

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-glindicz, 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**

'Most impressive. The more I look at it, the better it seems to be.'

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

Cover illustration: © iStockphoto/ Stacey Newman.



Working with Deaf People

A Handbook for
Healthcare Professionals

EDITED BY
Anna Middleton

CAMBRIDGE

Medicine

CAMBRIDGE
UNIVERSITY PRESS
www.cambridge.org

ISBN 978-0-521-69085-0



9 780521 690850

CAMBRIDGE UNIVERSITY PRESS
 Cambridge, New York, Melbourne, Madrid, Cape Town, Singapore,
 São Paulo, Delhi, Dubai, Tokyo
 Cambridge University Press
 The Edinburgh Building, Cambridge CB2 2RU, UK

Published in the United States of America by
 Cambridge University Press, New York

www.cambridge.org
 Information on this title: www.cambridge.org/9780521690850

© Cambridge University Press 2010

This publication is in copyright. Subject to statutory exception
 and to the provisions of relevant collective licensing agreements,
 no reproduction of any part may take place without the written
 permission of Cambridge University Press.

First published 2010

Printed in the United Kingdom at the University Press, Cambridge

A catalogue record for this publication is available from the British Library

Library of Congress Cataloguing in Publication data
 Working with deaf people : a handbook for healthcare professionals /
 Anna Middleton (editor).

P. : cm.

Includes bibliographical references and index.

ISBN 978-0-521-69085-0 (pbk.)

1. Medical personnel and patient—Handbooks, manuals, etc.

2. Deaf—Medical care—Handbooks, manuals, etc. I. Middleton, Anna. II. Title.

DNLM: 1. Communication. 2. Professional-Patient Relations.

RZ273.W667 2010

362.4'2-dc22

2009033489

ISBN 978-0-521-69085-0 Paperback

Additional resources for this publication at
www.cambridge.org/9780521690850

Cambridge University Press has no responsibility for the persistence or
 accuracy of URLs for external or third-party internet websites referred to in
 this publication, and does not guarantee that any content on such websites is,
 or will remain, accurate or appropriate.

Every effort has been made in preparing this publication to provide accurate
 and up-to-date information which is in accord with accepted standards and practice
 at the time of publication. Although case histories are drawn from actual cases, every
 effort has been made to disguise the identities of the individuals involved. Nevertheless,
 the authors, editors and publishers can make no warranties that the information
 contained herein is totally free from error, not least because clinical standards are
 constantly changing through research and regulation. The authors, editors and
 publishers therefore disclaim all liability for direct or consequential damages resulting
 from the use of material contained in this publication. Readers are strongly advised
 to pay careful attention to information provided by the manufacturer of any drugs
 or equipment that they plan to use.

CONTENTS

Glossary	page viii
Foreword	xiii
<i>Pre-publication peer reviews</i>	xv
<i>Preface</i>	xv
Use of the book	xix
Anti-discrimination legislation	xxiv
Work by hearing people 'on' deaf people	xxvi
Acknowledgements	xxvi
The authors	xxviii
1 Facts and figures about deafness, NF2 and deafblindness	1
Overview of deafness and hearing loss	1
Terminology	2
deaf and Deaf	4
Terms used by people with NF2	7
Terms used by people with deafblindness	7
Frequency of deafness, NF2 and deafblindness	9
Describing deafness and hearing loss	11
Causes of deafness	14
Neurofibromatosis Type 2 (NF2)	16
Deafblindness	21

- Age-related hearing loss in combination with different diseases affecting the eye is very common over the age of 65 and prevalence increases with age.

Older people with combined visual and hearing loss comprise the largest group of people who have deafblindness.

General themes to consider when working with deaf and hard of hearing clients

Anna Middleton

This chapter considers general communication issues that are relevant to deafness and hearing loss. Specific issues pertinent to people who are deaf due to NF2 and people who have deafblindness are considered in Chapters 4 and 5 respectively.

Seeing a hearing aid

- When meeting a deaf or hard of hearing person for the first time, seeing a hearing aid may offer some clues as to the form of communication the person uses.
- It is possible that they identify more with the Hearing World and if so will use lip-reading and speech to communicate.
- Alternatively they may still be culturally Deaf and prefer to use sign language, but for interactions with hearing people prefer to utilise the residual hearing they have as

this helps them with lip-reading. A Deaf person may also like to wear a hearing aid as it may offer help with ambient noise; for example, in a city where there is noisy traffic, having the hearing aid switched on may help with crossing the road and knowing where the traffic is coming from.

It should not be assumed if no hearing aid is seen that a person is not deaf; it may be that they are profoundly deaf and gain limited use from a hearing aid or are culturally Deaf and may just prefer not to wear one, or it may also mean that they have an as yet undiagnosed hearing loss.

Case study: seeing no hearing aids on a sign language user

Shan lived in the UK and had been profoundly deaf from birth. She used sign language as her first language and although she had been fitted with a hearing aid when she was a child had long thrown these away as they were more of a hindrance than a help. She also found that as she preferred to use sign language the hearing aids sometimes gave the impression to people that she could hear and use speech and this annoyed her. Also, she found that people sometimes stared at her hearing aid and so this was also a reason she just preferred not to wear one.

On a routine visit to her GP Shan approached the receptionist and pointed to her ears while mouthing

the word 'deaf'. She indicated that she wanted to write something down and the receptionist handed her a pen and some paper. Shan wrote 'appointment please today GP'. The receptionist understood what Shan wanted and so looked through the diary. Shan smiled and signed the word for deaf, which involves touching the ear; she then used sign language to indicate that she was a signer. The receptionist assumed Shan must be trying to tell her that she had forgotten to put her hearing aids in as she saw Shan touching her ear; the receptionist wrongly assumed all deaf people wore them. In fact, Shan just wanted to make it clear that she was a deaf sign language user.

Comments

The Department of Health in the UK recommend that all front-line health service staff receive deaf awareness training (Department of Health 2005). The receptionist was unaware that some deaf people do not wear a hearing aid. In addition to booking an appointment for Shan it would have also been helpful if she had asked about her communication needs and made arrangements so these could be met in the consultation with the GP.

Dissatisfaction with the health services

Existing healthcare services for people with deafness are known to be suboptimal (Steinberg, Sullivan et al. 1998,

Ubidio, Huntington et al. 2002, Iezzoni, O'Day et al. 2004, RNID 2004b, Reeves and Kokoruwe 2005, Steinberg, Barnett et al. 2006). This has led to a depressing level of dissatisfaction from deaf people about using them. The main problems are lack of deaf awareness amongst health professionals and inappropriate provision of communication support. This has led to a distrust, apprehension and negativity from many people about interacting with health professionals.

In 2004, the Royal National Institute for Deaf People (RNID), the UK's largest deafness charity, indicated that 'urgent action' was needed to improve the accessibility and communication for deaf and hard of hearing people using the National Health Service (NHS) in the UK. They also recommended that all front-line NHS staff should have deaf awareness training (RNID 2004b). This is also recommended by the Department of Health in the UK (Department of Health 2005).

