

Towards an inclusive health service: a report into the availability of health information for blind and partially sighted people.

Introduction

RNIB has commissioned research, conducted by Dr Foster Intelligence, to investigate – in the UK – the experiences of blind and partially sighted people who had used NHS services in the last twelve months. The study covered 600 blind and partially sighted people and 500 healthcare professionals in both primary and secondary care. The research has highlighted that barriers to health information remain widespread, and that more progress needs to be made to ensure that health information is accessible to blind and partially sighted people.

Key findings from the research

The research highlighted the experiences of blind and partially sighted people, including:

1. 95 per cent of blind and partially sighted people feel it is important to have health information in a format they can read for themselves, and most healthcare professionals agree with them on this. However, nine out of ten say they were not asked by NHS staff about what format they required when they were given information.
2. Blind and partially sighted people feel a loss of privacy and independence if they have to rely on someone else to access personal information. Only one per cent say they want information given via a carer or relative, yet 28 per cent of health professionals thought that blind and partially sighted people did want information conveyed to them in this way.
3. Eight out of ten blind and partially sighted people said they did not get medicine information in a format they could read. Safety is at risk if information about medicines is given in a format that blind and partially sighted people cannot read for themselves, as verbal instructions are all too easily forgotten.

4. Appointment letters which are not in accessible formats are directly linked to an increased level of missed appointments. Two out of ten people said they had missed an appointment because the appointment letter was not in an accessible format.
5. Seven out of ten blind and partially sighted people reported that personal information they were given from their GP was not in an accessible format.
6. General health information is not always accessible to blind and partially sighted people, for example guides on managing a long term health condition, and leaflets on how to stop smoking.
7. Nine out of ten say they do not always ask for or obtain information in accessible formats, with four out of ten saying it takes too much effort, and a small minority saying they did not ask for fear of being labelled as needing special treatment.
8. Six out of ten blind and partially sighted people were unaware of their legal right to accessible information under the Disability Discrimination Act (DDA) 1995.

The research also found that health professionals faced problems:

- Seven out of ten healthcare professionals either said their organisation does not have a clear policy on the provision of accessible information or they do not know if it did.
- Seven out of ten felt they lacked sufficient training to provide accessible information.
- Six out of ten said they did not have the means to produce accessible information.

The research found that the majority of healthcare providers were not contractually bound by commissioners, for example, Primary Care Trusts (PCTs) and health boards, to promote equal access to health information for blind and partially sighted people. Only six per cent of Primary Care Trusts and health boards assessed service providers' performance in giving accessible information to blind and partially sighted people, and 17 per cent required providers to identify actively blind and partially sighted people, record their individual reading needs and ensure that staff have visual awareness training.

Summary and recommendations

- Blind and partially sighted people want to be able to read their own health information so they can manage their personal health care. They often cannot do this because health professionals do not ask them what format they need, and they themselves often do not feel empowered to ask for it as a right.
- PCTs and Health Boards who commission health services should specify a requirement for providers to meet the health information needs of blind and partially sighted people, and assess their performance on this. Commissioners and providers should actively promote policies and guidance on how to meet the information needs of blind and partially sighted people, and ensure these policies are implemented.
- PCTs and Health Boards should ensure electronic record systems used by service providers are capable of recording patients' needs for accessible information, and can produce personal and general health information in appropriate formats.
- All healthcare professionals need to identify each individual's needs, record their reading requirements and ensure that accessible information is provided.

Order the report

To receive a copy of the Dr Foster research report please email hugh.huddy@rnib.org.uk or telephone 020 7391 2008. Please also state which format you require: PDF or Word document by email, hardcopy in clear print or large print, braille, audio on CD or MP3.

For more information visit rnib.org.uk/research

© RNIB 2009 Registered charity number 226227