
THE INFORMATION NEEDS OF VISUALLY IMPAIRED PEOPLE

**A review of research
for the RNIB**

Nick Moore

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Acumen

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INTRODUCTION

Britain is well on the way to becoming an information society - a society in which information is used intensively in all walks of life as a basic resource. As our world becomes more complex we all need to make greater use of information at work, for education and for leisure. Most critically, however, we need to acquire and process more and more information simply to function as a social being.

In a society of this kind, the lack of access to information contributes directly to social exclusion. Without adequate access to information, people are unable to play their parts as citizens, they cannot make informed choices as consumers and they are unable to benefit fully from all that society has to offer.

We acquire information using all of our senses but sight is the most important:

It has been estimated that human beings absorb as much as 80 per cent of information about their immediate environment by means of sight. (Willetts, 1997)

Visually impaired people, therefore, are at greatest risk of being socially excluded as a result of poor access to information.

A number of studies have touched on this issue in recent years. To provide a rounded picture, the Royal National Institute for the Blind commissioned this review of recent research to identify the scope of the problem and, in particular, to establish the nature of the information needs experienced by visually impaired people.

A full literature search was undertaken by Jil Fairclough of the University of Brighton, drawing on the resources of the Royal National Institute for the Blind and other libraries. This identified over 75 reports of research on which this report is based.

The picture presented by these reports is a varied one. Indeed, there is a degree of inconsistency in the results. This is perhaps understandable as relatively few of the projects set out to explore information needs as such. Most touched on the need for information - or the consequences of the lack of it - as part of a wider study of visual impairment. As a result, the picture that emerges from the sum of the research is patchy and incomplete. There is, however, much that can be learned, not least the fact that we are still very far away from a position where visually impaired people have the same level of access to information as the rest of the population.

To provide a framework within which the research can be reviewed, this report begins by setting out a model of social information needs.

A MODEL OF SOCIAL INFORMATION NEED

Information need is the lack of appropriate information on which to base choices that could lead to benefits or services that may improve people=s well-being. (Tester 1992)

Susan Tester=s definition is a good starting point for a consideration of what we mean by information need. It emphasises the fact that we seldom want - or need - information for information=s sake. Information is a means to an end, something that enables us to make choices that may improve our well-being. But like many fundamental definitions, it does not take us very far.

We play many different roles in our lives and each has an information component. We absorb, for example, a great deal of educational information during our school years. Similarly, at work, people need a steady flow of work-related information to perform the functions allotted to them. This study, however, is concerned with social information - the information that people need to live their daily lives.

Social information can be thought of as having six different dimensions, each of which can provide a basis for analysis. They are:

- C **Function** - *Why do people need information?*
- C **Form** - *What kind of information do people need?*
- C **Clusters** - *What do people need information about?*
- C **Agents** - *Who initiates the information activity?*
- C **Users** - *How do needs differ between different groups of people?*
- C **Mechanisms** - *Which mechanisms can be used to meet information needs?*

Let us consider each of these dimensions in more detail.

Function - Why do people need information?

People need social information to support them in the two roles they play as members of society - as citizens and consumers (Moore and Steele, 1991).

Information for citizenship

As citizens we are called upon to make democratic choices. To do this we need a considerable amount of information about the world around us, about the choices that are on offer and about the consequences of choosing one course of action in preference to another. The issues are clarified or, more precisely, clearly identified, at critical decision-points like elections or referendums. But there is an underlying expectation that we will all act as informed citizens, gathering, sifting and using information for the collective, as well as our individual benefit. This is a fundamental principle of democratic political systems - if citizens are not well-informed then democratic processes are little more than a sham.

One aspect of this is the need to hold organisations accountable for their actions. Such accountability is only possible if we are well-informed. In some cases, such as the levels of pollution produced by a factory, we are concerned with the effect of organisations on society as a whole. More usually, however, it is a case of an individual ensuring that organisations deal with them equitably.

People need, therefore, access to information that will enable them to play their full part as active citizens, making democratic choices, holding organisation of all kinds to account and exercising their rights and responsibilities as members of society.

Information for consumption

We also need access to information if we are to make informed choices about the goods and services that we consume. This is more than a question of choosing between one brand of margarine and another or selecting the most appropriate mobile telephone package. Increasingly we are required to make choices about the public services that we consume. Partly this is a result of the process of privatisation that transformed many public services into private sector companies. More generally, though, it is a consequence of a more fundamental change in approach to the provision of public services and utilities.

People are now offered much greater choice of schooling, healthcare, housing, social care and other public services in the belief that this element of consumer choice will lead to higher levels of efficiency and quality.

But for the choices to be real, they must be well-informed. Thus we have the publication of school league tables, information about hospital waiting lists and so on, all in an attempt to provide people with the information on which they can base their consumption decisions.

Without access to information of this kind, people lack the power to choose and, through their choices, to influence ways in which society is organised and goods and services are provided.

Form - What kind of information do people need?

We seek, process and absorb many different kinds of information. We gather information from the social environment that we inhabit and, through this, become more or less well-informed. But we also have specific information needs that prompt us to go in search of information.

Environmental scanning

All of us need to build up an understanding of the world we inhabit. We do this through absorbing large amounts of information in fairly random and unconscious ways. This information is then processed and added to what has gone before. Gradually we build up a cognitive map of our world. We recognise people and places. We develop an understanding of principles and procedures - like the fact that in Britain we need a licence in order to watch television. We appreciate quite abstract concepts like loyalty, and justice.

Some of this understanding is the product of formal and non-formal learning, indeed, such learning is often intended to provide a foundation upon which deeper understanding can develop. But most of the understanding comes about through random and unstructured acquisition and processing of information from the environment.

We carry out this environmental scanning all the time by absorbing information from newspapers, from the broadcast media, from family and friends, from overhearing something on the bus - in a wide range of different ways. All the information, once processed, goes towards building up our understanding of the world around us, leading to the ideal position where we are >well informed= (Ryan and McCloughlan 1999)

As society becomes more complex, it becomes more difficult to keep abreast of all the information that one needs. It becomes easier and easier to miss potentially important areas of information and thus to be unaware of issues that could have a bearing on one=s life. The extent to which people are unaware of these issues that are important to them is one measure of their degree of social exclusion. The paradox is that the greater our awareness, the larger is the task of maintaining a state of >well-informedness=. This seems to bear out the truism that the more information we receive the more we realise how poorly informed we are.

Answers to questions

Environmental scanning ensures that we are aware of what is going on around us and alerts us to the fact that there are issues to be considered and to do this means that we have to acquire specific pieces or sets of information.

At a basic level, people want to have answers to the questions that bother them. They want to be able to find out when they will be able to see the doctor, how they can apply for a welfare benefit, or where they can find a particular piece of equipment. They need to have access to a service that will deal with them as individuals, providing concrete responses to specific queries.

Clearly, the services that provide these answers need to be easily accessible, authoritative, and capable of providing information that meets the particular needs of the individual.

At a more fundamental level, however, people are searching for answers to questions that are more complex or less well-defined. Should we join the European Monetary Union? Would higher expenditure on health services benefit us more than reductions in the level of income tax? Here there is less scope for specific information services and a consequent need to gather information from different sources, weighing it up and coming to a personal conclusion.

Information alone is not enough

Even when people become aware of an issue or an entitlement, it is apparent that information alone is not enough to trigger action or even, in many cases, to provide an answer to a question. An often-quoted review of research carried out by the Department of Social Security found that a range of attitudinal barriers inhibited people from claiming benefits even though they thought they were entitled to them. The study concluded that we need to

... focus on ways of sharpening perceptions of eligibility rather than just increasing general awareness of the existence of benefits. Other methods of improving understanding, such as the provision of informed advice or the encouragement to claim, should be considered as a way of supplementing publicity. (Craig, 1991)

In some cases, too much information can be a problem. People can feel overwhelmed and unable to make proper sense of all the information they receive. So one of the functions of social information and advice services

is to reduce the overall amount of information available, re-presenting and re-packaging it in digestible amounts so that people can absorb the messages and use them to take action of one kind or another.

The experience of the National Disability Information Project showed that what people wanted was to have the information tailored or customised to suit their particular requirements and then for someone to work with them to take action on the information (Moore 1994).

This has led to a general view that, in an ideal world, there would be a continuum of social information provision that ranges from information through to advice and on to advocacy (see, for example, Moore, 1994 and Moore and Steele, 1991). This view is now being challenged by recent research into information about financial services. This suggests that people are becoming more suspicious of financial advisers and do not want to be *advised* on which course of action to take. Instead, they want an *explanation* of the options open to them, followed by *assistance* in exercising the option and, in some circumstances, an advocacy service to help them argue for their entitlements (see, for example, Hedges, 1998, National Consumer Council, 1995 and 1999, Vass, 1997 and Wood, 1999).

Clusters - What do people need information about?

Here, we are essentially concerned with the subject matter of social information. It is possible to approach this in a number of different ways.

Hierarchies of need

One approach (suggested by Selina Shah of the RNIB) is to think of hierarchies of need. The most commonly used is that derived by Abraham Maslow (1968). Starting from the most basic needs he defined five different levels:

- C ***Physiological needs:*** Food, water, warmth and protection. These needs are strongest because, if deprived, the person would die.
- C ***Safety needs:*** Felt by adults during periods of social disorganisation and, more frequently, by children.
- C ***Love, affection and belongingness needs:*** The need to escape loneliness and alienation and to give and receive love and affection.
- C ***Esteem needs:*** The need for stable, and firmly-based, high levels of self respect and esteem by others. If these needs are not met, the person feel inferior, weak, helpless and worthless.

