A Guide to Working with Deaf People in a Health Setting

Best Practice Guide

B·I·D SERVICES

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Foreword

Picture the scenario - you are holidaying in a remote part of the world where people communicate in a language in which you are not familiar. You suddenly find yourself having an illness of a serious nature yet you are unable to discuss your condition because the medical professional treating you have very little knowledge or understanding of your language. It is very likely that you would feel alarmed and worried that you were not able to communicate information about your condition. Now consider this - every day, such a scenario is experienced by deaf people in the UK. Like hearing people, deaf people need in depth and accurate information on their health too, so they can feel included in their medical care.

Unfortunately, the majority of health professionals do not have the necessary communication skills or knowledge of deaf awareness to meet the needs of deaf patients. This often results in deaf patients feeling excluded from decisions about their medical care. This needs to change. We would like to see a world in which the communication needs of deaf people are acknowledged and addressed by those responsible for providing services.

This booklet developed by the charity BID Services, seeks to provide information and advice on how to communicate effectively with deaf, deafened and hard of hearing people in a medical setting. It provides practical advice on how to bridge the gap between the deaf patient and the care professional and to enable both to work together to provide a sensitive and responsive service to deaf people and their families. I would like to thank BID Services who, as part of its Deaf Cancer Care Project in conjunction with Macmillan, developed this very useful guide.

Kind regards

John A. Hay, MBE

Introduction

Modern healthcare places great importance on giving people information to allow them to make healthy choices. Hearing people are bombarded with advice, but we have found a lack of even basic health information in British Sign Language (BSL).

Here are some of the statistics:

"In this internet enabled world of connectivity, 45% of Deaf people still have to walk into their surgery to make an appointment. When sign language users finally get to see their doctor, they are forced to communicate in ways that cause confusion, misunderstandings, missed diagnosis and poor treatment. 8 in 10 Deaf people want to use sign language, yet only 3 in 10 are given the chance."
(SignHealth, Sick of It Report 2014).

"There is a likelihood of reduced life expectancy in Deaf People."
Researchers at the University of Bristol in partnership with SignHealth.

"Missed diagnosis and poor treatment is costing the NHS £50 million a year."
Health Economists at the University of East Anglia, commissioned by SignHealth.

People who are deaf, deafened or hard of hearing often cope with communication difficulties in everyday life situations. Where there is deafness, challenges exist for both the patient and those providing the care.

Healthcare professionals need to obtain information and give advice, and patients need to ask questions and share their concerns. Therefore, to provide an equitable service for deaf people, it is vital that their communication needs should be acknowledged and addressed by those responsible for providing services.

This guide seeks to provide information and advice on how to communicate effectively with deaf, deafened and hard of hearing people. It provides practical advice and seeks to raise awareness of the issues faced by deaf people when communicating in a hearing world.

For the purpose of this guide and ease of reading, the term "deaf" is used as a general description to refer to those who are deaf, deafened or hard of hearing.

About BID Services

BID Services is a charity. We work in partnership with people with a sensory impairment, as well as those with a physical disability or mental health. Our mission is to provide high quality services and opportunities that make it possible for people to have choice and control over their lives. An important part of our work is to deliver deaf awareness training and British Sign Language courses to a range of organisations and professionals.

Our specialist service areas include Advocacy, Employment British Sign Language Interpreting and Training, Deaf Awareness Training, Specialist Equipment, Residential placements, Social Work, support for Tinnitus and Housing related Services. We work with children, young people and adults. For more information, visit our website www..bid.org.uk.

Our Mission

"We're here to make a positive difference to the people we support by offering a range of innovative services that empower people to control their own lives."

"BID Services can provide tailor made British Sign Language courses & Deaf Awareness training, especially aimed at Health & Social Care Professionals."

What is Deafness?

Deafness is the result of damage to any part of the ear and the degree of hearing loss depends on the severity of that damage. The implications of a hearing loss vary from person to person and are related to the individual's circumstances, thus making it difficult to define and classify deafness.

