



Deafblindness



National Institute for Empowerment of Persons with Multiple
Disabilities [NIEPMD]

(Department of Disability Affairs, Ministry of Social Justice & Empowerment, Govt. of India)

BOOK ON DEAFBLINDNESS

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सुदर्शन भगत
SUDARSHAN BHAGAT



सामाजिक न्याय और अधिकारिता राज्य मंत्री
भारत सरकार

MINISTER OF STATE FOR
SOCIAL JUSTICE & EMPOWERMENT
GOVERNMENT OF INDIA

MESSAGE

"The scholar of the new world absorbs all the resources of his time the heritage of the past and hopes of the future".

This saying of Emerson, beckons the learners to equip themselves especially the knowledge pertaining to the Deaf Blindness (Dual Sensory Impairment).

I am immensely pleased to learn that this resource book brings about information on various aspects such as the understanding of Deaf Blindness, its cause, approaches, strategies for intervention for all age range i.e. from early intervention and vocational guidance based upon the needs of the person with Deaf Blind.

I greatly appreciate Director and her team at NIEPMD for venturing into an area that is very challenging.

I wish them great success.

(Sudarshan Bhagat)

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MESSAGE

Empowerment of Persons with Disability is always a challenge even when it is a single disability but in a person having multiple disabilities like Deafblindness the challenge is exponential. The National Institute for Empowerment of Persons with Multiple Disabilities has been actively endeavouring empowerment of Persons with Multiple Disabilities since 2005.

The queries from parents & persons with Deafblindness made me feel that an easy to understand resource book on Deafblindness is the need of the hour. Director NIEPMD Smt Neeradha Chandramohan enthusiastically took up the task to produce this text. This book on Deafblindness contains comprehensive information as it covers all aspects of rehabilitation of persons with Deafblindness.

I wish Smt Neeradha Chandramohan, Director(NIEPMD) all success on such productions in the future.


STUTI KACKER

Acknowledgments

“Let noble thoughts flow from all sides”- Rig Veda.

The book on deafblindness contains 50 pages with information on signs and symptoms of deafblindness, early signs of identification and the significance of early interventions. The contents are explained in a very simple language enabling parents, professionals, administration, students to understand the basic information about deafblindness.

Life span activities for persons with deafblindness have been covered like during the age- birth to 3 years, focus on early intervention; from the age of 3 years to 14 years- Special education/ Inclusive Education and 14 + years about pre vocational and vocational skills training with examples are explicit for parents and teachers. The chapters are drawn

from the article published by the stalwarts in the field of deafblindness.

It is been referred that there are about 4,50,000 persons with deafblindness, in our country. Very few organizations are now catering services to this category of disability. Nonetheless, it is gaining momentum, parents and professionals realize the need of special training to this group, so also the human resource training is also geared up to train teachers to provide appropriate services. We acknowledge the contribution made by Ms. Beroz Vacha, Shri. Akhil Paul, Ms. Sampada Shevde, Dr. Namita Jacob and many others in the field of deafblindness whom the authors have interacted and shared their experiences in the book. This book is an outcome of our Secretary's guidance about deafblindness to create the technical knowhow to various stake holders. We hope that this book will serve the purpose- kindle interest and inspiration among parents, professionals, teachers,

administrators to serve persons with deafblindness and provide them a good quality of life.

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1. Introduction

Deafblindness is the combination of significant auditory and visual impairments in a person. Within this group of children there is great variability. Many children who are deafblind have some usable vision and/or hearing. The majority of children who are deafblind also have additional physical, medical and/or cognitive problems. These dual sensory losses vary in severity from person to person and do not necessarily lead to total deafness and/or total blindness. It is entirely possible that the person will retain some useful vision and hearing however loss vision and hearing does not have an additive but multiplicative effect hence the use of the term “Deafblind”.

About 95% of what we learn is through the distant senses of vision and hearing. Students who have hearing or vision impairment cannot access the same amount or quality of information without accommodation for their sensory losses.

Robert Smithdas, a man who is deafblind, said: *‘For a deafblind person, the world literally shrinks in size and scope, and whatever knowledge is obtained must come through the secondary senses of taste, touch, and smell, and the exercise of personal curiosity and initiative. Consequently, a deafblind person matures more slowly than is considered*

normally acceptable, and the individual will be prone to greater frustrations in expressing wants and needs.'

Blindness takes an individual away from things, and deafness takes him away from people.... Deaf-blindness creates unique problems of communication, mobility, and orientation peculiarly its own. (Robbins, 1983, p.3-3)

1.1 Definition of Deafblindness

Deafblindness is – “A combination of hearing and visual impairments causing such severe communication, development, and educational problems that the child cannot be accommodated in either a programme specifically for the deaf or a programme specifically for the blind.”

Deafblindness is classified as follows:

- Totally deaf and totally blind
- Totally deaf and partially blind
- Totally blind and partially deaf
- Partially blind and partially deaf

There are several definitions of deafblindness. But most of the definitions include the following characteristics:

- Simultaneous presence of vision and hearing impairment which may vary in degrees
- Does not imply total loss of either vision or hearing
- Communication is most severely affected
- Highly individualized training is needed to cope with the condition
- The world is much narrower as the distant senses are affected, and it is usually within the arm's reach.
- Affects person in totality
- Associated medical conditions with hearing and visual loss may be present

Persons with deafblindness can be categorized into four types:

Those who are born deaf and blind, which can happen if the mother, inter alia, contacted Rubella (German measles) during pregnancy.

Those who were born deaf and then lost their sight. This is often caused by the Usher Syndrome – deafness followed by a decrease in sight because of retinitis pigmentosa (tunnel vision). Other reasons for loss of vision later in life could also be cataract, glaucoma, accidental injury or trauma.

Those who were born blind and then lost their hearing due to severe infections, accidents or trauma.

The adventitious deafblind, as a result of old age, or through an illness or accident later in life.

1.2 Historical Perspective

Laura Bridgman, who was born in 1829, was the first deafblind person to learn to read and write under the guidance of Dr S.G. Howe at Perkins School for the Blind. The breakthrough at Perkins School for the Blind marked the beginning of education of persons with deafblindness in the world.



LAURA DEWEY BRIDGMAN is the first Deafblind person to learn and use lanauaae

The most famous person with deafblindness in history, Helen Keller, the American author, campaigner and lecturer was born on 27 June 1880 in Tuscumbia, Alabama. With her teacher Annie Sullivan's assistance, Helen became the first deafblind



“Blindness separates people from things; deafness separates people from people.”

— **Helen Keller**

person to go onto higher education, graduating from the prestigious Radcliffe College in Massachusetts with a Bachelor of Arts degree. While tracing the history of people with

deafblindness, the first mention is made in "The Story of Blindness" written in 1648 by Dr Gabriel Fartell in which he narrated that an Englishman, Dr. John Bulwar, wrote that a person born both deaf and blind could be taught to speak.

India saw the first programme for persons with deafblindness in the Helen Keller Institute for the Deaf and Deafblind (HKIDB), Mumbai (1977) started by Mrs. BerozVacha with students from different parts of India. It was a center based residential programme for children with deafblindness. Till 1997, there was very little awareness about deafblindness in India.

Some Indian Achievers

- Dr. Rajendra Singh Sethi - the first person with deafblindness to acquire a doctorate degree, editor of National Association for the Blind (NAB) India's magazine.
- Shri. Anindyo Bhattacharya - a person with deafblindness, lives in New York and works in Helen Keller National Centre
- Shri. Rajesh Sheth - a person with deafblindness in Limbdi, Gujarat who owns and manages a sweet shop.
- Shri.ZamirDhale - a person with deafblindness brought up in Mumbai and works as Advocacy Officer in Sense International (India)

- Shri. PradipSinha - a person with deafblindness, working as an Instructor in the computerized mini braille press at Helen Keller Institute for Deaf and Deafblind, Mumbai.
- Mr. Mahadevan - a person with deafblindness, working as an instructor of sign language for teacher trainees and possessing a National Award for Best Special Employee, awarded by govt. of India in the year 2011.
- Mr. Miranda - a person with deafblindness a first person to appear before University Grant commission to clear National Eligibility Test (NET) after completing Master in Sociology and Master in Public Administration. He is the first one to get UGC NET question paper in Braille format.

