# PREFACE

Deafblindness is a unique disability - a combination of sight and hearing impairment. Though the degree of deafness or blindness varies, the combination of dual sensory loss leads to unique problems in an individual's communication, mobility and their ability to access information. This handbook is an attempt to understand deafblindness in a simple and lucid way. The field of deafblindness is not similar to the understanding of visual impairment or hearing impairment per se, but it is more complex as the combined effect of the dual sensory loss on the individual with varied degrees of hearing and visual abilities, make the individual's need for services even more specific. This is the second edition of Handbook on Deafblindness. In this book we will attempt to provide updated information related to deafblindness and the unique features of an individual with deafblindness, along with the implications it has on various areas of development and strategies to facilitate learning. Apart from that this edition will include information on the Rights of Persons with Disabilities (RPWD) Act 20161 National Policy on Education and an updated information on different areas relevant to the field of deafblindness.

The goal of this book is to help professionals from the field of education, rehabilitation and health care gain a better understanding and to explore the rationale of assessments and challenges associated with the clinical and functional considerations for these individuals. The principal purpose behind developing this handbook is to increase the interest among the educators for taking up challenges and initiatives towards working with deafblind individuals. This handbook will help them to plan their strategies for working with deafblind children, plan their curriculum leading to overall and all-round development. It also discusses the need for transitioning and readiness for vocational life of an adolescent deafblind. It appreciates the need for sexuality and related sex education of the growing individual, in the context of the deafblind adolescent's life and their early adulthood. In addition, it talks about the vocational need and the legislative provisions for deafblind individuals in India. In general, this book is an attemptto explore all aspects of a deafblind individual's life.

Sense International India aims at creating a greater sensitisation to challenges that deafblind individuals face in their day to day simple chores. Through this handbook we aim to facilitate ways to create enriching opportunities for them to experience the simple pleasures of life which we often take for granted. We aim to encourage education and rehabilitation of persons with deafblindness with the ultimate aim of taking them on the path to inclusion.

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# What we would like the reader to take away from this hand book

We have been parents, teachers, and professionals for children with Deafblindness, Multiple disabilities and Multi Sensory Impairment, for sometime now and have often been challenged not only by their sensory issues but also by the time spent chasing down appropriate programmes, diagnosis and services. It was always not easy but it certainly has been a learning process for us. Instead of being tempted to judge and simply move on, we look at our children with more caring and analytical eyes.

This handbook is not intended to be diagnostic, scholarly or judgmental but on the other hand it is meant to be a tool for self study and in-service training. The handbook is written in simple language covering general aspects of deafblindness from early intervention to vocational rehabilitation as a life cycle approach.

The material is designed to provide

* Basic information about deafblindness and how it affects the learning strategies and interaction with students with deafblindness
* Information on development of communication and Orientation and Mobility skills.
* Discussion on important concepts like Assessment, Transitioning, Sexuality and Vocational rehabilitation
* Laws and schemes for people with deafblindness and other disabilities

The modules/chapters are designed for individual, self paced study. They have been laid out for ease of use and understanding. This handbook has B chapters, covering the following topics: Understanding deafblindness; Communication; Assessment of children with deafblindness; Strategies for working with deafblind children; Transition; Sexuality; Vocational rehabilitation for persons with deafblindness and Legislative framework in India. Each chapter is designed in the form of an individual module which can be independently covered in a training session. Words with italic fonts can be referred back from the glossary, at the end of the handbook.

# Chapter -1 Understanding Deafblindness

In this module the learner will understand

* Definitions of Deafblindness, Multi-Sensory Impairment and Multiple disabilities
* Causes of Deafblindness.
* Characteristics of an individual with Deafblindness.
* Impact on learning

Professionals and parents often land up into self questioning, when they face problems while working with the child with deafblindness, where to start and how to deliver the best to get the best for the child? Tried and trusted approaches that often work well with other children seem less effective with deafblind children, as the word deafblind itself describes it's a dual sensory deficit faced by an individual. Knowing what deafblindness is all about and its characteristic features would enable you to reach out to the core of this disability and build up the further understanding of the same.

Before reading this module further, do give a thought on how life would be without being privileged to see with our own eyes, hear with our ears and interacting with the environment? By doing so you will be able to adapt to the world of deafblindness with more intensity and will yourself come out with creative ideas to render your best efforts while working with deafblind children. A person who is deafbl ind has a unique experience of the world. For people who can see and hear, the world extends outward as far as his or her eyes and ears can reach. For the young child who is deafblind, the world is initially much narrower. If the child is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach. Therefore, a magic wand of acceptance along with understanding of deafblindness is required while you work with them. Hence, you become the magic wand for the child/ren you will be working with by gathering maximum information that will help you understand your child better.

There are various definitions on deafblindness in the world. But, in India we mainly refer to RPWD Act 2016. However, there are some other definitions on deafblindness which provides a better perspective and can be referred while planning the rehabilitation of persons with deafblindness.

## Definition of deafblindness

"A condition in which a person may have a combination of hearing and visual impairments causing severe communication, developmental, and educational needs" and includes:

* Moderate to profound hearing loss and significant visual impairments;
* Moderate to profound hearing loss and significant visual impairments with other disabilities
* Central processing problems of vision and hearing;
* Progressive sensory impairments including hearing and visual impairment; and
* Possible loss of auditory and visual processing disorder (associated with severe locomotor or intellectual conditions) and severe communication delay. (Sense International India, 2014)

However, in RPWD Act 2016 Deafblindness has been defined as "A condition in which a person may have combination of hearing and visual impairments causing severe communication, developmental, and educational problems". {Rights of Persons with Disabilities Act 2016, clause (zc) of section 2) India.

## Explanation of deafblindness

Deafblindness is "A combination of hearing and visual impairments causing such severe communication, developmental, and educational problems that the child cannot be accommodated in either a programme specifically for the deaf or a programme specifically for the blind."{The Education for All Handicapped Children Act (PL. 94-142) of 1975 and the Individuals with Disabilities Education Act (IDEA) (PL. 101-476)}

According to Department of Education Policy Statement (March 1989), Britain.....the term 'deafblind' is used to describe a heterogeneous group (of children) who may suffer from varying degrees of visual and hearing impairment, perhaps combined with learning and physical disabilities, which can cause severe communication, developmental and educational problems. A precise description is difficult because the degree of deafness and blindness, possibly combined with different degrees of other disabilities, are not uniform, and the educational needs of each (child) will have to be decided individually."

You would have noticed that the definitions speak about:

* Combination of vision and hearing impairment
* An unique disability
* Does not imply total vision or hearing loss
* Communication is most severely affected
* Highly individualised training for education and vocations
* The world is much narrower
* Affects person in totality
* Associated medical conditions

The above mentioned definition gives a gross overview about deafblindness; it's a collective combination of varied features affecting intensely, the life of an individual with deafblindness.

To get clear view over distinction between deafblindness, Multi-Sensory Impairment (MSI) and multiple disabilities, the latter two are discussed in brief.

### Multi-Sensory Impairment

When children or adults have severe developmental problems in addition to their deafblindness they are known to have multi-sensory impairment. Many of these children will also have a wide range of other disabilities - such as learning difficulties, epilepsy, feeding problems and severe disabilities. Children with multi-sensory impairment have a combination of visual and hearing difficulties. They are sometimes referred to as deafblind but may have some residual sight and/or hearing. Many also have additional disabilities but their complex needs mean that it may be difficult to ascertain their intellectual abilities.

Children with multi-sensory impairment have much greater difficulties in accessing the curriculum and the environment than those with a single sensory impairment. They have difficulties in perception, communication and in the acquisition of information. Incidental learning is limited. These children need teaching approaches which make good use of their residual hearing and vision, together with their other senses. They may need alternative means of communication.

### Multiple Disabilities

It refers to a combination of two or more disabling conditions that has a combined effect on the child's communication, mobility and performance of day-to-day tasks. We can say that just as every child is

different, so too is every child with multiple disabilities. However there are some things that this group of children (deafblind/MSI and multiple disabled) have in common:

* It affects the all round development of the child.
* Communication with the world around is most severely affected
* Opportunities to interact with the environment becomes very limited
* Ability to move around in the environment is restricted
* Need regular help in simple day-to-day activities such as wearing a shirt, opening a door, finding a chair to sit down and so on.
* A highly structured educational/ rehabilitation programme helps in their training
* (Need curriculum Adaptation to study in inclusive setup

Handbook on Multiple disabilities, published by The National Trust For The Welfare Of Persons With Autism, Cerebral Palsy, Mental Retardation And Multiple Disabilities

From the above definitions and their descriptions it is evident that deafblindness is a complex group presenting many different conditions concurrently. The essential thing to remember is the difficulties deafblind children face in communicating with the world around them and accessing information.

## Causes of Deafblindness

There is no single medical condition which can lead to the unique disability of Deafblindness. People can be born deafblind or may acquire deafblindness later in life. People born deafblind as a result of infection, genetic syndrome or birth defect are termed as having congenital deafblindness or early onset deafblindness. Those who acquire deafblindness later in life as a result of trauma or accident, genetic syndrome, ageing or progressive infection are termed as having acquired deafblindness.

It may seem puzzling that a genetic syndrome can result in deafblindness at birth or later in life. This is because genes might have an immediate effect on the developing foetus or its effects may not be apparent until later in life. Since there are various syndromes and medical conditions, it would not be possible to discuss all in brief in this handbook. Therefore, only few major causes are being discussed in the section below.

### Congenital or early onset deafblindness:

1. Infections as a cause of deafblindness:

* Rubella virus or commonly known as German Measles leading to Congenital Rubella Syndrome (CRS)
* Cytomegalovirus (CMV), Herpes Simplex and Toxoplasmosis
* Meningitis and Encephalitis

1. Genetic or chromosomal syndromes as a cause of deafblindness:

* CHARGE syndrome
* Down syndrome
* Goldenhar syndrome

1. Congenital birth trauma as a cause of deafblindness:

* Premature birth
* Low birth weight
* Anoxia or lack of oxygen
* Other trauma or birth injury

### Acquired Deafblindness

1. Genetic syndromes as a cause of deafblindness

* Usher Syndrome

2. Accidents or other trauma as a cause of deafblindness

3. Ageing as a cause of deafblindness

Let's look at the above cited causes of deafblindness in detail

#### Infections as a cause of Deafblindness

##### Rubella ( German Measles)

Rubella, also known as German Measles, causes a group of congenital defects known as Congenital Rubella Syndrome (CRS). The disease is easily transmitted from the pregnant mother to the unborn foetus. As in the other prenatal infectious disease, rubella does not usually cause serious symptoms in the affected adult. A pregnant woman who is not immunised normally contracts rubella through the nose and throat.

The infection spreads, transmitting the virus to the foetus across the placement barrier. Once the foetus is exposed to the virus, the cells of the developing eyes, ears, CNS, and heart can be damaged. The rubella virus may inhibit normal cell division or destroy the tissue of small blood vessels. In some instances, it can alter normal processes within foetal cells. The earlier the infection is contracted, the more serious the malformations. CRS occurs among at least 25 percent of infants born to women who had rubella during the first three months of pregnancy. Infection of a pregnant woman can result in a miscarriage, stillbirth or the birth of an infant with abnormalities which may involve multiple organ systems and can cause microcephaly, mental retardation, cataracts, glaucoma, other eye defects, late onset of diabetes, hypertension, enlarged liver and spleen, dental abnormalities and deafness. Hearing impairment in CRS is typically sensorineural but may include accompanying conductive problems. Other complications may include brain damage, cerebral palsy and learning disabilities.

There is no specific treatment for CRS. Certain problems that are common in the new born period, such as blood and liver abnormalities, usually go away without treatment. Other individual birth defects, such as eye or heart defects, can sometimes be corrected or at least improved with early surgery. Infants with hearing or vision loss benefit from special education programmes that provide early stimulation and build communication and learning skills.

Rubella can be prevented by immunisation

* All children should be vaccinated as a protection from rubella. The rubella vaccine is part of the MMR (measles, mumps, and rubella) vaccine series given to children beginning at 12 months of age.
* To help protect unborn babies from CRS, women must be immunised to rubella before they become pregnant. Women having child bearing age should find out their immunisation status and receive rubella vaccine if needed. Usually, a blood test is done during pregnancy to determine if a woman is protected against rubella. Any pregnant woman who has been exposed to rubella should be referred to the doctor and/or health specialist.

Diagnosis:

The diagnosis of congenitally acquired rubella is made by;

1. The presence of rubella lgM (lmmunoglobulin M, an antibody against rubella) in cord blood or serum samples taken in infancy.

2. Detection of rubella antibodies at a time when maternal antibodies should have disappeared (approx. six months of age)

3. Isolation of rubella virus from infected infants in the first few months of life.

##### Cytomegalovirus ( CMV)

This is a potential prenatal cause of deafblindness. It is a commonly occurring virus that belongs to the herpes virus group. If a pregnant woman contacts CMV, the virus may be passed on to the developing foetus. Pre-natal diagnosis is not possible and there is no vaccine. Problems resulting from congenital CMV include hearing impairment, vision impairment, jaundice, enlargement of the liver and spasticity.

##### Herpes Simplex

Herpes simplex virus, the cause of genital herpes - Oral herpes, the visible symptoms of which are colloquially called cold sores, infects the face and mouth. Oral herpes is the most common form of infection. Infection of the genitals, commonly known as herpes, is the second most common form of herpes. Other disorders such as Keratitis and cerebral herpes infection leading to encephalitis are also caused by the Herpes virus.

##### Toxoplasmosis

Toxoplasmosis is brought on by the common parasite toxoplasma and is contagious through contaminated food and cat faeces. It may have devastating impacts on persons with weakened immune systems or those who are pregnant. One or more of the symptoms, such as aching muscles, fever, and headache, may last for several weeks.

##### Meningitis and Encephalitis

Meningitis is the infection of the membranes surrounding the brain and spinal cord, caused by many different viruses and bacteria. It can cause impairments at any time in life, depending on strain. and severity of infection. Meningitis can lead to serious long-term consequences such as deafness, epilepsy, hydrocephalus and cognitive deficit, especially if not treated quickly.

Encephalitis literally means an inflammation of the brain, but it usually refers to brain inflammation caused by a virus or an autoimmune disease. Encephalitis may also be called acute viral encephalitis. Encephalitis is more serious than meningitis, because it affects the brain itself. If the meninges are inflamed as well as the brain, the condition is called meningoencephalitis. Some people who have encephalitis are left with permanent brain damage. The type and degree of brain injury can vary.

#### 2. Genetic or chromosomal syndromes as a cause of deafblindness

##### CHARGE Syndrome

CHARGE association (or syndrome) is an acronym referring to children with a specific pattern of birth defects. The acronym is 11C1 for Coloboma, 11H11 for Heart defects, 11A11 for Atresia of Choanae, 11R11 for Retardation of growth and development, 11G1 for Genitourinary problems and 11E11 for Ear abnormalities. The incidence of CHARGE is about 1 out of 10,000-12,DDD births. It affects males and females of all races equally.

* Coloboma: It means cleft or failure of the eyeball to close resulting in abnormalities of the retina or optic nerve. This may result in significant loss of vision, defects in visual acuity resulting in near or farsightedness, and oversensitivity to light.
* Heart defects: It includes Tetralogy of Fallot, the most frequent type of heart defect reported in the CHARGE association. It is a congenital heart defect which classically has four anatomical components. It is the most common cyanotic heart defect and the most common cause of blue baby syndrome. Tetralogy of Fallot results in low oxygenation of blood due to mixing of oxygenated and deoxygenated blood in the left ventricle through the VSD (ventricular septal defect) and preferential flow of both oxygenated and deoxygenated blood from the ventricles through the aorta because of obstruction to flow through the pulmonary valve.
* Atresia (blockage) of choanae (nasal passage): As the name suggests it is the blocking ofthe airways from the back of the nose to the throat that would not allow breathing through the nose.
* Retardation of growth and development: It is usually due to heart problems, nutritional problems or growth hormone deficiency. The developmental delay is often associated with sensory deficits (vision and hearing loss). Some children with CHARGE may have associated condition of mental retardation.
* Genitourinary problems: In boys it includes genital hypop/asia and possibly undescended testes. Girls may have small labia. Abnormal urinary tract or kidneys is common.
* Ear abnormalities: It leads to unusually shaped ears (short and wide with very little or no earlobe). Hearing loss, conductive and/or nerve, ranges from mild to profound hearing loss.

Diagnosis:

At least four of these abnormalities should be present if a child is to be diagnosed as having CHARGE Association. If any child is suspected to have CHARGE Association, cardio-respiratory, ophthalmologic and audiological evaluations may be performed as well as abdominal ultrasound and chromosome evaluation.

##### Down syndrome

Down syndrome is a congenital defect caused by a chromosomal abnormality, caused by the presence of all or part of an extra 21st chromosome. The affected individual has three chromosomes (Trisomy) instead of the normal two for the pair at 21st chromosome. However, when some of

the cells in the body are normal and other cells have

trisomy 21, it is called Mosaic. Generally there is some degree of mental retardation and characteristic physical features such as flattened skull, slanted eyes, thick protruded tongue, and broad hands and feet giving the

person a Mongolian look It is very often accompanied by

visual impairment and sometimes by hearing impairment.

An adult with down syndrome

##### Goldenhar Syndrome

It is a congenital birth defect which involves deformities of the face. It usually affects one side of the face. Characteristic features of this syndrome include:

• a partially formed or totally absent ear (microtia)

• the chin may be closer to the affected ear

• one corner of the mouth may be higher than the other

• benign growths of the eye

• absence of eye (Anophthalmia)

• Goldenhar is also known as Oculoauricular Dysplasia or OAV

#### 3. Congenital Birth Trauma as a cause of deafblindness

##### Premature birth

Birth between 24 to 37 weeks of gestation is considered as premature birth. Multiple problems and complications which may also lead to deafblindness/ MSI and multiple handicaps along with different degrees of mental retardation can be present in an infant who is born premature.

##### Low birth weight

Low birth weight is a weight of less than 2,500 grams (5 pounds, B ounces) at the time of birth. It is usually associated with premature births.

##### Anoxia

The term anoxia means a total decrease in the level of oxygen. It is a condition that occurs when oxygen is not being delivered to a part of body. If the condition does not involve total oxygen deprivation, it is often called hypoxia. Child can experience lack of oxygen due to the chord around neck which can lead to respiratory distress causing Asphyxia or Anoxia resulting in Brain damage. Seizures, myoclonic jerks (involuntary muscle spasms or twitches), and neck stiffness are some others symptoms of the anoxic condition.

##### Trauma or Birth Injury

Trauma during pregnancy can injure foetus in the mother's womb. This can also lead to premature birth and/or bleeding. Emotional trauma too can affect development of foetus. Brain injury during delivery or falling of the child after birth can cause severe disabilities. This trauma can also be due to improper use of forceps. Birth injury is damage sustained during the birthing process, usually occurring during transit through the birth canal. A difficult delivery, with the risk of injury to the foetus, may occur if the birth canal is too small or the foetus is too large (as sometimes occurs when the mother has diabetes). Injury is also more likely if the foetus is lying in an abnormal position before birth. In a difficult delivery of a large infant, some of the larger nerves to one or both of the newborn1s arms can be stretched and injured. Weakness (paralysis) of the newborn1s arm or hand may result. Occasionally, the nerve going to the diaphragm (the muscle that separates the organs of the chest from those of the abdomen) is damaged, resulting in paralysis of the diaphragm on the same side.

Acquired Deafblindness as a cause of deafblindness

#### 1. Genetic Syndromes Usher Syndrome

Usher Syndrome is a genetic disorder that is characterized by hearing impairment as well as an eye disease called Retinitis Pigmentosa. As a result vision degenerates (gets worse) over time. Some people with Usher syndrome also have balance problems. Usher syndrome is the most common condition (aside from aging) that affects both hearing and vision.

A child with deafblindness (low vision) learning eye-hand coordination

The syndrome is transmitted (passed along) in families by autosomal recessive inheritance, which requires the presence of two copies of Usher gene for the disorder to be manifested. Each parent of a boy or girl with Usher syndrome is a 11carrier11 with one standard and one mutated Usher gene but no sign of the syndrome. A child with the syndrome has it because s/he received two mutated Usher genes, one from each of the carrier parents.

Types of Usher syndrome

* There are three clinical types of Usher syndrome. They are called Usher syndrome type 1, Usher syndrome type 2 and Usher syndrome type 3. Types 1 and 2 are more common than type 3. All types of the syndromes are inherited in the same pattern -- as autosomal recessive traits.
* Usher syndrome type 1 (US 1) - Children with US1 are profoundly deaf (sensory neural hearing loss) from birth and have severe balance problems. Many of these individuals obtain little or no benefit from hearing aids. Most use sign language as their primary means of communication. Because of the balance problems, children with US1 are slow to sit without support and rarely learn to walk before they are 1 B months old. These children usually begin to develop vision problems by the time they are ten. Visual problems most often begin with difficulty seeing at night, but tend to progress rapidly until the individual is completely blind.
* Usher syndrome type 2 (US2) - Children with US2 are born with moderate to severe hearing impairment and normal balance. Although the severity of hearing impairment varies, most of these children perform well in regular classrooms and can benefit from hearing aids. These children most commonly use speech to communicate. Retinitis Pigmentosa, which is a degeneration of the retina (the part of the eye that receives images of objects), is characterised by bl ind spots that begin to appear shortly after the teenage years. The visual problems in US2 tend to progress more slowly than the visual problems in US1. When an individual's vision deteriorates to blindness, his or her ability to read speech from the lips is lost.
* Usher syndrome type 3 (US3) - Children born with US3 have normal hearing and normal to near­ normal balance. Hearing worsens over time. Children develop noticeable hearing problems by their teenage years and usually become deaf by mid to late adulthood. Retinitis pigmentosa in the form of night blindness usually begins sometime during puberty. Blind spots appear by the late teenage years to early adulthood. By mid adulthood, the individual is usually blind.

Diagnosis:

Hearing loss and Retinitis pigmentosa are rarely found in combination other than from Usher syndrome. Finding them together is strong presumptive evidence for Usher syndrome. Special tests such as Electronystagmography (ENG) to detect balance problems and Electroretinography (ERG) to detect Retinitis pigmentosa help detect Usher syndrome early. Early diagnosis is important in order to begin special educational training programmes to help the individual deal with the combined hearing and vision difficulties.

#### 2. Accidents or other trauma as a cause of deafblindness

Road accidents can cause deafblindness in people due to injury to parts of the brain that deal with information processing tasks through sight and hearing. Some traumas such as stroke or cerebral haemorrhage can have an effect on those specific parts of brain that deal with hearing and sight.

#### 3. Ageing as a cause of deafblindness

Most common cause of deafblindness is simply the age. After the age of 50 years, hearing and vision impairments become more common and prevalence of sensory impairment increases with age.