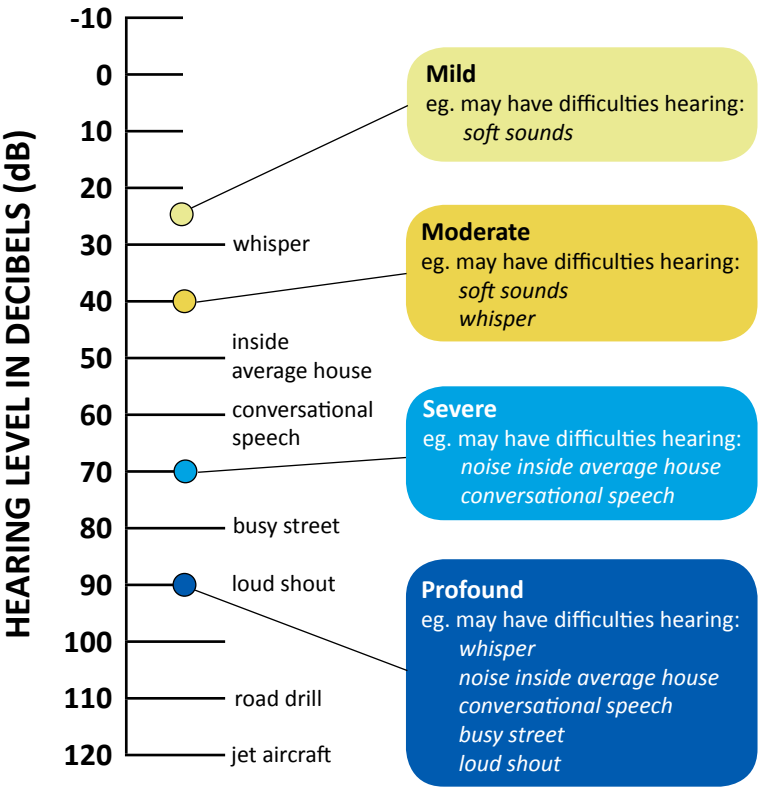
Deafness means that the person has some difficulty hearing sounds. Deaf people often cannot speak clearly. Many with a severe to profound loss may not be able to speak at all. Deafness can be seen as a communication impairment rather than merely a loss of sound perception. Therefore it affects all personal, social, educational and business situations.

There are various communication methods that are preferred by deaf people and this section of our booklet will explain the terms and definitions regarding deafness, as well as providing an introduction and summary of the preferred language of deaf individuals along with the various methods deaf people use to communicate. Terms such as 'deaf and dumb' have been replaced by more accurate descriptions, such as profoundly deaf, deafened and hard of hearing and these are now widely accepted within the Deaf community.

"The greatest difficulties faced by deaf individuals are related to problems of language acquisition and the development of a communication system."

Degrees of Hearing loss

Some medical terms that are commonly used to measure and explain the different ranges of hearing loss.



Statistics

This section gives you quick access to the main headline statistics about deafness, hearing loss and tinnitus in the UK.

The total population of the UK is estimated to be around 64.1 million (Based on National Statistics 2013).

There are more than 10 million people in the UK with some form of hearing loss, or 1 in 6 of the population.

From the total, 3.7 million are of working age (16 - 64) and 6.3 million are of retirement age (65+).

By 2031, it is estimated that there will be 14.5 million people with hearing loss in the UK.

More than 800,000 people in the UK are severely or profoundly deaf.

There are more than 45,000 deaf children in the UK, plus many more who experience temporary hearing loss.

More than 70% of over 70 year olds and 40% of over 50 year olds have some form of hearing loss.

There are approximately 356,000 people with combined visual and hearing impairments in the UK.

About 2 million people in the UK have hearing aids, but only 1.4 million use them regularly.

At least 4 million people who don't have hearing aids would benefit from using them.

On average, it takes ten years for people to address their hearing loss.