1.3Rehabilitation Strategy

Educating students who are deafblind comes with a unique set of challenges and joy. The primary emphasis of a programme for a student with deafblindness is the development of language and communication. It should support a total communication philosophy (Sign and spoken language, written language, Braille, pictures, objects, gestures, other low and high tech augmentative communication systems – may include any or all of these). The focus of

the programme should be to maximize the communication potential of each child.

Regardless of whether a child is in an academic class, playground or dining room, every environment and every professional has to support the development of communication.

The learning environment should encourage the development of students' strengths and empower them to become participating members of the community within the context of their own level of independence. During the past 25 years there have been significant changes in educational philosophy for the persons with deafblindness.

A much greater emphasis is placed upon meticulous observation and upon individualization of assessment and teaching approaches than we did 25 years ago. Educational programmes have increasingly begun to realize the importance of working along with the medical and para medical staff such as therapists and together, coming up with an educational programme. Initially, it was the special educator alone who made the educational programme. But now, considering the complex needs of children due to the changing population of children with deafblindness having increased challenges, working with a multidisciplinary team is realised as an essential step in programming.

2.Incidence and Magnitude of Deafblindness

There is no census data available regarding the size of the deafblind population in India. Estimates, based on information gathered from community-based projects run by disability organizations all over India indicate that there could be more than 485,000 deafblind people in our country. Overall we can predict that 0.04% of general population have deafblindness as a disability.

2.1. Diagnostic Services

The diagnosis of the condition of deafblindness can be made early by the clinical and related service professionals. The ophthalmologist and the audiologist can detect visual and hearing problem at birth. Today with modern equipment, detection at birth is possible. Moreover, various service providers for single category disability in course of time can suspect additional sensory loss among the children they have assessed and can refer the child for evaluation for additional disability.

The service providers and the professionals must be sensitised and made aware of the dual sensory impairment of deafblindness. Only then will they consciously and actively screen for deafblindness. The confirmation of the disability condition is on the basis of clinical evaluation by respective

professionals. Usually early identification can take place in special schools for the blind or in schools for the deaf or in schools for children with intellectual disability as most of the cases of deafblindness usually are misdiagnosed and sent to these special schools. There has to be active screening for early identification and early diagnosis of deafblindness though it is resource-intensive to do active screening at community level.

In addition a multi disciplinary team comprising of physiotherapist, Occupational Therapist, Clinical Psychologist, Speech Therapist, Special Educators, Medical doctor, Orientation and Mobility instructor and vocational instructor are required to provide holistic rehabilitation services. The list of organizations providing rehabilitation services for persons with deafblindness is Page No- 68.

3. Generic causes and Preventive Measures of Deafblindness

The cause for multi sensory impairment and deafblindness is more or less similar to the causes for single category disability. Some of the most common causes of deafblindness are Usher's Syndrome, Congenital Rubella Syndrome, CHARGE Association and Old Age. Other causes include severe head injuries, traumas, sexually transmitted diseases such as

syphilis and AIDS, drug overdosing, medical errors and self inflicted injuries.

3.1 Primary causes of vision and hearing loss:

- Hereditary (genetic)/ Chromosomal Disorders
- Prenatal viral/bacterial diseases, or harmful chemicals (Teratogens)
- Complications at birth
- Postnatal injuries and/or illnesses

Deafblindness is not caused by a single condition. People can be born deafblind, possibly as a result of infection, a genetic syndrome or birth trauma. This may result in congenital deafblindness. Acquired deafblindness refers to instances where a person becomes deafblind later in life, as a result of a progressive condition or through infection, accident or due to the process of ageing.

The main cause of deafblindness in children in the developing countries is rubella contracted by the pregnant mother. Other causes include premature birth, trauma during birth and various syndromes. These are discussed below.

Genetic conditions

A number of genetic conditions can give rise to deafblindness. **Usher's syndrome**, for example, is caused due to a gene irregularity, present from birth with effects appearing gradually over the years. Hearing impairment is usually present from birth or soon after, and can range from moderate to profound level of hearing loss. Visual impairment is progressive and can occur in late childhood to early adolescence. How much sight will be lost cannot be predicted.

Infections

Meningitis is an example of an infection, which can cause impairments at any time in life, depending on the strain and severity of the infection. Some particular types of meningitis affect young babies more than other age groups.

Rubella (Congenital Rubella Syndrome)

Rubella contacted during pregnancy is still a major cause of deafblindness in developing countries. Rubella, a childhood disease, caused by a



Skin Rashes over the Neck

virus, may be transmitted from person to person as droplets in air through coughing and sneezing or through close contact. Contact up to the 18th week of pregnancy is particularly serious.

Rubella may damage the eye, resulting in cataract (opaqueness of the lens) a typical sign of congenital rubella. One eye may escape harm or both may be affected. Sometimes microphthalmos (abnormally small eye or eyes) may be present as well. Pigmentary retinopathy (speckled colouring of the retina) is very common in children with congenital rubella, but does not affect the sight. Hearing loss, which may be conductive or sensor-neural, is one of the most common results of congenital rubella and may often appear as the only defect. Rashes as shown in the picture if noticed on any part of the part of the body is a sign of Rubella.

Heart abnormalities are sometimes seen in babies with congenital rubella and may include failure of the duct between the pulmonary artery and aorta to close (patent ductus arteriosus); opening(s) in the dividing wall between left and right ventricles (ventricular septal defect), or other heart defects.

Congenital rubella is preventable with the rubella vaccine, available as a single

vaccine or the combined measles, mumps and rubella (MMR) vaccine. The shot is generally administered to children around the age of one year, with a second dose before starting school (i.e. age 4 or 5 years). Women should be counseled to avoid becoming pregnant for 28 days after vaccination with measles or mumps vaccines or MMR or other rubella-containing vaccines. Mass vaccination programs are being implemented in many countries.

Cytomegalovirus

Cytomegalovirus (CMV) is a potential prenatal cause of deafblindness. Problems resulting from congenital cytomegalovirus infection vary, but may include jaundice, bloodspots on the skin, enlargement of the liver or spleen, spasticity (disordered control of movement), intracranial and other calcifications (the deposition of calcium within organic tissue), mental retardation and seizures. In some cases, hearing impairment may be the only sign of the CMV infection while others may have severe sight problems as well.

Toxoplasmosis

Toxoplasmosis is caused by a parasite called *toxoplasma gondii*. Babies born with toxoplasmosis (usually when infected between the third and sixth month) may develop severe

symptoms such as hydrocephalus, calcification in the brain and chorioretinitis (damage to the retina) and in some cases, epilepsy and deafness can also be present. Most worrying in this regard is the delayed manifestation of the eye disease which can manifest up to the late teens.

Birth trauma

Visual and hearing impairments can arise as a result of problems at birth or soon after. Such children may have additional, impairments such as severe physical defects, learning disabilities and communication problems

Accidents or other trauma

Any accident involving head injury can damage the parts of the brain that deal with processing information through sight and hearing. They can also damage parts of the auditory system. Other kinds of trauma, for instance, a stroke (a cerebral haemorrhage) can result in deafblindness.

Age-related Causes

The most common cause of deafblindness is simply aging. After the age of around 50 years, hearing and visual impairments become more common leading to senile deafblindness.

3.2. Syndromes

There are certain syndromes that result in deafblindness. Some of them are described below.

3.2.1. CHARGE Association.

CHARGE Association is a multi-featured disorder characterised by a unique combination of diverse abnormalities. The acronym 'CHARGE' is used to describe a heterogeneous group of children who exhibit at least four of the features of CHARGE, including one or other of choanal atresia and coloboma.

C – Coloboma, is an ocular deformity, the absence of a part of the eye.

H - Heart defects, include tetralogy of Fallot [it is a type of heart defect which causes low oxygen levels in the blood. This leads to a bluish-purple color to the skin], patent ductus arteriosus [is a condition that leads to abnormal blood flow in two major blood vessels that carry blood from the heart], atrial and ventricular septal defects [hole between the right and left ventricles of the heart], and others.

A - Choanal Atresia, a narrowing or a

blockage of the passage between the nasal cavity and the naso-pharynx. This is one of the major criteria for diagnosis.