* Paralytic attack
* Sometime in later age, due to paralytic attack mostly in paraplegic condition, as it effects the half part of the brain. There is immense chance of partial vision and hearing losses due to insult in occipital and temporal lobe of cerebrum.
* Other than these significant causes, there are some other causes that may cause deafblindness in individuals which are as follows:
* Nutrition
* During the pre-natal period, baby is completely dependent upon the mother for its nutritional needs. This is the most important time of an individual's life as far as nutrition is concerned. This time of rapid growth and development of the baby determines whether or not the child has met the developmental potential, not only as a baby but for the rest of his or her life. Poor nutrition and unbalanced diet during pregnancy can cause low birth weight or premature birth. Infants who survive these conditions are more likely to have mental retardation, cerebral palsy, epilepsy and respiratory disease which may result in deafblindness/MSI or multiple handicaps.
* Jaundice
* Jaundice results when a chemical called bilirubin builds up in the baby's blood. Too much bilirubin can cause hyperbilirubinemia. Kernicterus is a type of brain damage that causes athetoid cerebral palsy and hearing loss. It also causes problems with vision and teeth and sometimes can cause mental retardation. Maternal jaundice during pregnancy can also be vital for the developing foetus. High level of bilirubin can harm the developing brain of foetus and thus hearing and sight might get affected.
* Rh incompatibility
* Rh incompatibility is a condition which develops when there is a difference in Rh blood type between that of the pregnant mother (Rh negative) and that of the foetus (Rh positive). During pregnancy, red blood cells from the foetus can get into the mother's bloodstream as she nourishes her child through the placenta. If the mother is Rh-negative, her system cannot tolerate the presence of Rh-positive red blood cells. In such cases, the mother's immune system treats the Rh-positive foetal cells as if they were a foreign substance and makes antibodies against the foetal blood cells. These anti-Rh antibodies may cross the placenta into the foetus, where they destroy the foetus's circulating red blood cells. Rh incompatibility can result insevere anaemia, jaundice, brain damage and heart failure in a new born. In extreme cases, it can cause the death of the foetus because too many red blood cells have been depleted.
* Maternal fits
* Epileptic attacks and convulsions cause a risk of maternal and foetal hypoxia as well as increasing the foetal heart rate. During labour and delivery there is also the risk of premature labour in the epileptic mother.
* Fits
* Epilepsy is a brain disorder in which clusters of nerve cells, or neurons, in the brain sometimes signal abnormally. In epilepsy, the normal pattern of neuronal activity becomes disturbed, causing strange sensations, emotions, and behaviour or sometimes convulsions, muscle spasms and loss of consciousness. This abnormal signal sometimes destroys the brain cells.
* Drugs
* Addictive drugs such as cocaine, heroin, and amphetamines (speed) or barbiturates (downers) used during pregnancy place the baby's life at risk. The drugs may cause brain damage, such as when a foetus experiences a stroke due to cocaine exposure. Bleeding, stillbirths and premature delivery are only a few of the additional complications that can result from the use of narcotics during pregnancy.

## Characteristics of individuals with Deafblindness

It is commonly estimated that 95% of information comes to us through our v1s1on and hearing. Individuals who have a hearing or vision loss don't have access to the same amount of information without accommodation for their sensory loss. As discussed earlier that depending on the age of onset, the characteristic features of deafblind individuals vary from one another making them unique in themselves. Before discussing the characteristics of deafblind individuals in detail lets have a glance at

the features of deafblind individuals enlisted by Mcinnes and Treffery, 191:12. They described deafblind individuals as a group with wide ranging characteristics mentioned below:

* Lack the ability to communicate with his/her environment in a meaningful way
* Have a distorted perception of the world
* Be deprived of the information necessary to anticipate future events or the results of his/her actions
* Be deprived of many of the most basic extrinsic motivations
* Have medical problems that lead to serious developmental lags
* Be mislabeled as developmentally disabled or emotionally disturbed
* Be forced to develop unique learning styles to compensate for his or her sensory impairments
* Have extreme difficulty in establishing and maintaining interpersonal relationships

These are few of the more serious results of the loss of the effective use of distance senses. Professionals and other workers often fail to comprehend the importance of the complexity of this problem and utilize partial solutions to modify existing programmes to meet the needs of deafblind individuals. In order to find solutions to the complex problems of deafblind children, we must understand in details the areas wherein they find difficulty expressing and receiving information which leads to the development of clear perception of world and people around them. In order to understand deafblind children we must understand their characteristics in terms of communication, hearing, vision, motor skills, mobility and social relationships. Let's discuss each of them one by one to gain greater insights into the world of deafblindness.

### Communication

Communication is the area which is affected the most in deafblind individuals. Deafblindness greatly reduces the interaction level of an individual with his/her environment. As we grow and interact with our environment, there is a development of varied concepts around us that in turn leads to the subsequent learning of skills each time. We rely on the information that we get through our visual channels and from what we gather through hearing. Loss of any one distant sense i.e. vision/hearing will directly affect the communication skills. You would observe following points in an individual with deafbl indness:

Difficulty in communicating or inability to communicate in a meaningful way. Due to limited pathways to explore self in an environment, natural inputs that would help an individual to express himself completely are missing in a deafblind individual. Learning from our natural surrounding and learning the right way to communicate gives meaning to our communication and here sensory input from all the senses plays a major role.

Often, communication attempts are missed or misunderstood because the right method to communicate is unknown due to lack of observation and exposure on the part of deafblind individuals and on the immediate contact or caregivers as well. This leads to development of inappropriate communication skills and maladaptive communicative behaviour of deafblind individual.

* Difficulty in approaching a right communication partner who would understand and relate to the need.
* Poor understanding of world around them.
* Restricted modes to communicate as they are unable to speak, read and write.
* They do not have many developed social relationships and therefore remain isolated from the world.
* Due to lack of visual and auditory information there is reduced motivation to communicate.

Being unable to see and hear and due to missing environmental inputs, there is a void in linking with the formal communication system and therefore only a systematic approach towards teaching communication, starting from concrete to abstract, facilitates learning process in deafblind individuals.

### Vision

Sense of sight has been taken as primary source of learning for most of the individuals. Vision guides the developing child's motor milestones and also often takes a lead role in every developmental domain. Vision deficits restrict an individual from non-linguistic communication, i.e. the mode of communication not involving language but other ways such as gestures, signs, body language, e.g. inability to use eye contact to initiate and end communication.

A child going through functional vision assessment

Interpretation of body language (visually) to help understand a speaker's mood and meaning is lacking, may be because the conversation is out of their visual ranges.

Different conditions such as Nystagmus and eye poking become a hindrance to learning. There are certain challenges which are associated with the loss of vision

* Vision brings together information gathered through other senses
* Vision tells us about the world that is at a distance
* Vision helps us anticipate what is about to happen
* Vision give us a sense of the" whole" object or event
* Vision enables alertness and attention even without a structured period

Other visual characteristics of a deafblind individual includes

* Loss of visual acuity: Deafblind children have difficulty in seeing the objects accurately.
* Loss of visual field: Deafblind children may have limited field of vision which includes upper or lower field of central and peripheral vision . They have difficulty in moving the eye ball in vertical direction as other children do.
* Difficulty in moving eyes when fixating, following and/or scanning & tracking objects with his eyes.
* Reduced contrast sensitivity: Deafblind children may have difficulty in seeing the relative difference between the lightness and darkness of objects
* Processing problems: Deafblind children may have difficulty in making sense out of what s/he is seeing. This is especially common in deafblind children having Cortical visual impairment
* Completeness: Deafblind children may have difficulty in seeing parts of the image or complete picture together
* Squint: Squint or Strabismus refers to a condition in which the eyes do not work together. One or both eyes wander up, down, inward, or outward.
* Gazing: Gazing is the behaviour in which deafblind children try to see the object for long time to understand about the object.
* Oculomotor problems: Deafblind children may have difficulty in coordinated movements of the eyes which makes it difficult for the child to focus and fixate
* Nystagmus: Nystagmus is involuntary movement of eye balls. Due to this, child fails to see the object clearly and has difficulty in understanding objects.
* Eye poking: Many deafblind children show eye poking. It may be a stereotype behaviour that stimulates the vision; however, eye-poking may lead to intense, self-induced pain, and is a harmful behaviour because it can result in permanent visual loss and even in total blindness.

### Hearing

Out of the five senses that human beings are normally born with, nature has endowed the sense of hearing with significant social and biological functions, ranging from the reflex alerting to the sounds around us to the relatively effortless development of speech and language skills. Though these skills will be affected by the presence of a hearing loss, they do not disappear as long as some residual hearing remains and is fully utilized. At its most basic, sound is produced by a force (e.g., wind) acting on some object (e.g., trees, the ocean), the awareness of which (consciously or unconsciously) is a way that human beings adapt to, and feel part of, their immediate environment (e.g. the sounds of nature, traffic, and home appliances). The sense of hearing, the perception of sound and its biological purposes, is not therefore a trivial consideration that can be lightly dismissed. On the contrary, it is a human birth right that must be respected and utilized to the fullest extent possible.

We interpret our environment by hearing different information that comes our way and we develop concepts on our own without being taught by someone. For example certain sounds in the environment, bird's chirping, cow's mooing, all is learnt on our own, the relational factor is taught later, that is parents or immediate family members may ask, "did you hear how bird sounds?" and then ask "how does a bird sound?". But, when we talk about a child with deafblindness, these inputs are missing, the use of functional hearing also gets restricted due to lack of intervener who would direct and polish the residual hearing.

Following pointers will further help to know the characteristic of an individual with deafblindness:

* Children with deafblindness require training for utilizing their residual hearing to the maximum.
* Sometimes deafblind children respond to a particular sound and not to other sounds
* Balance difficulties: Balance, or one's sense of equilibrium, is controlled through the vestibular system that is also contained in the inner ear. Balance and equilibrium help us stay erect when standing, know where we are in relation to gravity, and help us walk, run, and move without falling. The functioning of the vestibular system depends on information from many systems, hearing as well as vision and muscle feedback.
* The vestibular system also controls the sense of movement and balance. Vestibular system is the sensory system considered to have the most important influence on the other sensory systems and on the ability to function in everyday life. The child with deafblindness, faces problems related to balance due to structural impairment in ear.

### Motor and Mobility

Children learn about their environment as they move through it. They learn about people, objects, sizes, shapes and distances. For typically developing children the senses of sight and hearing provide the greatest motivation for exploration. Children use their vision and hearing to gather information about their surroundings while growing, to understand their own bodies and their own capabilities of movement. The sight of toys or people and the sounds of voices or objects encourage them to move and discover. As they do so, they gather, recognize, and interpret an amazing array of sensory information. Children with deafblindness get constrained information through sensory system.

* Severe medical problems and/or other handicapping conditions, leads to serious developmental delays affecting motor and mobility problem that affects life1s expectancy of a child with deafblindness.
* Difficulty in independent exploration and hence getting a control over the environment.
* Due to the limited interaction with the environment, children with deafblindness do not get to explore themselves and in the immediate and surrounding environment.
* Conceptual development and experience of space and direction differ significantly from other children.

### Social relationship

We develop our social relationships by interacting with one another, through different modes of communication. Imagine a world with big void of communication, no one to interact with, and no one to talk to, with restricted pathways towards reaching others. Socialisation is altogether an outcome of communication. An individual with deafblindness has very poor scope of reaching out to others to share his/her needs, events, and entertainment.

Following pointers will enable you to know more characteristic features related to socialisation:

* Extreme difficulty in establishing and maintaining interpersonal relationships with others. As deafblind children have different ways of communication than other members of society, they face difficulty in initiating and understanding conversations.
* Isolation and Disconnection from society: Due to communication difficulty, deafblind children are isolated within their own community.
* Living in a world that may seem alternately coming at them or getting disappeared into the thin air creates a secluded environment. Deafblind children sit at one place and do not get opportunity to participate in day to day activities at home due to their limited self exploration of environment around them.
* Social deprivation: Communication, Orientation and Mobility difficulty, leads to a confined socialisation, they do not participate in social activities. Knowing what is happening around and participating accordingly enables the person to be socially active and participate fully.
* Isolation: Deafblind individual may detach from others and avoid social interaction. Due to unique way of communication, deafblind children hesitate in initiating conversation which results into detachment from society. And they also learn to avoid social interaction.

### Behavioural

Any behaviour of an individual has a reason behind it. Due to our skills and limitations we acquire certain behavioural patterns that get added to our personality. For example, an individual who recognises his limitations in fluent communication with others would gradually develop a behaviour of remaining quiet in a social gatherings, or may adapt to certain behavioural pattern that would stimulate his/her needs towards reaching out to others. We often look out for alternatives to our present and not satisfying conditions. It's an in built human nature to strive for self satisfaction that gives pleasure. We adapt to various behaviour patterns to rule out our confusions, our fears and also to add on to our own self with new positive concept.

Due to these deficits in an individual with deafblindness, s/he may acquire behavioural patterns that may not be well understood by others in the society. Some of them are mentioned below:

* Typical self-stimulatory behaviours such as eye poking, body rocking.
* Due to lack of observation and exposure to socially appropriate manner of eating food, child with deafblindness may acquire socially incorrect manner of eating food.
* The child also resists different types of food textures due to hypo/hyper sensitivity towards touch or sounds.
* They may have unusual sleep patterns.
* May exhibit variety of behaviour patterns to express their needs and emotions which may be unacceptable in society.
* Unique needs and learning styles due to sensory deficits.

Let's see as a whole, what are the general characteristic features of children and youth with deafblindness. However, all individuals with deafblindness may not exhibit all.

* A distorted perception of the world due to lack of direct information from the distance senses. Difficulty in generalizing learnt information to other settings.
* Deprived of many of the most basic extrinsic motivations such as curiosity. Lacks the ability to anticipate events.
* Lacks observational learning.
* Unable to take advantage from group instruction

## Impact of Deafblindness on learning

As mentioned earlier that 95% of whatever we learn comes through our eyes and ears. Children with deafblindness, therefore, face major challenges in learning. Due to limited vision and hearing these children face problems in communication, mobility and activities of daily living. Deafblindness causes such severe communication and other developmental and learning needs that the persons cannot be appropriately educated in special education programmes solely for children and youth with hearing impairments, visual impairments or severe disabilities, without supplementary assistance to address their educational needs due to these dual, concurrent disabilities. Children with deafblindness are educationally isolated because impairments of sight and hearing require attentive and unique educational approaches like curriculum adaptation, individualise education programme in order to ensure that children with this disability have the opportunity to reach their full potential.

For a child with deafblindness, the world is initially much narrower. If the child is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach. Their concept of the world depends upon what they have had the opportunity to physically come in contact with.

A girl with deafblindness learning through flash card

If a child with deafblindness has some useable vision/hearing, as many do, her or his world will be enlarged. Many deafblind children have enough vision to be able to move about in their environments, recognise familiar people, see sign language at close distances, and read large print. Others have sufficient hearing to recognise familiar sounds, understand some speech, or develop speech themselves. Children with intact vision and hearing learn effectively from all they do and from all that happens around them. These learning experiences include a series of day to day events happening around the child. Because the senses of vision and hearing help the child to organise the information

from the world around him, it is important to consider that the deafblind child does not have access to opportunities that helps in such incidental learning, as sighted and hearing children do have. Deafblind children acquire fragmented and distorted information from their contact with people and environment.

A child with deafblindness will learn to use all the information about the world around him with the use of his tactile, olfactory, kinaesthetic and proprioceptive senses along with whatever residual hearing and vision they might be having. And to make this kind of learning it is important for child with deafblindness to participate actively in the full sequence of the activity. In other words, deafblind

children will need to experience activities in the real-life settings as A child with deafblindness learning they are occurring naturally in the environment around them. Through art and craft, they will learn best by doing things together. Loss of sight and hearing also makes the child feel very fearful about the physical environment around him/her. S/He is not able to judge his own body in the space around him. His/her awareness about the organisation of the space and his/her safety concerns are also limited. It is therefore difficult for the child to get interested to move around in his/her environment independently and this has an unfavourable effect on his/her learning opportunities. Learning through doing, forms the basis of a strong learning environment for a child with deafblindness. It is evident that the child faces a major obstacle in learning because of the lack of opportunity to access visual and auditory cues from the environment, less able to anticipate events in his/her immediate environment and limited scope to make choices. To reduce this loss, it is important to develop routines in the life of a child with deafblindness.

# Chapter - 2 Communication

In this module the learner will understand

* Communication and different definitions
* Different Modes of communication
* Development of communication
* Fundamental concepts of communication
* Communication development in children with Deafblindness
* Understanding communicative environment
* Fostering communication in children with Deafblindness

An adult with deafblindness exploring plant through touch "Communication is a bridge". It's a basic need of any living creature. Everybody needs to communicate to fulfil their needs. Communication is a medium through which we exchange our feelings, our thoughts, our needs and desires. We use varied ways to send and receive messages. Communication need not be talking to one another, but reaching out to the other person giving and receiving information from the other person, using any mode. Communication opens all doors and enables us to reach one another and access our environmental information. It also helps us to exercise control over our environment.

The concept of communication is much broader than the concept of reception and expression of oral or written language. We receive communication from and communicate with our environment constantly throughout our waking hours. The smell of food being cooked in the kitchen, the sound of water running from the tap, the feel of a cloth, a raised eyebrow all communicate things to us about the world. We use body language, pictures, physical proximity or distance and oral and written language to communicate to others. Communication can be summed up as our attempts to obtain information from and impose order upon the world around us. (Mcinnes, J.M and Treffry J.A 1997). Children with visual impairments can very well hear the language and therefore develop and understand most of the related concepts very easily. They lack access to non linguistic forms of communication like eye contact, understanding the mood of the speaker through body language etc. Research has shown that a majority of our communication is non-verbal. And individuals with deafblindness have limited or no access to this major form of communication, in addition to having limited or no access to spoken language.

## Definition

Communication can be defined as the process of transmitting thoughts, ideas, information and messages from one person to other. There are a variety of ways that children with deafblindness communicate. For children who have hearing and vision problems, communication may be somewhat different. It may not always be one person talking and another person listening.

"Communication is a dynamic process that individuals use to exchange ideas, relate experiences, and share desires through speaking, writing, gestures or sign language" (Glenn & Smith, 1 QQB). "Communication includes language, speech and hearing and hence communication impairment can be viewed as any impairment related to these three areas" (Sunderland, 2004).

## Modes of communication

One may use different ways to express self and understand others. Similarly children with deafblindness use different modes to communicate. Following are the different modes of communication used by children with deafblindness:

### Sign Language

Sign language involves using specific hand shapes and body movements to express ideas and concepts. It can be visual or tactile. In visual signing, signs are made in front of the person. Positioning, distance, speed, complexity and lighting can be adjusted according to the need of individuals with deafblindness. Tactile signing involves signing with the receiver's hand resting lightly on the signer's hand. Tactile signing is suitable for people who have very little vision or no Child with deafblindness using sign language vision at all.

### Hands-on signing

This requires no sight and is based on touch. The person who is deafblind places his/her hands on the hands of the person signing so he/she can feel the hand shape, position and movement of the signer's hands to understand what is being

signed.

### Visual Frame Signing

This is used by people with hearing impairment with tunnel vision (tunnel vision is the loss of peripheral vision with retention of central vision, resulting in a constricted circular tunnel-like field of vision). It is similar to standard signing, but the hands are kept near the upper body and face, within the visual field of the individual with deafblindness so they do not disappear outside the tunnel.

### Finger spelling

Finger Spelling is another mode of manual signing performed using the fingers. Finger spelling is felt by the person with deafblindness using their palm. There are different manual finger alphabets like American/British/Indian manual alphabets. For example, American manual alphabets, which is practiced using a single hand with a particular hand shape for each alphabet in English whereas, British and India Alphabets are practiced with two hands.

Each alphabet of the word is spelt with changes in shape of the hand, and the deafblind individual can feel the spelling and makes out the word using his palm over the hands of the speller. This is very convenient and fast. The fingerspelling is used to spell out names of people and places for which there is not a sign.

### Print on palm

This method is used where letters are drawn on the palm of the deafblind person's hand, one after the other. The letters are block capitals, drawn with as few strokes as possible to make it easier to feel.

### Speech

Children with deafblindness who are hard of hearing may be able to hear speech. Some people with profound hearing loss are still able to speak clearly enough to be understood. Persons with acquired deafblindness especially who lost their sense of hearing after acquiring language will use speech for expressive communication.

### Lip reading/speech reading

Deafblind children with sufficient vision may use lip reading to understand speech. It is important to speak slowly with sufficient light on the face of the speaker to enable the child with deafbl indness to see clearly.

### Tadoma

Tadoma is tactile lip reading. The person reading the speech places his/her thumb on the speaker1s lips and his/her fingers along the jaw line, touching the speaker1s cheek and throat. From this he/she is able to pick up the vibrations of speech as well as the lip patterns.

A deafblind adult reading the words through Tadoma method

It is sometimes referred to as 1tactile lipreading1, as the person with deafblindness feels the movement of the lips, as well as vibrations of the vocal cords, puffing of the cheeks and the warm air produced by nasal sounds such as 1N1 and 1M1• Use of Tadoma however requires good fine tactile discrimination skills, cognitive skills and fine motor skills.

### Braille

Braille is a system of touch reading and writing in which raised dots represent the letters of the alphabet. Braille is read by moving the hand or parts of the hand from left to right along each line. Both hands are usually involved in the reading process and reading is generally done with the index fingers. Braille is a code and not a language almost all the languages existing in this world has braille code of their own.

### Moon code

The Moon system of embossed reading was invented by Dr William Moon in 1 l145. Moon writing is intended for blind or partially sighted people. The characters are fairly large and over half the letters bear a strong resemblance to the print equivalent. Moon alphabets/writings has been found particularly suitable for those who lose their sight later in life, or for people who may have a less effective sense of touch.

The Moon system of embossed reading is based upon the standard Roman alphabet. The Moon alphabet is made up of 14 characters used at different angles, each with a clear, broad outline.

### Haptic Communication

The word haptic is Greek and means touch. Haptic signals are preferably drawn on the upper part of the back or upper part of the arm. Through this persons with deafblindness are able to receive information about their surroundings, the mood and facial gestures of other people. It is not just interpreting what others say it enables the person with deafblindness to perceive the whole environment well. We could draw the environment to make them understand where they are sitting, shape of the hall etc.

### Gestures

Gestures or non verbal communication and body language communicate as effectively as words and may be even more effectively. We use gestures daily as they are woven inextricably into our social lives. For an individual with deafbl indness learning to communicate and express themselves through gestures is very difficult. Some children with deafblindness express their needs through vocalisations Communicating through gesture (crying/cooing/babbling).

### Symbols

A symbol is something that stands for and represents something else (referent). Communicating with the help of symbols is called symbolic communication. Spoken and written languages are examples of abstract symbols and real objects are examples of concrete symbols.

### Cues

A cue is a prompt that is individualised for each deafblind child and is used to encourage a specific behaviour. It is dependent on specific activity or context. For example tapping a child on chin may be a prompt for "open up mouth "if caregiver wants to brush Child's teeth, or for "take a bite" during meals or "close your mouth" to prevent drooling. However the same cue will not be used for all these. For each of these actions there has to be a different touch cue. There are different types of cues that are used in developing communication of a deafblind child, namely touch, movement, contextual cues and object cues (used for receptive communication). We would be discussing them in detail in the later section of this chapter. Gestures and cues are some of the ways to let a deafblind child know what is about to happen to him or her.

## Development of Communication

Communication process starts at birth and various kinds of sensory and other informational inputs are the most vital factors in ensuring its appropriate development. The capacity to communicate is an inborn one. The child starts interacting with the mother or other care givers right at birth. The mother attends to the child's cry, makes him comfortable, smiles at him, talks to him in baby language and the child gets attached to her. Child starts responding to her in his own little ways and an interaction starts. Some of the ways in which the child may communicate in early years are:

* Facial expression
* Vocalisations such as crying, cooing and babbling Change in muscle tone
* Touching or manipulating others Body movements
* Assuming positions Pointing
* Natural gestures
* Showing aggression (biting, pinching, throwing things etc.)

Deafblind children do not have the security and motivation to move around and interact with people and objects in their environment. The information they receive about their environment is also distorted and interferes with their interaction with others. Thus they often remain isolated and face the challenge of having very little opportunity to acquire communication skills incidentally. There should be some reason to communicate. Early communication should be based on emotional bonding and the needs of the child to have a control on his/her environment. We should avoid anticipating the needs of the child as this will reduce the opportunities he gets to communicate and for problem solving. As an educator or professional and parent we must ensure that he has problems to solve and choices to make and that he must communicate his decisions to you.

Let's try to understand the pathway of communication development in children through this example.

