Training Module on
Deafblindness

शिक्षा का अधिकार

सर्व शिक्षा अभियान
सब पढ़ें सब बढ़ें

Sarva Shiksha Abhiyan

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Introduction

Deafblindness is a unique disability- a combination of visual 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. Because 95% of what we learn about the world comes through sight and hearing, deafblind children face unique challenges in communication, mobility and accessing information; making deafblindness one of the most isolating disabilities.

Deafblindness is a low incidence disability and is hidden in community. There is no data available regarding the size of the deafblind population in India as, to date there has been no comprehensive study or research to determine the true incidence. Estimates, based on information gathered from community based projects, indicate that there could be more than 450,000 deafblind/ multiple disabled people in the country.

Sense International (India) was established in 1997 as the first national NGO in India to support the development of comprehensive services for deafblind people. Sense International (India) supports local organisations to develop sustainable services for deafblind people. Today SI (I) works with 39 partners in 19 states providing services to over 32,000 deafblind people. Our Key achievements include: deafblindness now officially recognised by the National Trust, Government of India; a dedicated Deafblind Teacher Training Programme; a national resource and information centre on deafblindness has been established and networks of families and teachers and deafblind people have been established.

Sarva Shiksha Abhiyan is an effort by the Government of India to universalise elementary education by community-ownership of the school system. It is a response to the demand for quality basic education all over the country. SSA ensures that every child with special needs, irrespective of the kind, category and degree of disability, is provided education in an appropriate environment. SSA adopts 'zero rejection' policy so that no child is left out of the education system. The thrust of SSA is on providing integrated and inclusive education to all children with special needs in general schools.

Sense International (India) is working in partnership with SSA. The main purpose of this proposed training module is to assist resource teachers, block resource coordinators of SSA with basic skills to identify, assess and strengthen services for deafblind children in local districts within the State. In addition, this training will enable them to work more effectively with learners/students who are deafblind. It would also increase the number of trained teachers in the field of DB. We aim to encourage education and rehabilitation of deafblind people with the ultimate aim of taking them on the path to inclusion.

Acknowledgements

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About Deafblindness

Introduction to Deafblindness

Section 1: What is 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 (P.L. 94-142) of 1975 and the Individuals with Disabilities Education Act (IDEA) (P. L.101-476*}

You would have noticed that the definitions speak about:

■   Combination of vision and hearing impairment

■   Does not imply total vision or hearing loss

■   Communication is most severely affected

■   Highly individualised training

■   The world is much narrower

■   Affects person in totality

■   Associated medical conditions

In India there are an estimated **450,000** deafblind people.

Section 2: Multi-sensory Impairment

People whose combined sight and hearing impairment cause difficulties with communication, access to information and mobility can be regarded as deafblind/MultiSensory Impaired (Department of Health). They have varying degrees of visual and hearing impairment, perhaps combined with learning and physical disabilities (Department of Education, 1989).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.

Section 3: 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. Some of the common causes are:

- 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) or Toxoplasmosis

    - Meningitis and Encephalitis

    2. Genetic or chromosomal syndromes as cause of deafblindness

    - CHARGE syndrome

    - Down syndrome

    - Goldenhar syndrome

    3. 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

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. 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 newborn 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. **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.

CHARGE Syndrome

CHARGE association (or syndrome) is an acronym referring to children with a specific pattern of birth defects. The acronym is: "C" for Coloboma (cleft or failure of the eyeball to close resulting in abnormalities of retina and optic nerve), "H" for Heart defects, "A" for Atresia of

Choanae (blockage of nasal passage), "R" for Retardation of growth and development, "G" for Genitourinary problems and "E" for Ear abnormalities (unusually shaped ears, sensorineural or conductive hearing loss). The incidence of CHARGE is about 1 out of 10,000-12,000 births.

It affects males and females of all races equally.

Usher Syndrome

Usher Syndrome is a genetic disorder that is characterized by hearing impairment as well as an eye disease called Retinitis Pigmentosa.

Most of the children with Usher Syndrome have a hearing impairment at birth. At a later stage vision problems also occur starting with night blindness. Vision gradually degenerates (gets worse) over time. Some of the children may be left with tunnel vision and some may go totally blind. 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.

Section 4: Impact 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 deafblindness:

- 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 play 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.

Motor Development 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, lead to serious developmental delays affecting motor and mobility problems that affect life 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.

Socialisation

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 and Sensory Issues

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 gathering, 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.

Sensory deprivation in an individual with deafblindness creates a big void in one's life. 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.

- Lack observational learning.

- Unable to take advantage from group instruction

Education and Learning

As mentioned earlier that 95% of whatever we learn comes through our eyes and ears. Deafblind children, 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. Deafblind children are educationally isolated because impairments of sight and hearing require attentive and unique educational approaches in order to ensure that children with this disability have the opportunity to reach their full potential.

For the deafblind child, 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.

If a deafblind child 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, recognize 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 deafblind child 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 deafblind child 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 they are occurring naturally in the environment around them. 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. He is not able to judge his own body in the space around him. His awareness about the organisation of the space and his safety concerns are also limited. It is therefore difficult for the child to get interested to move around in his environment independently and this has an unfavourable effect on his learning opportunities. Learning through doing, forms the basis of a strong learning environment for deafblind child. 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 immediate environment and limited scope to make choices. To reduce this loss, it is important to develop routines in the life of the deafblind child.

Section 5: Screening of Deafblind Children

Children with deafblindness can be identified in many ways

- Contacting village "sarpanch" and going through the village population data at the panchayat office.

- Conducting a door to door survey.

- Conducting screening camps in the villages.

- Contacting Primary Health Care (PHC) Centre doctors.

- Contacting Paediatric clinics.

- Getting information from Government hospitals.

