



# CAUSE AND CURE

## *Deafblind people's experience of the NHS*

### Deafblindness

There are over 2.7 million people in the UK<sup>1</sup> with a combined sight and hearing loss ranging from minimal to severe. The majority have acquired this dual sensory loss in adult life and are over 60 years of age. An estimated 24,000<sup>2</sup> are deafblind and the group most affected by difficulties with communication, access to information and mobility.

### Summary

A survey by Deafblind UK has revealed how access to health services is 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 communicate with them. The survey demonstrates that since the last survey in 2001<sup>3</sup> there has been improvement in some aspects of healthcare for deafblind people and deterioration in others, and points to the need for changes in awareness, information and communication.

### Key Findings

Most deafblind respondents felt they were shown a positive attitude by NHS staff. However, 60% felt that staff demonstrated a lack of awareness of their particular needs. This has increased since 2001, when only 52% of people reported this.

Only 16% of deafblind patients were offered longer appointments to allow for the use of alternative communication methods (e.g., deafblind manual, British Sign Language). In 2001, 47% were offered longer GP appointments and 31% longer outpatient appointments.

58% did not receive letters or appointment cards from any NHS organisation in a format they could access themselves (e.g., large print, Braille). This represents a significant improvement on the 90% reported in 2001.

73% reported no other improvements to help them to access NHS services since 2001.



For 77%, communication support and interpreting for health appointments was provided by family members and friends who do not possess the essential professional skills in the communication methods used by deafblind people. This represents a significant increase from 60.5% in 2001.

37% reported that when they are accompanied on medical appointments, healthcare staff exclude them and talk to the other person

As a direct result of combined sight and hearing loss, 10% had used their prescribed medication inappropriately and put themselves at risk

## Conclusions

The experience of the 486 deafblind respondents shows that:

Appointments are missed because information is not received in an accessible format or through not hearing their name being called in the waiting room. This promotes dependency on others to read and impart personal information, and ignores the need for privacy. RNID<sup>4</sup> research 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 the even greater difficulties in communication faced by deafblind people, this figure is likely to be higher for deafblind patients.

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

Inaccessible labelling and information leaflets means that up to 270,000 people with a combined sight and hearing loss may be at risk when using prescribed medication.

Lack of awareness of the effects of deafblindness results in healthcare staff becoming impatient. Deafblind people may construe this as aggression or rudeness.

*"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."*

*"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!'"*

Attitudes of healthcare staff aren't necessarily improved when deafblind patients are accompanied.

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

Deafblind people report feelings of inadequacy, low self-esteem and anger at being excluded and isolated, as a direct result of this practice. It can reduce levels of independence and unwittingly promote dependence on others.

*"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!"*

The use of unqualified communicators and interpreters increases the risk that the deafblind patient will receive inaccurate information.

Communicating with deafblind patients through specialist methods requires more time than for a dialogue by speech and listening.

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

*"I feel I am invisible! Staff are just not aware of my needs as a deafblind person"*





### Recommendations and Action

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 to achieve improvement in:

#### 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.

#### Accessible Information

Collaborating with the NHS to identify methods of individualising patient records to enable healthcare staff 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<sup>5</sup> 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.

#### 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.

For more information about this campaign and the work of Deafblind UK, visit [www.deafblind.org.uk](http://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](mailto:health@deafblind.org.uk)

#### Footnotes

<sup>1</sup> National Service Framework for Older People, Department of Health, May 2001.

<sup>2</sup> Social Care for Deafblind Children and Adults, LAC 2001(8), Department of Health.

<sup>3</sup> Who Cares? Access to Healthcare for Deafblind People.

<sup>4</sup> RNID 'A Simple Cure' 2004.

<sup>5</sup> EU Directive 2004/27/EC Article 56(a)