Lisa Harmer from the University of Rochester has written a useful review of research surrounding health services and deaf people (Harmer 1999). The following text is a quotation from this work and summarises very neatly some research in this area:

'A nonrandomized survey of d/hoh people by Zazove et al. (1993) reported that deaf people visit physicians more frequently than do hearing people, but the deaf individuals report less satisfaction with the health care

services they received Zazove hypothesized that deaf individuals may keep returning to physicians to seek assistance for problems and answers to questions that were not understood in prior visits. In that study d/hoh individuals also said when they attempted to exchange written notes with their doctor, the doctor's writing was often illegible, or the physician wrote at a level that was beyond the literacy skills of the client. In addition, patients regularly underwent tests or received prescriptions without understanding why the action had been undertaken.' (Harmer 1999, pp. 77-8)

Very similar findings have also been reported by the Royal National Institute for Deaf People in the UK (Dye and Kyle 2001, RNID 2004b) and also in the author's own work (Middleton, Turner et al. 2009).

- There has been a consistent lack of understanding amongst health professionals about the different ways of perceiving deafness.
- There has been a consistent lack of deaf awareness in the health service. This not only applies to deaf and Deaf people but also to those who are hard of hearing or deafened.
- Many Deaf people do not want to have a cochlear implant (Harmer 1999) and resent the assumption that there is something negligent about this attitude.

Case study: struggling to communicate in Accident and Emergency

Dominic is culturally Deaf. He works for his local Deaf community and mixes regularly with other Deaf people. He had been educated at a mainstream hearing school and had dropped out of school at 15 as his special needs were not being met. He found it difficult to learn speech and communicate with his hearing peers. He developed his Deaf identity from a sense of survival, and felt that it was only other culturally Deaf people who really understood him. He was involved in the march in London to have BSL recognised as a British language and was a prominent disability rights activist.

Dominic attends the Accident and Emergency department in his local hospital because he has broken his arm in a clash with police. Because of the pain in his arm he cannot sign properly nor write. When he arrives in A+E the doctor cannot understand what he is saying and struggles to communicate; he can see that Dominic is frustrated, frightened and angry. Dominic is defensive and shouts at the doctor; what he says sounds like 'interpreter'! The A+E doctor is just finishing a very busy shift and he is tired and could do without any confrontation. He asks one of the nurses if Dominic has a cochlear implant. Dominic lip-reads the words 'cochlear implant' and is livid. He shouts at the doctor 'IGNORANT!' and begins to cry.

One of the reception staff has recently done a signing class at night school and she hears this interaction. She comes over to Dominic and signs to him, 'I'm so sorry, I can see you are really upset, my signing isn't great, but I will sort out an interpreter immediately for you'. He looks at her in disbelief, surprised that suddenly there is an open line of communication. The fear in his face gradually lessens and he signs back to her 'thank you'. He feels he can now wait for an interpreter and relaxes a little as he will soon have the opportunity to express himself clearly to the doctor.

Comments

The A+E doctor was unaware that his question about a cochlear implant would cause such a reaction in Dominic; he didn't intend to inflame an already emotional situation. Once an interpreter arrives it may be helpful for the doctor to have a chat with Dominic and to say that he didn't mean to cause offence.

Some deaf and hard of hearing people have also had such a negative experience of health services in the past that they feel very defensive. On arrival at A+E there should be staff available on every shift to set up appropriate communication aids, for example, immediate access to an on-site interpreter, or access to a live on-line interpreting

(Continued)

service,¹ or preferably a member of staff who can communicate in sign language, even if at a basic level. Dominic should not be expected to lip-read and write to communicate in this situation; **in the UK it is the hospital's legal responsibility to ensure the client's communication needs are met.**

- Some deaf and hard of hearing people have indicated that they will only use the health service for really serious health matters as they have found it a stressful experience they would rather avoid if possible.

Use of genetics services

Despite genetic deafness being one of the most common genetic conditions, very few deaf or hard of hearing adults are referred or seek a referral for genetic counselling. It seems that one of the main assumptions about this is that deaf adults are just not interested in using services.

Research by the author has shown that this is just not the case and that when given accurate information about what genetic counselling is and what can be offered, many deaf and hard of hearing adults are interested in using the service. It is possible that given the problems deaf people face in using health services generally, they perceive they

¹ See end of this chapter for details.

will also have a negative experience if they access genetics services too.

Genetics professionals need to be aware that there is a general dissatisfaction with regard to poor communication with health professionals in general. This appears to be influencing attitudes towards genetics services and the propensity to use these services by deaf and hard of hearing clients.

Knowledge and fears of genetic counselling

It is not unusual for both deaf and hearing people to have limited knowledge of what genetic counselling is and what services are available within Clinical Genetics departments. The words 'genetics' and 'counselling' tied together cause confusion and are often misleading. People may assume that psychotherapy is on offer or that the sole aim of the service is to help people 'cope' with something genetic. Genetic counselling offers information about any inherited condition; such conditions might be evident through different generations of a family, e.g. inherited breast cancer or myotonic dystrophy.

Research by the author has shown that many deaf people are either unaware of what genetic counselling is or have misunderstandings – believing that what is offered routinely and indeed is encouraged is prenatal testing for inherited deafness with selective termination of pregnancy

for deaf babies. This is certainly not the case in reality. We have also shown that many deaf people are fearful and even distrustful of genetics services and this is likely to be grounded in the historical perspectives of deafness and eugenics (see later) (Middleton, Hewison et al. 1998). Conversely some deaf and hard of hearing people are extremely positive about genetics services, seeing them as offering information and support for deaf families either wanting, or preferring not, to pass on deafness to their children. The message being delivered here is that there are a multitude of perspectives towards genetics services and it should not be assumed that all people referred will be positive about this.

Health professionals need to be aware that deaf and hard of hearing people may have different attitudes towards genetics services. Some may feel positive, some neutral and some negative.

As with people in the general population, many deaf and hard of hearing people do not know what genetic counselling is. Thus expectations of what can be offered should be established at the beginning of a consultation.

Any written material for deaf and hard of hearing people about genetic counselling and what to expect from the genetic counselling service could very usefully include an acknowledgement of the fears about the

service. Personal experience has shown that the fears are very common and they may hinder the counselling process unless the genetic counsellor brings them out into the open and addresses them. The reason this is important is because inaccurate assumptions may linger and also influence the client's decision-making about certain aspects of their care. For example, a deaf client may turn down the offer of a prenatal genetic test for cystic fibrosis because they wrongly assume that the clinicians will also test for deafness at the same time.

Health professionals need to be aware that some deaf people have misunderstandings about what genetic counselling is and assume that one of the key aims is to offer prenatal testing for inherited deafness with termination of pregnancy if the fetus is found to be deaf. It can be helpful to reassure deaf clients that this is not a key aim of genetic counselling.

Case study: misunderstandings about genetic counselling

Mandy has a moderate hearing loss and uses speech to communicate. She lives with her husband in the USA. Her newborn son, Bradley, has just been diagnosed as profoundly deaf through the Newborn Hearing Screening Programme. The paediatric audiology team suggest to Mandy that they could refer her and the family to the local regional genetics service for genetic

(Continued)

counselling. Mandy is surprised and visibly shocked by this as she says she doesn't need any 'counselling'. She also says that she heard through a TV programme on genetics that it was possible to have a test in pregnancy for deafness and abortion if the baby is found to be deaf. She doesn't want this in a future pregnancy and wrongly assumes that a genetic counsellor would encourage her to have this.

