK. All the countries mentioned above have regulatory adjusted full early intervention. Its basic mutual characteristics are:

- a) Availability: full early intervention is available to the children and their parents as early as possible,
- b) Proximity – near to a place: full early intervention is being carried out in close proximity of the child's / family's home, that is, in basic environment of the user,
- c) Proximity – near to a person: full early intervention is adjusted to the user's actual needs and desires,
- d) Interdisciplinary working: full early inter-

vention is based on interdisciplinary work of various experts,

- e) Diversity of services: full early intervention includes various services, especially health, social and educational.

Systematic arrangement and implementation of full early intervention, of course, varies from country to country. One of the fundamental differences concerns the person providing implementation of early intervention. Mostly early intervention is being carried out by special centres for full early intervention, with the exception of some Nordic countries, where full early intervention is organized on a local level, as cooperation of health, social and educational institutions.

Unlike North America, where full early intervention is intended for children from zero to three years of age and their families, in most European countries the intervention is intended for parents and children immediately after birth until they enter the education system, which in most countries means until they enter the compulsory education system.

### **1.4. Individual family service plan**

All the countries observed have in common the fact that full early intervention is based on formation of individual family service plan which is formed on the basis of estimation of condition and needs on the part of parents and experts. The purpose of individual service plan is to provide the kind of intervention and support to children and their families that match their individual needs (Bruder, 2005). Individual family service plan needs to be changed all the time, evaluated and changed if necessary or adopted to newly formed situations.

The fundamental characteristic of the plan is establishment and evaluation of needs, whereat it is crucial that evaluation is considered a process and not a final condition. The picture below displays the main characteristics of evaluation as a process. The first phase, of course, is detection and diagnosis of the child's obstacles, deficiencies, or disturbances, followed by an evaluation of special needs and advantages that the experts identify upon proper diagnosis. When the children

with visual impairment are concerned, the team of experts, coordinated by paediatricians, physiotherapists, play therapists, psychologists and teachers of the visually impaired, form goals that the child and his/her family should accomplish, they plan the development of full early intervention, define forms of help and evaluate and supplement individual plan.

The basic principle of teamwork in formation, implementation, and evaluation of family service plan is that the child's family gets included into the team as an equal partner. In order for the experts to appropriately implement the full early intervention, they have to, irrespective of their elementary professional education, acquire additional specific skills. Education is carried out on three levels:

- a) The basic initial training is intended to all professionally involved in implementation of early intervention. The experts are acquainted with fundamental topics from the field of health, social work, psychology, upbringing, and education, with special emphasis on topics of work with families, teamwork, and details on child development.
- b) Additional further training is intended for intensive study of full early intervention and is implemented in the form of post-graduate study (specialist training and/or master's study) of various universities and supplementary seminars that are organized by the centres for full early intervention.
- c) Constant professional improvement in the form of intervention and supervision groups that enable the experts to exchange experience and upgrade their own work.

To serve as an example is one of the Italian centres for full early intervention of blind and visually impaired children (*Early Intervention Centre for Visually Impaired Children*, Cannero Riviera, Italy), that provide intervention for children from their birth until they reach 4 years of age. The child with their parents (or one of them) is staying continuously at the centre for two or three weeks and they all enjoy various treatments – the parents receive psychological and social counselling, and the children are given physiotherapy, occupational therapy, musical therapy, therapy with domestic animals, vision stimulation, physiotherapy in water,

facial therapy etc. After the arrival, the therapists are in constant contact with the family and they cooperate with the experts that intervene with the child in his/her home environment, and upon joint audit, the families return to the centres in a certain period of time if they wish. The centre also has an extensive library with texts in three languages that the parents and experts can borrow for free. Otherwise, also the children (and parents) are provided with intervention free of charge. Partly it is covered by the state and partly by various donor groups (Goergen, 2000).

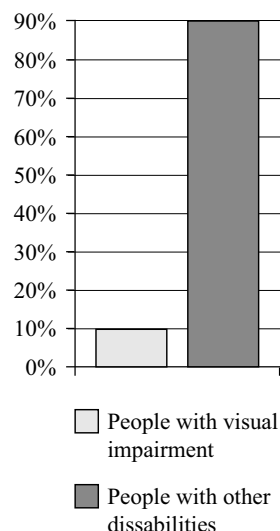
Another country that is already partly implementing full early intervention and is significantly ahead of legal decree is Croatia. In 2004, at the invitation of the centre »Mala kuća« in Zagreb, we, in the framework of the Slovenian Association of the Blind and Visually Impaired, together with the parents and experts, took a look of their activities that are being implemented with blind and visually impaired children and with children with supplementary impairments. Around 15 experts are employed at the centre, mostly special education teachers – certified teachers of the visually impaired, physiotherapists, play therapists, musical therapist, artistic therapists and other less professional workers, and they intend to employ a psychologist. There are also others, performing contractual work (doctors, hypotherapists, nurses, teachers etc.). After many years of successful work, among which we can mention the achievement that a blind child without additional disturbances, who is treated at their centre, at the age of three becomes capable of such independent coordination and orientation and manages everyday tasks in connection with self regulation, that with sufficient support he/she can join the regular kindergarten equally in the group of children who see.