*Seema has just awakened from her nap with a soiled nappy. She fusses a bit to let her mom know she's awake. She looks up as she hears footsteps and the opening of door to see her mom walking towards her crib. She listens to her mom talk to her as she bends down over her crib, picks her up, and carries her to the washroom. Seema recognizes where she is from many previous experiences. She knows what's coming! She watches her mom take a bag from the shelf, open it, and pull out a clean dry nappy. Seema is cooperating with her mom to put her dry nappy without any fuss. After mom removes her wet nappy, Seema watches her take the cover off a big round bucket of water, drop the nappy in and then replace the cover. Once she's cleaned up, she enjoys the freedom of kicking her feet without the restrictions of her bulky sleeper. When cleaned her mother starts playing with her, touches her cheeks, claps and make sounds, changed her expressions and speaks to her in a different tone. Seema too tries to bring her hands closer seeing her mother clapping and enjoys the moment.*

Through this example we can make out that Seema is beginning to learn to anticipate daily routines and to develop an understanding of many important concepts such as object permanence (something still exists even if I can't see, hear, or feel it), "containers" (in/out, open/close, size, shape) spatial organization and imitation.

Thus we can now make out that communication development follows the path mentioned below:

Body games >Anticipation >Intentional communication >Social >Mutual Feedback>Turn taking>Imitation

Now think of a deafblind child who due to his/her sensory deficits lacks all the experiences of taking and responding to information present in the environment.

Due to his sensory deficits his communication development is delayed to far greater extent and learning social interaction, communicating with others to express his needs and responding back to others requires lots of time and patience, both on the part of learner as well as the educator. Deafblindness leads to severe implications on the part of individual that makes communication development process a very lengthy and tedious one. This process becomes more difficult if there are additional disabilities along with dual sensory loss.

Some of these implications of deafblindness on communication abilities are enlisted below

* Eye contact that helps maintain communication with others is missing.
* Body language that helps person to take information about the speaker and sometimes also conveys meaning of speaker's information is not interpreted due to visual loss.
* Inability to anticipate what is going to happen next and understanding prompts hinders development of reciprocal interaction and turn taking.
* Inability to understand the meaning of communication expressed through tone of voice.

## Fundamental concepts of communication

In order to understand how we can work with our deafblind children in order to develop their communication skills we must learn about following fundamental concepts of communication:

1. Preintentional- Intentional communication

Preintentional communication is when child says or does things without intending to affect those around them. Some of the examples of pre-intentional communication are:

* General body movements: for instance, stiffening the body
* Arms, legs and hand movements
* Facial expressions

Intentional communication is when child says or does things with the purpose of sending a message to another person. This type of communication can be used to protest about what they are being asked to do and make request. Some of the examples of intentional communication are:

* Touching things to indicate that they want them
* Pushing things away, extending objects, smiling, pointing, kissing and hugging to express various needs

1. Presymbolic-Symbolic communication

Presymbolic communication is the early form of communication (also called pre-linguistic or preverbal communication) used by infants. In this form of communication there is a direct physical relationship between person who is communicating and what messages are sent. Vocalizations such as crying, cooing, fussing indicate physical state of child and reflect how child feels. This is one of the examples of pre-symbolic communication.

Symbolic communication, as the name suggests, is the one which is being done with the help and use of symbols (abstract or concrete). An object, picture, sign or word symbolizes a concept and can be used to discuss the concept in isolation, from the actual event. Accessing symbolic communication is a great step towards independence for a child since it allows them to request or remember something not physically or temporally present.

1. Receptive-Expressive communication

Receptive communication is the process of receiving and understanding the message. It is often difficult to determine how a child who is deafblind receives messages and responds to your communication. We would be discussing about the ways they receive information and messages through different types of cues in the later part of this chapter.

Expressive Communication as the names suggests involves sending a message to another person to make something happen or to stop what is going to happen. Symbols, signs and various other modes of communication listed in the beginning of this chapter are various ways of expressing feelings and desires by individuals with deafblindness.

## Communication development in children with deafblindness

As has been discussed in the earlier chapter and also throughout the book; development of communication in deafblind children is a very difficult and complex task. It is as complex as understanding deafblind children. Each deafblind individual is unique and therefore possesses unique ways of communicating with his/her immediate outside world. Let us learn about different levels at which educators and professionals can work and enable them to communicate with their social world.

In this section we will discuss different types of cues and symbols in detail used for receptive and expressive communication.

### Receptive communication

It is difficult for us to imagine how a child with deafblindness receives and interprets messages. It becomes more difficult for the child with additional impairments. In order to develop receptive communication skills, the child must be given cues about the expected response. There are different cues which help develop receptive communication skills in individuals with deafblindness.

1. Touch Cue: Cue is given by touching child1s body part related to the activity or action e.g. touching lips for feeding; waist for nappy change. Touch cues must be given just before doing the activity for better connection of the cues and the activity.
2. Movement Cue: Moving a child in a pattern that relates to an activity e.g. moving hand to mouth to eat, moving arms up and down to play drum
3. Contextual cues: Cues given or taken by the child during an activity or in a situation e.g. smell of cooking food, smell when passing by public toilets, grass in the garden.

Cues are helpful in developing communication as they help develop anticipation and make associations, the most vital aspect for developing communication skills. These are used often with individuals at early stages of development of communication. However there are few things that must be kept in mind while using cues with children.

* Cues must be used same way each time by every person
* Cues must immediately precede an activity for them to be relevant
* Cues have to be different from one another so that child may easily discriminate and relate to particular activity

Once child starts understanding and responding to touch, movement and contextual cues, educators and professionals can move towards developing next level of receptive communication, through object cues. Object cues are basically objects taken from daily activities that are presented to the child, as cues for these activities. There are different types of object cues which are presented to the child in the similar sequence as they are mentioned

1. Partial object cues: These are the partial representations that may be used in the place of whole object e.g. handle grip for tricycle
2. Associated objects cues: These are another type of cues which are related to the activity but in a less direct or clear way. For example, use of tokens for depicting lunch time in a cafeteria or a lunch ticket.
3. Arbitrary object cues: These are the objects which are not logically related to the activity and are used to represent the activity. For example, student goes to school office regularly. An object cue i.e. a block is fixed on the office door and a similar cue given to the student, student will find similar block on the office door.

It's not that we can use any object at any point of time as an object cue. In order to teach effective communication to the child through use of object cues, following factors must be kept in mind

* Initially objects chosen for cues should be those that a child is most likely to associate with the activity- for example a towel or a soap for a bath
* Object selected must be such that the child uses it during the activity
* Objects selected in the beginning must be real
* It could be replaced once connection has been made (It helps child understand that object symbolizes/represents activity)
* Once child develops receptive language skills by using different cues, Professionals and educators can start working on developing their expressive language skills using tangible symbols. Tangible symbols are type of concrete symbols which can be touched and are either three dimensional (objects) or two dimensional (pictures). These symbols can be physically manipulated by the user and have clear relationship with what they represent. User or the deafblind individual have to recognize or indicate them using motor response i.e. picking up, pointing or touching (therefore lesser demands on cognitive skills) from display of symbols. There are different types of tangible symbols:
  + Whole objects
  + Partial Representations
  + Imposed/Arbitrary symbols
  + Pictures (for low vision children)

There are different ways through which we can promote the use of tangible symbols by deafblind individual or in a way promote their receptive and expressive communication skills. Therefore we must keep in mind following points to promote the same:

* Miniature symbols must be avoided especially with children who are totally blind
* Check to see if the student understands the meaning of each and every symbol
* Find ways of recording the child's performance
* Expand the student's vocabulary
* Increase the number of symbols in the display
* Use the symbols in different contexts
* Encourage the child to use the symbols for a variety of functions
* Make the symbols more portable so that the child can use them in a variety of situations
* Change to the next level of symbols when appropriate

## Understanding Communicative Environment

When we talk about communicative environment, the focus is on the amount of consistency in interaction levels with child/person with deafblindness. If the information given or provided to the individual is consistent, adequate and appropriate, the response will also be at par. Like any other child, child with deafblindness also needs full and accurate information about the concepts and their environment to respond, if not they will be at a loss to respond to the environments or make decisions about how to participate in them.

Interactions can be characterised by repetition; experiences with objects, people, and events that are accompanied by others comments or descriptions of them. Children who are deafblind can miss much basic information about their surroundings that the natural repetition of daily interaction with the environment provides. Hence, if we concentrate on building concepts in different ways, with emphasising on the child's interaction level, like repeating the information quiet often in the similar way each time by each person who interacts with the child. For example, teacher uses a touch on Monika's shoulder to indicate that she can sit down and place Monika's hand on a chair to indicate where Monika can sit. Monika's parents use exactly the same pair of cues to help Monika sit herself for meals in art class; a classmate gives Monika the same cues. This consistency and the use of touch for communication cue allows Monika to participate in ordinary activities with a better understanding of what she is doing and why.

Following indicators about the communicative environment would enable you to understand the characteristics of environment that encourages efficient communication with deafblind individuals:

1. Respectful and responsive: The environment in which the deafblind child communicates needs a listener. The listener needs to respond positively to every communicative attempt the child makes.
2. Mutually Interactive: Non-directive environment should be equally responsive to deafblind children. Environment should not dictate the child how to communicate but facilitate the child to communicate. Both the child and the listener need to share and enjoy the conversations.
3. Scope for making choices: Deafblind children should be given opportunities for making choices whenever and wherever possible
4. Compensation for sensory loss: Environment should accommodate the unique sensory needs
5. Opportunities for generalising: Whatever the deafblind child has learnt in one environment, that learning should be transferable to other environment. Child needs similar communication options and opportunities to communicate in different settings and with different people
6. Variety of reasons to communicate: Environment should provide various reasons and stimulation for communication to deafblind children. A child should be motivated to communicate.
7. Assessment of Communication: Assessment of communication is very important for the deafblind children. To teach them to communicate with the society, we must assess their communication skills and abilities. There are different areas and aspects of communication. We can assess the child's preferred mode of communication for receptive and expressive communication, vocalisations, gestures, eye gaze, changes in movement, alertness, vocalisations, signing etc. What methods does the child use for receptive and/or expressive communication? How does the child use these? How does the child respond to the teachers, parent, and peers? i.e., cues, verbal requests, pause for turn-taking.
8. Communication Planning: Planning to teach communication to deafblind children is very challenging. Every person who communicates uses some FORM to communicate; every communicative attempt has a FUNCTION, TOPIC, CONTEXT and CONTENT.

## Forms of Communication

Form refers to how the child is communicating. Deafblind children communicate in a variety of forms like:

1. Facial expression
2. Pointing
3. Sign language
4. Using objects
5. Using pictures
6. Vocalisations
7. Speech
8. Large Print
9. Braille and some other methods mentioned earlier in this chapter

Forms of communication can be hugging familiar person to show love and affection. Behaviours can also be a way to show likes and/or dislikes about person, place, activity or object.

## Function of communication

Function of communication can be understood as purpose of communication. Every person who communicates has some reason or purpose. At an early age, children communicate for variety of reasons like:

* Protesting or rejecting
* Gaining attention, objects, giving orders etc.
* Requesting the continuation of ongoing activity(s)
* Making choice for, eatables, friends to play with toys etc.

At later stage in life the reasons to communicate could be

* Offering something to others
* Commenting and suggesting on things
* Greeting socially
* Giving and gaining information from others
* Making requests
* Seeking or giving Information

## Context and Topic of communication

Context of communication roughly means the "environment in which the child communicates" which includes people as well. The topic could be anything within or outside the environment. This could be any person, object, favourite game, pain, weather, food and so on. This also includes daily living activities. It is the environment and the immediate activity within which the child communicates.

### Content of communication

Content of the communication is what you want to communicate. 1When some body hugs someone, S/he wants to communicate that he loves him/her.1 To plan the communication for deafblind children, all these five components of communication should be kept in view.

### Teaching methods to expand communication

Teachers can use a number of methods to enhance the use of communication and the development of interactions at school and in the community by children with deafblindness.

Some of those useful methods are listed below:

* Family must be given priority; child1s interaction with his/her environment is dependent upon the family's activities and different source of interaction.
* Communication options should not be limited. Based on the skills the child will be learning and the communication pattern involved in the surrounding environment, the communicating partner with whom the child will be interacting, different communication options should be involved.
* Communication should occur with many different people (including peers).
* Communication should not be one sided/directive. Who so ever is interacting with the child should interact as a partner and not give orders. For example, "do what I am asking, without questioning".
* Communication between the partners should be as direct as possible. Interpreter may be involved to facilitate social interaction at all times. If interaction is frequent, all must learn appropriate ways of communicating, including the use of augmentative aids.
* Communication exchanges should occur frequently.
* Communication is a dynamic process, hence all our programme planning must enhance child1s interactions at every level (environmental, partners, skill areas). Communication should be part of all areas in the educational program for the child (IEP).
* During interaction systematic procedures should be used to expand the student1s communication system.

## Fostering Communication in children with Deafblindness

### Preparation: Communication initiation

Use of different gestures, touch cues, including signs allow the child with deafblindness to anticipate what 1s happening around, anticipate the activities, express a reaction to its occurrence, and become ready to participate in it. A child may dislike an activity even ifs/he is unaware that the activity will be presented to him/her.

For example if child is taken from one room to other without intimating and have been asked to put objects from one box to other. S/he will become confused and resistant, and will struggle with the boxes. When ever the activity is scheduled, even if the child likes the task, s/he may not like to indulge in the task because of compulsive indulgence. However, if the child was taken to the calendar box, wheres/he finds a sorting of objects in one section, the child will be prepared for the activity and would enjoy the whole activity.

### Choice of the activity

As we all keep changing with our choice of activities similarly children with deafblindness goes through the same depending upon the mood, physical well being, or other factors. If we structure our settings in such a way that it provides maximum opportunities to the child for making choice, helps him/her to make communicates his/her preferences and enables to have control over the environment. Successful control over the environment stimulates the child to communicate more and to get to still work more to have control over the environment.

### Environment

Children having dual sensory loss of varied degree, environmental conditions, such as the amount of lighting, noise, can have impact on the enjoyment of the activity or interaction and the amount of communication they understand and express. For instance, consider the case of Santosh who is 12 years old and has Usher Syndrome. He is learning Braille typing and reading. He has been given a task to read and type for maintaining learnt skill. When practicing task, he along with his friends sit together and practice. Sometimes he is made to sit a table in a darker area of the room by other classmates just to change the sitting position. There he is unable to see others well, and read what ever is given. Even though his friends help him to read, but still he feels uneasy in this situation. He shared his situation with the teacher, who encouraged him to tell to his friends what he needs and ask them to sit at a well-lit­ table, so he can participate in the conversation.

### Safety

Child needs to be comforted and should be a given a secure environment. Insecurity can push off even a most anticipated activity. Safety factors like travel conditions, Orientation and Mobility instruction and skills, and familiarity with the trainer should be considered.

### Familiarity

We all including children with deafblindness seek an environment that is familiar for learning a new skill. For example, a deafblind child is learning names of fruits and vegetables and is learning to go to the vegetable shop for strengthening the skill. Since s/he has limited vision and hearing, child's first trip would be confusing because of different light, smells and vibrations. The child may not remember and would seek teacher's involvement in locating the item. After a weeks trip to the shop, the child would be able to identify varied cues to relate self to the store and would be more comfortable to the whole thing.

# Chapter – 3 Assessment of Children and Adults with Deafblindness

In this module the learner will understand

* Basic concept of Assessment
* Goals and purpose of assessment
* Types of Assessments ans challenges in assessing children with Deafblindness
* Key elements to effective assessment of children who are deafblind
* Essential assessment domains
* Assessing adults with Deafblindness
* Tools for assessing children and adults with Deafblindness

Assessment and Evaluation are the two critical components of the special education process go beyond scores, standard deviations and levels of functions. Evaluation is defined as an act of determining a child's eligibility for special education. Assessment is a process through which one

determines the child's abilities and needs for services. Assessment is collating and bringing together information about the child's need, which may include social, psychological, and educational evaluations to determine services. Assessment is a process using observation, testing, and test analysis to determine an individual's strengths and weaknesses in order to plan his or her educational services. In short, assessment is a systematic method of gathering information in order to describe functioning, determine needs and set priorities and goals.

## What is assessment?

Assessment involves gathering of information in many ways, like testing the child directly, observing the child in varied environments as well as interviewing family members and significant others. Assessment is done before implementing the intervention programme. Assessment is the first step that is taken by an educator/ therapist to develop a holistic programme for the child. We assess the child's environment, child's communication, visual and Teacher assessing a child hearing abilities, cognitive abilities, physical, socialization skills, personal factors like child's likes and dislikes, strengths and areas where development is required. Assessment also includes retrieving information regarding medical and educational history. An assessment is the crucial stage in addressing the particular needs of the individual deafblind person. It provides a foundation on which a plan is made and services provided.

All the information so gathered is then summarised using brief and specific statements that demonstrate, what has been achieved by the child in each of the curricular areas over an extended period of time. Evaluation is the most important step often done at the end of the programme implementation to evaluate the effectiveness of the programme. Evaluation process is however an ongoing process that helps the educator to keep mending the approach with the child with deafblindness to provide for the best and holistic development of the child.

At the least, assessment process should include an evaluation of the child's communication, cognitive, adaptive and everyday functioning, including behavioural concerns (where appropriate). An evaluation of the family, home, and /or classroom should be considered to establish goals, resources and priorities.

## Goals of Assessment

It is important to keep questioning our own actions while we are working with the deafblind child. It is very important to keep on asking ourselves "Why?" all the time. Why does the child adapt this behaviour? What purpose could it serve? What does it mean or indicate? Constantly asking ourselves these questions and seeking the answers often gives valuable dimensions/perspectives regarding the interpretation of the child's varied behaviours which in turn gives us valuable information about the child. Regular and ongoing assessments of the children are very important. But more important than that is, for us to be clear, about why we need information about the child. What are we going to do with the assessment information, how are we going to use this, and with whom are we going to share this information. How is this information going to change our interaction and working with the child. Assessment has many valid uses. Given that the use of existing standardised instruments to obtain developmental information as part of the assessment process, brings about certain challenges and there does not appear to be a reasonable alternative (Sattler, 1992). Thus, it is necessary to understand the purpose of assessments and its challenges so that the tools which are available can be used correctly and the results can be interpreted in a valid way.

## Purpose of assessment

Whether the child has been deafblind from birth or has acquired a dual loss, the purpose of the assessment is to provide a description of a child's level of sensory, motor, cognitive and communication functions. The assessment should be set in the context of the clinical information including aetiology, visual acuity and hearing thresholds, and the assessor should integrate this information to provide a rounded picture/commentary of the child's needs and provide useful recommendations about strategies to meet them.

It is important to note here that sometimes it might so happen that we do not have access to clinical assessment services. In such cases it is important to take support from the parents, all the more, as valuable sources of information. This information coupled with our functional assessment would help us give a description of the child that would assist in our intervention.

* Assessment will help the educator, professional and parent:
* To identify the strengths and limitations of the child with deafblindness
* To know the developmental levels
* To know various needs like social, environmental, family, medical and communication
* To know what to teach and the best method to teach
* To identify appropriate programmes and instructional strategies
* To classify and place the child in the appropriate programme
* To provide with the most appropriate amplification, vision and mobility aids and /or other prosthesis
* To develop an Individualised Educational Plan
* To know the likes and dislikes of the child, what works well
* To Identify the need of adaptation and modification

## Types of Assessment

Traditional assessment methods include standardised tests and systematic observations. The various types of assessment like, Norm referenced assessment, Criterion reference assessment, curriculum and performance based assessment, formal, functional, ecological and observational assessment all compliment each other and form a firm foundation for making decisions about the child.

The use of more than one assessment procedure, ideally a combination of clinical and functional assessment, with more reliance and emphasis on functional assessment, provides a wealth of information about the child and interpersonal variables that affects the child's behaviour. Besides the type of assessment procedure adopted, we must keep in mind the challenges in assessing children with deafblindness and multi sensory impairments.

Child with deafblindness learning pre-braille skills

* Wide variety of needs
* Inconsistent behaviour
* Variable sensory function
* Ill health and many other conditions and/or disabilities (like epilepsy, spasticity, etc,) affecting children with deafblindness
* Basic perceptual differences between child and assessor.
* Reduction, distortion or absence of distance sensory information affects children's ability to anticipate, act to changes in events, and perceive consistency and structure experiences in pace and time
* Activities, which do not form a part of the deafblind child's typical routine, or which introduce unfamiliar people to the child, may induce confusion and stress which cannot be easily overcome
* Attention span may be limited
* Time of the day will also have an effect on the child's level of alertness in turn affecting the responses
* Assessment in an unfamiliar environment will also affect the results of assessment
* The type of material used for assessment also plays an important role
* Child may respond in different ways to different people making the interpretations difficult. Some children may give only subtle response and that should be observed and understood by the assessor
* Time taken for assessing the children with deafblindness also matters a lot, many children may take extra-long time to understand first and then to react
* Medication may have an effect on the responses.

While conducting assessments we need to keep in mind certain things that help us gain more insights about the Childs unique style of learning and expressing self. Sometimes while conducting assessment we tend to focus and concentrate completely on results of the assessment and might forget to consider other important aspects that might affect the reaction of the child.

Some important factors that affect the process of assessment are:

* Focus on child's deficits rather than skills
* Ignoring the child's motivators
* Pacing inappropriate for the child: the time of day, the place, the activity, the people present and the materials used
* Task too complicated and too challenging for the child
* Too serious - where is the play?
* Expectation that the child will "pass or fail"?
* Inappropriate assessment tools
* Mimicry of standardized clinical assessment procedures (timing, positioning, materials, expected outcomes)
* Lack of a whole-child perspective
* Assessor's blinkers (Expecting and anticipating a particular result from the assessment)
* What is a response?(Assessor himself or herself is unable to observe or not clear about the responses given by children in different situations observe or not clear about the responses given by children in different situations

## Key elements to effective assessment of children who are deafblind

Children with deafblindness or multiple disabilities tend to experience the world as it exists within their immediate reach (Barbara Miles, 2000). Many of these children may have some residual vision and/or hearing. However, the combination of this dual sensory impairment limits the extent of interaction they have with people, access to information about events and objects at a distance, incidental learning acquired just by seeing and hearing, and development of meaningful concepts about home, school, and community.

Successful assessments should include:

1. Family Participation

* Incorporate active family involvement throughout the assessment process.
* Interview the family regarding their priorities, immediate goals, and long term dreams.
* Include family input in planning assessment activities, time for assessment and materials for assessment
* Use family members to facilitate some assessment activities, as they are familiar and trusted by the child
* Give attention to any family concerns that remain following assessment
* Questioning the parents and family members and getting answers will not give exact picture about the child. Instead they should be asked to describe like story, assessor should listen well and note down the vital information shared by them.

1. Trans disciplinary Assessment

* Assessment of the deafblind child across natural settings and familiar environments (i.e. home, classroom).
* Selection of a variety of familiar, everyday activities where different skills can be assessed.
* Use of a transdisciplinary team approach in which educational team members share knowledge from their areas of expertise for other team members to incorporate in their practice.
* Follow-up team assessment by using information to plan the educational program.
* Focus IEP goals and short-term objectives on behavioural skills to be developed or expanded.

1. Assessment Strategies

* Base interactions on data in most recent vision and hearing reports. Selection of toys or other objects that use the child's preferred colours, textures and sounds. Presenting the objects in the positions where the child has the best vision and hearing. After the child is engaged, move the toys to varying positions to assess any response.
* Use the child's current communication program if one exists. Interpret the child's changes in behaviour as communication and prolong the exchange to learn more about how the child communicates.
* Select a single team member to act as activity facilitator to decrease the number of people with whom the child will interact.
* Choose activities based on family routines.
* Include components that apply to classroom instruction and appropriate age level activities.
* Ask the child to make choices, follow steps in a routine or indicate what comes next in an activity.
* Embed critical skills within activities to assess the child's level of understanding and response. Does the child initiate activity? What level of support or prompt is needed? What is the child's response if the routine is changed or sabotaged? What kind of choice­ making is shown?
* Create a report in which team members contribute to one comprehensive final document based on areas assessed. The report should include ideas for planning and educational programming

## Essential assessment domains

Things to be kept in mind while assessing children with deafblindness in the following essential domains

Social/Communication domain: (it includes vocalizations, gestures, eye gaze, changes in movement, alertness, verbalizations, signing)

* What modes/methods does the child use for receptive and/or expressive communication?
* How does the child use these?
* How does the child respond to the assessment facilitator, parent, and peer? I.e. cues, verbal requests, pause for turn-taking.
* Who are the child's communication partners?
* How do they communicate with the child?
* What are the child's preferred modes of communication?
* Does s/he understand objects?
* How does s/he use them?
* What are his/her topics for communication?
* Does s/he initiate interactions/conversations?
* Does s/he communicate at a pre-intentional or intentional level of communication?
* Does s/he use gestures or pointing? Does s/he show anticipation?