About 1 in ten adults in the UK have mild tinnitus and up to 1% have tinnitus that affects their quality of life.

* above information taken from Action on Hearing Loss: 2014

Professionals need to be aware that Deafness is a hidden disability and may not be a presenting factor

Communication Difficulties

Access to services is a common barrier faced daily by many deaf people. Something simple, like seeing a GP or attending hospital appointments can cause difficulties for many deaf people.

The main barrier faced is often that of communication. An all too common example are health issues, where deaf people could be misdiagnosed or receive the wrong medication due to poor communication. This is often because symptoms cannot be fully explained without appropriate and professional communication support. The result of a lack of good communication can and does have very negative effects on deaf people's physical and mental health. These experiences could be greatly improved through effective communication, knowledge and techniques and would open up services currently widely available to all, such as support, counselling and advocacy groups.

"I can lip-read quite well, but when I visit my doctor, she does not always look at me, so I find it very hard to understand what is being said."

Methods of Communication

British Sign Language (BSL)

BSL is a visual-gestural language which uses hand shapes, facial and body expression and gestures to express meaning. The meaning of a sign varies depending upon how it is made, where it is placed and the facial or bodily expressions and movements which accompany it. BSL has no written form, although there is a linguistic notational form used in the BSL/English dictionary. Like many of today's languages, BSL is constantly evolving as new signs are developed in the same way that new words are introduced into spoken languages. BSL is widely used by those who are pre-lingually deaf, or by those that find it the most effective form of communication.

In the UK, BSL is a language in its own right and has been officially recognised by the Government since 2003.

Sign Supported English (SSE)

In addition to people who use BSL as their preferred language some deaf people, especially those who were educated in a spoken English environment or who became deaf after acquiring spoken language, may prefer to use Sign Supported English (SSE). SSE is commonly used in education to support teaching.

SSE uses signs from BSL but with English grammar. It is not an independent language and the use of English to BSL signs and features will vary depending on the linguistic skills and knowledge of individual users. If English is the person's first

language they will often use signs taken from BSL but apply them in English word order accompanied by lip patterns. When using SSE, you speak and sign at the same time and the signs are actually used to support the spoken word. Many deaf people will use SSE as an aid to lip-reading.

Lip-reading

Lip-reading is 'reading' the visual clues of a spoken message. This is not just limited to lip patterns and also includes movements of the lips, tongue, the lower jaw, the eyes, the eyebrows and facial expression, body language and gesture as these are all clues to the lip-reader. The lip-reader will also observe the syllables, the natural flow, rhythm, phrasing and stress of speech. Lip-reading is not an exact science and, depending upon the skill and understanding of English, lip-readers will understand about 30 - 40% of the conversation; the rest is guess work by linking the sentences together. Ordinary speech is often very rapid, and the average lip-reader will not be able to see all the shapes of speech sounds. When the speaker talks faster than normal, lip-reading becomes even more difficult. Lipreading is hard work and tiring.

Reading lips can be particularly difficult under the following circumstances:

- Mumbling, fast speech or shouting
- Poor lighting
- Subject turns away, walks to and fro, or nods
- Hands are placed in front or over the mouth
- Eating, drinking or smoking whilst talking
- Moustache and/or beard

It becomes easier to lip-read when there is:

- Suitable lighting
- Face to face communication – suitable distance (3ft – 6ft)
- Eye contact
- Facial expression, body language and gesture
- Rephrasing - using sentences rather than individual words

"Many words look the same on the lips, like bat, pat and mat whereas other words produce no lip pattern at all. Without clues from the topic of conversation, residual hearing and the co-operation of the speaker, the deaf person may understand little of what is being said to them, increasing the chances of misunderstanding."

Hands on signing

Based upon British Sign Language, this method of communication allows the deafblind person to follow the flow of signing by placing his or her hands on top of those of the signer and feeling the signs as they are formed. This method of tactile communication is used predominantly by a small number of the deafblind community who used BSL as their main form of communication prior to losing their sight.

