

DEAFBLINDNESS

Chapter 1

Concept and Meaning of Deafblindness

Deafblindness is the combination of significant auditory and visual impairments in a person. These dual sensory losses vary in severity from person to person and do not necessarily lead to total deafness and/or total blindness. It is entirely possible that the person will retain some useful vision and hearing. However, in combination, these impairments of the distant senses causes serious developmental delays in the child, affecting cognitive development, social development, acquisition of communication and language skills, orientation and mobility.

A combination of visual and hearing impairment causes such severe developmental, communication and learning needs that the person cannot be educated in special education programs meant for the hearing impaired, for the visually impaired or for severe disabilities. Supplementary assistance would be required to address their unique educational needs consequential to the concurrent impairments of vision and hearing.

Deafblindness leads to a severe disabling condition caused by combined losses in hearing and vision. A deafblind child cannot be thought of as blind and also deaf, nor as deaf and also blind. Various terms have been used in the past to refer to this heterogeneous group of population. Earlier, the term 'deaf blind' or 'deaf-blind' was used. However, keeping with the belief that impairments in both hearing and vision have, not an additive, but a multiplicative effect on the affected

individual, the term 'deafblind' is now used (Aitken, 2000).

Deafblindness is a unique disability; it has its own concepts and terminology, its own methods of assessment and means of education, and its own modes of communication, which distinguishes "deafblindness" from deafness and blindness. Deafblindness is not a medical concept, surprisingly; medical literature makes few references to deafblindness. It is a developmental concept which helps us to understand the nature and the extent of a disability consequent to deafblindness. Because 95 percent of what we learn comes through our eyes and ears, deafblindness leads to difficulties in communication, mobility, and in accessing information.

Deafblind people fall into four groups:

1. Those who are born deaf and blind, which can happen if the mother, inter alia, contacted Rubella (German Measles) during pregnancy.
2. Those who were born deaf and then lost their sight. This is often caused by the Usher Syndrome – deafness followed by a decrease in sight because of retinitis pigmentosa (tunnel vision).
3. Those who were born blind and then lost their hearing.
4. The adventitious deafblind, as a result of old age, or through an illness or accident later in life.

Deafblindness and Communication

Quite a few deafblind people still have a little useful sight and hearing, which can be improved by wearing glasses and/or through hearing aid usage. However, conditions such as excessive background noise, poor illumination, depriving utility of visual cues, insufficient knowledge in hearing aid usage, poor initial selection of the instrument may limit the utility derived from wearing hearing aids.

Deafblind people who were born deaf or went deaf in early years may depend on Sign Language, rather than spoken language. Those who have some remaining sight may still be able to see Sign Language at close quarters. If they can't, they

may place their hands on the hands of the person signing to them to help recognise the signs through touch.

Other deafblind people who have either very limited or no sight or hearing at all, need the speaker to communicate with them on the palm of their hand. One-way is to trace out the letters of each word in block capitals, one on top of the other. This is simple but the drawback is that it is slow and also a person who has been blind all his/her life may not easily recognise the letters as they are more used to reading Braille.

A quicker method is called '**Deafblind manual alphabets**' and is like the finger spelling used in Sign Language, but placed on the hand. Different letters are spelt out by touching specific areas of the fingertips and palm of the deafblind person. For example "A" is made by touching the person's thumb. Deafblind manual can be learnt quickly. With practice, it may be possible to have a conversation at a reasonable pace by using this type of finger spelling. Sadly, many people don't learn this easy method of communication. If they meet a deafblind person who uses it, there may be a total breakdown of communication, which is frustrating and embarrassing for those involved.



Figure 1: Sign Language

Deafblindness and Mobility

Finding one's way from one place to another is difficult enough for someone with little or no sight, but it can get so much worse when the person has little or no hearing to help them find their way. Crossing a road when you can neither clearly hear nor see the traffic is extremely dangerous. The problem is made worse by the poor balance that many deafblind people have who find difficulty in walking without someone beside them to help. Whereas blind people use a white cane to show they have a problem with their sight, deafblind people use the same white cane but with red bands

around it, which shows that they have a loss, of hearing as well as sight.

Deafblindness and Accessing Information

A lot of important information appears in small print posing difficulties to the deafblind. For those who have some sight left may need much larger print to be able to read. Others may need it in tactile form such as Braille or Moon which they can 'read' with their fingertips. Those who have adequate hearing, may require audiocassette or compact disks.

Definition of Deafblindness

*"Deafblindness is the condition of having little or no useful **sight** and **hearing**. As with the word 'deaf', it can be capitalized to indicate that it is a culture; some prefer the spelling 'Deafblind'. The most well known deafblind person is the author, activist and lecturer Helen Keller."* Deaf-blind people have an experience quite distinct from people who are only deaf or blind and not both.

Federal Definition of Deafblindness – USA

"Concomitant hearing and visual impairments, the combination that creates such severe communication and other developmental and educational needs that they cannot be accommodated in special education in programs solely for children with deafness or children with blindness." FR Dept. of Education, 34 CFR Parts 300 & 303, Vol. 64, No. 48.3/12/99

Defining the term 'Deafblind'

"Deafblindness" is a condition presenting other difficulties than those caused by deafness and blindness. It is an "umbrella" term, which can include both children and adults who are:

- *Blind and profoundly deaf.*
- *Blind and severely or partially hearing impaired.*
- *Partially sighted and profoundly deaf.*
- *Partially sighted and severely or partially hearing impaired.*

*"The term, 'children with deafblindness', means children and youth having auditory **and** visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities to address their educational needs due to these concurrent disabilities."*

There is not yet one generally agreed definition of deafblindness, but most of the definitions include the following characteristics in the deafblind:

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

Description of Deafblindness

The term ‘Deafblind’ is used to describe a “heterogeneous group of (people) who may suffer from varying degrees of visual and hearing impairment, perhaps combined with learning and physical disabilities, which can cause severe communication, developmental and educational problems”.

{Department of Education Services (DES) Policy Statement (March 1989)}

Source: Quality Standards in Education Support Services for Children and Young People who are Deafblind/Multi-Sensory-Impaired, Sense, UK, page 5.

