

The housing and support needs of people aged 18-55 with sight loss

This publication summarises findings from research conducted by Professor Julienne Hanson and her team at University College London.

Summary

Many adults with sight loss feel strongly that housing and service providers do not understand their needs. Most organisations that provide housing and services for people of working age agree with this perception.

Very little research has been published on how best to guide housing choices or support service delivery for adults with sight loss. For this reason, in 2003 Thomas Pocklington Trust and the Housing Corporation jointly sponsored research on the subject. The two-year study involved interviewing blind and partially sighted adults and talking to stakeholder organisations that deliver housing and support services to adults with sight loss.

Some of the important findings were that:

- adequate housing is central to the quality of life of people of working age with sight loss. Such housing should:
 - be located in a familiar area close to public transport and local amenities
 - have flexible or additional space to store low-vision aids and assistive technology
 - provide a safe and secure environment for the visually impaired occupant.
- service providers should ensure that adults with sight loss have access to information in an appropriate format.



Other measures were also needed. These included:

- greater consultation with visually impaired service users
- holistic and person-centred needs assessment supported by partnership working
- attention to key indicators of additional social disadvantage
- more disability awareness training for staff.

Working-age adults with sight loss see themselves first and foremost as independent people who are integrated within mainstream society, but who just happen to have impaired vision. They are more likely than previous generations with sight loss to embrace normalisation and living independently.

These young adults therefore value the opportunity to live independently with people who, like themselves, embrace normalisation, and within a mainstream community setting rather than a specialist purpose-built one, provided they have a sympathetic landlord or help to hand if needed. Most of those in the study felt there should be a wider choice of housing and support, not just for people with sight loss but for anyone who would prefer a more supported housing setting.

Background to the project

The researchers set out to investigate the experiences and priorities of working-age people with sight loss in regard to their housing circumstances and related support issues. There were three reasons for this:

- Housing professionals and allied staff admit that they do not know enough about the needs of this population
- Advice to housing providers on ways to overcome disability discrimination does not include enough detailed description of the physical and practical everyday challenges faced by working-age adults with sight loss
- The housing needs of this population have been given limited attention in the past. They are either sketchily covered within generic studies of people with disabilities,¹ or discussed as only one of a raft of factors that may affect people with sight loss.²

¹ Dean J (2003) *Unaddressed: the housing aspirations of young disabled people in Scotland*, Joseph Rowntree Foundation, York. Bull R ed. (1998) *Housing options for disabled people*, Jessica Kingsley Publishers, London.

² See, for example, Hendey, N. and Pascall, G. (2001) *Disability and transition to adulthood: achieving independent living*, Pavilion Publishing, London.

This lack of attention to the needs of working adults with sight loss is perhaps surprising considering the size of the group. Data sources show that between 136,000 and 139,000 working-age people in the UK have difficulty seeing. Many of these people experience significantly reduced economic and social opportunities compared with their sighted peers.³

The Royal National Institute of the Blind (RNIB) Good Practice Guide on housing management for blind and partially sighted people noted that there was a 'high incidence' of vision impairment in the older population.⁴ Perhaps because of this larger incidence, the guide did not refer directly to younger people with sight loss. It did say that many housing associations will have a number of tenants with sight problems, and this should be presumed to refer to younger as well as older people with sight loss.

(In this paper, the focus will be on housing and support needs rather than prevalence, which has been reported elsewhere.⁵)

This study aimed to fill the knowledge gap in this area. It comprised three strands of research:

- A large (population) scale search of existing data, to determine the prevalence of sight loss among adults of working age and thus estimate how many people are affected
- A medium (organisation) scale study of 90 organisations (23 from London and 67 from the regions) that provide housing and support services to visually impaired adults of working age, to look at how service can be improved
- A small (personal) scale study covering 121 adults with sight loss living in London. They responded to a detailed questionnaire about their housing and support circumstances. Thirty of these, and another 110 informants from the regions, participated in one-to-one interviews, guided focus group discussions and telephone interviews. These were held to help the researchers gain additional insights into their housing and support needs.

The project itself was complicated, in that it involved a variety of

³ Osipovic D, Hanson J and Percival J (2003) *Data sources on prevalence of visual impairment*, The Bartlett School of Graduate Studies, University College London, London.

⁴ Derbyshire F (1998) *Better housing management for blind and partially sighted people: a good practice guide*, RNIB and the Housing Corporation, London.

⁵ Osipovic D, Hanson J and Percival J (2003) *Data sources on prevalence of visual impairment*, The Bartlett School of Graduate Studies, University College London, London.