## 1.5. Where is Slovenia

### *Statistical facts*

As in many other countries, also in Slovenia, the percentage of visually impaired people is lower in comparison to percentages of people with other disabilities. Figure 1 shows that only 10 percentages of people with disabilities in Slovenia are visually impaired.

**Figure 1.** Percentage of people with visual impairments.



**Figure 2.** Percentages of members of the Union of the Blind and Partially Sighted in Slovenia (2008).

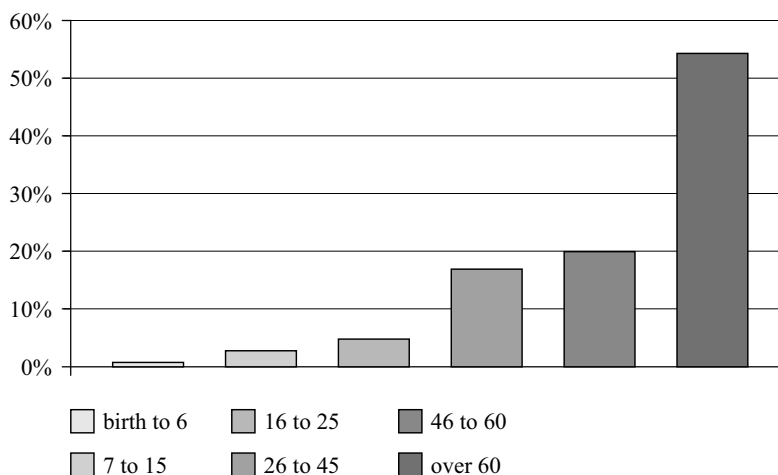


Figure 2 shows the distribution of members of Union of the blind and partially sighted as related to age. It could be seen that the youngest children represent the smallest group among members.

According to unofficial data, there are approximately 5 children with visual impairment under the age of three.

**Absence of early intervention services**

There is no early intervention services for the blind and visually impaired children and their families in Slovenia. Since 2000 onwards, when the Placement of Children with Special Needs Act was adopted in Slovenia (Official Gazette RS 54/2000), also blind and visually impaired children have had legal basis for wider possibilities for integrated forms of education. No attention is being paid to the youngest, and the ones from three to six years of age are not given enough attention. The youngest children (and not also their parents and other family members) are only addressed in Health Care and Health Insurance Act (Official Gazette RS 9/1992), under which they enjoy only basic health services in the framework of developmental infirmaries, if the latter exist in individual towns and if health workers who are trained and prepared to treat the blind or visually impaired child are employed there. Among them, there is

no certified teacher of the visually impaired. That means that Slovenian legislation still ignores the research findings that show how important is early intervention for blind and visually impaired children and their parents (Brambring, 1996; Rock et al., 1994; van Doesum et al., 2007; Warren, 1984; 1994). Košiček, Kobetić, Stančić and Joković Oreb (2009) explain that also in Croatia, there are no legislative rules for early intervention.

The only institution in Slovenia that employs teachers of the visually impaired, respectively, namely Institute for the blind and visually impaired youth, treats systematically only those children who are placed under Placement of Children with Special Needs Act, that is, children that are already visiting a kindergarten or school. It does not formally deal with younger children. Unlike some other institutes, the founder and financer of Slovenian Association of the Blind and Visually Impaired is the Ministry of Education and Sport of the RS only, and not also the Ministry of Health of the RS that should provide conditions for systematic early intervention of the blind and visually impaired children. The Ministry of Health of the RS (or any other Ministry) does not provide support of a certified teacher of the visually impaired to the youngest blind or visually impaired children, not even in the framework of developmental

infirmaries, paediatric clinic, or elsewhere. In other words: blind and visually impaired Slovenian children grow without a support of a certified teacher of the visually impaired, and the parents are left to themselves. They raise their children mainly with the help of manuals, internet resources and advices from other parents of blind and visually impaired children, and some take them to Odilien-Institute (*Odilien Institut für sehbehinderte end blinde Mensch*) in Graz that for Austrian citizens has been dealing with full early intervention of children and their families for an entire decade.

## 2. CONCLUSIONS AND PROPOSALS

### 2.1. Attempts at filling the gaps

Ten years after adoption of the stated act and after the accession of Slovenia to the European Union, which demands adaptation to certain standards, the experts and users have found ourselves before an important task, which demands from us:

- a) Critical reflexion of real implementation of legal stipulations, effectiveness of integration on all levels of performance (from helping parents, children, operation of commissions for placement, preparation and implementation of individualized programme, to evaluation of minimal standards that were set years ago for integration, quality of integration monitoring etc.) and critical review of implementing regulations that were adopted ex-post in order to reach the realization of the act as soon as possible (Arnkil, 2003; Bairrão, Felgueiras, Chaves De Almeida, 1999; Dote-Kwan, & Hughes, 1994).. This evaluation has to, however, be based exclusively on professional basis and consideration of a new, modern and democratic definition of children with special needs (The European Agency for Development in Special Needs Education; UNESCO, 1997).
- b) Modernization, audit and supplementation to a qualitative integration and inclusion, that we are acquiring with the help of the reflexive analysis mentioned above and with the help of cooperation and equal consideration of parents as well as users of the

given system. The foundation of the entire modernization of our practice has to; however, derive out of the child's needs.