A precise description is difficult because the degree of deafness and blindness, possibly combined with varying degrees of other disabilities, are not uniform, and the educational needs of each

(person) will have to be decided individually. In functional terms these children and young people may include those with:

- *Moderate to profound auditory and significant visual impairment.*
- *Moderate to profound auditory and significant visual impairments and other significant disabilities.*
- *Central processing problem of vision and hearing.*
- *Progressive sensory impairment.*
- *A significant visual impairment; and a possible loss of auditory processing mechanisms (associated with severe physical disabilities or severe cognitive disabilities) and severe communication delay.*

Chapter 2

Historical Perspective

The most famous deafblind person in history, Helen Keller, the American author, campaigner and lecturer was born with sight and hearing, on 27 June 1880 in Tuscumbia, Alabama. She lost both senses at the age of 19 months consequent to a bout of fever. Unable to communicate, she became a very difficult child and her parents had problems controlling her behaviour. However, all of this was to change when Helen, six years old was introduced to Annie Sullivan, her tutor. With Annie's assistance Helen became the first deafblind person to go onto higher education, graduating from the prestigious Radcliffe College in Massachusetts with a Bachelor of Arts degree.

Helen Keller is remembered even today, but she was not the only deafblind woman to be educated successfully. The American public was already familiar with the achievements of Laura Bridgman, who was born in 1829, half a century before Helen Keller. Laura was the first deafblind person to learn to read and write under the guidance of Dr. S.G. Howe at the Perkin's Institute. Like Helen, Laura became one of the most famous women in the world and was hailed a 'miracle' in newspapers and magazines.

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

more than 100 years before the Special Schools for the Deaf and for the Blind was established in France in 1760 and 1784, respectively. Dr. Fartell's story was published about 200 years before Ms. Laura Bridgman became the first deafblind and mute to acquire the use of language in 1837 at Perkins School for the Blind. The breakthrough at Perkins School marked the beginning of education of deafblind in the world.

In 1842, Charles Dickens covered the achievements of Laura Bridgman and Perkins School in his "American Notes", which influenced many educators in the disability field in Europe and America. Soon deafblind children started finding place in schools for the Blind or for the Deaf, i.e., France (1860), Sweden (1882), Germany (1887) and Finland (1889). By the end of the 19th century, a considerable amount of work for the deafblind was being carried out in various parts of the world, but there was nothing in Asia at this point of time. In 1954, "Sense" was conceived in the United Kingdom, by Margaret Brock and Peggy Freeman, two mothers both of whom had deafblind children.

It was more than 300 years after the first mention of "deafblind", that India saw a unit for deafblind in the Helen Keller Institute for the Deaf & Deafblind, Mumbai (1977). Till 1997, there was very little awareness about deafblindness in India. In this vast country there was only one school, the Helen Keller Institute for Deaf and Deafblind, catering to the needs of 23 deafblind students. The

situation was such that neither the Government, nor organisations working with the disabled people were aware of the deafblind population. Lack of awareness of this unique disability meant, and continues to mean, that many deafblind people are without support or labelled incorrectly (for example, as severely mentally retarded) and receive inappropriate support. This situation was recognized by Sense UK, the world's leading NGO for the deafblind.

After a thorough needs assessment and consultations with stakeholders in India, Sense International (India) was registered as a Trust in 1997. The aim of Sense International (India) is to support the development and establishment of more services for the deafblind throughout the country. Since then, Sense International (India) has been closely involved in the creation of services for the deafblind in the different States in India. Through local disability NGOs it is already supporting 36 projects in 19 states of India.

Deafblind People in History

- Hieronymous Lorm (19th Century) - Inventor and Novelist.
- Laura Bridgman (1829-89) - First Deafblind child to be successfully educated in USA.
- Mary Bradley (Time and Place of Birth not known, Died in 1866).
- Yvonne Pitrois (1880-1937) - French Biographer.

- Helen Keller (1880-1968) - Author, Activist and Lecturer.
- Alice Betteridge (1901-1966) - First Deafblind Australian to be educated. She was a Teacher, Traveller, and Writer.
- Jack Clemo (1916-1994) - British Poet who became deafblind in adulthood.
- Robert Smithdas (Born 1925) - The First deafblind Person in the US to receive a Master's Degree.
- Richard Kinney - Educator, Lecturer and Poet; President of the Hadley School for the Blind from 1975 to 1979.

Some Indian Achievers

- Dr. Rajendra Singh Sethi {First deafblind person to acquire a doctorate degree. Now a Board Member of National Trust and Governing Council member of Sense International (India)}.
- Anindyo Bhattacharji (Deafblind man lives in New York and works in Helen Keller National Centre).
- Rajesh Mehta (a deafblind man in Limbdi, Gujarat who owns and manages a sweetmeat shop).
- Zamir Dhale {Young deafblind man brought up in Mumbai and works as Advocacy Officer in Sense International (India)}.

Chapter 3

Causes of Deafblindness

In India, disability sometimes is referred to as the “result of wrong doings in the past life”. This myth is abating due to the awareness created by various Government and Non-Government organisations. The cause for multi-sensory impairment and deafblindness is more or less similar to the causes for single category disability.

Some of the most common causes of deafblindness are Usher’s Syndrome, Congenital Rubella Syndrome, CHARGE Association and Old Age. Other causes are severe head injuries; traumas; sexually transmitted diseases, such as syphilis and AIDS; drug overdosing; medical errors and self inflicted injuries.

Four primary causes of vision and hearing loss:

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

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

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

Genetic Conditions

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

Infections

Rubella contacted during pregnancy used to be a major cause of deafblindness before the introduction of vaccination programs in developed countries but it is still a major cause in developing countries. Other infections, affecting the foetus, include cytomegalovirus (CMV) or toxoplasmosis.

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

Rubella and Congenital Rubella Syndrome

Rubella, a childhood disease, caused by a virus, may be transmitted from person to person as droplets in air through coughing and sneezing or through close contact. A person with rubella is a carrier of the infection for about two weeks, or occasionally little longer, before the rash appears. However, an affected person may be unaware that he is infected and feel perfectly well and may not even develop a rash. If someone has been in contact with an infected person, there may be an incubatory period of two to three weeks, before the infection becomes manifested.

An infected person may feel generally unwell for a few days, perhaps have swollen glands, a slight temperature, or a sore throat, and may get a rash which starts around the face and can spread to lower parts of the body and the limbs. Some people, particularly women, may experience pain or discomfort in their joints. Other people may be carriers, but show no signs or symptoms of having rubella.

A woman who contracts rubella in pregnancy does not always pass it on to the foetus; the earlier in her pregnancy she has the infection, the more likely the transmission and a consequential, identifiable damage. Contact up to the 18th week of pregnancy is particularly serious. The pathway of the virus is through the maternal blood stream to the placenta and to the foetus. If transmission does occur, then it will happen just before or around the time that the woman gets the rubella rash. Occasionally, rubella in pregnancy can result in miscarriages or stillbirths.

Babies with congenital rubella have the virus circulating in their bodies for much longer than adults or children with the acquired infection. Thus a congenitally affected baby can remain a carrier for six months to a year, or occasionally even longer.

