

Sign language hand cream

Apply cream on your hands every time a patient who uses sign language arrives at your surgery or consulting room.

04/03/04

Dr Consultant

RNID Pharmacy

19-23 Featherstone Street, LONDON EC1Y 8SL

A simple cure

A national report into deaf and hard of hearing people's experiences of the National Health Service

Lipspeaking syrup

Take two 5ml spoonful every time a patient who prefers lipreading arrives at your surgery or consulting room.

04/03/04

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Deaf Awareness pills

Take two tablets every time a deaf or hard of hearing patient arrives at your surgery or consulting room.

Positive side effects are:

- improves your face-to-face communication skills
- encourages you to include visual displays in your waiting room
- ensures that your face is clearly visible

04/03/04

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RNID ● ||||

for deaf and hard of hearing people

Introduction and executive summary

One in every seven people in the UK has some level of hearing loss.

We know, therefore, that the average GP will have up to four patients with hearing loss in their surgery every day.

This report reveals that, despite the frequency with which deaf and hard of hearing people use the National Health Service (NHS), the level of service they receive, in both GP surgeries and hospitals, often falls short of what they could reasonably expect.

RNID regularly receives examples where deaf and hard of hearing people have experienced problems in using the NHS. As a result we decided to commission this report. The research took place in the context of the Disability Discrimination Act 1995 (DDA) placing a legal obligation on the NHS to make reasonable adjustments to accommodate disabled people's needs, which will come into force in October 2004. It is also worth recognising that the parts of the DDA most relevant to deaf and hard of hearing people are already in force.

A number of reports from within the NHS have already recognised some of the problems faced by disabled people:

■ The NHS in England found that “disabled people often face unacceptable difficulties when they try to use NHS services”.¹

■ The NHS in Scotland has also acknowledged this problem and stated that these difficulties “may make it difficult or, at worst, impossible for disabled people to access the services they are

entitled to, find their way around a premises and communicate with staff”.²

■ The Welsh Assembly Review of Health and Social Care, advised by Derek Wanless, recognised that “Wales does not get as much out of its health spending as it should. ... There is some good and some excellent performance in health and social care. But there is also widespread under-performance associated with systemic defects.”

Those defects are presenting real and serious barriers for deaf and hard of hearing patients.

Together with the UK Council on Deafness (UKCoD), RNID carried out this research in collaboration with individual deaf and hard of hearing groups and charities throughout the UK. It highlights current experiences of deaf and hard of hearing people when they visit their GP surgeries and hospitals.

Surveys were sent out to deaf and hard of hearing groups across the UK with some groups having a sign language user explain the research (a full list can be found in the acknowledgement section at the rear). 866 surveys were returned to RNID, who collated and processed the data, making it a definitive study of deaf and hard of hearing people's experiences of communication issues in the NHS.

The principle objective was to establish whether evidence received regularly by RNID and others suggesting widespread poor quality treatment was reflected in reality.

¹ “Doubly Disabled” Report, 1999 (NHS Executive)

² “NHS Scotland and the DDA” – www.show.scot.nhs.uk/hddda/

Breakdown of respondents to the survey

Total number of respondents



100% – 866 people

How many respondents use BSL as their preferred language?



29% – 251 people

Profoundly / severely deaf



54% – 468 people

Deafened



9% – 78 people

Hard of hearing



35% – 303 people

Tinnitus



28% – 242 people

Balance problems



19% – 165 people

Parent of deaf child



1% – 9 people

Visually impaired



9% – 78 people

Additional disabilities



15% – 130 people

(The categories are not mutually exclusive, i.e., it is possible to be hard of hearing and have tinnitus)

Figure 1

Our main findings were:

In GP surgeries

35% of deaf and hard of hearing people had experienced difficulty communicating with their GP or nurse and 32% found it difficult to explain their health problems to their GP.

15% of deaf and hard of hearing people said they avoid going to see their GP because of communication problems; this proportion doubles among British Sign Language (BSL) users.

28% of deaf and hard of hearing people found it difficult to contact their GP surgery to get an appointment because of their hearing loss.

35% of deaf and hard of hearing people had been left unclear about their condition because of communication problems with their GP or nurse.

33% of BSL users were either unsure about instructions for medication, or had taken too much or too little of a medication because of a communication problem.

24% of patients had missed an appointment because of poor communication – such as not being able to hear staff calling out their name – 19% of whom missed more than five appointments.

In hospitals

42% of deaf and hard of hearing people who had visited hospital (non-emergency) had found it difficult to communicate with NHS staff. This increased to 66% amongst BSL users.

77% of BSL users who had visited hospital could not easily communicate with NHS staff. The proportion who had experienced difficulty was the same for both emergency visits and non-emergency overnight stays.

70% of BSL users admitted to A&E units were not provided with a BSL/English interpreter to enable them to communicate.