R - Retarded growth, may manifest as the child matures.

G - Genitalia anomalies, is the incomplete development or under-development of the external genitals which is more common in males, very rarely seen in females.

E - Ear anomalies can affect the external ear (loop or cup shaped, large, small or absent), middle ear (ossicular malformations, chronic serous otitis, stapedius tendon anomalies), and/or the internal ear (especially high frequency sensori-neural hearing loss). Mixed hearing loss (i.e. conductive loss with sensori-neural loss) is the most common form of hearing loss in CHARGE Association. Malformation or absence of the semi-circular canals is fairly common.

Additional anomalies associated with this condition are abnormal tongue size, cleft lip and/or palate, facial palsy, renal abnormalities,

malformations of the larynx, atresia of the oesophagus with tracheoesophageal fistula and skeletal abnormalities.

3.2.2. Goldenhar Syndrome

Goldenhar Syndrome was named in 1952, as Dr. Goldenhar wrote about a number of facial problems that tend to occur together. Hearing varies from near normal to severe loss; visual defect includes diplopias of various degrees. Moderate learning disabilities may occur in about 10% of the cases.

3.2.3. Usher Syndrome

Usher Syndrome is named after Dr Charles H. Usher, who noticed the correlation between the two conditions, hearing loss combined with retinitis pigmentosa. Usher Syndrome affects between 3 to 6 percent of the deafcommunity. Currently, the following 3 types of Usher Syndrome are recognized.

Type I:

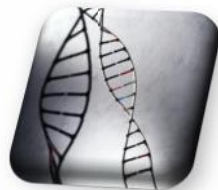
- Born profoundly deaf, has balance problems, night blindness in early childhood.

Type II:

- Born hard of hearing, has no balance problems, blind spots by teens, legally blind in early adulthood

Type III:

- Born with good hearing or mild hearing loss, has some balance problems, night blindness in childhood, blind spots by early adulthood, legally blind by middle age



4. Implications of Deafblindness

Deafblindness brings series of challenges into child life which hampers the development of the child. A child with deafblindness faces difficulties in communication, gathering information, Orientation and Mobility, socialisation which leads to isolation to the child. A person with normal visual acuity and auditory threshold learns more than 95% through their vision and hearing. Deafblindness affects the information transmission (seeing and listening) which helps one to develop their basic concepts and functional idea about the world. The intervention program for persons with deafblindness is mainly focuses on developing access to information so as the Deafblind person to develop the basic concepts.

A person with deafblindness must somehow develop the concept about the world with the limited information available to him or her. If the sensory disabilities are severe and no proper training is given to the child in order to develop appropriate concept about the world, the challenges faced by the child may be enormous and difficult. Behavioural and emotional difficulties are often accompanying deafblindness which are the natural outcomes

of the child's or adult's inability to understand and communicate.

Persons with good visual and auditory sensitivity take for granted the information that those senses provide to themselves. Events such as the approach of another person, pet animals run beside, a change in routine are all signalled by sights and sounds that allows a person to prepare them for the next action. The child or adult with deafblindness who misses these visual and auditory cues fails to anticipate the upcoming events which results to experience an unpredictable and threatening world. The world ends for a person with deafblindness end at their fingertips as the absence of distance senses like hearing and vision.

The challenge of learning to communicate is the greatest one that person who are deaf-blind face. Since communication and language hold the power to make their thoughts, needs, and desires known to others. A person who is deaf-blind also faces, the challenge of learning to move about in the world as freely and independently as possible. Adult individuals also must eventually find adult living and work situations that allow them to use their talents and abilities in the best way

possible. The achievement of such success depends in large part upon the education they have received since childhood, and particularly upon the communication with others that they have been able to develop.

5. Early Intervention

The importance of early identification and intervention of disabilities is well known and well documented. It holds true for deafblindness also. Early intervention and prevention pay substantial dividends to infants as well as to their families and society at large. In all likelihood, many infants who, in the past, grew up disabled could have developed normally if appropriate preventive steps had been taken early in their lives. Additionally, people with disabilities are far less disabled if effective interventions have been applied from birth.

5.1. Existing services and training

Unlike some of the single category disabilities, deafblindness is not visible. Children with deafblindness are often misdiagnosed or wrongly identified as children with autism or with intellectual and developmental disabilities. Sense International (India) (www.sense.org.uk) has developed simple screening formats that can facilitate the detection of deafblindness.

The increasing awareness about deafblindness has led to an increase in referrals from various hospitals and clinics to programmes providing services to children with deafblindness. Organizations like Helen Keller Institute for Deaf and Deafblind, Mumbai, Blind Peoples Association, Ahmadabad, National Association for the Blind, Mumbai and New Delhi, Clarke School for the Deaf, Chennai, Holy Cross Service Society, Trichy Tripolia Hospital in Patna and several others have units for Early intervention and identification of children with deafblindness.

4.2. Aims of intervention programs:

For infants with deafblindness or for those at risk the aims of intervention are multifaceted. Goals include diminishing the effects of dual sensory loss or the disabling condition on the child's growth and development and preventing, as much as possible, the worsening of the at-risk condition. Timing is critical in the delivery of the Interventions. The saying **"the earlier, the better"** is very true in this context. Moreover, early intervention may be less costly and more effective than providing services later in life.

Advocates of early intervention services for children at risk believe that intervention should begin as early as possible in an

environment that is free of traditional, categorical labels (e.g., mentally retarded, emotionally disturbed). Carefully selected intervention measures have the potential to lessen the long-term impact of the disability and counteract any negative effects of awaiting intervention. The postponement of services may undermine a child's overall development as well as his or her acquisition of specific skills.

Keeping in mind that Rubella is the major cause of deafblindness and many other disabling conditions related to vision / hearing / intelligence, we must work towards a situation where vaccination against rubella is available to the masses. At the moment, there is little or no awareness about rubella, except a few in cities and towns.

6.0. Education of children with Deafblindness

Individuals with deafblindness have unique life-long support needs that must be addressed in order for them to function in a world driven by



sight and sound. Consistent with this, they have unique needs within the educational system.

Assessment is the first step in education of children with deafblindness. It gives concrete information about current functioning of the child which helps a teacher to plan a education programme to the child. The **Callier-Azusa** is a developmental assessment for children who are



Deafblind or have multiple disabilities. It is use to **assess the developmental level** of children who could not be adequately

assessed by

another assessment tool because they require the child to have specific language, cooperation, or sensory modalities, or because they lack comprehensiveness at lower levels of development. It also helps to measure progress over time to determine the effectiveness of programming or specific educational and therapeutic strategies for a child. Callier Azusa is composed of **5 Areas a. Motor development b. Perceptual development c. Daily Living Skills d. Language development e. Socialization**. There are 18 subscales made up of sequential steps describing

developmental milestones in each area. Some steps are further divided into items. Items describe behaviours that appear in a specific period of development, but are NOT in sequential order.



Calendar system is one of the important system used for education of children with Deafblindness. Calendar systems provide a structured way which enables the child refer to events in a child's day.

Sometimes called "Anticipation Boxes" or "Object Calendars", a series of meaningful symbols are arranged in sequential order to let the child know what will happen next. Calendars also provide a way to make clear the beginning, middle, and end of an activity, as well as time concepts, such as before, after, later, and now. For individuals who are deafblind, calendar systems provide concrete information about what is going to happen in his/her day. Calendars come in many forms. The selection of a specific type of calendar is based on the needs and abilities of each

individual child. They may be as simple as a single basket containing an object that represents **“What I am going to do now.”** They may have a series of compartments that contain objects, parts of objects, photographs, line drawings or tactile symbols representing the activities of the day. Some calendars include a symbol for choice-making that allows the person to select a favorite activity.

ADL Training

Child with Deafblindness needs to be given training on all the activities of daily living (ADL) in order to develop independence. ADL includes toileting, brushing, bathing, dressing, grooming eating, washing and personal hygiene. Typically developing child gets maximum exposure of most of these activities by watching their parents in their early life. This exposure helps those children for attempting to imitate those tasks like adults. The same is difficult for a child with Deafblindness due to their limited sensory abilities. It is very vital for a child with Deafblind to get an exposure about these activities, which will help him/her to develop some kind of idea about those activities. These skills could be taught by hand under hand techniques (i.e. the child hands may be over father hands while father is brushing). The child shall develop an

understanding about the activities if the same is continued for a period time. Further, if the activities are divided into small small steps it will eventually result in better improvement. Ex. For teaching **washing activity** to a child with deafblindness the following steps called as '**task analysis**' could be followed.