Damage or disability unrelated to rubella is always possible. Rubella may damage the eye, resulting in cataract (opaqueness of the lens) a typical signs of congenital rubella. One eye may escape harm or both may be affected. Sometimes microphthalmos (abnormally small eye or eyes) may be present as well. Pigmentary retinopathy (speckled colouring of the retina) is very common in children with congenital rubella, but does not affect the sight. Hearing loss, which may be conductive or sensor-neural, is one of the commonest results of congenital rubella and may often appear as the only defect.

The organ of Corti, a part of the inner ear is often the part that is damaged by rubella. Hearing loss may be mild or severe, unilateral or bilateral and may be progressive.

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

Many rubella babies are underdeveloped in the womb. Perhaps the infected placenta is not able to function fully, affecting nutritional supply to the foetus. The rubella virus may also be directly responsible for slowing down the foetal rate of growth. The rubella virus may also cause mild to severe neurological problems. Learning disabilities, mental retardation and seizures may also occur.

Congenital rubella can affect people in different ways: some may develop problems later in life, including deterioration of hearing and vision and endocrine dysfunction. People with congenital rubella should undergo regular health check-ups, including vision and hearing assessments throughout their lives. According to World Health

Organisation weekly *Epidemiological Record*, No. 20, May 19, 2000, 75, 161-177 there is an estimation that more than 100,000 CRS cases occur in the developing countries alone. Congenital rubella is preventable with the rubella vaccine, available as a single vaccine or the combined measles, mumps and rubella (MMR) vaccine. Mass vaccination programs are being implemented in many countries.

Cytomegalovirus

Cytomegalovirus or CMV is a potential prenatal cause of deafblindness. In the UK Census Head Office, database records 7 people Deafblind through CMV compared to at least 280 Deafblind through rubella (*Deafblind International Review*, July–December 1995). Cytomegalovirus means a large cell, a commonly occurring virus belonging to the herpes virus group, which includes chicken pox, cold sore and glandular fever viruses. The infection may pass unnoticed or there may be mild flu-like symptoms in the pregnant mother. Once infected, the virus remains dormant. The virus can become active again at intervals. The virus is spread through saliva, urine and other body fluids. CMV is very difficult to avoid. It may be caught from someone who shows no signs of being ill.

CMV, like the rubella virus, can cross the placenta and affect the developing foetus. If CMV infects a pregnant woman, the foetus may be damaged. Only 10% of the affected babies may display symptoms and in only half of these children the disability will be serious. It is only the first or primary infection during pregnancy, which can cause problems. It is very rare that reactivation of CMV during pregnancy damages the foetus.

Problems resulting from congenital cytomegalovirus infection vary, but may include jaundice, bloodspots on the skin, enlargement of the liver or spleen, spasticity (disordered control

of movement), intracranial and other calcifications (the deposition of calcium within organic tissue), mental retardation and seizures. In some cases, hearing impairment may be the only sign of the CMV infection while others may have severe sight problems as well. Most children with congenital CMV are healthy and if not tested at birth will go undetected. It is not known why some are affected and others are not. Pre-natal diagnosis is not possible as at present there are no tests available or a vaccine. Estimates suggest that of 600,000 babies born in England and Wales perhaps 2,000 will have congenital Cytomegalovirus and of these about 200 have sensory problems as a result (*Deafblind International Review*, July–December 1995).

Toxoplasmosis

Toxoplasmosis is caused by a parasite called *toxoplasma gondii*. It forms cysts (hard-walled microscopic forms), which are passed in the faeces of its primary or main host, the cat which contaminate gardens and vegetables in their wanderings. Even though they bury their faeces, one can still come into contact with them, resulting in their eating the cystic form of toxoplasmosis.

Toxoplasmosis can affect almost all animals, including humans. Most animals carry it. Undercooked meat and the increasing consumption of unpasteurised goat's milk are two other potential causes. Luckily the resulting infection is usually very mild, it can be a glandular-like illness or produce symptoms of a mild flu. However, in a pregnant woman, the infection, though not afflicting her, can cause congenital abnormality in the unborn baby up to 40% of the cases. Of these, 10 per cent are likely to be seriously affected (*Deafblind International Review*, Jan.–June 1997).

If the disease is caught early in pregnancy, it is less likely to cross the placenta. If it does, the consequences are more serious. If the pregnant

woman catches the infection later, it is more likely to cross the placenta but the effects on the foetus are less severe.

Babies born with toxoplasmosis (usually when infected between the third and sixth month) may develop severe symptoms such as hydrocephalus, calcification in the brain and chorioretinitis (damage to the retina). Epilepsy and deafness can also result. Most worrying in this regard is the delayed manifestation of the eye disease up to the late teens.

The Public Health Laboratory in Swansea, UK, estimated in 1988 a rate of infection of two per 1,000 pregnant women. If the French figures of 40% of mothers passing infection to their babies are the same in the United Kingdom, it could mean that about 480 babies a year are affected in the UK (*Deafblind International Review*, Jan.–June 1997).

Most adults recover spontaneously from toxoplasmosis without any treatment, although it is possible to treat the condition using sulphur drugs. Eye treatment of toxoplasmosis infections is more complicated, and pregnant women must be given a different drug since the usual one is too toxic. No treatment manages to eradicate all cysts. This means that an infection, which may appear to have been cured, can recur later.

Birth Trauma

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

Accidents or Other Trauma

Any accident involving head injury can damage the parts of the brain that deal with processing information through sight and hearing.

They can also damage parts of the auditory system. The injury can have many different effects that are difficult to understand. Other kinds of trauma, for instance, a stroke (a cerebral haemorrhage) can result in deafblindness.

Age-related Causes

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

Syndromes

CHARGE Association

CHARGE Association is a multi-featured disorder characterised by a unique combination of diverse abnormalities, first described in 1979 but the acronym 'CHARGE' was first used in 1981. This is, therefore, a relatively recently recognised condition.

The acronym 'CHARGE' is used to describe a heterogeneous group of children who exhibit at least four of the features of CHARGE, including one or other of choanal atresia and colobomata (*Deafblind International Review*, Jan. - June 1996). The combination of critical features was identified as:

C – Coloboma, is an ocular deformity, the absence of a part of the eye. Visual impairment may or may not be present. Coloboma of the iris may lead to reduction in the ability to adjust to bright light; Coloboma of the retina will create a blank area in the child's visual field. Anophthalmos or microphthalmia may also be present.

H - Heart defects, include tetralogy of Fallot, patent ductus arteriosus, atrial and ventricular septal defects, and others.

A - Choanal Atresia, a narrowing or a blockage of the passage between the nasal cavity and the naso-pharynx, is one of the major criteria for diagnosis. The blockage may be unilateral or bilateral, membranous or bony.

R - Retarded growth, may become manifest as the child matures. The majority of children with CHARGE Association are below the third percentile of physical growth norms.