Danger

The evidence demonstrates a disturbing picture where people who rely on BSL for their communication needs are not being supported and must overcome difficult and often distressing obstacles in order to access the NHS.

Given the number of profoundly deaf people who said they were either unsure or had taken too much of a medication after leaving a GP's surgery, it is impossible not to conclude that a profoundly deaf patient faces a substantially greater risk of inadvertently taking an overdose of medication than hearing counterparts. This level of patient risk is simply unacceptable. The picture for hard of hearing people also gives cause for serious concern, with many unable to successfully book appointments or being unclear about their condition or diagnosis after a visit to the GP or hospital. It is also unacceptable that patients have to rely on family and friends, sometimes including young children, for doctors to convey critical information to them about their condition.

The ramifications for the NHS of a failure to provide adequate communication support to those who need it are serious. Yet many of the solutions involve little cost and would deliver better patient care. Compared to the cost of not getting communication right for deaf and hard of hearing people there is no case for a delay.

“Many people are ignorant”

“Many people are ignorant as to how to speak to a deaf person. Recently a consultant could only shout [at me] when all that was needed was to speak slowly and clearly.”

James, London

The law

Yet with less than a year to go before the DDA comes into full force, the NHS is in danger of failing in its duties. From October 2004 the DDA requires the NHS to overcome barriers created by the physical features of NHS facilities, including the design of hospital premises, physical access to NHS buildings or fixtures in them. Possible changes to facilitate deaf and hard of hearing people's access could include visual information displays, fitting permanent induction loops at reception counters and installing visual alert fire alarms.

The NHS is clearly failing to meet DDA obligations already in force. These require adjustments that are much simpler and less costly to make than physical alterations to buildings and facilities. But they necessitate a culture of awareness among front-line NHS staff of the communication requirements of deaf and hard of hearing people. There are many simple measures that would cut the number of missed appointments and miscommunication significantly, and greatly increase deaf and hard of hearing people's access to NHS services.

In terms of cost the implications are profound. Missed appointments are draining NHS staff time and resources. Misdiagnosis or the need for repeat appointments due to poor communication is exacerbating the situation for the NHS as a whole. Therefore poor communication with deaf and hard of hearing patients is not only harming patient care for those people, but for the resources available to the NHS to treat everybody.

This report shows that 24% of patients had missed an appointment because of poor communication – such as not being able to hear staff calling out their name. 19% of these missed more than five appointments and therefore had to make what was essentially an unnecessary follow-up appointment to have their consultation. We estimate that the cost to the NHS in terms of missed appointments alone could be as high as £20 million a year (see Figure 2). NHS staff wish to deliver a fair and effective level of service to their deaf and hard of hearing patients. However, this report makes it clear that both the infrastructure and resources are often not in place to allow them to do so.

The cost of missed appointments

24% of all respondents had missed an appointment at their GP surgery because of poor communication.

■ Total = 1,032,000 patients with missed appointments.

■ Average number of appointments missed = 2.89, giving total missed appointments = 2,982,000

At a cost of £65 per appointment missed = £194 million

Assuming experiences are recorded over a 10-year period on average, this then costs the NHS approximately £20 million a year.³

Figure 2

³ To ensure that the survey sample was representative of the UK's deaf and hard of hearing population it has been weighted accordingly.

Solutions

We accept that with a national shortage in BSL/English interpreters it will not be practical for the NHS to employ or to routinely have available interpreters for all situations. RNID and the Department for Work and Pensions (DWP), are working closely together to increase the number of available fully qualified BSL/English interpreters. However, there are other ways that hospitals and GP surgeries can supply communication support to BSL users. For example, using video telephones to support remote interpreting, thus making more intensive use of a scarce interpreting resource and tailoring support to the client's needs. It is also possible to take very practical steps to improve basic communication of staff in BSL and better written information in plain English.

We recognise that some health service professionals have concerns over privacy relating to the use of BSL/English interpreters for deaf people. However, it is established practice to do so. Guidance issued jointly by the Disability Rights Commission, the British Deaf Association and RNID on providing BSL/English interpreters under the DDA for service providers states “it is generally desirable to obtain a BSL/English interpreter in situations where clear communication is important.”⁴

For many hard of hearing people, installation of a simple loop system at the reception to allow them to make full use of their hearing aid in noisy GP practices and hospital situations is essential. While the use of visual displays can also ensure that deaf and hard of hearing patients, as well as other patients, can clearly see when they are being called for appointments. Provision of trained lipspeakers can also make a fundamental difference for some groups of hard of hearing people. Again, good communication skills including adequate lighting, clear appointment systems and information, and good disability awareness will resolve many problems.

It is vital that the NHS works with local and national stakeholders to identify and resolve the problems identified in this report and continues to engage with patient groups to modernise its services. This will ensure that the dedicated professionals working within the system can provide a fully accessible service to the nine million deaf and hard of hearing people in the UK.

