

A general reference manual, offering practical advice on how to prepare for a consultation with a person who is deaf, deafblind or Deaf (i.e. uses sign language as their first language), it describes the issues which need to be considered with respect to language, communication and culture. Every health professional, medical student and nursing student should have a copy of this book.

ANNA MIDDLETON is a **Consultant Research Genetic Counsellor and Research Fellow at the Institute of Medical Genetics, Cardiff University, UK.**

'This is a brilliant book that every health professional should read as part of their ongoing training.' **Steve Powell, CEO SignHealth, UK**

'This book presents some excellent material in a wide and complex field, written with such clarity that it will be useful to almost any reader whatever their background.' **Dr Lorraine Gailey, CEO Hearing Concern LINK, UK**

'This is a must-read book for all health professionals. Well worth keeping for those times when you may be confronted by a patient who requires different communication tactics that you have never used before.'
Paul Redfern, Consultant in Disability and Diversity, Middlesex, UK

'This book may be of particular interest to clinical geneticists and genetic counsellors.' **Rachel Belk, Genetic Counsellor, St Mary's Hospital, Manchester, UK**

'For those who have little experience of meeting deaf people, the case studies emphasize common pitfalls in communication, and I will be recommending the book to trainees who are new to the field.' **Dr Maria Bitner-Glindzicz, Consultant Geneticist, UCL Institute of Child Health, London, UK**

'I have worked with patients with deafblindness and NF2 for over 23 years, and I realize now that this is the first book to have addressed the basic knowledge of how to interact with people who are Deaf or Deafblind. I sincerely recommend this book.' **Professor Claes Möller, Head of Audiology and Medical Disability Research, University Hospital Örebro, Sweden**

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Professor Dafydd Stephens, Honorary Professor of Audiological Medicine, Cardiff University, UK

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Working with Deaf People

**A Handbook for
Healthcare Professionals**

EDITED BY
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Chapter 3

Specialist issues relevant to working with d/Deaf clients

Anna Middleton

Medical or cultural model?

Medical model

- Deafness is viewed through the 'pathological' or 'medical' model as a medical problem within the ear that needs solving.
- Health professionals tend to use the medical approach to deafness, seeing the need for a hearing aid or a cochlear implant, the assumption being that the client who is deaf or hard of hearing wishes to treat this.

Case study: hearing loss seen as a disability

Bernice is in her late 50s. She started losing her hearing as a child and has grown up as a hard of hearing person in the Hearing World. She uses speech to communicate, but doesn't feel that many people

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(unless they know her well) understand her. She never learnt sign language because when she was a child it was thought that deaf children only developed cognitively if they focussed on speech rather than sign and in those days sign language was not seen as very politically correct. Bernice feels very strongly that her deafness is a disability and she regularly attends her local audiology department to have her hearing aids checked and evaluated. Her hearing aids are her lifeline and without them she feels she would not be able to communicate at all.

Comment

Bernice views her hearing loss from the medical model. She seeks out health professionals who can try and treat the deafness. Despite the fact that sign language is no longer thought to adversely affect cognitive development, there are still people like Bernice who eschew using it at all and would be perturbed if it was used with them.

Case study: having a cochlear implant

Deepak has a profound, sensorineural hearing loss that has been progressively getting worse recently. He first noticed he was losing his hearing in his mid-twenties and now that he is in his fifties it has become really disabling. He no longer gets any use out of his

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hearing aids and he is beginning to feel more and more isolated.

Deepak's ENT surgeon suggests he would be an ideal candidate for a cochlear implant and so after discussion with his family he decides he has nothing to lose and so has the surgery. This is a great success and he begins to learn how to hear again and get used to the presence of sound in his life. He has numerous appointments with the speech therapists and gradually over time his own speech returns to how it used to be before he started to lose his hearing; his brain starts to remember and relearn how to process sound. Deepak is delighted his disability has been treated and he feels he can now function well again in the Hearing World.

Cultural model

- The cultural or linguistic model determines that deafness can be viewed differently; here being deaf is tied up with identity and defined by the use of an NSL.
- With the cultural model of deafness it is not a medical problem but more a way of life.

People who are 'culturally Deaf' (written with an uppercase D) feel that they do not have a disability but that it is society's attitudes that are the disabling factor.

- There is a strong identity that comes with using an NSL and Deaf people will often mix with other Deaf people socially and at work.
- It is thought there are somewhere between 50,000 and 70,000 deaf people who use British Sign Language (BSL) as their first or preferred language in the UK and consequently may view themselves as 'culturally Deaf' (RNID 2008).
- Having a strong family history of deafness where sign language is the first language often contributes to a sense of Deaf identity and membership of the Deaf community.

The 'Deaf culture' is international and there are vibrant Deaf communities, for example, in the UK, the USA, the Netherlands, Sweden, Norway, Germany and Australia.

- The Deaf community is also termed the Sign community in the UK.
- Audiological measurement does not determine membership of the Deaf community (Woll and Ladd 2003). However, many culturally Deaf people have a congenital or early-onset, profound level of deafness and hence use sign language. Conversely there are others with this audiological assessment who prefer to identify more with the Hearing World.
- Ninety per cent of Deaf individuals partner other Deaf individuals (Schein 1989).

- Families with a positive Deaf identity may prefer to have deaf children so that they can continue their culture and language in the next generation.
- Seventy per cent of deaf couples who have only deaf children are believed to be deaf because of changes to the GJB2 gene (Nance, Liu et al. 2000).

Deaf individuals are often interested to know whether and how they have inherited their deafness and what the chances are of passing this on to children (Arnos, Israel et al. 1992). However, they very rarely access healthcare services such as Clinical Genetics to get this information (personal communication from the East Anglia Clinical Genetics Service, Cambridge, and the All Wales Medical Genetics Service, Cardiff, 2008).