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

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

Additional anomalies associated with this condition are:

Abnormal tongue size, cleft lip and/or palate, facial palsy, renal abnormalities, malformations of the larynx, atresia of the oesophagus with tracheoesophageal fistula and skeletal abnormalities. Historically, the medical profession considered mental retardation a characteristic feature of CHARGE Association. Recent literature suggests this to be an outcome of the other combined anomalies rather than as an integral anomaly of the Association itself.

Goldenhar Syndrome

Goldenhar Syndrome was named in 1952. Dr. Goldenhar wrote about a number of facial problems that tend to occur together. The syndrome was named after him. It is quite variable with some common abnormalities and a variety of terms have been used to describe this disorder.

According to medical literature, when malformations primarily involve the jaw, mouth and ears, and, in most cases, affect one side of the body (unilateral), the disorder is often referred to as Hemifacial Microsomia. If abnormalities of the vertebrae and the eyes are also present, the disorder is often called Goldenhar Syndrome. Within medical literature, the term Oculo-Auriculo-Vertebral (OAV) Spectrum is often used synonymously with Goldenhar Syndrome and Hemifacial Microsomia. However, due to the complexity and varying severity and expression of OAV Spectrum, some researchers suggest that Hemifacial Microsomia and Goldenhar Syndrome actually representing different aspects or levels of severity of OAV Spectrum. Goldenhar Syndrome is also considered a variant of Cranofacial Microsomia, which is the second most common facial birth defect after cleft lip and palate.

Goldenhar is more prevalent in males (70%) and affected individuals may have asymmetrical small ears and mouth with hypoplasia of the jaw, mouth and eyes (with epibular dermoids) (*Deafblind International Review*, Jan.–June 1998). In addition, abnormalities often involve the skeletal, cardiac, renal and the central nervous systems. Hearing varies from near normal to severe loss; visual defect includes diplopias of various degrees. Moderate learning disabilities may occur in about 10% of the cases.

There is very little evidence to explain why Goldenhar Syndrome occurs. In most cases, it

seems to occur randomly, with no apparent cause; there is no family history. However, in some cases, positive family history has suggested autosomal dominant or recessive inheritance. In addition, some researchers suggest that the disorder may be caused by the interaction of many genes, possibly in combination with environmental factors – multifactorial inheritance. Children with Goldenhar Syndrome have normal intelligence and can look forward to a long life.

Usher Syndrome

Usher Syndrome is named after Dr. Charles H. Usher, who noticed the correlation between the two conditions, hearing loss combined with retinitis pigmentosa. Usher Syndrome affects

between 3 and 6 percent of the deaf community. Currently, the following three types of Usher Syndrome are recognized:

Type I

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

Type II

Born hard of hearing, has no balance problems. Blind spots by teens. Legally blind in early adulthood.

Type III

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

Chapter 4

Incidence and Magnitude of Deafblindness

Incidence of deafblindness is very low and exact data and number is not known. However, the generally accepted estimates are that approximately 10% of the general population has a hearing loss, out of which approximately 1% is also blind or has a serious loss of vision. According to Joseph McNulty, Director of the Helen Keller National Center, more than 70,000 deafblind people live in the United States. (One must keep in mind that many more deafblind people exist than have been officially recorded.)

Think Dual Sensory published in 1997 by the UK Department of Health suggested that some 2,000 people in Scotland could have some degree of deafblindness. Latest figures show that there are 1,983 people registered as deafblind in Scotland. Sense, the National Deafblind and Rubella Association, has been involved in conducting the latest survey in the UK. These surveys produced an average number of 21,000 deafblind people of all age groups in the UK (approx. 40/100,000). Survey findings ranged from 30/100,000 to 58/100,000.

Presently, the exact figure of deafblind people in the United States is unknown. The National Deafblind Children Count Registry, sponsored by the National Technical Assistance Center, a program of Helen Keller National Center, estimates that there are 10,000 deafblind children in the U.S. aged birth to 21. Based on these statistics, there are approximately 40,000 to 70,000

deafblind people in the United States (from birth to advanced age).

In India, it is estimated that the number of persons with various disability is over 90 million. There is no data available regarding the size of the deafblind population in India. As of date, there has been no comprehensive study or research done to determine the true incidence of deafblindness. Estimates, based on information gathered from community-based projects, indicate that there could be more than 400,000 deafblind people in our country. Overall we can predict that 0.04% of general population have deafblindness as disability.

Diagnostic Services

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

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

early identification can take place in special schools for the blind, or in school for the deaf or in school for the mentally retarded as most of the cases of deafblindness usually are misdiagnosed and sent to these special schools.

There has to be active screening for early identification and early diagnosis of deafblindness. Usually low incidence disability like deafblindness is hidden and only active screening of population can help discover deafblind cases. It is resource-intensive to do active screening at community level for identification of deafblind cases.

To detect deafblindness effectively, the screening must be done on specific populations such as children with one sensory disability in schools for the blind or in schools for the deaf and also in schools for the children with Learning Disability and Multiple Disabilities. Institutes like Blind People's Association, Ahmedabad; L. V. Prasad Eye Institute at Hyderabad; Helen Keller Institute for the Deaf & Deafblind, Mumbai; Clarke School for the Deaf and Mentally Retarded, Chennai; National Association for the Blind, Delhi; Spastic Society of Tamil Nadu, Chennai; National Institute for the Mentally Handicapped (NIMH), Secunderabad; Ali Yavar Jung National Institute for Hearing Handicapped (AYJNIHH), Mumbai; National Institute for the Empowerment of Persons with Multiple Disabilities (NIEPMD), Chennai; Holy Cross Service Society, Trichy are some of the places equipped to do this kind of diagnosis. There are many other institutions and organisations in our country where early detection of this condition may take place.

Early Identification and Prevention

National Programme on Orientation of Medical Officers Working in Primary Health Centres to Disability Management has a chapter on deafblindness so that as medical officers at primary health centres one can identify and refer

deafblind cases for rehabilitation. This module is approved by Rehabilitation Council of India. The Programme is implemented in various States of the country under the direct supervision of a State Implementation Committee (SICOM) constituted under the Chairmanship of the State Health Secretary or a Designated Officer.

An Apex Co-ordination Committee is also constituted by the RCI to co-ordinate, monitor and evaluate program implementation at the country level. Under this scheme, Sense International (India) has made a module on "Deafblindness", which is part of the orientation training of medical officers to manage disability issues related to deafblindness. It is only a secondary attempt for prevention and only a medical approach of management, if early cases are detected.