- Identifies dirty clothes storage basket/place

Step-1



- Carries clothes to washing area

Step-2



- Arranges required materials for washing]

Step-3



- Collects water in bucket for soaking clothes

Step-4



- Mixes detergent powder in the bucket of water

Step-5



- Soaks dirty clothes in soap water

Step-6



- Takes out dirty clothes from soap water bucket

Step-7



- Applies washing brush on identified dirty area of the clothes

Step-8



- Collects water in another bucket for rinsing washed clothes

Step-9



- Rinses washed clothes in water and removes detergent from clothes

Step-10



- Squeezes clothes and keeps them away from water

Step-11



- Takes washed clothes to the drying area

Step-12



- Puts clothes on hanger for drying

Step-13



- Cleans buckets and replaces the used materials in respective places

Step-14



- Collects and brings clothes to room from drying area

Step-15



- Folds clothes and keeps them in respective places

Step-16



The above mentioned 16 steps for teaching “washing activity” to a child with deafblindness are generally adopted. In case if the child finds it difficult in learning in between the steps mentioned above, it could be further simplified by adding more subtasks. Likewise all the ADL activities must be taught in similar way.

As per **Dr. Jan Van Dijk** learning stages for Deafblind is considered to be in 3 stages - Co-active, cooperative and reactive.

Co-Active– Doing thing together helps him to provide exposure of the activity.

Cooperative – The adult shall begin the activity and the child participates at their own level.

Reactive – The child shall start exhibiting the learnt skill.

The above stages need to be kept in mind before developing any skill for a child with Deafblindness. We must know in what stage exactly the child is, & accordingly the activities must be planned. For example a child with total vision and hearing loss, may not have any idea about washing a clothes. In that situation, the activity must be planned in co-active way as mentioned in the previous example of washing clothes. When the child is made to pick the cloth, he may move towards / to the place for

washing with that cloth. This indicates that he has learnt some knowledge on that activity once the child started exhibiting some learnt behaviours we must give enough time for the child for their response each step of the activity. This stage is called cooperative stage. After this stage one must focus on the under developed tasks (like joining dots to draw a line) to make the child to competent enough to perform the activity indecently. When the child performs the activity independently he has reached the reactive stage, which is the final stage in learning according to **Dr. Jan Van Dijk**.

6.1. Educational Provisions:

Education for a child or youth with deafblindness needs to be highly individualized; the limited channels available for learning necessitate organizing a program for each child that will address the child's unique ways of learning and his or her own interests. Assessment is crucial at every step of development and sensory deficits can easily mislead even experienced educators into under-estimating (or occasionally over-estimating) intelligence and consequently at risk of putting together an inappropriate program.

There are less than 100 school-aged children enrolled in regular schools throughout India who meet the criteria for deafblindness.

5.2. Difficulties faced in assessment:

At present, the school system often finds its resources in deafblindness to be inadequate. Assessing the skills of these children can be difficult since assessment instruments are generally not normed for this population. It is often impossible to adapt these materials to test children with deafblindness without negating the test's validity.

Another problem in assessing skills and providing instruction to children with deafblindness is that they may be unresponsive during testing unless they are working with someone with whom they have bonded.

5.3. Aids and appliances used by persons with deafblindness:

Generally children with deafblindness use a variety of adaptive assistive devices. Knowing how to use this equipment and how to keep it in working order is no small accomplishment. For example, a child may have both a personal hearing aid, glasses and a cane. They may rely on a communication book for much of their communication. The child and all of the people working with him have to be trained to use all these devices.

Throughout these children's lives, their eyes and ears either distort or altogether omit

incoming information. They only experience fragments of any experience.

Communication is one of the main areas which is critically affected by deafblindness and is usually the highest priority in their educational programming. These children's communication systems typically contain a variety of forms which can include signals, tactile sign language, object symbols, tactile symbol systems, Braille, as well as a variety of other options. Each child's system must be individually designed for him and used with a high degree of consistency across the day. Developing a communication system for these students frequently requires technical assistance for the staff since few have had pre-service training regarding this population.

6.4. Additional disabilities in children with deafblindness:

Many children with deaf-blindness suffer additional disabilities. This further complicates the situation. Many of these children dislike being touched. They may have disrupted sleeping patterns, poor overall health, and /or feeding difficulties. They may have ongoing medical problems that escalate the degree of vision or hearing loss.

6.5. Teaching children with deafblindness:

Children with deafblindness learn best when information is presented in a consistent and repetitive fashion. This places additional burdens on the staff working with the child. Staff working closely together to provide consistency and to coordinate support is imperative in educating a child with deaf-blindness. Planning time as a group is critical. Additionally, information and input from the family is vital to a well coordinated program.

6.6. Team approach for education of children with deafblindness :

The staff who typically would serve a child with deafblindness include: teachers of children with visual impairment, teacher of children with hearing impairment, intellectual disability, orientation and mobility instructor, general classroom teacher (regular education and special education) and assistant teacher, and often occupational and physical therapists as well as other related service staff such as a speech/ language therapist and audiologist.

However at present there are less than 100 special educators trained in deafblindness working in the various schools all over India.

Till date, Sense International (India) has collaborated with SSA/ MHRD to orient more than 1200 teachers nation-wide through the

“Regional Training Programmers”.

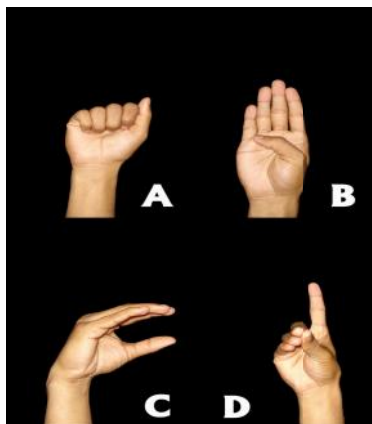
Although children with deafblindness present unique challenges to those who are charged with providing them appropriate education, it is important to state that these children CAN LEARN and make terrific strides with proper support .

6.7. Deafblindness and Communication

Communication connects all human beings with one another. Each person who interacts with the individual who is deafblind is a communication partner (family members, peers, teachers and others). Although individuals who

are deafblind are all different, they share a common difficulty in communicating with others.

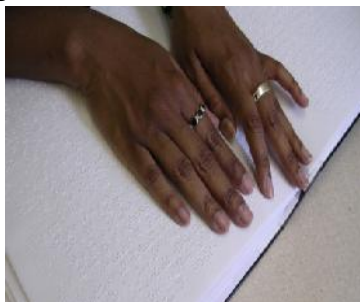
Communication is the greatest challenge in working with individuals who



are deafblind. Many of them do not speak, and some do not have formal language. They may use objects, body movements, facial expressions, and other non-traditional forms of communication; they may develop language

and use sign language; a few may understand and use speech.

When communicating with a deafblind child, there may be one form of communication for expression and a different one for reception. Choosing a form to use will



depend on the child's social, physical, perceptual and cognitive skills. Children with deafblindness will need to see, hear or feel gestures, objects, signs or words many times before they can learn to use them receptively or expressively. Some deafblind people learn to use objects to symbolise a particular activity. For example, a toothbrush may indicate time for brushing teeth, or a spoon may be used to show that it is lunch time. This method allows people who are deafblind to make choices, and enables others to let them know what activities are planned for them. Sometimes Communication Boards are used to convey a message or encourage the deafblind person to make a choice. The board can have display of words, tactile symbols, pictures, photographs or other tactile representations.

With deafblind persons who have no

other additional disabilities and have learnt formal language, a method of communication called 'Deafblind manual alphabets' is used. Deafblind Manual Alphabet is a tactile language, used to communicate with people who have little or no residual sight and hearing. It involves forming letter symbols or alphabets on the palm of a person's hand. It is simple to learn and easy to deliver, but much more difficult to understand. Different letters are spelt out by touching specific areas of the fingertips and palm of the person with deafblindness.



