**Composite Regional Centre for Persons with Disabilities**

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##  *INFORMATION BROCHURE*

***CONTINUING REHABILITATION EDUCATION (CRE)***

**“Understanding Deafblindness and MDVI (multiple disabilities with visual impairment)”**

***(27th – 29th July 2016)***

***Red Cross auditorium***

***Red cross building (Patna)***

***Composite Regional Centre for Persons with Disabilities***

*Department of Empowerment of Persons with Disabilities* (Divangjan)*,*

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*3 Days ( 27th to 29th July 2016) CRE on “Understanding Deafblindness and MDVI (Multiple Disabilities With Visual Impairment)”*

*CONCEPT NOTE*

*Background & Rationale:*

Deaf-blindness is the condition of little or no useful [sight](https://en.wikipedia.org/wiki/Visual_perception) and little or no useful hearing. It is  [having a severe impairment of both hearing and vision.](https://en.wikipedia.org/wiki/Deafblindness#cite_note-1)  Children with multiple disabilities and a visual impairment (MDVI) are a heterogeneous group. Multi disability and Visual Impairment (MDVI) is a condition whereby an individual has more than one disability over and above visual impairment. Sometimes it may be a combination of two, three, or even more impairments.  In addition to a visual impairment, a child with MDVI could have one or more additional needs ranging from physical disabilities, speech difficulties, behavioural difficulties and learning difficulties. [Helen Keller](https://en.wikipedia.org/wiki/Helen_Keller) was one such individual. Helen Keller said, “Blindness separates a person from things, but deafness separates him from people.”

**Types of deafblind**

The various [types &causes](https://www.sense.org.uk/content/types-and-conditions)  associated with forms of deafblindness are the following:

* [Congenital deafblindness](https://www.sense.org.uk/content/congenital-deafblindness)
* [Acquired deafblindness](https://www.sense.org.uk/content/acquired-deafblindness)
* [Usher syndrome](https://www.sense.org.uk/content/usher-syndrome)

***Congenitally deafblindness***

**Congenitally deafblind** is a term that describes any child who is born with a sight and hearing impairment or develops sight and hearing loss before they have developed language in their early years.

* Children who are born with vision and hearing impairments face a tough start. Exploring the world around them, finding a way to communicate their needs and learning to trust people can be difficult. Many children will also have other physical and learning disabilities to deal with.
* The child’s perception of the world is different. Parents, family, and teachers have a role in supporting them to make sense of the world if they are to reach their full potential.
* The child will need to use their other senses – touch, body awareness in space, balance, taste and smell – to access information which is more easily available to other children. This can delay development.
* Communication and learning are significant challenges for children with deafblindness, and key concepts are often achieved later than might be expected. Developing an awareness of others, self-perception, and the impact of actions on others can all be affected.
* This can often lead to a misdiagnosis of autism or a severe learning disability, when in fact the key factor impacting on learning is the combined sight and hearing loss.

***Acquired deafblindness***

* A person who loses their sight and hearing after they have developed language in their early years is said to have **acquired deafblindness.**
* An individual may already have a sight or hearing impairment, and suddenly or gradually lose the other sense. It could be related to a specific genetic condition from birth, or as a result of an illness or accident.
* People who have[Usher syndrome](https://www.sense.org.uk/usher), for example, will have grown up as deaf or hard-of-hearing, but then received the diagnosis that they are also losing their sight.
* As we age our hearing and sight will deteriorate. At first we may just need glasses or to turn the TV up a little. But if our sight or hearing deteriorate further, daily activities can become more difficult.
* Due to their changed circumstances, a person’s sight or hearing loss will mean making lifestyle adjustments, such as in how they communicate, find and use information, or get around.
* While the diagnosis of sight and hearing loss can have a significant emotional impact, many people with acquired deafblindness lead active, independent and fulfilling lives.

***Usher syndrome***

Usher syndrome is a genetic condition which affects vision, hearing and, in some cases, balance. It is broadly split into [three types](https://www.sense.org.uk/content/different-types-usher-syndrome).

Although Usher syndrome brings challenges, people with Usher lead fulfilling and independent lives. People with Usher can and do have relationships, get married, have children, go to university, travel, go to work and enjoy numerous leisure pursuits.

The time of onset as well as the degree to which vision, hearing and balance is affected varies between individuals. However, the main mechanism behind the impairments remains similar.

Vision loss caused by Usher syndrome is due to a condition called [retinitis pigmentosa](https://www.sense.org.uk/content/vision-loss-and-usher-syndrome-0). The hearing loss is due to a condition called [sensorineural deafness](https://www.sense.org.uk/content/hearing-loss-and-usher-syndrome%22%20%5Ct%20%22_self). Additionally, many people with Usher experience problems with [balance](https://www.sense.org.uk/content/balance-and-usher-syndrome).

