

CHAPTER XI

Special Need Visually Impaired Persons

Over the years, number of visually impaired children with other disabilities has been steadily increasing. This probably is happening due to declining child mortality, better health care services and better pre as well as postnatal care, all these factors result into higher chances of survival of such children. Huebner (1995) also confirms that advances in medical technology have significantly improved the longevity of children who experience them, so that a greater number of premature infants and young children are surviving with multiple congenital anomalies. With expansion of early identification and rehabilitation services to the rural areas and urban slums, such children are now being identified and, of course, need appropriate assessment, early intervention, education and rehabilitative services.

As the Helen Keller Institute for the Deaf and the Deafblind, Mumbai wanted to start a Teacher Training Course for the Deafblind, it approached the Rehabilitation Council of India for the recognition of the course during 1990. The Members of the Sub-Committee of the RCI on Visually Impaired were not sure about the demand for such a course as it was thought there were not many children who are deafblind. The members requested the RCI to compile information regarding the number of children who are deafblind. In response to a circular which was sent to most schools for the visually impaired in the country, a list of less than 100 such children could be compiled. Hence the idea of recognizing a Teacher Training course was dropped.

During 1998, the Blind People's Association started a comprehensive project with the support of Sense International India for the promotion of services for children who are deafblind. During first year itself, it identified 35 such children in Ahmedabad and surrounding areas. The organizations is already planning to establish 5 satellite centres at different locations in Gujarat for the promotion of comprehensive services for such children.

A similar trend has been observed in case of visually impaired children with additional disabilities. The Blind People's Association has already established 5 satellite centres at different location in Gujarat with the support of Hilton Perkins International. It has been conducting a refresher course with the support of the National Institute for the Visually Handicapped for the special teachers for the promotion of services for such children.

The Persons with Disabilities Act also recognizes "low vision" as a separate category of disability. The Section 2(u) provides a definition of "person with low vision"; Section 31 refers to low vision in context of provision of services of amanuensis; and Section 33 (i) refers to low vision in context of job reservation. In other words, the Act clearly recognizes low vision as a category of disability. Over the years, the schools for the blind and community based rehabilitation programmes have identified and enrolled a large number of low vision children. According to certain estimates, the number of low vision children is four times the number of totally blind children.

It is essential for the teachers/workers of the visually impaired to understand demographic pattern, specific needs and rehabilitation aspects of special need visually impaired children including those with low vision, deafblindness and multiple-disabilities.

I. Persons with Low Vision

(By : Ms. Karin van Dijk)

1. Introduction

Many people, who have been regarded and labelled as blind, have some useful vision. It is estimated that four times as many people have low vision as compared to the numbers of blind. Many need surgery or refractive services to improve their vision, others need low vision care.

There is a great need to develop appropriate services for people with low vision, especially children, as it is important to encourage them to use the vision they have, in addition they need to be taught how to interpret the little and sometimes incomplete visual information they get, next to the information received through the other senses.

In India, as in many other developing countries, education has been geared towards blind children and rehabilitation towards blind adults. Anyone with reduced vision and no vision at all was labelled blind, both by the eye care and the educational profession. As a consequence, low vision children with a potential to use vision for activities such as reading print have been taught as if they are blind.

In some cases, they have been regarded as backward or mentally handicapped, as they could, for example, only read slowly and not copy from the blackboard, due to their limited vision.

Adults, sometimes, have not performed certain activities that required vision, as they and their environment regarded them as blind. Others have been branded as cheats as they could, for example, read print, a 'sighted' method, but not walk around safely without using a cane, a 'blind' method.

The elderly population is growing and with it the number of people needing low vision care. This important group of people

is often forgotten in services for people with visual impairment, but needs to be included in the future. Often this group has poor access and little knowledge about possibilities to improve vision and/or its use.

The people with low vision of all ages have different visual abilities. Those with the same eye condition and visual acuity neither necessarily make the same use of their vision nor do they manage in the same way.

2. Definitions

(Kindly refer to Chapter 1 for definition of low vision)

As per WHO Working Definition of Low Vision (WHO, 1992), a person with low vision is one who has impairment of visual functioning even after treatment, and/or standard refractive correction, and has a visual acuity of less than 6/18 to light perception, or a visual field of less than 10 degrees from the point of fixation, but who uses, or is potentially able to use, vision for the planning and/or execution of a task.

When comparing this 1992 definition with the standard WHO definition, it is clear that there is an emphasis on what a person can still do with their vision in the working definition. This is useful in order to avoid labelling people blind unnecessarily. The standard definition is used in medical report and publications and is solely based on visual acuity and does not take into account functional vision.

It is important to make sure that everyone involved is educated about the facts, else, for example, a parent might think a low vision child should not use the eyes to read. Another example of wrong behaviour is that a husband discouraging his wife from wearing glasses.

3. Components of a Low Vision Programme

A teacher cannot work adequately with children who have not been clinically assessed and refracted. It is important to try to improve vision first through treatment and/or glasses. A number of children will then have normal vision and can leave the programme. Others will still be low vision, but with better visual acuity.

However, once a child has been identified as low vision. Information from a functional assessment can be very helpful to ophthalmic staff while prescribing the type of magnifying device. Therefore, functional assessment can come before a thorough clinical assessment, if a person has been identified as irrevocably low vision.

The following sequence may be followed while implementing a low vision programmes:

3.1 Identification and Referral

Methods	Staff that can be trained/involved	Resources needed
Through screening children in existing 'blind' programmes	Specialist teacher Rehabilitation workers	E-chart (+pinhole) Screening forms Referral forms
Through community vision screening programmes	Health workers Community workers Primary school teachers	same as above
Through eye care programmes	Ophthalmic personnel	

Points to remember:

- a. Particular attention needs to be paid to identification of impaired vision and visual problems in children from 0 to school-age.
- b. Early detection can prevent or make less severe a lot of visual impairment and/or assist children in maximizing the use of their remaining vision.
- c. Close cooperation with prevention of blindness or eye-care programmes is essential.

3.2 Clinical Assessment and Treatment of Eye Problems

The following activities should be performed for promoting clinical assessment and eye treatment:

- a. Clinical assessment, treatment/operations and refraction
- b. Assessment for and prescription magnifying devices needs to be part of the work of ophthalmic staff. In large cities a low vision specialist might have been trained to do the work.

3.3 Sharing Information

It is very important to make the individual, her family and all professionals concerned with low vision understand that even little vision can be useful and should be used, so people are not treated unnecessarily as if they could see nothing and are deprived of using their sight. For example, in India a child with a VA <6/60 is legally blind, but might be able to use print as a reading and/or writing medium. Many children who have corrected visual acuity in the better eye of less than 3/60 have useful residual vision and benefit from low vision services.

3.4 People's Belief about Vision

There are many different beliefs about eyes, using them to see when you do not have good vision, low vision, blindness and their possible causes. Here are some common beliefs or myths, followed by the real facts.

Myths.....Facts
My child's sight will wear out if it is used too much	Eyesight cannot be worn out by use. Your Child can use it as much as he/she likes!
Keeping a book very close when reading will reduce vision in the long term.	Vision will not reduce, although the muscles that move the eyes may tire. If this happens, rest for a few minutes.
If a hospital prescribes glasses this means that your child is losing sight slowly, surely. He/she will go blind in the long run.	No! Glasses improve vision for those who need them.
Reading in a dim light will damage sight.	It is not helpful to read in a dim light, but it cannot harm the eyes.
Electric lighting is bad for the eyes.	Good lighting of any sort is a valuable aid to vision.