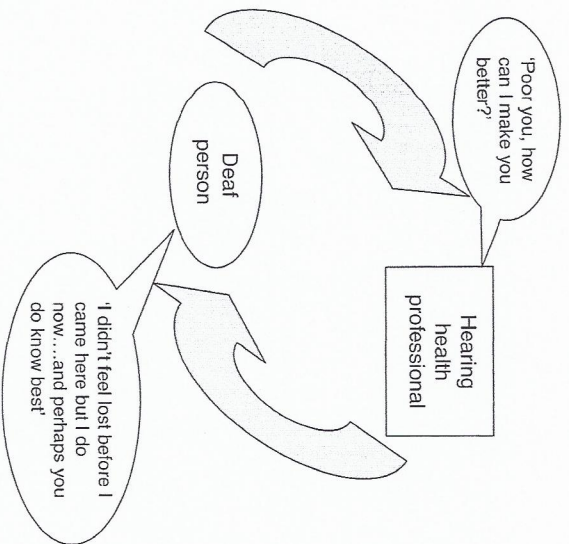
The paediatric audiologist reassures Mandy that the aim of genetic counselling is to offer information and support and that the genetics professionals would not force her to have any testing. The paediatric audiologist asks Mandy whether there are any medical conditions in the family that she is concerned about and she mentions that her cousin has Duchenne muscular dystrophy. The paediatric audiologist tells Mandy that genetic counselling can offer information about this too and can tell her whether she has a chance of having a child with Duchenne muscular dystrophy. Mandy is very keen to know more and asks for a referral to be made.

Current leaflets and DVDs focus on clinical aspects of genetic counselling without addressing the fears, suspicions or misconceptions some deaf people have. Additional literature is needed to complement current documents.

The inadvertently patronising health professional

'Health care providers who harbour conscious or unconscious biases against deaf individuals lack proper training to work effectively with them, do not understand their client's perspective and cannot provide good healthcare.' (Harmer 1999, p98)

With the above in mind, it is therefore very helpful for health professionals to move away from the mindset that a deaf person is disabled, handicapped or deficient in some way. If the health professional sees the person who is deaf as defective, it would naturally elevate the hearing health professional to a superior position as being 'non-defective'. This elevation creates a power differential that can be damaging for both sides. The client may automatically assume the position of 'helpless victim' and the doctor an attitude of 'poor you, how can I make you better?' This power dynamic can become exaggerated and lead to the client who is deaf feeling misunderstood and increasingly helpless and the hearing health professional taking on a more paternalistic and authoritative role. If taken to the extreme this could lead to a victim-and-bully dynamic.



Case study: viewing deafness holistically

Axel is a newly qualified doctor working for 6 months in an Ear, Nose and Throat (ENT) clinic in Denmark. His grandmother became deaf in her 50s and so he is familiar with how disabling a condition this is for her. Soren is in his 50s and has been losing his hearing since his teenage years. He has a condition called otosclerosis which is caused by hardening of the bones in the middle ear. This can sometimes be successfully treated by surgery. Soren has never really

been bothered by his hearing loss. He has a lively sense of humour, a positive attitude and an affable manner. He met and married a profoundly deaf woman in his 20s before he realised and had been diagnosed with otosclerosis himself. The two of them use a mixture of speech, lip-reading and sign language to communicate. They both work for the local council and have quite senior and respected positions. Soren's wife works in services for deaf people and Soren works in Sports and Leisure.

Soren's family doctor suggested he might wish to have a discussion about surgery for his otosclerosis and so he has gone to the ENT clinic to have a chat, but he is not overly keen on having an operation.

Axel meets Soren in clinic to discuss the pros and cons of surgery. Axel knows how successful the surgery can be and feels sure that Soren would have a better quality of life if Soren proceeded with this. He imagines that Soren must struggle to communicate day to day and feels that there is a tangible solution to restore his hearing. Axel assumes that deafness is a problem and being hearing would be preferable.

Soren has never been particularly bothered by his hearing loss, he has always managed to get around it and feels that although it might be irritating for other people, it is part of his identity and he is not sure that he needs to change this. He feels that he can communicate quite effectively with his wife, friends, family and colleagues and this has not held him back in any way. When he hears

(Continued)

from Axel what the surgery might involve, he makes his mind up definitely that he doesn't want to proceed.

Axel cannot understand why Soren would turn down the opportunity to restore some level of hearing. He feels sorry for Soren and thinks he is rather misguided. Soren feels annoyed that he cannot just be accepted for who he is and Axel's pity really irritates him.

What could be done differently?

Axel holds a strong unconscious view that deafness is a disability; this is based on his limited experience of his grandmother's deafness. This could be preventing him from seeing Soren as a whole person with a rich and fulfilling life. Axel has a medical perspective of deafness and is not familiar with applying his communication skills to elicit his client's perspective. If Axel was able to reflect on his preconceived ideas about deafness, he may be able to view Soren more holistically.

Qualitative research gathering the views of deaf, sign language users and hard of hearing speech users has shown that deaf and hard of hearing people feel that 'most physicians, largely unconsciously, hold fundamental assumptions about deafness, that, from the outset, undermine client-physician relationships. In particular, physicians do not fully appreciate the

totality of patients' lives' (Iezzoni, O'Day et al. 2004, p. 357).

'Many physicians hold paternalistic, ethnocentric attitudes towards their patients. Doctors also tend to view disabilities as deviations from the mainstream norm that should be corrected if possible. These beliefs and preconceptions affect both provider and client expectations, interactions, and decisions. Additional problems occur when the physician fails to recognize or appreciate the different frames of reference used by hearing and Deaf individuals when viewing many situations, including health care delivery. Deaf individuals may not perceive hearing loss as a disability and may have different goals and priorities in their health care treatment and their hearing health care provider.' (Harner 1999, p. 90)

The focus of the following sections moves from the health professional and back to the deaf client. Here we summarise some of the communication methods of relevance to deaf people.

Modes of communication

There are various discrete modes of communication that deaf and hard of hearing people use. The most common of these include: speech, National Signed Language (e.g.

British Sign Language – BSL, Irish Sign Language – ISL, Signed Supported Spoken Language (SSSL), which literally translates spoken language word for word into sign language, while maintaining the same word order as in the spoken language (e.g. Signed Supported English), lip/speech-reading, written notes and speech with finger-spelt cues.

Within a healthcare setting it is particularly important to recognise that fluency in language is not automatically necessary for fluency in communication. This means that body language, facial expression, gesturing and the giving and receiving of non-verbal cues may offer all sorts of information about what a person is feeling more so than language on its own.

Spoken language

The vast majority of people with a hearing loss have mild-moderate hearing loss. Such people will usually use spoken language as their main form of communication. Deafened people also use speech to communicate; this latter group may gain little use from hearing aids and so rely heavily on good communication skills from the person they are talking with. For both these groups of people there is usually a preference for having a healthcare consultation in speech together with a good level of deaf awareness on the part of the health professional (Middleton, Turner et al. 2009) (see later sections for details).

