

Guidelines on Best Practice for Service Provision to Deafblind People

At the Deafblind International World Conference in 1999 the following resolution was agreed:

"Deafblind International calls on national governments and international organizations throughout the world, when considering definitions of disability and descriptions of the categories of disability, to specifically recognise deafblindness. Deafblindness is a combination of visual and hearing impairment. Such recognition must be written into legislation - and should refer to the particular needs of deafblind people, which are different from the needs of people with a single sensory impairment."

Purpose

This document outlines Deafblind International's recommendations for service provision and is intended as a summative statement of the particular needs of deafblind people. It is intended as a set of guidelines for all those seeking to implement best practices for the population, including governments as well as public and private service providers.

This document aims to contribute to deafblind people receiving and achieving their human and civil rights. For deafblind people to have these rights met there will need to be recognition of deafblindness and access to specialized services and support. Deafblind International advocates that deafblindness should be recognized in legislation and policy at both the international and national levels.

Understanding deafblindness

Deafblindness is a unique disability. It means having both a hearing and a vision impairment that is severe enough to affect communication, mobility and access to information and the environment. Deafblind people may also have additional disabilities that are physical or cognitive. Only a small proportion of deafblind people are completely deaf and completely blind. As a result service planning and delivery requires appropriate responses or strategies.

A unique disability

Vision and hearing are the *two* main distance senses. They are vitally important for learning and communicating successfully, moving around with confidence and enjoying the company of others. The loss of one of the distance sense can usually be compensated for to some degree, by using the other as effectively as possible. For example: deaf people may use vision for communication by lip-reading or using sign language, and blind people may use hearing to undertake tasks that for most people involve using their vision e.g. enjoying a football match by listening to an audio description.

This is not possible for people with a dual loss where the impact is compounded. Even though a deafblind person may have some residual hearing or vision the combination of impairments has a disproportional effect on functioning.

Services designed to meet the needs of those with a single sensory loss will rarely be appropriate for a deafblind person unless the service is specifically modified to meet their individual needs.

Individual Differences in the Disability

Deafblind people are not a homogenous group. The common factor is a dual sensory impairment that gives rise to issues over access to information, communication and mobility.

Congenital Deafblindness is a description applied to people who are born with both hearing and visual impairments or became deafblind before developing language. A large majority of this population also have diverse degrees of intellectual impairment.

Acquired deafblindness applies to people who were blind and develop a hearing impairment after developing language; people who were hearing impaired and later developed a vision loss; and people who were sighted and hearing but have developed vision and hearing impairments from any number of causes including accident and old age.

Within these two broad groups there are many different specific aetiologies and causes.

Identification

Deafblind people are often seen as having a primary disability that is not deafblindness. They may be categorised as deaf or blind or intellectually impaired or learning disabled and may be receiving services or support designed for other disabled people e.g. many deafblind people may receive intellectual impairment / learning disability / mental retardation services. Often this does not meet their specific needs for communication and other instruction.

Some deafblind people do not see themselves fitting any “category” and, quite rightly, reject the term to describe themselves. For example:

- an older person who was sighted and hearing and is losing their vision and hearing. They may regard themselves as getting older and know their deterioration is an expected part of the ageing process that has to be accepted.
- a deaf sign language user who is part of the Deaf community and identifies himself or herself as a culturally deaf person who is losing their vision may regard himself or herself as a Deaf visually impaired person. They may not acknowledge their needs or may still feel their vision is adequate for their functioning.
- a person who has lost both vision and hearing from trauma will have little to no knowledge of deafness, blindness or deafblindness as a disability or of the specific services they would need. They have been part of the sighted and hearing world and are not familiar with services for persons with a disability.

This lack of acceptance of the term ‘deafblind’ may also be the position of family members and professionals.

If the deafblind person prefers a different terminology to “deafblind” then their preferred term should be used. However, this must not be allowed as an excuse to avoid meeting their needs that arise from their dual loss. To put this in another way, choice of language (or terminology or label) must not mean that specific specialist services are not available or are not offered.

Raising awareness through campaigning and advocacy

There is very little understanding amongst decision-makers about the needs of deafblind people, the services they require, and their potential contribution to society. Professionals also often have a lack of knowledge. This is partly because deafblindness is a very low incidence condition. Professionals in the medical, educational and social care fields all need to be made aware of the distinct disability of deafblindness and the resources and services that deafblind people need.

Similarly the general public have little awareness of deafblind people or their needs. Where there is some awareness there is likely to be an inaccurate understanding, based on their lack of experience, such as the perception that all deafblind people are like Helen Keller.

