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978-0-521-69085-0 - Working with Deaf People - A Handbook for Healthcare Professionals

Edited by Anna Middleton

Excerpt

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## Chapter 1

### Facts and figures about deafness, NF2 and deafblindness

Anna Middleton, Wanda Neary  
and Kerstin Möller

#### Overview of deafness and hearing loss

The clinical impact of deafness is variable. It may occur at any stage of life, it may impact on the individual's ability to function on a day-to-day basis and it may or may not be disabling.

Conversational speech can be measured as having a loudness of approximately 60 decibels (dB). Hearing is considered significantly restricted when the ear cannot interpret or process sounds of 25 dB or more.

The following is adapted from work by Prosser and Martini (2007).

- An individual with a '**mild**' hearing loss can only begin to hear sound if it is between 20 and 40 dB. They may have difficulty understanding conversations in a noisy room, or if the speaker is far away, but should be able to hear one-to-one conversations if the speaker's voice is not too soft. They may have problems hearing a person in front of them who is whispering.

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## 2 Facts and figures about deafness, NF2 and deafblindness

- An individual with a '**moderate**' hearing loss can begin to hear sound between 41 and 70 dB; people with such a loss have difficulty understanding normal conversational levels of speech, but may be able to hear loud noises, for example the sound of a lawnmower (about 90 dB).
- An individual with a '**severe**' hearing loss begins to hear sound between 71 and 95 dB. Such people will only be able to hear an individual speaker if they are at close range and the speaker is shouting; they may be able to hear a car horn (110 dB). A person with a mild, moderate or severe hearing loss may receive benefit from the use of a hearing aid.
- An individual with a '**profound**' hearing loss can only hear sound equivalent to or over 95 dB, for example a gunshot (140 dB). Profoundly deaf people will not be able to hear loud speech or background noise and may prefer to use sign language rather than speech as their form of communication. Some profoundly deaf people may also not receive much benefit from a hearing aid and as such may choose not to wear one.

(Prosser and Martini 2007)

## Terminology

There is often confusion about the terms used to describe deafness. This is largely because health professionals, academics and deaf and hard of hearing individuals themselves may use different terminology to describe related concepts (Grundfast and Rosen 1992).

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- Generally speaking, clinicians and molecular deafness academics often use the term ‘hearing impaired’ rather than ‘deaf’ as this latter term is often considered too non-specific. ‘Hearing impaired’ has a precise medical definition, as per the International Classification of Functioning, Disability and Health (Stephens and Danermark 2005).
- However, the term ‘hearing impaired’ is often not viewed as politically correct these days. It tends to be avoided by deaf and hard of hearing people themselves, as they do not like to be perceived as being defective or ‘impaired’.
- Use of the phrase ‘*the* deaf’ is also not perceived as politically correct either as it has a slightly condescending air to it. This has been replaced by the use of ‘deaf people’ or ‘people with deafness’ instead. For example, in the UK the charity ‘Hearing Dogs for *the* Deaf’ is now termed ‘Hearing Dogs for Deaf People’.
- Many people with disabilities have suggested it is most politically correct to refer to the *person* first and the ‘disability’ second, for example, ‘people with Down’s syndrome’ rather than ‘the Down’s client’. This phraseology may only partly apply to deafness – it is still acceptable to say ‘deaf people’ because deafness can be tied up with identity. But for the hard of hearing group it may be considered more sensitive to use the term ‘people with hearing loss’.

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#### 4 Facts and figures about deafness, NF2 and deafblindness

- Those with a mild or moderate level of deafness will often refer to themselves as being hard of hearing or having a hearing loss. Such people may also find great benefit from wearing a hearing aid and tend to use spoken language rather than signed language. Within interactions with hearing people they will often be able to use their residual hearing and amplified hearing as well as lip-reading to help their communication. People who have elderly-onset hearing loss often call themselves hard of hearing.
- People who are 'deafened' tend to have a profound level of deafness and usually will have started life as a hearing person. Their deafness may be progressive or may have a sudden onset. Deafened people usually feel they belong to the Hearing World rather than the Deaf community as they often do not use sign language. They may also receive little benefit from hearing aids, although cochlear implants may work well for this group. Within interactions with hearing people, deafened people may rely very heavily on lip-reading, writing and reading to communicate.