National Sign Language

Although it is socially acceptable for anyone to use sign language these days, it has not always been the case. In relatively recent times it was considered detrimental to the development of speech if sign language was used in education, many schools for deaf children were closed and a more oralist approach was adopted (Ladd 1988). This means that there are profoundly deaf adults who may have benefited enormously from sign language if they had been given access to it. Since they were not they remain on the edges of Hearing society, unable to fully communicate through speech and hearing because of the profound level of their deafness, but also on the edges of the Deaf World because they cannot use sign language.

National Sign Languages (NSL) and spoken language are not verbatim equivalents. NSLs have their own sentence construction, grammar and word groupings (Fischer and Hulst 2003).

For example, BSL and others, including ASL (American Sign Language), use specific positioning in front of the person signing to construct meaning, and a particular spatial position in conjunction with a sign will denote a specific pronoun (Ralston and Israel 1995). It would be unusual for a person using an NSL to use their voice while they are signing, but they may still mouth some words derived from spoken language at the same time. Therefore,

it would be atypical to deliver a spoken commentary while signing in an NSL. This is not the case, however, with Signed Supported Spoken Language (SSSL); because the signing is based on spoken language to start with, it is much easier to sign and speak concurrently.

National Sign Languages have their own dialects and local variations. For example, the BSLs used in Lincolnshire and Cornwall can be dissimilar at times, in the same way that regional spoken dialects can vary. Also, worldwide, sign languages vary from country to country, as each language has developed independently in the same way that spoken languages have.

When sign language is used, researchers report that different neural patterns are fired within the brain from those used by people speaking (Campbell, MacSweeney et al. 2008). Consequently there could also be different ways of processing memory and learning (Marschark 2003). This means that a deaf sign language user may have no differences in intelligence or educational ability from a speech user, but the way they receive, process and remember information might be different.

Sign Supported Spoken Language (SSSL)

Hearing parents and teachers of deaf children frequently use signs taken from an NSL together with their speech

when conversing with deaf children, as National Sign Languages are hard to learn. This is particularly the case if the child with deafness lives amongst a hearing family and sign language is not the main form of communication. This method allows deaf and hard of hearing children to learn to lip-read and also receive signed cues concurrently. SSSL (or Signed Supported English in the UK) tends to bridge a gap between the Hearing and Deaf Worlds and is mainly used by deaf and hard of hearing people who have come to signing later on in life or who mix most of the time in the Hearing World. People who would be considered part of the Deaf culture would usually use an NSL rather than SSSL.

Case study: becoming an SSE user

Marion was born hearing, but after getting meningitis at the age of 7 she lost some of her hearing. She went to a mainstream hearing school in Scotland, but never really felt as if she fitted in as she missed out on many of the conversations that her hearing friends had. Because of this she had hardly any friends at all and she felt really isolated.

At secondary school Marion met another child who had also had a similar experience and they became friends. This other child found a night-school class where it was possible to learn sign language. The class was run by a hearing teacher for deaf children and she taught them Sign Supported English (SSE). As spoken English was already a language they used and they were

(Continued)

quite good at lip-reading, the signs were easy to pick up as the teacher mouthed the English word at the same time as teaching the sign.

Within a year both Marion and her friend were fluent in SSE; this opened up a whole new level of communication and they realised that they could now begin to access the Deaf World. Although not fluent in BSL they had enough skills from the SSE to follow BSL conversations. This new language gave them the confidence to seek out others who used SSE and they joined a social club of local hard of hearing people.

Difficulties with speech

Spoken language is sometimes difficult for people with a congenital, profound level of deafness. This is because it is hard for the brain to process the use of sound if the ear has never been able to receive it. Lip-reading and speech-reading for a person who has never heard sound is therefore very difficult (Barnett 2002a). This may be addressed, to a degree, with specific training via education and speech therapy (Kaplan, Gladstone et al. 1993 in Ralston and Israel 1995).

Children from Deaf families who have been raised using sign language as their main form of communication may not experience the concepts of speech until they start school.

This may also be true for hearing children of deaf parents who have had little exposure to spoken language prior to starting school. Research has shown that it is possible for a hearing child to develop normal speech and language from within a Deaf family if they have interaction with hearing speakers approximately 5–10 hours per week (Schiff-Myers 1988 in Israel and Arnos 1995).

This means that, within a healthcare setting, very little communication through the spoken word may be possible. Therefore, it is vital that effective interpretation and/or communication support is available. Not only should this be for the actual clinic consultation, but also during pre-clinic contact with the reception and appointment staff.

Some people who have profound deafness may have received a high level of speech therapy as a child and thus may give the impression of good spoken skills. However, this has the potential to be misleading, as despite having the ability to use clear speech with excellent voice control, they may find it difficult to follow and receive speech in the same effortless manner. Consequently, it should not be assumed that the person who is deaf understands everything that is being said to them and it is the health professional's responsibility to make sure that a two-way conversation is facilitated. Frequently asking the client to indicate whether they are following what is being said is important.

Case study: mismatch in receiving language

Yves lives in France with his wife Constance. He attends a pregnancy booking appointment with his wife. When he speaks to the midwife his voice sounds monotone and she can tell immediately that he is deaf. He talks very articulately at the beginning about how delighted he is that Constance is pregnant and how much he is looking forward to the birth of their new baby.

The midwife begins to talk to Yves and Constance (who is hearing) about the pregnancy and possible screening tests. She directs her conversation mainly to Constance and she gets the impression that Yves must be following what she is saying as he is nodding as she is talking. Yves quietens down and when she asks at the end whether there are any questions, Yves does not answer. The midwife asks again whether there are any questions and Yves says that he didn't follow any of the conversation and asks what she was talking about. The midwife had misunderstood the cues she was getting from Yves and had assumed that just because she could easily understand his speech that he could understand hers.

Comments

The midwife needed to adapt her communication style with Yves. This could have involved paying particular attention to using clear lip-patterns, facing him all the time so that she could be clearly seen, starting at the

beginning what she was going to talk about and highlighting when she was going to change topic, rephrasing key messages and checking understanding throughout. She also should have checked at the beginning as to whether he was happy to just lip-read or whether he needed a lip-speaker or other sort of interpreter present.

It is also not uncommon for some deaf and hard of hearing people to give cues that are interpreted by a hearing person as meaning that they understand; for example, nodding. However, this may be misleading and a hearing person may wrongly assume there is more understanding than is actually the case.

Lip-reading

Lip-reading is difficult to do clearly as identical lip-patterns are often used with words which incorporate different sounds from the throat; these may be invisible to the viewer.

Lip-readers develop the ability to utilise many additional factors, such as tongue and jaw movements, gesturing and facial expressions to help with their understanding; collectively this is also known as speech-reading (Kaplan, Bally et al. 1987 in Ralston and Israel 1995).

Many words and sounds look exactly the same on the lips but may have completely different meanings. In fact less than 30% of English sounds can be clearly lip-read (Harmer 1999). For example, it is

(Continued)

virtually impossible to lip-read a difference between 'fifteen' and 'fifty' (Harner 1999). 'Where there's life there's hope' and 'where's the lavender soap' is another example of messages that are incredibly difficult to discern without the help of the voice.

