

Guidelines on best practice for persons living with deafblindness

CBM Inclusive Education Technical guideline

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All case studies are unpublished resources from CBM partner organisations. For privacy reasons, all names in the case studies have been changed.

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Table of Contents

- Foreword..... 2**
- Introduction 3**
- Part One: An Overview of Deafblindness 4**
 - 1. The impact of deafblindness on development and learning 4
 - 2. The need for a comprehensive range of programmes..... 6
 - 3. The need for systematic identification of persons living with deafblindness 8
 - 4. Family support and partnerships 9
- Part Two: Characteristics and Components of Education and Rehabilitation Programmes..... 11**
 - 5. General requirements 11
 - 6. Communication..... 12
 - 7. Social and emotional development 15
 - 8. Holistic, person-centred assessment..... 16
 - 9. Concept development 17
 - 10. Access to assistive devices, including alternative and augmentative communication..... 19
 - 11. Advocacy and self-determination..... 21
 - 12. Transition planning and on-going support..... 22
 - 13. Access to health and therapy services..... 24
- Part Three: Improving and Expanding Services for Persons Living with Deafblindness..... 25**
 - 14. Personnel development and training 25
 - 15. Networking between stakeholders 26
 - 16. Expansion of services 27
 - 17. Intersecting issues 28
- Useful resources..... 29**
- Glossary of terms and definitions 30**
- Reference list 31**
- Notes..... 33**

Foreword

CBM's mission as an international Christian development organisation is to work towards an inclusive world in which people with disabilities enjoy their human rights and achieve their potential. In order to realise this, CBM staff and partners place a strong emphasis on advocacy and capacity development to promote disability inclusion and human rights. As an organisation committed to learning, CBM is continually on a journey to improve our practice of disability-inclusive development. The skills and expertise of our organisation, our partnerships and alliances, have been developed during our 100-year plus existence. Today, as we honour our commitment to improve the quality of life of persons with disabilities in the world's poorest communities, we strive to do so with professionalism and respect for the people we work for and with. These guidelines help us meet this commitment.

CBM involves persons with disabilities and their families in developing local programmes, using participatory methods of planning and implementation. At a global level it works with partners such as International Disability Alliance (IDA), International Disability and Development Consortium (IDDC), World Health Organization (WHO), United Nations (UN) bodies, and professional associations.

CBM has been instrumental in developing services for persons with deafblindness in many low- and middle-income-countries. These services have been strengthened by networking with local governments and organisations for and of persons with disabilities, including the World Federation of the Deafblind (WFDB), Deafblind International (DbI), Perkins International, Sense International, and Royal Dutch Kentalis.

For further information about CBM visit www.cbm.org

“With these guidelines for best practice I would say that CBM shows insight and knowledge about the complexity of living with deafblindness. WFDB finds this publication an excellent tool, and a step forward in building awareness of the complexity and severity of deafblindness, and how to overcome the challenges and empower persons with deafblindness to be included in society, not only by presence and attendance, but also to actively contribute and bring value to society. This is in line with the promises of inclusion made by the UN Convention on the Rights of Persons with Disabilities, the 2030 Agenda and the Sustainable Development Goals.”

Geir Jensen: President, WFDB

[Back to top](#)

Introduction

These guidelines were developed to advance understanding of the needs and challenges of persons living with deafblindness and to promote their inclusion in society. The target audience are members of the CBM Federation with particular interest to, among others staff at Regional and Country Offices, Member Associations, co-workers, partners (including governments, education agencies, public and private service providers, and professionals), as well as persons living with deafblindness and their families.

Part One gives an overview of the impact deafblindness can have on an individual's development and learning. It emphasises the need for a continuum of services and programmes, including early detection, referral, educational input, and family support.

Part Two outlines components of education and rehabilitation programmes. It provides guidelines on communication, holistic assessment procedures, assistive devices, advocacy and self-determination, transition planning, and discusses the importance of on-going regular access to health and therapeutic services.

Part Three considers how to improve and expand existing services through the provision of on-going personnel capacity building, and through networking with key stakeholders, to consider intersecting issues and service expansion.

Each section includes an overview of the topic explored, some case studies and considerations for service implementation. CBM's approach to disability-inclusive development underpins suggestions made. For CBM this means focusing particularly on the rights and inclusion of people with disabilities. It actively seeks to ensure the full participation of people with disabilities as empowered self-advocates in all development processes and emergency responses and works to address the barriers which hinder their access and participationⁱ. Inclusive development strives for the active participation and representation of all people, regardless of age, gender, disability, ethnicity, race, class, religion, sexuality, or any other characteristic. Disability-inclusive development is part of this social justice movement that challenges exclusive policies, relations, and practices.ⁱⁱ

[Back to top](#)

Part One: An Overview of Deafblindness

1. The impact of deafblindness on development and learning

What is deafblindness?ⁱⁱⁱ

The term 'deafblindness' refers to combined hearing and vision loss. Although most individuals with deafblindness have some functional use of vision and hearing, the combination of losses greatly impairs the ability to gather auditory and visual information. This creates intensive communication and learning needs that cannot be met by programmes designed solely for persons who are blind or have low vision, or persons who are hard of hearing or deaf.

