make technology work

Report on technology access for deafblind people

Sense, 2005

Contents

1. Sense technology survey

Technology has become an essential part of everyone's lives. For over 23,000 people in the UK with impaired sight and hearing, technology is a lifeline, enabling them to communicate, access information and manage their lives independently. However, many deafblind people and their families have told Sense that they have problems accessing technology which is limiting the positive effect it can have on their lives. To find out whether these experiences are widely shared, we conducted a national survey of deafblind people and this report describes the results. This chapter explains how the survey was conducted and who took part. The final chapter sets out our agenda for action.

1.1 What is deafblindness?

In this report we use the term 'deafblindness' and 'deafblind people' to include all individuals who have both impaired hearing and sight. Other terms are also in use such as 'dual sensory loss' and 'multi-sensory impairment'. There are approximately 23,000 people in the UK who are deafblind.

Deafblindness is caused by many different things. Some babies are born deafblind as a result of premature birth, birth trauma or rubella during the mother's pregnancy. Some genetic conditions, such as Usher syndrome, result in deafblindness from the teenage years or later. People can also become deafblind at any time through meningitis or accidents. Increasingly, age-related conditions result in sight and hearing loss; people who have been deaf or visually

impaired all or most of their lives are particularly vulnerable if their other sense deteriorates in later life. Deafblindness is a spectrum. Most people are not completely deaf and blind but have some residual use of one or both senses. Some people have additional physical and/or learning disabilities.

1.2 About Sense

Sense is a national charity that supports and campaigns for children and adults who are deafblind. We provide specialist information, advice and services to deafblind people, their families, carers and the professionals who work with them. We also support people who have sensory impairments with additional disabilities.

1.3 About the survey

The survey was designed to enable deafblind people to tell us about their experiences of using technology in their everyday lives. For Sense, it was the first step to finding out how manufacturers and others can make technology more accessible to deafblind people.

We sent out a questionnaire to members of Sense and Deafblind UK (another charity representing deafblind people), some contacts of the Royal National Institute of the Blind (RNIB) and some social services workers. The questionnaire was sent out in large print, Braille, tape or Moon, depending on the needs of the person. The questionnaire allowed people to tell us about their experiences of using both assistive equipment and household equipment and to tell us what they think should change in the future.

326 people responded, including deafblind people, their families and carers from all over England and Wales.

1.4 About the respondents

Table 1opposite shows the age of the respondents.

Table 1 Age of respondents

AGE	NUMBER = 326	PERCENTAGE
Under 19	12	4
19–24	8	2
25–40	56	17
41–64	76	23
65–80	61	19
80+	101	31
Not stated	12	4

It is noticeable that the largest group of people is over the age of 80, which is consistent with accepted knowledge of the deafblind population. This age group is likely to be experienced with everyday household equipment (cookers, washing machines and so on) but least likely to be familiar with high-tech equipment such as mobile phones and computers.

Table 2 indicates whom the respondents live with. It is important for us to understand this as technology is potentially more vital (but more challenging) for people living alone.

Table 2 Living arrangements

LIVING WITH	NUMBER = 326	PERCENTAGE
Family	132	40.5
On their own	132	40.5
Friends	6	2
Residential home	34	10
Not stated	22	7

The majority of people live alone or with family, but a few people living in residential homes replied.

We also asked about people's occupational status as this may have a bearing on people's ability to pay for equipment and the results are shown in table 3.

Table 3 Occupational status of respondents

OCCUPATIONAL STATUS	NUMBER = 326	PERCENTAGE
Employed	27	8
Unemployed	47	15
Studying	36	11
Retired	183	56
Not stated	33	10

The figures show that only a minority of respondents are employed and that the majority are most likely to be managing on low incomes. The number of people of working age who are unemployed probably reflects the difficulty that deafblind people have getting jobs.

The respondents' preferred communication methods are shown in table 4 below.

Table 4 Respondents' preferred communication methods

WRITTEN COMMUNICATION	NUMBERS (%)	PERSONAL COMMUNICATION	NUMBERS (%)
Large print	185 (57%)	Spoken English	116 (36%)
Standard print	47 (14%)	British Sign Language	34 (10%)
Braille	26 (8%)	Deafblind manual	29 (9%)
Moon	8 (3%)	Hands on British Sign Language	26 (8%)
Not stated	60 (18%)	Tadoma	1 (0.3%)
		Symbols	1 (0.3%)
		Other	40 (12%)
		Not stated	79 (24%)

Large print is the most widely-used method of reading, while the largest group of respondents use spoken English. These again reflect the accepted knowledge of the deafblind community, with the large number of older people who have lost sight and hearing as they have aged. BSL (British Sign Language), which is a visual language used by people who are born deaf, is well represented among the people who responded to the survey.