- Information from child guidance centres.

- Survey data from other special schools/other organisations.

Tools required to Identify and Prioritise Needs

The following tools would be helpful in identification and prioritising the needs of deafblind children

- Survey format

- Screening schedule

- Medical certificate

- Functional assessment format

Identification Checklists

Observe the child in his familiar environment and answer the following questions in YES or NO. Consult with other family members too. If you get consistent and frequent YES answers, on the screening schedule for vision problems then please refer the child/person to an Ophthalmologist/ Eye Specialist. Similarly if you get consistent and frequent YES answers, on the screening schedule for hearing problems then please refer the child/person to ENT/Audiologist for a clinical Hearing testing at the nearest centre.

Hearing Impairment

1. Does the child have problems to hear when you speak to him from behind?   Yes / No

2. Does the child speak too loudly or too softy?   Yes / No

3. The child is not responding while calling by his / her name at a 3-5 feet distance?   Yes / No

4. Does the child exhibit voice problem and mispronunciation very often?   Yes / No

5. Does the child understand only after few repetitions?   Yes / No

6. Does the child answer your questions irrelevantly?   Yes / No

7. Does the child favour one each for listening purpose?   Yes / No

8. The child responds to the questions through gestures or signs?   Yes / No

9. Does the child have problems in play ground while playing within peers?   Yes / No

10. The child needs more repetitions in class?   Yes / No

11. The child tunes the TV / Radio too loud?   Yes / No

12. The child does not respond to the sounds in the classroom?   Yes / No

13. Is the child not able to speak properly even simple?   Yes / No

14. Does the child keenly observe the facial expressions / lip of you while talking?   Yes / No

Visual Impairment

1. Does the child have difficulty in counting the finger of an outstretched
    hand at a distance of one meter?   Yes / No

2. Does the child move his / her head towards the source of light?   Yes / No

3. Does the child rub his / her eyes frequently?   Yes / No

4. The child keeps the book too far / too close to his / her eyes while reading?   Yes / No

5. Does the child frequently ask other children while taking down
    the notes from the blackboard?   Yes / No

6. Does the child list against objects on the side?   Yes / No

7. The child has difficulty in reading from the black board, even if
    she is sitting in the first row?   Yes / No

8. The child is not able to identify / match colours?   Yes / No

9. Does the child having abnormal structure of eyes (bulging / too big / too small)?   Yes / No

10. Does the child get water frequently from his / her eyes?   Yes / No

11. The child has problem in following the moving objects?   Yes / No

12. Lighting variations in the environment confuse the child?   Yes / No

13. The child blinking eyes very often?   Yes / No

14. The child find difficult to identify objects / people at a distance of
    4-5 meters or further?   Yes / No

Section 6: Impact of DB on Learning

Refer section 4

Educational Aspect

Section 7: Assessment of Deafblind Children

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 hearing abilities, cognitive abilities, physical difficulties, 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.

Purpose of Assessment

Assessment will help the educator, professional and parent:

■   To identify the strengths and limitations of the deafblind child.

- 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 Individual Educational Plan.

Areas of Assessment

- 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? Tolerated? In use?

    - How does lighting affect him?

    - What is the child's preferred learning mode: visual, auditory, or tactual?

- Hearing

    - 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 she understand and respond to routine verbal instructions/commands?

    - Does she recognize people by their voice?

    - Does the child appear to use hearing aid to respond during the assessment to voice? Music? Speech?

- Are hearing aids recommended? Tolerated? In use?

- Social/ Communication domain

  - 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 he understand objects?

  - How does he use them?

  - What are his topics for communication?

  - Does he initiate interactions/conversations?

  - Does he communicate at a pre-intentional or intentional level of communication?

  - Does he use gestures or pointing? Does he show anticipation?

Tools for Assessment for the Children with Deafblindness

1. Learning through Doing

   This tool was developed by Blind Peoples Association, Ahmedabad and National Institute for the Visually Handicapped, (NIVH), 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.

2. Screening Checklist for Sensory Impairment

This tool was developed by National Institute for the Mentally Handicapped (NIMH), Secunderabad: Department of Special Education, NIMH has developed this checklist under the project 'Development of service models for children with mental retardation and multi sensory impairments'. The checklist contains provision for collecting basic information about the child and record statements in simple observable language indicating probable sensory impairment. This is a screening checklist covering the areas like vision, hearing and behaviour.

3. 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 18 subscales in five areas-

- Motor development

- Perceptual development

- Daily living skills

- Cognition, communication and language

- Social development.

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

4. Functional Assessment for Vision and Hearing Problem in Children

This tool was developed by Sense International (India): This format can be used for assessing the functional vision and hearing problems among deafblind children and adults 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 deafblind child's 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.

Section 9: 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.

Section 10: Communication

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 deafblind children 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, 1998).

"Communication includes language, speech and hearing and hence communication impairment can be viewed as any impairment related to these three areas" (Sunderland, 2004).

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.

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.

Developing Communication in Deafblind Children

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 the useful methods are listed below:

- Family must be given priority; child's interaction with his/her environment is dependent upon the family's activities and different sources 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 child's 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 student's communication system.

Fostering Communication

Preparation: Communication Initiation

Use of different gestures, touch cues, including signs allow the deafblind child to anticipate what is 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 if s/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. Whenever 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, where s/he finds a sorting of objects in one section, the child will be prepared for the activity and would enjoy the whole activity. These five components of communication should be kept in view.

Choice of the Activity

As we all keep changing with our choice of activities similarly children with deafblindness go through the same depending upon the mood, physical well being, or other factors. We could structure our settings in such a way that it provides maximum opportunities to the child for making choice, help him/her to communicate his/her preferences and enable 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.