For a comprehensive definition, see the Nordic Definition of Deafblindness: www.nordicwelfare.org/PageFiles/992/nordic-definition-of-deafblindness.pdf

The distance senses of hearing and vision enable individuals to receive information about the world beyond their reach. They are the main avenues for communication, learning, and socialisation. Individually, each sense can compensate for the loss or diminished capacity of the other, to some extent. However, the combination of simultaneous hearing and visual impairment has significant consequences for many crucial aspects of life, including communication, learning, mobility, social and emotional development, and access to information and one's surroundings.^{iv}

The population of individuals living with deafblindness is an extremely diverse group. Very few individuals are both profoundly deaf and completely blind. The majority have varying degrees of residual hearing and vision. For example, one person may have a severe hearing loss in combination with a level of residual vision that enables the use of close-vision sign language and the ability to read large, bold print. Another may be able to hear speech with the use of hearing aids and have night blindness as well as a restricted visual field.

There are many causes of deafblindness, including a wide variety of congenital conditions such as CHARGE Syndrome^v and Congenital Rubella Syndrome^{vi}. The incidence of the latter has declined due to the widespread use of vaccinations, but it remains a known cause of deafblindness in many Asian and African countries. Another well-known cause throughout the world is premature birth. Due to advances in medical technology over the past few decades, there has been an increase in survival rates of children born prematurely or with significant health problems. These children often have visual, hearing, and additional impairments.

Deafblindness is a low-incidence disability. There is some data available on its prevalence in countries like the United States^{vii} and the United Kingdom^{viii}, but estimated numbers of persons living with deafblindness in many parts of the world are unavailable.

Without access to programmes that include support services, individuals living with deafblindness may experience:

- isolation;
- limited opportunities to communicate with others and interact with their surroundings in a meaningful way;
- difficulty establishing and maintaining interpersonal relationships;
- very limited number and variety of life experiences, including social interactions;
- limited opportunities for the development of concepts related to the environment in which a person lives which are necessary to understand and make sense of the world (i.e. people/places/things have names, events/things happen in a certain order, things come from/are kept somewhere and so on);
- limited access to information needed to anticipate future events or the results of one's actions;
- deprivation of many of the most basic motivations and instincts to explore and learn, function, and engage with the world;
- higher likelihood of being mislabelled as developmentally or intellectually disabled, emotionally disturbed, or autistic;
- increased vulnerability to abuse, including sexual abuse and associated consequences, such as HIV and AIDS, other sexually transmitted diseases, unwanted pregnancies, and post-traumatic stress disorder;
- medical problems that can lead to serious developmental delays and further sensory and other impairments.

Case Study

Meet three young girls. All live with deafblindness and are similar ages, but they are very different from each other in many other respects.



© Holy Cross Service Society

Samiya is from India and was born with Congenital Rubella Syndrome. She had cataracts that were removed when she was very young, and is able to make good use of the little vision she has left. She has a severe to profound hearing loss and was recently fitted with hearing aids.



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Charisma lives in Tanzania. She was born without eyes (bilateral anophthalmia) and is completely blind. She has usable residual hearing, but a speech impairment that further complicates communication. She is able to vocalize a little, but does not yet speak.



© Holy Land Institute for the Deaf

Khitam is from Jordan. She was born prematurely, during the seventh month of pregnancy. She is completely blind and has a profound hearing loss. In addition she has cerebral palsy. Her muscles are weak, but with the help of physiotherapy she is now able to move more independently.

General principles for service delivery

- 1.1 Programmes serving individuals living with deafblindness need to consider a rights-based approach to their work, in line with the UN Convention on the Rights of Persons with Disabilities (CRPD).^{ix} Service providers should be guided by the CRPD General Principles (Article 3), especially the principles of respect for inherent dignity, full and effective participation and inclusion in society, and accessibility.
- 1.2 Communication and instruction needs to be in close proximity or through direct contact. Deafblindness negatively affects attachment, communication, and concept development, so individuals require individualised, systematic support and instruction.

2. The need for a comprehensive range of programmes

Because the population of persons living with deafblindness is so diverse, a variety of programmes and services is required to ensure that their rights are respected and their individual needs met. As a core feature, services must include opportunities for each person to participate meaningfully, to the fullest extent possible, in his or her home and community. [Back to top](#)

Considerations

- 2.1 Ideally, a continuum of services should be available, including:
 - a) early identification and intervention in infancy and early childhood;
 - b) appropriate education throughout childhood, adolescence, and young adulthood;
 - c) services to promote the transition from educational services to adult life;
 - d) community activities, livelihood, and social services for adults.
- 2.2 In order to meet the needs of this diverse population, communities should provide both:
 - a) services that support full inclusion in schools and communities (e.g., sign language and/or communication interpreters, instruction in orientation and mobility, instruction in social skills); and
 - b) specialised services (e.g. specialised education provision or rehabilitation programmes specifically for individuals living with deafblindness).
- 2.3 Services should be provided in the settings most appropriate for the individual.^x For example, a child who has severe hearing loss, but some usable vision may be best served within a signing environment. Conversely, a child with a severe visual impairment, but who has residual hearing may be better served in a setting designed to accommodate learners with low vision or blindness.
- 2.4 Access to comprehensive services – consistent with the five pillars of the WHO community-based rehabilitation (CBR, also referred to as community based inclusive development, CBID) matrix: health, education, livelihood, social, and empowerment – should be assessed.^{xi} No single organisation is likely to be able to cover all five areas, but community programmes can collaborate to provide a network of services.

2.5 At the heart of all services should be a focus on the rights, desires, hopes, and dreams of the individual living with deafblindness and his or her family.

Case Study



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Wincent (from a small village in Guatemala) is an outgoing, curious, and fun-loving boy who loves to talk. His favourite activity is playing ball

with his brothers and cousins. When Wincent was six months old, his parents realised that he could not see and they immediately sought professional help. As a result, Wincent began to receive educational services very early in life. At the age of three, he started attending a special school, where he was diagnosed with microcephaly and a mild hearing loss in addition to his blindness. Currently, he attends the special school three days per week. The other two days of the week he attends a regular local primary school where he enjoys being with and learning with his peers.