2. The use of assistive equipment

'Assistive equipment', that is equipment specially designed to be accessible to people with hearing and vision loss, is used by almost four out of five deafblind people. As one respondent said, "Without technology I would be completely lost." Yet almost half of the people who have such equipment report difficulties using it. Assistive equipment should be making activities more accessible, so it is shocking that instead of making people's lives easier, such a high proportion find the equipment difficult to use. This is disempowering and isolating for people who rely on technology to give them independence. This chapter looks at the specific difficulties of using this type of equipment and how people's needs for it are assessed.

Anne (not her real name) relies on a ventilator to help her breathe. On one occasion she wasn't getting enough air so she tried to find the alarm button to alert her carer. But, unable to see or feel the buttons she pressed the wrong one and switched the ventilator off. Her lack of hearing meant she could not hear that the ventilator was switched off. Anne was unconscious by the time her carer came to check on her. If the controls had been more accessible Anne could have increased the air pressure herself and would not have got into this potentially life-threatening situation.

Anne is an extreme case of someone who relies completely on technology for survival. Our survey established that 79% of people use assistive equipment and that 45% of them have difficulties using it.

Many of the difficulties arise from manufacturers' lack of understanding of the needs of people who cannot see or hear properly and some of the difficulties could have been avoided if such needs had been considered at the design stage. The equipment described below is explained in the glossary.

2.1 Textphones

38% of textphone users who replied to the questionnaire found them difficult to use. These are some of the reasons given.

- On many new textphones, the lack of contrast between the colour of the text and the colour of the background makes it difficult for many people to read. Older textphones have a blue/green fluorescent display screen which contrasts strongly with the dark background which many people find easier to see.
- Textphones that only have a single line of text are difficult for some deafblind people to use. The restrictions on their vision mean that they cannot always read the text fast enough to keep up with the conversation.
- Textphones do not have a facility for changing the size of the text, its colour and the background colour.

2.2 Hearing aids

28% of hearing aid users reported problems using their hearing aids.

- The small size of hearing aids and batteries make them difficult to use for people who have a visual impairment.
- Many people have a problem changing the battery in their hearing aids. Trying to close the tiny battery chamber can make the battery fall out just when it has been inserted and people with impaired sight then have trouble finding the dropped battery.
- Some people are unable to hear the alarm alerting them to change the battery before the power runs out. Some aids can shut off suddenly when the battery runs low.
- Parents of young deafblind children often have trouble gauging the right volume level for their child due to communication difficulties. Young children are unable to set the right volume for themselves.

- Getting correctly-fitted ear moulds is a problem for babies who need to wear hearing aids at an early age. The size and weight of hearing aids can also be difficult for this group.

Many respondents also reported long waiting times for their digital hearing aids. This is particularly a problem for deafblind people because of their heavy reliance on hearing aids for communication and mobility.

2.3 Vibrating alert pagers

Among those using a vibrating pager 31% reported that they have difficulty using them. Some pagers have a small number of vibrating indicators. This compares with a larger number of light indicators to draw the user's attention to a smoke alarm or a ringing telephone, for example. This means that the pager is more versatile for people with vision.

2.4 Computer adaptations

Refreshable braille display boards

35% of the people who use these find them difficult to use.

- The boards are sometimes unable to show all of the information shown on the visual display screen of the computer.
- Many people find the design uncomfortable to use which can make the braille difficult and slow to read.

Adapted software

- Deafblind people can find it difficult to install software themselves without the help of a hearing and sighted person.
- A screen reader can provide more information than a braille display board, but some deafblind people cannot use them because they are unable to hear the information when it is audio based.

2.5 General problems

Some of the assistive equipment deafblind people rely on such as braille clocks, vibrating lightprobes and sound monitors are no longer made. This means users cannot get them repaired and cannot replace them if they stop working.

Some deafblind people have been given incorrect information about technology which means that they are not getting the most out of it. For example, there are myths that it is impossible to access a computer with no eyesight and that phone lines are hazardous like live electrical wires and so they should not be touched. This illustrates the fact that deafblind people have limited access to sources of information.