Safety

Child needs to be comforted and should be 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 lights, smells and vibrations. The child may not remember and would seek teacher's involvement in locating the item. After a week's 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 new environment as well as the activity.

Use of Augmentative and Alternative Communication with Deafblind

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:

1. 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 deafblind individuals. 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 vision at all.

2. Hands-on Signing, Tactile Sign Language

    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.

3. Visual Frame Signing, Tactile Sign Language

    This is used by deaf people 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 deafblind individual so they do not disappear outside the "tunnel".

4. Finger Spelling

    The finger spelling is felt by the deafblind person. The best example is of the American manual alphabets, which are made using a single hand with a particular shape for each alphabet in English. Each word of English is spelt with changes in shape of the hand, which denote each of the letter in the word 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.

5. 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.

6. Speech

   Deafblind children 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.

7. 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 deafblindness to see clearly.

8. Tadoma

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

   It is sometimes referred to as 'tactile lipreading', as the deafblind person 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 'N' and 'M'. Use of Tadoma however requires good fine tactile discrimination skills, cognitive skills and fine motor skills.

9. Braille

   Braille is a system of touch reading and writing in which 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.

10. Moon Code

    The Moon system of embossed reading was invented by Dr William Moon in 1845. 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.

11. 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 a deafblind individual learning to communicate and express himself

through gestures is very difficult. Some deafblind children express their needs through vocalisations (crying/ cooing/babbling).

12. 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.

13. 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.

Section 11: Tactile Sign Language

Included under section 10.

Section 12: Inclusive Teaching Strategies: Teaching and Learning Materials

Teaching Learning Material (TLM) is a tool available to the teachers/ parents/ CBR workers to achieve learning outcome. It is not just a set of teacher made or purchased material, but a well designed tool for the child's needs.

The teacher decides at what level the child is and what activities within the level he/she wants to give. Once the decision is made, the teacher looks for appropriate teaching learning materials so that the teaching becomes effective and goal oriented.

E.g. TLM for Object Calendar

Objective: The students learn the 'start' and 'end' of an activity. They also learn the schedule of the day in relation to time.

Materials needed: Any object related to the activity being performed used as a symbol, containers to place the symbols, when arranged in a sequence as per the time table in a fixed place, this becomes the object calendar.

- Cassette (for music)

- Tumbler (for toileting)

- Clay (for clay work)

- Coloured stones (for art work, outing, etc)

- Tiffin carrier (for lunch time activity)

Section 13: Teaching Strategies

Right strategy involved in implementing the programme for children with deafblindness is a route towards successful results. 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 to meet curriculum goals and help in planning how and where to work on suitable activities.

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 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.

- Develop a positive self-esteem by giving the learner opportunities for choices.

- React to the learner's 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 'Experience books' to give deafblind students a way to have a conversation about what they have experienced.

- Let the students 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 doesn't have to "think" 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

- Independence is the goal

- Teach skills that are functional and meaningful

- Teach in a natural setting

- Provide assistance as needed

- Provide repeated opportunities to practice skills

- Take advantage of the teachable moment

- Speak to students using normal language and voice

- Use real objects

- Develop routine

- Plan inclusive activities

- Make use of resource persons from the community.

Section 14: Curriculum Development

1. 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

- Work

- Recreation and Leisure

- Community

- Academic areas

- Communication

2. 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.

3. 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.

4. 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 towards 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 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. He cannot tie together the fragmented input he receives without interpretation and instruction from others. He must be taught to use and accept this instruction.

5. 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.

Section 15: Classroom Adaptations

Deafblind children will have specific needs and that should be considered while designing a classroom for them. We must strongly adhere to user friendly approach. Any ornamentation and decoration cannot be accepted at the cost of learning of the child. The space design should be simple and functional. Each and every object/ element should have some purpose to it. Here, classroom is not just a physical environment but it also enhances the learning of the child.

Section 16: Teaching, Reading and Writing skills for Deafblind

Literacy in the broadest sense is listening, speaking, reading and writing. It involves the use of languages. Reading and writing allows information sharing and increases knowledge of the world around us. It allows us to acquire and share information, ideas and knowledge, stimulates mental activity and keeps us in touch with our environment.

Deafblind children may not be able to read and write like "normal children". Literacy for them may be in different forms and modes depending on the child's sensory, mental and cognitive abilities, literacy may mean that he can learn;

- More formal and structured language which may be in print or Braille

- He may be able to work on a Braille computer or access Internet

- Or he may be able to "read" a schedule that consists of objects arranged in the order of events they represent or to point to a picture to express his need, which is a more functional form of literacy.

DOs	DON'Ts
The design of the classroom should help the child to get multisensory learning	Avoid a room with too many corners and narrow spaces
Classroom should have adequate light conditions with good colour contrast on the walls	Avoid dull light or excessive glare in the classroom
The classroom should not have any obstacles, e.g. too many pathways in between narrow spaces, bumps on the floor etc	Avoid suffocating atmosphere in the classroom
Classroom should be preferably on the ground floor and it should be made accessible with the help of a ramp or loft	Avoid dark colours on the wall
	Avoid visual clutter in the classroom
Steps should also be provided with appropriate and uniform tread and riser, colour highlight on every step and a hand rail on both the sides	Avoid furniture with sharp edges
	Avoid changing the placement of the furniture in the classroom
Furniture should be adjustable according to the needs of the child	Avoid keeping too many things on the floor
Special teaching areas should be separately marked through colour contrast or tactile indications	Avoid open plug points and sockets in the classroom for safety reasons
	Avoid glossy floor that reflects unnecessary light
Keep rugs at the door to reduce the risk of children falling over the edges and elevations	Avoid unnecessary noise to facilitate better learning for the children.
The path of walking for children should be properly defined.	