Increasing awareness of deafblindness requires use of images and descriptions of deafblind people that demonstrate both the deafblind person’s needs, including the need for support and services, and the value and achievement of deafblind people. There are dangers that deafblind people are presented as either objects of pity or as heroes overcoming massive obstacles. Images need to reflect the diversity within the deafblind population - from children to older people – from people in the mainstream of life to those who need significant support.

Many deafblind people and their families will not be aware of deafblindness as a concept and the adaptations and services that could make a difference to their lives. Many deafblind people and members of their families need increased awareness of deafblindness and the support that could be provided.

Deafblind people themselves will often be the leaders and advocates in raising awareness. They will need access to support in order to be able to raise awareness of deafblindness, needs and issues. Frequently family members will take this role and they too will need support.

However, a successful awareness raising campaign is likely to involve professionals and supporters as well as deafblind people and families. Inclusion of people who are congenital deafblind or deafblind with intellectual impairment is important in such campaigns.

Identifying deafblind people

If deafblind people are to achieve their rights and receive support that enables them to participate in their communities then deafblind people must be identified.

Where a locality or country maintains databases on disabilities then deafblindness should be a specific category.

Providers of specialist services need to know what disabilities the users of their services - or potential users - have. And if any of those users are deafblind, the service provider needs to know whether they and their staff can meet deafblind people's needs.

When a mainstream service aims to provide equal access for disabled people the service provider should have identified if they, and their staff, are capable of communicating directly with and serving people who are deafblind.

Identification should lead to deafblind people and families receiving information on possible assessment and support that may be available. Identification should lead to an assessment of needs.

Provision of information

Information should be provided in the preferred format of the deafblind person. This might be large print or Braille or another alternative to standard print. If this is not possible then as much information as possible should be provided through direct communication with the deafblind person in their preferred communication system. If the deafblind person has significant cognitive challenges, the information should be provided to the family as well.

When information is provided in an alternative format then the alternative format should be produced at the same time as the standard print format. This means

that a child in school should have access to materials at the same time as their peers and that a deafblind person should not be disadvantaged at a meeting or when attending a presentation.

Services – participation in service planning

Deafblind people need to be able to make decisions themselves and take the lead in decision-making about the services they receive. At the very least they should be able to participate in the decision making process. In order to do this most deafblind people will need support and may need to make use of a specialized service in order to participate in decisions about their service provision. If the deafblind person cannot make a decision, or needs support because of cognitive challenges, the family or an advocate should be involved.

Deafblind people will need opportunities to learn how to use and direct their services. There should be a presumption of capacity in decision making by the individual deafblind person and recognition that making a decision will require support for access to information and communication.

Some deafblind people will not have capacity over some decisions. In this circumstance a parent or other family members should have the right to be involved in decisions and / or an advocate who speaks from the position of the deafblind person.

Families will always play a major role in a deafblind adult's life. They may have a caring role and/or be involved in providing support and services to the deafblind person. Family members should be consulted about the planning of services and their involvement in the future.

Services - early diagnosis and intervention

Early diagnosis and intervention are needed for children and adults from birth to old age. For the deafblind baby, child, adult or older person, early support is critical. For the infant significant developmental delay can occur if opportunities for learning and development are missed. The consequences of a period of intense isolation without opportunities for communication and participation in community, school or social life will be devastating for the person, whatever their age, and for their family too.

Services – assessment and education / rehabilitation

A deafblind person must have an assessment of their needs as soon as possible after diagnosis. The assessment must be undertaken by a person with understanding of deafblindness who has been specifically trained to undertake an assessment of a deafblind child or deafblind adult. If an assessment is to be

undertaken by a multi-disciplinary team then at least one of the professionals must be someone who has been specifically trained to undertake an assessment of a deafblind person.

The assessment must consider how the person is operating in the real life situation including use of functional vision and hearing, access to information, communication, and mobility. The assessment should lead to opportunities for education, habilitation and rehabilitation, the development of new skills, access to specialized services including one-to-one support, inclusion in mainstream activities and access to aids and equipment that will meet the needs of a deafblind person.

Appropriate educational opportunities needs to be provided to both children and adults.

When one or more family members are involved significantly in a deafblind person's life and are providing support or services, the needs of the individual family members will need to be assessed. Consideration should be given to providing the family member with support such as advice, information, psychological support, access to support groups or networks, training, and provision of respite care such as breaks from caretaking responsibility.

Services – specialized services

A specialized approach is sometimes not valued by decisions makers but will be the choice of many deafblind people and families and may be the best way to meet needs. The value and importance of specialized services needs to be recognised as crucial in supporting deafblind people to join their community and mainstream life and assuring that they receive appropriate service delivery.