Deafblind Manual Alphabet

The deafblind manual alphabet is a method of spelling out words onto a deafblind person's hand. Each letter is denoted by a particular sign or place on the hand.

Hearing aids

There are some deaf people who would prefer to wear hearing aids to communicate. Hearing aids can come in different sizes, shapes and types. Hearing aids are electronic pieces of equipment that are put in the ear which have a microphone to amplify sound. Hearing aids process varying levels of sound, meeting each person's hearing requirement depending on the hearing loss which can range from mild to profound. It is important to remember that hearing aids will amplify all sound received and can not distinguish between voices and background noise. A hearing aid will increase awareness to sounds including those sounds that a person may not wish to hear.

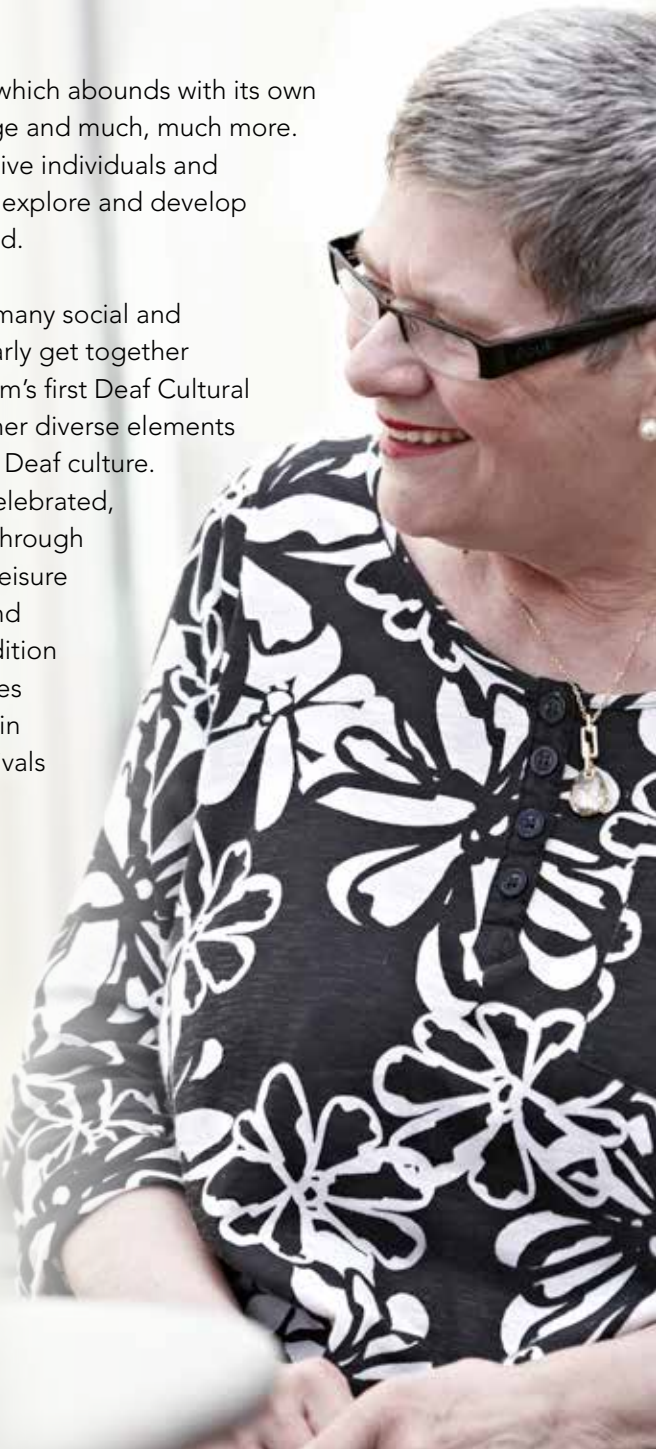
Some hearing aids are now available with fully digital technology. Unlike conventional analogue hearing aids, fully digital hearing aids can be tailored to process sounds that reduce background noise and improve clarity. There is another aid to hearing known as a Cochlear Implant, which is used to create sensory hearing for people who are profoundly deaf. There are two main parts to the cochlear implant: the internal component which is implanted during an operation, and the external component which is placed behind the ear.