Training a key person in the use of a magnifying device is vital, as the client needs to be trained over a period of time in its use. Teachers, CBR workers with support of family members can implement this training.

Now all patients with treatable and/or preventable low vision should have been helped, and only those with irrevocable low vision should be still in the special education or rehabilitation programme.

3.5 Referral to Programmes

The referral of low vision individuals to preschool, education, vocational training, community based rehabilitation and other special and integrated programmes should be encouraged. The absence of early intervention programmes or preschools in certain areas, or other relevant programmes will limit effective referral. Cooperation with programmes that could include people with low vision in future is a way of expanding referral options.

Training of staff to understand the implications of low vision is again a vital component.

3.6 Functional Assessment

Visual acuity figures do not tell what a person is able to do with his/her vision. It is essential to assess what can be seen and what not, under which circumstances and how vision is used for different tasks.

Involvement of the family members of a low vision person in the functional assessment is vital. They also need to understand what a person can see and what not, where there are possibilities and where there are problems.

Methods	Staff that can be trained/involved	Resources needed
Using low vision kit: 'Assessment of Low Vision in Developing Countries'	Specialist teachers CBR workers Vocational trainers Pre-school staff	Low vision kit Daily use objects Recording forms
Vision checklist for very young children	Pre-school staff CBR workers	Small torch Bright/shiny items. Daily used objects Recording forms

3.7 Training for Effective Use of Vision

Once the effects of low vision and how it is used for each individual person are understood, a training programme for each individual with low vision needs to be developed. It might include activities to encourage the use of vision, and/or to enhance visual efficiency and/or to change the environment. Training in the use of optical and non-optical low vision devices needs to be developed, discussed with the involvement of everyone and implemented.

Methods	Resources needed
Encouraging use of vision	Local, every day materials
Visual skills training	Low vision kit-books
Non-optical devices	Reading stands Black felt pens Reading slit Thick lines with good contrast in exercise books Sun glasses
Low vision (optical) devices	Locally produced magnifiers Magnifying glasses Telescopes
Orientation & mobility training	Using the above resources, while combining the use of vision and other senses
Changing the environment	Using colour, contrast and light to make the physical environment more visible.

4. Important Factors for Low Vision Care

- a. *Psycho-social Support*: A person with low vision needs to understand his/her own abilities and communicate these to the environment. Self-esteem needs to be built up as much as possible.
- b. *Integration*: Visual training programmes need to be integrated as much as possible in regular activities, at school, at home, at work.
- c. *Family Involvement*: Apart from the teachers and CBR workers mentioned before, involvement of family members is vital. They can stimulate a lot of the training needed, if they understand why and how.
- d. *Low Vision Devices*: Production, distribution, cost and durability of optical and non-optical low vision devices.
- e. *Eye Checkup*: Yearly/regular eye check and follow-ups where needed
- f. *Rehabilitation Inputs*: Continued input from education and rehabilitation personnel where needed.
- g. *Systematic Assessment*: It is very important to find out what each person with low vision can do with his/her vision, and to teach people how to make the best use of it.

(Book 2 “*Assessment of Low vision in Developing Countries*” gives detailed instructions. It is part of the low vision kit and can be ordered from the WHO).

5. Need for information

(General overview of important areas as given in Keeffe, 1995).

As the effects of low vision are not the same for all people, the following information should be compiled about each person:

- a. Extent of vision - near and distance visual acuity
- b. Size of the visual field (if relevant)
- c. Effects of light and glare
- d. Extent of recognition and naming of colours
- e. Extent to which contrast affects their activities
- f. Extent of use vision for different activities and purposes in the environment
- g. Extent to which a person sees and recognizes an object depends, amongst other on:
 - familiarity of the object
 - light
 - size
 - distance
 - contrast
 - colour
 - detail or simplicity of the object.

Many of these factors can be used to make thing easier to see. For example, placing agricultural tools in a brighter corner might make it easier to find them visually. Drawing maps using clear black lines on a light background enhances contrast.

6. Assessment of Functional Visual Skills

Assessment of the visual skills re-needed to carry out daily activities, in addition to the information needed on each person outlined above, is important. The following visual skills need to be assessed in order of complexity:

- Awareness and attention to objects
- Tracking
- Scanning
- Discrimination of objects
- Discrimination of details to identify actions and match objects
- Discrimination of details in pictures
- Identification of patterns, numbers and words

Detailed instructions and ideas are given in the *WHO Low Vision Kit*. It can be easily adapted to different age groups and to different purposes.

7. Effective Use of Vision

As outlined earlier, now the child can be trained for the effective use of vision, if needed, based on the findings of the assessment. The three important aspects are:

- Encouraging use of vision which is of particular importance to young children.
- Improving the method of use for vision, which is visual efficiency.
- Changing the environment, for example, by choosing a well-lighted place to work or using low vision devices, if needed.

(*Practical activities for training are given in the WHO Low Vision Kit*).

8. Low Vision Devices

Many people think that providing low vision care is the same as prescription and training in the use of low vision devices. This is not true. There will be many people with low vision who neither need these devices nor benefit from them. The training to use vision as best as possible might be of much more importance than just learning to use devices.

These are some of the non-optical devices that might be useful:

- Reading/writing stand
- Black pens, black felt pens
- Exercise books with thicker lines of good contrast, e.g. black
- Reading slit or typoscope
- Use of bright colours where needed
- Use of good contrast
- Adequate lighting or good use of available light
- Sunglasses
- Wearing a cap
- **Large print books**, if available



- Books on cassettes

Of course each person needs to be assessed to determine which device might be useful, if any. The useful optical devices should be locally available, robust and affordable. Again individual assessment of the need and repeated training in their use is vital. A basic service should be able to provide the following for near tasks.

- **Hand and stand magnifiers** of different strengths



- **Magnifying glasses**

In addition, services with more resources and training abilities can include:

- **Telescopes** for distance tasks



The optical devices need to be prescribed by a person trained in low vision, either an ophthalmic professional or a low vision specialist.

Training in their use can be done by trained teachers, CBR workers or trained family members.

(Details of how to train can be found in the WHO Low Vision Training Manual).

(For more information on low vision devices, refer to Chapter V)

9. Educational Programmes

If education programmes for visually impaired children are to include the needs of low vision children, the following conditions need to be created (Van Dijk, 1997):

- Create awareness about the meaning of low vision, best use of vision and importance of early referral among people with low vision, their families, regular and specialist teachers, eye care staff and the Ministry of Education. The main message needs to be: *“Low vision is not the same as blind”*.
- Develop adequate training of the existing special education and eye care staff in low vision.
- Ensure that educational placement takes visual abilities into account.
- Increase access to clinical assessment, especially in remote areas.
- Ensure that children are clinically and functionally assessed before deciding on the educational support needed. Many low vision children might not need a special school, but can be taught in a regular school with some support from a specialist teacher.
- Ensure access to affordable glasses to correct refractive errors, in order to improve low vision children’s vision as much as possible and to ‘weed’ out children with normal vision.

- g. Place emphasis on near vision assessment, to avoid children being labelled as blind and taught braille unnecessarily.
- h. Provide appropriate resources, less educational kits for blind children and more low cost devices such as locally made *reading/writing stands*, writing guides, and magnifying devices are needed.



- i. Develop close co-operation between all people involved, like the Ministries of Education, Health Personnel; Non-Governmental Organizations, donor agencies, the education services for the visually impaired and, last but not the least, the visually impaired child and his/her family. This is vital; without it an adequate service cannot be provided.