We will be working closely with Government, health professionals and other interested parties to ensure that the one in seven deaf and hard of hearing people who need to use the NHS receive the same first-class service that everybody has a right to expect.

⁴ Guidance on providing British Sign Language/English interpreters under the Disability Discrimination Act 1995; Disability Rights Commission, British Deaf Association, RNID

Patient choice

The NHS in England has rightly recognised that patient choice is crucial. It is impossible to exercise choice without clear communication and access to all the information. The *Building on the Best: Choice, Responsiveness and Equity in the NHS* report published in December 2003 highlights six initiatives that will be taken as the first steps to increase patient choice:

- Giving people a bigger say in how they are treated by being able to record their health and personal preferences in their health space that in time will link to their electronic patient record.
- Increasing access to a wider range of primary care services, particularly in deprived areas.
- Increasing choice of where, when and how to get medicines.
- Booking appointments at a time that suits patients and from a choice of hospitals.
- Widening choice of treatment and care at the beginning and end of life.
- Ensuring patients have the right information, at the right time, with the support to use it.

But to make informed choices patients will need to have all of the information at their disposal. Poor communication will result in deaf and hard of hearing patients losing out

on these welcome improvements in the relationship between patients and health professionals, as they deliver their care. The NHS must take action to meet its obligations under the DDA, but also ensure deaf and hard of hearing patients are not left behind in the development of best practice by the service.

Conclusion and recommendations

The NHS generally offers a first-class service to patients and without its expertise millions of deaf and hard of hearing people would find it impossible to receive first-class quality healthcare.

Nonetheless, this report demonstrates that there are currently serious problems in the delivery of services to deaf and hard of hearing people and that action is needed to address those shortcomings.

Under the DDA, by October 2004 the NHS will need to have made all 'reasonable adjustments' to ensure their services are fully accessible to disabled people. This means we need to see urgent action taken to improve the delivery of health services.

The NHS needs to work towards meeting existing and forthcoming obligations to its deaf and hard of hearing patients. They can do so by implementing the recommendations listed overleaf:

Recommendations

Front-line NHS staff communication

- Widen the use of existing technology such as loop systems for hearing aid users and visual displays in reception areas, GP surgeries and consulting rooms.
- Widen the availability of new technology such as video interpreting.
- Install visual displays in reception areas, instead of relying on patients to hear their name being called.
- Take active steps to involve deaf and hard of hearing people in the development of the service.
- An updated NHS Disability Access Audit which includes the needs of deaf and hard of hearing people.
- Ensure all written communication, such as letters confirming appointments, are written in clear English for BSL users.
- Ensure deaf and disability awareness training for 'front-line' staff and implement simple measures to ensure that communication needs are met.

Staff training

- NHS to instigate deaf awareness training for all medical and nursing undergraduates.
- NHS to instigate training seminars to ensure that all GP surgeries have at least one 'front-line' member of staff who has been formally trained in deaf awareness.
- NHS to instigate training seminars with the aim of ensuring that all hospitals have at least one 'front-line' member of staff who has been formally trained in deaf awareness.

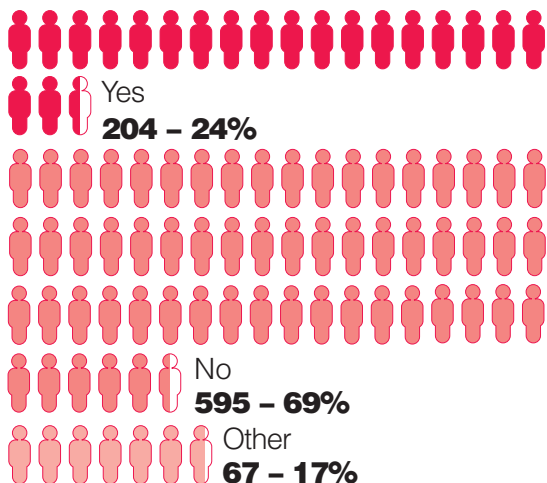
“No information”

“When I was moved on to a ward the information about my hearing loss was not transferred onto the board above my bed.”

