CAUSE AND CURE

Deafblind people's experience of the NHS

DEAFBLIND
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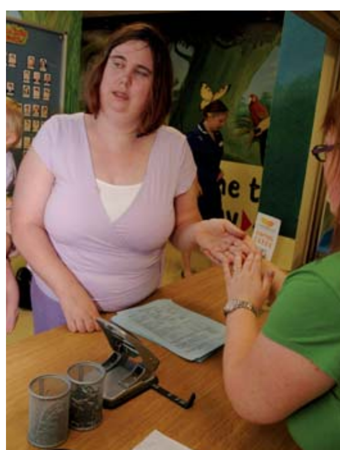
1. Summary

1.1 A survey by Deafblind UK has revealed how access to health services continues to be denied to deafblind people. The experiences of 486 deafblind people highlight how simple changes in practice and procedures by hospital and GP services would ensure that doctors and nursing staff could meet their needs. The survey demonstrates improvement in some aspects of healthcare for deafblind people and deterioration in others since 2001, and points to the need for changes in awareness, information and communication.

2. Context

2.1 This report is based on a 2006 national survey of deafblind people's experiences of the National Health Service (NHS). The results of the survey represent the most up to date information from deafblind people using the NHS. It was carried out by Deafblind UK, a leading charity working for the UK's 2.7 million people with combined sight and hearing impairments.

2.2 This report also draws on the results of the first national survey of deafblind people and their healthcare experiences – "Who Cares? Access to Healthcare for Deafblind People." This was part of the "Yes to Access" campaign report produced jointly by Sense and Deafblind UK in 2001. The report highlights where there have been improvements in the healthcare experience of deafblind people over the five years and where major problems persist.



3. What is Deafblindness?

"They don't realise my needs. Once my GP kept asking what colour a rash was – I kept telling her I couldn't see but she just didn't understand."

3.1 Deafblindness is a unique disability. It cannot be considered simply as a hearing loss and a sight loss – the sum is greater than the parts. "People are regarded as deafblind if their combined sight and hearing impairment causes difficulties with communication, access to information and mobility"[1].

3.2 There are over 2.7 million people in the UK[2], with combined sight and hearing impairments ranging from minimal to severe, including 24,000 deafblind people[3]. People who are deafblind are either born with sight and hearing impairments i.e., congenital deafblindness, or acquire them, usually in later life – the majority are over 60 years of age.

3.3 This group are generally able to cope with their daily lives, with varying degrees of difficulty, because they are in familiar surroundings. However, outside of their known environment coping mechanisms begin to fail, thus increasing their vulnerability. Healthcare settings are usually unfamiliar environments and pose barriers to deafblind people.

"I visited my hospital for tests, but then some tests were in a different building, a nurse kindly walked me over. Then as I entered the building the sudden change in light from being bright outside to dark left me totally unable to see. The nurse just said 'follow me' and when I asked for more help she replied 'you could follow me outside, why not now!"

4. Key Findings

4.1 The key findings of the Deafblind Health Survey for 2006 highlight some improvement in the standards of service offered to deafblind people since the original report in 2001. In particular:

4.1.1 Over 91% of deafblind people felt they are shown a positive attitude by health care staff, which has a positive impact on the standard of care received.

4.1.2 Almost 58% of deafblind patients did not receive letters or appointment cards from any NHS organisation in a format they could read themselves. Although this figure is relatively high, it represents a significant improvement on the 90% reported in 2001.

4.2 The findings demonstrate very clearly, that positive attitudes influence standards of service delivery, even if the understanding of deafblindness as a disability is poor. Equally, where attitudes are poor, standards of service suffer.

4.3 A significant factor adversely affecting quality of care was lack of awareness about the need for 'reasonable adjustments' to the way health services are provided for deafblind people:

4.3.1 Almost 59% of respondents felt that healthcare staff were not aware of their needs as a deafblind person. This is an increase from 52% in 2001.

4.3.2 For 77% of respondents, communication support and interpreting for health appointments was provided by family members and friends who do not posses the essential professional skills in the communication methods used by deafblind people. This represents a significant increase from 60% in 2001. This problem is exacerbated by a national shortage of qualified interpreters/communicators.

4.3.3 Conversations using deafblind communication methods require more time than dialogues involving speech and hearing. A lack of extended appointments can reduce a deafblind persons' ability to communicate effectively. The survey provided evidence that fewer than 16% of deafblind patients were offered longer appointments, compared to 2001 when 47% of deafblind people were offered longer GP appointments and 31% longer outpatient appointments. Further research needs to be undertaken to establish the reason for this change in practice and whether it is linked to the target driven culture within the NHS.

4.3.4 Over 73% of deafblind patients reported that (apart from the improvements referred to at 4.1.1 and 4.1.2 above), they were not aware of any NHS service changes that enabled them to better access health services.

4.3.5 10% of respondents reported that as a direct result of combined sight and hearing loss, they have used prescribed medication inappropriately and put themselves at risk.