**Intervention for children with MDVI**

A qualified teacher of the visually impaired may be the most appropriate professional to take responsibility for the delivery of the mobility and independence curriculum to children with MDVI as they can support other aspects of the child’s education at the same time.

**Methods of Communication for deafblind & MDVI**

Deaf-blind people communicate in many different ways determined by the nature of their condition, the age of onset, and what resources are available to them. For example, someone who grew up deaf and experienced vision loss later in life is likely to use a [sign language](https://en.wikipedia.org/wiki/Sign_language) (in a visually modified or tactile form). Others who grew up blind and later became deaf are more likely to use a tactile mode of their spoken/written language. Methods of communication include:

* Use of residual hearing (speaking clearly, [hearing aids](https://en.wikipedia.org/wiki/Hearing_aid)) or sight (signing within a restricted visual field, writing with large print).
* [Tactile signing](https://en.wikipedia.org/wiki/Tactile_signing), [sign language](https://en.wikipedia.org/wiki/Sign_language), or a manual alphabet such as the [American Manual Alphabet](https://en.wikipedia.org/wiki/American_Manual_Alphabet) or [Deaf-blind Alphabet](https://en.wikipedia.org/wiki/Two-handed_manual_alphabet#Deaf-blind_alphabet) (also known as "two-hand manual") with tactile or visual modifications.
* [Interpreting](https://en.wikipedia.org/wiki/Interpreting) services (such as sign language interpreters or communication aides).

**Methods of teaching language to deafblind and MDVI**

Educationally, individuals are considered to be deaf-blind when the combination of their hearing and sight loss causes such severe communication and other developmental and educational needs that they require significant and unique adaptations in their educational programs. Multisensory methods have been used to help deaf-blind people enhance their communication skills. These can be taught to very young children with developmental delays (to help with pre-intentional communication), young people with learning difficulties, or older people, including those with [dementia](https://en.wikipedia.org/wiki/Dementia). Some participants used the term to refer to children with complex needs irrespective of educational setting, whilst others spoke of children with MDVI as those who are educated in special school settings (i.e. non-visual impairment special schools including schools for children with severe learning difficulties or physical disabilities).These are the following methods of teaching language to deafblinds and MDVI:

### **Deafblind manual alphabet**

### The deafblind manual alphabet is a method of spelling out words onto a deafblind person's hand.

Each letter is denoted by a particular sign or place on the hand. It is straightforward to learn but is more complex to receive.

**Block**

Block is another manual form of communication where words are spelled out on to the palm of the deafblind person's hand. It is even simpler to learn than the deafblind manual alphabet, but will be a slower method to use.

* Trace each letter with your finger, in block capitals, on the palm. Use the whole of the palm for each letter
* Keep letters large and clear
* Place one letter on top of the last
* Pause slightly at the end of each word

### **Braille**

Braille is a system of writing and printing for visually impaired people, in which arrangements of raised dots representing letters and numbers are identified by touch.

It can be used by deafblind people who have an understanding of written language.

Although originally intended for the purpose of information being documented on paper, braille can now be used as a digital aid to conversation, with some smartphones offering braille displays, and computer braille keyboards allowing access to instant messaging software, Skype or chatrooms.

### **Moon**

Moon is similar to braille in that it is based on touch. Instead of raised dots, letters are represented by 14 raised characters at various angles.

It is less commonly used than Braille, but easier to learn. The ease of use means that it can be used by some people with learning disabilities and people who become blind through ageing.

All of these methods are reliant on the literacy of the individual.

**Objects of reference**

### Some congenitally deafblind or multi-sensory-impaired people learn to use particular objects to symbolise a significant activity. For example, a towel may indicate swimming, or a fork may be used to show that it is time for a meal.

This method allows people who are deafblind to make choices and enables others to let them know what is planned.

**Assessment, programme design for MDVI**

Any curriculum would need to be adapted for children with MDVI as their needs and abilities are so individual (as with any child with a visual impairment, but to a greater degree when a child has MDVI). A tight definition of mobility as ‘travel’ is likely to be inappropriate for some children with MDVI who will never be independently mobile or independent. The mobility and independence curriculum would therefore need a different emphasis for children with MDVI.