Deafblind Manual Alphabet

Tactile Sign Language:

The deafblind person puts his or her hands over the signer's hands to feel the shape, movement and location of the signs.

Individuals with deafblindness can use one-handed or two-handed tactile sign language.

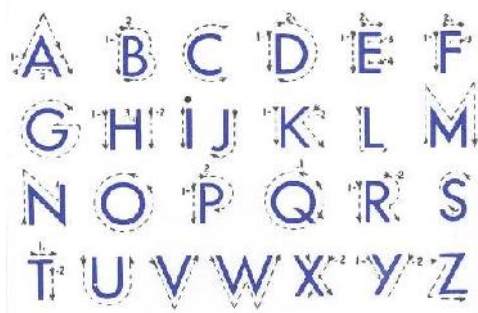


Two adults with Deafblind are interacting through tactile Sign Language.

Print on Palm (POP):

The person communicating with the person with deafblindness prints large block letters on the other person's palm. Each letter is written in the same location on the person's palm. Persons with deafblindness who are familiar with the English print alphabet frequently use print on palm to communicate with the public.

PRINT-ON-PALM



Many times children with deafblindness are unable to learn the manual alphabet or sign language due to the presence of additional intellectual impairment, challenges in learning, lack of trained professionals to teach them or lack of exposure to systematic language development.

However all children with deafblindness do learn to communicate using various alternate modes of communication,

6.8. Deafblindness and Mobility

Learning involves movement and exploration of the surroundings. Through this movement children develop their motor skills, an understanding of the physical world, and gain a basis for language and social rules through interaction with a variety of children and adults.

Children who are deafblind face a large challenge in learning how to move through their environment because their lack of sensory input removes the stimulus or reason to do so. Movement is also critical to the development of social relationships in childhood. This lack of movement also effects how a child with deafblindness perceives and organizes the world thus hindering basic conceptual development.

Planning for activities that include purposeful movement, including children in various play activities, environmental organization and landmarks and environmental cues are some of the strategies that encourage the development of orientation and mobility skills in children.

For outdoor mobility, people who are blind use a white cane to show they have a problem with their sight. People with deafblindness use the same white cane but with red bands around it, which shows that they have a loss of hearing as well as sight.

6.9. Encouraging Access to Information

Deafblindness is a disability of access to sights, sounds, and information. This causes chronic difficulties with incidental learning and concept development. For persons with deafblindness, the senses of touch, body awareness, balance, taste and smell can be used to access information and understand the world. To facilitate access to information, the Individual Education Plan (IEP) of the child will need to include adaptations, accommodations and/or modifications such as print or reading material in large print, Braille and assistance from an interpreter or teacher who will provide inputs for the environmental information.

Curricular modification through reducing and prioritizing the information that the student is responsible for learning is an important aspect. A teacher or a person who acts as a sighted guide for the person with deafblindness during mobility plays a significant role in providing information about the surroundings which the person with deafblindness cannot access through the sense of touch.

6.10. Appropriate Educational Alternatives for people with deafblindness:

Presently the educational services widely available in our country for deafblind children are home-based and in 29 special-centre based services in organisations throughout the country. Because of the influence of Sarva Shiksha Abhiyan (SSA), the opportunity for general education class and resource class is now also available for the deafblind children.

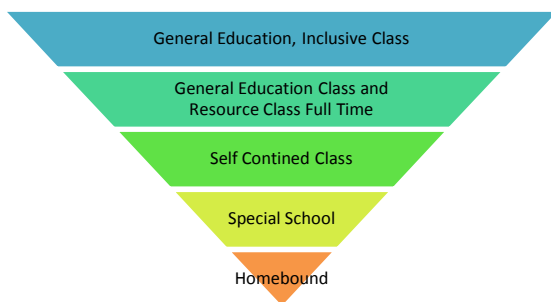


Fig: Deno's Cascade model of educational service delivery for special children.
Source: From Special Education as developmental capital by E. Deno. Exceptional Children, 37, 1970, 229-237, Council for Exceptional Children.

The educational services for children with deafblindness in India were initiated in the form of centre based and home based services, which is right at the base in the Deno's cascade. However gradually these have now moved on to the beginning of inclusive education with a few children with deafblindness receiving education in regular schools or through resource rooms in regular schools.

Sense International (India) has developed a regular training module on deafblindness for duration of three months for in-service teachers trained in single category disabilities in visual impairment or hearing impairment and currently working under SSA to train them so that they provide educational services to deafblind children through SSA. This syllabus for SSA is recognised by Rehabilitation Council of India.

More than 2000 resource teachers are trained on deafblindness with active support from Voice & Vision India and Sense International (India). As on date, about 32000 deafblind and multi-sensory impaired children (approximately 1.2% of disabled children enrolled inschools) are getting school-based or home-based services under the SSA. Source: Sense International India, Annual report – 2011-12.

Efforts are being made to incorporate the same in the SSA schemes of all the state governments. Although most of the deafblind children receive home based and centre-based educational services, some are enrolled in regular schools with the assistance of the resource room teacher.

6.11. Percentage of children having access to education

There are about more than 43,000 deafblind individuals receiving educational services in India as per the report of Sense International (India) Source: Sense International India, Annual report - 2010. Among them about 11000 deafblind children are receiving direct support and others are receiving indirect services through the SarvaShikshaAbhiyan (Education for All Scheme) of Government of India.

6.12. Points for consideration for education of children with deafblindness

The education of children with deafblindness is a relatively new area, there are certain points to consider, keeping in view the principles of education.

Principles of Education

- Educational placements should be selected on the basis of individual abilities and needs, age of onset and amount of auditory and visual impairments, mode of communication, cognition and existence of additional disabilities.
- Teachers who have had specific training in deafblindness are necessary to provide optimal integrated programming.
- Communication to be embedded in the curriculum across different areas and environments.
- Integration of appropriate age related educational and support services are necessary for a successful educational program for a student with deafblindness.
- Various specialists may contribute towards assessment, direct instruction, or consultation for the group.

Best Educational Practices for Students with Deafblindness

- Respect the child and see beyond the disability
- Always acknowledge your presence as you enter and absence as you leave
- Always encourage and motivate
- Use words and language naturally
- Provide assistance as per need
- Remember all behaviours communicate
- Plan a functional, age appropriate curriculum
- Plan for inclusive activities
- Involve parents as partners in the educational process
- Have a transition plan in place
- Explore various service delivery options such as community based instruction, home based instruction and regular school with resource room.

7. 0. Higher education

A few students with deafblindness in the Helen Keller Institute for Deaf and Deafblind, Mumbai have completed their Xth standard through the National Institute for Open Schooling (NIOS) and are now studying to complete their XII standard through the system. Technology and computer education has been a boon for these deafblind students and has helped to broaden their world in terms of access to information and participating in the examination process.

There are a few students with deafblindness in the Blind Peoples Association, Ahmadabad and Clarke School for the Deaf and Mentally Retarded, Chennai who are currently preparing to appear for their X standard examination.

Fredrick, a deafblind young adult from Trichy has successfully completed his preliminary examination of Indian Administrative Service (IAS).

8. 0.Vocational training and Employment Opportunities

Professional services for those with deafblindness in our country are growing and there are 45 service centers in 21 states of India including north eastern states of the country for individuals between the age group

of 1 year to 18 years of age. (List of Organization in Page No.68)

Vocational training is necessary for a young adult with Deafblindness to achieve independence, social integration and to lead a better quality of life. "The world of work is a place for individual to share skills and knowledge, socialise, create a sense of accomplishment and build self-esteem.(Perkins Activity and Resource Guide, 2004) Vocational training needs to be planned and given based upon the individual strength and trades of interest. Before giving training one must consider the following areas:

1. The adaptations of materials
2. The environment where he needs to communicate
3. Place of his accommodation and mode of travel
4. Free time activities

Vocational training is given for development of employable skills in the following areas which cover the generic and skills and specific trade skills.