- C ***Self-actualisation needs:*** The additional benefits that accrue to self-esteem through doing something that the individual feels to be worthwhile. This may be the exercise of a gift like musicianship, or the pursuit of a vocation or a calling.

For each of these levels, it is possible to define clusters of information that people need. The cluster of information associated with welfare benefits and income maintenance, for example, is an important contributor to the satisfaction of physiological needs. Clearly such a hierarchy can throw light on the general structure of social information needs. It can also be used to identify the information needs of specific groups of users.

Life events

Another way of thinking about information needs has been put forward by Susan Tester in her report of the study of the information needs of elderly people (Tester, 1992). She argues that information needs can be associated with major life events such as retirement, moving into residential care or major illness.

Each life event generates needs for new sets of information, high-lighting gaps in our cognitive maps that need to be filled through information-seeking behaviour of one kind or another.

This approach to defining information needs is currently shaping the government=s plans for the development of electronic government (Ref to Modernising government).

There are two drawbacks to the life events approach to defining clusters of social information needs. The first lies in the fact that a good number of social information needs fall outside any scheme of life events. The second is the fact that each person approaches a life event differently; they come with different backgrounds and circumstances and trying to account for these becomes difficult.

An alternative approach is to identify families of need. Some needs are self-contained and circumscribed - rather like a single person. The information needed to obtain a passport would be one example. Others are more complex. They have added dimensions and relationships but are still quite tightly defined - like a nuclear family. An example of this would be the information needs associated with choosing whether to enter higher education.

Then there are complex, multi-dimensional needs that contain different combinations of relationships, just like an extended family. The information needed to deal with a death is a case in point - so much depends on the status of the deceased that the needs and relationship will differ considerably from one case to another. In these complex, extended families, of social information need, it is almost impossible to define what pieces of information will be needed or to specify how the pieces relate to each other. Instead it is necessary to define the needs by means of algorithms - did the deceased leave a will? If so, do this, if not, do that. And so on.

The advantage of conceiving of information needs as families is that it becomes possible to start with any particular need, or request for information, and, from that, to work along the family trees to define all the related needs that are associated with it. Thus what may begin as a need to find out how to cope with an unpaid heating bill might lead on to an identification of needs for information about alternative payment mechanisms, information about bank accounts and direct debits, information about entitlements to welfare benefits, information about the charging practices of utility companies, information about energy saving and insulation, information about the rights of tenants, and so on. The important thing to recognise is that the particular family structures will be determined in each case by the individual and their circumstances.

Agents - Who initiates the information activity?

Our model of social information has to take account of three different agents, each of which initiates information activity. First we have the users of information who actively seek the information they require, or simply absorb it from the information that is around them in their environment. Then there are information providers who play a more or less active role in providing information to the users. The third category concerns the intermediaries who process information on behalf of users.

Seekers

We have seen that people both actively seek information and passively absorb it from the environment. The effectiveness of a social information system depends greatly on the ease with which people are able to do this.

Active information seeking depends on both a person's information-handling capability and the efficiency of the information services in the community - a trained information specialist has a greater chance of finding what they need than someone with very few information skills. Someone with access to a good public library and citizens advice bureau is more likely to be able to satisfy their information needs than someone in

a rural area visited infrequently by a mobile library. Someone with Internet access may be in a better position still.

Much the same applies to the passive absorption of information. The amount of information that exists in the environment we inhabit determines, to a great extent, the amount we absorb. Someone who travels frequently on the London Underground, for example, will be aware of the latest cinema releases because the films are heavily advertised there.

But personal capability also determines the amount of information absorbed. People with low levels of literacy skill absorb less written information than others with high literacy skills. Similarly, people with visual impairments will not be able to absorb as much as fully sighted people.

Providers

Information providers operate in very different ways. Some do little more than place information in the public domain so that it is there for people who want to find it. They do little to promote awareness of the information or to encourage use. *Hansard*, the record of Parliamentary debate, is a case in point. We know it exists and can go and find it when we need to. In contrast, other providers work really hard to make sure we are brought face-to-face with the information - or the messages - they want us to absorb. Here one only has to look on the average doormat to see examples of the lengths that advertisers will go to the put us in a position where we read their messages.

In between these two extremes there is a wide range of providers that in more or less active ways try to make their information available to those who need it.

Processors

In most information-intensive societies there is a flourishing group of agencies that process information on behalf of the users. Public libraries collect information from a wide range of sources and make it available for people to consult and to borrow. Newspapers and journals obtain information from press releases and from their own news-gathering activities and re-present this in user-friendly formats.

Others, like the Consumers Association, collect a large amount of information from providers and add value to it by adding their own

information or by structuring data in consistent formats so that it is easier to use.

These processing agents perform an important function within the social information system. They are intermediaries between providers and users and much depends on their efficiency and effectiveness. Democracies depend on the existence of a free press and informed consumption is greatly aided by the existence of publications like *Which?*.

Trust and authority

An important determinant of the impact that is made by providers and processors is the trust that users place in the information they provide. The mis-selling of pensions, for example, has done much to erode the trust that people place in financial advisers. Similarly the Consumers Association refuses to take advertising in its publications as to do so would jeopardise people's perceptions of its impartiality.

Authority is an important determinant of trust. Information users take into account the standing of the information provider, the extent to which it can be seen to be objective, its motives in providing the information and the likelihood that it will get things right. All these amount to the authority that the organisation brings to bear on the information. Thus information about pensions provided by the Financial Services Authority will tend to be given more credence than information provided by a pensions company or an independent financial adviser.

Users - How do needs differ between different groups of people?

Information needs vary considerably from individual to individual. Not only are individuals inherently different, they belong to different social groupings - an individual may, at one and the same time, be a parent, a fluent Spanish speaker, a social worker, a snooker enthusiast and a keen gardener with a liking for Chinese food. Not many other individuals will belong to the same pattern of social groupings and few, therefore, will have the same pattern of information needs.

It is possible, however, to define groups of users that share common information needs. Parents, whether they speak Spanish or not, have many information needs in common with other parents. Equally snooker enthusiasts share information needs whether or not they like Chinese food. The information needs are common but only in respect of the membership of that particular group. Group needs are not mutually exclusive.

When developing a model of social information need, it is possible to define an almost infinite number of groups of users. It is, consequently, difficult to prescribe a standard or general set of user groups that can be applied in a range of different circumstances - so much depends on the point of departure. If one is looking at patterns of provision, for example, geographical groupings might be appropriate, categorising users according to whether they lived in urban or rural areas.

In the case of visually impaired people, the research suggests that the key factors that affected the range and nature of needs were: age; the degree of impairment; the elapsed time since the onset of visual impairment; ethnic origin and the incidence of other disabilities. It is also possible to identify significant groups that share common information needs - carers, particularly parents of visually impaired children; professionals dealing with visually impaired people.

Mechanisms - Which mechanisms can be used to meet information needs?

A range of different mechanisms can be used to meet people's information needs. They do this by recording and storing information; by copying and reproducing it; by transmitting and communicating it; and by tailoring the information to meet the needs of the individual.

Recording and storage

It is important to be able to fix information and to hold it so that it can be used at a later date or sent to somewhere else. These have been the traditional roles of printed information. By writing something down we record and preserve it so that it can be used by others. It can be printed in multiple copies and distributed widely. The information can be stored in libraries, on shelves or tucked away in drawers.

The chances of information getting lost are remote, although the explosion in the amount of written information means that we face major problems of managing it. The other problem with storing recorded information is that it is almost impossible to up-date or to change as needed.

Digital media can be used for recording and storage in the form of discs and CD-ROMs. They thus have many of the attributes of printed information. Networked digital information, in contrast, is not very good for storage in the long term.

Copying and reproduction

Information technology and, in particular, the introduction of digital technology, has transformed our ability to copy and reproduce information. In the 1970s and 1980s photocopiers transformed our ability to copy written and printed information but the cost put them out of the reach of most individuals. Cassette recorders, on the other hand, continue to provide a very cheap and effective means of copying sound. Computer technology has now reached a point of development where it has become possible to copy and reproduce all forms of information that are in digital formats and to do so at a cost that is within reach of a large proportion of households.

We have reached a point where the main constraint on copying and reproduction is a legal one rather than a question of technology.

Transmission and communication

We require mechanisms to transmit and communicate the information from the provider to the user. Some of these mechanisms are long-standing and robust. The newspaper distribution system is a case in point. As is the system of television and radio broadcasting.

It is here, though, that advances in information technology have had the greatest impact. Digital networks now mean that it is possible to communicate information on demand over vast distances at very low cost and without significant time constraints. The Internet, and other digital networks are, therefore, transforming our ability to communicate information.

Tailoring and customisation

Most people want information that is tailored to meet their particular needs - information that is customised to take account of their circumstances. This calls for personalised forms of service and a high level of interactivity. A citizens advice bureau, for example, will diagnose a client's problem and will present advice - or explanations - that fit the particular needs of the individual. Solicitors and doctors perform much the same function.

Interactive digital networks provide limited opportunities for interactivity but their capacity to customise information is very poor when compared with a trained information or advice worker.