2.6 Were people's equipment needs assessed?

In England and Wales, deafblind children and adults have a right to be assessed by a specifically trained person/team. This is under Department of Health guidance Social Care for Deafblind Children and Adults (LAC 2001 (8)). The assessment should recommend the services and/or equipment that are most suitable to the needs of the deafblind person being assessed.

Our survey found that only 69% of respondents had been assessed by professionals to find out what assistive equipment they need. These assessments were carried out by 30 different types of professionals. They ranged from therapists to social services staff and staff in private heath service centres; however the largest proportion (44%) were carried out by social services staff.

The number of respondents who have clearly not been given the appropriate equipment indicates that these assessments, even when they are being carried out by the appropriate professionals, are not always being done adequately. This is probably because the professionals have not received the training they need to assess the specific needs of deafblind people and they may not know about the equipment that is available.

2.7 Paying for assistive equipment

35% of people with assistive equipment reported that they had bought it themselves, including one person who spent about £7000 on all their equipment.

Assistive equipment is often expensive because of its specialist nature and the small number of each product that is needed.

High costs mean people often find it difficult to keep up with new developments. The cost also means that many local authorities do not provide deafblind people with the most up-to-date, appropriate equipment they need.

2.8 A wish list for assistive equipment

We asked people to tell us what equipment they wished they could have. Many people expressed a wish for new gadgets to help them deal with various situations. While these ideas may seem impossible at the moment, they may be possible in the future.

Some deafblind people would like a small gadget for use when out and about which can receive information from visual displays, signs and tannoy announcements and convert them into appropriate formats. For example, at pedestrian crossings the gadget would activate the request for a pedestrian walk phase and then vibrate when the green signal is given. In shops the gadget could indicate the products sold (for example, bakery, pharmacy) and describe the shop layout. Some people wanted a gadget to open train doors.

The Ministry of Economy, Trade and Industry in Japan is currently developing small gadgets for guiding blind people in buildings and crossing roads. There has been some success but the work is still at development stage. Unfortunately, it will not be suitable for people who cannot access audio-based information. Recently Queen's University in Belfast and 13 other bodies across the European Union have been given funding to develop ways to guide blind and partially sighted people through the Internet, which is leading to schemes involving audio cues. However, there has been no consideration of access for deafblind people. It is important that the needs of deafblind people are included in the technology research that is taking place around the world. As can be seen elsewhere in this report, it is much more effective to take account of the needs of deafblind people when equipment or services are being designed than to attempt to make changes later.

3. Household equipment

Like everyone else, deafblind people need household equipment such as washing machines and cookers. However, three out of five people told us that they have experienced considerable difficulty finding products that they can use easily. This chapter explains the difficulties people encounter, including design and customer care in shops, and also describes the good experiences people have had.

Jim bought a new cooker but did not realise that the knobs for the two back rings turned clockwise to increase the heat while those for the front turned clockwise to reduce the heat. He put some oil in a frying pan on what he thought was the lowest setting, carried on chopping an onion and the pan caught fire. He had in fact put the ring on its highest setting. Had the functions been consistent, Jim's cooker would not have gone up in flames.

180 people (59% of respondents) said they have problems using household equipment. The four products most commonly mentioned by respondents were remote controls, cookers/ovens, mobile phones and washing machines.

3.1 Televisions and remote controls

Many Deafblind people can enjoy television as much as everyone else provided their needs are considered by manufacturers and broadcasters. These are the difficulties our respondents mentioned.

- The streamlined design of televisions means that the on/off switch is often quite hidden and difficult for visually impaired people to pick out.
- Many remote controls on newer televisions do not have a teletext enlargement button. In the past this has been a vital facility for people with limited vision.
- Many remote controls lack tactile markings and the text is in small print which makes it very difficult for a visually impaired person to read.
- The size, colour and background to subtitles cannot be changed on digital television. This does not suit many deafblind people who want to be able to customise the subtitles to suit their individual needs.
- The on-screen menus used to operate some digital TV receivers, videos and DVD players are not accessible to deafblind people. They are in a colour that does not contrast well with the background colour, making them difficult to read.

3.2 Mobile phones

Mobile phone technology has been a great leap forward for people with impaired hearing who, through text messaging, can communicate easily and cheaply. However, mobile phones pose many problems for anyone with impaired sight.