Through training of existing professionals, parents and the children, the education of low vision children can be improved significantly. The low vision component actually strengthens the cooperation between education and eye care services. The key staff, the specialist teachers and the ophthalmic staff enrich their work through the low vision training.

An educational programme based on actual needs of children and using appropriate resources can be developed this way.

The same applies to rehabilitation services.

10. Information for the Family

Here is a simple example of information that should be given to family and others involved

Hints and tips

- * Low vision children are like anyone else, except they can't see properly. Encourage the child to use sight as much as possible!!
- * Let the child's eyes be examined once a year.
- * If an operation is recommended, make sure that the child goes! It can give him/her some or may be all sight back!!!
- * Ask the specialist teacher to explain the child's eye disease and what he or she can see and cannot see. Also ask the child what he/she can see.
- * Light is very important to see well. Try to make lighting as good as possible.
- * Think about contrast and size. A light plate is easy to find on a dark table. And if an object is bigger, it is of course easier to see, for example a big ball.
- * If possible, provide the child with a black felt pen for writing; it will provide larger and clearer writing than other types of pen.
- * If the child needs to wear glasses, make sure;
 - He/she wears them when needed. Some children need to wear them always, others only for reading or only for distance.
 - They are cleaned every day with water.
 - They do not get scratched. They should be put in a safe place at night, wrapped in soft cloth.

11. Concluding remarks

Low vision is not just another specialism. Low vision services and training need to be part of each eye care, education and rehabilitation programme for the visually impaired. It needs to be integrated in each facet of these programmes.

For example, orientation and mobility training for visually impaired children means that low vision children learn to use vision, if that can be used for mobility, and the other senses where needed. It might mean that they learn to recognize and understand what certain shapes are in reality, how to interpret incomplete visual information and the like, when possible.

The same applies to activities of daily living. An individual with low vision might have to use hearing or touch to know water is boiling, but might use vision to see the difference between peeled and unpeeled potatoes. Where possible and practical, people with low vision should be taught and encouraged to use the sense of vision.

Other important overall issues are:

- Family/community involvement
- Training of all different professionals involved. It is preferred if existing staff is used and their skills enhanced. It is in many cases unrealistic to create a new cadre of low vision therapists.
- Use of existing structures, programmes, resources and staff
- Monitoring and regular evaluation of all aspects
- Coordination of the low vision programme; a national low vision group, comprising of all disciplines, could be established, preferably under a functioning national committee, like a prevention of blindness committee.

This also makes co-operation between the different organizations and programmes involved a regular feature.

References:

Keeffe, J. (1995): *Assessment of Low Vision in Developing Countries*, Book 1 and 2 "The Low Vision Kit", Geneva: WHO and Australia: Low Vision Project International

Van Dijk, K. (1996): *Developing National Low Vision Services in Developing Countries with Emphasis on Malawi*, Madrid, Spain: Proceedings of the International Low Vision Conference, 8-12 July

Van Dijk, K. (1997): *The Impact of a Low Vision Programme on Existing Education Services for the Blind in Malawi*, ICEVI Conference, Sao Paulo, Brazil, August

Van Dijk, K.; Keeffe, J.; and Nottle, H. (1997): *Low Vision Training Manual - For Use in Developing Countries*, Bensheim: Christoffel Blindenmission (CBM) and Australia: Centre for Eye Research

WHO (1992): *Management of Low Vision in Children*, Bangkok: Report of a WHO Consultation, 23-24 July

WHO (1996): *Low Vision Care for the Elderly*, Madrid: Report of a Workshop, 4-6 July

II. Persons who are Deafblind

(By: Akhil S. Paul, Director,
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1. Description of Deafblindness

Deafblindness is a combination of visual and hearing impairments and comes in varying degrees. It may seem that deafblindness refers to a total inability to see or hear. However, in reality:

“Deafblindness is a condition in which there is a combination of visual and hearing impairments that cause such severe communication and other developmental and learning needs that the persons cannot be appropriately educated in special education programs solely for children and youth with hearing impairments, visual impairments or severe disabilities, without supplementary assistance to address their educational needs due to these dual, concurrent disabilities”.

Children who are deafblind are educationally isolated because impairments of sight and hearing require thoughtful and unique educational approaches in order to ensure that children with this disability have the opportunity to reach their full potential.

For a young child who is deafblind, the world is initially much narrower. If the child is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach. Such children are effectively alone if no one is touching them. Their concepts of the world depend upon what or whom they have had the opportunity to physically contact.

If a child who is deafblind has some usable vision and/or hearing, as many do, her or his world will be enlarged. Many children who are deafblind have enough vision to be able to move about in their environment recognize familiar people, see sign language at close distances, and perhaps read large print. Others have sufficient hearing to recognize familiar sounds, understand some speech, or develop speech themselves. The range of sensory impairments included in the term “deafblindness” is great.

2. Population of the Deafblind

As far as developing world is concerned, there are not enough resources to provide health care and education for everyone. Disabled people, especially people who are deafblind, have little access to these services because of lack of awareness. In many countries, there has been little research, although we can assume that there are large numbers people who are deafblind. But no one really knows how many such people there are, where they are or what happens to them? In India we do not have any research or survey conducted regarding the population of persons who are deafblind but the Community Based Rehabilitation Projects have hinted that there might be around 2,50,000 persons with dual sensory /multi-sensory losses.

3. Major Causes of Deafblindness

The main cause of deafblindness in children in the developed nations, used to be Rubella contracted by the mother during pregnancy. There are still many causes including premature birth, birth trauma and number of syndromes as follows:

3.1 Syndromes and Genetic Conditions

- a. Alport's Syndrome
- b. Ape's Syndrome
- c. Bardet-Biedl Syndrome
- d. CHARGE Syndrome: In 1981, Dr. Roberta Pagon documented the series of characteristics now known as CHARGE. The collection of six multisystem congenital anomalies includes:
 - Coloboma of the eye
 - Heart malformation
 - Atresia of the choanae
 - Retardation of growth or development
 - Genital abnormalities
 - Ear abnormalities

Although some cases appear to be influenced by heredity, environmental factors have not been ruled out. Infants physically are fragile and often require repeated surgery to repair cardiac, palate, esophageal, and gastric complications. Hearing loss varies and is accompanied by outer-ear deformities. Facial palsy has also been reported in a significant number of cases (Huebner, 1995).

- e. Cockayne's Syndrome
- f. Crouzon's Syndrome
- g. Down Syndrome
- h. Duane's Syndrome
- i. Friedreich's Syndrome
- j. Goldenhar's Syndrome
- k. Hunter's Syndrome
- l. Marfan's Syndrome
- m. Mobius' Syndrome
- n. Neurofibromatosis
- o. Norrie's Syndrome
- p. Optico-Cochleo-Dentate Degeneration
- q. Refsum's Syndrome
- r. Trisomy 13-15 (Patau's) Syndrome: The chromosomes are found in pairs, in case of three chromosomes in the 13th pair is responsible for this syndrome. A significant percentage of children born with this condition die during infancy. Most of those who survive have severe mental retardation and marked physical characteristics. Varying degrees of auditory and visual complications may be present.
- s. Trisomy 18 (Edwards') Syndrome: Trisomy 18 syndrome is recognizable in the infants, as the head is narrow and elongated, with a bulge at the back of

the skull. Both visual and auditory complications are present. A very small percentage of infants survive to childhood. These children have low birth weight and fail to thrive. Females achieve longer survival rates than males.

t. Turner's Syndrome

u. Usher Syndrome: This is a genetic condition which affects hearing and sight. The hearing loss which is usually profound is apparent from birth while the sight loss may not be noticed until the individual has reached young adulthood. The vision becomes impaired when the retina stops functioning due to retinitis pigmentosa causing firstly, night blindness and then tunnel vision. Hearing levels, however, usually remains stable (Huebner, 1995).