### Sensory/Motor domain:

* What are the child's likes/dislikes in terms of textures, sounds, objects, colours, activities?
* Tolerance for different types of sensory input?
* Willingness to explore new and unfamiliar sensory input? Is s/he sensitive to touch of a person or object or food on specific parts of his/her face or mouth?
* Does s/he enjoy activities involving deep pressure on his body?
* How is his/her gait?
* Does s/he have bilateral coordination?
* Can s/he cross midline?
* How does muscle tone affect the child's ability to participate in activities? (Motor planning, stamina, reach and grasp)
* What supports and physical modifications are used and what are the results of each?
* What positioning works best for stabilization, comfort and greatest range of motion?

### Functional Vision domain:

* Does the child appear to have useful remaining vision?
* What focusing and tracking patterns are present?
* How does the child use near vision and distance vision?
* What is observed about the visual field-use of central or peripheral vision?
* Do visual fields appear to be intact?
* Does the child look at an object while interacting with it or look away, and then act?
* Does the child show colour preferences? Preference for movement rather than still objects?
* Are eyeglasses or low vision aids recommended or tolerated or in use?
* How does lighting affect him/her?
* What is the child's preferred learning mode: visual, auditory, or tactual?

### Functional Hearing domain:

* Is the child aware of sound?
* Does s/he alert to sound, orient to sound, localize sound, isolate a specific sound in the presence of other sounds?
* Does the child respond to a selected sound among other sounds?
* Is the child frightened by any sounds?
* Likes and dislikes in sounds?
* Does s/he understand and respond to routine verbal instructions/commands?
* Does s/he recognize people by their voice?
* Does the child appear to use hearing to respond during the assessment to voice, music and speech?
* Are hearing aids recommended or tolerated or in use?

All of the above, areas need to be assessed because they are interrelated in their influence on the deafblind child's ability to make sense of the world. Accurate functional data on vision and hearing is particularly critical since it is the combined effect of the dual sensory impairment that requires instructional approaches differing from strategies used with children having a vision or hearing impairment.

Only when the child is assessed in settings where s/he is familiar with the facilitators, routines, and materials will s/he have the opportunity to respond in a way that gives a true indication of developmental/cognitive level. The child will demonstrate competencies and areas where skills are emerging or as yet undeveloped. The more accurate the assessment of the child, the more effective will be the next steps toward greater meaning and participation at home, school and in the community.

## Assessment of adult with deafblindness

The assessment of adult deafblind should provide as far as possible a complete representation of the person's needs. It should be conducted in accordance with other relevant government initiatives as they apply to the individual. The assessment of adults with acquired deafblindness should

include:

* The degree of hearing and sight loss, and the functional impact of this on everyday life.
* Other health conditions or medical needs
* Communication needs - both receptive and expressive
* Mobility and orientation skills
* The potential for learning new skills and the appropriate time to introduce them
* Support in the home and community
* Equipment and adaptation requirements
* Social work support
* Welfare benefits and other finances
* Emotional and spiritual needs

When assessing congenitally deafblind adults the following issues should also be covered:

* Use of other senses
* Independence and self-help skills
* Ways to introduce new skills
* Daily needs
* Environmental needs
* Social needs
* Leisure activities

Vocational needs should be separately assessed for deafblind persons who are employed. The assessor should adapt deafblind person's preferred mode of communication or a method or a joint approach. Incorporating the view of the deafblind person, will bring several benefits. It will evade workers and others acting on wrong assumptions. It will be an indication for establishing a good relationship with the deafblind person. It will also enhance the status of both the deafblind person and their preferred communication method.

## What should go into the Assessment Report?

The assessment information will form a report. It should distil what has been learned during the assessment process and make observations and recommendations about the type of support each child may need to gain full access to the social environment. This may include, the three important points that we need to remember while preparing the assessment report i.e., what are the major observations? What do these observations mean? And what will we do with these observations? One has to be very careful while making assessment reports as this will help in guiding the future planning of the curriculum for the child.

## Tools for Assessing Children and Adults with Deafblindness

1. Learning through doing: This tool was developed by Blind Peoples Association, Ahmedabad and National Institute for the Empowerment of Persons with Visual Disabilities (NIEPVD), Dehradun to assess children with multiple disabilities. Many experts from the field have given their contributions to make this tool comprehensive. It was developed in 2002 and is an assessment tool as well as programming manual. It covers areas like:
   * Social areas
   * Personal care
   * Orientation and Mobility
   * Functional academics
   * Independent living/Vocational skills.

This tool also focuses upon recreational activities like festivals and animal movies. It also provides information related to assessment format, Individualized Educational Programme planning and periodic evaluation.

1. Callier-Azusa Scale: The Callier-Azusa scale is a developmental scale specifically designed to aid in the assessment of deafblind children and children with severe and profound disabilities. It is designed to be particularly comprehensive at lower developmental levels.

This scale is not a teaching curriculum; its purpose is to provide the assessment information necessary to synthesize developmentally appropriate skills for a child. This scale can also be used for evaluation purposes.

The Callier Azusa Scale is composed of 1 B subscales in five areas-

* 1. Motor development
  2. Perceptual development
  3. Daily living skills
  4. Cognition, communication and language
  5. Social development

Administration of the scale is based on behaviours which typically occur in conjunction with classroom activities. This scale must be administered by individuals who are thoroughly familiar with the child's behaviour.

1. Functional assessment: for vision and hearing problem in children developed by Sense International India. This format can be used for assessing the functional vision and hearing problems among children and adults with deafblindness in special schools, villages or in camps. The simple questionnaire can be answered by observing the child in his familiar environment, with the support of the family members, teachers and the community.

We must understand that a child with deafblindness assessment needs to be carried out by an appropriately qualified and experienced specialist because deafblindness affects all areas of development including the formation of parent-child relationships and advice and support to the family is vitally important. Families and children benefit greatly from a multi/trans disciplinary approach involving a range of professionals, including specialists from health and education, who can share their knowledge to provide support.

# Chapter - 4 Strategies for working with children with deafblindness

In this module the learner will understand

* Using right strategy with children with Deafblindness
* Considerations for selecting teaching strategies.
* Basic steps involved in using teaching strategies.
* Developing teaching programme for deafblind students.

Right strategy involved in implementing the programme for children with deafblindness is a route towards successful results in developmental areas. Right strategy is the strategy which is especially developed for a child for meeting his/her specific needs focussing on his/her holistic development (total development as a whole). Strategy is not a curriculum or a document, it helps teachers to use appropriate activities and plans to meet curriculum goals and help in planning how and where to work on suitable activities.

When working with children with deafblindness, the characteristics of successful programmes should include the provision of a highly structured curriculum with specific, clearly stated objectives, focusing on the individual needs and level of understanding, attention span of each child and instruction that is step-by-step in nature. With the individual needs of the child, different objectives and instructional procedures are framed for each student. Practical experiences in natural environments give hands on experience to the child and he learns by exploring environment on his own. Structured routines preset for the child enables the child to anticipate the next event coming its way. Teacher needs to be creative enough to introduce a new teaching strategy if the current strategy is not fruitful; persistence on an unsuccessful teaching strategy should be avoided. Age-appropriate materials are important, as are motivation of the student and the provision of successful experiences. The emphasis should be on what the student can do in given situations, not on his or her limitations but beyond that. Over-learning (going over a skill after it seems to be mastered) is important and much repetition may be necessary. Planning for the transfer of instruction to real life situations is also very important. A successful programme for children with deafblindness is future-oriented; its goal is to prepare students to function as independently as possible once they leave school. Challenges that students have in educational and other life area settings include:

* Difficulty with communication: Due to restricted mode of communication, there is lack of opportunities to get more and more information.
* Distorted perceptions: Difficulty in grasping the whole picture or relating one element to the whole.
* Lack of anticipation: Difficulty in knowing what is going to happen next because the context normally provided through 'overseeing' or 'overhearing' information and cues is missing or distorted.
* Lack of motivation: The motivating factors may be missing from a situation, going unseen or unheard.
* Lack of incidental learning: Firsthand individualized experiences are a much more effective way for someone who is deafblind to learn than incidental observation or group experiences.
* Lack of structured environment: There is lack of disable friendly environment. The structured and communicable environment helps to learn about environment.

## Considerations for selecting teaching strategies

1. Age appropriateness: Always select instructional materials and activities that are suitable as per the age of the student.
2. Avoidance of stereotypic judgements: Do not assume that a person with Multiple Disabilities is unable to perform certain skills and participate in specific activities and events just because he has many limitations.
3. Cultural background: Choose material and activities that reflect the student's cultural and family background and expose him to new culture that reflects the cultural diversity of his community.
4. Involvement of other Peers: Involve the student whenever possible in activities with non-handicapped peers. The student with deafblindness can usually participate in some way.
5. Peer interest: Encourage the student's to support or assist his/her friends and peers. Match students with different skills so that they can assist each other.
6. Privacy: Remember to respect the student's privacy. For example, respect his/her privacy when teaching self-care skills such as toileting and bathing. However, do not sacrifice safety for privacy.
7. Interests and choices: Deafblind students' interests and choices must be considered at every stage of learning.
8. Learning style: It is important to know the learning style of the students; whether tactile, visual, auditory or kinaesthetic.
9. Attention span: It is important to know the attention limit of individual child.
10. Condition of sight and hearing: It is important to keeping in mind about the condition, type of vision and hearing. It helps in using assistive devices and technology.

Following points would help you identify effective teaching strategies and techniques for deafblind child:

* Help the learner communicate and understand different communication modes.
* Make use of the residual hearing and the residual vision. But at the same time educator must also be aware of what the learner can and cannot hear or see and how it changes in different environments. Accordingly, modify the student's immediate environment or help the student deal with the change in environment.
* Respect and encourage the use of touch since hands may be the link to everything and everybody.
* Give plenty of time for reactions and decisions. With less access to context, it may take longer to 'put the pieces together'.
* Build a strong relationship/bond with the student
* Give them safe environment in which they feel secure
* Develop a positive self-esteem by giving the learner opportunities for choices.
* React to the learner1s actions and communication attempts every time they happen.
* Give immediate feedback to their actions, including reinforcing success and giving strategies to refine their actions.
* Plan experiences so that problem solving is required.
* Use functional activities that can be learned in the natural routines of the day.
* Plan activities and experiences so they involve the learner at every step, from start to finish, of an activity. Too often, people and objects appear as if by magic and disappear the same way. Consider the use of 1Experience books1 to give deafblind student a way to have a conversation about what they have experienced.
* Let the student know who is in the room, when they enter and leave if they are not able to see. Even if they can see a person enter, they may not be able to identify who that person is.
* Incorporate communication in all areas of the Individualised Educational Programme.
* Remain calm. A student may react negatively to a teacher who is losing or has lost control.

Basic steps involved in using teaching strategies

* Describe the strategy: Students obtain an understanding of the strategy and its purpose­ why it is important, when it can be used, and how to use it. .
* Model its use: The teacher models the strategy, explaining to the students how to perform it.
* Provide ample assisted practice time. The teacher monitors, provides cues, and gives feedback. Practice results in automaticity so the student doesn1t have to 11think11 about using the strategy.
* Promote student self-monitoring and evaluation.
* Encourage continued use and generalisation of the strategy. Students are encouraged to try the strategy in other learning situations.

## Developing a Teaching Programme for students with Deafblindness

### Independence is the goal

No matter how small or big the task, the child should learn to use it to make Iife easy and simpler for him. Teaching strategies selected should be such that it helps in acquiring new skills and maintaining already present skills.

Preparing for independent life

### Teach skills that are functional and meaningful

With the limited opportunities available to the child, it is wise to teach him things that are directly with the limited opportunities available to the child, it is wise to teach him things that are directly related to his environment and those that he has high chances of doing throughout the day. Teaching skill meaningfully means whatever objectives one has selected for the child; it should give meaning to his/her life and should be of functional use. Each skill selected should focus on, how this skill is going to help in attaining self dependency level. For example, if teaching direction towards kitchen is the goal this can be done by hanging spoons or any other kitchen item on the walls leading towards kitchen area. In a similar manner, other objects belonging to the kitchen or related to cooking can also be selected. But, if one starts with objects that are totally unrelated or are completely new to the student then it will create confusion.

### Teach skills in a natural setting

This point has been emphasised number of times. Children memorize things more easily that they experience in their day to day life. This helps them to learn better and remember naturally. Natural setting is the child's environment in which s/he grows and wheres/he is present most of the time. This helps them to relate to all happenings around them and this increases their adaptability towards new things in the known environment.

### Break tasks into small steps

Small steps help children to practice better and remember better. Analysing task as per the need of the child, not only helps the teacher to teach in more systematic and simpler manner, but also the motivation level remains high as the child has smaller targets to achieve, this gives a sense of accomplishment to the child and helps him/her to learn further ahead.

### Provide assistance as needed

Encourage the child in every attempt. Do not laugh at or scold the child whens/he is performing his/her best with you. Providing assistance whenever the child seeks support is important. Different stages of learning new task require constant acknowledgement by others, as it provides reassurance for the attempted task and motivation for the next step.

Similarly child with deafblindness requires assistance while learning new skills. Teacher's input is very important, instead of being agitated with child's slow pace of learning, maintaining a constant learning environment is required. Assistance does not mean, providing total support to the child while performing the task. The level of assistance or prompts gets reduced gradually with the child's progress in the task. This is referred to as Fading.

### Provide repeated opportunities to practice skills

This will help the deafblind child to get repeated opportunities to try out the activity again and again. Once the child has acquired the skill, to maintain the learnt skill it is important to give the child maximum opportunity to practice it; this is called maintenance. Task may be the same but with variety of experiences and varied environments. For example, if teaching the child to segregate two different objects, multiple activities can be added in, like segregation of banana and grapes, potato and tomato, etc. This is emphasizing onto segregating two different objects. Once the child is able to maintain the skill in similar setting, the task needs to be performed in different environments too, for example, segregating grocery items, segregating rice from dal, depending upon the child's functional vision, motor skills and severity of the present condition. This is called Generalization of the learnt task.

### Take advantage of the teachable moment

Sometimes you may not plan to teach an activity, but the deafblind child shows curiosity to explore a particular object. Use this time to teach him more about that object. This is the best time to teach to the child as the activity gets developed on its own. Being a teacher you need to be highly sensitive and observant and move on with the child. For example, when sitting with a younger sibling, if child suddenly starts playing with the younger one, this time will help him/her to explore lot many things and get motivated to learn ahead.

Use Total Communication

Use speech, object/pictures, signs, gestures etc. It gives opportunity to learn through different modes and support to learn more easily. It supports to use residual hearing and vision.

### Speak to students using normal language and voice

We need not shout and scream or order them because we are trying to teach them. Do not exaggerate your expressions or voice modulation, when teaching a child with hearing and vision deficits.

### Use real objects

When experience to know about the world is so Iimited, it is better to use objects that he sees and uses everyday, rather than expensive and unusual things with him. The more experience the child will get to know what is there in his/her environment, the mores/he will be able to adapt into it and respond well to the skills taught. Using teaching learning materials (TLM) that are not related to the real world or are artificial objects made of plastic would add complexity in understanding.

This is where functionality of the task comes in. If presenting material for teaching a task, that has no meaning to the child, it will not make him learn the task rather this will complicate his life, image yourself in a scenario, where you are unable to relate to the environment. You will be lost, similarly our child having a limited area to explore, and if that too will be complicated, it will be shattering for the child.

### Develop Routine

Child must have a fixed time table of the activities for the entire day. This helps the child to have more control over his life and to anticipate what is going to happen with him next. This also helps to encourage communication attempts by the child immensely. To make the child understand and relate the event to the routine, a certain signal or a cue helps him/her to anticipate the next routine. Children with deafblindness, learn variety of signals or cues to relate with the routine event, for example, presentation of basket with assorted things, will act as a signal for starting a sorting activity, so, whenever the basket will be presented to the child, she will understand that this is the time to start with the sorting activity.

Such cues/ signals, help the child to be more aware about the environment around him/her, cues like a sound to indicate the activity, like hitting of plate with spoon may act as a cue for lunch time; change to the specific position, sitting on the floor may act as cue to start with the play activity. Starting with simpler routine and later extending with series of activities would be a good strategy to begin with. Simpler routine can add down meaning to the entire training session. Examples of Nitu and Pooja will further facilitate in understanding the above mentioned strategies

Nitu sits in circle with other children, for the starting session of the day. Her teacher places a light cloth to her head (object cue) and then over her face. She sings a special song (auditory cue) and then pauses to allow her to pull the cloth off. She is rewarded by a balloon blown by her teacher. They then repeat the exercise. Nitu had the opportunity to learn the small routine of cloth on, song, cloth off and balloon. And she has a specific part to play in it.

Pooja is having her legs massaged by her mother(touch cue).When this is done, mother will put splint on her legs, and make her stand on her in the standing frame(position cue).Once in her standing frame, Pooja will immediately be brought her food.

Multi sensory approach is the best: It is best to make use of all remaining sensory abilities of the child - seeing, hearing, touching, smelling and movement should all be a part of the teaching moments. Making use of all the sensory system helps make the teaching learning process more acceptable to the deafblind child. However, this should not be generalized as there are some deafblind children who function better by using only one sensory modality at a time.

### Plan inclusive activities

With highly individualised activities being planned for the child, there is always the risk that either the parent or one care giver is constantly trying to teach the child. Remember it is important for the deafblind child to know what others enjoy doing and for him to be a part of that too. Plan certain activities that he can do with his brothers or sister, neighbours, uncles and aunts.

### Make use of resource persons from the community

An old grandmother from the neighbour's house or your local watchman (chowkidar) or even your school gardener can teach your child something essential in his life. Take the best advantage of these 'teachers'.

## Curriculum planning for students with deafblindness

### Functional curriculum approach:

The Functional curriculum model is based on the current and future needs of deafblind students. Students are not taught skills to progress through developmental milestones; rather the focus is on skills that will best prepare deafblind student to function throughout life. Deafblind student is assessed performing a variety of skills and the curriculum is developed from this assessment. The skills to be taught are based on daily living skills, work, recreational activities, regular education, and the curriculum addresses the needs of deafblind child in the following areas:

Independent Living Activities: Independent living activities such as personal care activities - brushing, bathing, eating, toileting, grooming, etc are included as part of the 'teaching' experiences. In the early stages the parents/the teacher wi II 'do' the activities together coactively. Later the child learns to do it on his own. It is important for the adult to give this opportunity to the child numerous times. Doing it for the child deprives the child of a learning opportunity. This area also includes training in cooking, shopping, washing clothes, orientation and mobility, cleaning and maintaining own belongings. The empowering of the child and his/her right to do things for himself/herself start very early in his life. The opportunities for offering choices are many and consistent during these training situations. Let us understand these ideas better by getting to know more about Deepak. Deepak is a 15 year old young boy. Deepak was born with total blindness. He is also observed to have mental retardation. Deepak enjoys rocking his body and playing with his fingers. He is very particular about his daily routine and gets very upset if there is any sudden change. Deepak has been receiving specialised services in a centre based programme over the last 6 years. He also receives support on a regular basis at his home.

Deepak is learning to button and unbutton his shirts and trousers at the time of dressing up. He is also learning to clean his private parts at the time of taking his bath. Deepak assists his father in shaving by setting up things for him and putting them away after his father has finished shaving. Deepak is learning to use the cane to walk in a straight line on the roads outside his home and school. He is also learning to locate the direction of the traffic sounds while crossing the roads. He moves along independently within home and school. At the playground, Deepak can take a stroll by himself and reach you on hearing your voice.

He loves good food and tells the name of each dish on smelling it. He finds it difficult to share his food with others. "Baigan ka bharta1 is his favourite dish. His weight needs to be monitored and he hates it if people stop him from taking extra helpings of his favourite dishes.

Work: The area of work includes training in setting where the child is expected to perform a job. Such training starts very early in life, and does not necessarily have to imply remunerative outcomes. Such training activities would include learning to keep away ones own toys after play, laying the table for dinner for the family, washing one's clothes, stacking packets of pulses and

spices in a neighbourhood kirana shop (general store) operating a Training at work place

telephone booth, manning a tea stall, feeding paper into the printer and so on. Including work skills as a part of the curriculum also helps in training in concepts of now and later, my role and his role, reading time, simple academics, meaningful occupation and overall, a sense of self esteem.

Continuing to learn more about this, let us now see how Deepak is learning 'work' skills. Deepak has now developed an understanding of clear areas for different activities through repeated opportunities. He also anticipates his routine for the day, by walking up to these areas and searching and locating the related materials. For example, one of his tasks during the day is to walk up to the office lounge of the school and pick up the newspaper of the day for discussion during class hours. After discussion, he accompanies his other classmates to go and return the newspaper in the same lounge. During the span of the school week, he is learning to shop for his craft activities and cooking activities. Deepak is assigned the job of collecting the dustbins from each class room every evening and emptying the contents into the main dustbin of the school and putting the bins back in the respective rooms. He is also learning to dial his residence number and speak to his mother about the food that he has eaten and if he has enjoyed the taste that day. At home, it is his responsibility to carry the glasses of milk to his siblings' table every evening and collect the empty glasses after they have finished with it.

There are numerous such 'work' activities that Deepak does throughout the day for which people depend on him, appreciate his time and help and miss him if he 'takes off' for a day from work.

Recreation and leisure: Training in this area includes those environments in which the child functions during his free time. Numerous opportunities for exercising choices for likes and dislikes are effectively included in this area as with the other areas of training. Leisure and recreation as a part of the teaching time gives an opportunity to seek out preferences for friends, materials and activities that he may not usually get to exercise during the day.

Amidst all the learning and working, Deepak makes sure that he gets some time all to himself during a day. One of his happiest moments during the day is the time in the evening when he walks across the road with his sister to buy himself a 'Pepsi'. He deserves it after a hard day's work. Deepak also enjoys private time twice a day, when he loves to sit by himself in his school and home corner and occasionally play with his body. Being a growing boy, he enjoys getting into a fist fight occasionally with his peers and main competitors for his teachers attention. Everyday Deepak goes for a stroll in the park, where he runs, jumps, chases the dog and in-between all this manages to pick up little sticks and stones and stuffs them into his pocket for later use. He loves to play endlessly with these things when left by himself.

*Community:* Learning takes place in the child's natural environment. It could be at the garden, at the neighbour’s house, playing a game with the neighbour's daughter or in the local shop etc. Such opportunities help the deafblind child to learn a particular set of tasks at its most naturally occurring setting.

Deepak frequently interacts with people in the shops across his house while he goes for his household shopping along with his mother. He also has the same experience when he goes shopping for his school activities. Everyday stroll at the park next to his school means that he is familiar with the gardener at the park. His 'work activities' also ensure that he has regular contact with the cleaner, watchman and receptionist at school.

Academic areas: Apart from the above learning areas the child should get an opportunity to pursue the regular academic areas as his/her sighted/hearing peers would do in mainstream schools.