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

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

Over the past decade, there has been a growing recognition of the educational, social and health needs of young children with disabilities in

our county. Classic studies in the behavioural sciences from the 1960s and 1970s indicated that early stimulation is critical to the later development of language, intelligence, and personality. The early experiences of infants and children who are at risk provide the basis for subsequent learning, growth, and development.

Advocates of early intervention services for children at risk believe that intervention should begin as early as possible in an environment that is free of traditional, categorical labels, e.g., mentally retarded, emotionally disturbed. Carefully selected intervention measures have the potential to lessen the long-term impact of the disability and counteract any negative effects of awaiting intervention. The postponement of services may undermine a child's overall development as well as his or her acquisition of specific skills.

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

Educational Provisions

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

Helen Keller supposedly said (or wrote to

Dr. Kerr Love in 1910) "*Blindness cuts us off from things, but deafness cuts us off from people*" (Personal record written by herself edited by James Kerr Love, 1933, page 68). This potential isolation is one important reason why it is necessary to engage the services of persons familiar with the combination of both blindness and deafness when planning an educational program for the deafblind. Doing so will help a child or youth who has these deficiencies receive an education which maximizes her or his potential for meaningful contact with her/his environment. The earlier these services can be obtained, the better for the child.

The challenge of learning language is perhaps the greatest which a deafblind child faces. It is also the greatest opportunity, since language holds the key to make their thoughts, needs, and desires known. The ability to use words can also open up worlds beyond the reach of their fingertips through the services of interpreters, books, and an ever increasing array of electronic communication devices. In order to learn language, children who are deafblind must depend upon others to make language accessible to them. Given that accessibility, they face the challenges of engaging in interactions to the best of their abilities and of utilizing the language opportunities provided for them.

Aims of Education for Children who are Deafblind

In the past, children with both visual and hearing impairments were assumed to be profoundly retarded as they were unable to communicate with anyone. Time has shown, however, that given the appropriate teaching and attention, many of these children can achieve their potential never dreamt of before. The overall aim of a school for deafblind children is to enable each child according to his/her ability to become a happy integrated member of society.

A Philosophy for Educating Deafblind Children

Keeping in mind what Helen Keller supposedly said, we understand that – “Deafblindness isolates; it cuts the individual off from other people and from the reality of her/his surroundings”. It stunts physical, emotional, social and intellectual development. So the educators have to try and enter into the lives of deafblind children and into their experiences. We will have to enter into their world and form a relationship with them, so that there is mutual understanding, and then only can we pave the way for them to come into “our world” and share one world.

Appropriate Educational Alternatives for Children and Youth with Deafblindness

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

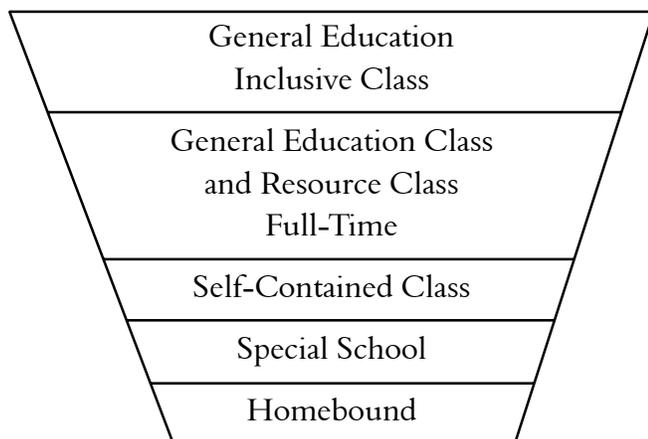


Figure 2: Deno's Cascade model of educational service delivery for special children.

Source: From *Special Education as Developmental Capital* by E. Deno. *Exceptional Children*, 37, 1970, 229-237, Council for Exceptional Children.

The in-service training for the resource teacher in SSA on “Deafblindness” was initiated by Sense International (India) in the State of Uttar Pradesh with active support and collaboration with the State Government through Shikshit Yuva Sewa Samiti, Basti. There is a specific module on deafblindness prepared by Sense International (India) for the UP Government. A three-month regular training module on ‘deafblindness’ for in-service teachers trained in single category disabilities either on ‘visual impairment’ or in ‘hearing impairment’ and currently working under SSA has been made by Sense International (India) to train them so that they provide educational services to deafblind children through SSA. This syllabus for SSA is recognised by Rehabilitation Council of India.

Efforts are being made to incorporate the same in all the state government SSA schemes. Although most of the deafblind children receive home-based and center-based educational services, some are enrolled in normal schools with the assistance of the resource room teacher. Some of the deafblind adults are now in university programs and in one such instance, Fredrick, a deafblind young adult from Trichy has cleared his preliminary examination of Indian Administrative Service (IAS).

Percentage of Children having Access to Education

There are about more than 7,000 deafblind individuals receiving educational services in India as per the report of Sense International (India). Among them about 1,500 deafblind children are receiving direct support and about 5,500 deafblind children are receiving indirect services through the Sarva Shiksha Abhiyan (Education for All Scheme) of Government of India.

Education of the Deafblind

The approach to education of individuals who are deafblind has changed significantly since the rubella epidemic occurred in the United States and Western Europe in the early 1960s. Dr. J. van Dijk and Catherine Nelson propagate that prior to the epidemic, only incidental successes in educating children who were deafblind had been reported. In the United States, Samuel Gridley Howe wrote in a detailed manner about his student, Laura Bridgman; and Anne Sullivan reported on the enormous educational progress of Helen Keller. In Norway, Ragnild Kaata, a deafblind student, was taught to talk; and in France, Marie Heurtin received wide attention for the level of language she was able to achieve. Dr. J. van Dijk and Catherine Nelson propagate that the methods developed in the Netherlands influenced later theories and practices in the education of deafblind children and how these theories have evolved and changed over time.

Through the collaboration and sharing of knowledge from many countries, successful methodologies to teach individuals who are deafblind have increased rapidly since the time of the Rubella outbreak. This knowledge has successfully been disseminated to many educators around the world. Such collaboration must stay alive as we address new challenges with a low-incidence and ever-changing population.

Principles of Educational Programming for Deafblind Child

- Early identification of sensory deficits is essential to provide optimal opportunities for individuals with deafblindness.
- Communication is the corner stone of an educational plan for a student who has deafblindness.

- Educational placements should be selected on the basis of individual abilities and needs.
- Age of onset of sensory impairments, amount of auditory and visual impairments, mode of communication, cognition, and existence of additional disabilities are major factors in determining the appropriate educational settings.
- Teachers with specific training are necessary to provide optimal integrated programming for students with dual sensory impairments.
- There is a variety of appropriate educational alternatives for children and youth with deafblindness.
- A functional program is integrated into community life and is based on real life situations. It must include opportunities to develop communication, social, recreational and leisure skills including pre-vocational/vocational training, transition planning, self-help, domestic skills, orientation and independence within all environments.
- Integration of appropriate and related support services are necessary for a successful educational program for a student with deafblindness.
- Various specialists may contribute towards assessment, direct instruction, or consultation for the group.