The importance of giving clear lip-patterns is therefore obvious when communicating with lip-readers. This also includes not obstructing the face, e.g. by covering the mouth with fingers or hair, and not chewing food. Eye contact is also important and it is imperative not to turn away the face to look at a set of hospital records or a computer screen.

Case study: communicating with a hearing aid user

Elaine is Canadian. She started to lose her hearing in her 40s. She finally admitted she couldn't hear well when she turned 50 and asked her GP for a referral to have her hearing checked. She had a moderate, progressive hearing loss diagnosed at the local Audiology department. Elaine had to attend numerous hospital appointments to have a hearing aid fitted and checked and for her case to be reviewed. Once the most appropriate aid was found and was adjusted so that it worked well, Elaine found that she could hear again and was overjoyed that her 'disability' was resolved.

In one of the appointments at the hospital, Elaine arrived by car and couldn't find a parking space, and so she approached a member of the security staff to find out where she should go. The security advisor saw Elaine's hearing aid and assumed she must be deaf or hard of hearing and so spoke to her very slowly, exaggerating his lip-patterns and raising his voice. He had seen his mother speak this way to elderly relatives and so assumed that this was appropriate for Elaine.

Elaine winced as her hearing aid amplified this sound; she could hear him perfectly without his needing to speak louder. In addition to this the exaggerated lip-patterns were most unhelpful as they distorted his speech. Elaine said to the security advisor that she could hear him fine without his needing to change anything in the way he spoke, but she did say it was helpful if he faced her so that she could see what he was saying. They then continued to have a pleasant conversation about the difficulties of parking at the hospital.

Comment

A hearing aid user relies on a whole mixture of skills when listening to someone using speech. Not only are they utilising the amplified sound via the hearing aid, but they are also using visual information, gained through non-verbal cues, for example via the expressions on the speaker's face as well as their lip movements. Exaggerated lip-patterns and an increase

(Continued)

in volume may not only interfere with the way the hearing aid amplifies speech but may also distort the lip-patterns, so affecting how these are read. There are many hearing aid users who can cope fine with just their hearing aid alone, but it is still helpful to offer additional communication support through paying extra attention to helping with lip-reading.

One factor that significantly helps lip-reading is being able to predict what the conversation will be (Harmer 1999). For example, if waiting in a queue at a fast-food restaurant it is predictable that the first question from the staff will be 'what can I get you today?'

It is therefore helpful in a conversation with a lip-reader to offer signposting to the conversation. For example, 'I'm going to ask you about your diagnosis first then we can discuss your treatment options'.

Reading/writing skills

As signed languages are not a literal translation of written and spoken language, deaf sign language users may find it difficult reading written text as this is in their second language and they will have to translate it. These difficulties are in no way due to intellectual incompetence

but more probably due to difficulties in receiving the most appropriate education to overcome such issues. This is an incredibly important point for clinicians to recognise, particularly if they are looking to see whether there is a syndromal cause for the deafness in the client they are seeing – it is very relevant to know whether the person who is deaf has learning difficulties. They may inadvertently assume they do, on sight of some written material in the deaf person's writing, when in fact the person who is deaf is just conversing in their second language.

Research from Europe and the USA indicates that deaf children of deaf parents achieve more educationally than deaf children of hearing parents (Stephens 2005). This has been confirmed by a recent large-scale study in the UK (Fortnum, Barton et al. 2006). The reasoning behind this finding is that deaf parents offer positive role models to deaf children and also have prior knowledge of how to solve communication problems. They also know more about deaf education than most hearing parents do because they have personal experience of it themselves. All these factors appear to influence better academic achievement for deaf children.

Written materials provided for deaf clients should be considered carefully for ease of translation into sign language. Where it is not possible to use anything other than something written down, this needs to be structured in plain English and thought needs to be given to the sentence construction (keep sentences short without meandering) and language use (no jargon).

There are companies that will translate written material into plain English specifically for sign language users for a fee (see list of websites at the end of the book). Where possible, written materials should also be provided on DVD in sign language. Again there are companies that will create such DVDs within a 24-hour turnaround time.

The genetic counselling team at St Mary's Hospital in Manchester, UK, set up a specific clinical service for deaf clients and their families. They appreciated that the department's existing written leaflets giving details about the clinic and what to expect from the service were not immediately accessible to their deaf clients who used sign language as their first language. They therefore employed a team of Deaf interpreters to translate the written text into BSL. These translations were videotaped and back-translated by an expert in sign language to check for accuracy and understanding. A DVD and video were then created to hand out to potential clients delivering the information in BSL together with a voice-over in spoken language and subtitles (Belk and Middleton 2004, Belk 2006). This is a very useful tool for providing equal access to services and also complies with the UK Disability Discrimination Act (1995).

Not only should client information be provided in plain English or in an NSL on DVD, but so too should consent forms and questionnaires that are used to collect client

information, for example the Cancer Family History form often used within genetic counselling.

Using written notes in a consultation can be incredibly helpful for people who use speech as their main language. However, for those who use sign language, written notes in a consultation may be more of a hindrance as the person may struggle to read and process them.

A busy health professional is also likely to write in a briefer manner in a written note, given the time it takes to write one, than they would be if they were explaining in speech (Harmer 1999). This means that a deaf person, particularly a sign language user, is receiving their medical information not only in a language they do not routinely use, but also in a shorter form than their hearing counterpart would receive. It is not difficult to see that this means a standard service is being provided.

If a client uses sign language as their first language there is no excuse whatsoever for not booking a sign language interpreter for the healthcare consultation.

Meador and Zazove give an example of what happened in a surgical consultation when no interpreter was booked and the Deaf sign language user had to try and communicate by translating the doctor's handwritten notes:

(Continued)

"The physician wrote, "You may need surgery". The client understood this to mean, "You need surgery in May". In ASL, the English sentence, "You may need surgery" would be signed, "You maybe need surgery". In ASL, the English sentence, "You need surgery in May" could be interpreted as "You (in) May need surgery."'" (Meador and Zazove 2005, p. 219)

Hearing Dogs for Deaf People

Hearing Dogs for Deaf People are working dogs that assist their owner by alerting them to specific sounds, e.g. the telephone ringing or a tannoy announcement.

In the UK the owner has a right to bring them into any public place, including hospitals and health settings where their owner may need assistance. When working they should not be petted nor given any specific attention.

However, offering them a bowl of water is acceptable, just in the same way as one might offer a hearing interpreter a glass of water while they are working!

In the UK, Hearing Dogs for Deaf People wear a burgundy jacket, whereas dogs working for other groups, e.g. for disabled or blind people, wear different-coloured jackets.

Planning a deaf-friendly service

If health professionals are planning on overhauling their current environment so that it better suits their deaf clients

then it would be most helpful to do this with input from the client group who are going to use it. In order to do this properly it may be appropriate to bring in an external, deaf awareness or deaf equality consultancy service to look at what is currently available and make recommendations. Those companies that are run by deaf consultants and provide training by deaf people are often the most enlightening. Another related nuance is that deaf sign language users will have slightly different awareness needs from hard of hearing speech users and so consideration should be given to this.