### **deaf and Deaf**

The following text provides a very general guide to the use of the terms deaf, hard of hearing, deafened and Deaf in the UK. These concepts are fluid and changeable and there are no universally accepted definitions, used by affected

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people themselves, that translate across the world.

However, we have attempted to capture the way the terms are broadly used.

- People who refer to themselves as ‘deaf’ usually have a profound level of deafness, which may also be static rather than progressive.

People who refer to themselves as ‘Deaf’ (written with an uppercase D) are indicating that they have a culture and identity that is linked in with their deafness and that they use sign language as their preferred communication (Padden and Humphries 2005).

- Those who refer to themselves as ‘deaf’ may use some spoken language and some sign language in different contexts. Alternatively, they may prefer to only use sign language. They may also feel most comfortable within the Deaf World/community/culture (a minority group within mainstream society where those who belong mainly communicate in sign language).
- Some who refer to themselves as ‘hard of hearing’ may do so to indicate that they *are not* profoundly deaf and yet they may still mix within the Deaf community, and thus may use both sign language and spoken communication in different situations.
- Conversely some people call themselves ‘hard of hearing’ or ‘deafened’ to indicate that they are not part of the Deaf community.

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## 6 Facts and figures about deafness, NF2 and deafblindness

People who refer to themselves as ‘hard of hearing’, ‘hearing impaired’ or ‘deafened’ often feel they belong to the Hearing World and/or Hard of Hearing World (consisting of other people with a similar perception of hearing loss). This tends to be a group that is not fluent in sign language and relies on using spoken language.

### Case study: developing a Deaf identity

Jo from Northern Ireland had been profoundly deaf since birth, as were his mother and maternal grandfather. Jo had a severe level of deafness, together with a white forelock and different-coloured eyes. He was diagnosed by his paediatrician as having Waardenburg syndrome.

At age 5, Jo found it difficult to fit into the mainstream hearing school recommended by his Local Education Authority and so his parents decided to send him to a specialist school for deaf children, similar to the one his mother had been to. Here he was offered a Total Communication approach – and so had speech therapy to help him learn speech, but also he learnt sign language.

By the age of 10 he found mixing with other deaf children gave him a sense of normality that he didn’t feel amongst hearing children and gradually he found he felt more comfortable using sign language rather than speech. Both his parents were members of the local Deaf club and also used sign language at home.

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Over time Jo found that his experiences in school and at the local Deaf club helped him to develop a Deaf identity – he felt more comfortable mixing with other Deaf people and communicating in sign language. After leaving school he trained to become a social worker for deaf people.

### Terms used by people with NF2

- People with NF2 are born into the Hearing World; they usually use spoken language when communicating.
- When they develop hearing loss, which is most commonly in their 20s or 30s, people with NF2 usually describe themselves as deaf.
- Most people with NF2 learn to lip-read; they use speech and written communication.
- Some receive a cochlear implant, or an auditory brainstem implant, which aids their lip-reading.
- Only a small minority of people with NF2 learn to communicate using an NSL and consider themselves part of the Deaf community.

### Terms used by people with deafblindness

- People with deafblindness are a heterogeneous group. Those who are born with a hearing loss will often call themselves hearing impaired or deaf.
- As their sight deteriorates they may call themselves ‘deaf with visual impairment’.