There three types in Usher:

- Type I:* Profound hearing loss from birth, poor balance, retinitis pigmentosa noticeable before age of 10.
- Type II:* Partial-to-severe hearing loss from birth, normal balance, retinitis pigmentosa noticeable before age of 20 and
- Type III:* Normal sight and hearing at birth, when retinitis pigmentosa is diagnosed there can be mild-to-moderate hearing loss present. Both hearing loss and retinitis pigmentosa increase through adulthood.

v. Wildervanck Syndrome

3.2 Maternal Infections and Diseases during Pregnancy

Many maternal conditions, such as infection and disease contracted during pregnancy, can interrupt the normal development of fetus or newborn infants. If a woman contracts an infection during pregnancy, it may cause illness in the newborn or actual damage to the foetus resulting sensory, physical, or mental impairments.

3.2.1 TORCH Group: The parental infections diseases that most often cause congenital abnormalities known as the S(TORCH) group, for:

- a. Syphilis
 - b. Toxoplasmosis
 - c. Rubella: It is also known as German measles, causes a group of congenital defects known as Congenital Rubella Syndrome (CRS). The disease is easily transmitted from pregnant mother to the unborn foetus. Since the development of the rubella vaccine, the incidence of congenital rubella syndrome has decreased dramatically in the developed countries. In the areas where rubella vaccine is not given, the incidence of disease may be higher.
- A pregnant woman who is not immune normally contracts rubella through the nose and throat. The infection spreads, transmitting the virus to the foetus across the placental barrier. Once the foetus is exposed to the virus, the cells of the developing eyes, ears, brain, central nervous system, and heart can be damaged. Hearing impairment in congenital rubella syndrome is typically sensorineural but may include accompanying conductive problems (Huebner, 1995).
- d. Cytomegalovirus (cytomegalic inclusion disease)
 - e. Herpes simplex (Huebner, 1995).
 - f. Aids

3.3 Teratogens (abnormal development of embryo)

The following factors may play a role in interrupting the normal development of a foetus. The factors represent the known effects on an otherwise normally developed foetus:

- a. Prescription drugs
- b. Drugs known to be Ototoxic (harmful to developing ear structure)
- c. Illicit Drugs used during pregnancy
- d. Other Teratogens e.g. radiations, pollution, toxic agents etc.

3.4 Prematurity and Low Birth Weight

Prematurity and low birth weight are associated with various following problems and complications during pregnancy:

- Mother is adolescent or pregnancy involves multiple births
- Location of placenta or the position of fetus in the womb
- Membranes rupture early
- Infection during pregnancy
- Mother has chronic illness, such as diabetes
- Toxemia (hypertension) of pregnancy
- Specific malnutrition or trauma to the fetus
- Less intake or over intake of oxygen.

Many premature infants develop respiratory distress syndrome which is co-related with blindness. Premature and low weight infants are at risk for other complications, such as intracranial hemorrhage, malnutrition, jaundice, hearing loss, and congestive heart failure (Huebner, 1995).

3.5 Infections during the Newborn and Infancy Period

Either following infections itself or inflammation caused to a newborn or infant can cause mental retardation, visual impairment, hearing impairment, neuro-motor problems, or any combination of these:

- a. *Meningitis*: caused by bacteria, affects the blood and spreads rapidly to the cerebrospinal fluid, ultimately affecting the meninges, the layers of tissue covering the spinal cord and the brain. It may result in profound, bilateral deafness, likewise such an infection can cause visual impairment if the infection spreads to the visual pathways of the brain.
- b. *Encephalitis*: is an infection of brain tissue primarily caused by a virus, which specifically affects central nervous system tissue. Newborns are at risk for major complications from this infections simply because of the immaturity of the central nervous system.

3.6 Causes of Disability in Childhood

- a. *Diseases in Childhood*: Bacterial and viral infections seldom cause lasting visual impairment, and auditory system is much more susceptible to permanent damage. These diseases include measles, mumps, chicken pox, influenza, and the common cold. Usually in cases of high fever, damage to auditory system is caused.
- b. *Paediatric Trauma*: The eye is exceedingly vulnerable to injury. Trauma to the eye may occur when infants are shaken or hit above the head. Accidental injury also accounts for several types of hearing impairment in children. Both direct blows to the head and penetrating wounds of the skull cause damage to the auditory system, as does exposure to noise (Huebner, 1995).
- c. *Asphyxia*: Stoppage of breathing due to obstruction in the air passage.
- d. Seizure, fits etc.

Some people are deafblind from birth. Others may be born deaf or hard-of-hearing and become blind or visually impaired later in life; or the reverse may be the case. Still others may be adventitiously deafblind, that is, they are born with both sight and hearing but lose some or all of these senses as a result of accident or illness.

Deafblindness is often accompanied by additional disabilities. Causes such as maternal rubella can also affect the heart and the brain. Some genetic syndromes or brain injuries that cause deafblindness may also cause developmental delays and/or physical disabilities.

4. Needs of a Person with Deafblindness

Deafblindness is a combination of visual and hearing impairments and comes in varying degrees. Because 95 percent of all one learns comes through one's eyes and ears, deafblindness causes unique problems in communication, mobility and accessing information. A person who is deafblind must somehow make sense of the world using the limited information available to him or her. If the person's sensory disabilities are great, and if people in the environment have not made an effort to order the world for him or her in a way that makes it easier to understand, this challenge may be overwhelming. Behavioural and emotional difficulties often accompany deafblindness and are the natural outcomes of the child's or adult's inability to understand and communicate.

4.1 Perceiving Verbal and Visual Cues

The people who can see and hear often take for granted the information that those senses provide. Events such as the approach of another person, an upcoming meal, the decision to go out, a change in routine are all signalled by sights and sounds that allow a person to prepare for them. The child or adult who misses these cues because of limited sight and/or hearing may come to experience the world as an unpredictable, and possibly

a threatening place. To a great extent, persons who are deafblind must depend upon the goodwill and sensitivity of those around them to make their world safe and understandable.

4.2 Language Accessibility

The challenge of learning language is perhaps the greatest one that children who are deafblind face. It is also the greatest opportunity, since language holds the power 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 use of interpreters, books, and an ever increasing array of electronic communication devices. In order to learn language, such children depend upon others to make language accessible to them. Given that accessibility, such children face the challenges of engaging in interactions to the best of their abilities and of availing themselves of the language opportunities provided for them.

4.3 Mobility

A person who is deafblind also faces, further, the challenge of learning to move about in the world as freely and independently as possible. Adult individuals also must eventually find adult living and work situations that allow them to use their talents and abilities in the best possible way. The achievement of success depends largely not only on the severity of their impairments but also upon the education they received since childhood, and particularly upon the communication with others that they have been able to develop.

5. Needs of the Family, Teachers and Care-givers

5.1 Communication

The disability of deafblindness places unique demands upon families, teachers, and care-givers who must make sure that the person who is deafblind has access to the world beyond the limited reach of his or her eyes, ears and fingertips. The

people in the environment of such children or adults must seek to include them, moment-by-moment, in the flow of life and in the physical environment that surrounds them. If they do not, the child will be isolated and will not have the opportunity to grow and to learn. If they do, the child will be afforded the opportunity to develop to his or her fullest potential.