Case study: deafness seen as an identity

Miranda is culturally Deaf, she uses sign language as her preferred language and does not perceive her deafness as a problem. She is an excellent lip-reader and also has clear speech and can communicate well with health professionals.

She goes to see her GP because she has just discovered she is pregnant; she is excited about having a baby and as this is her first she wants to ask her GP about antenatal care and the next steps she needs to take to organise this.

The GP welcomes Miranda into her office and offers her congratulations for the pregnancy. After a time she asks Miranda whether she has a family history of deafness and Miranda says quite proudly that she comes from a family with four generations of deafness.

The GP confides that there is a chance that her baby might be deaf too and asks in a concerned voice whether Miranda has considered this. Miranda says 'of course!' and states that if the baby is deaf this will be fine as it will be the same as the rest of the family and actually she would prefer to have deaf children for this reason.

The GP is visibly shocked and says she is surprised that Miranda would want to pass on her disability to her children. Miranda says that she doesn't feel her deafness is a disability and there really is no problem with being deaf.

The GP looks confused and Miranda feels scolded and misunderstood; she wonders how her GP does not know about the sense of pride that culturally Deaf people have in their history, language and community. Miranda leaves the consultation feeling deflated and disappointed.

Comment

It is not unusual for some Deaf people to prefer to have deaf children. Many families have several generations of deafness and a real sense of pride in

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this. Research has shown that deaf children with deaf parents do better in terms of educational and academic achievements, employment and psychological functioning, when compared with deaf children from hearing families.

It is well known that some deaf families prefer to have deaf children and celebrate the birth of a new deaf baby into the family (Hoffmeister 1985, Dolnick 1993, Erting 1994, Middleton, Hewison et al. 1998). However, the birth of a deaf baby into a hearing family with no knowledge, experience or expectation of deafness can be devastating. Parents may grieve the loss of a child they had been hoping for and have to embrace a whole new mindset as they come to terms with raising a child who cannot hear.

Case study: shock at a new diagnosis

Jerrick and Aretha are both hearing. They have no family history of deafness and do not personally know any deaf people. They are in their early 20s and are the first of their peers to become pregnant. The baby will be the first grandchild for both sides of the family and is awaited with great anticipation and excitement.

After delivering a beautiful baby girl and while still in hospital, Aretha consents to the baby's hearing being tested. She is soon told that the baby has a severe level of

hearing loss and that further tests will be needed. Aretha and Jerrick are absolutely shocked to the core; it had never crossed their mind that their baby might be anything but 'perfect'. They were still getting used to the idea of having a baby, let alone a baby with perceived special needs. They are devastated and grieve for the baby that they had thought they were having. It takes them both a long time to accept that their family will no longer be as they had expected. In time they begin to accept that their beautiful baby is still their precious child and that they need to construct a new future for themselves.

Health professionals need to be aware that some deaf people prefer to have deaf children, others prefer to have hearing children; some want deafness to be eliminated and others are appalled by this idea.

Historical context to deafness, eugenics and genetics

There have been many endeavours over the last few hundred years to use perceived knowledge about the inheritance of deafness to negatively influence the reproduction of deaf people.

Assuming that all deaf couples will have deaf children (an inaccurate assumption) has led eugenicists throughout history to create policy that prevented deaf couples from

having children. One of the best-known proponents of this was Alexander Graham Bell (inventor of the telephone and also a leader in the eugenics movement), who wrote a paper in 1883 called 'Memoir Upon the Formation of a Deaf Variety of the Human Race' and presented this to the National Academy of Sciences. Within this work he suggested that all deaf people should only marry hearing people rather than deaf people so that deafness could be reduced in society (Bell 1883). He was actually very supportive of deaf people and felt he was doing society a favour as his own experience of deafness in his wife and mother led him to believe that it was a disability to be avoided at all costs. However, his views now hold a place in history as a very negative influence within the Deaf community and as such often become a talking point when issues relating to eugenics are raised.

Additional events of great historical significance which threatened the Deaf community were the eugenic policies of the Nazis in the Second World War. Seventeen thousand deaf people were specifically targeted as part of the Nazi programme 'Operation T4', where deaf children and adults were forcibly sterilised and killed so that they could not have deaf children (Biesold 1999 in Schuchman 2004).

Both these events relied on the inaccurate assumption that deaf people have deaf children. In fact, recessive

deafness is the most common form of genetic deafness and 90% of deaf children are born to hearing parents. The idea that the human race can be 'improved' by using genetic technology or genetic information to stop particular people having children comes under the umbrella of 'eugenics'. Many deaf people mistakenly think that modern-day genetics services follow the same eugenic principles. Indeed, when deaf people are asked their views about current genetics services the issue of prenatal testing and selective termination for deafness often arises. Participants in the most recent research work by the author have indicated there are large misunderstandings about the aims of current genetic counselling services. The actual ethos of existing services is not to give advice nor encourage specific actions to be taken, for example, having a prenatal test for deafness. Indeed prenatal testing for deafness is very rarely requested in genetics services. Many deaf people feel that genetic testing for deafness 'devalues' deaf people (Middleton, Hewison et al. 1998).

Health professionals need to be aware of the historical context within which modern-day genetics services sit and that some deaf and hard of hearing people may associate genetic counselling with eugenic practices of the past.

Because of the sensitivity surrounding the medical model of deafness amongst some deaf people, it is

very important for all health professionals to have an understanding of this. It is one possible explanation as to why some deaf people rarely attend medical appointments.

