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**Cross Party Group on Deafness**

**Deafblind Scotland: Defining Deafblindness**

**Background to deafblindness**

Deafblindness is the combined loss of both vision and hearing. For some people this may be a complete sensory loss whilst for others there may be some residual sight or hearing that can be used. Deafblindness has been described in a number of ways but in understanding the impact on people’s lives it is important that it is not viewed in terms of two single sensory losses as this uniquely disabling condition is greater than the sum of its parts. When an individual experiences a single sensory loss or are Deaf from birth they often cope by making the best use of their other senses however, with a dual sensory loss this coping strategy becomes less effective. Around three quarters of all deafblind people are older and have acquired deafblindness as they age. This is a heterogeneous group of people with each individual’s journey to deafblindness being unique. Currently within Scotland there is no consensus on a clinical definition of deafblindness or a definition recognised in Scottish legislation. In the absence of this a commonly adopted definition is that deafblindness is ‘a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability’[[1]](#endnote-1) <https://nordicwelfare.org/en/disability-issues/the-deafblind-field/> This combination of sensory losses has been described as resulting in significant difficulties in areas of everyday life, including:-

* accessing information and learning resources and opportunities;
* mobility and navigating the physical environment; and
* Communicating and building and maintaining relationships.

The age of onset of a person’s visual and hearing loss (or Deafness) can have a profound impact on the consequences of deafblindness. This is particularly the case in relation to communication and language development. It is therefore important to distinguish between:-

* Congenital deafblindness – where a child is born Deaf with sight loss or where a child acquires hearing loss and sight loss before the development of language. Occurring at a pre-lingual stage this form of deafblindness requires the child to develop language whilst deafblind.
* Acquired deafblindness – where vision and/or hearing loss is acquired during the course of life following language development, where language maintenance or adaption is the focus. An individual may have one sensory loss and acquire a second during their life or both senses may deteriorate across life.
* Usher Syndrome – is a genetic condition which causes hearing loss from birth, and a progressive loss of vision due to Retinitis Pigmentosa (RP) in adult life.
* CHARGE – is a genetic condition. Most people with CHARGE will develop hearing and sight loss and balance problems, along with life-limiting medical conditions from birth.

**Prevalence of deafblindness**

As there is no agreed clinical criteria or thresholds for assessing when someone may be considered to be deafblind, the numbers of people affected are often underestimated leading to many people who experience severe difficulty with communication, information and mobility due to a dual sensory loss not being identified. Historically figures as low as 5,000 people in Scotland have been cited. Furthermore, international research <https://senseinternational.org.uk/what-we-do/understanding-deafblindness/data-on-deafblindness/>] would indicate that this figure is artificially low with estimates of at least 0.2% of a global population experiencing Deafblindness and that developed nations such as Scotland should expect to see between 0.3% (based on Ireland) and 0.8% (USA) of the population being considered deafblind when applying the Nordic definition. In Scotland that would equate to between 16,000 and 43,000 affected people. The Centre for Disability estimates that deafblindness levels in Scotland would sit somewhere around 12,800 in 2019 for those with the severest levels of dual sensory loss and 34,000 for people who may still have difficulties with communication, mobility and information as previously set out. These estimates suggest a rise to between 17,500 and 37,500 in 2024 <http://www.wfdb.eu/wp-content/uploads/2019/04/WFDB-global-report-2018.pdf>. In the absence of agreed diagnostic thresholds this remains an estimate but based on international research this seems a realistic albeit wide prevalence range. It is also of course a disability that will grow if the population continues to age with men experiencing higher rates of the most severe deafblindness. More research is needed to establish greater accuracy of prevalence rates, however, there is work underway as part of a partnership research project that Deafblind Scotland is engaged with through the National Sensory Hub that is applying mathematical modelling to create an estimate of deafblind prevalence rates. This form of modelling is applied to good effect in other age-related disease process and should provide the most accurate estimate of deafblindness in Scotland to date.