5.1.1 Conversation - a Good Communication: The most important challenge for parents, care-givers, and teachers is to communicate meaningfully with the child who is deafblind. Continual good communication will help foster his or her healthy development. Communication involves much more than mere language. Good communication can best be thought of as conversations that employ body language and gestures, as well as both signed and spoken words. A conversation with such a child may begin with a partner who simply notices what the child is paying attention to at the moment and finds a way to let the child know that his or her interest is shared.

5.1.2 Use of Touch: This shared interest, once established, can become a topic around which a conversation can be built. Mutual conversational topics are typically established between a parent and a sighted or hearing child by making eye contact and by gestures such as pointing or nodding, or by exchanges of sounds and facial expressions. Lacking significant amounts of sight and hearing, children who are deafblind will often need touch in order for them to be sure that their partner shares their focus of attention. The parent or teacher may, for example, touch an interesting object along with the child in a non-directive way. Or, the mother may imitate child's movements, allowing the child tactual access to that imitation, if necessary. (*This is the tactual equivalent of the actions of a mother who instinctively imitates her child's babbling sounds*). Establishing a mutual interest like this will open up the possibility for conversational interaction.

5.1.3 Learning to Pause: Teachers and parents can continue conversations with children who are deafblind by learning to pause after the initial rapport has been established. These children frequently have very slow response times. Respecting the child's own timing is crucial to establishing successful interactions. Pausing long enough to allow the child to take another turn in the interaction, then responding to that turn, pausing again, and so on. This back-and-forth exchange becomes a conversation which if repeated consistently, builds relationships and become the eventual basis for language learning.

5.1.4 Use of Symbols: As the child who is deafblind becomes comfortable interacting non-verbally with others, she or he becomes ready to receive some form of symbolic communication as part of those interactions. Often it is necessary to precede the introduction of words with the use of simple gestures and/or objects which serve as symbols or representations for activities. Doing so may help a child develop the understanding that one thing can stand for another.

5.1.5 Language Stimulation: Think of the many thousands of words and sentences that most children hear before they speak their own first words. A child who is deafblind needs comparable language stimulation, adjusted to his or her ability to receive and make sense of it. The parents, care-givers, and teachers face the challenge of providing an environment rich in language that is meaningful and accessible to such child. Only with such a rich language environment, the child will have the opportunity to acquire language herself or himself.

5.1.6 Use of Communication System: Those around the child can create a rich language environment by continually commenting on the child's own experience using sign language, speech, or whatever symbol system is accessible to the child. These comments are best made during conversational interactions. A teacher or a parent may, for example, use gesture or sign language to name the object that he or she and the child are both touching, or name the movement that they share. This

naming of objects and actions, done many times, may begin to give the child who is deafblind a similar opportunity afforded to the hearing child - that of making meaningful connections between words and the things for which they stand.

The principal communication systems for persons who are deafblind are these:

- Touch cues
- Object symbols
- Sign language
- Gestures
- Picture symbols
- Finger spelling
- Tadoma method of speech reading
- Large print writing and reading
- Braille reading and writing
- Lipreading speech

5.1.7 Predictable Routine: Along with nonverbal and verbal conversations, a child who is deafblind needs a reliable routine of meaningful activities, and some way or ways that this routine can be communicated to her or him. Touch cues, gestures, and use of object symbols are some typical ways in which to let a child who is deafblind know what is about to happen to her or him. Each time before the child is picked up, for example, the care-giver may gently lift his or her arms a bit, and then pause, giving the child time to ready herself or himself for being handled.

Such consistency in handling will help the child to feel secure and to begin to make the world predictable, thus allowing the child to develop expectations. Children and adults who are deafblind and are able to use symbolic communication may also be more reliant on predictable routine than people who are sighted and hearing. Predictable routine may help to ease the anxiety which is often caused by the lack of sensory information.

5.2 Orientation and Mobility

In addition, the child who is deafblind will need help learning to move about in the world. Without vision, or with reduced vision, he or she will not only have difficulty navigating, but may also lack the motivation to move outward in the first place. Helping a young child who is deafblind learn to move may begin with thoughtful attention to the physical space around him or her so that whatever movements the child instinctively makes are rewarded with interesting stimulation that motivates further movement.

Orientation and mobility specialists can help parents and teachers to construct safe and motivating spaces for the young child who is deafblind. In many instances such children may also have additional physical and health problems that limit their ability to move about. The parents and teachers may need to include physical and occupational therapists, vision teachers, health professionals, and orientation and mobility specialists on the team to plan accessible and motivating spaces for these children. Older children or adults who have lost vision can also receive help from trained specialists in order to achieve as much confidence and independence as possible in moving about in their world.

5.3 Educational Needs

Education for a child or youth who are deafblind needs to be highly individualized; the limited channels available for learning necessitate organizing a programme 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 the way. Sensory deficits can easily mislead even experienced educators into underestimating (or occasionally overestimating) intelligence and constructing inappropriate programmes.

Helen Keller once said, "*Blindness separates a person from things, but deafness separates him from people.*" 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 programme for a child who is deafblind. Doing so will help a child or youth with these disabilities receive an education which maximizes her or his potential for learning and for meaningful contact with her or his environment. The earlier these services can be obtained, the better for the child.

5.4 Inclusion in Family

Clearly the challenges for parents, teachers and care-givers of children who are deafblind are many. Not least among them is the challenge of including the child in the mainstream of family and community life. Since such a child does not necessarily respond to care in the ways we might expect, parents will be particularly challenged in their efforts to include her or him.

The mother or father of an infant who can see is usually rewarded with smiles and lively eye contact from the child. The parent of a child who is deafblind must look for more subtle rewards: small hand or body movements, for instance, may be the child's way of expressing pleasure or connection. The parents may also need to change their perceptions regarding typical developmental milestones. They can learn, as many have, to rejoice as fully in the ability of their child who is deafblind to sign a new word, or to feed herself, or to return a greeting as they do over another child's success. Parents, then, may need to shift expectations and perceptions in significant ways.

They also need to do the natural grieving that accompanies the birth of a child who is disabled. Teachers and care-givers must also make these perceptual shifts. Parents' groups and resources for teachers can provide much-needed support for those who live and work with children and adults who are deafblind. Such supports will help foster the mutually rewarding their inclusion into their families and communities.

5.6 Transition

When a person who is deafblind nears the end of his or her training/education, transition and rehabilitation, help will be required to assist in planning so that as an adult the individual can find suitable work situations. Because of the diversity of needs, such services for a person who is deafblind can rarely be provided by a single person or agency; careful and respectful teamwork is required among specialists and agencies concerned with such things as housing, vocational and rehabilitation needs, deafness, blindness, orientation and mobility, medical needs, and mental health.

The adult who is deafblind must be central to the transition planning, whenever possible. The individual's own goals, directions, interests, and abilities must guide the planning at every step of the way. Skilled interpreters, family members and friends who know the person well can help the adult who is deafblind have the most important voice in planning his or her own future.

6. Conclusion

Though deafblindness presents many unique challenges to both those who have visual and hearing impairments and to their care-givers and friends, these challenges are by no means insurmountable. Many persons who are deafblind have achieved a quality of life that is excellent and they have several things in common. First, they have each, in their own way, come to accept the absence of sight and hearing as a life situation which gives them a unique and valuable experience of the world. This fundamental acceptance can occur regardless of the severity of the particular sensory losses or other challenges that a person has. Second, they have had educational experiences which have helped them maximize their abilities to communicate and to function productively. Finally, these happy, involved persons who are deafblind live in families, communities, or social groups that have an attitude of welcoming acceptance.