This is determined by the needs of the child himself. However, academic subjects are taught to deafblind children as prescribed in the mainstream curriculum with minor adaptations and support if the child is ready and the learning is relevant for him to interact with the world around him especially in his social relationships with peers. Such regular academic subjects are further simplified and taught to children, who cannot as much benefit from the prescribed school curriculum but would however benefit learning about it in a context that they can directly feel and perceive.

During the course of the day, numerous opportunities prop up for Deepak to count the number of plates or dustbins, money or shopping. He also reads his tactile shopping list made of wrappers of things he has to purchase such as medicine and bandage, for preparing a school first aid kit, toiletries, wrappers for his own and father's grooming needs and so on. He is learning to associate the time of the day with the beginning and end of the activity. While crossing the streets, or operating the gas stove he is learning to identify his safety needs.

Communication: Developing a communication foundation for learning is a priority. Typically communication is tactile in nature using cues, objects, gestures and later on sign language or tactile symbols or some combination of forms. Language is developed through the use of routines, calendar systems, discussion boxes, etc. Because of the degree of vision impairment and the inexperience the child has with real events in the world, the use of print, pictures and demonstration will be of little or no value to the child. S/He may not understand, pretend or role-play as an event that relates to some real experience.

The child with deafblindness may first need to be moved co-actively through an activity to know what is expected of him/her. After s/he understands what is expected, this support would be faded to avoid building prompt dependence. Because concepts develop so slowly for the child, there should be a focus on making learning functional. Great care needs to be given to developing clear goals and objectives for this child. Typically these objectives need to be limited in number since this child will need many opportunities to practice skills before s/he is able to generalize the concept to other situations.

The child would have a very limited knowledge of animals because s/he can not observe them or hear them. S/He has not seen television shows about animals. S/He may have a pet at home, but might only encounter it if the pet is placed in his/her lap or brought to him/her. His/Her experience with that animal would be primarily tactile. S/He may be able to distinguish his/her long-hair cat from his/her long-hair dog, ifs/he only pets the animal. Ors/he may experience the animal as a thing that licks or smells in a certain way.

For this reason, vocabulary (concepts) which are taught should be broader in nature. Careful consideration should be given to concepts which can be applied to other units throughout the year and across a variety of settings. The child with deafblindness could meaningfully participate in the play centers, his/her school or park but his/her goals would be different from the other children.

However, if good interaction and communication skills are modeled for the other students/siblings/peers and an effort is made to draw them into successful play situations together, they may be able to provide instructional support for some activities.

### Individualised Educational Planning (IEP)

The IEP is the foundation of the child's educational programme and must be developed with care. It is a complete programme for an individual child implemented for a specific period of time to provide appropriate education and training to the child.

For a student with deafblindness, the combined effects of the vision and hearing loss create a barrier that significantly delays or restricts the ability to gather information from the environment. This causes chronic difficulties with incidental learning and concept development. Students cannot learn what they do not detect, and they may be unaware of what they are missing. Access to information is a primary issue for all students with deafblindness. Other than this, social issues, orientation and mobility, communication, behavioural issues and transitional issues should be addressed in each IEP.

Why is it called so - Individualised, because the education /training programme is specifically designed to meet the learning needs of the individual child rather than a general syllabus for a group or class full of such children. The IEP also specifies the instructional strategies to be used with the child, the interests and likes, his preferred mode of learning, his pace and speed of learning, and limitations due to other associated problems including motor difficulties. In other words it is a complete programme by itself for an individual child that will be implemented for a specific period of time. Thus the main aim of the IEP is to provide appropriate education and training to the child. IEP is the written plan that an educator follows for the child to meet his/her needs to convert them into strengths, or say reach out to the maximum possible manner to create self dependency.

To put it simply, IEP includes, a brief background of the child (medical and educational), statement of present level of functioning, annual goals, including short term objectives, teaching strategies, specific educational services to be provided, the child's ability to be able to participate, the projected dates for initiation and anticipated duration of such service, appropriate objective criteria and evaluation procedures and schedules for determining, at least on an annual basis, whether instructional objectives are being achieved.

### Inclusive Education

A frequently recommended educational practice is that students with disabilities, including severe disabilities, should receive education in mainstream educational classes with their non-disabled peers.

Inclusive education is a strategy contributing towards the ultimate goal of promoting an inclusive society, one which enables all children/adults, whatever their age, gender, disability and ethnicity to participate in and contribute to the society. While we talk of inclusive education for deafblind students, it is important to understand basic concepts related to inclusion.

#### What Is Inclusion

* Chronologically age-appropriate general education settings
* All students having the option to participate in school and after-school activities
* Opportunities to interact and develop friendships
* Students attending neighbourhood schools
* Collaboration
* Related services: Trans-disciplinary teaming
* Viewing special education as a service, not as a place
* Planning for transitions

#### What is NOT Inclusion

* Dumping students without supports and needs based services
* Doing away with special education services
* Ignoring each student's unique needs
* Sacrificing the education of general education students
* All the students having to learn the same thing, at the same time, in the same way

#### Benefits of Inclusion to students with disabilities including deafblindness:

* Peer role models
* Positive alternative to increase the coverage of reach to deafblind children
* Equal education and opportunities in their own locations
* Sharing and pooling of resources
* Decreased rates of inappropriate behaviour
* Increased proportion of Individualised Educational Plan objectives achieved
* Enhanced skill acquisition and generalisation
* Increased inclusion in future environment
* Increased opportunities for interaction
* Increased social initiations
* Friendships
* Improved appearance

### Curricular adaptation

Curriculum for deafblind children should be adapted according to the need, strength, age, sex, and socio-cultural status of the child. Every deafblind child needs adapted curriculum according to the above mentioned criteria. The curriculum focus for the child with deafblindness will differ from that of the child with single sensory impairment. The deaf education focus may be primarily on using language to code existing concepts. The curriculum focus for a child with visual impairment may be more oriented toward building concepts and experiences which can provide a firm cognitive foundation for language. The curriculum focus for a child with deafblindness should be on bonding and developing interactions and routines for expanding the frequency and functions of communication, along with efforts to use his/her real life experiences to develop concepts which will be the foundation for future communication and language development. This child will not learn about objects or actions incidentally. S/He cannot tie together the fragmented input s/he receives without interpretation and instruction from others. S/He must be taught to use and accept this instruction.

### Orientation and Mobility

Orientation: Orientation is the ability to locate oneself in one's environment. It is a skill that is related to the use of the remaining senses to establish one's position in, and in relation to significant objects in the environment. The process of using the available environmental information to select and follow the correct path is called 'Orientation'. It has been established that when vision or hearing of a person is completely or partially impaired, he has to depend upon his remaining senses to be able to move around freely. The senses of touch, smell and taste can all be used to help him to recognise her/his position in relation to the obstacles and landmarks around him in the environment.

However it should be noted that Orientation is a cognitive skill and hence like all other skills would require a lot of time and practice on the part of deafblind student to develop an orientation of his familiar environment as well.

Mobility is defined as "movement from one place to another" not just a

particular technique or device. The aim of obtaining freedom of movement, safety in travelling as well as minimising the level of stress placed. A well-developed mobility facilitates independent movement. Mobility refers to total bodily movement which involves a change in spatial location accomplished in an upright position under one1s own power. It describes all situations ranging from moving around within a single room in a house, through to travelling from one town to another or even between countries. It is the action of travelling, of going from one place to another. To be mobile, deafblind person should be able to gather and use sufficient information from the environment to avoid hazards and to reach his destination safely.

Thus it is the ability to move in the environment in relation to oneself from one place to another. Orientation and mobility are focus areas of concern for the child who is deafblind. Safety is also of critical importance to this child. Not only must the environment be made safe for him, but he must feel safe in order to move around on his own. If he does not, he is likely to stay glued to one spot resisting interaction with his environment and the people in it. Instruction and support from an orientation and mobility specialist is very important. The O & M instructor may work directly with the child to orient him to the environment, and provide training on travel techniques and equipment to be used.

### Environmental modification

Environmental modifications for deafblind children are necessary in order to give greater and easy access of environment. Environmental modification does not refer to change in physical environment only but also includes people around deafblind children. At the time of planning for environmental modification, communication aspects must be kept in focus. While using sign language, background and colour contrast must be taken care of.

For example, when arranging a room for the group of deafblind students, it is mandatory to add object cues/symbols wherever required within the classroom for making it easy for the students to orient self and be self dependent to the maximum possible extent. The environment should ideally be predictable, responsive and organized. Changes may occur but with proper and structured planning. The environment should be stimulating and engaging; activities should lead to direct outcomes for the students, not just provide stimulations. Engaging environments are arranged to invite active participation, teaching and learning, social interaction, and minimum confusion.

##### Features of an engaging environment:

* Well organised and should reflect schedule that indicates who teaches/interacts with the specific student at a specific time for specific activities or skills.
* The student should have space that clearly belongs to her/him.
* There should be adequate labelling in the environment, which may be in the form of Braille labels, pictures or large print, which helps students to identify various things in the environment
* Visual, auditory and tactile environment should be considered
* Personal identifiers as well as markers for location should be used
* There should be specific areas for specific activities and for quite time.
* Materials should be organised, so that the child knows where they are and can get them or request them.
* The age of the student must be considered in developing an organised environment. For older students entire school may be considered as an environment.
* Establishing a schedule that varies fast paced activities, slow paced activities, and preferred and non preferred activities is also important in organising the learning environment.

##### Features of a Predictable Environment

Consistency, that is each person involved in with the deafblind child uses the same specific tactile and object cues each time to announce, for example, touching at the shoulder with a specific pressure to indicate to sit. Same touch with the same pressure if used by all helps the child to get a consistent cue for sitting.

Temporal regularity is the other one, which means that activities occur at the same time each day for the

same amount of time. If there are changes in the routine, they are announced to the child, and there is a system for the student to know his/her daily schedule, which might be in the form of a calendar system, to help determine his/her schedule.

##### Interactions and the Social Environment

Distance between deafblind person and teacher/family members can vary according to the needs. While interacting with deafblind person, one needs to be close to him/her if tactile signing is necessary. The environment should be stimulating for communication. It is important to respond to the child every times/he attempts to communicate so that his/her attempts are reinforced. Social interactions with key persons in a variety of environments form the basis for instruction in communication. It is important to remember that communication will also serve the basis for teaching many skills and activities that the individual having deafblindness will learn. Teaching communication through meaningful social interactions requires careful assessment to determine how student communicates with others, including family members, teachers, peers, neighbourhood friends, and members of the educational team, in various activities and places.

Modification in environment needs to be done to facilitate mobility of deafblind persons. To help deafbl ind person to move in environment independently, safe landmarks should be made. If the person has residual vision, stimulation to use the vision should be given, along with encouraging the child to use the other senses.

Thus a pleasant and organized environment allows deafblind children to make the most of every opportunity to learn, as they begin to make sense of world and what they are able to do.

Some important points to consider while designing teaching programmes

* Motivation
* Small Steps - Task analysis
* Pace
* Repetitions
* Presentation
* Prompts
* Working hand over hand v/s Hand under hand
* Modelling
* Co-active to Re-active learning
* Learning style
* Age appropriate activities

## Conclusion:

The educational needs of child with deafblindness are unique. Although they are hearing loss but the adaptations needed for their learning style will differ from the child who only has deafness. Although they are blind the adaptations needed for their learning style will differ from the child who only has blindness. If the unique learning style of deafblind child is not addressed, the child is at the risk of being excluded from the classroom, the family and the community. They will not be able to enjoy their rights and opportunities.

# Chapter – 5 Transition among adolescents with deafblindness

In this module the learner will understand

* Concept of transition
* Need for transition planning
* Roles and responsibilities of transition team
* Personal Futures Planning (PFP)

We all experience transitions as we move from one environment or period in our lives to the next. Ironically, change is one of the few constants in life. For young people, one of the most exciting periods of change comes when they finish school and look to the future as young adults, often moving out of the safety of home to new adventures in employment and/or post-secondary education. With this new found independence also come new relationships and new ways of viewing and interacting with the "old" relationships of family and friends.

If we reflect carefully on all the transitions in our life we would realize that all these transitions were the result of carefully planned experiences in our life, which helped to make the transitions smoothly.

While this particular time can be challenging for any teenager, young people with disabilities, deafblindness in particular, often have significant difficulties making a successful transition from the relative safety of home and school to adult life. The type and severity of disability can impact this further, but a larger influence is the presence or lack of a coordinated plan for transition that starts early and involves everyone in the young person's life.

'Transition' means a coordinated set of activities that will help the child to move from school to postsecondary education, adult services, community participation, independent living and employment. Transition services and planning are as important and vital to young persons who are deafblind as they are to other youths.

Similar to other adolescents of their age group, individuals who are deafblind need opportunities to:

* Practice self-determination,
* Develop and clarify their interests and abilities,
* Develop independent living skills to the greatest extent possible,
* Learn methods to increase the depth and breadth of social relationships and
* Experience a wide variety of employment settings and activities.

## Need for transition planning

Transition planning has been in existence as a practice for a few years for students with different Transition planning has been in existence as a practice for a few years for students with different disabilities. For children with deafblindness, simple transitions such as shifting from one activity to another or sometimes from one environment to another is a challenge, which many of us have to deal with in our day to day life. Due to the lack of an effective parameter, and the diversity in the needs of children with deafblindness, it has been hard to maintain records in terms of the age to begin a transition plan, uniformity in evaluations, standards to be ensured at work places with regards to nature of job, wages, accessibility etc. and the extent of the role of different professionals, family members, employers etc. in the transition planning process.

There has been an effort towards systematic evaluation of a person1s ability and matching this with a work situation in the community. Most of the times however, for persons with deafblindness having significant cognitive delay, the work situation is related to very sheltered workshops engaged in assembly line jobs with little or no contact with peers from mainstream society. For the more severely involved deafblind persons the job situation remains the same or even worse.

There is now a law that is giving a structure to education, employment and all related areas for persons with disabilities and yet does not specify the transition period.

To achieve the goals stated for education and employment, the need of the hour is to develop a need based transition plan that is effective in bridging the gap between education and employment and leading towards self- sufficiency. This could perhaps lead to the inclusion in the law at a later amendment. The need therefore is to discuss about developing an effective 1transition plan for students with deafblindness in many ways. With deafblindness yet to be recognised as a separate category of

disability, it is important to develop an effective transition plan for young students at an appropriate age, so that the person himself or herself moves towards self-sufficiency and in other cases, the people involved in the rehabilitation of the individual support the deafblind individual achieve these goals leading towards self-sufficiency.

The outcome of the plan is that families share the experience of success, teachers and other team members get motivated by this very tangible experience and the community at large gets to be more sensitised and interactive.

## Roles and Responsibilities of transition team

The success of the transition plan depends on the people involved in working on this programme and the manner in which each member works independently, and yet blends his/her work into the team effort. The transition team therefore involves the following members:

1. The student with deafblindness himself/ herself, also known as the Focus person - the students contribute information about their preferences and dreams and participates in the decision making process, as far as possible.
2. The family members contribute information about the Focus person's history and take an active part in creating and implementing the dream. They are recognised as those who would know the most about their child. They get familiar with the local agencies providing support, benefits available to them and the reality of pursuing a dream that is appropriate for their child.
3. The educators or the school staff members - They are involved in the skills training to their student at home, at work, in school and at leisure activities outside school. This person works in close contact between the family and the child and helps both sides realise their goal in a planned manner. S/he helps in referring families to other information sources, building awareness for the family about the child's potentials and limitations and providing placement related information regarding the readiness of the skills and special requirements at work, strengths and weaknesses of the chi Id.
4. The Placement Officer or Vocational trainer or the coordinator is generally the link between the school or the training agency and the community that has the potential of offering jobs. The placement officer or vocational trainer or the coordinator gathers information regarding the child's dreams, parent's expectations, child's adaptability to different situations, his/her repertoire of skills etc. and matches this with available opportunities
5. The employers and the co-workers are also involved in the transition team in a significant way at a later stage. The initial meetings and brainstorming sessions take place between other members of the team. Later there are many rounds of discussions and observations between the employers and co-workers and other members of the team before the student moves to the work place. The employer helps in identifying and restructuring a job to help his new special employee give maximum possible output. Hence it is extremely important that the employer has a positive approach towards his/her special employee.

## Personal Futures Planning (PFP)

The Personal Futures Planning (hereafter PFP) is an ongoing process that focuses on the strengths and capabilities of an individual with disabilities (called Focus person). PFP is a person centred planning approach seeking to identify and mobilise formal and informal support on the needs of an individual with severe disabilities including deafblindness. The process is characterised by planning that describes the capacities and opportunities in people and environment. It does this by providing an ongoing means to creatively solve the problems/challenges encountered along the way. This is accomplished by a small group of people involved in the transition planning, also known as the 'Circle of support'.

### When is PFP required'?

The focus person needs to have a PFP whenever required. PFP is an effective tool to bring about the needed changes required in the person's life. It is also extremely helpful in making the process of transition smooth and easy for the person.

### Stages of the PFP process

#### Stage- 1 : Setting up the PFP process

It is important that there be an initial meeting of the focus person, family members, educator, placement officer and a facilitator. The facilitator needs to lead the discussion of the group and answer any queries that others may have about the PFP process. During this stage it is also discussed about including other people in this group who are closely involved in the focus person's day to day life in a significant way, who are the person's 'Circle of Support'. However the most important aim of this stage is to work out ways and means in which the focus person can most actively and effectively participate in the process.

#### Stage -2: Developing the personal profile

During the next few meetings the 'Circle of support' analyses and lists down the focus person's strengths, abilities and skills. This is documented through a series of pictorial maps.

These maps are created as each member narrates her/his information about the focus person. The maps include:

a. Background: It includes significant life information on life events such as cause of deafblindness, health concerns if any and emotional issues. However, it features those positive experiences that can be used as building blocks for future dreams.

b. Relationships: The purpose of this map is to identify the personal support and assistance available now and in the future to the focus person. In the Indian scenario, this is of vital importance as in most cases it is the family network that provides different types of support to deafblind persons for the entire life span.

c. Places: This map examines where the focus person spends a major part of his time by analysing her/his daily routine activities. This information is a great indicator of the person's experiences in inclusive settings and the manner in which such settings are least threatening and most interactive for her/him. The map could also include some places where the focus person has not been till now but intends/wishes to visit in the future.

d. Choices: This map depicts the degree of control that the focus person exercises in his/her own life by examining the choices that the person makes about such things as personal care needs, recreation activities, likes and dislikes etc.

e. Hopes and fears: This map helps the focus person and his/her circle of support to explore the hopes and fears about their dreams of the future.

#### Stage 3: Creating the dream

This stage is the critical stage of the PFP. This is when things really begin to happen. With the new insights about the focus person percolating within everyone's mind for a few weeks, the members of the 'Circle of support' are now ready to create a comprehensive picture of the focus person's future. The process does not stop here as the team also begins to identify the steps in which the person can move towards his/her goal.

Questions that develop the dream are: How does the focus person envision her/his living situation? What does s/he wish to work as? How does s/he wish to be involved in the community? Questions regarding relationships, health, recreation etc are also addressed and the map that emerges depicts the Futures Map.

This map then needs to be translated into a reality. Members select and start to work on one or two priority areas. They brainstorm and develop strategies that will take the focus person closer to his/her goals. Collectively they address opportunities and challenges and try to solve the questions arising in a creative manner. The action plan that emerges from this stage clearly indicates who is to do what.

#### Stage 4: Making the dream real

The circle of support meets periodically at this stage to review the progress made in each of their responsibilities and to evaluate the collective goals as they all move ahead. If any barriers/ challenges are encountered then this is the time for the team to shift gears to accommodate the new demands of the process. A new action plan is developed; tasks assigned and a

date for the next meeting is set.

### Benefits of PFP

It certainly assists the focus person in developing a better image. It enables the person to participate more fully in planning and decision making for his/her life. It increases the person's social network and natural supports. It sensitises those members of the community involved in the circle of support towards the abilities of the deafblind persons. Of course the family members also benefit due to a clearer future vision and realistic steps towards this vision. Due to constant brainstorming and creative solutions many new educational, housing and recreational options emerge.

This stage of the PFP process translates accomplishments and strengths of the Focus person that were previously not recognised by the other members of the 'Circle of support'. It often leaves the group amazed and motivated.

# Chapter 6- Sexuality issues for Adolescent and Young Adults with deafblindness

In this module the learner will understand

* Sexuality issues among persons with deafblindness
* Sexuality education for persons with Deafblindness
* Do's and Don t's for sexuality education in individuals with Deafblindness
* Some common myths and facts about sexuality of persons with Deafblindness

Sexuality is an extensive term that covers a range of issues. It includes not only sexual behaviour but also, sexual identity, gender identity, sexual orientation, roles, personality, relationship patterns, thoughts, feelings, attitudes etc. It also includes social, ethical, moral, cultural and spiritual concerns of an individual. (TARSHI, 2010).

From the above definition, sexuality means different to different people and is often expressed in our daily activities. Sexuality is also often reflected in our work through gender stereotypes distinction like= expression of affection, parenthood, child-rearing, watching the television and many other activities of daily living.

Often concerns related to sexuality in our society is observed in the form of abuse, violence, unsafe sex, unwanted pregnancies which no doubt are important to address. But we often fail to relate sexuality with the idea of intimacy, self-expression, eroticism, self-worth, pleasure, etc. All people have right to sexual well-being, therefore, for people with deafblindness and multiple disabilities It is important to know that they can express their sexuality provided (a) one has overcome physical barriers and accept one's own self as worthy and (b) one is comfortable with their sexuality and gender.

People with disability form significant percentage of India's population. In spite of such large number there is very little research on the needs and concerns related to sexuality in disabilities.

In societies where beauty, youth and fitness are few of the parameters to talk about sexuality, people with deafblindness and disability are often stigmatised. The more they look different from 'ideal body' as projected by media and films the more discriminated and stigmatised they are.

Adolescents and young adults with deafblindness have the same rights regardless of their learning style, age, or level of functioning. Just like their non-disabled peers, they have the right to enjoy and take pride in this part of human experience. They too have a need to give and receive physical love and affection. As sexuality comprises of more than these facets, we need to protect the rights of persons with deafblindness categorising under sexual minorities such lesbian, gay, bisexual, transgender or transsexual people with deafblindness at various intersecting levels. Because sexuality is such an important part of defining who one is it is very important to have information and guidance about sexuality. Especially considering deafblindness as a complex disability, the role of parents, caregivers, and teachers becomes much more importance in providing appropriate information.

Parents, care providers and teachers often faces challenges of addressing sexuality related concerns of their children and adults with deafblindness which often bring home the reality of their children as sexual and reproductive beings.

Often, these experiences of bringing up children with deafblindness is not easy and state too do not provide many resources and services for the same. Most common situation where parents of girls with deafblindness are concerned about managing menstruation and safeguarding them from abuse. On the other hand, parents of adolescent boys with deafblindness worry about controlling activities such as masturbation and inappropriate touching of either other's body part or own body parts.

Also, it has been observed that parents, caregivers or teachers feel the need of addressing these issues when the child with deafblindness start exhibiting so-called undesirable behaviour in public. The approach which is then used if more of a problem solving than addressing the sexual desires.

The role of parents and teachers then should be to develop a positive self concept and create an environment promoting free expression in a desirable and socially acceptable manner. Dealing with sexuality among a group of children and adults with deafblindness is no different than among non­ disabled group. The format has to be tailored to compensate for the particular disability. The challenge, however lies in making them understand sexual and reproductive health, the silence and stigma around these issues and articulating the needs.

Adolescents and young adults with deafblindness are not asexual only because they are deafblind. Although some syndromes and conditions may affect sexual development and functioning, most of these adolescents and young adults follow typical patterns related to the physical development of sexual traits and drive. It is often assumed that persons with deafblindness, especially those with significant developmental delays are completely different from the rest of humanity, and are not accorded the same respect to privacy, degree of modesty or personal space. "After all," we tell ourselves, "they can't tell if anyone is looking." Touching them in a very intimate way without asking their permission or giving them any control is considered acceptable. Their need or desire for physical affection is mostly subjugated.