**Defining Deafblindness**

As previously set out Scotland does not have a definition of deafblindness that is either agreed by clinicians or a social model definition of deafblindness that has legal support. In this absence those working with people who have a dual sensory loss tend to default to the Nordic definition of deafblindness as this has been adopted by the World Federation of Deafblindness and the World Health Organisation. This definition is based on the social model of disability. However, it is important to note that in the absence of an agreed clinical threshold we have not seen the development of clinical specialities such as can be seen in other areas of complex disability. Across the UK in 1995 the Department of Health established a legal definition of deafblindness ‘A person is regarded as deafblind if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility. This includes people with progressive sight and hearing loss’. This legal definition became incorporated in the Department of Health’s Deafblind Guidance in 2014 <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/388198/Care_and_Support_for_Deafblind_Children_and_Adults_Policy_Guidance_12_12_14_FINAL.pdf>. Local authorities in England and Wales now have a responsibility to follow the requirements of the Deafblind Guidance. This means that if you have a combined sight and hearing loss and live in England and Wales there is an entitlement to an assessment under the Department of Health’s guidance. This also requires that the person carrying out the assessment must have knowledge of deafblindness to CQF level 3 or beyond. Although similar health guidance exists in Scotland as outlined later in this paper in the absence of any legal definition being incorporated into health or social care legislation in Scotland the guidance is placed more as best practice than a right.

**The Problem of identity and identification**

There exists Scottish sensory loss policy and practice guidance related to people in receipt of community care <https://www.sehd.scot.nhs.uk/mels/HDL2007_20.pdf> which identifies specific action that local authorities and their partners should adopt to meet the needs of people with a sensory loss, including identifying needs. There is however, a significant implementation gap with Deafblind Scotland frequently being made aware of people with a dual sensory loss at a impactful level that have not been identified by public services as having a support need. The case study of Ms J in Box 1 is only one example.

Furthermore, few people with dual sensory loss would self-identify as being ‘deafblind’ this is mainly due to a gradual onset which presents difficulties in identifying for oneself when the problem of sensory losses have become so compounded that they have reached a level or threshold that could be framed as deafblindness. Deafblind Scotland have worked with partners within the National Sensory Hub and NRS to try to ensure that the 2022 National Census may encourage people to identify themselves by ticking the box of sight loss and the box of hearing loss. This should provide another route to building a clearer picture of the numbers of people living with this dual sensory loss as few people would be likely to tick a box asking if they were ‘deafblind’. A terminology problem we have tested with our own Deafblind Scotland membership. This problem of under identification also plays out in a similar way within services that are in a position to refer people to or assess their eligibility for specialist deafblind support. Through our work as one of the 4 BSL partnership members funded to support the implementation of the BSL National Plan, we know that public services also do not feel confident in identifying when someone is deafblind. Again, this appears to be due to not being clear on the threshold for diagnosis of deafblindness. We worked to mitigate this through the provision of Deafblind Awareness and Equality training as part of this BSL Plan implementation programme. It became evident within this work that there was a need to focus not only on raising awareness of sensory loss but also providing practical skills, giving service providers the confidence to identify people and thereafter to act to secure appropriate services for them. In the absence of a clinical or legal definition of deafblindness, services are likely to continue to struggle to test when threshold for deafblindness and specialist support has been met.

Box 1.

Case study Ms J – Glasgow

During lockdown last year, we received a hand-written letter from a woman in her 80’s living on her own, unable to leave her bed due to physical health problems. She told us that she had a Care at Home service providing for her personal care needs and communicates with them through writing information on a white board. She had no access to technology or a mobile phone. During lockdown she had no way of contacting her family.  *Never learned any gadget at all.  Never thought I would lose hearing after losing my sight. Is there any more people like me?  I am so scared and frightened and frightened.’* After receiving this letter, we sent a specialist Guide Communicator to visit Ms J and found that she did not have any alternative communication skills other than speech but had some central vision. As a result, we were able to support her, to send an email to her sister using a synaptic tablet. Over the subsequent weeks despite not being in receipt of local authority funding for communication support we were able to provide a regular Guide Communicator through short term project funding as part of our Wellbeing Project. This enabled her to learn to use the tablet independently, but we were also able to teach her and some of her regular carers some basic BSL. She now face-times her sister regularly.

**Absence of understood rights**

Currently within the United Nations Convention on the Rights of People with Disabilities and within the Equality Act (1998) the definition of disability is that you are considered as having a disability ‘if you have a physical or mental impairment’ that has a ‘substantial’ and ‘long-term negative effect on your ability to do normal daily activities’. Now that congenital deafblindness is rarer due to the reduction of the incidence of measles then the majority of people acquire deafblindness across life. For some this is part of the condition Ushers Syndrome but for the larger number deafblindness sets in as they grow older through gradual loss of hearing and diseases or long term conditions such as diabetic eye disorders and macular degeneration. Most people experiencing deafblindness would also not view themselves as having a physical disability as they often acquire this as the result of a what they would consider to be part of the ageing process. An unintended consequence of the absence of a legal definition of deafblindness is that disability movements calling on public bodies to protect the rights of people with disabilities do not always include the voices of people with sensory loss and seldom deafblindness as they may not be understood as living with a physical disability even within the disability movement. As a result physical access and equality is often the focus rather than sensory equality where residual sight or hearing are maximised or where spaces are developed that take account of the importance use of other sensory stimuli such as tactile, haptic and kinaesthetic. One welcome development is that one of the proposals within the Review of the Public Sector Equality Duty is the proposal to specify a duty to provide inclusive communication access. If adopted this should enhance the rights of people with dual sensory loss in relation to the provision of communication support potentially preventing others from sharing the experience of Ms J.