Planning a deaf-friendly genetics service

In addition to the general guidance above, it is paramount that appropriate members of the genetics team receive deaf awareness training. At the moment, deaf adults very rarely access genetic counselling services; this is due to a number of access issues that are being identified in current research. Once these access issues are addressed it is likely that deaf adults will come for genetic counselling much more frequently, not just to discuss deafness but also to discuss other conditions that might be running through their family. It is paramount that staff know how to work appropriately with this client group.

Training recommendations for staff working in genetics services

- Genetics professionals need to be aware that deaf people are interested to know why they are deaf and whether this can be passed on to their children.
- Genetics professionals need to be aware that deaf people are interested in having genetic counselling for conditions other than deafness.

- Substantial deaf awareness training is recommended for at least one member of administration staff and one member of clinical staff in each genetics department. This training should be offered by someone who is deaf or, if this is not feasible, should have significant input from someone who is deaf.
- All genetics professionals who *regularly* see deaf and hard of hearing clients (for example, on a monthly basis) should have deaf awareness training
- At least one member of the genetics team *frequently* seeing deaf sign language users (for example, as part of a specialist deafness clinic, perhaps on a monthly or even weekly basis) should undertake NSL training at least to a basic level.
- Genetics professionals who specialise in working with deaf clients and who frequently see deaf sign language users should aim for fluency in their NSL and be able to deliver a consultation in NSL.

Practical issues to think about in relation to any healthcare consultation

Each clinical department should discuss practical issues relating to clinic attendance, e.g. use of text messaging and email to arrange appointments and ensuring familiarity with telephone relay services.

Timing of consultations

Consultations that are facilitated by the use of an interpreter may take slightly longer than consultations without an interpreter because the interpreting process of speech into sign may not be in exact real time. This is particularly the case if the health professional is speaking fast or there are several complicated concepts to relay; it is not unusual for the interpreter to need time to 'catch up' with their translation. This means that the health professional should pause every few minutes or so; this could helpfully happen each time there is a shift in topic.

Good deaf awareness on the part of the health professional will also mean that the main messages of what they want to say are repeated, rephrased and also checked for understanding. This applies both to consultations that are interpreted and also to those that are not, as working with hard of hearing speech users also requires the same consideration.

A client who uses speech may require the health professional to use a mixture of clear (and possibly slower) speech, together with handwritten notes or, if present, electronic notes (see the previous chapter on note-taking). The hard of hearing speech user will need time to lip-read as well as avert their eyes to the written word and then back again.

Any speech delivered by the health professional is wasted while the client who is deaf or hard of hearing is not looking, so there will need to be several pauses while the client is allowed time to move their eyes to the written text and then look back to the health professional.

Case study: communication with an elderly, hard of hearing client

Ivanna is in her 80s and has been losing her hearing over the previous 20 years. She has a severe hearing loss and does not wear a hearing aid. She attends a physiotherapy appointment 6 weeks after a fracture in her hand has healed. The physiotherapist needs to consider carefully how she communicates with Ivanna since Ivanna cannot hear a normal conversation without additional communication help.

The physio sits directly in front of Ivanna, with the light in front of her so that her face is clearly visible. She also makes sure that she meets with Ivanna in a quiet environment where background noise is minimised and they are not likely to be interrupted. She speaks more slowly than she normally would (but is careful not to sound patronising or laboured) and she also uses a louder voice. The physio has a pen and paper to hand so that she can draw and write on it to help support what she is saying and she also makes sure that she

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doesn't turn away her face or obstruct her mouth while she is talking. She asks periodically whether Ivanna is following the conversation and frequently summarises what she has said.

The process of trying to follow a mixed form of communication (e.g. lip-reading and following an interpreter or note-taker) is tiring and so it is also important not to allow these appointments to go on too long.

It would be far better to book two 45-minute sessions than expect a deaf client to sit through 1.5 hours in one go. Conversely if the clinic appointment slot is only for 10 minutes, it is likely that this will need to be doubled for a deaf client, to allow for communication issues to be addressed.

It is vital for health professionals to have flexibility in their appointment system so that if additional time is required for a consultation involving deaf clients, then this can be utilised.

Use of language

All sensitive health professionals should think carefully about the language they use with all of their clients. This is particularly pertinent when working with deaf clients because there is no single way to view deafness – not

everyone perceives it as a disability and to those who do, for some it may be more serious than for others. Therefore, any value-laden terms should be avoided. For example, saying to the new parents of a deaf baby, 'I am so terribly sorry to tell you your baby is deaf', may be really overstepping the mark if the family do not see deafness as the end of the world. Conversely it should not be assumed that a deaf person wouldn't perceive their deafness as an absolute tragedy and thus the reverse is just as inappropriate: 'I'm pleased to tell you that the only problem with your baby is that he is deaf'. It is just safest to be as neutral as possible in the language used: 'Our results show that your baby is deaf' and then immediately adjust further responses to the client based on their reaction to the information.

Health professionals need to be aware that, as deaf people may have different views towards having deaf children, they should not use value-laden language when discussing having children.

Case study: joy at the deafness diagnosis

Bruno and Adelle are both deaf sign language users from Germany. They belong to the local Deaf community and have a strong Deaf identity.

They have just had a baby called Ava and have come to their local hospital to see the paediatric audiologist to have Ava's hearing tested. They are excited to know

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whether Ava is deaf. Bruno comes from a hearing family and Adelle has several generations of deafness in the family.

The paediatric audiologist arranges an NSL interpreter for the consultation. After the testing is complete she gives Bruno and Adelle the results. She starts the conversation by saying, 'I'm so terribly sorry to have to tell you that Ava is sadly deaf'.