[Back to top](#)

3. The need for systematic identification of persons living with deafblindness

The population of persons living with deafblindness is grossly under-identified. In many areas they are kept at home or otherwise isolated. Consequently, they may be unknown even within the communities where they live. Children in particular may be misidentified as being autistic, having an intellectual or learning disability, or multiple disabilities. Service providers must be knowledgeable about the disability of deafblindness and its impact on development and learning. They must be able to apply this knowledge creatively as they work to assess the abilities, needs, and priorities of the individuals they serve.

Considerations

- 3.1 Local programmes to systematically detect persons with deafblindness are essential. These should include early vision and hearing screening programmes to identify children who are suspected to be deafblind and in need of more in-depth assessment.
- 3.2 Individuals who are suspected to be deafblind should receive a comprehensive assessment to correctly diagnose the condition, ascertain the cause and nature of the deafblindness, and identify potential education and rehabilitation needs. The assessment results will inform subsequent referrals.
- 3.3 Assessment should be carried out by service providers with specific training in deafblindness.
- 3.4 Medical personnel, educators, and social service providers should receive training to increase their awareness of deafblindness.

Case Study

What if no one noticed your struggle to hear and see, and you did not receive services that would help you until you were older?



© Helen Keller Indonesia

Unfortunately, this is what happened to Priska, who is from a small town in Central Java, one of the bigger islands of Indonesia. She was born with vision and hearing loss, but this was not identified until she was ten years old, when she was diagnosed with

Congenital Rubella Syndrome. There is a school for the deaf in her town, but Priska was not enrolled simply because her family was unaware of her disability. They had not received proper information and support from local medical and educational services.

Despite a late start, things are now going well for Priska. She attends a vocational training programme at a school for students living with deafblindness in one of Indonesia's bigger cities. She enjoys traditional dancing, cooking, and shopping, and is learning to prepare and sell snacks. One day she hopes to start a small shop selling snacks in her hometown.

4. Family support and partnerships

Family members are the first and most consistent care providers of a child or other relative living with deafblindness, and they possess a unique understanding of the individual's needs. They will always need to play a significant role in the person's life.

Considerations

- 4.1 Family members should be significantly involved in services provided to individuals living with deafblindness, including screening and assessment, education, and activities that support transition to adult life.
- 4.2 Programmes should be aware that family members may themselves also stigmatise or exclude individuals living with deafblindness. Therefore, there is a need to seek ways of overcoming stigma and exclusion within families as well as in the wider communities in which they live.
- 4.3 Service programme staff should make regular home visits to provide support and information, and assess changing needs.
- 4.4 Programmes should have procedures in place that ensure good, consistent communication between service providers, family members, and the person living with deafblindness.
- 4.5 Programmes should provide training and support to the family, as well as to individuals living with deafblindness. This will encourage collaboration between service providers and the family. It also increases the likelihood that the skills learned by an individual living with deafblindness at school or in community centres – for example, a specific communication system – will be used at home.
- 4.6 Members of the family need opportunities to meet others (e.g., through parents' groups) to share experiences and provide support to each other.^{xii}

Case Study

The importance of parent support groups



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Annika is a girl from a fishing village on Lake Victoria in Tanzania. She was born with deafblindness, which was identified at a very young age. Despite an early diagnosis, her mother had little hope for Annika's prospects and showed little interest in her daughter's potential. At the age of seven, Annika had surgery on her eyes, which restored some of her vision. Soon after, the local school for the deaf opened a deafblind unit and Annika started her schooling along with five other students

She is now learning Tanzanian Sign Language, as well as literacy, numeracy, and daily living skills. She has many friends and enjoys spending time with others. Recently, her mother has shown much more interest in Annika. She is no longer ashamed of her daughter. Traditional beliefs of being cursed, witchcraft, and taboos are slowly being replaced by a more positive attitude, as family and other members of the community are beginning to see Annika's abilities and progress at school. Parents' groups and networks can offer great support in overcoming barriers and combatting misconceptions. Just imagine how different it would have been if Annika's mother had a group of other mothers around her who had been through similar circumstances and experiences.

For Vikram's mother in India, it was a different story. She received a great deal of help and support from other parents, and this is what she says:

"Vikram is now a young man and as his mother I am very proud of his progress and his achievements. I think it is a must for parents to play an active role at school, and I would want all parents to form networks to help, support, and encourage each other in times of need."

[Back to top](#)

Part Two: Characteristics and Components of Education and Rehabilitation Programmes

5. General requirements

This section describes specific characteristics and components of high-quality education and rehabilitation programmes for individuals living with deafblindness. These recommendations are aligned with Article 24 (Education) of the UN CRPD. According to the Convention, every person, including those with disabilities, has a right to access an inclusive, quality, and free primary and secondary education in the communities in which they live. The Convention recognizes that some groups are at risk of exclusion. Persons living with deafblindness are one of those groups, as they require specific ways of learning that compensate for vision and hearing impairments.^{xiii} This highly specialized expertise might not be available in community settings. Therefore, "inclusion involves a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences".^{xiv}

On a practical level, persons living with deafblindness lack or have limited opportunities for incidental learning^{xv} – the type of learning that people with sight and hearing experience automatically and without effort, as they are exposed to a continual flow of visual and auditory information from the world around them.