The model

The model that is set out here is complex and multi-dimensional. In this it reflects the social information system itself. In brief, it consists of six

different, though related, dimensions each of which can be further sub-divided as follows:

- C **Function** - *Why do people need information?*
 - S For citizenship
 - S For consumption

- C **Form** - *What kind of information do people need?*
 - S Environmental scanning
 - S Answers to questions
 - S Information
 - S Explanation
 - S Assistance
 - S Advocacy

- C **Clusters** - *What do people need information about?*
 - S Hierarchies of need
 - S Life events
 - S Families of needs

- C **Agents** - *Who initiates the information activity?*
 - S Seekers
 - S Providers
 - S Processors

- C **Users** - *How do needs differ between different groups of people?*
 - S User groups defined according to point of departure

- C **Mechanisms** - *Which mechanisms can be used to meet information needs?*

- S Recording and storage
- S Transmission and communication
- S Copying and reproduction
- S Tailoring and customisation

This basic model provides us with a framework for analysing the research into the information needs of visually impaired people.

FUNCTION - WHY DO PEOPLE NEED INFORMATION?

A useful starting point may be to recognise that visually impaired people need all the information that fully sighted people need: they need to be sufficiently well informed to be able to participate fully as citizens; they need to know about their rights and entitlements; they need information that will enable them to make rational choices as consumers and they need information to support them in their work, their learning and their leisure. The thing that differentiates visually impaired people is the fact that they may need to receive all this information in accessible formats.

In addition to the information needs that they share with everyone else, visually impaired people need information that relates to their position as disabled people. Like wheelchair users or people with hearing difficulties, they need information about specific rights and entitlements open to disabled people. Some would also argue that they need information that would support their political consciousness as disabled people (Hasler, 1993).

Finally, they need information that relates specifically to their status as visually impaired people. This includes information about their condition, the aids, equipment and services that are available, as well as self-help groups.

One way to conceive of the information needs of visually impaired people, therefore, is to identify the core of needs that is concerned specifically with visual impairment. This is surrounded by a related set of needs that are common to all disabled people, which, in turn, is surrounded by a periphery of information needs that are shared by all members of society. Overlaying this is the need for information to be made available in accessible formats.

Information for citizenship

Few of the research studies reviewed dealt with information for citizenship in any great depth. Most were concerned with consumption issues. This is surprising. There has been a considerable shift in the perception of disabled people as citizens resulting from the emergence of the disability rights movement and pressures that built up during the late 1980s and 1990s for disability rights legislation (Moore, 1994).

The Disability Discrimination Act gives disabled people certain rights and imposes a number of duties on providers, employers and other organisation. The government has developed a number of information campaigns to get the message across to disabled people and to others

affected by the legislation. Yet we were unable to identify any research that assesses the extent to which this information had met the needs of visually impaired people.

We do, however, know that unmet information needs meant that visually impaired people tend to feel a lack of power and excluded from decisions. In their work with older people, Lloyd and Thornton (1998) found that there was general feeling of powerlessness stemming from a lack of information. Beryl Palmer similarly found that communication problems resulted in people feeling left out (Palmer, undated).

Kerrigan and Gooding looked at the need to hold organisations accountable for their actions. They noted that in the context of the effectiveness of the Access to work scheme visually impaired people were not sufficiently well informed to be able to hold the scheme to account:

If a request for support is turned down, it is extremely difficult for a disabled person to appeal without having access to information about eligibility criteria, the rules of the scheme and how the different elements of support operate.
(Kerrigan and Gooding, 1995)

At a broader level there is a gap in our understanding of the extent to which visually impaired people's needs for general citizenship information is being met. We do not know, therefore, whether visually impaired people more or less well-informed about political issues such as devolution, the European Union or the activities of their local council.

Information for consumption

There is more evidence about the gap between the need for and the provision of the information that visually impaired people need as consumers. In her research into the individual support needs of older people with serious loss of sight, for example, Alison Nelson identified a real need for information to be readily available so that people could exercise choices in the care they received (Nelson, 1999).

Similarly, Lloyd and Thornton (1998), Adrian Cox (1999) and Beryl Palmer (Undated) found that lack of access to information about the availability of services meant that people lacked the power to choose and, through their choices, to influence ways in which society is organised and goods and services are provided. This perception was confirmed by Rea Maglajlic and David Brandon in the context of visually impaired people having to make choices about residential care (Maglajlic and Brandon, 1999). The

lack of information among potential services users also contributed to a feeling that services were under-used (Cox, 1999 and RNIB, 1998c).

There was also a big gap between the need for and the provision of information about welfare benefits (Cox, 1999, Tinker and others, 1993 and Walker and others, 1992).

In a consumer society, being unable to exercise consumer choice, either through lack of resources or lack of information is a measure of social exclusion. The research suggests that visually impaired people are excluded on both counts.

Form - What kind of information do people need?

Here we are concerned with both the extent to which visually impaired people are able to absorb information from the world around them and their ability to find answers to questions.

Environmental scanning

It would be reasonable to expect that visually impaired people have particular problems with environmental scanning. As we noted earlier, it has been estimated that sighted people absorb over three quarters of the information they receive by sight. Having no sight, or only a limited ability to see, therefore, puts visually impaired people at a real disadvantage.

This deduction must, however, be qualified. A large proportion of visually impaired people are elderly and have lost their sight late in life. They will have been able to build up their cognitive maps during many years of full sight and their disadvantage relates to information about contemporary issues. There is also a line of argument that suggests that because visually impaired people are not distracted by all the printed and graphical information around them they can concentrate more effectively on absorbing information aurally and by touch. There is, however, little research evidence to bear this supposition out.

The research that we have shows that we are far from being in a position where visually impaired people are well informed about the world around them. Kerrigan and Gooding, for example, high-lighted the case of a man who had given up his job when he became disabled because he was unaware of the support services that were available to him (Kerrigan and Gooding, 1995). Nasa Begum also noted that lack of information led to a lack of awareness about the range of service that were on offer (Begum, 1992) and a similar situation was identified by Benson and Waterhouse when looking at awareness of local authority services (Benson and Waterhouse, undated).

This lack of awareness can lead to a failure to obtain services or benefits to which visually impaired people are entitled. It can also mean that people are unable to seek further information that will be of use to them simply because they are unaware of the issues. A study of the needs of parents of visually impaired children, for example, revealed some of the problems that arose when parents were insufficiently aware of the issues they had to grapple with:

While half the parents reported that information, advice and support were available if the right questions were asked,

interviews revealed the difficulty involved in asking the right questions in the first place. (RNIB and LOOK 1996)

Answers to questions

People with visual impairments seem to face real problems when seeking answers to the questions that concern them.

People in general will not ask for information unless they think that the information will be of value to them. They may not ask for information if they do not know where to find it. But visually impaired people have an additional dimension to the access problem: they may not ask for information unless they are reasonably sure that it can be provided in a format that is accessible to them. (Levitt, 1997)

Clearly, the services that provide these answers need to be easily accessible, authoritative, and capable of providing information that meets the particular needs of the individual. Even when the services exist, the onus still seems to rest on the individual:

The information that people receive depends very much upon that individuals= determination or knowledge of what is available and where. (Deaton, 1993)

The basic requirement is to provide the right information at the right time in the right format (Nelson, 1999, Ryan and McCloughlan, 1999). It is clear from the research, however, that we are still a long way from this position:

There was consistent feedback that meeting the information needs of visually impaired people at the operational level was not as good as it could be. (Benson Waterhouse, undated)

Similar conclusions were reached in other studies (Begum, 1992, Cox, 1999, Kerrigan and Gooding, 1995, Maglajlic and Brandon, 1999)

Information alone is not enough

We identified earlier that information alone is seldom enough. People want to have things explained to them so that they know what the options are. They may also need help and assistance to take action of some kind - claiming a benefit or arranging visits to different residential care homes. In some circumstances they need a third party to act as an advocate on their behalf.

The need for someone to explain things is particularly acute for blind or severely impaired people who find it difficult to make notes or to store the information they receive in written or other forms so that they can refer to it later or keep returning to it to check that their interpretation is correct. Instead they have to retain much of the information in their memory. This information overload can lead to confusion and inaction (Nelson 1999).

So, the ability to consult someone who can explain things is critical. In many cases family and friends perform the service, advising visually impaired people how best to proceed (Lloyd and Thornton, 1998, Manthorp 1996, Walker and others 1992). The effectiveness of this approach depends on the extent to which the family and friends themselves are well-informed and, clearly, they often are not. Even professional advisers and support groups need comprehensive information if they are to provide the kinds of advice that people need (Kerrigan and Gooding, 1995).

For many of their daily social information needs visually impaired people can turn to the network of information and advice services that exists in Britain - the citizens advice bureaux, law centres, housing aid centres and so on. The relevance of these services for visually impaired people, however, is determined greatly by the extent to which they are able to make information available in alternative formats. Explanations given orally by an adviser are useful but good advice services usually reinforce oral explanation with printed information in the form of leaflets or even notes of telephone numbers and people to contact. Few, if any, of these advice services are well-resourced and they therefore find it difficult to accommodate the additional costs associated with making the needed information available in accessible formats. The spirit is willing but the budget is weak.

The services provided by DIAL UK and other similar services aimed at disabled people have demonstrated the value of having advice services that are designed to meet the particular needs of disabled people (Moore, 1994).