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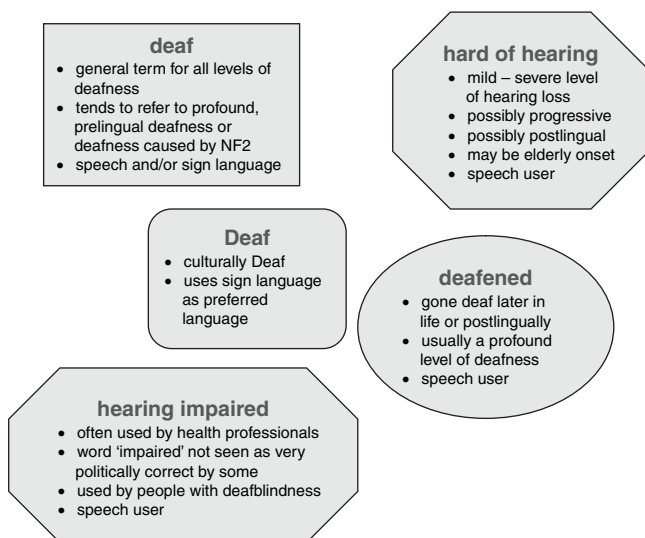
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## 8 Facts and figures about deafness, NF2 and deafblindness

- If they have learnt sign language as their first language they may call themselves Deaf.
- Some people call themselves deafblind; however, many are not aware that the combination of their hearing and visual loss is significant and so may just mention one sensory loss.
- Using the term 'impairment' in the label 'visual impairment' is politically correct; there is not the same stigma attached to this term as there is for 'hearing impairment' for those who have deafness in isolation.
- For ease of language and reading the term 'deafness' and 'deaf people' is used collectively in this book to refer to people with any level and perception of hearing loss.





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## Deafness can be perceived in different ways

- A person who considers themselves hard of hearing or deafened may find their hearing loss is an irritation for them and their significant others. They may also have to make large adjustments in their life both practically and emotionally in order to adapt to this.
- A person who considers themselves culturally Deaf may feel a sense of pride in their deafness and may not feel it is a problem at all (Ladd 1988, 2003) – in fact within their family and social position, they may feel that it is preferable to be deaf rather than hearing.

Deaf sign language users and hard of hearing speech users may have completely opposing views and perspectives towards deafness.

Having a clear family history of deafness can be very positive for individuals who are deaf. Several research studies have shown that, irrespective of the level of deafness, age of onset or impact of deafness, if there are other relatives who can be role models for the individual who is deaf, then this can be of enormous psychological benefit (Stephens 2007).

## Frequency of deafness, NF2 and deafblindness

- In the developed world deafness is the most common congenital disorder (Hilgert, Smith et al. 2008).

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## 10 Facts and figures about deafness, NF2 and deafblindness

- Approximately 1 in 500 babies are born with a hearing loss greater than 40 dB (Morton and Nance 2006).
- Hearing loss increases with age; 16% of adults have a bilateral hearing loss greater than 25 dB (Davis 1989, Morton 1991) and by the age of 80 nearly half the population will have a hearing loss greater than 25 dB (Morton 1991).
- The diagnostic prevalence of NF2 is 1 in 210,000 and the birth incidence has been estimated to be approximately 1 in 40,000 (Evans, Huson et al. 1992a); many individuals do not develop features of the condition until the third decade or later, although individuals with aggressive disease die before the third decade.
- The vast majority of people with NF2 develop deafness either due to the presence of vestibular Schwannomas (tumours of the eighth nerve) or due to the surgical removal of vestibular Schwannomas.
- Deafblindness is very rare, especially in young people. Prelingual deafblindness affects 1 in 10,000 children (Möller 2007).
- Usher syndrome affects about 3 per 100,000 (Sadeghi 2005).
- Developing a combination of visual and hearing impairment increases with age and particularly after the 7th decade.
- Visual impairment is the most common impairment in people with hearing loss. Thirty per cent of children with hearing loss or deafness have been found to have visual impairment (Nikolopoulos, Lioumi et al. 2006).