Considerations

- 5.1 To make up for a lack of incidental learning opportunities, education and rehabilitation services should strongly emphasise real-life, meaningful activities that promote concept and skill development and enable the individual to be included in home and community life.
- 5.2 Teaching activities and materials should be age- and developmentally-appropriate and build upon the interests of the individual.
- 5.3 Most individuals living with deafblindness require one-to-one support for communication and to access learning and social environments.^{xvi}
- 5.4 Education and rehabilitation should reflect high expectations by teaching academic skills – particularly literacy and mathematics – as well as daily- and independent-living skills.

[Back to top](#)

6. Communication

Communication is the foundation of all learning and relationships. Important aspects of communication include not only a method of communication, but also reasons to communicate, partners with whom to communicate, and meaningful topics.^{xvii} The limitations imposed by deafblindness require that communication development be fully integrated throughout all education and rehabilitation experiences. Because of a lack of opportunity, children and youth living with deafblindness may not develop attachments and other important aspects of relationships that form the basis for communication development. Communication is complex, even for individuals who have formed relationships. It requires the availability of skilled communication partners who provide opportunities for the individual to express thoughts, feelings, interests, and questions, and participate in conversations.^{xviii}

Article 24 of the UN CRPD emphasizes that appropriate measures should be in place to maximize social and academic development and to ensure that education is delivered in the most appropriate languages and modes and means of communication for the person living with deafblindness.

“Once I knew only darkness and stillness... my life was without past or future... but a little word from the fingers of another fell into my hand that clutched at emptiness, and my heart leaped to the rapture of living.” (Helen Keller)

Considerations

- 6.1 A service provider must take all the time necessary to form a trusting relationship with a person living with deafblindness, as well as to foster relationships between the individual and others.
- 6.2 Educators and other professionals must have the knowledge and expertise needed to facilitate communication development for both pre-intentional and pre-symbolic communication, as well as for those with advanced levels of communication.
- 6.3 There are a variety of modes of communication (both non-verbal and verbal) that can be used. Families and service providers should be fluent in the specific modes that are most natural and appropriate for the persons with whom they interact.
- 6.4 Persons living with deafblindness should have access to communication and communication partners throughout the day. Sharing, choice-making, turn-taking, and other developmental and conceptual building blocks of communication should be included in every activity.
- 6.5 Because communication is ultimately about interaction as well as information exchange, attention should be paid to developing the pragmatic aspects of communication, such as initiation, conversation, and the use of social conventions such as greetings, questions, and how and when to shift or expand conversational topics.

Communication is a process between two or more individuals. These individuals take turns expressing and perceiving messages. Between them, meaning is created and negotiated so that both understand and are understood.^{xix}

People living with deafblindness face numerous communication challenges and obstacles. The main vehicle for communication is **language**, and language relies heavily on sight and hearing. Nevertheless, it is possible to communicate without the use of a formal language. Messages can be conveyed through touch, gestures, drama, pictures, and even sounds. All of these methods provide a good starting point for the introduction of formal language. Communication should be embedded across all activities of life and should be a priority in education.

Although the number of people living with deafblindness is relatively small, the variety of techniques and support systems for communication is extensive. The mode or modes of communication most appropriate for a particular individual depend on his or her level of hearing loss, type and severity of visual impairment, the time of onset of deafblindness, and his or her preferences.

Techniques based on signs

- visual sign language adapted to the visual loss;
- tactile sign language;
- haptic communication – a tactile system in which signs/signals are conveyed on the back, upper arm, back of the hand, or knee to provide contextual information that compliments signed or spoken language.

Techniques based on written language

- tactile manual alphabet – one-handed, two-handed, or Lorm (a specific tactile manual alphabet used in many German-speaking countries);
- braille using alphabet cards, finger-braille, or technical devices (e.g., electronic braille display);
- block printing of capital letters on the palm;
- Morse code;
- written information using normal or large print, or fonts enlarged on a computer screen or tablet.

Techniques based on speech

- oral language adapted according to the hearing loss;
- lip-reading;
- Tadoma method – tactile reception of movements of lips and larynx.



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Tactile fingerspelling on the palm



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Sign language in a small visual field



© CBM Joe Morrissey

Tactile sign language



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Finger-braille

[Back to top](#)

7. Social and emotional development

Closely intertwined with communication is the need to build relationships with each person living with deafblindness, and facilitate connections with family, peers, and others in their homes and communities. Without the opportunity to form meaningful relationships^{xx} based on mutual benefits and contributions, the person will not be able to distinguish other people from objects or tools in their environment. Furthermore, persons who lose a second distance sense after they have lost the first sense (e.g. a person who is initially hard of hearing or deaf and later develops a visual impairment) face isolation and emotional pain as a result of the limitations imposed by the dual sensory loss, and experience great frustration due to the need to modify known ways of communicating and functioning. They are at risk of developing mental health conditions, such as depression.

Considerations

Professionals and family members need to:

- 7.1 Foster the abilities of the person living with deafblindness to develop relationships.
- 7.2 Help other individuals in the person's life understand how to interact with him or her.
- 7.3 Thoughtfully develop social networks, by carefully orchestrating opportunities for the individual to meet with and interact with others.
- 7.4 Understand that persons with a single distance sensory loss, who are facing the loss of the second sense, must have access to mental health services. Their families and others in their social network may also benefit from these services, to gain knowledge of how best to support the individual as he or she adjusts to the loss.