Adelle and Bruno smile at each other; inwardly they are delighted with this news, but they do not like to show this too much in case they are seen as uncaring parents. The paediatric audiologist spends the next 10 minutes talking about options for treatment such as a cochlear implant and fitting for a hearing aid. Adelle and Bruno just nod and take the leaflets she provides.

As they leave the consultation room and are in the corridor outside, alone, they hug each other. They can't wait to tell Adelle's family as they know they will be so excited, although they know that Bruno's hearing parents will be disappointed. As they leave the hospital they throw the written material from the health professional in the bin – they can neither understand it as it is in written language nor want it as they do not see Ava as needing to be treated.

Comments

The paediatric audiologist should have used neutral language to deliver the news about Ava, rather than the

value-laden words 'I'm so terribly sorry'. If she had also more awareness about Deaf culture she would have known to ask whether they wanted to know about cochlear implants rather than just assuming this. The written material needed to be adapted so it was relevant and sensitive for deaf and hard of hearing people but also written in a manner that could more easily be understood by sign language users.

For those working in a genetics clinic, words such as 'mutation', 'gene fault' and 'risk of abnormality' are often used. However, there is so much scope for mis-translation of these concepts and also risk of offence that it is particularly important to avoid these at all costs. Alternative words such as 'possibility' could be used instead of 'risk' or 'different' instead of 'abnormal'.

Case study: use of sensitive language

Kalina attends a genetic counselling consultation; she is a deaf sign language user. An NSL interpreter has been booked for the consultation. The interpreter arrives late and also had not had any time to discuss possible ways of interpreting genetics concepts before the actual consultation.

The clinical geneticist (doctor) talks to Kalina about the family history of deafness and says that it is likely that there is a mutation in one of the deafness genes that has caused the members of Kalina's family to be deaf. The interpreter doesn't really understand what

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'mutation' means but doesn't have time to ask so she interprets this as 'mutant deafness'. Kalina sees this and feels very offended that she is being labelled as having 'mutant deafness'. She does not concentrate on anything else the clinical geneticist says in the rest of the consultation as she feels more and more upset about this.

The clinical geneticist is oblivious as to how her speech is being interpreted and if she had known that the word 'mutation' was causing so much concern she would never have used it. It would have been just as easy for her to use the phrase 'altered gene' as this has the same technical meaning.

Comments

The clinical geneticist should have made time to meet with the interpreter first so that she could explain the genetic terminology she intended on using and check the interpreter's understanding of this. She could have also kept a closer eye on the interaction between interpreter and deaf client so that she could pick up from the non-verbal cues that the client was confused and offended by something. The clinical geneticist should also have been aware of the sensitivity to terms such as 'mutation' and used alternatives.

Health professionals need to be aware of the sensitivity some deaf people have towards genetic language. Avoid words such as 'mutant', 'mutation', 'abnormal', 'normal'; be sensitive to words such as 'risk'.

There must be specific training for interpreters working within genetic counselling settings, to enable them to properly discuss genetics issues with deaf clients.

It is not usual for genetic terms to exist in some languages. For example 'recessive', 'gene', 'chromosome' and 'DNA' cannot be literally translated into Urdu as the translations do not make any sense, e.g. 'recessive' translates to 'out of sight' in Urdu (Shaw and Ahmed 2004, p. 330). In a consultation with a deaf person using BSL the same sign may be used by the interpreter to describe several different concepts, e.g. 'chromosome', 'gene' and 'DNA'. This may happen largely because the interpreter has limited genetic knowledge and presumes that these words in spoken English all have the same meaning. The conclusions drawn by Shaw and Ahmed can be applied here. They suggest that it is most helpful to keep the English word and not attempt to translate it directly, but then offer a description in the native language (Shaw and Ahmed 2004). This means in sign language that the genetic term could be finger-spelt first (e.g. c-h-r-o-m-o-s-o-m-e) and then a shorthand sign given to it that denotes this finger-spelt word. The new sign can then be described by the signer, for example, 'chromosome is a word used to indicate a

collection of genes, all packaged up on top of each other'. This means that the interpreter must have a medical understanding of the term 'chromosome' and 'gene' first so that they can describe it in BSL (Middleton, Robson et al. 2007). As suggested earlier, this is one of the reasons why it is paramount to have a conversation with interpreters before the consultation so that these sorts of concepts can be clarified.

It could also be helpful to send pictures and descriptions of common medical terms that are likely to be used in the consultation to both the interpreter and the client; this can be done ahead of the consultation.

Taking a family history

Ninety per cent of deaf children are born to hearing parents (Cohen and Gorlin 1995). Hearing parents of deaf children may struggle to communicate with their children as they are growing up and this can sometimes result in a level of emotional detachment, lack of closeness or even feelings of exclusion.

Given the fact that the hearing child may also miss out on many spoken discussions and incidental conversations about the family, it is not unusual for deaf adults from hearing families to have a lack of awareness about specific medical information about their relatives.

They may be unaware of distant relatives with cancer because it was all too easy to miss the family conversation about this. For a health professional needing to collect family history information from a deaf client, it may be necessary to get permission to call their hearing relatives for more data (Israel and Arnos 1995).

Case study: isolation from family information

Trude first shows signs of hearing loss when she is 10 years old. By the age of 15 she has a diagnosed mild-moderate level of hearing loss; she is told that over time her hearing is likely to worsen.

Trude is very self-conscious of her hearing aids and is very shy. The new diagnosis hits her hard and she withdraws from her family and friends. She spends most of her time on the computer in her bedroom. Trude is from a large family and has four other siblings, all of them younger.

Trude finds it difficult to follow conversations in the home as there is usually a lot of background noise. She also finds that it irritates her siblings each time she asks them to repeat something so she has just given up joining in family conversations. This is also the case when other relatives come to stay.

