

Handout: People who are deafblind

Introduction

People are regarded as deafblind “if their combined sight and hearing impairment causes difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss”¹.

Local authorities must ensure that an expert in deafblindness is involved in the assessment of adults who are deafblind, including where a deafblind person is carrying out a supported self-assessment jointly with the authority. During an assessment if there is the appearance of both sensory impairments, even if, when taken separately, each sensory impairment appears relatively mild, the assessor must consider whether the person is deafblind as defined above.

The assessment process starts from first contact, which means that to comply with the requirement for a specialist assessor for deafblind people, all those involved in assessment, including first contact teams, need to be able to identify the signs of dual sensory loss and know how to refer for a specialist assessment.

Specialist Assessment

This specialist assessment must be carried out by an assessor or team that has specific training of at least QCF or OCN level 3, or above where the person has higher or more complex needs. Training and expertise should in particular include; communication, one-to-one human contact, social interaction and emotional wellbeing, support with mobility, assistive technology and rehabilitation. The type and degree of specialism required should be judged on a case by case basis, according to the extent of the person’s condition and their communication needs. Local authorities should also recognise that deafblindness is a dual sensory condition which requires a knowledge and understanding of the two respective conditions in unison, which cannot be replicated by taking an individual approach to both senses.

Local authorities should recognise that adults may not define themselves as deafblind. Instead they may describe their vision and hearing loss in terms which indicate that they have significant difficulty in their day-to-day lives. The assessment should therefore take the initiative to establish maximum possible communication with the adult to ensure that individuals are as fully engaged as possible and have the opportunity to express their wishes and desired outcomes. This is particularly important where the person is carrying out a supported self-assessment jointly with

¹ Department of Health (1997) Think Dual Sensory: Good practice guidelines for older people with dual sensory loss

the local authority. The person ensuring that the self-assessment is a complete and accurate reflection of needs must have specific training and expertise that will enable maximum possible communication and an accurate and complete assessment.

Whilst the person carrying out the assessment must have the suitable training and expertise, it may not be possible for them to carry out the assessment without an interpreter, for instance where the adult uses sign language. Therefore, where necessary a qualified interpreter with training appropriate for the deafblind adult's communication should be used. It is not normally appropriate to use a family member or carer as an interpreter, though sometimes this is appropriate, for instance where the adult's communication is idiosyncratic or personal to them and would only be understood by those close to them. This should only take place where the adult agrees or – if they lack capacity – where it is in their best interests.

The assessment should take into account both the current and future needs of the person being assessed, particularly where the adult's deafblindness is at risk of deteriorating. In such cases the adult may benefit from learning alternative forms of communication before their condition has deteriorated to a point where their current or preferred form of communication is no longer suitable.

Recognising deafblind people

People with dual sensory impairment in contact with social services may not be recognised as being deafblind. This can be because an initial assessment was carried out when only one sense was impaired or because both senses have deteriorated since the care package has started. Other impairments (such as a learning disability) may 'mask' the deafblindness. Many people may answer “no” to questions such as “Do you have a sensory loss?” because this is not how they view their experience. This is particularly true of older people.

A particular approach for helping non-specialists recognise and understand the impact of deafblindness is to provide a set of descriptors, one for people born deafblind and the other for those who acquire the disability. The following descriptors are taken from the statutory guidance Care for Deafblind Children and Adults.

Congenital deafblindness

People who are born with hearing and sight impairment may display any of the following characteristics:

- no response to sound and/or light or little/poor response
- tactile defensiveness - avoiding touch (children - especially younger children)
- problems with eye contact/social participation at an early age

- slowness in developing and generalising skills (children)
- adopting an unusual posture for undertaking tasks - using residual hearing or sight eccentrically (children)
- difficulty making sense of the world around them
- developmental delay
- personalised methods of communication
- repetitive behaviour
- behaviour likely to harm themselves or others
- withdrawal/isolation
- use of smell, taste, touch to gain information

Acquired deafblindness

People who acquire a hearing and sight impairment later in life may display any combination of the following characteristics:

hearing

- Non-response when you speak from behind
- Need for the television/radio/stereo to be louder than is comfortable for others
- Difficulty following speech with unfamiliar people or accents
- Difficulty following changes of speaker during conversation
- Lack of awareness of noises outside immediate environment, e.g. building works, traffic noise
- Tendency to withdraw from social interaction
- Use of hearing aids, loop system etc.
- Complaints that everyone mumbles or speaks too quickly

vision

- Need for additional lighting
- Lack of awareness that you have changed position
- Inability to find things when placed in unfamiliar position
- Clumsiness
- Unusual use of touch to support mobility or task
- Difficulties caused by changes in light levels
- Difficulties with unfamiliar routes of places
- Difficulty recognising someone they know until they introduce themselves
- Difficulties with television and newspapers
- Unusual eye contact