Recommendations may include a financial investment to provide video-telephones, a minicom,² a designated phone that can send and receive text messages and access to the Internet. Internet access could provide access to email, MSN messenger, Sightspeed and Skype³ as well as online interpreting services.

² The minicom is a telephone used by deaf and hard of hearing people, using written text as the mode of communication. In the past, it was recommended that organisations interfacing with deaf and hard of hearing members of the public should all have a minicom; however, more recently it has become recognised that many deaf and hard of hearing people prefer to use mobile phone texting or emails. If the hearing staff are not familiar with using a minicom and deaf clients prefer to use other forms of communication then the minicom may be a pointless expenditure.

³ MSN messenger, Sightspeed and Skype are all examples of software that allow video-conferencing to take place over the Internet. Thus they are ideal ways for sign language users to communicate visually without the need for written language.

Such services could be used for booking appointments instead of using a telephone service. It is important to offer a choice of communication methods, for example, making email and texting available to book clinic appointments. It may also be necessary to fit a visual noticeboard, for example, to indicate when the next appointment is ready, in addition to an induction loop for hearing aid users.

Together with the practical items that should be installed it would also be important for all front-line administration staff, including the receptionist, who is the first person all clients see when they walk in the front door, as well as the administrator who books the clinic appointments, to receive some deaf awareness training.

Again, this can be organised by an external consultancy or there may even be in-house training if the department is in a large, teaching hospital, which is likely to have a designated disability awareness officer. Deaf awareness training is obviously of the utmost importance also for the clinical staff too. Refresher courses should be available to update skills and make sure that new staff are trained.

Before the healthcare consultation

It is important to appreciate that a deaf person cannot begin to communicate if they cannot see the health

professional or the interpreter (Barnett 2002a). This means that if they are waiting in the waiting room they will not hear their name being called out and will not pick up cues that it is their turn unless specific eye contact is given, perhaps by the receptionist or health professional approaching them directly when it is their turn.

Alternatively, visual cues can be used. For example, a number could be assigned to each client as they arrive; this number could then be displayed clearly in the waiting room when it is the client's time to be seen. Alternatively an electronic noticeboard could be used, where the client's name is shown as soon as their consultation is ready. This latter approach can work effectively but may not be completely satisfactory as all clients' names are very publicly declared to all present, which could be seen as breaking a level of confidentiality. Another effective tool could be to give each client a pager on arrival in the clinic which then vibrates when it is their turn to see the health professional.

A very simple solution to help deaf and hard of hearing clients in the waiting room is to position all the seats so that they face the reception or the visual board so that it is very easy to just look up and see what is going on.

If the client is waiting in a consultation room and the health professional needs to enter, the client may not hear a knock on the door and so it is important for the health professional to gently open the door and establish eye

contact before entering (Barnett 2002a). It is also pivotally important that, if a physical examination is necessary, eye contact is established first so that the client is not suddenly surprised (Barnett 2002a).

Medical records should be clearly marked with the communication requirements of the deaf or hard of hearing client. In written medical records this could take the form of a bulleted list on the front cover, written in large type, which says, for example:

- Profoundly deaf
- Uses British Sign Language or uses a hearing aid and lip-reading
- Likes to use interpreters from local agency (tel. no)

Alternatively, if the medical records are electronic then it should be possible to put the above list on an auto-alert so that each time any computer entry is made against this client's name, their communication needs are given.

Preferences for communication in a clinical setting

Recent research has shown that Deaf people who use sign language have different preferences for communication in a clinic from those who primarily use speech as their first language (Dye and Kyle 2001, Middleton, Turner et al. 2009). This work shows that very few Deaf sign language users want a consultation in speech; most prefer to either use an interpreter or to have a consultation directly with a

signing health professional. Hard of hearing speech users may be content to have consultations in speech but only if there is a good level of deaf awareness on the part of the health professional. Very few speech users indicate they can cope with a consultation in speech alone that lacks deaf awareness (Middleton, Turner et al. 2009).

Health professionals need to be aware that there are a variety of ways that Deaf sign users and hard of hearing speech users prefer to communicate within a clinic setting.

Deaf awareness

There are a large number of publications indicating that health professionals consistently lack deaf awareness skills (Steinberg, Sullivan et al. 1998, Hamner 1999, Munoz-Baell and Ruiz 2000, Ubido, Huntington et al. 2002, Lezzoni, O'Day et al. 2004, Meador and Zazove 2005, Steinberg, Barnett et al. 2006). The Royal National Institute for Deaf People in the UK has indicated that action is needed urgently to address this (RNID 2004b). However, such action does not seem to have been taken. Despite calls for health professionals to receive deaf awareness training (Department of Health 2005) it does not appear that this is happening in reality.

One of the biggest obstacles for health professionals is recognising that a client is deaf or has a hearing loss. This is particularly relevant for people who don't wear a hearing

aid or who have not yet acknowledged that they are losing their hearing. The health professional therefore needs to pay specific attention to assessing whether their client understands the communication.

Steven Barnett from the University of Rochester has written an excellent paper on 'Communication with Deaf and Hard of Hearing People: A Guide for Medical Education' published in *Academic Medicine* in 2002. He summarises the deaf awareness skills needed when communicating with different groups with deafness and this is quoted below (some of the language has been adapted for a UK audience).

Deaf awareness for deaf sign language users

Greeting

Welcome the client with a sign language greeting (or ask the client to teach you one).

Ask the client how best to communicate with him or her.

Environment

Room is well lit, and the light is not shining in the client's eyes.

People are positioned so that the client who is deaf can see the doctor and the interpreter.

Expressive communication

Work with a qualified interpreter.

Speak to the client, not the interpreter.

Topic changes are stated explicitly.
Note-writing and written materials may have limited usefulness.

Ask the client periodically about the quality of the communication.

Ask the client for periodic summaries to check accuracy of communication.

Receptive communication

Look at the client while listening to the interpreter.

When uncertain, ask the client (not the interpreter) for clarification.

Summarise the client's story to check accuracy.

(Barnett 2002a, p. 696)

Deaf awareness for hard of hearing speech users

Greeting

Ask the client how best to communicate with him or her.

Environment

Background noise is minimised.

[Health professional's] face is well lit.

Expressive communication

Eye contact is established before speaking.

View of mouth is not obscured (by hands, pens, charts etc.).

Adjust voice pitch if this helps.

Topic changes are stated explicitly.

(Continued)

Repeat information that is not understood. Rephrase if it is still not understood.

Use assistive listening devices (e.g. hearing aids, note-takers) if they help.

Note-writing may be helpful.

Ask the client periodically about the quality of the communication.

Ask the client for periodic summaries to check accuracy of communication.

Receptive communication

When uncertain, ask the client to repeat or clarify.

Repeat the client's statement to confirm comprehension.

If still unclear, note-writing may help.

Summarise the client's story to check accuracy.

(Barnett 2002a, pp. 695–6)

Case study: the importance of seeing the health professional's face

Helene was in the delivery suite of her local hospital about to give birth to her first child. The obstetrician felt the labour was not progressing as well as it might and that an emergency caesarean was necessary.

Helene was wheeled on her bed into an operating theatre and the medical staff began to put their gowns

on. The obstetrician and anaesthetist both put their masks on and neither realised that Helene had a mild-moderate level of hearing loss and prior to this had been lip-reading them.