Early Exposure to Reading and Writing

Deafblind child needs constant exposure and access to concept development and language learning. Since these children receive limited and incomplete information about their environment, we need to ensure that we provide as much exposure to languages learning as possible. Concrete hands-on experiences with things form a foundation of learning for them. Concepts will only develop through exposure to languages provided through natural, meaningful experiences like playing, cooking, shopping and travelling. The child needs to explore things that motivate him. We need to

help the child understand his experiences, and with time help him develop abstract concepts for e.g. point out familiar / unfamiliar features, relate new experiences to familiar ones and help the child anticipate what may be expected in various surroundings.

Language teaching must be based on multiple experiences that will help the child understand the meaning of words that he is learning to use. Materials used for language must be real, touchable things that the child can use. Multi-sensory cues can be used to encourage the child to acquire concepts and language.

Getting Children ready for more formal Reading and Writing

Reading

Reading is based on language, and language is based on concepts developed from interactions with people and the environment. Part of those interactions is spoken or signed language – sharing ideas about the environment and naming objects, people and abstract concepts like feelings. As the child begins to make sense of the written word, his language expands and he begins to read for both information and pleasure.

A child's beginning reading vocabulary includes his name, names of people in his life and objects and his possessions. By the time children are ready to read and write they will have already acquired a great deal of receptive language. Deafblind children with additional disabilities also need to be exposed to language and conversational interactions before we expect them to be able to read and write.

After a child begins to read single words through repeated exposure in meaningful situations, his reading vocabulary can be expanded to include his day-to-day activities and names of his favourite objects and activities. His possessions and environment can be labelled with motivating and interesting words.

Language and concepts can be taught and expanded very effectively through the Unit-based approach. A unit-based approach uses a central theme to teach all subjects and language. It is an integrated way of teaching and linking subject matter and encouraging reading in children. For, e.g. if the theme is "Transport", then all the languages and concepts taught to the child in that month will be on different transports. How they work, people who work them, math problems on transport, drawing / making transport models, songs on transport and so on.

A simple picture story book that is visual / tactile and has single words on each page is a good way to encourage reading. As the child's language grows, more complex story books can be used for story telling as well as reading. Teacher made books, charts, storybooks and experience stories made with the children are the best way to teach children language, concepts and reading.

For children who are at the object or picture reading level, the teacher gradually fades away the objects and pictures and substitutes them with the print form as the child's competencies increase.

Children who are more academic can be introduced to regular graded reading series. For Deafblind children with additional disabilities, care must be taken to ensure that the language in these books is interesting and not too full of idioms and abstract language that discourage the child from reading.

Bright, attractive classrooms and teaching areas that have a good visual and tactile display of language materials greatly encourage a child to read.

Writing

Deafblind Children may have problems in writing due to vision impairments and difficulties with eye hand coordination. As teachers we need to be aware of the special need of our children.

Children need to be encouraged to express their ideas and thoughts in writing as much as possible. If the child is slow, we need to give him extra time to write. If he has difficulty in forming letters, give him support. Even if the letters are not clearly formed, we must accept them. The child can be encouraged to form better letters in other teaching sessions. For children, who have difficulty in writing full sentences, we can give them objective papers to write that require him to only check, cross or circle an answer. If a child has problems in seeing clearly, we can provide the child with wide-lined paper, dark pencils or markers. White paper with black pens makes a good colour contrast for children with low vision.

The language of the child must be corrected with caution. His diary writing needs to be left uncorrected to avoid lowering of the child's self esteem. The teacher can keep the child's grammar mistakes in mind when teaching language and thus correct them in a different class.

Should a deafblind child be taught Braille or print?

Whether a child will be able to learn Braille or Print will depend on his;

1. Cognitive ability

2. His residual senses

3. His interest level, and

4. The practicality of his reading and writing in future

Print needs to be taught to a child who is more visual than tactual. Although the size of the letters can be increased to make reading easier, the practical aspects must be considered as this will make reading more difficult if he sees only one letter at a time.

Braille is a more complex system that has alphabets and contractions and abbreviations as well as punctuation symbols. The differences between Braille symbols are finer than print letters and recognition depends on making detailed spatial discriminations. Braille requires the development of motor skills as well as fine tactile skills. Braille also requires spatial orientation, both in recognizing letters as well as following lines in an organized way across the page. Pre-Braille activities that encourage fine tactile discrimination skills will prepare the child to read Braille. A child who is to learn Braille needs experiences to help him understand the functions of Braille as well as countless opportunities to practice tactual discrimination. The child can be exposed to Braille in many forms - name labels, simple books to play and touch, labels on his object calendar and signs in his school and home environment. Thus a child who has good useful vision, which he uses to get information, can learn print, whereas a child who is more tactual can learn Braille. But to learn Braille, a child also needs to be bright, have curiosity about his environment and have good language skills. Braille is very suitable for academic children whose language, reading and writing skills will continue to expand and develop.

Section 17: Transition Planning

'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.

The Transition Team

- Student himself

- Family members

- Educators or the school staff members

- Placement officer

- Employers and the co-workers

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 centered 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 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:

- Background
- Relationships
- Places
- Choices
- Hopes and fears

Stage 3: Creating the Dream

This stage is the critical stage of the PFP.

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

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 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.

Section 19: Inclusion

Inclusion supports the right of all children, regardless of their diverse abilities, to participate actively in natural settings within their communities. A natural setting is one in which the child would spend time if he or she had not had a disability.

Full inclusion means that all students, regardless of handicapping condition or severity, will be in a regular classroom/programme full time.

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.