[Back to top](#)

8. Holistic, person-centred assessment

Thorough assessment is essential to design effective education and rehabilitation programmes. Because different environments can either support or interfere with learning and functioning, assessments should be conducted in the home, school, work, or community settings in which the individual typically participates. Individuals' capacities are best revealed in the context of familiar activities and environments.^{xxi} Assessment is an on-going process to determine the current level of skills and abilities, monitor progress and evaluate the effectiveness of the intervention. Assessments can and should be carried out in a variety of ways using formal and informal tools including observations, rating scales, check-lists, work samples, interviews etc.

Considerations

8.1 Assessment processes must be designed to:

- a) create a clear picture of the person in his or her environment;
- b) answer specific questions that inform educational or rehabilitation planning;
- c) document the outcome of interventions.

8.2 Processes should include the family and others who know the person well.

8.3 Processes should take place in a variety of settings in which the individual being assessed commonly participates.

8.4 Processes should occur in the context of a variety of activities that are familiar to the individual being assessed.

8.5 Processes should be conducted by service providers with specific knowledge and skills in deafblindness.^{xxii}

[Back to top](#)

9. Concept development

Individuals with sight and hearing typically develop an understanding of concepts incidentally, through exposure to everyday life experiences. Because of limited access to incidental learning, however, persons living with deafblindness require systematic instruction of concepts.^{xxiii} The teaching of concepts (understanding characteristics of people, places, and things) often occurs in the context of teaching skills (the ability to do a task or activity), but concepts must be specifically taught. For example, an individual may be taught the skills needed to use particular objects for specific purposes, but it is also important to teach concepts related to those objects (e.g., objects are different from each other, have names, have specific uses, require care).

An understanding of concepts helps the person living with deafblindness to understand better the world around him or her, anticipate what will happen in the future, and build a sense of security.

Considerations

- 9.1 Provide concept instruction in the context of regular, everyday activities.
- 9.2 Engage the individual in all aspects of an activity, even if emphasis is placed on mastery of only a few steps at a time.
- 9.3 Within each activity, incorporate concepts and skills at the highest level possible. For example, one person might have the ability to determine the amount of change he or she can expect when paying for a purchase, while another might not be able to count change, but can participate by receiving the change (a cue that the transaction is finished).
- 9.4 Where necessary, provide adaptations or assistance for steps of an activity that the person cannot do independently. This allows the individual to participate in the whole activity. For example, when making an apple cake, the individual living with deafblindness may independently measure and put the ingredients into a bowl, but the instructor may need to use hand-under-hand touch to cut the apple. Being able to participate in all steps of an activity is essential for conceptual learning.
- 9.5 The environment should be arranged to provide information about how to participate in activities. For example, create labels (made from objects, pictures, or braille) and put them on items the person encounters in his or her surroundings.

Case Study

Mohammad, from Jordan, was born prematurely. He has a little light perception in one eye and has a severe hearing loss. He communicates through tactile Jordanian Sign Language. Mohammad joined the deafblind unit in a large school for the deaf at the age of eight. Not long after he enrolled, it became clear that he really enjoyed cooking. Cooking stimulates all the senses. Besides doing something with your hands, there are wonderful smells and the joy of tasting. Cooking became a weekly scheduled activity for Mohammad. He took part in the preparation of different dishes, from omelettes made with eggs he found in the chicken pen,



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to pancakes, cookies, cakes, and even special Ramadan sweets

Initially Mohammad would participate in gathering, tasting, and naming the different ingredients. He would then measure, combine, and mix them in a bowl. Over the years, he took on more responsibility. As the photograph shows, he became very good at breaking eggs into a mixing bowl. He has excellent orientation skills and knows where to find the cooking items and utensils he needs. The storage containers in the kitchen where he cooks have tactile labels. For example, because sugar is coarse, a square piece of coarse sandpaper was glued to the outside of the sugar container as a symbol for its contents. A piece of velvet was used as a symbol for the flour container, because flour has a fine, soft texture. Recipe boards were created on which Mohammad could 'read' what to do next. Over time, the boards were converted to pages with braille instructions. Together, they formed Mohammad's first tactile cookbook.

These days, he shares the activity of cooking with one of the younger deafblind students in his school. Mohammad knows how to give someone else a turn and to allow time for the other student to receive assistance from the teachers. He enjoys working with others, but the happiest moment of cooking for him will always be after all the work is done (including the dishes) and he sits down to enjoy the taste of what he created.

[Back to top](#)

10. Access to assistive devices, including alternative and augmentative communication

Meaningful participation in routines and environments requires that persons living with deafblindness have access to basic devices, ranging from calendar systems to low vision and amplification devices.^{xxiv} By providing information, a means of communication, and compensation for sensory losses, assistive devices give meaning to everyday activities, social interactions, and one's surroundings. Access to tools such as white canes and augmentative or alternative communication devices facilitate the person's functioning within the world around them. Even simple modifications to everyday objects and spaces have great value.

Considerations

- 10.1 Environmental adaptations and modifications should optimise the person's participation in home, school, and community settings and situations.
- 10.2 Determination of the most optimal adaptations and aids for each individual should be guided by a systematic assessment process.
- 10.3 If alternative and augmentative communication aids are used, these should be incorporated as just one part of a holistic approach to communication which takes into account different communication partners, contexts and situations.
- 10.4 The individual living with deafblindness, the family members, and service providers should receive instruction regarding how to care for and maintain adaptive aids such as hearing aids, low vision aids (optical and non-optical), and other assistive devices.