- a. Independence in self help skills, health and hygiene
- b. Communication and language
- c. Social, Emotional and Interpersonal skills
- d. Orientation and Mobility

e. Basic Math, Time and Money management

About 27 products have been identified such as

1. Candle
2. Jewellery using semi – precious stones
3. Chocolate
4. Food items
5. Pot pourri
6. Incense
7. seasonal products – Raki
8. Diyas
9. Greeting cards
10. Flags
11. File pads
12. Phenyl & soap products
13. Screen Printing/printing cards
14. Plant nursery
15. Beading
16. Weaving
17. Craft work
18. Paper Bags
19. Stitching pillow cover
20. Painting on t-shirts
21. Paper cups
22. Solar drying-amla candy
23. Tie & dye
24. Petty shop keeping
25. Basket/hat making
26. Dhop-incense stick making
27. book binding for vocational training of persons with Deafblindness.

A Step training method is illustrated below for plant nursery.

- Identifies the required

Step-1



- Identifies & takes the

Step-2



- Reaches to the area where mud & Manure are mixed

Step-3



- Fills mud completely in the polythene cover

Step-4



- Places the plant/seed inside the polythene cover

Step-5



- Adds manure in the cover

Step-6



- Waters the plant using sprinkler

Step-7



- Places the nursery plant in sunlight for optimum growth

Step-8



- Waters daily to all the plants

Step-9



There is now a greater need for vocational training and gainful employment of the adult population with deafblindness. Pre-vocational and vocational services for deafblind in the form of a sheltered workshop are in place at organizations such as the Helen Keller Institute for Deaf and Deafblind, Mumbai, Blind Peoples Association, Ahmadabad, Holy Cross Service Society, Trichy, Clarke School for the Deaf and Mentally Retarded, Chennai and National Association for the Blind, Delhi and National Institute for Empowerment of Persons with Multiple Disabilities Chennai.





Some of the adults in the Community Based Rehabilitation (CBR) projects are self employed with support from the family. To quote two examples, as mentioned earlier, Rajesh Sheth, a person with deafblindness in Limbdi, Gujarat from Blind Peoples Association, Ahmadabad owns and manages a sweet shop. Zamir Dhale, a deafblind man brought up in Mumbai, works as Advocacy Officer in Sense International (India).

The Helen Keller Institute operates a computerized mini braille press in Mumbai, wherein students with deafblindness have access to computer education and the related technology required for computer access such as refreshable Braille display, Power Braille, Screen magnification softwares and adapted computer equipment.

Over 20 individuals with deafblindness have received computer instruction at the institute and are now adept at using the computer and internet. Some of the ex-students are now employed at the institute as instructors for

computer education for students with hearing impairment.

9. Parental and Community Participation

Parents and family members play a central role in the lives of all children - especially those with deafblindness. A partnership between parents and professionals is very essential for ensuring that children who are deafblind receive every opportunity to achieve their potential. By strengthening this partnership, there is a great deal of learning for both groups, which help the deafblind child to reach his maximum potential.

9.1. Changing Role of Parents in India

With services for deafblind children increasing in the country, there are increased chances for parents of children with deafblindness to meet with teachers and other professionals closely working with their child on a regular basis.

This is not only true in big cities and special centres, but across the country in CBR programmes also. Parents have been meeting other parents of deafblind children at local, regional and national levels, through the registered national parents' network named as **'Prayaas'(C/o Sense International India, Ahmadabad)**. One of the common concerns

during such meets is the need to constantly update their knowledge on deafblindness so that they can be equal and true partners in the decision making process for their children. The network is also an opportunity for parents to strengthen their efforts towards various advocacy initiatives for individuals with deafblindness at the state, regional and national level.

Several parents have undergone the one year full time training in deafblindness to be able to identify and understand the needs of their children. Some of the parents after training are working in programmes for children with deafblindness across the country as special educators and are playing an important role in advocacy issues.

9.2. Role of the Government Organizations and NGOs: (Policies, Programs and Activities)

The Persons with Disabilities (Equal Opportunities, Full Participation and Protection of Rights) Act in 1995, does not include deafblindness specifically.

Following the ratification of the UN Convention on the Rights of People with Disabilities (UNCRPD), the Government of India has initiated the process of drafting a new Bill on the Rights of People with Disabilities in

2011, which recognises deafblindness as a separate category of disability. Deafblindness, a combination of varying degrees of visual and hearing impairments, makes it one of the most isolating of all disabilities, which deserves stand alone recognition.

The following are some of the achievements resulted from direct involvement of the government:

- A module on deafblindness is now added in the curriculum of all primary and secondary school teacher training of single category disability, accredited by Rehabilitation Council of India.
- The National Institutes (NIVH, NIMH, NIEPMD, and AYJNIHH) in the country have now deafblindness incorporated in their training programme and services.
- Mr. Akhil Paul, Director of Sense International (India) was one of the Founder Members of the Board of Directors of National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. In the present Board, Mr. ZamirDhale, who is a deafblind person, is a Member.
- National Policy on Disability has deafblindness incorporated as a sub group under multiple disabilities.

- Deafblindness is now included under the assistance to disabled persons for Purchase/Fitting of Aids & Appliances scheme of Government of India, where communication equipments as aid for deafblind persons are clearly mentioned.
- National Trust Act for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities has included deafblindness into its multiple disability categories.
- Deafblindness is incorporated in the Disability Management Training of Primary Health Centre (PHC) for orienting doctors to various disabilities.
- Rehabilitation Council of India has approved and incorporated deafblindness in the module for the curriculum of Caregiver Training Course.
- Rehabilitation Council of India has recognized teacher training programme on deafblindness, which is a two year 'Diploma course in Special Education on Deafblindness', under the aegis of the National Institute for the Visually Handicapped, Dehradun.
- Voice and Vision India in collaboration with National Trust conducts various regional trainings on 'Early Intervention for children with Sensory Multiple disabilities'.

- The SarvaShikshaAbhiyan (SSA), Government of India's flagship programme for achieving Universal Elementary Education (UEE) has included training and information material on deafblindness in regional languages across the States such as Uttar Pradesh, Tamil Nadu, Chhattisgarh and Bihar.
- The Resource Teachers and Coordinators working in the SarvaShikshaAbhiyan (SSA) are being trained on Deafblindness through local NGOs.
- The UNESCAP has recommended to include deafblindness in the "services for multiply disabled".
- The recent UN Convention on protection of disabled persons' rights recognises "deafblind" children and their needs in the Article 24-(c) (Education) and says "Ensuring that the education of persons, and in particular children, who are blind, deaf and deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development".

There are now 45 NGOs in 21 states across the country, which are directly providing services to deafblind children and their families.

9.3. India Deafblind Consortium

India Deafblind Consortium (IDC) is a group of like-minded professionals and parents who are currently engaged in analysis of the current deafblind scenario in India, in comparison with social, economic and geopolitical context. On the basis of findings IDC influence current policies of the country for inclusion of the rights of deafblind people. It also supports lobbying for specific issues related to deafblindness in the country. India Deafblind Consortium stands for:

- The benefits of the persons with deafblindness.
- Promotion of equality of opportunity and non-discrimination.
- Promotion of the rights of the deafblind people for the development of their full potential.
- Enabling children and young adults with deafblindness as participating members of society within their local communities.
- Help children, youth with deafblindness and their families to exercise control over their own lives.

The India Deafblind Consortium (IDC) promotes early identification, diagnosis and intervention services. It also recognizes the importance of family life for persons with deafblindness; access to communication and care; access to need-based educational services and special aids and equipment. It also promotes provision of specialized staff and equal employment opportunities. It stands for development of independence and promote right to travel. The India Deafblind Consortium (IDC) believes in the strengthening of local and regional issues, empowerment of those in the rural areas and promotion of human rights.

10. Human Resource Development

Human resource development is the key to initiate and maintain quality services for the deafblind. Since the field is a new one in the country, there is an obvious need for training and increasing the expertise to sustain the different services and programs. Effective human resource development strategies will prove to be the backbone for providing consistent and quality services to persons with db. In terms of training of professionals, the current scenario in the country is as follows:

- Rehabilitation Council of India recognised the first teacher training course in deafblindness in Asia and the National Institute for the Visually Handicapped (NIVH) certified the said course. The course is being currently conducted at three places; Helen Keller Institute for the Deaf and Deafblind, Mumbai; The Clarke school for the Deaf and the Mentally Retarded, Chennai; and at National Institute for the Empowerment of Persons with Multiple Disabilities, Chennai. Besides the recognised and certified courses mentioned above, a number of informal training activities are being undertaken in the field of deafblindness in the country, a few of the significant ones being:
 - Awareness training programmes for in-service single category teachers, itinerant/resource teachers, medical professionals, community workers and so on.
 - Orientation programme on deafblindness for teachers working with children having deafness/blindness/multiple disabilities/cerebral-palsy/mental retardation.
 - Specific need-based training on topics such as early identification; assessment, communication; program planning;

classroom management; and so on for teachers working with children with deafblindness.