According to unofficial data from 2007, there are approximately five non-placed children with more severe visual impediments, who are younger than three years (Figure 2). Although the number is very low, after performed diagnosis procedure and possible treatment, only health workers in the framework of developmental infirmaries, certified teachers of the visually impaired excluded, deal with them. This fact shows extreme neglect of the youngest blind and visually impaired children, who are deprived of equal chances of development from the earliest period onwards. Blind and visually impaired children from their birth until they reach three years of age are entirely neglected by the state, professionally and educationally, since they do not enjoy any kind of special and professional support of a certified teacher of the visually impaired, and their parents are left to rely on their own "common sense" upbringing styles (Kobal Grum, & Kobal, 2009).

Through associations of the blind and visually impaired, twice a year a few days' seminar is organized for families with blind and visually impaired preschool children and children who have, in addition to vision impairment, also additional impairments in physical and/or mental development. Naturally, for full early intervention of children and families this is not merely enough.

### 2.2. The need of systematically provided full early intervention of blind and visually impaired children and their families

Representatives of various professions, civil society, and parents have been striving for a long time for the blind and visually impaired children and their family members in Slovenia to systematically provide full early intervention. For this purpose, many meetings and consultations have been held. Among more resounding responses of the Ministry of Health, that should be, modelled on the European Union, the holder of systematic full early intervention of children with special needs and their families (Letter, 2006), the interpretation of Article 23 on health care and health insurance is worth mentioning:

“...Article 23 of the Health Care and Health Insurance Act under Item 1 of the first paragraph stipulates that with compulsory health insurance, the persons insured are assured payment of health services entirely (100%), namely in cases stated under the 13 paragraphs. Among others, the third paragraph stipulates that treatment and rehabilitation of children, pupils and students, who go through mainstream schooling, and children and youngsters with physical or mental handicap is provided (paid) entirely from the funds of compulsory health insurance. This means that these children and youngsters are, among others, provided also with full early intervention. More precise scope of all rights, assured to persons insured, among them also to children and youngsters with handicap in physical or mental development is stipulated by Compulsory health insurance rules (Official Gazette RS 30/2003), adopted upon agreement by the Minister of Health, by Health Insurance Institute of Slovenia. In addition to the stated, the stated persons insured also have ensured additional treatment, stipulated by the Instructions for the implementation of preventive health protection at the primary level (Official Gazette RS, 19/1998), issued by the Minister of Health. With the mentioned instructions, additional treatment of behavioral and developmentally handicapped children is stipulated, namely in the form of systematic preventive monitoring of a child with developmental or behavioural disorder, the purpose of which is full intervention of a child, adjusted health and educational work, as well as close cooperation with the family of the affected and with educational institutions and associations. This, namely, is the condition for reaching common goal – to provide the child with expert training for life and work in the community they reside (p. 1-2)”.

This is how the issue of full early intervention of the blind and visually impaired children and their families is back again, where it started from: at the very beginning. Official interpretation of full early intervention of children and their families namely is still rooted in outlived views, where:

- It regards early intervention of children as one-sided and imposes all responsibility for intervention to health care staff only. Here, it

interprets the medical model of approach to a child with special needs insufficiently and does not take into consideration his/her fundamental bases that the gravity and severity of vision impairment are proportional with the scope and interdisciplinarity of professional support (Guralnick, 1997; 2001; Shonkoff, & Meisels, 2000).

- It primarily provides health care for the child only, and only presupposes cooperation with the family, whereat it specifies neither form nor content of cooperation
- It merely presupposes and recommends cooperation with educational institutions; however, also in this case it specifies neither form nor content of such a close cooperation. Concretely in case of support of a certified teacher of the visually impaired, the latter is not in any case systematically ensured in 2008.

According to the reserach (Chen, 1999; Crane, & Cuthbertson, 1997). ), it seems that the individual family service plan, when the blind and visually impaired children are in question, operates in Slovenia on the first level only, that is, on early discovery and diagnosis of their visual impairment. Already at the beginning of the next level, when the child's specific needs have to be specified and recognized, and his/her shortcomings and advantages established, where also psychologists and special pedagogues are involved, the individual plan of help for the child gets concluded. In case of intervention of parents or families of a blind or visually impaired child, the individual family service plan is not even specified, much less in implementation. That is why an interdisciplinary group of experts for early intervention of blind and visually impaired children and their families should be formed, that would approach each blind and visually impaired child and his/her family in coordinated, efficient and individualized way, and with its systematic approach enable successful preparations for transition to various institutionalized forms of education. To begin with, two will suffice: (a) immediate and constant support of a certified teacher of the visually impaired, (b) to the child and parents and psychological support to parents.



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