Best Educational Practices for Students with Deafblindness

- Acknowledge your presence.
- Address children directly.
- Always encourage and motivate.
- Avoid too much help.
- Community based instruction.
- Describe things to them.
- Functional, age appropriate curricula.
- Integration with non-disabled peers.

- Integrative service delivery approach.
- Keep positive attitude and patience.
- Non-aversive behaviour management.
- Offer help to deafblind child.
- Parent involvement.
- Respecting children.
- Transition planning.
- Using words naturally.

Parental Involvement

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

Parent-Professional Partnership

Just as every child is unique, so is every family. They have their own concerns, worries, strengths and priorities which must be taken into cognizance by the professional. The professionals must respect the family's concerns. It is also important that the professional respect the family's need for privacy. It is essential that both parents and professionals have realistic expectations of each other's time and efforts with the deafblind child. The family's involvement in their deafblind child's daily routine activities helps them to learn as much about their child's joys and strengths as it helps the child to learn and grow better.

The Importance of Family

For most of us, the family is the constant thread in our lives. Our abilities as adults to be trusting and confident are greatly rooted in our

relationships—good or bad—with our family. This is also true for all children, including deafblind. The development of many skills depends upon the child's opportunities to freely and safely explore the environment. Close physical and emotional contact has a tremendous impact on the learning abilities of deafblind children.

From the child's point of view, the mother's arms stand to represent the whole world. Although there is always a lot of sound and movements around the child, it is the mothers' touch, voice and looks that are most meaningful for the child in the early years of development. As the skills to use his eyes, ears and body increases, so does his world, which expand to include more people and objects.

Building up the Partnership

It is therefore the responsibility of the professional, to help the parents to get more and more tuned to look at the different and unique ways in which their child is growing and learning. To help parents and other family members build an equal partnership with them through the following:

- Make the family more knowledgeable about their deafblind child's assets and deficiencies.
- Build more methods and strategies that can help the family members to get small, but positive experiences with the deafblind child.
- Develop more 'Touch' and 'Movement' techniques in family members for interacting with the deafblind child.
- Open new ways of looking at their deafblind child's strengths and skills that are different from their normal brothers and sisters.

- Encourage and support the family to speak up for their own and their deafblind child's rights in the community.

Changing Role of Parents in India

With services for deafblind children increasing in the country, there are increased chances for parents to meet with teachers and other professionals closely working with their deafblind child on a regular basis. In India, where the Individualized Educational Plan (IEP) is being used to work with the deafblind children, parents are using their knowledge and priorities to influence the decisions taken by the professionals for the future of their children.

This is not only true in big cities and special centres, but across the country in Community Rehabilitation Programs (CBR) also. Parents have been meeting other parents of deafblind children at local, regional and national levels, through the registered national parents' network named as '*Prayaas*'. One of the common concerns during such meets is the need to constantly update their knowledge on deafblindness so that they can be equal and true partners in the decision making process for their children.

Similarly, teachers have their own national network named as '*Abhi-Prerna*', which brings them together to exchange their practices and expand their knowledge of ever-changing interventions, strategies and developments in deafblind field world over. India is not behind in catching up with the developed countries and now there is a core of professionals who, specialize on various issues related to deafblindness in our country.

Teachers' Training Programs

Recognizing the desperate shortage of informed and trained staff and the highest priority training has assumed in enabling the growth of services, Sense International (India) has encouraged the establishment of recognized training courses in the past. Sense International (India) advocates an increase in professional development opportunities and urge the inclusion of specialist training in all plans for the development of services. Today there are three teacher training centres in the country providing two-year diploma level course in Special Education on Deafblindness, recognised by Rehabilitation Council of India.

Chapter 5

Manpower Development

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

- Rehabilitation Council of India recognised the first teacher training course in deafblindness in Asia and the National Institute for the Visually Handicapped (NIVH) certified the said course. The course is being currently conducted at three places: Helen Keller Institute for the Deaf and Deafblind (HKIDB), Mumbai; The Clarke School for the Deaf and the Mentally Retarded, Chennai; and at National Institute for the Empowerment of Persons with Multiple Disabilities, Chennai.
- A component on deafblindness is now included in the training of primary and secondary school teachers.
- There is a three-month training module for the in-service teachers who got training in single category disabilities of Visual Impairment or Hearing Impairment.

Besides the recognised and certified courses mentioned above, a number of informal training activities are being undertaken in the field of deafblindness in the country, a few of the significant ones being:

- Awareness training programmes for in-service single category teachers, itinerant/resource teachers, medical professionals, community workers and so on.
- Orientation programme on deafblindness for teachers working with children having deaf/blind/multi-handicapped/cerebral palsy/mental retardation.
- Specific need-based training on topics such as early identification; assessment; communication; program planning; classroom management; and so on for teachers working with deafblind children.
- Leadership training for personnel from various organisations who are managing different kinds of services for deafblind children.
- Intensive 'hands-on' training for workers at the program sites by experts.

The first Deafblind Asian Conference in February 2000 at Ahmedabad set the pace for brainstorming session on the various issues concerning human resources development specific

to the deafblind field. Similarly, the National Experts Meets (NEM), organised by Sense International (India) have been instrumental in identifying the staff development needs and match it with appropriate existing training opportunities or in creating new training activities.

As the field is emerging, there has been a recurring concern for the need to develop more formal training programs for the different target groups. The present efforts focus on:

- Formal in-service teacher training for single category teachers to equip them with additional skills to work with deafblind children in their classrooms.
- Conducting recognised teacher-training course on deafblindness through the distant learning mode.
- Conducting regional teacher training courses on deafblindness.
- Deafblind component to be added as part of the standard curriculum for the training of PHC doctors.
- A professional development program for participants from different South Asian countries such as Sri Lanka, Bangladesh, Nepal and Pakistan.
- Higher education options like B.Ed., M.Ed. course in deafblind promoting more educational research for deafblind children.
- Deafblind component to be added as part of the standard curriculum for therapist like OTs, PTs and Speech Language Therapists.