- Regional five day workshops on ‘Early Intervention for Sensory Multiple Disabilities’ conducted by Voice and Vision India in collaboration with the National Trust.
- Leadership training for personnel from various organisations who are managing different kinds of services for deafblind children.
- Master Teachers course run by Voice and Vision India to create a team of regional resource persons to provide services to children with multiple disabilities and deafblindness.
- Intensive ‘hands-on’ training for workers at the program sites by experts.

11. Senior citizens with deafblindness

A majority of persons with deafblindness are in the geriatric age group. They need a much specialised service which is very different from the services for the children and young adults. Although there are some services available for the young, there is hardly any specialised service for the aged individuals with deafblindness in the country.

12. Technology

As the field is emerging, there has been a greater need for developing technology for different target groups among the deafblind population. There are many known devices, which the deafblind individual needs for smooth functioning and assistance. Some of them are listed below:

Braille Display

It is an electro-mechanical device for displaying braille characters, usually by means of raising dots through holes on a flat surface. Persons with deafblindness who use computers, use it to read text output and access the information.



ZamirDhale, Advocacy officer with Sense International (India) and an adult with deafblindness using the Braille display

Screen Magnification Software

A **screen magnifier** is software that helps to present enlarged screen content. It is a type of assistive technology suitable for individuals with deafblindness who have functional vision.

Distance vision telescopes are the only optical devices that assist persons with low vision and hearing impairment with distance tasks if conventional glasses are unsuccessful. These are useful for specific tasks requiring magnification at distances, like reading blackboard in school, reading bus numbers, watching television.

Optical Devices for near vision Tasks

Magnification is determined by assessing the acuity level needed to perform a desired task, which is accomplished with conventional lenses.

Magnifiers

Magnifiers are used for reading at more customary distance. Various



types of magnifiers are useful for children with deafblindness for various tasks required for day to day functioning.

Braille Note Taker

The Braille note taker will have Braille cell display and braille key board with internal memory and navigation keys. This device used by persons with Blindness/Deafblindness for various purposes including communication. This device shall be used as braille display with Windows, Mac, IOS, or Android screen reader.

Information about various assistive devices available for persons with visually impaired and additional disabilities from the following agencies:

National Institute for the Visually Handicapped

(Under Ministry of Social Justice and Empowerment, Govt. of India)

116, Rajpur Road, Dehradun
Uttarakhand.

Phone: 0135-2526062, 2526063, 2104813

Fax: 0135-2748147

Barrier Break

Office No. 102, Highway Commercial Complex,
IB Patel Road, Opposite LaghuUdyog Industrial
Estate,

Goregaon (E), Mumbai – 400 063.

Mobile: +91 (22) 26860485-87

: +91 (22) 268 0489-90

Email: info@barrierbreak.com

: Sales@barrierbreak.com
: Programs@barrierbreak.com
:pr@barrierbrea.com

Karishma Enterprises

No.132, Maker Tower 'B',
Cuffe Parade, Mumbai 400 005. India.
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Phone : 91-(0)22-22181853
Fax : 91-(0)22-22153291
Email: contact@KarishmaEnterprises.com (OR)
ramagarwal@gmail.com

Sparsh Products

No.151-5, Rajpur Road,
Dehradun 248 001, India.
Mobile: +91 9837088334
Ph/Fax: +91 135-2735011
Email: sparshproducts@gmail.com
: info@sparshproducts.com
Website: www.sparshproducts.com
: www.sparshbraille.com

Worth Trust

No.48, New Thiruvallam Road,
Katpadi-632 007
Tamil Nadu, India.
Phone: Off: (0416) 2242739
Fax: (0416) 2243939
Email: myke@worthtrust.org.in
Web: www.worthtrust.org.in
Mobile: 9442592306

13. Research & Development

The deafblindness related information in the country is a new and emerging area. Though there has been a considerable amount of work in the field there are very instances of research in the field of deafblindness in India.

One of the significant research in the field is the study on *Cognitive Functioning of Children with Severe Intellectual Disabilities and Children with Deafblindness: A Study of the Perceptions of Teachers and Parents in the USA and India* - -Narayan, Jayanthi; Bruce, Susan M.; Bhandari, Reena; Kolli, Padmavathi published in the *Journal Of Applied Research In Intellectual Disabilities*, vol. 23, pp. 263-278. (2010). The purpose of this study was to explore how teachers and parents perceive the cognitive functioning of their child/student with intellectual disability or deafblindness and to compare how these perceptions differ between parents and teachers in the USA and India. The participants were 125 teachers and parents from both countries. They completed a questionnaire of 13 yes/no items with space for the respondents to explain their responses and provide examples. Analysis of the yes/no questions revealed that many of the perceptions of the participants were similar in both countries, as were the examples cited in the narrative

responses. The teachers in this study tended to credit performance more readily than parents and were more likely to report emerging skills and teaching strategies. The narratives highlighted the importance of functional assessment in the child's natural environment over time to most fully capture the child's present abilities and potential.

There are various publications related to deafblindness in the form of books, handbooks, booklets published by Sense International (India) and Voice and Vision India on various topics such as communication, curriculum, assessment, developing literacy, nutrition, working with parents, adaptations and low cost teaching learning material, sensory integration, environmental adaptations and play. Formats for screening, identification and assessment of vision and hearing have also been developed. There are also a few videos for sensitization and working with children with deafblindness.

As of now, there is no data available regarding the size of the deafblind population in India as to date there has been no comprehensive study or research to determine the true incidence. It would be extremely helpful to conduct a study to determine this number.

Future Vision and Improvements in the next Decade

The future of the field of deafblindness lies in making bigger impact which comes from stronger network, structured advocacy and policy work, improve service delivery, quality enhancement, build local capacity and regional lobbying. More regional focus with increased capacity along with stronger partners providing leadership on issues will enhance the growth of the field and development of services for people with deafblindness which could lead to changes in the practices of the special education services.

List of Organizations

S. No.	Name of Organization	Location City, State	Contact No.
1.	Abhoy Mission	Agartala, Tripura	Mr. Shyamal Deb +91-381-2338607 +91-9436123069 abhoymission@rediffmail.com
2.	Akanksha Lion's School for the Mentally Handicapped	Raipur, Chhattisgarh	Mr. MohitSahu (CEO) Phone : 0771-4013771,0771-4035441 reachus@aakankshaindia.org
3.	AndhjanKalyan Trust	Dhoraji, Gujarat	Mr. Prafulbhai Vyas +91-2824-223502, aktrust.drj@gmail.com info@aktrust.org
4.	Ashadeep School for the Deaf	Patna, Bihar	Sr. Catherine +91-612-2270691 deep.ashadeep@gmail.com ashadeep@gmail.com
5.	Ashirvad Trust for Disabled	Sayla, Gujarat	Mr. Rambhai Jadav + 91-2755 281185 +91- 2755 281184 contact@ashirwadsayla.org jadavatd@yahoo.com
6.	Association for the welfare of Handicapped	Faridabad, Haryana	Ms. HimaniArora +91-129 - 2484611, awh_fbd@rediffmail.com
7.	Bethany Society	Shilong, Meghalaya	Mr. Carmo Noronha +91-364-2210631 bethanyngo@rediffmail.com
8.	Blind People's Association (India)	Ahmedabad, Gujarat	Ms. Nandini Rawal +91-79-26304070 +91-79-2630 3513 nandinibpa@gmail.com
9.	Blind Welfare Council	Dahod, Gujrat	Mr. Yusufi Kapadiya +91-2673-221367 bwcdahod@gmail.com