On joining a new GP practice, the practice nurse asks Trude whether she has a family history of heart disease, high blood pressure and cancer. Trude realises that she has absolutely no idea; she has never

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heard any family conversations about any of these conditions.

Trude also realises how detached she has become from her family. Her hearing loss has brought a distance between them and she resolves to begin to address this. She thinks about the isolation she feels and wonders how her parents have let this happen.

Asking about a family history of deafness

Given the sensitivities surrounding genetics and eugenics it is not surprising that some deaf people who are aware of this history can be a little sensitive about answering questions from health professionals about their family history of deafness.

Many deaf people still view anything about genetics and the inheritance of deafness with suspicion. If a health professional needs to explore a family history of deafness, for example, so that they can rule out a particular syndrome, then they may need to ask explicit information about who was deaf in the family and how this affected the relative. It is therefore paramount that they explain this is what they are doing and the reasoning for this.

Health professionals need to explain carefully why they might need to ask questions about a family history of deafness (e.g. to explore whether there is a syndrome associated with the deafness) since the motives behind this questioning may be misunderstood.

Health-related knowledge

It is not unusual for deaf people to miss out on general health-related information that is available to hearing peers through overheard conversations with family, incidental chat, TV or radio programmes (Rogel 2008). Therefore, basic knowledge about health issues that one might assume everyone has may be missing (Barnett 2002a). For example, Harmer gives details of several studies offering evidence about the lack of specific health information (Harmer 1999, pp. 82–3). Hearing students may have higher levels of knowledge about medical terminology than deaf students and may also know more about dealing with common medical emergencies (Kleinig and Mohay 1991). Deaf adults indicated in a survey that they did not know what normal body temperature was (Lass, Franklin et al. 1978) and were also unable to correctly identify the meaning of words such as 'anxiety' or 'nausea' (McEwen and Anton-Culver 1988).

Case study: knowledge of medical language

Jason was 3 when he was diagnosed as being profoundly deaf. His mother was also deaf and his father hearing. Jason's parents decided that they wanted a specialist, sign language education for him and so when he reached the aged of 7 they sent him to board at a residential school 400 miles away from their home. Jason came home to his family for school holidays and gradually over the years developed into a strong, independent, confident young man.

His time away from home meant that he missed out on family conversations about health and illness; he didn't know his grandmother had osteoporosis or that his brother had dislocated his shoulder. Due to the fact that he was rarely present at home he missed the incidental conversations that used medical terminology.

If ever there was a health issue at school then the nurse dealt with it and in extreme cases the local hospital was involved. It was only when Jason studied biology at school that he became aware of a whole, new medical language that existed. He was fortunate in that this school offered him the opportunity to participate in this academic subject, but many of his deaf peers whom he met later in his life had not had this opportunity and Jason was surprised that they didn't know even very basic medical terms.

In the same way that deaf people may miss out on general health information about themselves and their family, they may also miss out on how to appropriately use healthcare services.

This is particularly pertinent for those deaf people who very rarely use services. For example, they may go to an Accident and Emergency department for a complaint that could be dealt with by a GP or they may bring an urgent medical query to a consultation in Audiology Services. Health professionals should be prepared to direct deaf people clearly to appropriate services, perhaps by making actual referrals or, if already in a hospital setting, walking around to the appropriate department with them so that they can be registered with a different department.

Differences between healthcare culture and Deaf culture

It is usual for health professionals to have certain expectations of how a client should 'behave' in a consultation. For example, they hope that the client will provide the relevant medical information and history in an efficient manner so that they can make a diagnosis. They will be looking out for specific cues to help them to piece together a picture. It is usual, within Deaf culture, to relay a story, using lots of repetition, facial expression and imitation, which may make it difficult for someone unfamiliar with this mode of communication to 'hear'

the medical messages (Harmer 1999). This means that 'differing expectations about normal conversation structure may be a cause of confusion' (Barnett 2002a, p. 697).

Kelly Rogel, a deaf genetic counsellor from the USA, has summarised the above nuances (Rogel 2008). She suggests that the sign language story-telling within a health consultation may offer the main message at the beginning, with the explanations surrounding this afterwards. This contrasts with speech, where a hearing person may relay the story in a more linear fashion and build up to the punchline (with key medical cues) at the end. Meador and Zazove report that 'English [*spoken*] communication works its way up to the main point and then concludes; ASL [*signed*] communication starts with the main point and winds down. Therefore, physicians may believe communications are finished when Deaf clients are still "winding down" the conversation' (Meador and Zazove 2005, p. 218). Rogel cites work by Barnett which suggests that speech users will end a conversation quickly whereas sign language users find this rude and may prefer to continue telling the story (Barnett 2002b).

Rogel concludes that there is much scope for misinterpretation of body language too. For example, within the Hearing World, if a person nods their head when someone is speaking to them it indicates that they are agreeing with what is being said, whereas within Deaf culture head-nodding indicates that the sign language user

is following what is being said, rather than actually agreeing with it (Barnett 2002b). In addition to this, people with hearing loss who use their residual hearing in communication will often give the impression of following a conversation (by nodding) when in fact they are struggling to hear and therefore understand what is being said, but feel embarrassed about expressing this.

Health professionals should consider restructuring the conversation with sign language users so that they allow for the main health issues to be discussed at the beginning, with the general chit-chat to happen at the end.

Health professionals should not assume that a person who is nodding understands what is being said.

A person using sign language integrates non-verbal body language into their communication; this is inextricably linked to the grammar of sign language. For example, variations in facial expression can be used to discriminate between a pain that is mild and a pain that is intolerable. This is one of the features that make sign language so descriptive. Some hearing speech users, who use words to add texture to their descriptions and who do not typically give much away in their facial expressions, may find this unfamiliar territory. As Barnett writes, 'Different interpretations of nonverbal gestures, such as body

posture, facial expression and touch can also lead to misunderstandings' (Barnett 2002a, p. 697).