Present Date Technology

As the field is emerging there has been a greater need for developing technology for

different target groups among the deafblind. There are many known devices, which the deafblind individual needs for smooth functioning and assistance. Some of them are listed below:

Daily Living Devices

- Braille Slates
- Braille Writing Devices
- Electronic Calculators
- Reading Aids
- Rulers and Measures
- Other Measuring Instruments

Educational Devices

- Devices for Embossed Graphics
- Educational Materials for Utilization of Low Vision
- Electronic Calculators
- Mathematics Teaching Devices
- Music Instruments
- Pre-School and Primary Educational Devices
- Science Teaching Devices

Information and Communication

Technology Devices

- Audio Playback Equipment
- Braille Displays
- Braille Editing and Translation Software
- Braille Stereotypes and Duplicators
- Closed Circuit Televisions
- Computer Controlled Braille Embossers
- Electronic Note Takers and Organizers
- Electronic Reading Devices
- Other Information and Communication Technology Devices

- Screen Magnification Software
- Screen Reading Software
- Special Computer Accessories
- Speech Synthesizers
- Web Browsers for Non-Visual Output

Low Vision Related Devices

- Distance Vision Telescopes
- Frames, Accessories and Other Aids
- Hand and Stand Magnifiers with Illumination
- Hand and Stand Magnifiers without Illumination
- Near Vision Telescopes
- Spectacles and Head-Borne Magnifiers

Mobility and Orientation Devices

- Canes
- Electronic Devices

Professional services for the deafblind in our country are growing and there are 36 service centres in 19 states of India including the north eastern states. There is now a greater need for vocational training and gainful employment needs of the adult deafblind population. Moreover, a majority of the deafblind are in the geriatric age group. They need a much specialised service which is very different from the services for children and young adults. Although there are some services available for the young, there is hardly any specialised service for the aged deafblind individual in the country.

Chapter 6

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

With the enormous challenges of poverty, education and health facing the country, the disability area has not received the appropriate focus it deserves, either from the Government or the NGOs. Though the Government has enacted the Persons with Disabilities (Equal Opportunities, Full Participation and Protection of Rights) Act in 1995, implementation still remains a major challenge for all concerned. We hope deafblindness will be recognised as a separate category of disability by the Government. Deafblindness, a combination of varying degrees of visual and hearing impairments, causes severe problems in communication, mobility and accessing information from the outside world, making it one of the most isolating of all disabilities, which deserves stand alone recognition.

An organised approach towards advocacy has recently started in this regard. The Government involvement in the development of Sense International (India) as well as of deafblind field right from the beginning was very promising and supportive. The emphasis was always on relationship building and developing connectivity with stakeholders. Sense International (India) consistently followed and propagated same as the advocacy process till date. Dissemination and exchange of information about the methodology and knowledge on deafblindness along with proactive leadership development has enabled the field of deafblindness to grow in our country.

The following are some of the achievements which have resulted from direct involvement of the Government:

1. A module on deafblindness is now added in the curriculum of all primary and secondary school teachers of single category disability, accredited by Rehabilitation Council of India.
2. The National Institutes (NIVH, NIMH, NIEPMD, and AYJNIHH) in the country have now deafblindness incorporated in their training programme and services.
3. Mr. Akhil Paul, Director of Sense International (India) was one of the Founder Members of the Board of Directors of National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. In the present Board, Dr. Rajinder Singh Sethi, who is himself deafblind, is a Member.
4. National Policy on Disability has deafblindness incorporated as a sub-group under multiple disabilities.
5. Deafblindness is now included under the assistance to disabled persons for Purchase/Fitting of Aids & Appliances scheme of Government of India, where communication equipments as aid for deafblind persons is clearly mentioned.
6. National Trust Act for the Welfare of Persons with Autism, Cerebral Palsy, Mental

Retardation and Multiple Disabilities has included deafblindness into its multiple disability categories.

7. Deafblindness is incorporated in the Disability Management Training of Primary Health Centre (PHC) for orienting doctors to various disabilities.
8. Rehabilitation Council of India has approved and incorporated deafblindness in the module for the curriculum of Caregiver Training Course.
9. Rehabilitation Council of India has recognized a teacher training programme on deafblindness. It is a two-year 'Diploma Course in Special Education on Deafblindness', under the aegis of the National Institute for the Visually Handicapped, Dehradun.
10. The Sarva Shiksha Abhiyan (SSA), Government of India's flagship programme for achieving Universal Elementary Education (UEE) has included training and information material on deafblindness in regional languages across the States such as Uttar Pradesh, Tamil Nadu, Chhattisgarh and Bihar.
11. The Resource Teachers and Coordinators working in the Sarva Shiksha Abhiyan (SSA) are being trained on deafblindness through local NGOs.
12. The recommendations of UNESCAP include deafblindness in the "services for multiple disabled".
13. The UN Convention on Protection of the Disabled Persons' Rights recognises "deafblind" children and their needs in the Article 24 (Education) and says "Ensuring that the education of persons, and in particular children, who are blind, deaf and deafblind,

is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development".

The above is only illustrative; there are more results, big and small, on account of the work undertaken by Sense International (India) since its inception in 1997 for the development of services for the deafblind individuals in our country. The phenomenal changes in the field of deafblindness that have been witnessed in the last 10 years have been due to the active and concerted efforts of the Central/State Governments and many like-minded NGOs. There has been active co-operation and collaboration among the different NGOs and the Government bodies towards establishing the various policies and services for deafblind persons that have tried to ensure the rights of this target group.

Apart from the bold initiatives taken up by the Government, the last five years have seen many NGOs coming together for the common purpose of reaching out to as many deafblind children and their families as possible. There are now 36 NGOs in 19 states across the country, which are directly providing services to deafblind children and their families. These NGOs come from varied disability backgrounds such as visual impairment, hearing impairment, learning disability and cerebral palsy. Besides the services for deafblind children and their families, these organisations are also actively involved in spreading awareness on deafblindness and advocating for their rights at the local and regional levels.

The local organisations are also involved in screening and identification of deafblind children in the rural and urban areas of their respective regions. These organisations coordinate with other related professionals such as medical doctors,

speech therapists, psychiatrists, neurologists, and mobility instructors to add quality to the services. There is an active and healthy relationship between the service-providing organisations and other social, government and community groups with the aim of bringing in sustainability in the programs for deafblind children and their families.

One of the key responsibilities taken up by the local organisations is that of training. Each organisation has been using its background experience, infrastructure and special expertise in the area of deafblindness to train different workers and professionals. These training activities could vary from state level meetings and workshops to specific training for field workers, teachers, anganwadi workers, PHC doctors and others.

The positive direction of the deafblind movement has been due to the individual and collective steps taken at both the Government and the NGO levels. A perennial need is felt to build partnerships between the Government and the NGOs to ensure smooth functioning and overall development of activities through efforts made at the right time by the right kind of people and agencies.

Networking has always been one of the strongest tools of learning and influencing not only the international organisations, but also the national and the local NGOs, which has proved very beneficial for the deafblind sector. Consequently, organisations have had the advantage of learning from each other and collaborating with many established and experienced International agencies such as Sense, UK; Hilton-Perkins International, USA; International Council for Education of People with Visual Impairment (ICEVI); Viataal International, Netherlands; and Deafblind International (DBI).