Inclusion of Students who are Deafblind

Students who are deafblind represent a heterogeneous group in terms of cognitive and functional capacities. The unique support needs of these students include specialized communication and mobility instruction. The specific condition of deafblindness requires that, in addition to functional curricula that is age appropriate, at least the following be a part of the students' IEP:

- Communication goals reflecting the students' most useful modality

- Sensory development activities

- Teaching strategies that consider the students' preferred learning styles

- Mobility training

- Cognitive skills expansion through adaptation of sensory input

- Increased opportunities for social interaction

- Instruction in reading and writing, if appropriate.

Planning, organising and delivering Inclusive Programs

- Consider student's previous experience/knowledge

- Focus on student's learning outcomes rather than be 'rigid' over the content

- Value differences in outcome

- Recognise that student's learning outcomes can be demonstrated in novel contexts

- Plan for differing completion speeds

- Plan to provide students with additional help

- Plan to provide extension support for those who need it.

What Does An Inclusive Classroom Look Like?

Inclusive classrooms look different all the time because the environment is created by whatever interactions the teacher and students have as a group or as individuals in the group. It's a lot of students doing different things with people helping them, students moving from one environment to another. It's also a classroom where everybody is smiling, the students are actively engaged, and the teacher is delighted to be there.

Students spend a lot of time in learning centres where they make a lot of choices about what they're working on. It's a classroom where learning often happens in small groups with peers helping and supporting each others. It's a classroom with a lot of time for social interaction that means something to curriculum expectations.

It's a classroom that is "student-centred". Students have a high level of responsibility for creating their community. They help structure the rules and are expected to follow them and to meet contracted expectations for curriculum. It's a classroom where students know others will be doing different things and the issue of fairness doesn't come into play because that's just the way it is.

It's a classroom that reaches beyond the classroom and into the community as a resource for learning new skills. *Inclusion without resources, without support, without teacher preparation time, without commitment, without a vision statement, without restructuring, without staff development, won't work.*

Peer Sensitization

Inclusion of persons with disabilities in mainstream society attains reality when participation occurs to the fullest extent with acceptance from other people in society. Peer support groups have proven to be an effective way of enabling pupils with disabilities to participate more fully in all aspects of school life and have proven to be at times more effective than adults.

Some of the activities that could be taken up for this purpose are:

- Sensitizing children on the issues of disability and right to education for 'ALL' children through discussion, audio-visual aids, storytelling, picture reading, giving information and examples of distinguished persons with disabilities and their contribution to the society

- Mobilize children to collect information about the children with disabilities in their own locality and their rights to education.

- Mobility Orientation (the ability to locate oneself in one's environment and to move in the environment from one place to another). This could be done under blindfold and earplugs.

- Overall development with a focus on daily living activities using other senses (hearing, touch, taste, smell etc.) Encouraging children to identify objects and talk about them without using

their senses of vision and hearing is a good way to help them understand the role of other senses in day- to-day life.

■ Various activities in day-to-day life such as making a sandwich, brushing could be done under blindfold.

■ Group activities to be planned for the child with deafblindness and other children in the form of games such as draw the tail on the donkey under blindfold, playing with an auditory or textured ball.

Determining Goals and Roles of Personnel

Educating all students, regardless of disabling condition, in their neighbourhood school is the goal of inclusive education. A strong sense of community in the classroom, throughout the school and among parents of all students is necessary for an inclusive program. A flexible curriculum and support for staff and students are necessary components of an inclusive model.

Establishing school-based plans for educating children with disabling conditions in the regular classroom setting is a shared responsibility of regular and special educators. Inclusive education requires a restructuring of how services are delivered to children, and a focused effort for "push-in" rather than "pull-out" services is the key. Parents' awareness of these changes increases the roles of the students, school personnel and home. This partnership supports a plan for educational change.

Collaboration of regular and special education teachers naturally occurs as children with special needs spend more time in regular education. Consultant services develop into a support system for professionals in the school in order to help students succeed in the classroom. Collaborative efforts should focus on shared concerns that could be worked on in school and at home so that parents are partners in their children's education. Collaboration is a crucial component for improvement of educational services to students with special needs.

Giving teachers' control of a classroom, policy, and programs is a useful tool in support of collaboration. Effective education collaboration needs to focus on shared responsibilities, mutual respect, joint planning, reciprocal support, a common educational philosophy and systemic evaluation and dissemination of information.

Section 20: Needs and Concerns of DB Adolescents

Many children and adolescents who are deaf-blind express themselves in forms other than speech. Since communication and language skills are involved in virtually all academic and social activities, it is especially important for psychologists to understand how a student communicates with others. Psychologists may examine an individual's means of expression (e.g., gestures, words and tactual

signs), vocabulary, comprehension, use of symbols and social interaction skills. Personality, behavioural and emotional functioning may be assessed when there are concerns about self-esteem, problem behaviours, anxieties, attention span, mood swings, disturbances in basic routines (e.g., sleep, mealtime) and adjustments to changes and transitions. Some instruments are used to obtain information about a student's sense of identity, thoughtfulness, motivation, moral reasoning, interpersonal feelings, and attitudes. Others can help educators and parents understand patterns of behaviours that interfere with learning or social interaction, or that may be self-injurious. Educational tests, or measures of academic achievement, assess proficiency in reading, arithmetic, spelling, concept learning, Braille and other areas that are directly relevant to school learning. Results provide information about students' degrees of progress, areas of difficulty, appropriate levels of curricular instruction and special aptitudes.

Measures of social and adaptive abilities focus on basic life skills involved in self-care, orientation and mobility, play, domestic chores and routines, dressing, eating, community experiences, leisure, work and interpersonal relationships. Assessment of these skills must always be included in the psychological evaluation of a person who is deaf-blind. Results help determine in what areas and to what extent interventions or adaptations may be required to promote one's independence. Some psychologists also evaluate vocational aptitudes to help define a person's work interests and talents. In transition planning or the consideration of services that an individual who is deaf-blind will require after leaving school, vocational assessment may suggest the environment, supports and training program in which work skills can best be enhanced.