Case study: mismatches in translation

Tom is a consultant radiologist with a very dry sense of humour and a 'dead-pan' manner about him. He is articulate and witty and uses words very cleverly, giving nothing away in his facial expressions. He is sometimes difficult to read in that his colleagues are often not sure whether he is joking or being serious.

Tom meets Sarah, a deaf client who uses sign language. Sarah has found a breast lump that looks very suspicious on the mammogram and Tom will be performing an ultrasound-guided biopsy of the lump. An interpreter has been booked for their consultation. Tom has not worked with any deaf sign language users before and so is unaware that he needs to adjust his communication style.

Tom enters the consultation room and Sarah is lying on the bed with a gown around her, prepared and ready for the procedure; she has already done a lot of reading up about what to expect so she feels confident about what Tom is going to do. Tom knows she is probably nervous and so to break the ice he says with a very serious face, 'don't worry, we won't remove your whole breast on this occasion'. This might have been an opportunity with a hearing client for a smile as his dead-pan manner could be

interpreted as quite funny. However, what Tom says is translated directly by the interpreter and Sarah can see from his facial expression that he looks, and therefore must be, serious.

She is confused; she didn't think there was even a possibility that her whole breast would be removed. As Tom approaches her with the ultrasound equipment she jumps away, suddenly feeling very self-conscious. She puts one hand across her breast and with the other signs, 'you are not going to remove the breast are you?' Tom is surprised: how could Sarah have misunderstood his joke? He apologises and reassures her. Sarah spends the rest of the procedure feeling very anxious and unsure whether she can trust this doctor.

What could be done differently?

Tom needed to adapt his expressive communication with a sign language user. He could have checked with the interpreter before the consultation with regard to how his words would be interpreted and the interpreter would also have had a chance to get to know him a little and consequently could have picked up on his dead-pan manner. This shows the importance of having a briefing session with an interpreter before the consultation. This case also shows that deaf sign language users depend on facial expressions for clues about communication and not the voice or words that are used.

When Deaf NSL users communicate with each other, perhaps in a large grouping of several NSL users, it is not unusual for the group to behave differently from the way a speech-using, hearing group of people might. For example, a person who wants to catch someone else's eye may flap their hand in front of the person's face to get their attention or they may stamp their foot so that vibrations can be felt.

If, in a clinical consultation, there is a family of sign language users all being seen together, it is socially acceptable for the health professional to use a hand wave in front of someone's face to indicate that they need to slow down or to only sign one at a time so that the interpreter can keep up.

- Eye contact is very important in a conversation with a deaf sign language user. It implies that the signer is being given full attention and the recipient is focussing on them. This is still the case if the signers themselves are looking at the interpreter or elsewhere.
- A hearing person who continually looks away while they are communicating or who shuts their eyes to think may be seen by a sign language user as an oddity or as not paying attention or even as being rude.

Sometimes the deaf or hard of hearing person will stop the conversation and wait for eye contact to be established before resuming what they are saying. This is because it is possible for the deaf person to forget that hearing people can listen to a conversation without also looking at the person they are conversing with.

An inappropriate focus on deafness

Research has shown that health professionals may sometimes focus too much on deafness in a consultation, particularly when other issues are the reason for referral.

When Iezzoni et al. interviewed deaf and hard of hearing people about their experiences of the healthcare system, they showed that 'respondents wondered why physicians repeatedly question them about what caused their deafness when hearing is irrelevant to their current health concerns' (Iezzoni, O'Day et al. 2004, p. 358). This same finding was evident in the author's latest research on attitudes towards the use of genetics services. Here it was found that deaf and hard of hearing participants reported that their GP as well as other health professionals often focussed more on their deafness than the pertinent health concerns about which they had come to see the health professional.

Case study: not needing to focus on deafness

Li had a family history of young-onset breast cancer in her mother and maternal aunt. She was referred to the local Breast Unit to find out the significance of the family breast cancers.

Li had been profoundly deaf from birth and so too had most of her family. When the breast care nurse drew up the family tree the first question she asked was: 'Is there anyone else in the family who is deaf?' Li wasn't sure of the relevance of this as she had come to discuss breast cancer, but she answered anyway that her parents, her brother and all of her mother's family were congenitally deaf. The breast care nurse seemed excited by this and said, 'Gosh I've never seen such a large family with deafness before!' She then proceeded to colour in the family tree with symbols to indicate who had deafness.

Li became irritated as she didn't want to discuss deafness, she didn't see this as a medical problem that needed to be noted on a medical chart and she was pretty sure this wasn't relevant to the breast cancer. She asked the breast care nurse if there was a link between breast cancer and deafness and the nurse said no. Li then said that she didn't want to focus any longer on the deafness.

Comment

The health professional here is in danger of losing the client's trust, which may affect how they

engage with this particular clinical service in the future. It is important to be guided by the client and to make specific attempts to pick up on how they feel about the discussions being had. This can often be done by looking at non-verbal cues the client is giving which indicate frustration or dissatisfaction.

Health professionals need to be aware that some deaf and hard of hearing people may prefer not to focus on deafness within a consultation, particularly if they have been referred because of a different reason.

Visual aids

Deaf and hard of hearing people, both sign language users and speech users, tend to be visual people. They are used to reading language through observation of lip-patterns, gestures, body language, eye contact and a whole range of visual cues. It therefore makes sense to make use of this skill within a healthcare setting.