It is sometimes necessary to go beyond explanation and advice and actively to work on behalf of the individual concerned by providing an advocacy service. Such services are becoming more common, often developing from generalist advice services such as citizens advice bureaux or DIAL groups. Essentially they seek to argue the case for and on behalf of an individual who is having difficulty in their dealings with an organisation. One study included a review of the effectiveness of a citizens advocacy services designed specifically to meet the needs of visually impaired people and concluded that it was very worthwhile (Lovelock and Powell 1995).

Clusters - What do people need information about?

It is clear that there are different groups of people who need information in connection with visual impairment. It is equally clear that the actual information needed varies from group to group. What is not clear from the research is the extent to which there is a core of information that is needed by all.

Hierarchies of need

Abraham Maslow=s hierachy of needs does seem to provide a useful approach to the identification of the clusters of information need that are experienced by visually impaired people. The six levels of need that Maslow identified are:

- C ***Physiological needs:*** Food, water, warmth and protection. These needs are strongest because, if deprived, the person would die.
- C ***Safety needs:*** Felt by adults during periods of social disorganisation and, more frequently, by children.
- C ***Love, affection and belongingness needs:*** The need to escape loneliness and alienation and to give and receive love and affection.
- C ***Esteem needs:*** The need for stable, and firmly-based, high levels of self respect and esteem by others. If these needs are not met, the person feel inferior, weak, helpless and worthless.
- C ***Self-actualisation needs:*** The additional benefits that accrue to self-esteem through doing something that the individual feels to be worthwhile. This may be the exercise of a gift like musicianship, or the pursuit of a vocation or a calling.

There is certainly a set of information needs that correspond to Maslow=s basic physiological needs. A number of the studies emphasised the need for information about the person=s condition, its treatment and likely outcome (Cole and Cheeseman, 1998, Jack and Waring, 1998, Magajlic and Brandon, 1999, Manthorp, 1996, Nelson, 1999, Palmer (undated), RNIB 1996, RNIB, 1998c, RNIB and LOOK, 1996, Tinker and others, 1993 and Walker and others 1992).

Closely allied to this is the need to secure adequate financial resources to provide for food, warmth and shelter. Again, a number of studies emphasise the importance of the need for information about benefits and financial resources (Cox, 1999, Deaton, 1993, Manthorp, 1996, RNIB, 1998b, SCOPE, 1995, Tinker and others, 1993 and Walker and others, 1992). There is also an identifiable set of needs relating to housing and accommodation (Cox, 1999, Maglajlic and Brandon, 1999).

The category of safety needs - the needs felt during periods of social disruption - correspond to the acute information needs experienced by people at the time when their loss of sight is diagnosed (Jack and Waring, 1998 and Masey, 1997). These needs are also experienced by parents when their children's sight loss is diagnosed (Cunningham and others, 1996 and RNIB and LOOK, 1996).

Associated information needs experienced at this time are the needs for information about aids, equipment and services available to visually impaired people (Cox, 1999, Deaton, 1993, Lloyd and Thornton, 1998, Manthorp, 1996, RNIB, 1998c and Walker and others, 1992).

Maslow's third level covers people's need for love, affection and a sense of belonging - the need to escape loneliness and isolation. Many people interviewed in the course of the research studies reviewed here commented on their loneliness and sense of isolation. They felt a strong need to talk to other people, to discuss their problems and, at the most basic level, to have some personal contact with another individual (see, particularly, Cox, 1999, Manthorp, 1996 and Nelson, 1999). This need for love, affection and a sense of belonging does seem to be more acute among visually impaired people than among the general population.

The two higher levels of need - self esteem and self actualisation - appear to be real but unmet among visually impaired people as, indeed, they are among the population as a whole. Loss of self-esteem was apparent among many of the interviewees and very few appeared to have reached a level of self-actualisation. Information provision alone is unlikely to satisfy these needs. But their realisation would undoubtedly generate additional information and communication needs. Here, therefore, information need is a consequence of the realisation of a psychological need as opposed to a means of satisfying the need.

Most visually impaired people are concerned with obtaining the information they require to satisfy the three basic levels of need. Aspiring to the two higher levels is, for most, still just an aspiration.

Life events

Another way of thinking about information needs is to associate them with major life events such as the loss of sight, moving into residential care or

major illness. This approach helps to explain some of the information needs experienced by visually impaired people.

There is a cluster of needs associated with, for example, the loss of sight (Jack and Waring, 1998, Masey, 1997 and Nelson, 1999) and with the move into residential care (Maglajlic and Brandon, 1999). Similarly, parents experience different sets of need when their children first experience sight loss, when they begin education and when that education is completed (Walker and others, 1992).

It would be possible to explore the life events experienced by visually impaired people and to plot the information needs associated with each transition. This approach was adopted by Jack and Waring (1998) in their study of people=s experiences as they attended hospital out-patients clinics.

The clusters

While these approaches provide a means of considering the overall pattern of information need, it is worth re-stating the fact that no clear patterns emerged from the research studies themselves. Several of them attempted to defined the relative importance of information needs. There was, however, little consistency in the rankings. Even between the studies of groups with similar characteristics, such as members of ethnic minorities (Ahmed, 1991 and Cole and Cheeseman, 1998) there was no apparent similarity in the relative importance assigned to information on different topics.

In part this may be a reflection of the small samples used in most of the studies. Typically the research involved interviews with about 50 people and from this it would be unreasonable to expect consistent rankings. Unfortunately, the main study which involved a sample that was large enough to provide comparable and statistically significant data (Bruce and others, 1991) did not cover the subjects on which people needed information. The comparable study of parents (Walker and others, 1992) did produce a ranking in which information on the child=s medical condition, education and benefits were each felt to be needed by about one in four of the respondents.

There was also a tendency for the information needs to be interpreted in the context of the broader aims of the study. Cole and Cheeseman (1998), for example, asked about people=s needs for information but did so in the context of a set of questions about help and advice about sight problems.

It is not, therefore, possible to identify the actual hierarchy of information needs that are experienced by visually impaired people. The furthest we can go from the research is to identify the different topics on which information was needed and to discuss each in turn. It is possible to identify eight main clusters of need:

- C The condition, its treatment and likely outcome
- C Benefits and money
- C General health
- C Aids and equipment
- C Housing and accommodation
- C Mobility
- C Services and facilities
- C Employment, education and training

The condition, its treatment and likely outcome

Clearly, information about people=s condition, the ways it can be treated and the likely outcome are of critical importance, particularly at the time when loss of sight is first diagnosed or when a person=s sight is deteriorating rapidly. Yet it is perhaps here that we find the most negative views about the provision of information.

In their thorough study of people attending out-patients clinics, Jack and Waring found that people felt that they had been very poorly informed. They commented on the low level of provision generally and, in particular, on the fact that they were supplied with almost no written information (Jack and Waring 1998) They wanted information about their condition, about registration and about the support services available.

When asked if any written information had been made available to take away almost all participants (except those at the eye department with support workers) had recalled not being told anything about such information at the hospital. One participant said >they don=t give you any information=. Jack and Waring, 1998

Similar failings in the provision of information about conditions were noted in a number of other studies (Cole and Cheeseman, 1998, Maglajlic and Brandon, 1999, Manthorp, 1996, Nelson, 1999, Palmer (Undated), RNIB, 1996, RNIB, 1998c, RNIB and LOOK 1996, Tinker and others, 1993 and Walker and others, 1992).

The need for information about eye conditions is felt most acutely at the time when the problem is diagnosed. It is at this point that people are most vociferous about the lack of information available to them. This does, however, need to be put into context. There is considerable

research evidence (reviewed in Kempson, 1987) to show that at times of stress, people forget quite a large proportion of the information that is given to them orally. Some also forget or lose information that is made available in printed form. The stresses associated with the diagnosis and the bad news that is received mean that people are unable, or unwilling, to focus on what they are being told. They also seldom have time to formulate the questions that they need to ask. As one person put it:

Before certification I had questions, but the consultant put the fear of God into me. (Manthorp, 1996)

To overcome, or ameliorate these problems, a number of studies commented on the need for printed information or support services to reinforce the information given orally by medical staff. Jack and Waring (1998) noted that where eye clinics had support workers, people felt better informed. A similar conclusion was reached by Alison Nelson in her study of older people with serious sight loss (Nelson, 1999) and by Helen Manthorp in her study of the South Worcestershire Visual Impairment Project (Manthorp, 1996).

It seems, therefore, that there are significant information needs associated with individuals = medical condition but few people feel that their needs were adequately met. In particular, people felt the need for written or printed information to reinforce what they had been told orally by medical staff. This points to the value of support services in hospitals and eye clinics that can meet people = s information needs after the consultation.

Benefits and money

Visually impaired people are not, on the whole, well-off. In fact, they are among the poorest in society. In 1990 nearly three-quarters of visually impaired people of working age lived in households with a weekly income that was less than 70 percent of the average, with about one in three living in extreme poverty. The situation is even worse for older visually impaired people. Half of those aged between 60 and 74 lived in extreme poverty, while for the group aged 75 and over the proportion rose to two-thirds (Bruce and others, 1991).

It is not surprising, therefore, that many visually impaired people identified the need for information about benefits and money.

Deaton (1993) found that less than half the 50 people interviewed had been given any information about benefits. The RNIB found a similar proportion of older people were unsure about their entitlement to benefits and ...