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Calendar system



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White cane



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Moveable desk lighting

Assistive Products rather than **Assistive Devices**: considerations for the future

Dr Martin Luther King once said 'I have a dream'. I would like to share with you my dream. In the future I would like us to use the term **assistive products** instead of **assistive devices**. Here I will explain why:

Services today (e.g., interpreter-guide, interveners for persons living with deafblindness, etc.) are generally left out of government-funded support programmes regarding assistive products, just because a service is not considered an assistive product. However, society is evolving constantly; transforming from one stage to another faster than ever before. Through these transformations we as members of society adopt new technologies and with it also new behaviour, new ways of interacting. We as society now view services as products, and products are delivered as services. This is the society we as persons with deafblindness interact with, and are promised inclusion in.

How does this transformation concern persons with deafblindness, and best practices for society to break the barriers created for their inclusion? Transformations in society dictate transformation in the way we accommodate for inclusion of persons living with deafblindness within society at large.

If we can include services as assistive products instead of additional, separate services as they are regarded now, we might have a better chance of obtaining funding for these services in the future through governmental support programmes. Having interpreters or interveners as part of a provision of assistive products would enable improved universal minimum standards to be set for such services. For interpreter-guides for persons living with deafblindness, these would include considerations for communication, mobility, attendance and participation regardless of where they might live and whether an interpreter-guide is needed for educational, social, leisure, or work-related activities. This would be in line with the transformations we see elsewhere in society today, where products are often perceived as services and services as products.

As President of the WFDB, my dream is that we will achieve this acknowledgment of interpreter-guide services as an assistive product, delivered by a professional, and hopefully public, service provider.
Geir Jensen (President WFDB)

[Back to top](#)

11. Advocacy and self-determination

Because deafblindness is a low-incidence disability, general understanding and awareness of deafblindness and how people living with deafblindness can access their rights, is often limited (or inaccurate).^{xxv}

Considerations

- 11.1 Decision-makers, professionals, families, and community members should be made aware of the rights and specific needs of persons living with deafblindness, as well as their achievements and valuable contributions to society.
- 11.2 With appropriate support, persons living with deafblindness can determine their own goals and actions, as well as advocate for change. The WFDB, the main disabled peoples' organisation (DPO) for persons with deafblindness and a member of IDA, was closely involved in the development of the UN CRPD.
- 11.3 Family members are vital partners in advocating for the rights of persons living with deafblindness.
- 11.4 In order to advocate for themselves, individuals living with deafblindness must have opportunities to learn about their own likes, dislikes, strengths, and needs; their bodies and emotions; and the demands and opportunities of the world around them.
- 11.5 Most importantly, they must have choices and options, and be able to communicate their preferences, requirements, and expectations.

Case Study



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Aravind is a teenager from Tamil Nadu, India. He has Congenital Rubella Syndrome and, as a result, has a profound hearing loss and severe vision loss. He communicates fluently using tactile sign language. Aravind is an ambitious person. He likes computers and wants to work in an office when he completes his studies. He is good in English, science, and mathematics, and is especially interested in doing Sudoku puzzles.

He has an excellent memory; he remembers all his peers' and teachers' birthdays. Recently, Aravind addressed a large group of parents and teachers during the State Meeting of Networks of parents and teachers of persons with deafblindness in Tamil Nadu. He has met the State Commissioner for Disabled and is happy that he can be a voice for many other boys, girls, young men, and young women with deafblindness. [Back to top](#)

12. Transition planning and on-going support

Transition to adult life is often the point at which persons living with deafblindness return to isolation and limited opportunities, despite having had education and vocational training. Because of the nature of deafblindness, on-going support continues to be required in adulthood, particularly in the areas of communication and medical services.

Considerations

- 12.1 Given the need for on-going support and communication, transition from childhood to adulthood must be thoughtfully planned and executed.^{xxvi}
- 12.2 Transition planning should begin in early childhood, so that the individual receives educational experiences that include preparation for adult life. It also requires that families, teachers, and the young person him- or herself, believe that all persons, regardless of their disabilities, can be contributing members of their community.
- 12.3 Planning for transition should be organised around the preferences and expectations of the person and of his or her family, taking advantage of opportunities within their community.
- 12.4 Preparing for transition includes building the individual's social networks and providing career and vocational learning opportunities. This will help to ensure that he or she has had sufficient opportunities to learn about potential livelihood options and to develop the types of relationships that will provide the support needed to function in adulthood.
- 12.5 The individual living with deafblindness should be at the centre of the transition planning process. With the individual at the centre, family and service providers can think more creatively about how to develop the person's potential and address his or her specific needs.
- 12.6 Same-age peers may also be included in development of a transition plan. They can help families and educators better understand the preferences and interests of the individual living with deafblindness.

Transition planning

A helpful and inspiring resource is the website (Perkins International):

www.TransitionPlanningAsia.org

The site is designed to be an interactive hub for teachers, families, and other caregivers to share ideas and questions about youth who are blind or visually impaired with additional disabilities (including deafblindness) as they leave school or prepare to enter more fully into community life.



It has basic information, tools, and resources, as well as places to share case studies, functional activities, and questions. People are encouraged to post their own suggestions, stories, photos, and videos. It specifically relates to the Asian context, but many ideas and suggestions could be adapted to fit other cultures and settings.

[Back to top](#)

13. Access to health and therapy services

Persons living with deafblindness often have complex health conditions associated with the cause of their deafblindness. The health of the visual and auditory systems also requires regular monitoring.