For hearing and sighted people, knowing where you are, experiencing your environment, understanding what is going on around you, knowing who is with you, communicating with other people, taking decisions and getting around are all taken for granted. Deafblind people need very specialized services to do all these everyday things. These specialized services can include use of technology but for most deafblind people regular support from other people will be their key to participation.

Services - one-to-one human support

Deafblind people want to be part of their communities. To do this they need support from another individual who acts as an information provider, communication channel and guide. Nearly every deafblind person needs such services.

Human support services will need to be tailored to the needs of the individual person and to the cultures, education and care structures within a particular

society. However all societies will need to recognise that exceptional or different ways and means will need to be found to meet the needs of deafblind people and give them full rights as citizens. Those ways and means will need to include provision of one-to-one human support or an intensive staff ratio in a way that fits with social structures and resources.

Different types of services have been developed in countries to meet the needs of different groups of deafblind people in different situations. (See Appendix 1) People who are deafblind are often not aware of the support services that could be provided and will need an understanding of the limits of any service provision.

Part of the provision of services will need to be the development of training programmes for the people who provide human support services, and the adoption of service standards and agreed levels of competency.

Opportunities to communicate and for social relationships

Deafblind people often remark that they feel isolated and excluded. Group situations are challenging unless the groups are appropriately structured and managed. One-to-one communication will usually be the preferred and most effective interpersonal communication for a deafblind person. This will allow for participation both at an individual level and in a group situation.

Deafblind communication takes longer and this must be taken into account when decisions are made about allocating resources to services.

The communication methods that deafblind people use may not be well known or easily available to everyone. There can be significant benefit for deafblind people to have regular opportunities to get together with other people who use the same communication methods. Because of this a deafblind person may prefer to be with other deafblind people who use similar communication methods. As deafblindness is such a low incidence disability meeting this need may be achievable through regional or specialized programs, peer support groups or associations of the deafblind, rather than a local service.

Deafblind people can be good role models and mentors for other deafblind people. Training and support should be provided to facilitate this. Deafblind people can offer support in a way that others, without the experience, can never do.

Family life

Deafblind people will be involved in family life as a child, brother or sister, parent and/or grandparent. Specialized support and services will usually need to be provided in a way that takes account of these relationships. For example the family will need to be able to communicate with the deafblind member of the

family. So communication skills training will need to be provided for family members as well as for the deafblind person.

Deafblind people may be married and have children. They will then need access to services in order to be able to be partners and parents e.g. eg the meetings that all parents attend in relation to their children, at school, college, special events and medical related matters.

Members of the family will always play a significant role in supporting the deafblind person. They will need access to personal support and respite or breaks from their caring responsibilities.

Adaptations and equipment

The environment is often a barrier to access for deafblind people. Modifications such as good lighting and a reduction in background noise may mean that residual vision and hearing can be used. Modifications such as use of contrasting colours, tactile information on the floor and clear signage or tactile signage can enable people to be more mobile and feel safe in an environment.

Public buildings can be particularly restrictive when glass, mirrored or chrome surfaces cannot easily be seen and marble and some other surfaces encourage glare.

Receptions and public meeting rooms should be designed to give good access. In many countries this should include provision of induction loops.

Design of household and kitchen equipment should be as inclusive as possible.

Design of specialized equipment should be as inclusive as possible. In designing aids for blind people or for deaf people consideration should be given to whether the design could meet the needs of deafblind people.

Some specialized equipment will need to be designed specifically for deafblind people. This may require collaboration between countries for a product to have a sufficiently large market for the economics to be viable and the price to be acceptable.

Deafblind people will need access to specialized equipment and training to use and maintain that equipment in order to have equal access to opportunities. Specialized equipment can range from simple and cheap modifications to equipment to expensive hardware and software for computers e.g. Braille displays.

Specialized equipment and support at work, should preferably be provided or funded by the state or a non-government organisation in order to reduce

discrimination against potential deafblind employees. In other words it should not cost an employer more to employ a deafblind person.

Deafblind people will need access to advice over provision of equipment and how to install, use and maintain it. They will need training and ongoing support including assistance when something breaks or no longer works.

In some countries a red and white cane signifies that the person using the cane to aid their mobility is a deafblind person. In these countries it is useful for the general public to be aware that “red and white” means deafblind. Inclusion of questions about this within driving tests can make a significant difference to awareness.

Training staff

Deafblind people should receive rehabilitation services and support services provided by people who are aware of deafblindness and have received specific training to meet the needs of deafblind people.

This training will need to include meeting and working with a number of deafblind people. Given the low incidence of deafblindness this may be achieved through the development of national or regional centres of excellence.