This can be done via the use of diagrams, models, animations, drawings and hand signals (for example, one hand to indicate a recessive gene and the other a dominant gene).

Repetition and rehearsal

- Using an NSL requires a different memory process from using speech (Marschark 2003).
- Teachers of deaf children have long known this and it is recognised that this can be addressed using repetition and rehearsal (Gibson 2004). This structure should also be adopted within a healthcare consultation.

Case study: visual communication to describe medical terms

Roberto and his wife Maria attend a genetic counselling consultation. They are both profoundly deaf.

Their genetic counsellor, Alison, has established prior to the session that they require a BSL/English interpreter and has booked a local freelance worker who is a full member of the NRCPD (Alison checked through the Signature website).

Alison has already had a long chat with the interpreter on the phone to discuss the sorts of genetic terminology she will be describing in the consultation and how she plans to structure the session.

They have discussed how the interpreter plans to sign particular concepts, such as 'dominant inheritance' and 'gene alteration'. Alison has also given the interpreter a basic biology lesson on what DNA is as well as 'gene' and 'chromosome' and 'genome'. In

addition to this she has sent some written information and drawings in the post to the interpreter. Alison has also provided information about the room they will be using and how the light is positioned, and has already given some thought as to where it might be appropriate to arrange the seating.

In the consultation, Roberto and Maria ask for information about the chances of having deaf children. It is clear to Alison that there is a dominantly inherited, genetic deafness on Roberto's side of the family and an environmental cause to Maria's deafness.

Alison first defines the terms she is going to use, 'genome', 'chromosome', 'gene' and 'DNA', and shows the couple pictures of these using a library metaphor – the 'DNA' represents the words in a book, each individual book represents a 'gene', each shelf of books represents a 'chromosome' and a set of shelves represents a 'genome'. She checks that the couple are following her and asks several times for them to give feedback on what she is saying so that she can check their understanding.

When Alison describes 'dominant inheritance' she draws on a piece of paper, being careful to not talk at the same time so that the couple can watch her draw. When they look up she describes what she has drawn. In order to reinforce the points she is making she also describes 'dominant inheritance' using her two hands to represent two genes, she then moves her hands to indicate one gene being passed on and the other not.

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Alison asks Roberto and Maria to summarise what their understanding of the genetic terminology is and also asks them to draw out the inheritance pattern too.

At the end of the consultation, Alison gives the couple a DVD containing an NSL version of the department leaflet on 'What is dominant inheritance?' so that they have a sign language record of the information.

Comment

Alison has used four different visual methods to relay information – pre-printed pictures, live drawing, hand signals and a DVD summary. This has all been delivered in sign language, with several opportunities to repeat and rephrase the different concepts. The couple's understanding has also been checked throughout the consultation.

A list of NRCPD-registered interpreters in England, Wales and Northern Ireland can be found at www.signature.org.uk.

Psychological impact of hearing loss

An adult who has grown up hearing and using spoken language may find it incredibly difficult to adapt to the development of a hearing loss. It is common for a whole range of emotions to be attached to this: 'embarrassment,

loss of confidence, anger and resentment are among the most common feelings they have to deal with everyday' (Munoz-Baell and Ruiz 2000, p. 41).

The impact of this can mean that such hard of hearing and deafened people find they shy away from public situations, go out less frequently and withdraw from the events in which they would otherwise be involved. Gradually over time this can lead to isolation, depression and loss of self-esteem.

Case study: negative impact of hearing loss

Luc was diagnosed with severe hearing loss when he was in his early 20s. He wears a hearing aid and works as a postman in the Czech Republic. He finds the hearing aid seems to put people off talking to him and finds it difficult to make new friends. He doesn't go out much, for example to pubs or clubs, as he finds the background noise too difficult to handle. He lives on his own and feels really isolated. Most nights are spent watching TV with the subtitles or playing computer games. His doctor recommends he attends a lip-reading class and eventually he plucks up the courage to go. It is only through meeting other people with hearing loss that he starts to realise how depressed he has been feeling. Mixing with others in the same situation really helps him to

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think about his own self-esteem and confidence and he realises he needs to take steps to address his feelings about losing his hearing.

A hard of hearing or deafened client attending a health-related consultation may not only feel anxious about the health issue they are there to discuss, but on top of this may feel embarrassed about their hearing loss or the way their voice sounds and consequently the emotional impact of the hearing loss is likely to add another dimension to the healthcare consultation.

Within a hearing family, hearing children usually learn how to label their feelings and emotions through their voice and via spoken validation from their parents. However, deaf and hard of hearing children of hearing parents, who may struggle with communication, may have a delay in the acquisition of effective language. This in turn could play a part in delaying the development of emotional reasoning and the labelling of feelings together with the cognitive processes that accompany these (Henderson and Hendershott 1991 in Ralston and Israel 1995). This means that it may be more difficult for deaf and hard of hearing adults to express and describe their feelings and emotions than for a deaf child raised by deaf parents or a hearing

child raised by hearing parents, who are less likely to have had the same communication difficulties.

The positive impact of having a family history of deafness

There is research evidence to indicate that deaf children of deaf parents fare better than deaf children of hearing parents in a number of different measures. For example, deaf children of deaf parents have fewer emotional and behavioural problems, better psychological functioning and fewer mental health issues compared to deaf children of hearing parents (Stephens 2005). As approximately 90% of deaf children are born to hearing parents there are evident issues for the large majority of deaf adults with congenital deafness.

Dafydd Stephens and Lesley Jones have edited a book *'The Impact of Genetic Hearing Impairment'* (2005), published by Whurr, which brings together a whole mixture of chapters that review the literature on the psychological impact of hearing loss on individuals; the reader is directed towards this for a more extensive overview.