10.	CADRE India	Kanyakumari, Tamilnadu	Mr. Mohankumar E. +91-4651-261211 cadreindia@gmail.com
11.	Caritas Goa	Goa	+91-832-2226509 caritas@caritasgoa.org csjggoa@gmail.com
12.	Clarke School for the Deaf and Mentally Retarded	Chennai, Tamilnadu	Dr. Leelavathy Patrick +91-44-28475422 +91-44-28474910 clarkskn@md2.vsnl.net.in
13.	Digdarshika	Bhopal, Madhya Pradesh	Mrs. UshaUpadhyay +91-755-2680017 digdarshika.db@gmail.com
14.	Helen Keller Institute for the Deaf and Deafblind	Mumbai, Maharashtra	Ms. SheelaSinha +91-22-23019215 hkidb.mumbai@gmail.com
15.	Holy Cross Service Society	Trichy, Tamilnadu	Prof. Prabakar I. +91-431-2771544 holy.cross.service.society@gmail.com
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17.	Kutch Vikas Trust	Bhuj, Gujarat	Fr. George Elavunkal +91-2832-274229, 274230 & 274286 kutchvikastrust@gmail.com
18.	L. V. Prasad Eye Institute	Hyderabad, Andhra Pradesh	Ms. Beula Christy +91-40-30612822, 30612823, 30612331 beula@lvpei.org
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21.	National Association for the Blind	Bangalore, Karnataka	Mr. M. Srinivas +91-80-25281590/25289939 ceo@nabkarnataka.org
22.	National Association for the Blind	Nashik, Maharashtra	Mr. Rameshwar Kalantri +91-253-2353578, 2364378 nabdeafblind.86@rediffmail.com
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25.	National Association for the Blind	Mumbai, Maharashtra	Mr. Ajay Rai +91-22-2493 5365 / 6683 8686 nabed@vsnl.com
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28.	NIEPMD	Chennai, Tamilnadu	Dr. NeeradhaChandramohan +91- 44-27472389 niepmd@gmail.com
29.	National Institute for the Hearing Handicapped	Mumbai, Maharashtra	Director +91-22-26400215/26409176/ 26400263 ayjnihhmum@gmail.com
30.	Nav Bharat Jagriti Kendra	Hazaribagh, Jharkhand	Mr. Satish Giriya +91-6546-263332 satishgiriya@gmail.com nbjkco@gmail.com
31.	NavChetna	Sri Ganganagar, Rajasthan	Mr. Om Baweja +91-154-2451052 +91-9024027339 navchetna2000@rediffmail.com

32.	Nehru SevaSangh	Banpur, Orissa	Ms. Sarojini Das +91-6756-223086 nehru_seva_sangh@sify.com
33.	SakshamDaksh	Noida, Uttar Pradesh	Ms. BipashaSengupta +91-11-42411015, 45793601 info@saksham.org
34.	Sharp Memorial School for the Blind	Dehradun, Uttarakhand	Ms. Sumana Samuel +91-135-2734238, 2788177 sharpmemorial.1887@gmail.com
35.	ShikshitYuvaSewaSamiti	Basti, Uttar Pradesh	Mr. GopalKrishanAgrawal +91-5542-242280 sysbasti@gmail.com
36.	ShriAndhjanVividhlaxiTalim Kendra	Jamnagar, Gujarat	Mr. PrakashMankodi +91-288-2712348, 2712380 pjmankodi@yahoo.co.in
37.	Society for the Visually Handicapped	Kolkata, West Bengal	Dr. Ruma Chatterjee +91-33-24759581 svh@vsnl.com ruma1@rojectmail.com
38.	Tripolia Social Service Society	Patna, Bihar	Sr. JoicySaldanha +91-612-2311065 joicysaldanha@gmail.com
39.	Uma Educational Trust Society	Kakinada, Andhra Pradesh	Mr. S. P. Reddy +91 884 2306039 umamanovikasakendram@gmail.com spreddy@umvk.org umamanovikas@yahoo.com
40.	Umang	Jaipur, Rajasthan	Mrs. Deepak Kalra +91-141-2395099 umangjaipur@gmail.com
41.	Upahar Madurai	Madurai, Tamilnadu	Mr. L. Shanmugam +91-452-2693666 upaharieic@gmail.com

List of Braille Press in India

Sl. NO	State	Address
1	West Bengal	The Regional Braille Press, Ramakrishna Blind Boy's Academy, 24, Paraganas, Narendrapur – 743508 West Bengal
2	Tamilnadu	The Director, college of Education, Sri Ramakrishna Mission Vidhyalaya, SRKV Post, Perianaickenpalayam, Coimbatore, Tamil Nadu - 641 020
3	New Delhi	The Secretary General, All India Confederation of the Blind Braille Bhawan, (Near Rajiv Gandhi Cancer Hospital), Sector V Rohini, Delhi – 110 085
4	Chattisgarh	The Manager, Govt. Braille Press, Tifra Police line Road, Bilaspur, Chattisgarh - 495223
5	Tamilnadu	The Manager, Regional Braille Press, Govt. Higher Secondary School for the Blind, Poonamallee, Chennai – 600 056
6	Karnataka	The Manager, Govt. Braille Press, Govt. Blind School, Tilak Nagar, SivajiRao Road, Mysore, Karnataka

7	Punjab	The Manager, Braille Press, Govt. Institute for the Blind, Jamalpur, Ludhiana, Punjab.
8	Assam	The Manager, Govt. Braille Press, Near Govt. Blind School Vaishshta, Guwahati, Assam
9	Maharashtra	The Manager, Braille Press, National Association for the Blind, 11, Khan Abdul Gaffar Road, Worli Surface, Mumbai, Maharashtra
10	Haryana	The Manager, National Federation for the Blind Press, Near Atamshudi Ashram, Delhi Road, Bahadurgarh, Haryana
11	Gujarat	The Executive Director, Blind People Association, Dr. Vikram Sarabhai Road, Vastrapur, Ahmedabad, Gujarat
12	Kerala	The Manager, Kerala Federation for the Blind, Kunukuzhi, Trivendrum, Kerala
13	Rajasthan	The Secretary, LKC Sri Jagdamba Andh Vidyalaya, Hanumangarh Road, Sri Ganga Nagar, Rajasthan
14	Orissa	The Hon. Secretary, Red Cross School for the blind, City Hospital Road, Bhrampur – 760 001

15	Tamilnadu	The General Secretary, Braille Press Christian Foundation for the Blind, 2 nd officers Lane, GST Road, Pallavaram, Chennai
16	Maharashtra	The Poona Blind Men'S Association Technical Training Centre, 109, Dr. Helen Keller Raod, RamtekdiHadapsar, Pune – 411 012
17	Dehradun	The Manager, Central Braille Press, NIVH, 116, Rajpur Road, Dehradun – 248001
18	Uttar Pradesh	The Exicutive Officer, Rehabilitation Society of the Visually Handicapped, c-223, Nirala Nagar, Lucknow - 226020

Digital Library

Brazil	- Service to Blind Central Library Universidad Federal of the Paraiba (UFPB)
Canada	- Canadian National Institute for the Blind Library (CNIB)
Finland	- Celia Library for the Visually Impaired (Celia)
Netherlands	- FNB Netherlands (FNB)
South Africa	- South African Library for the Blind (SALB)
Sweden	- Swedish Library of Talking Books and Braille (TPB)
United Kingdom	- National Library for the Blind (NLB)

Sl. NO	Library	Type of formats offered	Delivery methods of Materials
1	NLB	Braille Audio E-Books Tactile Large Print	- Hard Copy Circulation - E-mail delivery
2	CNIB	Braille Audio E-Books Tactile	- Hard Copy Circulation -CD on demand university students - Online Digital audio/download
3	Celia	Braille Audio E-Books Tactile	- Hard Copy Circulation - E-Books downloaded (password Protected Access to server)
4	TBP	Braille Audio E-Books Tactile	- Hard Copy Circulation - CD on demand university students - Online digital audio/download (University libraries can download)
5	FNB	Braille Audio E-Books Tactile Large Print	- CD on Demand - Braille on demand - E-mail delivery - Online digital text/download - Print on demand(large Print, Tactile)
6	SALB	Braille Audio E-Books	- Hard Copy Circulation - CD on demand

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