5. Conclusions

5.1 Attitude and Awareness

"Sometimes healthcare staff are not aware we [deafblind people] have problems despite having a red and white cane[4]. Attitudes can go from being helpful to treating us as if we are retarded in some way."

5.1.1 The vast majority of respondents felt that positive attitudes towards deafblind patients influenced the quality of service provided. However, it is clear that lack of awareness of their particular needs and how to meet them represents major barriers to achieving a better standard of healthcare. The survey highlights a reduced level of awareness of deafblind patients' needs since 2001.

> *"I feel I am invisible! The staff are just not aware of my needs [as a deafblind person] in general."*

5.1.2 Missed appointments – can be the result of a number of problems, but two that have been highlighted are: not receiving information in an accessible format or attending the appointment and not hearing their name being called out.

5.1.3 Aggressive / rude behaviour – many deafblind patients reported instances of healthcare staff becoming impatient because of a lack of awareness of the disability. This can be perceived as aggression or rudeness by the deafblind patient.

5.1.4 Almost 37% of deafblind people feel that when they are accompanied, staff attitudes change to exclude them as the patient from their own health appointment. As a direct result of this practice, deafblind people report feelings of inadequacy, low self-esteem and anger at being excluded and isolated. It can reduce levels of independence and unwittingly promote dependence on others.

> *"They ignore me and do the 'does she take sugar bit' … I am ignored, I may as well be an animal at the vets."*

5.2 Information

> *"We are treated as though we don't need to know about our own health issues. At a hospital a doctor asked me where my husband was because she didn't want to talk to me!"*

5.2.1 The impact of deafblindness on communication, access to information and mobility, affects each individual differently. If their individual needs are not understood, then access to healthcare is at best restricted, and at worst, denied.

5.2.2 Almost 58%[5] of deafblind patients still do not receive letters or appointment cards from any NHS organisation in a format they can access themselves.

"They forget people's conditions and / or in the 'system' letters are often automatically generated. So even though they may be aware of my needs they are seldom met".

5.2.3 NHS letters and appointment cards frequently use print that is too small to read for most people who have sight problems. This forces reliance on others to read and impart important and personal information. The result can be decreased self-esteem, dependency and lack of privacy. It also enforces reliance and can increase the already higher risk of depression amongst deafblind adults. (A research paper in 2005 provided evidence that 60% of deafblind people are likely to suffer from some form of mental health problem[6], and that this is mainly caused by issues relating to feelings of isolation and dependency).

5.2.4 On a more practical note, if appointment cards and letters cannot be read then appointments will be missed. This wastes NHS resources and can reduce preventative health measures and even promote poor healthcare. A lack of individualised 'written' communication services has a negative impact on the level of healthcare services being offered to deafblind people. The RNID's recent research[7], highlights that 24% of deaf people have missed at least one NHS appointment due to poor communication, at an estimated cost of £20 million. Given their greater difficulties in communication, this figure is likely to be higher for deafblind patients.

5.2.5 Lack of individualised services is also found in the use of prescribed medication. 10% of respondents report having used medication inappropriately due to their impairment. This suggests that up to 270,000 people with a combined sight and hearing loss are at risk when using prescribed medication. This is primarily due to inaccessible formatting of labelling and information leaflets and has wide reaching consequences, since both overdosing and missing medication, can result in serious health problems or side-effects.

5.3 Communication Support

5.3.1 The NHS in England found that "disabled people often face unacceptable difficulties when they try to use NHS services" [8].

The RNID survey (op cit) demonstrated some of these problems, including that '35% of deaf and hard of hearing people had been left unclear about their condition because of communication problems with their GP or nurse. 42% of deaf and hard of hearing people who had visited hospital (non-emergency) had found it difficult to communicate with NHS staff'. Deafblind UK believes it is reasonable to assume that these figures would be much higher for deafblind people.

5.3.2 Deafblind people communicate using a variety of adapted and special methods. For healthcare appointments, most need the services of a Language Service Professional (LSP), who has skills in sign language, the deafblind manual, lipspeaking or speech to text methods. Some deafblind people will also require the service of a guide to escort them to and from medical appointments.

5.3.3 The reliance of over three-quarters of respondents on friends and family to provide communication and guiding support for medical appointments (up by 16% since 2001), is cause for serious concern.

5.3.4 Whilst acting in the best interests of the individual, friends and family do not posses professional skills in the communication methods used by deafblind people. Misunderstanding and misinformation about diagnosis and treatment can have serious consequences, and is exacerbated by the fact the deafblind patient has no means of checking whether information is conveyed accurately to her/him via a friend or relative.

5.3.5 The only way of ensuring accuracy and professional practice in communication between deafblind people and healthcare staff is by the use of professional LSPs who are qualified, registered and regulated. This principle (underpinned by the Disability Discrimination Act (DDA)), is widely practised by the NHS in its provision for Deaf sign language users - most Trusts now have contracts to provide interpreters. However, Trusts have shown much less understanding of how to apply this principle to the varied needs of deafblind people.