... additionally, one in ten of the sample knew of benefits to which they may be entitled but do not claim them, mainly because of a lack of information. (RNIB 1998b)

In their study of disabled people, SCOPE found a similar position. One respondent said:

You are not told what benefits you could apply for. You have to rely on someone mentioning it incidentally. (SCOPE, 1995)

A number of other studies confirm this general lack of information and awareness (Cox, 1999, Tinker and others, 1993 and Walker and others, 1992). The exception, which perhaps proves the general rule, was Helen Manthorp's study of the South Worcestershire Project. She found that the majority of the 54 people she interviewed felt reasonably well-informed about benefits. She went on to note, however, that levels of take-up were low and that nearly half the sample felt that finance was a major problem. Moreover, over half the respondents expressed a desire for practical help and advice on matters like benefit claims (Manthorp, 1996). This perhaps confirms the view that, in many areas, people are unaware of the degree to which they are uninformed. It might also confirm the conclusion noted above, that information alone is not enough to trigger action and that people need support and help to translate awareness of an entitlement into an actual claim for benefit (Craig, 1991).

Given the high incidence of poverty among visually impaired people, the provision of information about benefits, and the support needed to make a successful claim, ought to be given a high priority. Yet the research suggests that people are not well informed and as a result may be failing to claim benefits to which they are entitled.

General health

In addition to the need for information about their condition and its treatment, visually impaired people have the same wide range of health information needs as everyone else.

For many years, attention was directed almost exclusively towards information about illnesses, their treatment and about how to live with chronic conditions. A number of consumer information services such as Help for Health and the College of Health were established to meet these consumer health information needs and, by and large, they were seen to be providing a highly-valued services (Kempson, 1987).

More recently, attention has broadened to include information about prevention and healthy living - the aim being to prevent avoidable illness rather than simply to cope when it arrives. To this end, all health authorities are required to provide a consumer health information service,

most of them doing so by contracting with one or other of the telephone-based services.

Between 1998 and 2000 a national telephone-based entry point for the National health Service has been established - NHS Direct. A central feature of this service is the provision of information and advice on conditions, illnesses, their treatment and self-help. Many people have made use of the services and it seems set to become a valued and established element within the national provision of health care.

In December 1999 the Prime Minister launched NHS Direct Online. This is a web-based information service designed to complement the NHS Direct telephone service. If anything, this has been even more successful than the telephone service. Use of the site has now stabilised at about 100,000 hits per day.

Clearly, this kind of health information service offers considerable potential for visually impaired people. They can access the service without leaving their homes using a familiar technology - the telephone - or a newer, but increasingly common technology that will allow them to output information in a variety of different formats.

Aids and equipment

A number of studies identified the need for information about aids and equipment (Cox, 1999, Deaton, 1993, Lloyd and Thornton, 1998, Manthorp, 1996 and Walker and others, 1992). The need for this information is most acute during and immediately following the loss of sight as people adjust to new ways of doing things. Yet, again, levels of information provision and the consequent levels of awareness were low.

In one study of people with both a loss of sight and hearing, only nine out of the 50 surveyed had received information about aids and equipment, although rather more had actually received aids and adaptations (Cox, 1999). Deaton found that the social services departments were generally quite good about providing information about equipment (Deaton 1993). In contrast, Cox (1999) found that only seven out of fifty had received information from social services and that it was seldom in accessible formats.

Housing and accommodation

People were seldom any better informed about housing and accommodation - another of Maslow's most basic needs (Cox, 1999).

The need was pressing for those who had to move from living independently to life in sheltered or residential care. Rea Maglajlic and

David Brandon studied the information needs of three groups of older visually impaired people living in these three types of accommodation (Maglajlic and Brandon, 1999). They found that there was a very real need for good information about the options available so that people could make informed choices but that, in the main, people did not feel sufficiently well informed. This confirms earlier research into the needs of people entering residential care (Steele, 1991).

Mobility

Lack of mobility is a severe constraint on a person. Not only are they unable to take advantage of many services - including many information services - they also become cut off from the world, lacking social interaction and human contact (RNIB, 1998b).

Clearly, anyone with a visual impairment faces problems moving around outside the home. Many of these stem from lack of information. People need a considerable amount of information before setting out - they need details of bus or rail timetables, they might need to consult a map or to record how to get to where they are going. Once on the journey they will miss all sorts of visual cues that sighted people take for granted, such as displays showing the platform a train will depart from, the number of a bus, signposts and directions or the names of buildings.

In part, these barriers to mobility can be overcome using tactile maps and signs, and by providing telephone-based timetable information and ticket booking services and the government has provided useful information on how this might be achieved (Department of Transport, 1992). But we are still a long way from a position where visually impaired people's mobility information needs are fully addressed.

Services and facilities

A similar picture emerges with information about the services and facilities that are made available to visually impaired people. People did not feel well informed. Few were able to claim that they had received information about available services and, as a consequence, there was a strong feeling that the facilities were under-used (Cox, 1999, Lloyd and Thornton, 1998 and RNIB, 1998c)

Employment

The present government's stated intention is to enable as many disabled people as possible to enter the workforce. To do this, disabled people, including those with a visual impairment, should be well-informed about the employment opportunities that are open to them. In particular, there should be good provision of information about the specific employment measures that are used to make work a practical proposition.

Only one study explored this set of issues and it was carried out in 1994-95 before the present government=s intentions became concrete. Kerrigan and Gooding (1995) set out to explore the effectiveness of the Access to Work scheme. The picture they paint is a depressing one. Despite the virtues, or the drawbacks, of the scheme, its effectiveness was severely constrained by lack of awareness on the part of employers and individuals. This lack of awareness was a result of low levels of information provision:

Visually impaired people reported problems where information was not available in tape, braille or large print. At present the short Access to Work client leaflet distributed by the Placement Assessment and Counselling Teams is available in braille and tape but this is the only Access to Work information produced in this format. This means that visually impaired people receive print information which they cannot access until they find someone to read it for them. This is frustrating, causes delays and undermines the purpose of the scheme which is to improve access to employment opportunities. Kerrigan and Gooding, 1995)

Once again it would appear that the effectiveness of socially-worthy provision is reduced through the lack of adequate information. This is undesirable in general terms and is an issue that the providing authorities should address as a matter of some urgency. From the perspective of the visually impaired person, however, it has the effect of preventing them from satisfying fully even the most basic of Maslow=s social and psychological needs, condemning them to a life characterised by low levels of achievement with all the consequences that has for self esteem.

Nasa Begum sums up the situation very well:

This research has shown that the availability of information in an appropriate form is a key factor in enabling people to gain access to the resources and facilities that they require. (Begum, 1992)

A number of studies refer to other information needs experienced by visually impaired people or, at least, to sub-sets of the visually impaired. Ahmed (1991) and Begum (1992) identify a need for religious and cultural information among members of ethnic minority communities. Deaton (1993) points to the need for information about transport and shopping. While Deaton (1993) and Manthorp (1996) highlight the need for information about leisure opportunities. Walker and others (1992) as well

as Deaton (1993) identify the need for information about educational opportunities, particularly among the parents of visually impaired children.

Agents - Who initiates the information activity?

Here we are concerned with the respective roles of seekers, providers and processors of information.

Seekers

It is clear from the research that visually impaired people felt that they had to seek out the information they need rather than having it drawn to their attention (Lovelock and Powell, 1995, Masey, 1997, and Tester, 1992).

A study of people with low vision who felt that the onus was on them to find the information they required:

Many people with low vision felt that they had received no information at all regarding the help that was available. Furthermore, many who had been given information were unhappy that they had to ask for it. As one person put it, >I feel it shouldn=t be so hard to find things out. I shouldn=t have to phone around hundreds of people.= (Ryan and McCloughlan 1999)

In a more general survey of disabled people, carried out by a research team from SCOPE, a respondent said:

>You are not told what benefits you could apply for but have to rely on someone mentioning it incidentally=. (SCOPE 1995)

Andrew Jack and Kris Waring (1998) also found that few people attending eye clinics felt that they had been given the information they needed. This lack of provision was identified in a number of other studies (Cole and Cheeseman, 1998, Maglajlic and Brandon, 1999, Manthorp, 1996, Nelson, 1999, Palmer (Undated), RNIB, 1996, RNIB, 1998c, RNIB and LOOK 1996, Tinker and others, 1993 and Walker and others, 1992).

Providers

There are clearly different levels of provision. In some cases, service providers produce printed or recorded information to reinforce what was said orally. This makes a real contribution towards meeting individuals= needs, partly by reducing the requirement on the individual to ask for the information they need (Manthorp, 1996 and Nelson, 1999).

In other cases, attempts are made to provide a service that is more closely related to the needs of different individuals. Some eye clinics go further and provide information services and support workers. Where such active provision is made, it appears to be very effective (Jack and Waring, 1998 and Walker and others, 1992).

Such services, however, are quite specific and seldom extend beyond the provision of information about the condition, its treatment and the availability of aids and equipment. The information needs of visually impaired people, however, extend well beyond this. They have extensive needs for information related to their impairment. They also have the same social information needs as everyone else. Yet many, if not most of the research studies covered by this review showed that visually impaired people felt ill-informed, conscious that there was a great deal that they should know but had been unable to discover.

This suggests that service providers of all kinds should pay greater attention to the provision of information about their services and facilities. Some will be directly concerned with blind and visually impaired people and should, therefore, be aware of the need to make the information available in accessible formats. Others, providing services and facilities that are used by visually impaired people along with everyone else need to take greater account of the importance of providing information in formats that can be used by people with little or no sight.