They were now in an urgent situation, which was made even more frightening for Helene as suddenly she had lost communication with the two key health professionals caring for her.

She was unable to consent to the epidural as she couldn't see the anaesthetist asking her about this and it was only when her husband stepped in and asked the doctor to remove his mask did they realise how significant this was.

Comments

One of the theatre nurses could have taken the initiative and stood in view of Helene, and she could have repeated what the medics were saying with clear lip-patterns. In such an urgent situation, when the medical priority is to deliver the baby and keep the mother safe, there is often no time to make large adjustments to allow for communication access. However, it would not have been too difficult for a member of staff to spend time with Helene, speaking to her face-to-face, to enable her to continue to participate in her care. The level of Helene's hearing loss should also have been noted by health professionals before an urgent situation developed.

In addition to deaf awareness training there is also deaf equality training, which has an emphasis on meeting the requirements of the disability legislation. There are companies that will tailor the training to the specific needs of the client (see websites at the end of the book). For example, GP practice managers and clinic receptionists would be given slightly different information on what needs to be provided in order to comply with the Disability Discrimination Act in the UK.

Communication in a clinical setting

In order to comply with disability legislation, health service providers must make all attempts to meet clients' communication needs. This means the provision of various aids for deaf people, such as investing in an induction loop for hearing aid users, allowing clinics to be booked via text or email and having access to online interpreters.

It also means using the preferred sort of interpreter, and not just booking one who uses an NSL. As will be explained below, there is a large difference between interpreters and communication support staff who use an NSL, SSSL, lip-speakers, note-takers and speech-to-text reporters and it is pivotal to pick the right one.

The client should be consulted about their preferences for type of interpreter but also, where possible, they should

be informed of the name of the interpreter. Interpreters are often well known within the Deaf community (as they may also be hearing children of deaf parents) and sometimes, particularly for a healthcare consultation, the client who is deaf may prefer to use someone they already know.

Alternatively, they may have strong preferences to only use someone who is unknown to them. Deaf clients also may prefer to book and bring their own interpreter. They may also prefer to have a specific gender of interpreter, for example, if the consultation is in a gynaecology clinic.

The healthcare service should always cover the cost of the interpreter's fees and travel and sometimes this may also include a booking fee if an agency is used.

Hearing children from deaf families are often used as informal interpreters for their parents. Whilst this may be the parent's choice out of desperation or lack of knowledge of interpreter provision, health professionals should resist this. The mental well-being of any child under the age of 16 should be paramount as they need to develop their own identity and establish a balance between the Deaf and Hearing Worlds (Myers and Marcus 1993 in Israel 1995). It is also possible that using a child as the interpreter will mean that biased information is delivered to the parent (Barnett 2002a), as the child may feel they need to protect the parent or shield them from some information. The

Deaf parent may also not wish to disclose sensitive information in front of their child.

Health professionals need to ask clients which communication methods they prefer to use in a clinic consultation; they also have a legal obligation to make attempts to meet these.

Types of interpreter and communication support

There are several different ways of interpreting information that are used to support communication for deaf and hard of hearing clients. For example, an interpreter might interpret information between an NSL or an SSSL and spoken language. Alternatively a 'communication support professional', such as a lip-speaker, can convert from spoken language into clearer spoken language and a speech-to-text reporter (STTR) converts speech into written text.

Finally, deaf relay interpreters may be used who convert sign language given by a hearing interpreter and turn this into a more personal sign language that is tailor-made for the client. This is particularly useful for deaf clients who perhaps have very little medical knowledge or language or who have visual problems and are unable to follow a hearing interpreter they do not know or one who is not used to working with visual disability. The way this works is that the clinician speaks, the hearing interpreter interprets this into an NSL and the deaf interpreter

translates the NSL into a more accessible NSL. The reason a deaf relay interpreter is useful is because they may have particular knowledge or understanding of an individual deaf client and the way they specifically receive signs.

Working with interpreters

As interpreters often work in many different settings, for example, in social services, the legal system or in signing performances at the theatre, it is vitally important to clarify that they are comfortable working in a medical situation.

If the health professional has not worked with an interpreter before or has not worked with a specific interpreter who has been booked for a consultation, it is pivotal to arrange a pre-clinic contact either in person or over the phone to discuss what to expect of the consultation.

A rehearsal of the language to be used is of paramount importance so that the interpreter can check their own understanding and practise the phraseology they plan to use. It is not necessary for the health professional to divulge copious amounts of private medical information about the client who is deaf ahead of the consultation. However, particularly if startling or unexpected news is to be conveyed, it can be helpful to forewarn the interpreter of this so that they can be prepared to deliver this information exactly as the health professional intends.

When working with interpreters, it is important for the health professional not to presume that all of their words and gestures will be translated word for word or even concept for concept with the same tone and inflection of speech.

There are likely to be some differences, and it is important to keep an eye on the interpreter so that it is possible to see whether they are keeping up and whether it would be useful to slow down. It is worth pausing between changes in topic so that there is time for the interpreter to catch up and also so they can indicate such a change to the client. The hearing health professional needs to be aware of working *with* the interpreter so that together they can get across the messages that the clinician intends.

It is not unusual for a deaf client to sometimes look to the interpreter for support or comfort, almost as if the interpreter is their ally and advocate. This is not the interpreter's role and in the healthcare setting it is the health professional who needs to be supporting the client if this is needed.

The process of interpretation of NSL into speech involves a complex process of reading the signs used, facial expressions (which offer grammatical information) as well

as spatial positioning of the hands and body. The interpreter may sometimes have to 'fill in the gaps' of what is being signed to make sense of the message in spoken language.

Inexperienced interpreters can sometimes succumb to the subconscious pressure from a vulnerable client to support them; this may mean that they 'fill in the gaps' in the interpreting process more than usual, trying very hard to make sense of what a deaf client is signing. However, if that deaf client has mental health or psychiatric issues then it is vitally important that no gaps are filled in and that the interpretation is as true to what the deaf client is expressing as possible.

For this reason it is therefore very important for health professionals to discuss this issue before a consultation and also have a de-briefing session after the client has left to clarify whether the interpreter feels that the client is confused or talking in riddles.

The RNID and British Deaf Association (BDA) provide several factsheets on working with interpreters (see www.rnid.org.uk and www.bda.org.uk). The following sections are based on this information and full credit is given to these organisations for this.

Most UK hospitals have access to registered interpreters through an agency they have a contract with. However, it

may be preferable to get to know and use the local freelance interpreters, who usually charge less than agencies. Agencies may also send a different interpreter for each consultation, whereas getting to know a local freelancer may mean that there is an opportunity to build a stronger rapport and thus a greater knowledge base of what exactly is required. A consultation that is expected to last more than 30 minutes may require two interpreters due to the demanding nature of the work. The normal pattern is that interpreters require a break approximately every 30 minutes.

In addition to discussing the content of the consultation with the interpreter prior to the client arriving, it is also expected that there would be a discussion about the seating arrangements within the room. This would involve consideration of the acoustics, position of the light so as to ensure they and the health professional are not in shadow, ensuring there is enough space for hand movements and making sure that the health professional and interpreter can be seen at the same time.