> *"Consultants are often very busy, and I often feel rushed – I think of things afterwards that I should have asked but I was rushed."*

5.3.6 In some cases longer appointments are necessary to accommodate slower communication methods. In the survey 67% of deafblind people felt that extended appointments would be useful to them. The lack of professional communication support and the limited availability of extended appointments seriously reduces a deafblind persons' ability to communicate effectively with healthcare services.

5.4 Physical Environment

> *"An eye consultant asked me to put my chin here. Where is here!"*

5.4.1 It is often the environment itself that disables deafblind people. Simple and inexpensive adaptations can be made in hospitals and GP surgeries to reduce the disabling effects of unfamiliar surroundings. Over 73% of deafblind people reported that no NHS service had made any improvements to help them access services, and highlighted the need for changes in the following areas:

Colour schemes with good contrasting shades can help people with low vision.

Home visits for housebound deafblind patients.

Textphone facilities and/or a willingness to use Typetalk/Text Direct[9].

Appointments in ground floor rooms.

Willingness to guide deafblind patients around unfamiliar environments.

Accepting communication with and requests for information from deafblind people by means other than the post and telephone, e.g., email, fax etc.

6. Recommendations and Action

6.1 The survey identifies some improvements in deafblind people's experience of using health services since 2001. However, changes in attitudes, practices and

procedures are needed to ensure more equitable treatment and better access to healthcare for this group. Deafblind UK is committed to working with NHS service providers and other relevant bodies such as Sense, Age Concern and Help the Aged to achieve improvement in:

6.2 Awareness

Working with the NHS to ensure that awareness training is included within any equality and diversity training for NHS staff.

Promoting the work of the NHS Patient Advice and Liaison Service and Independent Complaints Advocacy Service to deafblind people, to empower them to use these services.

6.3 Accessible Information

Collaborating with the NHS to identify methods of individualising patient records to enable healthcare staff to identify a deafblind patients' support needs and communication requirements.

Continuing to advocate for large print to be used for all letters, appointment cards and information leaflets.

Working with other organisations, such as the National Patient Safety Agency to promote the extension of the European Directive[10] on medications. We believe this will improve access to medicines and reduce the risk of harm. We will promote the good practice of companies already taking steps to meet this directive.

6.4 Communication

Lobbying to ensure that NHS contracts for interpreting and communication support meet the needs of all deafblind people.

Empowering deafblind people to request extended NHS appointments to assist with their communication needs.

6.5 Physical Environment

Empowering Deafblind UK members to be pro-active in requesting changes to the physical environment that will benefit them and reduce the disabling effect of the surroundings.

Persuading NHS organisations and healthcare providers to identify appropriate changes to the physical environment which will improve access to health services and information.

Working with other interested organisations to increase lobbying strength on this issue.

For more information about this campaign and the work of Deafblind UK, visit www.deafblind.org.uk or alternatively contact a member of the Policy, Campaigns and Awareness team on 01733 358100 (phone and textphone) or email health@deafblind.org.uk

Appendix
How Deafblind UK conducted the health survey

The health survey was conducted in 2006 by questionnaire which was sent to the 2,717 of Deafblind UK's members who could be contacted by post, in their preferred format (e.g., large print, Braille). 486 members replied. This represents a response rate of 18% which, given the significant difficulties faced by deafblind people, is an impressive result and demonstrates the importance they place on healthcare issues.

Additional support was offered to help members complete the survey. This included completion of the questionnaire over the phone or face to face with a communicator-guide.

Footnotes

[1] Social Care for Deafblind Children and Adults, LAC 2001(8), Department of Health.

[2] National Service Framework for Older People, Department of Health May 2001.

[3] Social Care for Deafblind Children and Adults, LAC 2001(8), Department of Health.

[4] Red and White Canes are used by some deafblind people. The Red and White Cane is the international symbol of deafblindness.

[5] This figure is the combined figure for GP's and hospitals and clinics. The separate figures are; 59% of deafblind patients do not receive letters and appointment cards from their GP that they can read, and 57% of deafblind patients do not receive letters and appointment cards from hospitals / clinics that they can read.

[6] Sarah Bodsworth and Isabel Clare, University of Cambridge in association with Deafblind UK. (2005) Summary document: Deafblindness And Mental Health: The Mental Health Needs of Adults with Dual Sensory Impairment (unpublished)

[7] RNID 'A Simple Cure' 2004.

[8] "Doubly Disabled" Report, 1999 (NHS Executive)

[8] This is the combined figure for GP's, and hospitals / clinics. The separate figures are 69% of GP services have made no improvements for deafblind patients, and 76% of hospitals / clinics have made no improvements for their deafblind patients.

[9] Textphones are a means of conducting a typed telephone conversation using a computer-type keyboard. Typetalk/Text Direct are telephone relay services which allow a deaf person using a textphone to communicate with a hearing person using an ordinary telephone.

[10] EU Directive 2004/27/EC Article 56(a)

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