Processors

Over and above the direct provision of information by service providers and others, there is a need for more general provision of information and advice services to which visually impaired people can turn when seeking information and support. Here, there is a requirement for two forms of provision. First visually impaired people should have access to information services that are designed to meet their needs *as visually impaired people*. These specialist services, such as those offered by the RNIB and by others such as Action for Blind People, can make a real difference to the lives of their users (Moore, 1994). Visually impaired people also, however, need ready access to all the other information and advice services that are available within the community.

In some cases, these information services are fairly accessible. Telephone-based services such as NHS Direct are one example. In other cases, visually impaired people face barriers that need to be overcome. Many public advice services, for example, provide only limited telephone-based services and do not offer home visits. They depend instead on clients making personal visits and this can be difficult for people for whom mobility is an issue. Further, many make extensive use of printed

information to supplement the oral advice. Again, this can be a barrier to use unless it is available in large print and alternative formats.

These issues are not new. What the research does is to draw attention to the fact that the problems remain largely unresolved.

Users - How do needs differ between different groups of people?

Many of the research studies emphasise the fact that information needs are not homogeneous. They vary from group to group and from individual to individual. The key factors affecting the range and nature of needs were felt to be age, the degree of impairment, the elapsed time since the onset of visual impairment, ethnic origin and the incidence of other disabilities (Begum, 1992, Bruce and others, 1991, Herbst, 1997, Masey, 1997, RNIB 1998c).

It is also important to recognise that these user groups are not mutually exclusive and that any individual will usually belong to more than one group.

It is, therefore necessary to treat all generalisations about information needs with a degree of caution. That being said, however, it does seem to be possible to identify a number of groups that can be thought of as having a common core of information needs.

The degree of impairment

We live in a world which tends to be dominated by printed information. The extent to which people can read printed media is, therefore, a significant determinant of their information-seeking behaviour. The 1991 RNIB survey of blind and partially sighted adults, for example, shows that twice as many partially sighted people read newspapers, letters and bills as do those who are registered blind (Bruce and others, 1991). The differences extend to the use of other media:

Blind people were more likely to rely on asking and telephoning people and on the radio, Talking Books, talking newspapers and Braille books. While partially sighted people use all these media, they do so to a lesser extent and rely on television and local newspapers more. (Bruce and others, 1991)

Newly visually-impaired people

Closely related to the degree of impairment is the elapsed time since the onset of impairment. Clearly people need time to learn new skills and, particularly when sight is lost suddenly, there can be a period when people face very real information difficulties as they adjust to their changed information-gathering capabilities.

They also face very real information needs as they come to terms with their condition. Yet provision to this group appears to be very poor. A study of people=s progression through hospital consultations in connection with loss of sight found that:

When asked if any written information had been made available to take away almost all participants had recalled not being told anything about such information at the hospital. One participant said >they don=t give you any information=. Family members and friends thought that this kind of written information about the condition was very important and would have liked this from the eye department. (Jack and Waring, 1998)

Helen Masey found that, even within this group, there were considerable differences that were determined by personal circumstances, cause of sight loss and the degree of support available to the individual (Masey, 1997). She found that the high level of activity and the amount of contact with new organisations and professionals frequently led to confusion as did the amount of information that was sometimes made available. Some people felt deluged and had difficulties assimilating all the information that was presented to them.

She found that, following registration and assessment, there was a feeling of abandonment that called for a high degree of personal support. She concluded her study by stating that:

... there is no one way of providing information to newly visually impaired people. There is a need for easy access to a number of different media which allows informed choice about the information required by each individual. (Masey, 1997)

Older people

Two-thirds of the visually impaired population are aged over 75 (Bruce and others, 1991). It is, therefore, perhaps a little misleading to think of older people as a sub-set of the main visually impaired population. They are the majority and, as such, they reflect the full range of impairments, personal circumstances and levels of support. They have also been the subject of a number of research studies.

The picture that results is a varied one. Some studies portray older people as a passive group who make few demands, expect little and receive less (Lloyd and Thornton, 1998). This appears particularly to be the case when the elderly people are in residential care. In her study of

visually impaired people in supported care, Bernadette Moll found that the majority of respondents said that they received all the information they needed. But she implied that they may well have been under-stating their needs:

Many residents did feel the need for more information. However, others said that they preferred not to clutter their heads with too many things. (Moll, 1996)

In their study of three groups of older visually impaired people - those living independently, those living in sheltered accommodation and those in residential care - Rea Maglajlic and David Brandon found that information needs differed between the groups. Those in residential care relied mainly on the home staff for their information but generally felt ill-informed. Those in sheltered accommodation had information needs that were unmet, some saying that they had received no relevant information. While those living independently generally found that professionals were good at explaining things (Maglajlic and Brandon 1999)

Alison Nelson found that when elderly people suffer a loss of sight they have critical information needs. Failure to satisfy these needs leads to social exclusion and to a loss of emotional well-being (Nelson 1999).

Older people seem particularly vulnerable. The RNIB = *Lost vision* report noted that 80 per cent of older visually impaired people cannot read their bills and personal letters, thus facing a significant loss of privacy through having to rely on others to read them for them (RNIB 1998b).

Elderly people generally are poorly informed (Epstein, 1980) and, in their study of the information needs of elderly people, Anthea Tinker and her colleagues found that visually impaired people felt less well-informed than their peers (Tinker and others 1993).

Children

At the other end of the age range, children also constitute a vulnerable group. The 1991 RNIB survey of blind and partially sighted children found that the parents of partially sighted children felt that they had to search very hard to find the information that they required and when they found it, they were often dissatisfied with the results. The most pressing information needs were felt when they first learned about their child=s loss of sight. At that point:

... what they needed most ... was someone knowledgeable to talk to. (Walker and others, 1992)

Multiple disability

Blind and partially sighted people have problems enough. These are, however, compounded when visual impairment is coupled with another disability, particularly the loss of another sense. Adrian Cox undertook a study of people who had both a sight and a hearing loss. He found that people received little or no information from either statutory or non-statutory agencies and very little provision of information in accessible formats - two-thirds, for example, had not received any information about benefits (Cox, 1999). In common with many other groups, the majority of those surveyed expressed a strong desire to communicate with someone knowledgeable about their concerns and feelings.

Ethnic minorities

People from ethnic minorities are generally thought to be poorly provided with information. This is more than a question of the information being provided in the appropriate language, it concerns the cultural context within which questions and answers are framed and negotiations take place. There are also particular information needs relating to religion and cultural practices.

It is not, therefore, surprising that the studies of disabled and visually impaired people from ethnic minorities paint a fairly gloomy picture. Low levels of information provision lead to a general lack of awareness about the services available (Begum, 1992) and, faced with this, there is a tendency to turn to informal information sources within family and kinship groups (Ahmed, 1991 and Cole and Cheeseman, 1998).

Carers

It is clear that many visually impaired people place a heavy reliance on their carers, family and friends as sources of information and advice (see, for example, Palmer, undated). It is important to recognise, therefore, that carers themselves need to be well-informed.

Parents represent a group of carers that is highly motivated to acquire and process information on behalf of their child. Their need for information is greatest in the period following the diagnosis of sight loss by the child. One study noted that the need for information varies but is related to the length of time that the parent has had to wait for the diagnosis, their expectations at the time of the disclosure interview and their feelings at the time (Cunningham and others, 1996). Most parents at this time wanted to talk to a knowledgeable person, although not necessarily a medical professional, and contact with a parent support network (RNIB and LOOK, 1996).

In the period following the initial diagnosis, parents need information about the condition and its treatment; what they as parents can do to help and where they can turn for further advice. As time goes on, the range of information needs extends to include things like specialist toys, education and the availability of local services (RNIB, 1996)

As time goes by, parents develop quite sophisticated networks of information sources to meet their needs (Walker and others, 1992).

In 1994 SCOPE carried out a general study of the experience of carers in Britain and found that two-thirds of them found it difficult to get the information they needed. They found it especially difficult to get adequate information about benefits and personal finances. As with many other groups, what they wanted was someone to talk to (SCOPE, 1995).

Professionals

Professionals and support staff also need to be well-informed. They need information to enable them to do their jobs but they must also recognise that people will turn to them as information sources in their own right (Kerrigan and Gooding, 1995). This applies equally to care staff in residential homes, home helps, social workers and to hospital consultants. General practitioners, in particular are regarded by nearly all groups as very authoritative sources of information on a wide range of topics. Social workers, on the other hand, were perceived in one study as people who were not very good at sorting things out (Lloyd and Thornton, 1998).

Mechanisms - Which mechanisms can be used to meet information needs?

At various stages in this report we have noted the need to make information available in accessible formats, indeed, the issue of accessibility is explicitly discussed in a number of the studies (Begum, 1992, Benson and Waterhouse, undated, Deaton, 1993, RNIB, 1995 and Bruce and others, 1991). When thinking about how best to meet the information needs of visually impaired people, however, it is necessary to think of different mechanisms that will enable information to be: recorded and stored; transmitted and communicated; copied and reproduced, and tailored and customised.

Recording and storage

The traditional way of recording and storing information is to write it down. As information technology has progressed, the written word has been printed to aid distribution and now is being recorded in digital form so that it can be transmitted easily and cheaply and output in a variety of different formats. In the main, however, we still live in a world that is dominated by printed information.