The British Deaf Association recommend that health professionals allow at least 8 weeks to book an interpreter; if there is less time than this then it is likely that interpreters will already be booked. As well as requiring an overview of the general themes to be discussed prior to the

pre-clinic contact, interpreters will also need to know the number of people who are deaf and the number of people who will be attending the consultation. The BDA also suggest the following protocol for using an interpreter (British Deaf Association 2005).

- Talk directly to the Deaf person. Correct: 'Did you have trouble finding us today?' Incorrect: 'Please ask if s/he had trouble finding us today.'
- The spoken side of the interpretation is called the 'voice-over' and will always be in first person, e.g.: 'I had no trouble finding you; your directions were very clear.' The Deaf person is 'speaking' with the interpreter's voice.
- Look at the Deaf person and not the interpreter. Maintaining good eye contact will reinforce the feeling of direct communication.
- The interpreter will not take part in the discussion, and is impartial. During the communication, do not ask an interpreter for their opinion or advice.
- The interpreter relays what they hear, so the Deaf person has full access to all communication. Do not say anything you don't want everyone to know!
- The interpreter will interrupt if they need something to be repeated or clarified. Equally, if you are not sure of something, you can ask the Deaf person to repeat or rephrase it. If you think the interpreter may have misunderstood or missed something, it's fine to ask to go back and find out for sure.

(Continued)

- Position the interpreter close to the main speaker if possible, and clearly visible to the Deaf person. The interpreter should be well lit, but not from behind – so do not put them in front of a bright window!
- Don't be put off if the Deaf person doesn't watch you when you are talking, because they'll be watching the interpreter.
- The interpreter can only listen to or watch one person at a time, so – as with any communication – it is important to take turns and not talk over each other.
- Speak clearly at your normal pace. Interpretation is almost simultaneous, but there will be a slight delay as the interpreter picks up the meaning of a phrase. If you usually speak very quickly, you may need to slow down a little (the interpreter can advise you). Allow time for Deaf people to respond or ask questions.
- Afterwards, as part of the feedback process, check with the Deaf person whether interpreting arrangements were satisfactory, and whether they would be happy to use the same interpreter again. If you have suggestions for improvement, tell the interpreter or the agency.

(British Deaf Association 2005)

- Interpreters are highly qualified professionals who spend many years training to achieve acknowledged qualifications, for example via the UK

organisation Signature (which used to be the Council for the Advancement of Communication with Deaf People).

- There are some who do not achieve such standards who advertise themselves as available to interpret but they have only completed a BSL Level 2 training (intermediate). A sign language user with this level of training is unsuitable to interpret for a medical consultation and should not use the term 'interpreter'.
- It is very important to book an interpreter who is, for example, registered with the National Registers of Communication Professionals Working with Deaf and Deafblind People (NRCPD, relevant for interpreters from England, Wales and Republic of Ireland). Other countries will have similar registers of interpreters.
- Signature have an online directory of qualified interpreters and communication support professionals for the UK (see www.signature.org.uk), which includes: BSL/English interpreters, lip-speakers, speech-to-text reporters, electronic and manual note-takers and LSPs – Deafblind Manual. This latter communication involves using a 'deafblind manual alphabet' and spelling out words and visual information onto the deafblind person's hand. There are qualifications and a register of professionals from each of these categories. There are likely to be similar organising bodies elsewhere around the world.

When looking through the Register of BSL/English interpreters in the UK, choose someone who is a full member, i.e. not a 'junior' or 'trainee' member. A full member will be fully experienced in working in sensitive situations, as found in healthcare.

Lip-speakers

'Lip-speakers' are 'communication support professionals' who help deafened and hard of hearing people who prefer to use speech to communicate. They do not use their voice but mouth the words being said by the hearing person, using very clear lip-patterns and often with the addition of finger-spelling and use of single finger-spelt letters. Everyday speech uses up to 200 words a minute; this may mean that it is difficult for a person who is lip-reading at this speed to absorb all that is said. The lip-speaker will often use fewer words but with the same meaning. As with other forms of communication support this is very skilled and extensive training is required.

Text-based communication support

The RNID have produced an excellent series of information leaflets on the options for assisting deaf people with communication (see www.rnid.org.uk). The following sections summarise some of these leaflets and credit is given to the RNID for this.

Translating spoken language into written text can take several different forms. An electronic note-taker uses a computer to type up a summary of the spoken conversation; not every word is turned into written text. There is usually a time-delay between the speech and the written notes appearing. It is possible to network another computer to the note-taker's so that the person who is deaf can join in with a text conversation. In the UK, if the note-taker uses RNID SpeedText[®] then a real-time conversation can occur, as every word can be typed without the need to summarise it.

Speech-to-text reporters (STTR) enter words phonetically into a software program and these are then converted into full written text. This enables the reporter to deliver text in real time without delay although it requires high-speed reading in order to keep up.

STTRs use Palantype[®] or Stenograph[®] in the UK; these are both trade names for the specialised keyboards and associated software used by the STTR.

There is discussion within the interpreting arena as to whether lip-speakers and others who convert, for example, spoken English into other forms of English are actually 'interpreting' as such. What lip-speakers and note-takers do is re-present English in a different English format, whereas with interpreting, for example, from BSL into spoken English, the interpreter uses his or her skills to create the most accurate interpretation of what is being signed, reading facial expressions and body language in addition to the actual signs being used.

Online interpreters

When face-to-face interpreting is not feasible, perhaps because a previously booked interpreter has cancelled at very short notice or because the hospital appointment is likely to be very short, online interpreting can be very useful. It is by no means a substitute for having a face-to-face contact, but it is certainly very helpful when the alternative is to have no interpreter. All the health professional needs is access to a computer, webcam or even videophone.

For access to interpreters via the web there are companies that provide live online interpreting (see websites at the end of the book for details).

Communication over the telephone

Relay telephone systems (e.g. Text Relay in the UK) use an operator to type speech from a hearing person which is then relayed to the person who is deaf via their minicom or computer. The minicom is a telephone which uses text instead of speech as the form of communication and is still used by some deaf people (particularly those from an older generation). Over the last 20 years there has been a great expansion in the technologies available to support and enable d/Deaf people in their communication; see

Harkins and Bakke (2003) for an overview. This technology should be incorporated into clinical practice and more importantly a choice should be offered.

It is not unusual for deaf people to have very high levels of technological literacy. This may involve the routine use of the iPhone and Blackberry to check emails on the move or use of the Internet and a webcam at home. Text messaging received via a vibrating alert is part of daily life; videophones/video messengers, such as MSN messenger, Skype or Sightspeed (a video-conferencing facility), offer easy methods of contacting deaf clients via a computer.

Voice-to-text software

The use of voice-to-text software in a healthcare setting is becoming increasingly popular; as the technology continues to improve it is likely that it will become much more widely available. Not only can it be used to help the health professional with dictation and writing up post-clinic notes, it can also be used in the actual consultation to help people who have difficulty hearing what is being said. All that needs to be done is to position the computer screen so that it can easily be seen by the client, minimising glare from a window or overhead light, and change the size of the text so that it is large enough to be clearly read.