Managers and directors of services will need awareness of deafblindness and a senior manager should have responsibility for ensuring that deafblind people’s needs are met.

A range of opportunities for training and gaining qualifications related to deafblindness at different levels should to be available for managers, teachers, assessors / evaluators, support workers and interpreters.

Co-operation between countries could be considered as a way of developing this range of opportunities.

Service Aims

In many countries services and support is designed to enable the deafblind person to participate in family and community life and to contribute economically. This involves supporting the individual to make choices, take decisions about their lives, and develop their own lifestyles. This will require a person centred approach with the focus on the individual.

A service plan must be individualized to meet the needs of the deafblind person and their family.

Deafblind people will require the support of others to be active participants in their society. However this “dependency” should not be viewed negatively as the provision of this support enables a meaningful life. In fact, whether at work, home or out with friends personal support of some kind will be essential in order to maximise full participation.

Specialized equipment has made huge difference to deafblind people in many countries where access to technology is available and affordable. Shopping, reading mail, and visiting the doctor are just a few of the every day things that can be tackled more easily. In the workplace technological developments have made a huge difference to deafblind people but always in conjunction with human support.

Specialized services

The unique nature and different needs of deafblind people are often overlooked, and not met. In a mainstreamed/ generic /non-specialized service the needs of deafblind people will need to be addressed separately. Different and specialist approaches will be required in order to access mainstream services. For example, the provision of one-to-one communication support for a deafblind child may enable that child to participate in an inclusive youth club with other children. Deafblind people benefit from a predictable environment that is not constantly changing as it enables them to be independently mobile and use the resources within the environment confidently. People will also benefit from meetings and activities geared to their needs – for example slower and more basic use of language and time for communication support to be used successfully.

Deafblind people will often benefit from an environment where other people use the same language or communication system. For example people who use sign language may want to live with others who they can communicate with easily.

Some deafblind people will be frail or particularly vulnerable and may need an environment that significantly reduces risk.

A specialized service should be available for an individual if that option is a positive choice and best meets the person’s needs. Such a service should not be regarded as the option only if all other approaches have failed. Choices should be available.

Quality of services

Good quality support is achieved in countries where there are very different levels of resources available. Specific culturally appropriate ways can be found to meet the needs of deafblind people. However all quality support and services for deafblind people depend on an understanding of deafblindness,

identification of deafblind people, early intervention, overcoming isolation, provision of some one-to-one support and opportunities for communication and participation. They will also depend on suitable resourcing. The development of standards related to quality services has assisted in developing a baseline of support in some countries.

Minority Ethnic and Language Groups

Wherever they are in the world, some deafblind people will be included within minority cultural groups of that locale. Particular attention will need to be paid to ensuring that members of minority groups are not excluded from support or services. Members of minority groups will often have additional difficulties over access to information.

Services need to be adjusted to meet cultural and religious needs. To provide such a service will require consultation and involvement of people from the respective minority groups.

Guidelines on Best Practice for Service Provision to Deafblind People

Recommendations for Service Planners and Providers

Deafblindness is a unique disability. It means having both a hearing impairment and a visual impairment that is severe enough to affect communication, mobility and access to information and the environment. A deafblind person may have some residual hearing or vision or both but the combination of impairments has a disproportional affect on living and learning. The impact of the dual loss is very significant. In addition, many deafblind people have additional or multiple disabilities and health needs.

Deafblind people are often the most isolated disabled people and are excluded from participation in mainstream activity. Their needs are often marginalised, not prioritised and not met. If deafblind people are to have full human rights then there must be specific planning to address their needs and services that enable their access and participation:

- deafblindness should be recognised as a category of sensory impairment
- plans to identify deafblind people should be put in place and each person should be offered accessible information and an appropriate functional assessment of their needs for support
- assessments should be undertaken by someone who is specifically trained to assess deafblind people
- issues of work force development to increase specialist knowledge and practice about deafblindness should be addressed
- awareness training activities should be available
- the needs of deafblind people need to be *specifically* addressed when planning services and providing support to disabled people.
- specialised services should be developed and should be perceived as a valued element of a spectrum of services that are available to the individual and their family. These should include the use of technological solutions and human support
- the deafblind person and what he/she wants should be at the heart of service planning and provision. There should be recognition that they will need specialist support to participate fully
- families should be fully involved and will be the key to supporting infants children and young people as well as adult family members
- Communication support (one-to one) should be developed and available

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Appendix

The roles of human support service providers – examples from DbI members

In some countries different types of services have been developed to meet the needs of different sub-groups of deafblind people and different situations. The staff or volunteers may be known by different names and this can reflect variations in duties and differences between services but there will also be many similarities. However sometimes the same name is used but there are still some different principles in place and variations in duties to be undertaken. Some of these differences are now outlined but, more importantly, some of the common themes are identified.