## Sexuality education for persons with deafblindness

The concept of sexuality education includes discussing about physical and emotional changes during puberty, protecting self from unwanted and harmful consequences and understanding the concept of one's space.

### Public and private behaviours

Much of what the average person knows about sexuality comes from informal or incidental learning sources. Adolescents and young adults with deafblindness do not have access to the same amount or type of information as sighted-hearing children. They often cannot successfully learn about their own sexuality in typical ways because of their sensory impairments. Sighted-hearing adolescents and young adults learn about sexuality in their environment by listening, watching, media sources etc. Typical adolescents and young adults who are very young have awareness that people can see and hear them. As a result, they naturally develop a sense of humility as they get older. They know about being private and not being seen. Non-disabled adolescents and young adults will learn quickly about the difference between public and private behaviours. Most Adolescents and young adults with deafblindness , especially those with significant developmental delays do not have this awareness. Being surrounded by one of more care providers means that they have very little privacy. Also, they often cannot successfully learn about their own sexuality in typical ways because of their sensory impairments. Sighted-hearing children and adults learn about sexuality in their environment by listening, watching, media sources etc. They may not even be able to see if other people are nearby. They may not know that a door or curtain needs to be shut. These adolescents and young adults with deafblindness have to be carefully taught about public and private behaviours and they have to be given strategies for ensuring privacy. Hence concepts such as privacy need to be inculcated right from the beginning when the child is being taught things such as dressing, undressing in private and closing the door or curtain when using the toilet.

For example,: Sighted- hearing children who are very young have awareness that people can see and hear them. As a result, they naturally develop a sense of self-effacement as they get older. They know about being private and not being seen. Sighted-hearing children and adults will learn quickly about the difference between public and private behaviours.

Another example can be, even when information on sexuality is provided it is more about menstrual management and hygiene for girls. But not about prevention of abuse, safer sex, contraception and other sexual and reproductive health concerns which are often thought as irrelevant.

Persons with deafblindness experience sexuality and have similar desires as their non-disabled counterparts. They also have right to explore their sexuality, to be comfortable with their body and different sexual acts and to know and seek what is pleasure. Children and adults with deafblindness may need assistance in order to understand the information. During this information dissemination they frequently miss out on feedback from others. When they are given feedback, it is often confusing. A person may tolerate a child's hand as it moves across a face or an arm, but if it touches the private area, the person is likely to move away or push away the child's hands. How does the child know that we consider these areas of the body to be private? To him/her these areas of the body may be just as other body parts. It is important to remember that touch is one of the primary teaching and learning channels for most adolescents and young adults with deafblindness. This often creates problems for them in learning about sexual issues in adaptive ways. Parents and professionals need to imagine how the children's behaviours will be tolerated when they are adults. Hence sexuality education needs to be a part of the child's educational curriculum not only during or after puberty but right from childhood or mostly it can be started from 3 years of age onwards.

As we discuss about the public and private behaviour it is important for a child and adult with deafblindness to know about the information concerning sexual abuse and violence and the right to protection from it.

### Sexuality and adult responses

Parents often feel confused about sexuality and disability with their deafblind child. They may think in some instances that their child's sexual development will be delayed or that the child may not develop sexually because s/he has a disability. The reality is that most conditions or syndromes that cause deafblindness do not have any impact on sexual development. Some sexual behaviours from the child are not acknowledged as being sexual. Instead parents view them as "deafblind behaviours."

Sometimes parents allow behaviours that they would not allow a child without disabilities. For example adolescent/young adult with deafblindness touching others to explore whom they are communicating with, may be considered fine, but similar gesture would not be considered fine by the one without disabilities. They may not know how to prevent their child from exhibiting certain behaviours. If the child did not have a disability they would just tell the child to stop. Telling child with deafblindness to stop behaviour usually does not work, and neither does a using physical restraint or punishment. In fact, these may only lead to power struggles and an escalation of that behaviour.

Parents often might also unintentionally oversee the need for regular medical checkups for their children with deafblindness. E.g. gynaecological exams may not seem necessary, considering the common belief that their girl with deafblindness may never be sexually active. However, many of the syndromes that cause deafblindness have secondary conditions that may go undetected.

From the educator's perspective, when a child is deafblind, there is a tremendous focus on communication, concept development, orientation and mobility, functional skills and motor development. Educators feel an urgency to focus on these more traditional areas of instruction and they often feel that instruction in the area of sexuality is not a priority. Even if it is not certain that a child will live independently or holds a job in the future, it is certain thats/he has a gender and will be a sexual being. For this reason, sex education must be a priority for instruction. Frequently educators may believe that sex education is the responsibility of the family and not the school. Sometimes teachers' personal comfort-levels, beliefs, and values may hinder them in their ability to address issues related to sexuality. Even when they do try to provide instruction, their approaches may not always be well adapted to meet the needs of a deafblind child. Their efforts often tend to focus on stopping behaviours rather than on supporting the child to appropriately express his or her sexuality. Educators sometimes feel it is easier to ignore behaviours and issues about sexuality. They are unenthusiastic to provide instruction. This is especially true when they do not receive pre-service or even in-service training on providing sex education to a child with deafblindness.

As parents and educators, it is our responsibility to meet the needs of individuals with deafblindness in becoming sexually competent. They have a right to experience this rich and important aspect of being human. We owe it to them to become knowledgeable about their needs and own self and to provide the support and instructions whenever required. But does that mean we provide support to person who does not know how to masturbate? Does one get sex workers to work with these men and women? What are the solutions one can look at?

Sex education is a critical and frequently neglected area of instruction and it is important to learn everything one can, related to the special needs of the adolescent/young adult and start early to instruct the child with sensory impairment about his or her sexuality related issues.

Parents, care providers, educators face lot of anxiety and have many questions around issue of sexuality especially when children with deafblindness are growing up and often these issues are ignores. It is then becomes important to acknowledge the reality and address these concerns than being silent around them. Adding to this, a strong network needs can be developed involving all stakeholders to advocate for these issues.

## Do's and Don'ts for Sexuality education in individuals with Deafblindness

Children with deafblindness follow the same pattern of sexual development as any other child and they need to receive the same information about sexuality. When a child is having deafblindness, there is a tremendous need to focus on communication, concept development, functional skills and motor development. Educators feel the urgency to focus more on these traditional areas of instruction and they often feel that instruction in the area of sexuality is not a priority and sometimes it's also because of the gender difference among the teacher and the child, which makes it difficult to teach certain skills. Both educators and parents need to understand that children with deafblindness have the same right of being taught about this issue regardless of their learning style, age or level of functioning. Therefore, it is important to know some do1s and don1ts related to sexuality issues for persons with deafblindness.

### Do's

1. Encourage children to develop a proper body image and body concept.
2. Educate the student about human anatomy and gender differences as early as possible.
3. Develop the understanding of private parts and parts of the body and also emphasize on where others can touch you or you can touch others.
4. Encourage understanding of the different types of touch, appropriate touch and touch with respect to the opposite sex.
5. Encourage personal hygiene with respect to private body parts.
6. Include skills such as appropriate menstrual care in the educational curriculum.
7. Teach them to participate and cooperate in medical examinations when needed.
8. Encourage parents to discuss their child's sexual behaviours.
9. Incorporate specific instructional goals and objectives in the IEP in the area of sexuality education every year.
10. Teach appropriate ways to gain attention and ask permission before touching.
11. Develop body awareness through developmentally appropriate activities such as body games, water play, massage, etc. according to the age of the student.
12. Request others to use appropriate touch and respect personal boundaries.
13. Prepare the child for the changes s/he is likely to encounter with the onset of puberty.
14. Teach the concepts of near and far by acting out.
15. Teach appropriate touch through Modeling.
16. Develop a behavior plan that is both proactive and reactive.
17. Use appropriate greetings and display of affection with the child.
18. Provide preliminary and ongoing training on this issue to parents and educators.
19. Develop routines that build in "Modesty " features.
20. Use calendars to help teach the concept of "wait".
21. Complicated clothing may sometimes help.
22. Teach the concepts of private and public.
23. Preserve the dignity and privacy of all students with deafblindness during instruction and care giving activities.
24. Teach them how to handle their personal sexual needs in private.
25. Teach them personal grooming and hygiene according to the gender needs.

### Don t's:

1. Do not feel that sexuality issue is not a priority for instruction.
2. Think that it is the schools/ management responsibility.
3. Don't ignore any underlying medical issues which may be causing certain behaviours.
4. Ignore the behaviors and issues on sexuality.
5. Give inconsistent feedback.
6. Ignore change in behaviors in deafblind children.
7. Ignore parents concern on sexuality issues.
8. Feel uncomfortable in seeking help from professionals.
9. Sexually abuse or molest the child.
10. Restrict the child from the sexual needs just because s/he is deafblind.
11. Restrict the right of expressing the sexual needs of a child by giving antisexual medications.
12. Do not over react, hesitate or feel shy; be calm and firm when you intervene.

## Some common myths and facts about sexuality of persons with deafblindness

|  |  |  |
| --- | --- | --- |
| S. No | Myth | Fact |
|  | Adolescents and young adults with deafblindness do not have sexual needs | Adolescents and young adults with deafblindness have normal physiological and sexual needs. |
|  | Adolescents and young adults with deafblindness have normal physiological and sexual needs. | Adolescents and young adults with deafblindness have similar sexual needs as their normal peers |
|  | Adolescents and young adults with deafblindness will have to control their needs. | Adolescents and young adults with deafblindness will have to meet their needs. |
|  | Adolescents and young adults with deafblindness will learn to take care of it themselves. | Adolescents and young adults with deafblindness need help......Big time help! |
|  | Adolescents and young adults with deafblindness are showing that they are naughty and deviant. | Adolescents and young adults with deafblindness are screaming out for some attention and love. |
|  | Adolescents and young adults with deafblindness do not feel emotions/ cannot maintain relationships | Adolescents and young adults with deafblindness need to feel important and belonged by you. |
|  | Sexual behaviour is not the teachers/schools problem. | Family and teacher need to support adolescents and young adults with deafblindness in addressing the issues. |
|  | Only adolescents/adults can have sexual needs. | Younger adolescents and young adults can also show 'sexual' behaviours. |
|  | Marriage will solve everything. | The person needs to be prepared for marriage |

It is important to understand the importance of sex education being part of Individualised Educational Plan. The above chapter is included for initiative to be taken as a parent/special educator to cater to the needs of individuals with deafblindness in this area as well by incorporating it in the curriculum.

# Chapter - 7 Vocational Rehabilitation of persons with deafblindness

In this module the learner will understand

* Concept of vocational training and rehabilitation of persons with Deafblindness
* Job analysis
* Vocational training and employment Schemes
* And how to avail loans after the vocational training

## Vocational training

Vocational training consists of basic and advance training both technical and non technical, skills updating or retraining. This training enables persons with deafblindness to enhance their knowledge, skills and competency for a suitable job. General studies and instruction leading up to actual vocational training are also part of the rehabilitation process.

## Rehabilitation

Rehabilitation includes all measures aimed at reducing the impact of disability for an individual enabling him or her to achieve independence, social integration, better quality of life and self - actualization. It includes not only the training of persons with disabilities but also interventions in the general system of society, adaptations of the environment, protection of human rights and empowerment. It is an integrated approach including but not limited to physical, psychosocial, cultural, spiritual, educational, or vocational measures that create conditions for the PWD (persons with disability) to attain the highest possible level of functional ability. Persons above age of 16 can be included in vocational rehabilitation. Any person whose working and earning capacity is significantly impaired are ideal for receiving the vocational rehabilitation. This helps individuals with deafblindness to pursue meaningful careers and employment as per their abilities and capabilities. And with vocational training persons with deafblindness become capable of leading a privileged and dignified life in the society.

## Vocational RehabiIitation

Vocational rehabilitation for an individual with deafblindness includes support in adapting to new life situations. A Person with deafblindness usually needs special skills to improve his/her capacity to work or study. These special skills are mobility, communication and use of technical aids. Usually changes in working environment are necessary and these changes are also part of vocational rehabilitation.

For example suitable lighting for visual situation (special light fittings and spots) and hearing aids. Vocational rehabilitation is carried out in rehabilitation centres, training centres, educational establishments and at workplaces and in the community.

Vocational rehabilitation work includes analysis of the job and creating a plan for an individual, which includes job selection and job analysis according to individual capacity of the person with deafblindness. To find a suitable job, detailed survey of the community is very important as it will give the brief idea of the person's ability. Individual preferences of the person with deafblindness should be respected for vocational training.

Vocational rehabilitation aims at enhancing work capacity, so that the person may deliver the best with his/her capabilities and gets adapted within the environment and finds a comfortable place in work situation. Vocational rehabilitation can also be an assessment of rehabilitation need, trial work and training, necessary vocational training (basic training, skills updating, retraining), receiving financial assistance to help with self-employment and receiving technical aids for work and study

## Job Analysis: Why is it required'?

Job analysis is the procedure used by trainers to train for the job skills according to the standards and manner of the job. Job analysis is a process to identify and determine the job duties and requirements. An important concept of Job analysis is that the analysis is conducted of the job, not the person. It addresses the relationship between each task steps. It can also be used as performance checklist for the trainee.

Job analysis can be used in training/needs assessment to identify or develop:

* Training content
* Assessment tests to measure effectiveness of training,
* Equipment to be used in delivering the training,
* Methods of training

### Job analysis: What it consists of?

#### Core work Areas

Core work areas are those tasks which are likely to be the most frequently performed during the work. This forms the bulk of a job that makes the job distinct and appropriate for the trainee. A major part of vocational training includes tasks identified as Core work areas. For example, if the job identified is making gold jewel and the core work area includes making wax model before the final stage, or later during construction, dipping the gold into water/chemical each time while moulding it to make a jewel. These are the core tasks required for the trainee for the task of making a jewel. (Such tasks can be taught to person with deafblindness having low vision)

1. Episodic work: Episodic work occurs infrequently i.e. two or three times a day or once a day or possibly even a few times a week. These tasks are also directly related to the work but they may not occur on a regular basis. For example, if task involves writing and sending emails, the episodic task could be emptying the trash section in the outlook express once a week.
2. Work related behaviour: Work related behaviours are necessary for being successful in the job. These behaviours are also necessary to create a good working environment to continue in employment and being an inseparable member of the team with the additional quality of good working skills. Some of the work related behaviours are punctuality, relationship with employer and co-workers, reaction to stress on different tasks, accuracy and speed of task to be performed, following instructions of supervisor( s), ability to communicate and withstanding work related fatigue well.
3. Work related skills: Work related skills are not directly required by the employee but are vital for successful performance on the job. These skills include self-help, mobility and functional academics in addition to skills that relate to becoming a responsible worker.

### Future support

Providing job is not the end point of rehabilitation of persons with deafblindness. Professional and family support is equally vital for them. Person with deafblindness do have difficulty in communication, orientation and mobility and access to information. To make the environment comfortable and accessible for persons with deafblindness, professional support will be needed from time to time.

An individual with deafblindness may also acquire non adaptive behavioural issues that may not be socially acceptable or may hinder in the work environment, which may result into losing a job. As a part of an ongoing vocational rehabilitation program, professional support may help an individual to maintain socially acceptable behaviour by applying it in different work environment settings and unlearn behaviour that may disrupt the job profile. A structured behaviour management plan inclusive in the program would look in to such needs too.

## Vocational Training and employment Schemes

* Training at Vocational Rehabilitation Centers (VRC's), Regional Rehabilitation Training Center (RRTC's), District Rehabilitation Centers (DRC's), Indian Technical Institutes (ITl's) and Polytechs -can be availed by the disabled people after completing 10th or 12th Standard.
* There is 3% reservation for disabled persons in all Govt. /UGC run vocational training courses.
* The National Handicapped Finance and Development Corporation (NHFDC) provide and support training and funds to persons with disability.

### National Career Service Centre for Differently Abled ( NCSCDA)

Under Directorate General of Employment and Training, The Ministry of Labour and Employment has established NCSCDA formerly known as Vocational Rehabilitation Centre for Handicapped (VRC's). This was initiated mainly to provide relief and help in rehabilitating persons with all types of disabilities, including deafblindness so that they stand on their own feet economically and have a place in the society. The main purpose of NCSCDA is to enable persons with disabilities to secure suitable employment after the training and live a life of dignity with affordable amount they get from their service. The ultimate aim of NCSCDA is to integrate or reintegrate people with disabilities in the mainstream society.

Listed below are the services rendered to all PwDs by the NCSCDA.

1. Interviewing adult handicapped persons for knowing their personal, social, family, educational, economic and vocational background causing adjustment problem.
2. Admission of the PwD's to examine them medically, to assess their physical efficiencies, measure their psychological strengths and weaknesses in respect of their intelligence, aptitude, areas of interest, psychomotor dexterity, personality traits and areas of adjustment.
3. Assessing the residual capacities, attributes, and functional skills of different categories of handicapped.
4. Examination of the PwD's by a panel of medical specialists to identify the degree of disability and functional capacities and suggest remedial measures.
5. Testing of the PwD's on the job capabilities in different trades sanctioned under National Skill Council programmes such as Electronics, Electrical, General Mechanic, Radio & TV repair, Commercial Practice, Air-conditioning & refrigeration, Automobile, Cutting and Tailoring, Computer Applications, Wood Work & Chair Caning, Arts & Crafts, Screen Printing, Photography, Metal Trades, Secretarial Practice, Painting, etc.
6. Imparting workshop training to develop vocational adjustment in respect of their work habits, on the job sustainability, to ensure their job adjustment best suited to their strengths and weaknesses.
7. Evaluating the PwD's at the Centre to assist them in preparing their vocational plan for enhancing their levels of knowledge & skills suited to local job market needs and also assisting, guiding and motivating them for diverting to self-employment.
8. Imparting in-plant training under the scheme of Ministry of Social Justice and Empowerment during which clients are given stipend to sustain their interest and motivation in the training.
9. Sponsoring and assisting the handicapped persons to utilize the facilities of reservations against the seats in various educational/training institutions.
10. Referring the handicapped persons to the employers against vacancies notified to the NCSCDA and taking follow up action including sponsoring them for training for the vacancy.
11. Recommending the PwD's for grant of loans by the concerned financial institutions under differential rate of interest or setting up of different ventures under various self­ employment schemes.

The National Handicapped Finance and Development Corporation (NHFDC) has been set up by the Ministry of Social Justice & Empowerment, Government of India on 24th January 1997.

NHFDC functions as an apex institution for channelising the funds to persons with disabilities through the State Channelising Agencies (SCA's) nominated by the State Government(s) or through Non Government Organisations (under Micro Credit Scheme).

The Schemes provided are as listed below-

1. Wide range of income generating activities to disabled persons.

The corporation provides financial assistance for:

1. Setting up small business in Service/f rading sector:
2. Purchase of vehicle for commercial activity
3. Setting up small industrial unit
4. Agricultural activities
5. Self-employment amongst persons with intellectual disability, cerebral palsy, autism and multiple disabilities including deafblindness
6. Loan for Education/Training to Disabled Persons

Purpose:

The purpose of the Loan for Education/training to Persons with Disabilities is to meet tuition and other fees/ maintenance, cost of books and equipment etc. for pursuing professional courses in a recognised educational institution in India and abroad.

Eligibility:

1. Any Indian Citizen with 40% or more disability.

2. Income Declaration Certificate of parents/ guardian

3. Educational Qualification Certificate

4. Caste Certificate for SC/ST/OBC

5. Age above 1El years. However, in case of persons with Intellectual disability, the eligible age would be above 14 years. The age criteria would not be required for educational loans. Age certificate issued by competent authority authorized by the State Government or as mentioned in the 10th certificate or any other certificate issued by the Government would be sufficient.

# Chapter – 8 Legislative framework for Persons with deafblindness in India

In this module the learner will understand

* United Nation Convention on the Rights of Persons with Disabilities (UNCRPD) - 2007
* Rights of persons with disabilities Act ( RPWD) - 2016
* The National Trust for the Welfare of Persons with Autism,
* Cerebral Palsy, Intellectual Disability and Multiple Disabilities including Deafblindness Act, 1 999
* National Institute for empowerment of Persons with Multiple Disabilities (NIEPMD)
* Rehabilitation Council of India Act - 1 992
* Right to Education Act - 2009
* National Education Policy-2020
* Grant-in-Aid schemes of the Ministry of Social Justice and Empowerment

## United Nation Convention on the Rights of Persons with Disabilities (UNCRPD) - 2007

The UN Declaration on Human Rights and UNCRPD states that all human beings including the deafblind people have the right to a life of freedom, with the same possibility for participation in society.

Deafblindness is a unique disability and by now you would have also understood that deafblindness is associated with complete isolation from the surroundings. This points at state1s duty to provide technical aids, interpreter/guide, enhance communication facilities by implementing Universal Sign language, accessible environment and facilitate the transport services etc., which are needed in deafblind people1s everyday life, to help them have access to education, work and leisure in much easier manner.

In India after the ratification of UNCRPD, and after struggle, attempts of so many years, deafbl indness is included in the RPWD Act 2016 under Multiple Disabilities with the legal identity with many support systems in different domains of life. This chapter throws light on the laws related to deafblindness and other conditions in India.

## The Rights of Persons with Disabilities (RPWD) Act, 2016

The Rights of Persons with Disabilities Act, 2016 gives effect to UNCRPD and makes way for the principles for the empowerment of persons with disabilities including deafblindness to ensure full and active participation in the society and provides support and rights to people with disabilities to enable them to have equal opportunities in participating as productive and contributing citizens.

* 1. respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
  2. non-discrimination;
  3. full and effective participation and inclusion in society;
  4. respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
  5. equality of opportunity;
  6. accessibility;
  7. equality between men and women;
  8. respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities;

Act includes measures for the prevention and early detection of disability, education including inclusive education & adult education, health, rehabilitation, recreation, special provisions for persons with high support needs social security skill development & employment (focuses on Vocational training and self-employment, non-discrimination in employment, policy on equal opportunity, maintenance of records, appointment of grievance redressal officer), research and manpower development. Act also specially focuses on Rights & entitlements (Focus on equality and non­ discrimination, women and children with disabilities, community life, protection from cruelty, inhumane treatment, abuse, violence, & exploitation. It also focus home and family, protection and safety, reproductive rights, access to voting and justice, ensure legal capacity, guardianship, designation of authorities to support).

RPWD Act 2016 covers 21 disabilities which are listed below;

1. Physical Disabilities (11 disabilities)
2. Locomotor disabilities, which includes Leprosy cured, Cerebral palsy, dwarfism, muscular dystrophy, acid attack victims.
3. Visual Impairment includes -blindness and low vision
4. Hearing Impairment includes -deaf and hard of hearing
5. Speech and Language disability
6. Intellectual disability (2) includes specified learning disabilities, and autism
7. Mental behaviour (1) includes mental illness
8. Disability caused due to (5)-
9. Chronic neurological conditions includes multiple sclerosis and parkinson's.
10. Blood Disorder includes - haemophilia, thalassemia, and sickle cell disease
11. Multiple Disabilities (more than one of the above specified disabilities) including deafblindness which means a condition in which a person may have combination of hearing and visual impairments causing severe communication, developmental, and educational problems.
12. Any other category as may be notified by the Central Government

Government shall appoint in every Government establishment, not less than 4% of the total number of vacancies in the cadre strength in each group of posts meant to be filled with persons with benchmark disabilities of which, 1 %. each shall be reserved for persons with benchmark disabilities under clauses (a), (b) and (c) and 1 %. for persons with benchmark disabilities under clauses (d) and (e), namely:-

* 1. blindness and low vision;
  2. deaf and hard of hearing;
  3. locomotor disability including cerebral palsy, leprosy cured, dwarfism, acid attack victims and muscular dystrophy;
  4. autism, intellectual disability, specific learning disability and mental illness;
  5. multiple disabilities from amongst persons under clauses (a) to (d) including deaf-blindness in the posts identified for each disabilities

The RPWD 201Ei Act also defines duties and responsibilities of appropriate government; act clearly defines duties which includes - awareness campaigns, accessibility, access to transport, access to information and communication technology, consumer goods which will be universally designed, mandatory observance of accessibility norms, Time limit for making existing infrastructure and premises accessible and action for that purpose, time limit for accessibility by service providers, human resource development, social audit.