Emotional issues to consider in a consultation

- Given the above, the adult who is deaf or hard of hearing who attends a healthcare consultation, whether they have been deaf from birth or whether they have lost their hearing as an adult, has a chance of being

emotionally fragile and may have had to deal with difficult psychological issues throughout their lives.

- It is well known that deaf people generally have a much higher risk of mental health issues than hearing people (Department of Health 2005).
- It is vitally important that all health professionals involved use sensitive, empathic listening skills, make allowances for frustrations, do not respond negatively to seemingly overactive emotional responses to events and spend time to understand and support deaf and hard of hearing clients.

It is likely that deaf and hard of hearing people have previously had poor experiences of the health service, either through childhood or as an adult (as mentioned already in Chapter 2). This prior experience may mean that they come to a medical setting anticipating a poor service again and this may manifest as a defensive or aggressive stance. This will undoubtedly add to the emotional charge of a consultation.

When seeing a deaf client within a clinic setting consideration **MUST** be given to the potential for emotional fragility.

- If the health professional experiences a defensive stance from a deaf client it is important to view this with an

empathic manner and to take care not to put additional stress on the client who is deaf, perhaps by overloading them with too much information.

- It can also help to use basic counselling skills, such as acknowledging openly some of the obvious difficulties; for example, by saying things like 'I can see you are really frustrated; however, I'm going to try really hard to understand what is going on for you' or 'I can understand that you are fed up with health professionals; help me to learn what I need to do to help you'.
- Emotional engagement within a healthcare consultation may be different for deaf and hard of hearing clients compared to hearing clients, although of course there are likely to be many exceptions and it is important not to over-generalise this. Any differences should also not be perceived as deficiencies, it is just a case of being aware and not surprised if differences exist.

Case study: taking it slowly

Kai is a deaf, Australian Sign Language (Auslan) user. He has had recurrent indigestion over a number of years and has been referred to an upper GI health professional to discuss having an exploratory endoscopy.

Kai has had a dreadful experience of the health service; he broke his leg when he was a teenager and was in hospital for a couple of months after having

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complications post-surgery. None of his communication needs were met at the time, he had to struggle to lip-read what the doctors and nurses said to him and didn't understand most of what happened to him. This experience left him feeling angry and distrustful of all health professionals and he had avoided having anything to do with the health service since.

Kai arrived late for the consultation. A sign language interpreter had been booked and the upper GI nurse and interpreter have been waiting for him as he was the last appointment of the day. The nurse had deliberately structured her clinic in this way in case Kai had needed additional time.

The health professionals were aware that Kai might find the consultation difficult and so were mentally prepared to pay particular attention to his emotional needs. The clinic nurse went into the waiting room with the interpreter and asked his name and whether he would like to come into the consultation room. He looked sullen and unresponsive as he walked behind her into the room. As he slouched into his chair the nurse put her medical notes to one side, pulled her chair up in front of his and started with 'How are you?'

Kai signed that he hated hospitals and hoped that the consultation wouldn't take long. The nurse said, 'You can take as long as you need'. She said that the team were focussed on his needs; they wouldn't offer too

much information in this first session but would use the time to take a full history and build a rapport between them. The nurse could see that Kai was suspicious and alienated and she knew that if she didn't give him the time and focus he needed it was unlikely he would engage with the service again.

Tinnitus

Tinnitus, or ringing in the ears, is incredibly common; in the UK one-third of adults have experienced this (Davis 1995). Tinnitus can occur in otherwise 'hearing' people but can also occur in people with hearing loss and deafness. People with a family history of deafness are thought to have a higher incidence of tinnitus and also a higher annoyance with this condition (Stephens, Lewis et al. 2003). Tinnitus is known to be incredibly distracting, can interfere with sleep and in some instances can severely affect quality of life.

Coping with tinnitus while also trying to cope with the information delivered in a healthcare setting (possibly also via an interpreter or communication support professional) can affect concentration enormously. Tinnitus can also become worse in times of stress. It is therefore vital that health professionals are particularly sensitive that this is an additional factor which may impact negatively on the exchange of communication. This is another reason why it is important to have more frequent, shorter consultations.

Post-clinic issues

As already discussed in Chapter 2, it is important to provide a choice of how post-clinic information is provided. Some deaf clients, particularly those who prefer to use speech, may be content to receive a written letter or leaflet summarising the take-home messages. As with all clients, deaf and hearing, this information should be adapted to the client's reading skills, should avoid jargon and be pitched appropriately.

Deaf sign language users may prefer to receive their post-clinic information in the form of a DVD in sign language. External companies are able to create such DVDs within a 24-hour turnaround, for a cost, and so this should not be difficult to organise. Research has shown that if a video or DVD is to be included that summarises a lot of health information, it is important to stick to a single health topic at a time. Too much information in one go can be confusing and difficult to process (Folkins, Sadler et al. 2005).

Health professionals may need to adapt how they provide post-clinic information to deaf and hard of hearing clients. Long client letters with genetics jargon are unacceptable for both deaf sign users and hard of hearing speech users.

Health professionals may need to translate client letters into plain English and/or an NSL on DVD.

Specialist issues relevant to working with clients with neurofibromatosis Type 2

Wanda Neary

Overview of NF2

For people with NF2 there are four major areas that impact on their lives (Neary, Stephens et al. 2006):

- hearing difficulties
- balance problems
- facial weakness
- difficulties with vision.

NF2 is a potentially life-threatening condition – the benign tumours in the head which cause the deafness may grow so large that they ultimately cut off brain function or the surgery to remove them may irreparably damage the brain. The combination of deafness with balance, visual, physical and psychological problems makes it very burdensome to some people. It is important for health professionals seeing clients with NF2 to have an awareness

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