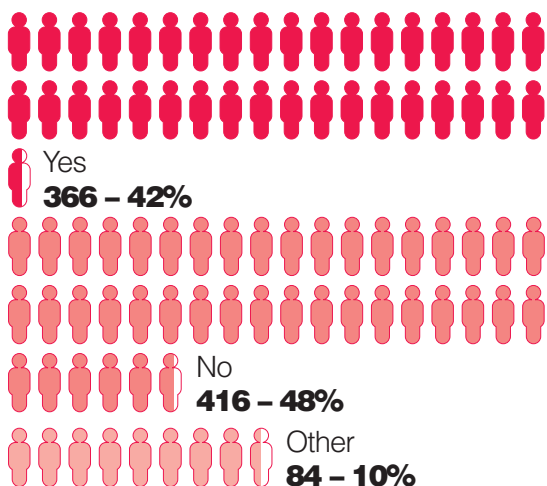
Maria, Wales

Summary of impact

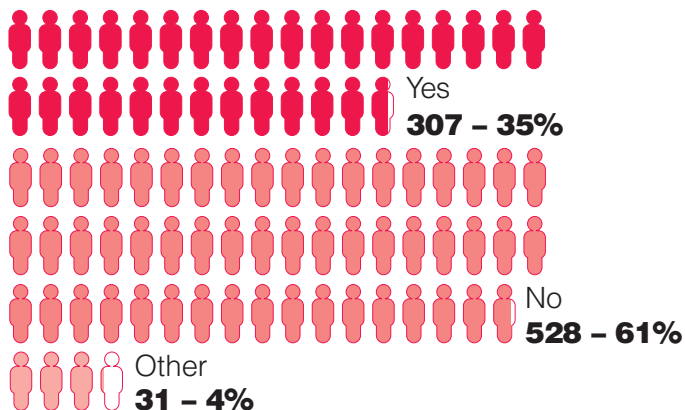
Have you ever missed an appointment at your GP surgery because of poor communication?



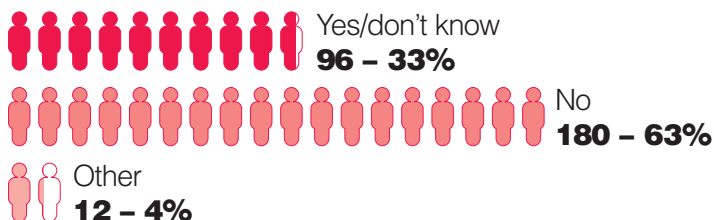
If you ever visited a hospital for non-emergency did you find it difficult to communicate with NHS staff?



Have you been unclear about your condition because of a problem communicating with your GP or Nurse?



Have you ever taken too small or large a dose of a particular medication because of a communication problem?



Was a BSL/English interpreter available? (for those who require one admitted to A&E unit)

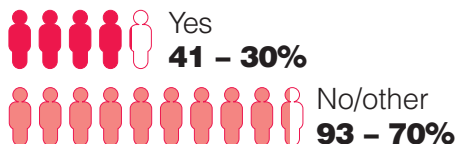


Figure 3

Case study – Anne

Anne's 13-month old son was in hospital with double pneumonia. For a couple of days he had to be supplied with oxygen. After a few days his oxygen levels were considered good enough to be taken off the oxygen machine as a trial. Anne was with her son on her own. After around an hour he didn't seem well, he grew very quiet and his oxygen level seemed to be dropping.

Anne attempted to urgently attract the attention of medical staff. She said:

“I was worried and so went to ask for a nurse. The nurse at the reception barely took time to listen to me and pointed to another nurse, I went up to that person and then to other nurses, but was ignored. Or they said something that I missed as it was very quickly, in passing. I pressed on the ‘call’ button, but nobody came, and only when I started crying someone came.”

Case study – Mary

Mary's teenaged daughter was rushed to hospital in the middle of the night with a number of symptoms. When Mary reached the hospital there was no communication support available, there was a BSL/English interpreting service available – but only during office hours.

It took over an hour for a doctor to inform Mary that her daughter had almost been placed in intensive care.

Later, Mary's daughter stabilised and she was moved to a resuscitation room, where a male nurse who had been in the room with Mary and her daughter seemed

unwilling to communicate with her.

Suddenly, the nurse wheeled her daughter out of the room without attempting to inform Mary of where they were going, or what was happening. They were moved to the children's ward.

As Mary sat by her daughter's bedside the night nurse came across and attempted to wake her daughter up. Mary protested that she was asleep, but was told that she needed her daughter to be part of a discussion. It transpired that the night nurse only wanted Mary's daughter to act as an interpreter.

Acknowledgements

■ This report would not have been possible without the active cooperation and facilitation of the United Kingdom Council on Deafness (UKCoD).

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United Kingdom Council on Deafness

Birmingham Institute for the Deaf

Brent Deaf People's Ltd

Cornwall Deaf Association

Ddeaf Equality Forward

Deaf Connexions

DeafLincs

Deafness Support Network

deafPLUS

Deafway

Gloucestershire Deaf Association

Gwynedd Hard of Hearing Forum

HI Kent

Hull Deaf Institute

Leicester Centre for Deaf People

Mansfield Society for Deaf People

Northallerton & District Centre for the Deaf

Royal Association for Deaf people

Sussex Deaf Association

Walsall Deaf People's Centre

West Sussex Deaf and Hard of Hearing Association



UK Council on Deafness

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