**Modes of communication for deafblind and MDVI**

* [Non-verbal](https://www.sense.org.uk/content/non-verbal-communication) - includes body movements; breathing patterns; eye pointing
* [Alphabet based communication](https://www.sense.org.uk/content/alphabet-based-communication) - deafblind manual; large print; Braille; block
* [Symbol systems](https://www.sense.org.uk/content/symbol-systems) - objects of reference
* [Sign systems](https://www.sense.org.uk/content/sign-systems-and-languages) - British Sign Language (BSL)
* [Speech-based](https://www.sense.org.uk/content/speech-based-communication) - includes clear speech; lipreading

[**Communication aids**](https://www.sense.org.uk/content/communication-aids) - including technological switches; Braille

[**Intensive interaction**](https://www.sense.org.uk/content/intensive-interaction) - imitation; observation; using rhythm

[**Total communication**](https://www.sense.org.uk/content/total-communication) - combining methods

The total communication approach is about using the right combination of communication methods for an individual to ensure the most successful forms of contact, information exchange and conversation.

For example, an individual may receive information via speech and signs while expressing themselves via signs and symbols.

Through observation it is often possible to understand the meaning of these unique methods of communication and to learn how to react to and interact with the deafblind person.

### **Technological aids to communication**

* **Hearing aids**may benefit people born with a hearing impairment or those whose hearing has deteriorated but who still retain some residual hearing. They will not always necessarily boost hearing to a level that will allow them to receive spoken communication
* **Cochlear implants**can significantly improve some people’s hearing but, like hearing aids, their use will not necessarily facilitate the reception of speech
* **Telecommunications**is a rapidly developing area of technology with increasing potential particularly for people with acquired deafblindness. Some telephones, including mobiles, have increased amplification, hearing aid compatibility, magnification software and braille displays. Many people with acquired deafblindness also use textphones and / or text relay services
* **Emerging technologies**including purpose-designed software for laptops and tablets are being increasingly used both by multi-sensory-impaired people and those working with them to develop their communication skills

**Assistive Technology for deafblind and MDVI**

Braille equipment includes a variety of multipurpose devices, which enhance access to distance communication. Some can be used as stand-alone devices connected via Wi-Fi, while others are paired with a mobile device to provide tactile access to e-mail, text messaging, and other modern communication resources. To receive braille equipment, an eligible consumer must be proficient in braille and must have access to the internet or cellular service.

The telebraille does not have a computer communications modem but it does have a TTY (TDD) modem. The Braille display is about 15 characters in width, although there is a knockout to allow additional characters to be installed, at considerable additional cost. The Telebraille is able to communicate in ASCI mode but it is not compatible to conventional computer modems. Graphic braille display can be used in sensing graphic data like map, image and text data that requires multi-line display capabilities like spreadsheet, equations.

 **CONCLUSION**

 The work is not finished. We believe that it s very important that deafblind people have a chance to meet together and to properly share and exchange their views – with each other and directly, without intermediaries and we are trying to find ways to achieve this. It is important to be sensitive to the aspirations of deafblind people and we need to find ways to support them in what they want.

*CRE:*

* *CRC Patna has organised a three days programme under the auspices of NIOH Kolkata and RCI New Delhi to explore the various options available for developing language skills and social competence in deafblind and MDVI.*

*OBJECTIVES:*

* *To upgrade the existing knowledge & skills of in service & practicing rehabilitation professionals and personal working for the rehabilitation of deafblind and MDVI.*
* *To upgrade the professional knowledge of master trainers working in the related field.*

*AIMS:*

* *To explore about different communication options available for deafblind and MDVI.*
* *To develop skills & competencies to cater the educational needs of deafblind and MDVI.*
* To carry out more detailed analysis on what is the need of deafblind and MDVI.

*PARTICIPANTS:*

* *Forty participants comprising teachers working in schools for the deaf and hard of hearing and inclusive schools shall be part of the programme. Preference shall be given to those directly dealing with the students having deafblindness.*

*VENUE AND TIMING:*

* *Programme is being organized at Auditorium Hall, Red Cross Building, Gandhi Maidan Patna from 27th - 29th July 2016 (10.00 am to 5.00 pm).*

*CONTENT OF THE PROGRAMME:*

* *In the light of this background, CRC Patna has planned to organize three days CRE accredited (from RCI New Delhi) programme to explore the communication options and educational needs for deafblind and MDVI with the following contents:-*
* *Overview of modes and methods of communication for deafblind.*
* *Pre-requisites, philosophy & strategies for creating a responsive learning environment.*
* *Modification of TLM as per the requirement of deafblind and MDVI*
* *Educational implication and learning environment for deafblind and MDVI*

*TOPICS TO BE DISCUSSED:*

* *Types and characteristics of deafblindness*
* *Concept & definition of deaf blindness& MDVI*
* *Signs& symptoms of identifying deafblindness*
* *Screening and assessment of deafblind and MDVI*
* *Educational implication and classroom management of deafblind and MDVI*
* *Creating a conducive learning environment and home environment for deafblind and MDVI*
* *Modification of TLM for the optimum learning of deafblind and MDVI*

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