Leaving school and making plans for the future is an important time for all young adults and parents. This is especially true for people who are born deafblind and their parents and carers.

Making Decisions

Most deafblind adolescents will need a lot of support from their parents and teachers when they are thinking about their plans for the future. This may be the first time that they have been asked about their plans and what they would like to do.

Many deafblind young adults may have strong ideas about what they would like to do in the future. Some may need help to make these decisions and so it is important that they are supported by people who know them well, who know about their skills and strengths, as well as being realistic about the choices available. Others will need parents or carers to make a decision on their behalf.

Section 21: Behaviour Management in Children with DB

Some individuals who are deafblind may engage in behaviour, which troubles and challenges the people who care or interact with them. This behaviour can possibly interfere with their inclusion in the society and become a barrier in forming close relationships. In severe instances it can put the

health and safety of these individuals and those around them at risk. As a result, finding ways to minimize this behaviour should be a top priority.

Finding out what Behaviour Means

Decreasing challenging behaviour begins by understanding why a child is behaving in a certain way. Behaviour that is undesirable to others may be the way a child has learned to most effectively respond to a given situation or relationship. This behaviour occurs because no other responses make sense to him. Those who care about the child may unknowingly even help bring about and encourage this behaviour.

Doing a Functional Analysis

The function of behaviour is sometimes obvious. In many cases, however, it is not easy to determine. The same behaviour may mean different things in different situations; however, it is very important to speculate on why the behaviour is occurring if there is not an obvious answer. Trial and error can test speculative answers as strategies are developed based on these speculations.

The function of behaviour is the purpose it serves for the individual. Asking the following questions can help determine what the child is trying to achieve with the behaviour:

- Is the individual trying to get something with the behaviour?

- Is the individual trying to avoid or escape something with the behaviour?

- Is the individual trying to cope with a confusing or threatening situation?

- Is the individual trying to gain some control or equalize power?

- Does the individual know the appropriate way to behave?

- Is the behaviour a way to cope with physical or medical problems?

- Is the behaviour pleasurable?

There are several areas that should always be considered in order to determine the message of the behaviour:

- Consider problems with people.

- Consider problems with the activity and / or level of support.

- Consider problem in the setting.

- Consider problems with the time of day or day of the week.

- Consider the conditions of the individual's lifestyle.

Developing Strategies for Addressing Behaviour:

- Prevention is better than reaction

- Manipulating situations

- Teaching new skills

- Receptive communication and access to information

- Expressive communication

- Choice making

- Other skills

- Improving quality of life

- Reacting to troubling behaviours.

Points to Remember

1. Behaviour that others find undesirable may be serving an important function for a child who is deafblind.

2. Troubling behaviour should be treated as communication, with efforts made to uncover the message in the behaviour.

3. A functional analysis involves asking questions to determine the child's motivation for behaving in challenging ways.

4. To determine the meaning of behaviour, caregivers should gather information about the people, places, times and activities involved in situations where the behaviour is most likely to occur.

5. Determining the underlying cause of behaviour is the best way to develop strategies for addressing it.

6. Strategies for addressing troubling behaviour should focus on preventing problems rather than reacting to them.

7. Situations and environments can be modified to make troubling behaviour less likely in the short-term.

8. Teaching new skills can help children gradually replace troubling behaviour.

9. Improving a child's satisfaction with his quality of life can have a positive impact on his behaviour.

10. When troubling behaviour occurs, the reaction of others should be to redirect and teach, without inadvertently reinforcing the behaviour.

Section 22: Service Delivery Models

All students with deafblindness are entitled to a variety of service delivery models that include Home based programs, Community based Rehabilitation, Centre based Model and Residential Model, Specialized school programs, special day classes in public and private schools and in inclusive general education classes in public schools. Meeting the complex educational needs of these children and youth with who have deafblindness in a wide variety of settings offers a unique challenge which is the focus of this section.

Methodology & Approach

Centre Based Model/Special Educational Units: Most special schools in India serve children with a single disability, children with multiple disabilities are often left out. Many NGOS have established specialist education units within schools for children with single disability such as blindness, deafness, cerebral palsy, etc to serve deafblind children aged 4–14 years. The units provide pre-school training and education in daily living skills, as well as more intensive training in motor development, personal activities, social and communication skills, academic areas and pre-vocational subjects. After intensive training in a specialist education unit, children are admitted to mainstream schools alongside their sighted peers, through the SSA or Integrated Education for Disabled Children. This allows Children with deafblindness to gain independence and become part of mainstream life.

Home Based Model: Under this Model specialist services are brought to the communities and homes where children with deafblindness live through home-based care. Experience shows that when a child with deafblindness learns successfully in the presence of his or her family, the family members are much more likely to develop positive and supportive attitudes about their child's potential. This leads to better results and improves the family's ability to care for their child as well as helps to increase people's understanding about disability and reduce the stigma associated with it.

Community Based Model: Community based programmes are implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services. The programmes are developed in response to a need to reach out to a greater proportion of the rural disabled population in India. Local volunteers are identified and trained to provide services and support to children in such remote areas and specific community based activities are implemented for greater interaction and consecutive progress. These volunteers eventually integrate into the system to widen to reach out to the needs of these children.

Respite Care: Is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home. Respite programs provide planned short-term and time-limited breaks for families and other unpaid care

givers of children with deafblindness, of children with a developmental delay and adults with an intellectual disability in order to support and maintain the primary care giving relationship. Respite also provides a positive experience for the person receiving care. The term "short break" is used in some countries to describe respite care.

Section 23: Sensory Integration Therapy for Children with DB

Sensory Integration is the process by which the central nervous system coordinates input from sensory receptors throughout the body, associates this input with stored memories of prior experiences and produces adaptive responses to life situations.