References

- Baldwin, V.** (1994): *Annual Deafblind Census*, Monmouth: Teaching: Research Division
- Barbara, M.** (1995): *Overview on Deafblindness*, Watertown, Mass: Helen Keller National Centre: Perkins School for the Blind
- Deafblind Services Liaison Group** (1988): *Breaking Through*, London: Royal National Institute for the Blind; NDBL; Sense; RNID.
- Guest, Mary:** *Usher Syndrome: Condition which Affects Hearing & vision*, London: Sense Usher Services
- Huebner, K. M; Prickett, J. G; Weich, T. R; Joffee, E.** (1995): *Hand in Hand*, New York: American Foundation for the Blind, Vol. II, Appendix A, P. 22-38
- Wolff, Heller, K.; & Kennedy, C.** (1994): *Etiologies and Characteristics of Deaf-Blindness*, Monmouth: Teaching Research Publications.
- Watson, D.; and Taff-Watson, M. (Eds.)**, (1993): *A Model Services Delivery System for Persons who are Deafblind - II* Edition, Arkansas: University of Arkansas

III. Visually Impaired Children with Multiple Disabilities (VIMD Children)

(By: Vimal B. Thawani, Project Coordinator, Blind People's Association)

Realizing the need for promotion of services for children with multiple disabilities, the Persons with Disabilities Act, 1995 has made a provision for establishing an Institution for Persons with Severe Disabilities. It also recognizes the need for promotion of comprehensive services for such persons. It also defines "persons with severe disabilities" means a person with eighty percent, or more of one or more disabilities.

1. Definitions

1.1 A Person with Multiple Disabilities

Is a "person who has combination of two or more certifiable handicapping conditions whose impact is so severe that the educational needs of the person can not be met in a programme designed for the separate handicapping conditions".

Illustration: Under the IDEA, a child is considered multiply handicapped if she has two or more handicapping conditions that require educational attention. According to this definition, a child who has cerebral palsy which makes it impossible for her to write with a pencil and who also has low vision which makes enlarged print necessary for reading would be considered multiply disabled. A child with the same visual conditions whose reading skills are delayed for no identifiable reason would not be considered to have multiple disabilities (Erin, 1995)

1.2 Visually Impaired Person with Multiple Disabilities

Is a "person who in addition to visual impairment has at least one other disability, regardless of the extent of either, this combination of which causes such severe problems that they

can not receive adequate services in the educational programme for visually impaired person or in those established for persons with other handicaps." (Bureau of Education, USA).

2. Characteristics of Persons with Multiple Disabilities

Best & Brown (1994) use the term 'multi-sensory impairment' to describe a situation rather than a condition, the situation being characterized by an individual being unable to:

- gather sufficient information from the environment to learn independently;
- make sufficient use of the environment to function independently.

Other characteristics of multiple disabilities are:

- a. Children with severe or profound learning disabilities have particular difficulty in separating relevant cues from irrelevant aspects of the environment (Ashman & Conway, 1989).
- b. Children have problems in retaining information in short and long term memory.
- c. It disrupts the processing of information and their abilities to organize problem-solving responses to a situation (Muldoon and Pickwell, 1993).
- d. There is interference in the basic abilities of early communication which include making eye contacts and attending to and interpreting facial expressions and body gestures (Kiernan et al, 1982).
- e. It affects interactive relationship with parents and caretakers who may be unable to understand the child's needs or intentions (Beveridge, 1989).
- f. Have acquired splinter skills - may have some high level skills but not able to do other more simple things.

- g. Such children need very structured instructions.
- h. They need a variety of supporters - a large and diverse support system.
- i. They have trouble with abstract thinking.
- j. They need to learn small steps with a lot of patience.
- k. Each child has her own temperament and her own set of experiences (Erin, 1995).
- l. Each child may be affected in different ways by a medical condition or physical disability (Erin, 1995).
- m. It makes it almost impossible to predict how much any child will learn and what she will be able to do as an adult (Erin, 1995).

3. Visual Conditions with Other Disabilities

Any of the visual impairments and conditions listed in Chapter II can occur with or without other disabilities. Several following visual conditions, however, almost always occur with another disability (Erin, 1995):

3.1 Cortical Visual Impairments

Are caused by an abnormality in the brain. The eyeball and other optical structure are often normal, but for some reason, the brain has difficulty processing and interpreting visual information. The damage that causes the visual impairment may result from the:

- loss of oxygen to the brain;
- bleeding in the brain; or
- other type of trauma.

The same injury to the brain may also result in:

- cerebral palsy
- mental retardation
- seizures, or
- language difficulties.

Such condition may have total loss of vision or low vision and use of vision often improves over time. Their vision may seem to change at different times of the day, they may seem to stare straight ahead or through things. They behave in a puzzling way.

3.2 Optic Nerve Atrophy

Affects the optic nerve which has been damaged in some of the following ways:

- It has not developed (Nerve Hypoplasia)
- It may fail to develop properly because of something that has occurred early in pregnancy.
- Mother's exposure to a toxic substance or an accidental change in the genes which can result in damage to other parts of the brain.

The children with optic nerve atrophy or hypoplasia have a loss of peripheral vision and can only see objects that are straight ahead of them; others lose central vision and may notice objects to the sides more clearly.

3.3 Other Conditions

Various other conditions can also affect both the brain and the visual system.

- Cyromegalovirus - a common virus that can damage child's brain before birth.
- Toxoplasmosis - a common parasite commonly transmitted by cats which can invade the brain and eyes.
- Rubella can affect the developing foetus if the mother has illness in her early pregnancy.
- Anoxia - loss of oxygen to the brain can lead to brain damage.

The loss of vision caused by these conditions can range from a mild impairment to complete blindness. The children with visual impairment and brain damage may seem to use their vision differently at different times of the day. In addition, these children often have trouble with perceptual responses such as perceiving depth, remembering visual information, searching for objects they see, and identifying important visual information.

4. Impact of Multiple Disabilities

According to de' Jong (1992), population of persons with multiple disabilities may be considered to represent two categories of needs: the key words used to describe these categories are “*additive*” and “*interactive*”.

4.1 Additive Impact

Within this group, the impact of two or more disabilities on living and learning can be considered as additive or the sum of the impact of the separate disabilities. Approaches for persons with one of each of the represented disabilities can, therefore, be used in combination. An example of an individual representing this category is the child who is visually impaired and has lost his legs due to amputation. This child can be provided lower prosthesis and taught through the same methods used to teach other visually impaired children.

4.2 Interactive Impact

Within this group, the impact of two or more disabilities on living and learning can be considered as interactive. Thus, a combination of approaches from the single disability area would not be adequate to serve this person's needs; rather, a specific approach must be used. An example of an individual representing the category described as “*interactive*” is the child with visual impairment and cerebral palsy. The spasticity resulting from the cerebral palsy precludes the use of a tactile method which is traditionally used with a visually impaired child. As visual

approach would be ineffective for this child, a new and unique approach must be developed.

For those children whose disabilities have an interactive impact on learning as well as functioning, new care and education strategies have to be developed. This is often difficult because those strategies developed to address the needs represented by one of the disabilities may exacerbate the needs presented by the child's other disabilities. For example, in case of deafblindness, due to combined sight and hearing loss, the person can neither be approached as a deaf person or as a visually impaired person. This multi-sensory impaired individual has to be perceived and approached as a person with the unique disability of deafblindness. Thus each interacting combination leads to unique needs and consequently individual specific approaches.