Considerations

- 13.1 Individuals living with deafblindness typically require regular medical evaluations to manage sensory conditions, prevent deterioration of any partial vision and hearing, and monitor their general health and well-being.
- 13.2 Because limitations in vision and hearing also limit the motivation and opportunity for physical movement, fine and gross motor development, physical strength and coordination may be impaired. Persons living with deafblindness require consultation and, at times, direct intervention from physical therapists to develop muscle tone and foster the development of coordination, muscle strength, and fine and gross motor skills.
- 13.3 Individuals typically experience a range of challenges to their remaining sensory systems, particularly their vestibular and kinaesthetic senses. These challenges affect balance, tolerance for tactile sensations, and the ability of the brain to integrate and process sensory input.^{xxvii} Consultation with and direct service from occupational therapists can provide assistance to:
 - a) understand and manage behaviours related to sensory integration (e.g., hitting, rocking, swaying, pressing parts of the body, or assuming odd postures);
 - b) optimise levels of arousal and attention.
- 13.4 Because one of the greatest challenges is development of communication, persons living with deafblindness and their service providers will also benefit from consultation with and direct services from speech, language, and audiology specialists to optimise speech, language, and audition and the use of auditory aids such as hearing devices and cochlear implants.

[Back to top](#)

Part Three: Improving and Expanding Services for Persons Living with Deafblindness

14. Personnel development and training

Deafblindness is a unique, complex disability and, as noted previously, the population of individuals living with deafblindness is extremely diverse, with each individual having specific characteristics, strengths, and needs. Consequently, personnel who work with this population need an array of knowledge and skills.^{xxviii}

Considerations

- 14.1 Educators, para-professionals, and support staff should receive specific training that enables them to address the unique educational and rehabilitation needs of individual girls, boys, women, and men living with deafblindness.
- 14.2 Service providers also require on-going training to further develop competency in a variety of key areas, including: assessment, communication development, communication-based positive behaviour support, social development, sensory development, sensory integration, instructional strategies, functional curriculum, individualised educational planning, transition to adult life, activities of daily living, vocational training, orientation and mobility, and inclusion. Staff should be encouraged to participate in conferences and other training events on relevant topics conducted in their country or region, as well as in-service training programmes.
- 14.3 The creation of regional and/or national centres of excellence would provide the expertise to demonstrate evidence-based effective practices and increase local capacity through training and assistance to education and rehabilitation programmes.

[Back to top](#)

15. Networking between stakeholders

Given the complexity of deafblindness and the uniqueness of each person living with deafblindness, it is crucial that service providers share their insights, knowledge, skills, and questions.^{xxix} When stakeholders (families, service providers, persons living with deafblindness) and organisations collaborate,^{xxx} they build 'collective expertise' that is much greater than that of any one person.

Considerations

- 15.1 Those working with persons living with deafblindness should systematically seek out and share knowledge and questions with others who have different perspectives and areas of expertise. This collaboration should occur during assessment, programme planning, implementation, and evaluation of the effectiveness of any care and intervention.
- 15.2 Systematic documentation of experiences and interactions with the individual needs to be in place, so that members of the team can learn from each other.
- 15.3 It is important that programmes, especially service providers, network with DPOs. Deafblind-specific DPOs are rare, especially in low-income areas, but other types of DPOs can be involved in programme planning and implementation of services for individuals living with deafblindness. Individuals living with deafblindness should have opportunities to participate in DPOs that provide support for an array of disabilities.

[Back to top](#)

16. Expansion of services

Despite increasing awareness of the needs and potential of persons living with deafblindness, support and specialist services are still woefully inadequate. As a relatively small population, with complex and diverse needs, they are often one of the 'last served'. Services to assist persons living with deafblindness are frequently the last to be developed, particularly in economies that struggle to meet the needs of persons without disabilities and those with single or mild disabilities.

Considerations

- 16.1 Governments and other duty bearers should partner to ensure that they develop the capacity to meet their responsibilities toward citizens living with deafblindness and their families.
- 16.2 In line with the principle of 'nothing about us, without us', persons living with deafblindness, their families, and community members must participate meaningfully in conceptualising and developing programmes that serve them.
- 16.3 On-going coordination and collaboration among all community sectors (e.g., health, education, rehabilitation) that provide or are developing programmes will serve to maximise resources and knowledge.
- 16.4 The range of options for persons living with deafblindness should be as diverse as that of the general population. Providers of education and rehabilitation programmes across the spectrum (for persons with or without disabilities) must be involved. In this way, the unique needs of persons living with deafblindness can be addressed effectively and efficiently, while taking advantage of existing resources and opportunities.
- 16.5 In areas where there are currently few or no services, informal education and CBR programmes can form a starting point for developing the knowledge, skills, and approaches required to meet the unique needs of persons living with deafblindness and their families.
- 16.6 Regions and countries should implement multiple levels of personnel preparation in deafblindness, including programme-based in-service training and pre-service training within universities and colleges. Personnel should include educators (including those who are deaf, blind, or deafblind themselves), rehabilitation specialists, interpreters, facilitators, and CBR staff. Additionally, specific knowledge and skills in deafblindness should be incorporated into the preparation of related service specialists such as occupational therapists, physiotherapists, speech and language therapists, orientation and mobility instructors, audiologists, and low vision specialists.

[Back to top](#)

17. Intersecting issues

As with any development programme, it is essential that programmes for people living with deafblindness address issues where disabilities intersect with other factors that may lead to discrimination or risk of abuse.