A student with sensory integration dysfunction will show many of the following characteristics:

- Poor muscle tone

- Poor tactile discrimination or tolerance

- Delayed reflex development

- Abnormal like or dislike of vestibular or balance activities

- Delays in both fine and gross motor skills

- Immature posture and gait pattern

- Poor balance

Sensory Integration Training

The purpose of sensory integrative training is to enhance the brain's ability to learn the processes involved in accomplishing skills. It focuses on development of the capacity to receive, perceive, remember and motor plan, thereby treating the origin of the problem not its behavioral symptom. For example, if a child is rocking constantly, stopping the rocking behaviour is treating the symptom. If the reason for the rocking behaviour is discovered and addressed, then the origin of the problem is being treated and with appropriate training, can hopefully be solved.

SI Activities

- Swinging in a blanket held by two people

- "Crawling" supported in a towel-sling under the tummy

- Pulling around on the floor in a blanket

- Crawling trolleys or tyres with wheels to lie across

- Rift on 'scooterboard' – child could grasp a hoop to be pulled

- A large skateboard

- Pulling around on a toy horse

- Toys for sitting on to move – rockers or peddlers

- Horse riding

- Swimming

- Use of adult as 'equipment' – horse riding, log rolling

- Walking around with child on back in backpack

- Use of physiotherapy ball

- Outdoor play equipment – slides, swings, see-saws, tunnels and barrels.

- Paddling pool

- Use of hoses, sprinklers and watering cans

- Atomizer spray

- Squeeze bottles and other empty plastic containers

- Bubble bath

- Shaving foam

- Use of bath aid to support child in shallow water.

- **Use of strong visual clues in the environment,** for example;

    - red doors against white wall

    - yellow plate and cup

    - Silver foil in changing corner

- **Varied Lighting** if possible for distraction-free "looking";

    - Use torches, lights, shiny mirrors etc.

    - An ultraviolet light box can be useful for some children.

Section 24: ADL Training

While training a child with DB, the following principles have to be used:

- Task Analysis: breaking a complex task into simpler steps

- Chaining: teaching steps by joining one step to the next

- Prompting, cueing and fading: providing support

Adaptations for DB children

- Feeding: Good supportive seating

- Dressing: differential tabs can be sewn on clothing to indicate front and back. Child needs practice time with buttons and zippers

- Toilet Training:

    - Follow a consistent schedule.

    - An established route to the bathroom

    - Familiar sounds

    - Consistent use of one or two words or sounds for toileting

    - Establishing an association between changing wet clothes and going to the bathroom

Orientation and Mobility

Orientation and Mobility (O&M) instruction provides students who are deafblind with a set of foundation skills to use residual visual, auditory and other sensory information to understand his or her environment. For the deafblind child, movement is an opportunity to gather sensory information, to communicate and to make choices. O&M instruction provides opportunities and skills that can broaden the student's awareness of the environment, resulting in increased motivation, independence and safety.

Definitions

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.

Mobility: Mobility is defined as "movement" not just a particular technique or device. It includes obtaining freedom of movement, safety in travelling as well as minimizing the level of stress placed. A well-developed mobility facilitates independent movement.

Importance of Orientation and Mobility:

1. It is an important pre-requisite for the integration of the deafblind person into the community and working life.

2. Being able to travel freely is very important for the sense of independence.

3. O&M training is not just the overcoming of practical difficulties, but also, a step towards developing and maintaining one's own character.

4. Safety of the individual and his fellow men is enhanced.

5. It enables him to learn to become more independent in indoor as well as outdoor mobility.

6. The success of the vocational training programmes also pre-supposes the importance and necessity of independent travel.

7. It allows a person more freedom and makes him/her less dependent on family and friends.

8. It also educates the public for changing attitude.

9. Proper O&M is a step toward comprehensive rehabilitation, self confidence and liberation from solitary home confinement.

10. A person with excellent and graceful O&M skills is said to have attained independence and is easily acceptable by the sighted community.

11. It is essential for correcting gait and postures.

Using Other Senses for Orientation

The deafblind person attains independence in travel if trained in effective and proper use of remaining senses. Sensory stimuli termed as 'Clues' generally enable him to determine his position or direction in respect of the environment. Sensory training should be provided in the following areas:

Touch: The deafblind person can orient himself by his sense of touch. It is essential for concept clarity and determination of exactness of the object. He can use hands or foot to explore the environment in the following ways:

1. **Hands can be used to:**

   - Understand spatial quality, surface texture, temperature, movement and weight

   - Establish the position and identify objects

   - Trail along any object for maintaining contact for mobility

   - Avail information about the layout of the environment through object symbols, landmarks, tactile maps, models, embossed diagrams and relief maps.

   - Understand the variety of objects available.

2. **Foot can be used to:**

   - Understand position of various landmarks on the pathways etc.

   - Understand the relative position of buildings and the direction and lengths of connecting roads.

   - Feel changes in surface texture, slope etc.

- Understand differences in geographical conditions.

The touch has its limitation as large objects and the environment in general is invariably beyond tactile exploration.

3. **Smell is useful for orientation both in house and outside in the following ways:**

    - Particular shops, factories or establishments can be identified by odour.

    - Smell from kitchen, store, puja room or dining room can be useful as a cue for direction.

    - Through smell, one can establish presence of particular animals in the proximity

    - Typical odour from the sewerage or open drains in the rural areas can be used as landmarks.

    - Sense of smell is useful for understanding one's relative position in an agricultural or a dairy farm or a garden

    - To relate or associate different items from their smell.

4. **Temperature:** Changes of temperature on the face or body can be used to provide orientation information. For example, it is possible to recognize position of the sun by part of the face which feels hot. The relative position can be understood by a change from shade to sun.