5. Needs of Individuals

The persons with multiple disabilities and a visual impairment do not form a homogenous group. The true extent of the visual function of such a person is frequently unknown and may vary depending on person's general health and physical condition. As a result guidelines for working with this population often offer only a general framework for appropriate intervention (McLinden, 1997). Every such child has a unique set of learning problems and his appropriate learning modes are different from other children. Faced with such a diverse population, a multi-pronged and multi-option approach has to be adopted (Mohit, 1995). Paul (1995) also supports this contention and feels that such person presents such a wide range of needs that no single professional or individual can cater to their needs alone. Therefore, a team approach should be used to design and implement a comprehensive programme for each individual.

The team should be composed of a variety of professionals, family members and other care-givers. Mohit (1995) also advocates that keeping in view the diversity of needs and all relevant

factors including onset and extent of disability, the age of the child, the socioeconomic status, family attitude and so on, a range of professional interventions, service delivery approaches and curriculum approaches are essential for implementing a comprehensive programme for each VIMD child.

According to Paul (1995), the multi-disciplinary team may consist of:

- Special Educator
- Physiotherapist
- Occupational Therapist
- Low Vision Specialist
- Speech Therapist
- Audiologist
- Orientation & Mobility Specialist
- Psychologist
- Vocational Counsellor
- Social Worker, and
- Family members.

It is essential to remember that each VIMD child is unique with his/her own distinct set of problems, learning abilities and residual skills. Some may need intensive and repetitive instructions in mastering of single skills while others may glide through (Paul, 1995).

6. Service Spectrum

Each disability hinders normal development in several ways. A combination of disabilities hinders in many more ways, which seems logical so far (de'Jong, 1995). But sometimes there are combinations of disabilities with very peculiar effects; in certain situations their compensation and approaches do clash together. They interfere in such a way that the well known approach cannot be used and a new specific one has to be created.

As the nature of interventions and services would depend upon combination of disabilities and many other factors, it is almost impossible to list a uniform set of services to be provided to persons with multiple disabilities. de'Jong (1992) has made an attempt on listing age specific primary needs of such persons:

6.1 Infants and Toddlers

The primary needs of young children with multiple disabilities (age birth to 3 years) include:

- early identification and child-find programmes;
- parent counselling and family services;
- home-based services delivered by persons with special training;
- medical and therapeutic services to enhance healthcare and motor development needs.

6.2 Pre-school Children

In addition to parental involvement and other above mentioned services, the preschool children should be provided services of:

- opportunity to participate in a day programme like a peer group;
- incorporation of specialized educational and medical interventions as per needs of children;
- availability of functional curriculum;
- cooperation between specialists and the care-givers.

6.3 School-age Children

The primary needs of school-age children include educational opportunities and services offered in a variety of settings viz.

- public school
- resource rooms
- residential schools
- and educational opportunities

The children must be provided specially trained teachers and specialized services on a direct service and/or consultative basis. All children must have access to materials, facilities, technology and equipment so as to ensure equal access and full integration into educational opportunities. The development of appropriate curricula to meet specific needs of these children should be emphasized.

6.4 Adolescents and Young Adults

The programmes for this groups should help to:

- remove social and environmental barriers;
- provide experiences; and
- impart social, self-help, vocational and income generation skills.

6.5 Adults

For this group “economic rehabilitation” should be an important goal. The focus of programme for this group should be:

- social integration;
- sports, recreation, social and cultural activities;
- vocational, on-the-job, craft training or any other training in income generation;
- job options, housing opportunities and support service; and
- appropriate concessions, facilities and legislative support etc.

6.6 Elderly Population

The primary needs of this group include:

- identification programmes
- home-based rehabilitation services
- health care
- recreation and leisure-time activities.

The focus of all these services should be social integration, development of functional skills, independence in activities of daily living and self-confidence. The ultimate objective should be to promote their economic independence.

7. Assessment of Children with Multiple Disabilities

As discussed earlier, each child with multiple disabilities is a unique one with specific needs, unique combination of disabilities, unique experiences and unique impact of the same.

There are number of standerised tests available for assessment but the question arrises whether these formal assessment instruments are comprehensive enough or not ?

The answer is partially "yes". However, much depends on the type of impairment and the purpose of assessment.

7.1 Aim of Assessment

For the purpose of comprehensive rehabilitation programme planning, the main aims of assessment would be to:



Clinical Assessment

- establish a base-line in order to identify strengths and weaknesses;

- reassess to record change in order to identify performance in different areas of activity and compare change in areas of curriculum;
- ascertain teaching steps in order to plan next steps in assessment of the learner; and
- suggest learning or curriculum objectives.

Different people have different expectations of the role of assessment. Within education, the purpose might be early identification, screening, prediction of performance, establishing whether a learner's performance deviates from the norms for some other reason.

7.2 Categories of Formal Assessment

Two of the most common categories of formal assessment tools in use within education are:

- Norm referenced, and
- Criterion referenced.

7.2.1 Norm-referenced Assessment: When assessment is norm-referenced that is based on a sample population, it becomes testing. Results may then indicate if the learner performance deviates from the norm. A norm is a normal or average performance as devised from the standard sample of the population. Any norm is restricted to the particular population from which it was derived. Willard (1982) has argued that the learner's needs are not facts about people, but personal goals and things or activities valued by people. For learners who have special educational needs, the usefulness of testing can be suspected and their accuracy often questionable. It is right to remain sceptical and suspicious of this type of assessment and testing. But norm-referenced testing is not the only way to carry-out assessment.

7.2.2 Criterion - referenced Assessment: In some circumstances, criterion-referenced approaches have advantages over those

which are norm-referenced. Close and explicit association between assessment and learning objectives allows for the fine tuning of observational skills. The aim is not to place the learner along some sort of continuum but to establish the standard or criterion to be aimed at. But under the surface of criterion referenced testing there are assumptions about what constitutes "normal" child development. What Tobin (1994) calls an "*internal checklist*" is drawn from educator's experience.

Although criterion-referenced instruments have advantages and they can also present problems of their own. The fact is that they are :

- relatively easy to produce;
- can require little in the way of validation;
- allow the designer to make her mark with the new assessment; and
- require little in the way of statistical knowledge to interpret.

Criterion referenced assessments sometimes become misleading and they should be used with caution. In short, norm and criterion-referenced forms of assessment are rather narrow and formal in their application, depending on checklists, developmental scales and so on. There is place for observational assessment, with the educator observing behaviours, interpreting in the light of other knowledge about this and other learners, and determining educational objectives. Only use of objective assessments without parallel application and enhancement of observational skills, will achieve a little.

7.3 Functional Assessment Approaches

Instead of abstracting tasks from settings, functional assessment tries to structure the environment to offer opportunity for observing skills in practical use. Functional approaches assume that it is not possible to prescribe for each and every possible situation that may arise with a learner. There is no single correct answer or indeed a question.



7.4 Elements of Functional Assessment

- Functional assessment should include assessment of learner own constellation of abilities and disabilities; cognitive abilities, sensory perceptual abilities, memory, problem solving abilities and communicative abilities.
- How the learner functions in different environments ? That would include, classroom, home, play ground etc. Sometimes learner performs well in one setting than the other, and with one teacher than the other.

Having identified personal factors and environmental factors, we would want to discover what resources are available. These might include a sibling, a neighbour or a particular teacher; may be formal resources like availability of funds or time available for training staff and user etc.

One extremely important part of any assessment will be to identify which parts of the curriculum lend themselves to

incorporating other features. In the process of functional assessment, the assessor takes an active part in identifying these opportunities; they are not contained within artificially constructed categories.

Assessment should allow for a mix of qualitative and quantitative methods, reflecting a world views that there is a pluralistic, dynamic and complex, approaching people in a value oriented way and recognising the inter relatedness of human activities (Aitken, 1995). In this view, assessment is not something done to a learner at certain stages but a continuous process of evaluation of the relationship between learner goals and performances, the educator, the curriculum and its development and of the resources available (Aitken, 1995).