Deaf Culture

There is a rich deaf culture which abounds with its own history, arts, sports, language and much, much more. It has a strong base of creative individuals and professionals who regularly explore and develop innovations in the deaf world.

Deaf people participate in many social and cultural activities and regularly get together in places such as Birmingham's first Deaf Cultural Centre, which brings together diverse elements of the Deaf community and Deaf culture. At the centre, deafness is celebrated, explored and represented through a series of community and leisure projects, arts, exhibitions and regular social events. In addition to this, the Deaf communities regularly arrange meetings in clubs, pubs and attend festivals which are commonly known to deaf people.

These are just some of the ways that deaf people explore their culture and shape the world around them, raising awareness of the barriers that they face in everyday life.



Working with Deaf Patients

As Health and Social Care Professionals, you will be well aware that when a person is facing a life-limiting illness they may require other additional forms of supportive care in addition to treatment. It is important that deaf people are able to access available support services if they are to receive equitable and appropriate care. Working effectively with deaf patients can ensure that supportive care is fully integrated with diagnosis and treatment. An effective multi disciplinary approach can ensure that the standard components of care are achieved. The following gives best practice advice for provider services to meet the needs of a patient who is deaf.

Assessment & Information sharing (diagnosis, treatment, and review)

- Provide access to the patient by using interpreting support, where required for each visit in order to ensure the patient participates and is fully involved and included in decision making.
- Don't make assumptions, ask the patient who they want with them during any appointments/consultations.
- Identify communication methods and preferences. Make a referral to relevant agencies to secure a qualified interpreter e.g. BSL, SSE, Lip speaker, etc. (see page 23).
- Provide information in a variety of mediums so as to be accessible in the patient's first language (e.g. BSL, visual means, recorded to DVD). (For information on translation services, contact BID Services).

- Do not assume that all deaf people wear hearing aids, can lip read or understand written English.
- As a professional try to ensure that you access bespoke Deaf Awareness Training where possible.
- Mark files to identify the patient's deafness and their preferred mode of communication.
- Ensure adequate time is allocated for appointments/ consultations.
- If using an interpreter please direct your conversation to the patient and not to the interpreter or other family/ friends who may be present.
- Please check the patient's understanding of the information given as they may not always have the confidence to ask for clarification or explanation.
- Avoid the use of jargon.
- Use visual methods to aid understanding such as drawings or pictures.
- Following assessment referrals to appropriate services may be required including specialised social work with deaf people.

Self Help & Support

- Self help groups may need interpreting support for deaf patients to make them accessible.
- Where there are significant needs or numbers of patients, dedicated and discreet groups can be established.
- Identification of deaf patients across local authorities will inform this process.

Psychological Support

- Some patients may require psychological intervention to help them cope with the impact of their illness and

to manage their associated feelings and fears.

- It would be beneficial to use the same interpreter consistently in order to maintain a good working relationship, and strive to make the patient feel more at ease, comfortable and able to participate.

Symptom Control/Rehabilitation

- Ask patients if they require interpreting support.
- Enable participation, involvement, control and decision making in symptom treatment, medication, contra indications etc.
- Offer patient rehabilitation options and consider how communication needs may be met.

Social Support

- Some deaf people will be dependant on deaf culture for their social interactions/networks. Access to these may be essential through this process.

Complimentary Therapies

- Provide information about these services in BSL, visual means or recorded to DVD so that the patient is given choice and control.

Spiritual Support

- Access to spiritual leaders of all denominations needs to be available and provision made via interpreting support where required.
- Hospitals and hospices already have allocated Chaplains who will be able to refer to the appropriate clergy who are deaf aware and have signing skills.