    The response of the body to external stimuli, termed as kinaesthetic sense enables a person to avail environmental information like heat, cold, rain, breeze, sharp turn etc.

5. **Kinesthetic Sense:** The receptors in the joints and muscles are giving information to the brain about the physical position of the individual in the environment. This mode of information is termed as kinaesthetic sense. With this information, the deafblind person comes to know on what type of ground or surface i.e. grass, road, mud he is walking.

    It is possible to remember and repeat particular body movements. Taking meals involves a number of sequential body activities which can be remembered and repeated when required. With practice, particular muscular movement can be produced automatically in a similar situation. It is possible to replicate the extensive body movements involved in walking from one place to another. Getting into a bus, going up the stairs or opening the door generally involves particular muscular movement which can be repeated time and again in a similar manner.

    It is a misunderstanding that lack of vision is compensated by extraordinary development of other senses. In reality, acquired blindness or deafness results into shattered confidence in other senses. However, through appropriate training and practice, one can develop skill of understanding the environment through the cumulative use of other senses.

6. **Sense of Taste:** It has less utility for sensory training in orientation and mobility as it does not provide any information about the relative environment. This sense needs to be provoked for its utility. It helps the deafblind person to associate names of the particular substances with their particular taste:

    ■   Sweet with sugar, candy, sweets

    ■   Sour with citrus fruits, juices

    ■   Bitter with medicines, herbs, plants

    ■   Hot with tea, coffee, milk

    ■   Cold with ice-cream, ice, cold water etc.

    The sense of taste is particularly useful for identifying the ingredients of food items, dietary substances and like items.

Orientation and Mobility Checklist

This check list can be used in assessing the present level of the child's O&M skills. It will also give leads to determine the priority O&M goals to teach your deafblind child.

Orientation of self to Immediate Environment

■   Holds head up while in sitting position

■   Moves arms and legs

■   Rolls over

■   Rolls over objects, e.g. pillows, bed covers, soft toys

■   Sits without support

■   Crawls

■   Stands with support

■   Localizes to sound

■   Reaches towards objects

Moving in the Home Environment

■   Demonstrates good balance

■   Stands without support

■   Walks with support

■   Walks without support

- Demonstrates good postural control

- Explores immediate environment through tactile and olfactory senses

- Climbs steps with support

- Climbs without support

- Kicks a ball

- Jumps with both feet

- Moves limbs in water

- Moves towards sound and smell

- Runs

- Manoeuvres around obstacles

- Explores environment beyond the immediate

- Uses play equipment.

Body Awareness

- Touches own major body parts upon request (e.g. head, arms, legs)

- Touches minor body parts on self upon request (e.g. fingers, shoulder, ankle)

- Names own major body parts

- Names own minor body parts

- Locates body parts on a model or another person

- Moves named body parts upon request.

Basic Concepts

- Demonstrates an understanding of

- Up / Down

- In /out

- Front / Back

- Top / Bottom

- Forward / Backward

- Left / right

- Sideways

- Above / under

- Before / after

- Behind / in front

- Now / Afterwards

- Identifies different textures

- Identifies own belongings.

Travel Skills

- Trails a surface

- Holds cane

- Uses upper and lower protective techniques

- Uses sighted guide technique

- Uses appropriate diagonal cane technique

- Explores outside environment

- Climbs in and out of public transport, finding a seat with support

- Uses public transport with support

- Uses public transport with increasing independence

- Shops with assistance

- Travels independently within the neighbourhood

- Demonstrates awareness of safety hazards, such as traffic, fire, emergency vehicles

- Crosses roads with support

- Demonstrates awareness of road hazards, such as potholes

- Asks passersby for help

- Uses communication cards as a support

- Demonstrates a concept of buildings

- Creates mental maps of immediate environment.

Check Your Progress

True or False

1.   The word deafblind means the person is completely deaf and blind.

2.   A deafblind child/ adult will be dependent throughout his life.

3.   Rewarding a child is not good for the child as the child will become dependent on rewards throughout his life.

4.   Classroom should preferably on the ground floor.

5.   Reward should be given before the child finishes an activity to encourage him.

6.   While teaching a deafblind child, the activity should be broken down into small steps and taught one at a time.

Fill in the blanks

7.   ————- is the ability to locate oneself in one's environment

8.   ———— approach uses all remaining sensory abilities of the child

9.   Tactile lip reading is called as ————

10.   Learning takes place best in

   a)   Classroom setting

   b)   Natural settings

11.   Functional curriculum approach is based on what?

12.   What is Individualised Educational Planning (IEP)?

Choose the best answer

13.   What are the causes for deafblindness?

   a)   Genetic disorders

   b)   Maternal illness during pregnancy

   c)   Hypoxia during birth

   d)   All of the above.

14.   Which of the following is true?

   a)   While talking to a deaf blind person, shout to him near his ears

   b)   All deafblind people lead isolated and socially impoverished life

   c)   Children with deafblindness can be trained to become independent in life

d)   All people with deafblindness are mentally retarded as well.

15. Classroom setting should

   a)   Have adequate lighting with good colour contrast on the floor

   b)   Have too many corners and narrow spaces

   c)   Change the placement of furniture

   d)   Have too many things on the floor.

16. What are the common communication methods that deafblind people use?

   a)   Tactile sign language

   b)   Print on palm

   c)   Tactile finger spelling

   d)   All of the above.

Answer Key

1.   False

2.   False

3.   False

4.   True

5.   False

6.   True

7.   Orientation

8.   Multisensory

9.   Tadoma

10. b

11. Based on the current and future needs of the child

12. It is a complete programme for an individual child implemented for a specific period of time to provided appropriate education and training

13. d

14. c

15. a

16. d

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