Registration of institution for persons with disabilities and grant to such institutions defines competent authority will be appointed for the purpose, registration, application and grant of registration, revocation of registration, and appeal. Certification of specified disabilities- formulate guidelines for assessment of specified disabilities, procedures of certification, appeal against a decision of certifying authority.

Central & State Advisory board on disability and district level committee - members can be nominated by central and state authority, PWDs, meeting in every 6 month, state govt. depute district level committee.

Chief Commissioner and State Commissioner, Special Courts, National and State Fund for Persons with disabilities, Offences and Provision of penalty, Miscellaneous includes; application of other laws not barred, protection of action taken in good faith, power to remove difficulties, power to amend schedule, power to Central govt. to make rules, power of state govt. to make rules within 6 month (commencement date), repeal and saving of PWD act 1995

For more information on RPWD Act 2D 1 li, please visit the website http://disabilityaffairs.gov.in/ content/

## The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999

The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities was enacted by Parliament into law in December 1999.

The Act supports the needs of multiply disabled persons and their family members by promoting and facilitating awareness workshops in rural and urban communities; collating and disseminating information on multiple disabilities; and helping local organisations set up day care and respite care services for children and adults with multiple disabilities. The National Trust has been a boon for parents of children with multiple disabilities and one of the major strengths of the Trust is its vision for the parents of these children. It believes that parents are the key persons in decisions involving the present and future of their children and this principle is being promoted through its various Local Level Committees and activities.

The objectives of the National Trust are:

1. To enable and empower persons with disabilities (covered by the National Trust) to live as independently and as fully as possible within and as close to the community to which they belong;
2. To strengthen facilities to provide support to persons with disabilities to live within their own families;
3. To extend support to registered organisations to provide need based services during the period of crisis in the family of persons with disabilities;
4. To deal with problems of persons with disabilities who do not have family support;
5. To promote measures for the care and protection of persons with disability in the event of death of their parents or guardian;
6. To evolve procedures for the appointment of guardians and trustees for persons with disabilities requiring such protection;
7. To facilitate the realisation of equal opportunities, protection of rights and full participation of persons with disabilities; and
8. To do any other act, which is incidental to the aforesaid objects

The National Trust has also launched various Schemes for its beneficiaries and there are some schemes which would benefit the deafblind/MSI children of our country.

It seeks to answer the question asked by parents of persons with disabilities - specifically Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities - "What happens to my child when I'm no more?"

The objects of the National Trust are to enable Independence and Inclusion of persons with disability, and Community Participation in support and recognition of the Rights of the Disabled.

Among recent initiatives of the National Trust, they are extending support through 1 D schemes such as:

* Gyan Prabha - Gyan Prabha scheme aims to encourage people with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities for pursuing educational courses like graduation courses, professional courses and vocational training leading to employment or self-employment. This scheme aims at motivating a

Person with Disability (PwD) covered under the National Trust Act to pursue higher education or skill development courses.

Gharaunda - The objective of Gharaunda scheme is to provide an assured home and minimum quality of care services throughout the life of the person with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities and ensure the following for them:

* + Facilitate establishment of requisite infrastructure for the assured care system throughout the country
  + Encourage assisted living with independence and dignity
  + Provide care services on a sustainable basis

This scheme aims at setting up Gharaunda Centres for life long shelter and care of Persons with Disability (PwD) covered under the National Trust Act.

* Disha - This is an early intervention and school readiness scheme for children in the age group of 0-10 years with the four disabilities covered under the National Trust Act that aims at providing training (specifically school readiness) and counselling to both children and parents. This scheme aims at setting up Disha Centres for early intervention for Person with Disability (PwD) in 0-10 years of age covered under the National Trust Act, through therapies, trainings and providing support to family members.
* Vikas - This is a Day care scheme, primarily to expand the range of opportunities available to a person with disability attaining the age of 10 years for enhancing interpersonal and vocational skills as they are on a transition to higher age groups.The centre will also offer caregiving support to Person with Disability (PwD) during the time the PwD is in the Vikaas centre. In addition it also helps in supporting family members of the PwDs with disabilities covered under the National Trust Act to get some time during the day to fulfil other responsibilities. This scheme aims at setting up Vikaas Centres for welfare of PwDs.
* Sambhav - This is a scheme to setup additional resource centres, one each in each city of the country (apart from Delhi where there is currently a Sambhav centre) with population greater than 5 million (As per 2011 census), to collate and collect the Aids, software and other form of assistive devices developed with a provision of display and demonstration of the devices. The scheme also includes maintaining information, pertaining to aids and assistive devices present at Sambhav centre, on the National Trust website. This scheme aims at setting up of one Sambhav Centre in each city of India with population greater than 5 million(As per 2011 census).

Aids and Assistive Devices

Aids and assistive devices are the supporting devices used by persons with disabilities in improving their quality of life in terms of mobility, communication and for performing their daily activities. There is a wide range of assistive devices available to meet the needs of person with disabilities. By use of these Aids & assistive devices, people with disabilities becomes independent and their participation in the society increases.

Following are some examples of aids & assistive devices given below:

* Aids for Daily Living: Which covers self help aids for use in activities such as eating, bathing, cooking, dressing, toileting, home maintenance, etc. These include modified eating utensils, adapted books, pencil holders, page turners, dressing aids, adapted personal hygiene aids.
* Mobility Aids: Devices that help people move within their environment, electric or manual wheelchairs, modifications of vehicles for travel, scooters, crutches, canes and walkers.
* Home/workplace modifications: structural adaptations that remove or reduce physical barriers such as ramps, lifts, modification in the bathroom to make it accessible, automatic door openers and expanded doorways etc.
* Seating and Positioning: Adapted seating, cushions, standing tables, positioning belts, braces and wedges to maintain posture, and devices that provide body support to help people perform a range of daily tasks.
* Alternative and augmentative communication devices (AAC): These devices help people with speech impairments or person having low vocal volume to communicate such as speech generating devices, voice amplification aids and communication software. For visually impaired person, devices as magnifier, Braille or speech output devices, large print screens, closed circuit television for magnifying documents, etc.
* Prosthetics and Orthotics: Replacement or augmentation of body parts with artificial limbs or other orthotic aids such as splints or braces. There are also prosthetics to assist with cognitive limitations or deficits, including audio tapes or pagers (that function ass or reminders).
* Vehicle Modifications: Adaptive driving aids, hand controls, wheelchair and other lifts, modified vans, or other motor vehicles used for personal transportation.
* Sensory aids for vision/hearing impaired: such as magnifiers, large print screens, hearing aids, visual ing systems, Braille and speech/telecommunication output devices;
* Computer Access Aids: Headsticks, light pointers, modified or alternate keyboards, switches activated by pressure, sound or voice, touch screens, special software, voice to text software that enable persons with disabilities to use a computer. This category includes speech recognition software.
* Recreational aids: to enable participation in social/cultural events and sports. Devices to enable participation in sports, social, cultural events which includes audio deion for movies, adaptive controls for video games etc.
* Environmental Controls: Electronic systems that help people control various appliances, switches for telephone, TV, or other appliances which are activated by pressure, eyebrows or breath.

The National Trust has already established a National Resource Centre for display of available assistive devices called 1Sambhav1 at AADI (a registered organisation of the National Trust), New Delhi to demonstrate the possibility of independent or assisted living for persons with developmental disabilities through the use of aids & assistive devices and technologies.

* Samarth - The objective of Samarth scheme is to provide respite home for orphans or abandoned PwDs, families in crisis and also for Persons with Disabilities (PwD) from BPL & LIG families including destitutes with atleast one of the four disabilities covered under the National Trust Act. It also aims at creating opportunities for family members to get respite time in order to fulfil other responsibilities.

It would be the responsibility of the RO to bring in PwDs who are either Non-LIGs or who are not covered in the above mentioned category, to ensure sustainability. This scheme aims at setting up Samarth Centres for providing respite and residential care of the specified categories of Persons with Disability (PwD).

* Sahyogi - To provide caregiver training and create a skilled workforce to support high need persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, their families and institutions (hospitals, schools, NGOs etc.). This scheme aims at setting up Caregiver Cells (CGCs) to provide training and create a skilled workforce of caregivers to provide adequate and nurturing care for Person with Disabilities (PwD) and their families who require it.It also seeks to provide parents an opportunity to get trained in caregiving if they so desire. This scheme will provide a choice of training through two levels of courses to allow it to create caregivers suited to work both with families of persons with Disabilities (PwDs) and other institutions catering to the needs of the PwDs (NGOs, work centres etc.).
* Prerna - Prerna is the marketing scheme of the National Trust with an objective to create viable and widespread channels for sale of products and services produced by Person with disability (PwD) covered under the National Trust Act. This scheme aims at providing funds to participate in events such as exhibitions, melas, fairs, etc. to sell the products made by PwDs. The scheme also provides an incentive to the Registered Organisation(RO) based on the sales turnover of the products made by PwDs.
* Niramaya - This scheme pays special homage to the real problems of the poor people with disabilities and this is shown in the policy where even transport arrangements are made to ensure that the patients reach the hospitals. The scheme has a wide spectrum of various well needed medical and para-medical services. Nonetheless, it also covers OPD services. The premium of the insurance scheme is paid by the National Trust for the Below Poverty Line persons, which is made under the constitution of India and gets financial assistance from each general budget. A special and necessary provision is made under a clause of the scheme in which the above poverty line persons can also avail this facility by paying the suitable premium.
  + The scheme envisages delivering comprehensive cover which will
  + Have a single premium across age band
  + Provide same coverage irrespective of the type of disability covered under the National Trust Act
  + Insurance cover upto Rs. 1.0 lakh
  + All persons with disabilities will be eligible and included and there will be no 'selection'

The scheme further envisages that there shall be

* No exclusion of Pre-existing condition
* Same cover as that for other persons
* Services ranging from regular Medical Checkups to Hospitalization, Therapy to Corrective Surgery, Transportation
* Conditions requiring repetitive medical intervention as an in-patient
* Pre & Post hospitalization expenses, subject to limits
* No pre-insurance medical tests
* Cashless hospitalization in empanelled hospitals, reimbursement of claims in case of OPD services and treatment through non-empanelled hospitals.
* Badhte Kadam - Badhte Kadam aims at community awareness, sensitisation, social integration and mainstreaming of Persons with Disabilities. It has below mentioned objectives:
  + 1. Raise awareness in the public, regarding Person with Disability (PwD) covered under the National Trust Act and encourage their inclusion in the society, social integration and participation of persons with disabilities in all aspects of life.
    2. Disseminate information on preventive strategies for the disabilities under the National Trust Act, 1 ggg
    3. Sensitize community stakeholders
    4. Publicize and maximize benefits of the National Trust schemes for Registered Organization (RO),PwDs and for families of PwDs.
    5. Increase representation in remote areas and in areas where the National Trust is under represented

For more details please visit- http://www.thenationaltrust.gov.in/content/

National Institute for empowerment of Persons with Multiple Disabilities ( NIEPMD) established in the year 2005, on East Coast Road, Muttukadu, Chennai, Tamil Nadu, (about 30 km from Chennai Central railway station, Mofussil bus terminus and airport) Under Department of Empowerment of Persons with Disabilties (Divyangjan), Ministry of Social Justice & Empowerment, Govt. of India, to serve as a national resource center for empowerment of persons with Multiple Disabilities such as those with two or more disabilities in a person.

The Disabilities enumerated as per PWD (1995) Act, are Low Vision, Blindness, Locomotor Disability, Hearing Impairment, Mental Retardation, Mental Illness, Leprosy Cured Persons and as per The National Trust (1999) Act, are Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities.

For more details please visit- http://niepmd.tn.nic.in/index.php

## Rehabilitation Council of India Act (RCI), 1992

The Rehabilitation Council of India was set up as a registered society in 191::16. However, it was soon found that a society could not ensure proper standardisation and acceptance of the standards by other organisations. The Parliament enacted Rehabilitation Council of India Act in 1992 and it became Statutory Body on 22nd June 1993.

The RCI Act was amended by the Parliament in 2000 to make it more broad based. The Act casts time­ consuming responsibility on the Council and prescribes that any one delivering services to people with disabilities, who do not possess qualifications recognised by RCI, could be prosecuted. Thus the Council has the twin responsibility of standardising and regulating the training of personnel and professionals in the field of rehabilitation and special education.

### Objectives

* 1. To regulate the training policies and programmes in the field of rehabilitation of persons with disabilities
  2. To bring about standardisation of training courses for professionals dealing with persons with disabilities
  3. To prescribe minimum standards of education and training of various categories of professionals/ personnel dealing with people with disabilities
  4. To regulate these standards in all training institutions uniformly throughout the country
  5. To recognise institutions/ organisations/ universities running master's degree/ bachelor's degree/ Postgraduate Diploma/ Diploma/ Certificate courses in the field of rehabilitation of persons with disabilities
  6. To recognise degree/diploma/certificate awarded by foreign universities/ institutions on reciprocal basis
  7. To promote research in Rehabilitation and special education
  8. To maintain Central rehabilitation register for registration of professionals/ personnel
  9. To collect information on a regular basis on education and training in the field of rehabilitation of people with disabilities from institutions in India and abroad.
  10. To encourage continuing education in the field of rehabilitation and special education by way of collaboration with organisations working in the field of disabilities.
  11. To recognise Vocational rehabilitation centres as manpower development centre.
  12. To register vocational instructors and other personnel working in the Vocational rehabilitation centres.
  13. To recognize the national institutes and apex institutions on disability as manpower development centres and
  14. To register personnel working in national institutes and apex institutions on disability under the Ministry of Social Justice and Empowerment

## Right to Education Act - 2009

The Constitution (Eighty-sixth Amendment) Act, 2002 inserted Article 21-A in the Constitution of India to provide free and compulsory education of all children in the age group of six to fourteen years as a Fundamental Right in such a manner as the State may, by law, determine. The Right of Children to Free and Compulsory Education (RTE) Act, 200Q, which represents the consequential legislation envisaged under Article 21-A, means that every child has a right to full time elementary education of satisfactory and equitable quality in a formal school which satisfies certain essential norms and standards.

Article 21-A and the RTE Act came into effect on 1 April 2010. The title of the RTE Act incorporates the words 'free and compulsory'. 'Free education' means that no child, other than a child who has been admitted by his or her parents to a school which is not supported by the appropriate Government, shall be liable to pay any kind of fee or charges or expenses which may prevent him or her from pursuing and completing elementary education. 'Compulsory education' casts an obligation on the appropriate Government and local authorities to provide and ensure admission, attendance and completion of elementary education by all children in the 6-14 age group. With this, India has moved forward to a rights based framework that casts a legal obligation on the Central and State Governments to implement this fundamental child right as enshrined in the Article 21 A of the Constitution, in accordance with the provisions of the RTE Act.

The RTE Act provides for the:

* Right of children to free and compulsory education till completion of elemen-tary education in a neighbourhood school.
* It clarifies that 'compulsory education' means obligation of the appropriate government to provide free elementary education and ensure compulsory admission, attendance and completion of elementary education to every child in the six to fourteen age group. 'Free' means that no child shall be lia-ble to pay any kind of fee or charges or expenses which may prevent him or her from pursuing and completing elementary education.
* It makes provisions for a non-admitted child to be admitted to an age appro-priate class.
* It specifies the duties and responsibilities of appropriate Governments, local authority and parents in providing free and compulsory education, and shar-ing of financial and other responsibilities between the Central and State Gov-ernments.
* It lays down the norms and standards relating inter alia to Pupil Teacher Ra-tios (PTRs), buildings and infrastructure, school-working days, teacher-working hours.
* It provides for rational deployment of teachers by ensuring that the specified pupil teacher ratio is maintained for each school, rather than just as an aver-age for the State or District or Block, thus ensuring that there is no urban-rural imbalance in teacher postings. It also provides for prohibition of de-ployment of teachers for non-educational work, other than decennial census, elections to local authority, state legislatures and parliament, and disaster re-lief.
* It provides for appointment of appropriately trained teachers, i.e. teachers with the requisite entry and academic qualifications.
* It prohibits (a) physical punishment and mental harassment; (b) screening procedures for admission of children; (c) capitation fee; (d) private tuition by teachers and (e) running of schools without recognition,
* It provides for development of curriculum in consonance with the values en-shrined in the Constitution, and which would ensure the all-round develop-ment of the child, building on the child's knowledge, potentiality and talent and making the child free of fear, trauma and anxiety through a system of child friendly and child centred learning.

## Samagra Shiksha

The Samagra Shiksha - is an Integrated Scheme on School Education envisages the 1school1 as a continuum from pre-school, primary, upper primary, secondary to Senior Secondary levels. The vision of the Scheme is to ensure inclusive and equitable quality education from pre-school to senior secondary stage in accordance with the Sustainable Development Goal (SDG) for Education. This scheme is a combination of educational schemes of Sarva Shiksha Abhiyan (SSA), Rashtriya

Madhyamik Shiksha Abhiyan (RMSA) and Teacher Education with the goal of improving school effectiveness measured in terms of equal opportunities for schooling and equitable learning outcomes.

Major objectives:

* Providing quality education and enhancing learning outcomes of students
* Bridging social and gender gaps in school education
* Ensuring equity and inclusion at all levels of school education
* Ensuring minimum standards in schooling provisions
* Promoting Vocationalisation of education
* Support States in implementation of Right of Children to Free and Compulsory Education (RTE) Act, 200Q
* Strengthening and up-gradation of SCERTs/State Institutes of Education and DIET as a nodal agencies for teacher training
* Holistic view of education, as interpreted in the National Curriculum Framework 2005, with implications for a systemic revamp of the entire content and process of education with significant implications for curriculum, teacher education, educational planning and management.
* Equity, to mean not only equal opportunity, but also creation of conditions in which the disadvantaged sections of the society - children of SC, ST, Muslim minority, landless agricultural workers and children with special needs, etc. - can avail of the opportunity.
* Access, not to be confined to ensuring that a school becomes accessible to all children within specified distance but implies an understanding of the edu-cational needs and predicament of the traditionally excluded categories - the SC, ST and others sections of the most disadvantaged groups, the Muslim minority, girls in general, and children with special needs.
* Gender concern, implying not only an effort to enable girls to keep pace with boys but to view education in the perspective spelt out in the National Policy on Education 1986/92; i.e. a decisive intervention to bring about a basic change in the status of women.
* Centrality of teacher, to motivate them to innovate and create a culture in the classroom, and beyond the classroom, that might produce an inclusive envi-ronment for children, especially for girls from oppressed and marginalised backgrounds.
* Moral compulsion is imposed through the RTE Act on parents, teachers, edu-cational administrators and other stakeholders, rather than shifting emphasis on punitive processes.
* Convergent and integrated system of educational management is pre-requisite for implementation of the RTE law. All states must move in that di-rection as speedily as feasible.

For more details http://mhrd.gov.in/sarva-sh iksha-abh iyan http://mhrd.gov.in/rte http://ssashagun.nic.in/

https://samagra.education.gov.in/about.htm I

## National Education Policy-2020

In the independent India, first Education Policy came in 19613- for radical restructuring for national integration and education was made compulsory for all children up to 14. Its in this policy, the government propagated the three language formula. The second policy was formulated in 19136, mainly to remove disparities and to equalise educational opportunity for women, ST, SC. This policy propagated for a child-centred approach; adult education and open university.

The NEP2020 came as the 21st Century Education, with the idea of 1Ek Bharat Shrestha Bharat' which is focussed on development of the creative potential of all to ensure inclusive and equitable quality education and to promote lifelong learning opportunities for all (SDG-4).

The NEP2020 proposes the revision and revamping of all aspects of the education structure including regulation and governance and it plans to build upon India's traditions and value systems. The most important aspect for us is that the NEP 2020 believes that education of Children with Special Needs (CwSN) must be treated as 1education1• It states that pedagogy must evolve to make education:

* More experiential, holistic, integrated,
* Inquiry-driven, discovery-oriented, learner-centred,
* Discussion-based, flexible, and, of course, enjoyable aged groups, the Muslim minority, girls in general, and children with special needs.

There is no separate chapter on education of CwSN but all the sections of the NEP2020 equally apply to CwSN, especially one of the principles talks about 'extensive use of technology in teaching and learning, removing language barriers, increasing access for divyang students'. The NEP2020 is in complete consonance with the provisions of the RPWD Act 201El and endorses all its recommendations with regard to school education.

Fundamental Principles of NEP2□2□:

* Recognizing, identifying, and fostering the unique capabilities of each student, by sensitizing teachers as well as parents to promote each student's holistic development in both academic and non-academic spheres;
* Highest priority to achieving Foundational Literacy and Numeracy by all students by Grd 3;
* Flexibility, so that learners have the ability to choose their learning trajectories
* Multidisciplinary and a holistic education
* Emphasis on conceptual understanding rather than rote learning
* Promoting multilingualism and the power of language in teaching and learning;
* Life skills such as communication, cooperation, teamwork, and resilience;
* Extensive use of technology in teaching and learning, removing language barriers, increasing access for divyang students'
* Synergy in curriculum across all levels of education from early childhood care and education to school education to higher education;
* Access to quality education must be considered a basic right of every child;

For full text of NEP 2020 in English/ Hindi- https://www.mhrd.gov.in/relevant-documents

## Grant-in-Aid schemes of the Ministry of Social Justice and Empowerment

The different Grant-in-Aid schemes offered are following:

1. Assistance to Voluntary organisations for disabled

The scheme was started with a view to provide assistance to voluntary organisations working in the field of disability including deafblindness. It is a comprehensive scheme to cover different areas of rehabilitation - physical, psychological, social and economic. Financial support is given up to the extent of 90 per cent of the total project cost (up to 95 per cent for the rural areas) for recurring items Iike staff salary, maintenance charges, contingencies and non-recurring items like construction of the building. Rs. 5 lakhs of financial assistance is given for projects such as vocational training centres, special schools, counselling centres, hostels, training centres for personnel, placement services, etc.

1. Assistance to Disabled persons for Purchase/Fitting of Aids/ Appliances

The main objective of the scheme is to assist needy physically handicapped persons in procuring durable, sophisticated and scientifically manufactured aids and appliances that promote their physical, social and psychological rehabilitation. The scheme is implemented through centres run by the companies registered under Companies Act, registered societies, trusts or any other institutions recognised by the Ministry of Social Justice and Empowerment. A large number of governmental and non-governmental agencies are engaged for the implementation of the scheme. Aids and appliances such as wheelchairs, crutches, callipers, hearing aids, Braille slates, etc. are given to different categories of disabled persons. Indian citizens possessing a certificate from a registered medical practitioner can benefit under the scheme. Disabled persons in need of aids and appliances are given travel allowance subject to a limit of Rs. 150/- for visit to implementing agencies1 center. The boarding and lodging expenses at the rate of Rs. 1 D per day subject to a limit of Rs. 150/- per beneficiary are also admissible in cases where the income of such persons is up to Rs. 1200/- per month. According to the scheme, aids and appliances up to the value of Rs. 3600/- are distributed to the disabled persons free of cost if the monthly income of the disabled is up to Rs. 1200/- and at 50 per cent of the cost if it is between Rs. 1201/- and Rs. 2500/-.

1. Assistance to Organisations for Persons with Cerebral Palsy and Mental Retardation

Under the scheme, assistance is given to NGOs up to the extent of 1 DD per cent for running training courses for teachers in the area of cerebral palsy and mental retardation. Both recurring and non­ recurring items are considered for sanction.