End of life and Bereavement Care

- Hospices, psychosocial and family support, Health and social care provision will require the interpreting and communication support described.
- Hospices and other support services providing care at the end of life need to ensure that they are able to communicate effectively with their patients. (See above for assessment, treatment etc).
- Consultation with the patient about their communication needs and preferences should be established. If using an interpreter try to use the same one where possible to ensure consistency for the patient.
- It is important to also consider the needs of the family and the support they require during the last months or days of their loved one's life and in their bereavement. Some family members may be deaf and require access to bereavement services and use of interpreters.
- 'After death care' - remember that family members who are deaf may require emotional support.

Local Authority (LA)

Each Local Authority provides a social work service to deaf people in a variety of ways. Contact your local Social Care and Health Sensory Impairment Team for more information and referral procedures.

Health Service

GP's and hospitals have a responsibility to provide communication support under the Equality Act (2010) in England, Scotland and Wales. This is essential for the purposes of diagnosis and treatment planning. Over 300 GP surgeries in England have access to a Sign Translate Service facilitating immediate interpreting support. This forms the initial basis for identifying deaf patients and their communication modes.

Local Deaf Centre/Clubs

There are a number of deaf clubs across the country. BID Services can signpost to these and other social networks.

Sign Language/Deaf Awareness Training

Signature offers information on local BSL courses and other organisations offering Deaf Awareness Training for professionals (see page 27).

Other Organisations

There are both local and national organisations that provide services, information and guidance for working with deaf patients including Action on Hearing Loss, the National Deaf Children's Society (NDCS), etc. Refer to local directories for further details. Some of these are Charities, Third Sector and Voluntary Organisations (see page 27).

Interpreting Services

Interpreting is a recognised profession. Interpreters and other communication professionals have been trained to a very high standard over many years and have a wealth of experience of working in a wide range of domains.

When booking a communication professional, it is important to employ someone who has the correct qualifications and is registered with The National Registers of Communication Professionals working with Deaf and Deafblind people (NRCPD). Conditions of registration include achieving a recognised qualification; meeting safe to practice standards and working to a strict professional code of practice. In addition, where required to by registration, Disclosure and Barring Service checks are provided (DBS) Enhanced Disclosure certificate, and Professional Indemnity Insurance (PII).

Minimum Recommended Qualifications

English/BSL (or SSE) Interpreters:

- Member of the Register of BSL/English Interpreters (MRSLI)
- Trainee Interpreter (TI), or a
- Junior Trainee Interpreter (JTI)

*Lipspeakers:

- Registered Level 2 Lipspeakers
- Member of the Register of Level 3 Lipspeakers

*Deafblind Language Service Professional:

- Level 4 Certificate in Deafblind Interpreting (Manual)

*Notetakers (Manual and Electronic):

- Registered Level 2 Notetakers
- Member of the Register of Level 3 Notetakers

*Speech to Text Reporters:

- Member of the Register of Speech to Text Reporters

*It is not compulsory to supply evidence of DBS Enhanced Disclosure and Professional Indemnity Insurance (PII). (Please note Employers are responsible for checking DBS information).

BID Services offers communication professionals who meet the above criteria and who can be booked when communication with a deaf person is required. We also offer Deaf Awareness training and British Sign Language courses. Dependant on the needs of the deaf person, different kinds of communication professionals can be used. In a sensitive setting such as medical appointments, clear and total communication between medical professionals and patients is important. As a patient, you would expect nothing less than complete communication about your health. With help from a communication professional, you can ensure that your deaf patients get the same high quality of care.

By using services provided by registered professionals you can clearly demonstrate a commitment to meet responsibilities to provide equal access under human rights and disability discrimination legislation.

Working with an Interpreter

Here are some points to bear in mind when working with an interpreter.

Speak at a steady regular pace - too fast, the interpreter may not be able to keep up. Too slow or waiting for the interpreter to catch up is not helpful as they may need a whole message before it can be translated.