Printed information

A large number of visually impaired people do, in fact, read printed information. Nearly half read newsprint and over half read the headlines. Only a quarter read books, however, and just four in ten are able to read letters and bills (Bruce and others, 1991). Other studies confirm the importance of printed information (Centre for Health and Social Research, 1999, Royal Blind Society of NSW, 1996 and Willetts, 1997).

Leaflets are, potentially, an important source of information. Joyce Epstein, in her seminal work on information needs, however, highlighted the fact that the usefulness of a leaflet depended greatly on it being available in the right place at the right time (Epstein, 1980). Most leaflets are ignored, thrown away, lost or filed and remain unused until they become out of date. Only a very small proportion arrive in the hands of someone who needs that information at that moment. Despite this, they are still perceived as important sources of information with people wanting to have them delivered to their homes (Begum, 1992 and Tinker and others, 1993).

For many, printed information needs to be presented in large print. In addition to the 25 per cent of visually impaired people who read printed books, a further 23 per cent read large print (Bruce and others, 1991).

Again, these figures are borne out by other studies (Centre for Health and Social Research, 1999, Levitt, 1997 and RNIB, 1998c).

While a significant majority of visually impaired people can read normal or large print, many find it difficult or tiring and about 40 per cent seem to prefer to have information read to them (Bruce and others, 1991 and Levitt, 1997).

Braille

For many people, braille is perceived as the blind person=s alternative to print. The number of people who can and do read braille, however, is small in relation to the total population of visually impaired people. Bruce and others (1991) estimate the number of regular readers to be about 13,000 out of a total population of 757,000 visually impaired people. Deaton (1993) also found that only a small proportion of people chose to use information in braille.

The overall impression given by the research reviewed here was that braille did not represent a mainstream mechanism for meeting people=s information needs.

Cassette tapes

It is now possible to make sound recording cheaply and easily. Tape recordings have, therefore become a potentially powerful means of recording and storing information for visually impaired people. Cassette tapes are, indeed, much more popular than braille, although only about one in eight identify them as an important source of information (Bruce and others, 1991), despite the fact that nearly half of visually impaired people possess a tape player.

This finding from the biggest survey of visually impaired people contrasts quite markedly with some of the other studies reviewed here. Cole and Cheeseman (1998), for example, found quite a strong desire for taped information among visually impaired people from ethnic minorities. Similarly Deaton (1993) found in a survey of visually impaired people in Greater London that tapes were the most popular medium for over half the 50 respondents. Rea Maglajlic and David Brandon (1999) also found that people were quite keen on taped information. One of the people they interviewed said:

... tapes are good - you can run them back and forth.

In Australia the Royal Blind Society of New South Wales (1996) found that audio cassettes were the main alternative format used by visually impaired people.

Finally, Tom Levitt found that tapes were a relatively popular medium but noted that long tapes needed some form of index and without this they were often discarded (Levitt, 1997).

Libraries, Citizens Advice Bureaux and the Internet

Given their central role in the provision of information within society, it is perhaps surprising that few of the studies made specific mention of libraries and citizens advice bureaux. One commented that they were infrequently used as information sources (Deaton, 1993). Yet these, in their different ways, provide enormous community-based stores of information.

Libraries were, however, used as sources of reading material for leisure purposes. Over 40 per cent of respondents in a recent RNIB study used their local public library. Half of them visited the library themselves. Eight out of ten people used the library to borrow spoken word cassettes (Chartres, 1999a). Libraries made less impact on people from ethnic minority communities:

The overall impression given by the groups about libraries was that the staff were helpful, but they did not fully understand the reading needs of visually impaired people from ethnic minority communities. The libraries would need to stock more large print books as well as audio-cassettes and on a wider range of subjects ... if they were to encourage greater use by the communities. (Chartres, 1998)

Increasingly, public information services like libraries and citizens advice bureaux have tried to make specific provision in order to meet the needs of visually impaired and other disabled people. As yet, however, they seem to have made little impact. The recent award by the Department of Culture Media and Sport of £200,000 a year for three years to support the improvement of library-based services for visually impaired people will, no doubt, make a difference but there is still a long way to go (Owen, 2000).

The World Wide Web represents a rapidly growing store of information. At the beginning of 2000 it was estimated that the WWW contained over one billion pages of information and that it was growing at the rate of about one million pages a week. As a store of information, however, the WWW has its problems. It is inherently unstable - one cannot guarantee that a website that exists today will still be there tomorrow and, once the provider withdraws the information, it is almost impossible to find the information again.

Transmission and communication

There is little value in having impressive stores of recorded information if it cannot be transmitted and communicated to the user. Therein lies one of the main drawbacks of printed information - it is relatively costly to transmit and, if the user cannot read print, there are major difficulties associated with communicating the information content. Libraries have traditionally sought to overcome these difficulties by using inter-library loan services and by providing computer-based and personal reading services. But by comparison with the transmission and communication capability of broadcast and digital media, these devices appear slow, cumbersome and very expensive.

Broadcast media

Broadcast media are, arguably, the most powerful means of communication in late twentieth century society. Radio, in particular, is of great importance to visually impaired people - and the prize clearly goes to Radio Four's *In touch* programme (Deaton, 1993).

About two-thirds of respondents to the big 1991 survey said that radio and television were important sources of information (Bruce and others, 1991).

The importance of broadcast media lies less in their ability to provide specific information directed to the needs of visually impaired people. Rather, they constitute one of the primary means that visually impaired people have of scanning the information environment. One can absorb a great deal from listening to television and to radio and, clearly, they are a powerful means of enabling visually impaired people to keep in touch with what is going on.

Here, technological development is likely to improve matters considerably. The introduction of digital television will mean that many more channels will be available, thus enabling broadcasters to cater for minority audiences. The cost of broadcasting will also fall, putting it within the reach of a wide range of organisations. So far, most of the discussion has focussed on television stations run by football clubs or local councils. But it is not inconceivable that an organisation like the RNIB could operate a channel designed to meet the specific information needs of its constituency. Further, the interactive capability of digital television would mean that such a television station would provide an opportunity to interact with the audience in potentially useful ways.

The Internet

The great advantages of the information stored in the WWW lie in the transmission capability of the Internet and in the fact that the information is

digital and so can be output in different formats. Digital information, therefore, offers great potential for the presentation and use of information in accessible formats. There is, of course, a high threshold: computers and digital equipment is expensive and, as we have seen, visually impaired people frequently live in poverty; there is also the investment needed in initial training and familiarisation with a technology that has been designed by and for sighted people. Notwithstanding these initial constraints, the long-term benefits are considerable. It becomes possible to receive information in one format and, relatively easily, convert it into a number of alternative formats to suit a person's needs.

Telephone

The telephone is a powerful means of communicating information. In particular, it helps overcome problems of distance and geographical access while enabling visually impaired people to speak to another person. Just over half the people interviewed by Ian Bruce and his colleagues said that telephoning people was an important source of information (Bruce and others, 1991).

Some people used the telephone simply to keep in touch with family and friends (Manthorp, 1996). Others saw it as a powerful means of acquiring information and one that was more popular than taped or printed information (Masey, 1997). Bernadette Moll found that over half of the elderly visually impaired people living in supported care that she interviewed used the telephone and that most would like to have one in their own home (Moll 1996).

There was, however, an impression that the capacity of the telephone system was not being fully exploited. In their study of the Access to Work scheme, for example, Kerrigan and Gooding suggested that it would be useful if the Placement Assessment and Counselling teams provided a service that enabled people to fill in forms by telephone, noting that a service of this type is offered by the Benefits Agency (Kerrigan and Gooding, 1995).

As telephone-based services and call centres such as NHS Direct become more and more common, it will be easier for visually impaired people to obtain information and to transact all kinds of business without needing to leave their homes. This may not do much to combat a sense of isolation but it will help overcome many of the difficulties they now face. The challenge will be to ensure that full use is made of the capability of the telephone system to deliver information. Also, that the telephone-based transaction services are supported by adequate information to enable visually impaired people to make full and effective use of them.

Tailoring and customisation

There is a clear need for information to be customised to meet the particular needs of individuals. It is usually the case that the more critical the importance of the information, the greater is the need for customisation. We have seen that there is a significant information deficit among visually impaired people, leading to things like low take-up of benefits and feelings of isolation. There would appear, therefore to be a *prima facie* case for providing information services that can tailor the information to meet the needs of individuals.

This points us directly to people as information providers.

People

When asked to choose between saying a medium was important or unimportant, respondents gave > asking people= most votes (85 per cent) for being important. (Bruce and others, 1991)

It is sometimes said that the best information is that which comes wrapped in a person. Many of the research studies reinforce the importance of people in the process of customising information to satisfy information needs.

The need to talk to someone knowledgeable is critical at times of stress. Helen Masey (1997), for example, found that newly visually impaired people expressed a strong desire to talk to someone. In part it was a case of not being able to access information in other formats:

With new sight loss even accessible print is inaccessible for those who could use it at a later stage (Masey, 1997)

Helen Manthorp in South Worcestershire also found that people had a critical need to talk to someone at the point of certification:

The shock factor means that people may be coping with >absorbing the news=, as one person put it ... In retrospect, some people felt that, when recalling their experience of certification at the hospital, you should have >someone to explain it to you=. (Manthorp, 1996)

But there was a more fundamental desire to manage flows of information and to relate the information received to the circumstances of the individual. The process of questions and answers enables people to do this (RNIB and LOOK, 1996 and SCOPE, 1995).