- The trend is for mobile phones to become smaller with tiny keypads, making them difficult for visually impaired people to use.
- People with impaired sight also find it difficult to use cramped, small, non-raised and non-clickable buttons on many mobile phones.
- Many mobile phones have poor backlighting and poor contrast between the text and the background on the screen display.
- The text on mobile phones cannot be enlarged and the colour of the text and the background cannot be changed.

3.3 Cookers and washing machines

- The text on the control panels of cookers and washing machines is often small, does not contrast with the background colour and does not have tactile markings. All these features make it difficult for people with a visual impairment to read.

- The knobs on ovens and cookers can be difficult to use and it can be easy to turn them to the wrong setting, allowing food to burn or remain uncooked.
- Deafblind people cannot see the lights or hear the noises which warn people that ovens and cookers have been left on, which could put them in considerable danger.

3.4 General problems

- The text and illustrations used in instruction manuals are often small and difficult for visually impaired people to read.
- Many products are incompatible with people's preferred communication methods such as BSL and symbols because they rely on an understanding of written English. People whose first language is BSL often find written English difficult to understand, especially when the language is technical.
- There are so many different products on the market that the choice is overwhelming. The information about all these products is rarely available in alternative formats and so deafblind people find it difficult to keep up with new developments.

Manufactured goods are not covered by UK disability law, because they are regulated at a European level. For example, this means there is no legal requirement to make instruction booklets accessible.

3.5 Customer service

The majority of deafblind people need support to choose suitable household equipment. Our survey indicated that:

- 41% of respondents received help from someone in choosing and purchasing suitable products at electrical shops;
- 41% of people did not get any help, of whom 58% would have welcomed help.
- 18% of people did not answer this question.

People received help from staff in shops or from manufacturing companies, family members and friends and social workers. A few people received help from Sense, Deafblind UK and RNIB. More family and friends helped deafblind people in buying suitable products than manufacturers, shop assistants and professionals,

despite the fact that the people who manufacture and sell products should know the most about them.

Our survey showed that many deafblind people have experienced problems communicating with staff in shops and getting the information and support they need to make decisions about suitable products.

Deafblind people have also experienced problems with engineers who are called out to repair household goods. They need to be aware of the needs of deafblind customers, so that the deafblind person can understand the problem and what is being done to solve it.

The information and customer care provided by staff in electrical shops and engineers who are called out to repair household goods needs to improve. This could involve improving their communication skills and their awareness of deafblind issues.

3.6 Some good experiences

The good experiences deafblind people have had are very instructive for manufacturers and the retail sector.

One respondent uses text enlargement software called Mobile Magnifier on his mobile phone, which enables him to read and send text messages easily. This was previously something he could only do with support, so his independence has been greatly enhanced by this piece of equipment.

"Cordless headphones have greatly improved my enjoyment of television." (The respondent no longer has to deal with tangled wires.)

"A wide screen TV is really good to watch."

"Digital hearing aids are very good and a vast improvement on analogue hearing aids."

"The shake awake alarm I use is very good as it has large numbers."

"My computer helps me keep in touch with people around the world and helps me pass the time."

"Zanussi service engineers visited my home to change the front panel of the washing machine and replace it with a braille display."

4. Agenda for Action – what needs to change?

Technology has the potential to transform the lives of deafblind people, making communication, information and mobility possible. This survey has shown that deafblind people have had both good and bad experiences of using assistive and mainstream technology. Unfortunately, in both cases the bad experiences outnumber the good. But it does not have to be like this. This final chapter explains deafblind people's worries about the technology of the future and gives our recommendations for action by all the players, from manufacturers to government, who can make a positive difference.

4.1 What worries do deafblind people have about the future?

Respondents mentioned the following concerns about the future.

- Manufacturers are not aware of the needs of deafblind people and so have not seen the need to ensure that design is inclusive. As a minority group, deafblind people are afraid that they will continue to be ignored.
- Fashion and advances in technology have dictated that technology is more sophisticated and is getting smaller, which makes access harder for many deafblind people.
- Problems with technology will continue to cause many deafblind people to remain isolated and unable to access information.
- Many people are worried that the assistive equipment they own will quickly become out of date due to fast-changing mainstream technology.
- Many respondents fear they will be unable to purchase new equipment due to high prices.

- Advances in technology are so fast that many people fear not being able to keep pace and, as a result, losing their independence and becoming more isolated.