A deaf person can find it difficult to concentrate on an interpreter for long periods of time - This is because it involves constant eye contact in order to obtain the message. Therefore a deaf person may need more breaks than the average hearing person.

In group settings - it is useful for all participants to raise their hands in response to answering questions or making comments so an interpreter can catch up and the deaf person knows who is speaking. Allow only one person to talk at once. An interpreter can only interpret for one person at a time.

Explain any jargon - to the interpreter beforehand and keep to a minimum. Words that may be natural for you may not be to someone else.

An interpreter - will ask if you mind them interrupting you or the deaf person in order to clarify anything they may miss. This ensures that communication can be effective.

To help improve communication, we recommend 10 small things you can do to make a big difference;

1. Try to be open and communicate naturally
2. Use gesture and body movement to help explain where something is located or when directing someone
3. Make sure the person has a clear view of your face and the lighting is good - this helps with lip-reading and clearly shows your facial expression
4. Reduce background noise and use your loop system if you have one – this is especially helpful for hearing aid users
5. Have a pen and paper ready
6. Try not to use jargon – keep it short & simple
7. Do not shout
8. Do not exclude the deaf person – address them directly
9. Be patient and make time to communicate
10. Don't give up - if you are not understood the first time, try again using a different method of communication

Useful Contacts

BID Services
Deaf Cultural Centre, Ladywood Road, Birmingham B16 8SZ
Telephone: 0121 246 6100, textphone: 0121 246 6101,
fax: 0121 246 6125, email: info@bid.org.uk, website: www.bid.org.uk

Action on Hearing Loss
Head Office, 19-23 Featherstone Street, London EC1Y 8SL
Telephone: 020 7296 8000, textphone: 020 7296 8001, email:
informationline@hearingloss.org.uk, website: www.hearingloss.org.uk

DeafblindUK
National Centre for Deafblindness, John and Lucille van Geest Place
Cygnet Road, Hampton, Peterborough, PE7 8FD
Telephone/textphone: 01733 358 100, fax: 01733 358 356,
email: info@deafblind.org.uk, website: www.deafblind.org.uk

Sense
101 Pentonville Road, London, N1 9LG.
Telephone: 0300 330 9250 / 020 7520 0999, fax: 0300 320 9251 / 020
7520 0958, email: facilities@sense.org.uk, website: www.sense.org.uk

British Deaf Association
3rd Floor, 356 Holloway Road, London, N7 6PA
Telephone: 0207 697 4140, SMS: 07795 410 724,
email: bda@bda.org.uk, website: www.bda.org.uk

SignHealth
5 Baring Road, Beaconsfield, Buckinghamshire HP9 2NB
Telephone: 01494 687600, email: info@signhealth.org.uk,
website: www.signhealth.org.uk

The National Deaf Children's Society
Ground Floor South, Castle House, 37 - 45 Paul Street, London EC2A
4LS. Telephone: 020 7490 8656, textphone: 020 7490 8656, fax: 020
7251 5020, email: ndcs@ndcs.org.uk, website: www.ndcs.org.uk

Signature
Mersey House, Mandale Business Park, Belmont, Durham DH1 1TH
Telephone: 0191 383 1155, Text: 07974 121594, fax: 0191 383 7914,
website: www.signature.org.uk

Or contact your Local Social Services, Sensory or Disability Team

BID Services
Deaf Cultural Centre
Ladywood Road, Birmingham, B16 8SZ

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Website www.bid.org.uk

Acknowledgements
BID Services would like to thank John Hay and members of the steering group for their contributions to the development of this guide

References
Action on Hearing Loss - www.hearingloss.org.uk
Deafblind UK - www.deafblind.org.uk
National Institute for Health and Care Excellence - www.nice.org.uk
National Statistics Office - www.statistics.gov.uk
SignHealth - Sick of It Report

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Company Ltd by Guarantee No: 3124204

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