The question is, to whom does one turn? Many see the general practitioner as the fount of all wisdom (Ahmed, 1991, Cole and Cheeseman, 1998, Lloyd and Thornton, 1998, Ryan and McCloughlan, 1999 and Steele, 1991). Clearly general practitioners are important elements in the information chain but the range of information they can provide is limited. Yet people perceive them as an all-purpose resource while at the same time recognising that they have severe constraints on their time.

Other medical specialists can play a key role in providing information about eyesight conditions. The amount of information they can impart during a consultation is limited and, as we have seen (Kempson, 1987) many people fail to retain more than a small proportion of what they have been told. There is, therefore, a need to reinforce the medical specialist's information in other ways, either through the provision of written or printed information, or through the provision of support services within the hospital or clinic to which people can turn following the consultation (Jack and Waring, 1998 and Walker and others, 1992) These support services can do more than just reinforce the medical information. They are well-placed to contribute to the process of informing people about a wide range of services, facilities and entitlements (Lovelock and Powell, 1995). This interface between the medical and social worlds was felt to be an essential part of the provision of support for newly visually impaired people (Manthorp, 1996 and Ryan and McCloughlan, 1999).

Outside the formal structure, family, friends and neighbours play a very important part in the provision of information particularly within ethnic minority communities (Ahmed, 1991 and Begum, 1992). Older people, too draw heavily on family and friends for information (Cox, 1999, Deaton, 1993, Lloyd and Thornton, 1998, Manthorp, 1996, Royal Blind Society of NSW, 1996 and SCOPE, 1995). In many cases they were the most frequently used information source.

Self help groups are also important sources of information. In the study of visually impaired children, Errol Walker and his colleagues (1992) found that soon after the child had been diagnosed as having a sight loss, parents sought out people in similar situations, exchanging information and experience.

We have noted the information role of medical specialists and information support staff. We should not, however, overlook the important information function fulfilled by other staff with whom visually impaired people come into contact. Reception staff in social services offices need to be well-informed if they are to be able to deal with people sensitively, providing basic information on services and their availability (Benson and

Waterhouse, undated). Similarly, care home staff provide much of the information consumed by older people living in residential care (Maglajlic and Brandon, 1999).

Finally, we should recognise the important part that people play as sources of anxiety relief. Simply having someone to talk to can help to combat loneliness and a sense of isolation, it can lead to emotional well-being and can allay people's concerns and feelings of uncertainty (Cox, 1999, Manthorp, 1996 and Nelson, 1999).

Communication is one of the central features of our life as social human beings. The visually impaired patient could be thought of as requiring even more oral communication because of their visual sensory deficit. (Jack and Waring, 1998)

The need to talk to someone was particularly marked among older people who, in some cases, found it reassuring:

> Talking is better. You can find the snags if there are any and put your suggestions forward ... it is good to talk to someone who can give you time - be patient with you.
(Maglajlic and Brandon, 1999)

Timing and reinforcement

For information to be most effective it needs to be delivered at the right time and, in most cases, reinforced by complementary information, often delivered in a different format. Thus, Andrew Jack and Kris Waring (1998) found that information given orally by a consultant needed to be reinforced by written information. A similar conclusion was arrived at by Alison Nelson who suggested that written information should not be a substitute for oral communication from consultants but should be seen as a means to substantiate it (Nelson, 1999) and the same was found in the study conducted by RNIB and LOOK (1996).

The reinforcement need is seen most explicitly in the case of oral information provided by medical specialists, but the principle applies generally. People may find a leaflet about entitlement to benefits useful but they usually want to supplement this formal information with other information and advice from friends and neighbours or from an advice service. Few of us have the kinds of information needs that can be satisfied by means of a single message or communication.

It is also necessary to match the medium to the message. As Willetts has pointed out:

Large print may be suitable for reading leaflets but too tiring for someone with reduced vision to manage in a longer document form when audio tape would be more appropriate. (Willets, 1993)

Visually impaired people make use of a wide range of sources of information in different formats for different purposes. The key to success is to ensure that the right information is available at the right time and in the right formats.

Conclusion and recommendations

In an information-intensive society we all need ready access to a wide range of information if we are to function effectively. Lack of access to that range of information is increasingly seen as one of the defining characteristics of social exclusion.

Visually impaired people face more challenges than most when meeting their information needs. Not only do they have additional needs that are particular to them as visually impaired people, they also are constrained in the range of formats and delivery mechanisms that they can use in order to access the information that we all need as citizens and as consumers.

It is perhaps not surprising, therefore, to discover that the research reviewed here reveals a picture of a group that are ill-informed, lacking access to the information they need and having to make efforts to find information that should be delivered to them as a matter of course.

It may not be surprising, but that does not mean that it is excusable. We have recognised the importance of information as a means of combatting social exclusion. We know a great deal about how to deliver information so that it can be effective. The commercial sector is investing huge sums of money in advanced information systems that will, in a digital environment, enable us to do as yet unimagined things. But most visually impaired people live in a state of information deprivation where they lack access to the information that they need to satisfy their most basic physiological, psychological and social needs.

However one looks at the issue there is a significant gap between need and provision.

Key groups at risk

Each of the different groups of visually impaired people experience an information deficit. The gap between need and provision is particularly large among those who have recently lost their sight. They have pressing needs to come to terms with their condition and its treatment and to adjust to a new way of life. They may also have significant income-maintenance problems, leading to a need for information about welfare benefits.

Parents of children who are losing or have lost their sight have similarly pressing needs, but they are, arguably, the group that is best placed to find solutions to the information problems.

Elderly people are frequently cut off from information flows. They are often isolated and reluctant or unable to learn how to use some of the techniques that might help them overcome the information deficit.

Visually impaired people from ethnic minorities also suffer considerable information deprivation. In addition to the problems faced by other visually impaired people, they face language problems, in some cases, problems of cultural adjustment and a paucity of material - even in unaccessible formats - in their mother tongues.

People who lost their sight early in life have, in many cases, learned how to cope but even here there is a real problem of information deprivation as they are much less well able to obtain background information from the environment and may thus be unaware of important issues that have a bearing on their well-being.

It is, therefore, difficult to single out particular groups that are at risk when all face real difficulties.

Key information clusters

A similar picture emerges when considering the clusters of information that people need. In just about all cases there is, again, a significant gap between provision and need.

Physiological needs

The highest priority should probably be given to the clusters of information that are associated with the lowest levels of Maslow=s hierarchy of needs. These are the clusters of information associated with: the condition and its treatment; welfare benefits and income maintenance; and to housing and accommodation.

The research suggests that significant benefit would result from strengthening the provision of information and support services in eye clinics and building on these to develop local centres of information for visually impaired people.

The Benefits Agency has an enviable record as a provider of information about benefits and has always tried to meet the particular needs of disabled people. Yet there still appears to be a gap between need and provision. The Agency might usefully be encouraged to undertake research to explore why this is so.

Safety needs and the need for affection and a sense of belonging

These are experienced particularly at the time when a person's sight is being lost and among blind and severely impaired people who are frequently poor, lonely, bored and depressed.

Here two different types of information are called for. The loss of sight presents people with a series of pressing and quite focussed information needs - what will happen to my job? What will I do if I cannot drive? And so on. These need to be addressed by effective and efficient information services that can respond on a one-to-one basis, customising the information, explanation and advice to suit the individuals' circumstances.

Isolation and loneliness calls for a very different approach. What is needed here are more general communication services that will erode the sense of isolation and boredom and that will enable people to keep in contact with the world around them and to interact with others. Networked digital technology offers great potential here if problems of cost and reluctance to use can be overcome.

Research or service development

In the face of the yawning gap between provision and need, it is difficult to argue strongly for further research at the cost of investment in service development. The research reviewed here, even though it is patchy, provides a clear picture of unmet need. In such circumstances, priority should be given to the development of services that will reduce the gap. We know enough about the overall shape and magnitude of the problem, attention should be given to finding ways of solving it. We are also in a position to determine in broad terms which solutions are likely to be most effective.

As the gap between provision and need becomes narrower, there will be a greater need for research to enable service providers to fine-tune their services in order to increase their effectiveness. But we are a long way from such a desirable position.

Where research is needed is into the effectiveness of different approaches to information provision, comparing one service with another to identify the approaches that are most cost effective.

There is also a need to undertake some work to establish benchmarks and standards to guide service providers. The development of our public library service benefited greatly from the formulation and application of the Bourdillon standards in the early 1960s. These specified the basic levels of resources that are required to sustain a viable library service and were

used by the government and by local authorities to guide the development of the service ¹.

A similar approach brought about a consolidation of local advice service provision using resource standards published by the National Consumer Council (Kempson, 1986).

There would be considerable merit in devising a set of resource-based standards for information services directed towards visually impaired people. These would provide guidance on issues like the level of resources required to provide an effective information and support service at eye clinics. They would also provide guidance to other generalist advice services on the level of resources they should commit to meeting the needs of visually impaired people.

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¹The value of the standards diminished during the 1970s as more and more authorities attained them and attention shifted to the measurement of performance as a means of sustaining and stimulating development. Much of the impetus for this was lost during the 1980s and 1990 when successive reductions in local authority expenditure meant that libraries were unable to generate acceptable levels of performance because their resource levels had fallen below those specified in the 1962 standards. Now, in 2000, the standards are being re-formulated to kick-start the process of development all over again.

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