## Concessions and Subsidies for persons with disabilities including deafblindness and their parents in India

### Educational Schemes for the Disabled persons

#### Children education allowance

Under Children Education Allowance scheme, reimbursement for tuition fee, admission fee, laboratory fee, special fee charged for agriculture, electronics, music or any other subject, Fee charged for practical work under the programme of work experience, fee paid for the use of any aid or appliance by the child, library fee, games/sports fee and fee for extra-curricular activities can be claimed. This also includes reimbursement for purchase of one set of text books and notebooks, two sets of uniforms and one set of school shoes which can be claimed for a child, in a year.

Under the Scheme of Children Education Allowance reimbursement can be availed by Government Servants upto to a maximum of 2 children. The annual ceiling fixed for reimbursement of Children Education Allowance is Rs.12000.

In case both the spouses are Government servants, only one of them can avail reimbursement under Children Education Allowance.

Under this scheme, reimbursement can be claimed once every quarter. The amount that can be claimed in a quarter could be more than Rs.3000, and in another quarter less than Rs.3000, subject to the annual ceiling of Rs .12000 per child being maintained.

The Scheme for Integrated Education of Disabled Children (SIEDC) provides educational opportunities for disabled children in the general school system so as to facilitate their protection and significant integration in the system.

### Education of Disadvantaged Group through National Institute of Open School

To cater to the special needs of people who are physically/ mentally challenged, socially and geographically isolated, marginalised and are from disadvantaged sections such as street children, working children, rural women; the NIOS has special accredited institutions called Special Accredited Institutions for Education of the Disadvantaged ( SAIED).

For admission for differently-able persons, as a supporting document, a medical certificate from a government hospital and not from a private nursing home, is required which clearly indicates the nature and extent of disability.

### The Central Board of Secondary Education ( CBSE)

The CBSE allows provision of the facility of amanuensis (a writer or scribe) for blind and physically disabled children when they sit for the tenth standard and twelfth standard board examinations. It also opened a cell for parents to lodge the grievances of parents regarding placement of disabled children.

#### CBSE Relaxation for Disabled Children

The facilities extended by the Board to the disabled candidates (Dyslexic, Blind, Spastic and Candidates with Visual Impairment) and also could be entertained by the deafblind are as under:

* + 1. The persons with disabilities (Dyslexic, Blind, Spastic and Candidate with Visual Impairment) have the option of studying one compulsory language as against two. The language opted by them should be in consonance with the overall spirit of the Three Language Formula prescribed by the Board. Besides one language they can offer any four of the following subjects: Mathematics, Science and Technology, Social Science, Another Language, Music, Painting, Home Science and Introductory Information Technology.
    2. From the 2002 Examination, alternate questions in lieu of questions requiring special skills based on visual inputs have been provided in Mathematics and Science for Sec. School Examination (Class X).
    3. Blind, Physically Handicapped and Dyslexic Students are permitted to use a amanuensis/writer. The amanuensis/writer must be a student of a class lower than the one for which the candidate is taking the examination.
    4. The visually handicapped students appearing from Delhi were provided Questions Papers with enlarged print for 2003 Examination.
    5. Disabled candidates are allowed additional one hour (60 minutes ) for each paper of external examination.

## Scheme of National Scholarship for Persons with Disabilities

This scheme is to provide financial assistance to disabled students for pursuing higher and technical education. They will also be supported for acquiring special aids and appliances for studies.

Eligibility for the scheme is based on following criteria:

* 1. Financial assistance will be available to disabled Indian students.
  2. They will need disabilities certificate as per definition under PWD Act 1995 to avail financial assistance under the scheme.
  3. Financial assistance will be given for the study of recognized post matric/post secondary courses in recognized institutions.
  4. Scholarship will be awarded for one course to one student.
  5. Financial assistance will also be given for purchase of a computer with editing software for blind & deaf graduate and postgraduate students pursuing professional courses and purchase of support access software for cerebral palsied students.
  6. Students with disabilities, who have passed matriculation/secondary or any higher examination from a recognised board/University, will be eligible for the assistance.
  7. Continuation/ renewal of the award for next year will depend on successfully completing the course in the preceding year with minimum 50 percent marks.
  8. Assistance will not be available for courses having duration of less than one year.
  9. A scholarship holder under this scheme will not hold any other scholarship/stipend. If awarded any other scholarship/stipend, the student can exercise his/her option for choosing the scholarship and inform awarding authority about the same.
  10. For availing financial assistance under this scheme monthly family income of the beneficiary should not be more than Rs. 15,000/- from all sources. Family income will include income of the parent and in their absence income of the guardian.

### 3% reservation in all UGC colleges for all courses

There is 3% reservation for person with disabilities in all UGC colleges for all courses.

### UGC guidelines for support to students with disabilities

The UGC had started the scheme of assistance to universities/colleges to facilitate Teacher Preparation in Special Education (TEPSE) and Higher Education for Persons with Special Needs (Differently-abled Persons) (HEPSN) during the Ninth Five-Year Plan, keeping in view the need to provide special education programmes as well as infrastructure to differently-abled persons. The infrastructure needs to be designed in a manner to enable them to easily access classrooms, laboratories, toilets, etc.

The objectives of the scheme are as follows:

* 1. To encourage universities/colleges of education in the country to promote teacher preparation programmes in the field of special education.
  2. To provide equal educational opportunities to disabled persons in higher education institutions.
  3. To create awareness among the functionaries of higher education about the specific educational needs of persons with disabilities.
  4. To equip higher education institutions with the facilities to provide access to disabled persons.
  5. To provide appropriate financial assistance to disabled individuals to increase their sustainability in higher education.
  6. To explore suitable placement opportunities for educated disabled graduates in public as well as private sector enterprises.
  7. To monitor the implementation of all existing and future legislation and policies pertain to higher education of persons with disabilities.

This scheme is aimed particularly at:

* 1. Providing assistance to universities/colleges of education to start teacher preparation courses in special education at the B.Ed./ M.Ed. level and
  2. Creating appropriate facilities for persons with special needs in higher education.

## Policies for guardians of handicapped persons

The Life Insurance Corporation of India (LIC) has come out with two policies for guardians of handicapped persons that aim to provide them (handicapped person) financial security in the event of their (guardians') death.

Jeevan Vishwas policy covers the life risk of the proposer, parent or guardian of a physically, or mentally-handicapped person and provides a regular income to the dependent. The policy pays the basic sum assured along with the accrued guaranteed additions and loyalty additions if the proposer survives the maturity date of the pol icy or on his death when the policy is in force.

Jeevan Aadhar policy covers the life risk to the proposer and pays an annuity to the handicapped dependent or to any person or a trust for the benefit of the dependent.

## Employees Provident Fund

The Central Government has made amendments in the Employees Pension Scheme, 1995 called Employees Pension (Amendment) scheme, 1999. According to this scheme "If a member dies leaving behind a family having son or daughter who is permanently and totally disabled, such son or daughter shall be entitled to Payment of monthly children pension or orphan pension, as the case may be, irrespective of age and number of children in the family in addition to the pension provided under clause (d) of sub para 3, Section 6a.

## Tax Deduction

The Government of India has given various income-tax deductions from the total income tax of people with disabilities. The limit under Section BO-DD and BD-U of Income tax Act deducts tax upto INR 40,000 of person with disabilities. Persons dependent on Handicapped enjoy tax deductions against expenditure on medical treatment, training, and rehabilitation of challenged dependents or amount deposited in an approved scheme of Life Insurance Cooperation (LIC) and United Trust of India (UTI).

## Railways Concessions

Railways allow disabled persons to travel at concession fares up to 75% in the first and second classes. Escorts accompanying blind, orthopedically and mentally handicapped persons are also eligible to 75% concession in the basic fare.

## Air Travel Concessions

Indian Airlines allow 50% concession fares to blind persons on single journeys.

## Postage

Payment of postage, both inland and foreign, for transmission by post of 'Blind Literature' packets is exempted if sent by surface route.

## Customs/Excise

Braille paper has been exempted from excise and customs duty provided the paper is supplied direct to a school for the blind or to a Braille press against an indent placed by the National Institute for the Visually Handicapped, Dehradun. All audio cassettes recorded with material from books, newspapers or magazines for the blind are exempt from custom duty. Several other items have also been exempted from customs duty if imported for the use of a disabled person.

## Hotel discounts

India Tourism Development Corporation (ITDC) has decided that in all its hotels across the country, it will offer the following two discounts to people with disabilities:

* 1. 50% on room rent, accompanying person/ attendant shall not be charged extra i.e. ITDC shall charge 50% on single room tariff for double room.
  2. 30% discount on food on the a-la-carte menu.

## Indira Gandhi National Disability Pension Scheme (IGNDPS)

Government of India has introduced scheme i.e. Indira Gandhi National Disability Pension Scheme (IGNDPS) under National Social Assistance Programme (NSAP). This schemes have to be introduced in the State with the contribution of 50% of the fund required for implementation of scheme. The objectives of the schemes & eligibility criteria & other details are given below.

Eligibility criteria and requirement of documents:

To get the benefit of the scheme, following criteria need to be fulfilled by an applicant

* + 1. She/He must not be less than 1 B years of age and not above 64 years.
    2. She/He should be from a family which is below the poverty line.
    3. She/He shall be with severe disability (i.e. more than BO% disability) or multiple disabilities (having more than one disability and at least 40% incapacitation in each kind of disability, totalling disabilities BO% or more).
    4. She/He shall get the pension until she/he attains the age of 65 years.
    5. In case of any dispute related to determination of age, birth certificate /certificate of the Headmaster of the Primary/ Madhyamik School in which she/he studied last/ horoscope will be accepted. If the applicant did not study in a school, certificate of the Pradhan / concerned member of the Gram Panchayat will be accepted.
    6. She/He shall have to produce certificate issued by Social Welfare Department of the District regarding her/his disability in support of her/his claim.
    7. Monthly pension will be disbursed through the Bank Accounts/ Post Office Accounts of the pensioners.
    8. he applicant has to produce photocopy of her Bank/Post Office A/c. at the time of submission of her application.
    9. No pension will be disbursed until the names of the newly identified pensioners are uploaded to the Website of the Ministry of Rural Development, Government of India.

For more detail, visit websites http://socialjustice.nic. in/schemespro3 .php#a3 http://social justice.n ic. in/policiesacts3 .php#a2 http://socialjustice.nic. in/pdf/adipsch.pdf

http://www.thenationaltrust.co.in/nt/index.php?option=com\_content&task=view&id=21Q&ltemid=2El3

http://social justice.n ic. in/pdf/adipsch.pdf http://socialjustice.nic.in/pdf/naward2D11.pdf http://nsap. nic. in http://disabiIityaffairs.gov.in/content/page/guidelines.php

# References

1. Understanding Deafblindness: Issues, Perspectives, and Strategies, Vol. I (2002). Editor: Linda Alsop, SKI - HI Institute, Utah. Published by Home Oriented Program Essential, dba HOPE, Inc. Utah, USA
2. Understanding Deafblindness: Issues, Perspectives, and Strategies, Vol. II (2002). Editor: Linda Alsop, SKI - HI Institute, Utah. Published by Home Oriented Program Essential, dba HOPE, Inc. Utah, USA
3. Deaf-Blind Infants and Children: A Developmental Guide (1997). Mcinnes, J.M., Treffry, J. A., University of Toronto Press, Toronto
4. Education of Children with Deafblindness and Additional Disabilities: Source book for Master Trainers (2003). Voice and Vision Task Force. Published by: National Institute for the Mentally Handicapped, Secunderabad, India
5. Children with Developmental Disabilities: A training guide for parents, teachers and caregivers (2004). Venkatesan. S,. Published by: Sage Publications India Pvt. Ltd. New Delhi, India
6. Nothing About Us Without Us: developing innovative technologies for, by and with disabled persons (1991:l). David Warner. Published by: Healthwrights, California, USA
7. Transition of Persons With Mental Retardation From School to Work - A Guide (2001 ). Thressiakutty, A. T., Govinda Rao, L. National Institute for the Mentally Handicapped, Secunderabad, India.
8. El. Learning Through Doing: A manual for parents and care givers of children who are visually impaired with additional disabilities (2002).Edited By Charlotte Cushman, Hilton/Perkins Program, USA. Published by: Blind People's Association, Ahmedabad, India
9. The Callier - Azusa Scale (1971:l), Edited By Robert Stillman. The south Central Regional Center for Services to Deaf-Blind Children, Texas and The University of Texas At Dallas Callier Center for Communication Disorders, Texas, USA
10. Introduction to Sexuality education for Individuals who are Deaf-Blind and Significantly Developmentally Delayed (2001 ). Moss, Kate. Blaha, Robin. DB- Link, Oregon, USA
11. Sign Language with People who are Deaf-Blind: Suggestions for tactile and Visual Modifications. Susie Morgan. www. Deafblind.com/archieves.html# Sign language with people who are deaf-blind
12. Transition Guide for youth who are Deafblind. Deaf-Blind Program. Center for disabilities, Department of Paediatrics, The University of South Dakota, School of Medicine, USA
13. Department of Education (DES) Policy Statement (March 19l19). Government of Britain.
14. Individuals with Disability Education Act, Government of United States of America. Persons with Disability (Equal Opportunity Protection of Rights and Full Participation) Act 1995, Government of India
15. Mc Innes, J.M and Treffry J.A Deafblind Children and Infants , pg 5B , University of Toronto Press, London 1997
16. Glen, E. E. & Smith, T. T. (199B). Building self-esteem of children and adolescents with communication disorders. Professional School Counselling, 2 (1), pp. 39-46.
17. Sunderland, L. C. (2004). Speech, language, and audiology services in public schools. Intervention in School and Clinic, 39 (4), pp.209-217.
18. 1 B. Developing concepts with children who are deafblind - Barbara Miles, M.Ed.
19. Barbara Mcletchie, Ph.D.
20. Evelyn P. Kelso, M.A., Educational Consultant, ATECH/ASSETT, New Hampshire
21. Issues in the Evaluation of Infants and Young Children Who Are Suspected of or Who Are Deaf-Blind, Holte, Lenore; Prickett, Jeanne Glidden; Van Dyke, Don C.; Olson, Richard J.; Lubrica, Pena; Knutson, Claudia L.; Knutson, John F.; & Brennan, Susan, 2006. Infants and Young Children, 19(3), 213-227. (2006)
22. Miles, B. (2000) Overview of Deaf-Blindness, DBLink
23. Rehabilitation Council of India Act, 1992. Government of India.
24. The Persons with Disabilities (EQUAL OPPORTUNITIES, PROTECTION OF RIGHTS AND FULL PARTICIPATION) Act, 1995. Government of India.
25. The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999. Government of India.

# Websites References

1. Sarva Shiksha Abhiyan, [www.ssa.nic.in](http://www.ssa.nic.in)
2. Special Educational Needs and Disability Act 2001 (SENDA). Government of Britain. Britain
3. www.dblink.org/lib/topics.cfm
4. www.tsbvi.edu
5. www.cde.state.co.us/cdesped/index.htm
6. www.ridbc.org.au/information/deaf/deaf\_what.html
7. [www.education.gsu.edu/georgiadeafbl indproj/index.htm](http://www.education.gsu.edu/georgiadeafbl%20indproj/index.htm)
8. www.sesa.org
9. www.dba.asn.au
10. www.ou.edu/okdbp/index.html
11. www.home.connexus.net.au/~dba/etiol.htm
12. www.web.indstate.edu/soe/blunmerg/deafblind.html
13. www.dbproject.mn.org
14. www.encec.org
15. www.w3.whosea.org/eip.htm
16. http://www.cuedspeech.co.uk/home.htm
17. www.thenationaltrust.in/
18. www.pwdact.org.au

# GLOSSARY

* Assessment: Assessment is the process of documenting, usually in measurable terms, knowledge, skiIls, attitudes and beliefs.
* Atresia: is a condition in which there is absence or closure of a normal body orifice or tubular passage such as the anus, intestine, or external ear canal, the congenital absence or the pathological closure of an opening, passage or cavity.
* Augmentative Communication: Augmentative and alternative communication (AAC) includes all forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas. We all use AAC when we make facial expressions or gestures, use symbols or pictures, or write.People with severe speech or language problems rely on AAC to supplement existing speech or replace speech that is not functional. Special augmentative aids, such as picture and symbol communication boards and electronic devices, are available to help people express themselves. This may increase social interaction, school performance, and feelings of self-worth
* Autosomal Recessive: Autosomal recessive is one of several ways that a trait, disorder, or disease can be passed down through families. An autosomal recessive disorder means two copies of an abnormal gene one copy from each parent. must be present in order for the disease or trait to develop. The gene is on an autosome, a non-sex chromosome. The parents are carriers who have only one copy of the gene and do not exhibit the trait because the gene is recessive to its normal counterpart gene. If both parents are carriers, there is a 25% chance of a child inheriting both abnormal genes and, consequently, developing the disease. There is a 50% chance of a child inheriting only one abnormal gene and of being a carrier, like the parents, and there is a 25% chance of the child inheriting both normal genes.
* Bilirubin: Bilirubin is a brownish yellow substance found in bile (Bile is produced by the liver, stored in the gallbladder, and released into the small intestine where food is digested). It is produced when the liver breaks down old red blood cells. Bilirubin is then removed from the body through the stool (faeces) and gives stool its normal brown colour.
* Choanal Artesia: It is a congenital disorder where the back of the nasal passage (choanae) is blocked, usually by abnormal bony or soft tissue formed during foetal development.
* Colostrum: Colostrum (also known as first milk or 11immune milk11) is a form of milk produced by the mammary glands of mammals in late pregnancy and the few days after giving birth. Colostrum is high in carbohydrates, protein, and antibodies and low in fat (as human newborns may find fat difficult to digest). Newborns have very small digestive systems, and colostrum delivers its nutrients in a very concentrated low-volume form.
* Coloboma: Coloboma is a hole in one of the structures of the eye, such as the lens, eyelid, iris, retina, choroid or optic disc. The hole is present from birth and can be caused when a gap called the choroid fissure between two structures in the eye, which is present early in development in the uterus, fails to close up completely before a child is born. A coloboma can occur in one or both eyes.
* Communication: Communication is a process that allows organisms to exchange information by several methods. Communication requires that all parties understand a common language that is exchanged. There are auditory means, such as speaking or singing, and nonverbal, physical means, such as body language, sign language, paralanguage, touch, eye contact, or the use of writing.
* Cyanotic: Showing cyanosis (bluish discoloration of the skin and mucous membranes due to not enough oxygen in the blood).
* Electronystagmography: Electronystagmography (ENG) is a diagnostic test to record involuntary movements of the eye caused by a condition known as nystagmus. It can also be used to diagnose the cause of vertigo, dizziness or balance dysfunction by testing the vestibular system.
* Electroretinography: Electroretinography is used to measure the electrical responses of various cell types in the retina, including the light-sensitive cells (rods and cones) and the ganglion cells. Electrodes are placed on the cornea and the skin near the eye. During a recording, the patient is watching a standardized stimulus and the resulting signal is interpreted in terms of its amplitude (voltage) and time course. Stimuli include flashes (flash ERG) and reversing checkerboard patterns (pattern ERG).
* Evaluation: Evaluation is the systematic acquisition and assessment of information to provide useful feedback about some object
* Functional vision assessment: A functional vision assessment measures how well a child uses vision to perform routine tasks in different places and with different materials throughout the day. The functional vision assessment "paints a picture" of how a child uses vision and what visual skills the child needs to develop further.
* A functional vision assessment may be conducted for a child with dual sensory loss and other physical disabilities. For this child, positioning is critical, as the child needs to be positioned so that his/her head, neck and trunk are stable to get the best use of vision.
* Hypoxia: It is a pathological condition in which the body as a whole (generalized hypoxia) or region of the body (tissue hypoxia) is deprived of adequate oxygen supply. Hypoxia in which there is complete deprivation of oxygen supply is referred to as anoxia.
* Hypoplasia: It is underdevelopment or incomplete development of a tissue or organ.
* Jaundice: Jaundice, also known as icterus (attributive adjective: "icteric"), is yellowish discoloration of the skin, sclera (whites of the eyes) and mucous membranes caused by hyperbilirubinemia (increased levels of bilirubin in the blood). This hyperbilirubinemia subsequently causes increased levels of bilirubin in the extra cellular fluids.
* Maladaptive behaviour: A maladaptive behavior is a behavior or trait that is not adaptive - it is counterproductive to the individual. Maladaptivity is frequently used as an indicator of abnormality or mental dysfunction, since its assessment is relatively free from subjectivity. However, many behaviors considered moral can be apparently maladaptive, such as dissent or abstinence.
* Non-linguistic communication: "Linguistic" means pertaining to language. "Non-linguistic" means not using language. Non-linguistic communication is the imparting of information without using language. Or in other words, sending and receiving messages without using a communication system that has the
* characteristic features of a language as identified by linguists. Gestures, written symbols, or voice sounds don1t constitute 11language11 unless they take place within a language framework. For example, the voicing of sounds that are not part of any system is not called language, it is called babbling.
* Nystagmus: Nystagmus is an uncontrolled movement of the eyes, usually from side to side, but sometimes the eyes swing up and down or even in a circular movement. Most people with Nystagmus have reduced vision
* Pre natal period: The prenatal period can be considered that time of development and growth of a baby prior to birth. During this time the baby is completely dependent upon the mother for its nutritional needs. This is the most importanttime of an individual1s life as far as nutrition is concerned.
* Proprioception: Proprioception is the sense of the relative position of neighbouring parts of the body. Unlike the six exteroceptive senses (sight, taste, smell, touch, hearing, and balance) by which we perceive the outside world, and interoceptive senses, by which we perceive the pain and the stretching of internal organs, proprioception is a third distinct sensory modality that provides feedback solely on the status of the body internally. It is the sense that indicates whether the body is moving with required effort, as well as where the various parts of the body are located in relation to each other.
* Residual vision: Any remaining sight, no matter how little, by means of which the person can add to his/her experience, enjoyment and learning about the world. This includes sight which is so poor as to enable the person to tell only light from darkness.
* Retinitis Pigmentosa: Retinitis pigmentosa is actually the name given to a group of hereditary eye disorders, all of which involve the eye1s retina, the light-sensitive nerve layer that lines the back of the eye, and all of which cause a gradual, yet progressive, loss or reduction in visual ability.
* Rhesus (Rh) blood group system: It refers to the five main Rhesus antigens (C, c, D, E and e) as well as the many other less frequent Rhesus antigens. The terms Rhesus factor and Rh factor are equivalent and refer to the Rh D antigen only. There may be prenatal danger to the foetus when a pregnant woman is RhD-negative and the biological father is RhD-positive.
* Sign Language: A sign language (also signed language) is a language which uses manual communica­ tion, body language and lip patterns instead of sound to convey meaning simultaneously combining hand shapes, orientation and movement of the hands, arms or body, and facial expressions to express fluidly a speaker's thoughts.
* Squint: A squint (strabismus) is a condition of the eye that causes one of the eyes to turn inwards (converge), outwards (diverge) or sometimes upwards, while the other eye looks forward. The cause, severity, and direction of a squint vary from person to person. It is usually spotted in childhood, sometimes within weeks of a baby being born, and affects 5-13% of children (1-2 in every 30).
* Visual acuity: Visual acuity is an indication of clarity or clearness of one's vision. It is a measurement of, how well a person sees. The eye has a visual acuity threshold below which an object will go undetected. This threshold varies from person to person, but as an example, the case of a person with normal 20/20 vision can be considered.
* Visual Field: The visual field is the total area in which objects can be seen in the peripheral vision while the eye is focused on a central point.
* Visual system: The visual system is the part of the nervous system which allows organisms to see. It interprets the information from visible light to build a representation of the world surrounding the body. The visual system has the complex task of (re)constructing a three dimensional world from a two dimensional projection of that world. The psychological manifestation of visual information is known as visual perception.
* Ventricular Septal Defect (VSD): It is a defect in the ventricular septum, the wall dividing the left and right ventricles of the heart.