At the national level, the approach towards development of networking among the deafblind people, their families and teachers have led to some very positive developments including interactions between families and organisations across the country. The stakeholders in the deafblind sector would continue to learn from both national and international collaborations with like-minded organisations and the Governments at central and state levels to ensure that every deafblind person in the country has access to services which are need-based and appropriate.

With the changing role of families, it is envisaged that the input of parents and families of deafblind people will be central to further development of services for the deafblind persons. The dream for the field of deafblindness in our country is:

- Recognition of deafblindness as a separate and unique disability.
- Access to need-based services by the deafblind individuals.
- Partnerships with state governments; other NGOs; INGOs and strengthening networks of deafblind people, their families and teachers.
- Focussed efforts on HRD for qualified human resources and sensitized educators from single disability to the needs of the deafblind people.
- Maintaining quality and improved practices by involvement of and consultation with practitioners, deafblind people and their families.

India Deafblind Consortium

India Deafblind Consortium (IDC) is a group of like minded professionals and parents who

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

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

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

Research & Development

The deafblind related matters in the country is a new and emerging area one of the highlights of which has been its professional and cohesive

approach. Being able to learn from each other is much valued as an approach through which it has been possible to bring about phenomenal changes in a short span of time. It is time to look beyond the present achievements to how it could be further strengthened and the ways in which new endeavours can be initiated. A few of these are as follows:

- (a) **Identity:** The need of the hour is to identify deafblindness as a unique category of disability in all the relevant statutory laws and documents. Such recognition will enable in looking at and addressing the specific needs of this target group.
- (b) **Incidence and Prevalence:** Deafblindness must be taken up as a separate category in different surveys, such as the National Sample Survey, Country Census which will indicate the actual number of deafblind children and adults in our country. Such numbers are valuable in the decision-making process, in planning for human resource development, service-delivery, budgetary allocation, etc.
- (c) **Assessment and Evaluation:** It is necessary to develop a mechanism for valid assessment for use across the country (with meaningful regional variations), for identifying deafblind persons and their needs. A screening tool will empower even the grass root-level workers to identify the deafblind persons in their respective areas which further helps in reaching out to more deafblind persons and the appropriate target groups. Such assessment and evaluation tools could also be utilized by agencies such as the NSSO for the purpose of the survey.
- (d) **Human Resource Development:** More professionals from the single category disability areas must be involved in the

emerging new field. This would add more content to the work being done with the target group. Staff development activities will now need to focus on specific target groups such as CBR workers, special educators, field supervisors, project coordinators and project directors, medical workers. With a tailor-made-curriculum, the chances of application of newly gained skills will increase at the same time follow-up of staff development activities will be more effective.

- (e) **Philosophy of Deafblind Education:** With the establishment of number of services, in the past 10 years, teachers and other professionals are now confident about the basic nature of their work. They have been able to respond to the immediate needs of both, deafblind children and their families to a great extent. It is time to promote what may be called ‘the Philosophy of Deafblind Education’.

This approach, while it incorporates many ideas and practices of all the other disability areas such as visual and hearing impairment and learning disabilities, has a set of codes and good practices that is distinct to the field of deafblindness. Primarily, this would mean looking at access to communication for and by the deafblind person.

Some of the steps towards this objective could be by establishing a curriculum framework for deafblind children that looks at all developmental and functional tasks from the communication perspective. This would also entail the development of appropriate materials in keeping with this philosophy.

- (f) **Social Communication:** The development of appropriate social communication materials is of utmost importance in order to spread awareness about deafblindness and its

various ramifications. The need for preventive measures, care and rehabilitation messages can be conveyed through appropriate local, regional and social communication materials. The Indian movie “BLACK” in which the heroin is cast as a deafblind young lady has helped reach and sensitize the masses on deafblindness.

- (g) **Networking:** The field of deafblind in the country is one which is small and emerging. It has received much strength and support from the related fields of disabilities. It has also been able to reach its present identity and status due to its constant attempts to be a part of the international deafblind network. Therefore, the need to form and sustain the networking activities both within the NGOs and with the Government sector is of primary importance.
- (h) **Advocacy:** Striving to develop, support and sustain programs and services for deafblind persons is important so as to empower the deafblind community and their family members to take their own responsibility at the local, regional and national levels. Advocacy should also affect local self-help groups, social organisations, other related NGOs, parent-support groups, corporate concerns as well as the Government. Organizations working in either disability or non-disability (developmental) areas must collaborate and incorporate component on ‘deafblindness’ in their present work.
- (i) **Involvement of Parents:** The deafblind individuals, their parents and other family members being the primary stakeholders in the services established around the country, it is imperative that they be involved in the decision-making process concerning their child. Such involvement in the policy making and program planning will not only make

them more realistic, but also incorporate a logical monitoring and evaluation mechanism in this process.

There are several key initiatives currently being undertaken by government and non-government organizations. There have been regular workshops on Deafblindness/Multi Sensory Impairment to orient teachers on the needs of the deafblind. But there is still an urgent and vital need for involvement of other sectors in order to muster the ultimate acceptance, equal opportunity, promotion and protection of the rights of the deafblind.

Human Rights

We also need to take a look at the human rights issues of the deafblind cutting across themes of gender, socio-economic status, health, education, etc., and respond to the totality with a developmental view.

Future Vision and Improvements in the Next Decade

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

We see a future where the traditional need-

based educational plan will be replaced with a plan which will empower a deafblind child to exercise his/her right to his/her education and services. In the days to come, a more holistic view of deafblindness with greater inter-sector collaboration is envisaged as an outcome of inter-linking of all sectors of development. It can be safely concluded that interaction across themes will bring a promising future and that there will be strong partnership through networking among the agencies and the stakeholders with advocacy and policy work being focussed.

Conclusions

The deafblind initiative began with a single organization for the deafblind, but after almost a decade we are not alone in realizing our dreams. From few services a decade ago to at least one service centre in the 19 States of India is a testimony to the progress made. The partner NGOs and the Government along with Sense International (India) is instrumental in the development of the field to its present stage in the country.

There is strong movement for the deafblind in the country which includes committed NGOs as partners; motivated and active families of the deafblind; qualified and enthusiastic teachers; trained and concerned professionals, supportive and sensitive Government and the well-informed deafblind themselves. Promoting good practices for the rehabilitation of deafblind people, the efforts so far are commendable, but falls short of meeting the needs of 425,000 deafblind people in our country. We still need many more services and manpower and each one of you can contribute to this in your own ways.

Experts who contributed to the section on Deafblindness

Mr. Akhil Paul (Editor)

Mr. Bikash Das

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