4.2 Recommendations for manufacturers – design for all

Assistive technology and household equipment that is more inclusively designed could open up new markets. The technology that works well for people with impaired sight and hearing will also work well for the millions of people with either deafness or impaired sight. People with arthritis in their hands (of whom there are about 4.4 million in the UK (Arthritis Research Campaign)) also need well-designed functional features, such as control buttons. These groups of people with special needs combine to make a huge market and one which will grow as our population ages. More inclusive design does not usually disbenefit other users so there is no reason NOT to do it.

Our recommendations include:

- **At the design stage,** get advice from deafblind people to ensure you fully understand their needs.
- **Think tactile** – people with poor sight and deafblind people use their sense of touch. For example, large, tactile, raised keys/buttons on telephones, textphones, other keyboards and appliances help everyone who cannot see properly. Remote controls for TVs should include a teletext enlargement button.
- **Think about legibility** for all those with poor sight. Text on keys should be larger, bolder and the colour of the text should contrast with the background colour. Textphones should have good colour contrast between the text and the background.
- **Offer models with larger screens and controls**, for example, on mobile phones and remote controls.
- **Enable screens to be customised** to individual needs.
- **Vibrating pagers need the same number of different vibrating indicators as light indicators**, so that they provide the same information to people with vision loss.
- **Ensure consistency.** For example, control knobs should always turn the same way.

- **Think about your product literature.** Is it available in plain English with clear and large illustrations? Can you provide it in large print, on audio-tape or braille on request?

Recommendations for specific assistive equipment:

- **Refreshable braille displays:** the design needs to be reconsidered to make them more comfortable and easier to use, so that the braille can be read faster. Manufacturers should invite input from blind people in the design of such equipment.
- **Screen readers:** developers of screen readers for computers need to think of braille as an alternative to speech not as an addition to speech. They should ensure that all information that is available to the screen reader is also available to the braille display.

4.3 Recommendations for retailers – customer care

Many of the people in our survey said they would like more help from retail staff who provide them with equipment. They need help to select the right equipment and guidance on how to use it. Good customer care is often what brings shoppers back for more.

Here is how to help deafblind people:

- **Train your key staff,** including repair engineers, to work with deafblind customers (see the Sense website for information about possible training).
- If you have an induction loop system, **make sure staff know how to use it.**
- **Check whether your company is fully complying** with the Disability Discrimination Act.

4.4 Recommendations for social services staff – a frontline service

Many of the people who took part in the survey said they would like more help from the social services staff who advise and provide them with equipment. Not fully understanding how to use the equipment they have is a common problem.

Our recommendations are:

- **Make sure that all deafblind people are receiving the assessments** they have a right to.
- **Ensure that assessments are carried out by professionals** who have been specifically trained for this role.
- **Enable rehabilitation officers and other staff to train deafblind people** on how to use assistive technology. This may involve knowing how to access the appropriate interpreters/ communicators.

4.5 Recommendations for government – setting the standards

Central government can lead by example and, where necessary, intervene when specialised equipment has a small market.

Our recommendations are:

- **Fast-track deafblind people** for digital hearing aids because of the difference they can make to both communication and independence.
- **Intervene when necessary** to ensure the market produces the technology that is critical to deafblind people's daily lives.
- **Recognise that some deafblind people need access to support** in the form of interpreters/communicators and guides. Technology cannot solve every problem.
- **Ensure that major research programmes on disabled access** include consideration of deafblind people's needs.
- **Work at a European level** to ensure deafblind people's access to manufactured goods.

Glossary of Terms

Textphone
A type of telephone for the hearing impaired that includes a keyboard and a display screen. This allows telephone conversations to take place using text alone, with no need for sound.

Refreshable Braille Display Board
A device used by the visually impaired that instantaneously converts text on a computer screen to Braille so that it can be read on a display board.

Vibrating Lightprobe
A pocket-sized device used by the visually impaired to measure light intensity. The vibration pulse of the device changes to indicate the changing intensity of the light. It is commonly used to identify light spots on electronic devices.

Sound Monitor
A device used by the hearing impaired to detect sounds and alert the user by means of a vibration or strobe. It is commonly used to monitor sounds such as a baby's cry, a doorbell or an alarm clock.

Vibrating Alert Pagers
A small, portable device used by deaf and deafblind people to alert the user to specific signals. It uses a variety of different vibrating patterns to indicate different signals, for example the doorbell or the telephone.

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We would like to record our thanks to Deafblind UK for circulating the survey to their members. Readers who want to know more about their work can contact them on 01733 358100 (voice or text) or visit www.deafblind.org.uk

Notes