Assessment is an ongoing activity, rather than a single or static occurrence

8. Curricular Approaches

As for a person with multiple disabilities, it is essential to cope up with the learning environment, learning is a continuous process of adaptation. The developmental team functions as a bridge between the learning environment and specific needs of the individual. The team makes critical decisions as regard development of appropriate curriculum.

Hussey (1997) observes that the current educational philosophy suggests that curriculum framework for VIMD children will consist of three elements, the National Curriculum, a Developmental Curriculum and the Complementary Curriculum.

8.1 National Curriculum

The Central Scheme on Integrated Education of Disabled Children as well as the Persons with Disabilities Act desires all children with disabilities to be imparted educational instructions in the regular school. It however recognizes the specific needs of such children and provides for services of special educators and support of special educational devices. According to Hussey

(1997), one of the key principles of the National Curriculum is differentiation within a common framework. The impulse of these legislative measures is to promote a curriculum to be shared by all schools, rather than a discrete one for children with special needs.

Akhil (1995) suggests two curriculum approaches viz. "developmental" curriculum and "functional" curriculum. Hussey (1997) prefers the term "complementary" curriculum instead of "functional" curriculum.

8.2 Developmental Curriculum

It refers to learning of basic skills as in case of non-disabled children. It desires that development of curriculum for children with multiple disabilities should be based upon and in the same sequence as in case of non-disabled children. The content in this case is determined through the administration of tests and checklists based on performance and capabilities of non-disabled children.

According to Hussey (1997), the developmental curriculum is concerned with four fundamental (but not exclusive) areas of development:

- physical development (including development of body awareness and control of movement)
- social development (including promotion of the emergent personalities and development of acceptable behaviour)
- intellectual development - the promotion of awareness, understanding and knowledge
- communication development (promotion of the expressive and receptive skills needed in human relationship and learning).

According to Paul (1995), this approach has major advantages in terms of providing overall picture of child's abilities, providing

common ground for comparison of development of children with or without disabilities. It has limitations in terms that children with severe disabilities do not develop skills in the normal sequence and materials and situations prescribed are not age specific and meaningful to a child with disabilities. It is also difficult to prepare and manage a child specific Individual Education Plan. The latest trend is to adopt and follow functional curriculum in case of visually impaired children with multiple disabilities.

8.3 Functional Curriculum

This approach is based upon the principle that access to education is often dependent on the ability of the child to explore his or her environment and to develop a communication system. This curriculum may be delivered by a variety of professionals including speech therapists, orientation & mobility instructors, physiotherapists, psychiatrists, psychologists and special educators. A professional advises as to how their aim can be incorporated into a child's educational plan. Their role needs to be valued within the whole approach of the school. It provides holistic approach to each child's education.

According to Erin (1995) the most important skills for VIMD children to learn are functional skills. These are the skills that enable such child to do ordinary daily skills. These may be as simple as grasping a spoon or as complex as travelling to new a job independently. But in any case, the skills is something that will require assistance from any other person if the child can not learn to do it on his own. Thus it is essential to incorporate teaching of functional skills in the curriculum.

This approach is designed to determine skills required for a particular person in his existing and future environment. The persons are taught only those skills that will facilitate their integration into the natural setting. These skills must enable an individual to control, modify, interact and perform in the environment. The areas taught in this approach include skills

of independent living, self care, recreation/leisure, education, vocational activities etc.



The approach is based on the principle that the functional skills can be effectively learnt when taught through a pre-planned and structured programme. The children in this case are taught skills which are age appropriate through relevant materials and best suited sequence.

Akhil (1995) recommends the following procedure for developing a functional curriculum:

- a. Parent interview
- b. Student preference survey
- c. Ecological inventory
 - Dividing the curriculum into domains
 - Determining the environment
 - Dividing each environment
 - Determining the specific activities
 - Determining the skills
- d. Discrepancy analysis

The functional approach is realistic, practical and effective. It may seem time consuming to begin with. It however reduces the time that otherwise would have been spent later.

It is thus essential to work in partnership with the individual and their families to provide a realistic educational programme suited to each child's specific individual felt-needs.

9. Vision Stimulation Room

The Blind People's Association with the design support of the National Institute of Design and financial support of the Sense International has set up the Vision Stimulation Room with three objectives:

- Sensory Stimulation of children with multiple disabilities
- Sensory training in use of residual abilities
- Assessment -clinical and functional aspects

The room is equipped with

- Strobes, flasher lights, spotlights, mirror ball, focus light, ultraviolet lights to measure tracking, fixating and use of vision,

- Resonance boards, stimulation box for stimulating toddlers, vibrators, sound devices of different frequencies and intensities.
- Tactually stimulating surfaces of different qualities arranged in the room to stimulate the child and encourage it to explore with its sense.
- Suspended objects of different surfaces, lengths, textures to encourage the child to explore feel and process this information meaningfully.

The Room has been designed by the National Institute of Design (Ahmedabad) and developed under the guidance and with the support of the Sense International. The room has myriad of lights of different intensities and qualities from strobes to ultraviolet to flashers. These are arranged in specific places from the ceiling, floor and walls to assess the extent of residual vision and also effectively measure the extent of gaze fixation, tracking and moving. The lights are also used for stimulating children with low vision to effectively harness vision. The room encourages the stimulation of the other two senses of touch and hearing equally. There is a tactile corner and a resonance board for stimulating the tactile senses of especially young toddlers.

The room also has installed a variety of auditory devices for encouraging the use of residual auditory abilities and for harnessing senses for identifying, discriminating and processing sounds, its origin and quality. With the stimulation, the child learns to understand its residual ability and to use the same in day to day life. The sensory stimulation room thus helps in concept development and communication through other senses and integration of different sensory information.

Achievements: This design for this project has been developed by the NID at no cost. No budget, no developmental cost, no cost to S&T Mission. This is the most well designed Vision

Stimulation Room in the country. The Sense International is now sharing details of the design with its partners around the world.

References

Aitken, (Dr.) Stuart (1995) : *Educational Assessment of Deafblind Learners* in **Etheridge, David** (Edited by) : *The Education of Dual Sensory Impaired Children*, London, David Fulton Publishers, P. 1-17

de Jong, Coen G. A. (1995): *Educational Opportunities for all Multihandicapped Children*, a paper presented in ICEVI Asian Conference, Ahmedabad, 9-11 January, 1995

de Jong, Coen G. A; and Campbell Lawrence F. (1992): *Report/Recommendations of the ICEVI Multi-handicapped Working Group*, (Unpublished), P. 13

Erin, Jane (1995): *Children with Multiple and Visual Disabilities*, in Hollbrook, Cay M (Ed.), *Children with Visual Impairments*, Bethesda (USA): Woodbine House, P. 287 - 316

McLinden, Mike (1997): *Children with Multiple Disabilities and a Visual Impairment*

Hussey, David (1997) : *Curriculum Issues in Mason, Heather & Others, Visual Impairment: Access to Education for Children and Young People*, London: David Fulton Publishers, P. 314 - 334

Mohit, Anuradha (1995): *Issues concerning Programme Planning for Visually Impaired Multi-handicapped children*, a paper presented in ICEVI Asian Conference, Ahmedabad, 9-11 January, 1995

Paul, Akhil (1995): *Developing Functional Curriculum for Persons with Multiple Disabilities*, a paper presented in ICEVI Asian Conference, Ahmedabad, 9-11 January, 1995