Deafblind people having the decision making right is a principle in the work of **interpreter-guides**, **Support Service Providers (SSP)** (for example in the USA), **Intervenors** (for example in Canada) and **communicator guides** (for example in the UK). An SSP, an Intervenor and a communicator guide each provide support in a variety of situations, provide environmental information, facilitate communication and support mobility.

An “**SSP** is a person who provides for communication and mobility needs. In general SSPs are expected to have at least moderate fluency in American Sign Language. Some SSPs are skilled interpreters who include interpreting as a part of their responsibilities while others are student interpreters who do everything except interpret.”

A **communicator-guide** may or may not be able to sign. They need particular skills in order to be able to work with particular people. A communicator guide working only with an older person who uses speech or tactile communication of letters (finger spelling or manual or Block) to communicate will not need skills in hands on sign language. A communicator guide working with a Deaf sign language user who now needs to receive communications in tactile form or “hands on” will need to be a sign language interpreter who has additional skills and experience in tactile communication and an understanding of the needs of the particular individual.

An **Intervenor**, not unlike the SSP, facilitates the interaction of a person who is deafblind with other people and the environment. The Intervenor provides information about the environment and what is happening (using receptive language), assists the individual who is deafblind to communicate (using expressive language), provides or develops concepts where necessary, confirms actions, assists with life skills and most importantly, assists the individual to achieve as much independence as possible within their situation. The Intervenor takes direction from the individual who is deafblind. They are expected to become proficient in the mode of communication of the person they are working with e.g. American Sign Language, Signed English, Two-Handed Manual, Oral, Fingerspelling, Print on Palm, Object Cues, etc.. The concept of intervention and

the role of the Intervenor was developed in Canada but is now also used in some other countries. Intervenors in other countries may have a slightly different role, job description and level of training to Intervenors in Canada.

Alternatively a Deaf sign language user who because of visual impairment needs to receive communications in tactile form or “hands on” may be supported by a non-oral Deaf sign language user. When interpretation of spoken language is then required, a speech to sign interpreter will be required to interpret for the supporter (the supporter being a Deaf “relay interpreter” who communicates “hands on” with the deafblind person).

Different courses for people providing one-to-one support will be needed depending on whether a person will work with any deafblind person or only specific deafblind people. In the UK there are different “externally verified qualifications” for a support worker, intervenor, and communicator guide, and training for communicator guides or interpreter guides using British Sign Language in a restricted visual frame or hands on is under development. Apart from the intervenor training, these are externally verified within a coherent framework and can contribute to a Deafblind Certificate and Diploma at university level.

In some countries different people provide the communication support and guiding. For example in Sweden a deafblind person can make use of both interpreters and a guide in order to be able to attend and participate in a conference.

It can be argued that all deafblind interpreters must be prepared to also be guides. The critical issue is that deafblind people need “interpreters” and “guides” and need access to information while being guided. Different service systems can provide these in different ways but both need to be provided. So, interpreters not guiding may be acceptable, provided guides are also available.

Sign language interpreters sometimes do not provide the extra considerations required for working with persons who are deafblind. They are trained to interpret but are not usually trained to alter the communication to meet individual needs of deafblind people e.g. move to tactile communication if the lighting changes and causes a problem or modify language to accommodate the individual’s level of understanding. Trained Intervenors with interpretation skills in the client preferred communication system(s) will have the guiding skills required. There should be specialist interpreters with guiding skills available for deafblind people.

A deafblind child or adult involved in an education or developmental program should receive support from a person working one-to-one with them whose role includes enabling participation in the programme. In some countries¹ this task of providing such support is called intervention and the person providing the support

¹ Intervenors in Canada have a much greater role than this paragraph implies.

is an Intervenor. In other countries persons providing such support might be called teacher aides, teacher's assistants or paraprofessionals.

In a school setting it is not always appropriate for a child to have one-to-one support. Here the individualization of the curriculum is essential. Children need to learn to work in a group and participate with their peers. The deafblind learner typically needs an intensive level of direct teaching, comprising of a mix of individual and small group instruction as determined by a comprehensive assessment of needs.

**Produced by
Deafblind International**

Our address

Deafblind International Secretariat
Post box # 9601, Janakpuri
New Delhi - 110085, INDIA.

Telefax: +91-11-25618430

Email: secretariat@deafblindinternational.org

Available at

www.deafblindinternational.org.uk