**The impact on access to services**

Even as far back as the Government’s 2007 guidance for Community Care Services for people with sensory loss, this issue of lack of identification of deafblind people was recognised where it was noted that most deafblind people are ‘elderly and that their dual sensory loss is unrecognised’. In this guidance a number of actions aimed at improving this situation were outlined such as:

* Identifying, making contact with and keeping a record of people with dual sensory loss
* Ensuring assessments are carried out by specially trained and qualified workers equipped to assess the needs of dual sensory loss
* Ensuring services are equipped to meet the needs of deafblind people through the introduction of effective standards.
* Promoting inclusion through information in accessible formats and methods
* Awareness training to increase knowledge of frontline staff.

There has been some progress in a number of these areas such as sensory loss teams within HSCPs and some frontline staff training progressed through our work with the BSL National Plan and through actions undertaken as part of the See Hear Strategy. However, with the exception of a few notable areas assessments of needs are most often undertaken by staff who have no awareness, knowledge or skills related to engaging deafblind people. Provision of accessible formats for deafblind people also remain rare. This was evidenced within our survey of public services where the majority said these accessible formats for deafblind people were not available. Again a lack of agreed definition of deafblindness that is incorporated in legislation or within other statutory instruments remains problematic and where some gains have been made in single sensory loss this is not the case for the deafblind community who are most often older and therefore under represented within key policy or service developments. A notable and welcome exception to this is the BSL (Scotland) Act 2015, where deafblind Tactile BSL Users have their rights acknowledged although this only accounts for less than 10% of Deafblind people. .

One example is the NHS MEL (1998) 4 guidance <https://www.sehd.scot.nhs.uk/mels/1998_04.pdf> which requires chief executives and managers in all NHS boards to put arrangements in place to make sure that deafblind people have the service of a guide communicator when they attend hospital or a GP surgery. Only two NHS Boards Inn Greater Glasgow and Clyde and Lanarkshire make provision for this.

A critical point of note is that without identification and at an early stage then transitioning from a single sensory loss to a dual sensory loss can be traumatic and cause significant problems in building skills that would support transition. This lack of early identification can leave people when they go on to have significant dual sensory loss with virtually no alternative methods of communication creating profound loneliness, stress and a very limited and poor quality of life. Failing to identify transition to a second sensory loss upstream can also be in part why we see such levels of distress and depression in deafblind people. More research is needed but it is clear from research already undertaken that there is a three-fold risk of depression. One of our members described her life ‘like being locked in a cupboard with a door only opening when a Guide Communicator walked through’..

**A Proposed Way Forward**

We would propose that Scotland needs to use some of the current legislative developments to define deafblindness, such as recognition as a unique disability within the wider definition of Disability adopted as part of the emerging Scottish Human Rights Act. This will help drive the adoption of rights-based guidance that fully brings to life the intent of the Scottish Government’s 2007 guidance. This would support identification of people with a dual sensory loss at the earliest point of transition and establish the right to an assessment by a skilled practitioner. The best international example of where a definition of deafblindness has driven the creation of a specialism including much needed research on the condition whilst also improving access to services is Norway where there is a Central Team which is a sub-division of the Ministry of Health. This team holds a register of deafblind people and commissions the Government funded specialist services and the right to set hours of communication and transitional support within these. Currently the only comprehensive services in Scotland are run by charitable means through Deafblind Scotland and each individual service is negotiated through Self-directed support or self payment, whereby some people are assessed as being eligible for SDS funded Guide Communicator support services but many more are not. Unlike Norway there is no State funded support for transitional support for deafblind people to learn new skills during the onset of a second sensory loss or emotional support to help cope with the distress resulting from this. In the absence of a legal definition we would propose that refreshing sensory loss guidance with a specific focus on Deafblindness framed by an agreed definition is the minimum action required to address these significant service gaps. However, without legal rights this may have only the partial adherence by public bodies that we have seen with the Mel (1998) 4 well intentioned guidance.

For further information on Deafblindness <https://dbscotland.org.uk/wp-content/uploads/2015/08/BSL-TOOLKIT-with-pics-v3.pdf>

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