Considerations

- 17.1 **Gender:** Women and girls with disabilities, including those living with deafblindness, may face gender-based discrimination as a result of cultural attitudes and assumptions. In line with Articles 3 and 6 of the CRPD, programmes must ensure that girls and women living with deafblindness are able to access services on an equal basis with boys and men. The goal should be to ensure gender equity. For example, organisations should consider disaggregating data by gender and offer gender-awareness training. Separate toilets should be available for both sexes, and educators should stimulate equal participation of girls and boys in classroom activities.
- 17.2 **Safeguarding children and vulnerable adults:** Girls, boys, women, and men living with deafblindness are significantly more vulnerable to physical, emotional, and sexual abuse and neglect. They may have limited awareness and understanding of their right to privacy and freedom from abuse (Articles 16 and 22 of the CRPD). Additionally, limitations in expressive communication can reduce the likelihood of abuse being reported, which increases their vulnerability. Organisations must have clear safeguarding policies and procedures in place, with regular training opportunities to ensure that all personnel concerned are aware of the importance of safeguarding.
- 17.3 **Disaster risk reduction / preparedness:**^{xxxi} Persons living with deafblindness face much higher risks in situations of emergency or disaster. To reduce these risks, persons living with deafblindness should be included in disaster preparedness plans, for instance by mapping where they live, and working out the best ways of preparing for evacuation and for safeguarding during an emergency. Furthermore, when possible, persons living with deafblindness should be actively involved in making these plans, as they can offer valuable and specific insights.

[Back to top](#)

Useful resources

Websites

www.wfdb.eu

www.deafblindinternational.org

www.sense.org.uk

www.senseinternational.org.uk

www.senseintindia.org

www.nationaldb.org

www.perkins.org

www.perkins.org/international

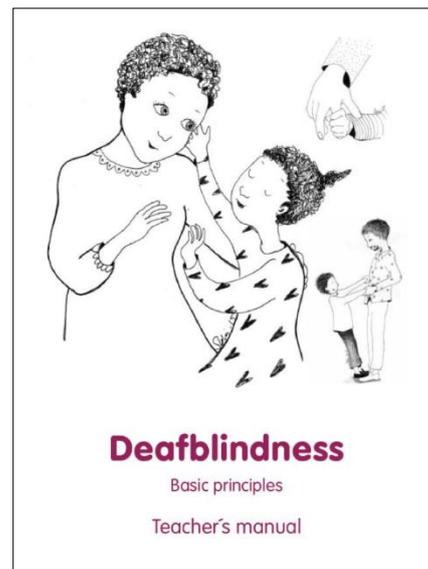
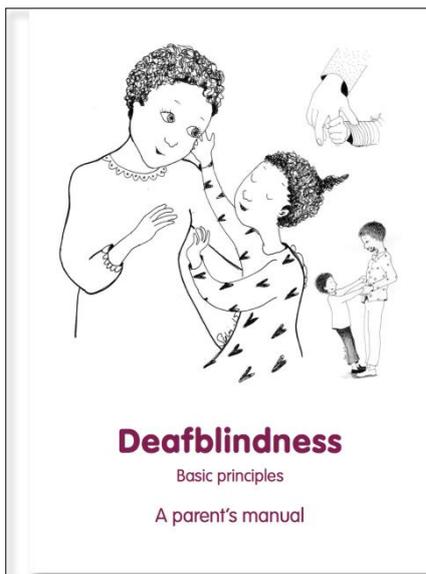
www.perkinselearning.org

www.pathstoliteracy.org

www.wonderbaby.org

www.chargesyndrome.org

Deafblindness. Basic Principles.



These books seek to turn something very complicated into an easy and accessible guide for everyone. They provide an overview of the basic principles for how to interact with persons with deafblindness.

They are aimed at parents, teachers, CBR workers, and other persons who work with families with children with deafblindness.

Deafblindness. Basic Principles. Parent's manual:

www.yumpu.com/en/document/view/55089246/deafblindness-basic-principles-a-parents-manual

Deafblindness. Basic Principles. Teacher's manual:

www.yumpu.com/en/document/view/56058213/deafblindness-basic-principles-teachers

[Back to top](#)

Glossary of terms and definitions

Hearing impairment

This is a generic term that includes both persons who are deaf or hard of hearing. It refers to any type, degree, or onset of hearing loss.

Profound hearing loss

A hearing impairment that is so severe that the person is unable to process linguistic information via hearing, with or without amplification.

Deaf

The term can refer to all persons with a hearing loss, however generally refers to the population of those with severe to profound hearing loss, or a person who sees him or herself as belonging to a linguistic minority communicating through sign language as part of a Deaf culture and community.

Hard of hearing

A hearing impairment that is less than profound, but affects the ability to apprehend sound. Many individuals who are hard of hearing can benefit from the use of hearing aids to access residual hearing, enabling the development of speech and communication.

Hearing aids

Small electronic devices worn in or behind in the ear that amplify sound.

Cochlear implant

A small, complex electronic device that can help to provide a sense of sound to a person who is profoundly deaf or who has a severe hearing loss. The implant consists of an external portion that sits behind the ear, and a second portion that is surgically placed in the inner ear. Unlike hearing aids, which make sounds louder, cochlear implants do the work of damaged parts of the inner ear (cochlea) to provide sound signals to the brain.

Visual impairment

This is a generic term including both blindness and low vision. It refers to any type or degree of vision loss.

Blindness

A person with blindness has complete lack of light perception (less than 3/60 or 20/400 in the better eye).

Low vision

A person with low vision uses, or is potentially able to use, vision for the planning or carrying out of a task, but has impairment of visual functioning even after

treatment and/or standard refractive correction. There is visual acuity of less than 6/18 (20/80) or a visual field of less than 10° diameter in his/her better eye.

Low vision devices

Low vision devices help to improve visual functioning of a person with low vision. They may be optical (e.g., magnifying glass) or non-optical (e.g., reading stand or a broad felt pen).

[Back to top](#)

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[Back to top](#)

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[Back to top](#)