Tate R, Smeeth L, Evans J, Fletcher A, Owen C and Rudnicka A (2005) *The prevalence of visual impairment in the UK: a review of the literature*, RNIB, London.

research methods, including database search and literature review, formal questionnaires, in-depth and telephone interviews, focus groups and interactive workshops. The main question behind the research was, however, very simple:

"What do housing and service providers need to know, and to do, to improve the delivery of housing and support services for adults of working age with sight loss?"

Methodology and sample characteristics

Visually impaired participants were recruited through social care and allied professionals, the media and word of mouth. An initial telephone contact was followed up by more detailed interviews. Stakeholders were mostly recruited by recommendation and personal contact, then sent an email describing the project in detail.

Research methodology

Service users

One hundred and twenty-one visually impaired service users from London answered the questionnaire, which covered seven areas: personal details, current housing circumstances and preferences, support needs, access to places and interests, social contacts, finances and, finally, sight and general health.

In-depth interviews were later carried out with a sub-sample of 30 individuals who were broadly representative of the larger London sample.

These in-depth interviews focused on four topics:

- 1 - housing and its relevance to routines and contacts
- 2 - service providers' awareness of housing needs
- 3 - the comparative merits of mainstream housing and specialist supported housing
- 4 - the interviewee's ideal housing situation in five years' time.

One-to-one, mainly telephone, interviews and group discussions on the same four topics were also held with 110 service users in the Midlands, the south-west, and the north-east of the country. These regions were chosen as they include a wide range of urban, suburban, small town and rural locations, and also to reveal any impact that the north-south divide might have on people with sight loss in respect of access to wealth, work and affordable housing.

Service providers

Twenty-three housing and social care providers in London were also surveyed, all of which provide services to adults aged 18-55 with sight loss. These providers included nine local authority social service departments, six local authority housing departments, four voluntary sector organisations and three housing associations. They had to answer twelve questions covering issues that had been uncovered in the literature review and preliminary discussions with stakeholders, as well as issues that concerned the research sponsors.

Eleven of these questions were generic, covering matters such as the numbers of visually impaired service users in the 18-55 age group, methods of communication with clients, and liaison with other organisations. Participants were asked to give examples of good practice in service development and list things their organisation would like to do better. They were also asked about the most common housing problems that faced people of working age with sight loss and how these varied across the 18-55 age spectrum, as well as issues that particularly affected people with sight loss from minority ethnic backgrounds or with additional disabilities.

The stakeholders were also asked about their future plans for service development and delivery, and any staff training initiatives on equality and diversity.

Housing providers were asked to provide information about special design features for clients with sight loss, whilst service providers were asked about the most important support needs of their visually impaired service users and how these varied with age.

In London, the responses to these questions were gathered mainly through a pre-arranged telephone call with the organisation's representative, usually a relatively senior manager, and lasting about 45 minutes. One or two respondents replied by email and there was one face-to-face interview, at the request of the stakeholder.

The approach adopted in the regions was rather different, in that 67 stakeholders were invited to attend four half-day workshops, two in the midlands and one each in the north-east and the south-west. These workshops explored the same issues as the London stakeholders. The participants worked in small groups before reconvening to share examples of good practice, challenges to service delivery and ways to improve housing and services for younger people with sight loss. The workshop facilitators kept a record of key points, which were ranked according to their popularity with attendees.

Sample characteristics

We achieved a balanced sample of visually impaired informants in terms of the main variables targeted by the study, including age, gender, ethnicity, income, employment, socio-economic position, degree and type of sight loss, nature and cause of additional disabilities or impairments, and the stage in life at which they had begun to experience significant sight loss. In terms of their accommodation and use of services, we achieved an appropriate mix of locations and housing settings that reflect the diversity of accommodation in London and the regions, and a mix of tenure, household composition, support and social networks.

The stakeholder sample included a wide spectrum of middle/senior management personnel from local authority housing departments and sensory support services teams, housing associations, local charities and the voluntary sector and community health. All of them were engaged at a strategic level in delivering housing, health and support services to visually impaired adults of working age.

The experience of sight loss

Before trying to answer the questions posed by this research project, it is worth emphasising that the evidence amassed over the past two years shows that adults of working age with sight loss are seriously disadvantaged in a number of important respects, compared to their sighted peers.

They have fewer opportunities for education and employment, and reduced mobility. Those whose sight is impaired as adults have to undergo a painful and demanding process of readjustment including facing up to a reduction in independence. Impaired vision can make it more difficult to communicate with others, and this may make people feel socially isolated and less confident in forming new relationships.

Apart from these rather obvious factors associated with sight loss, adults with impaired vision are also disadvantaged in other ways when compared with the population at large.

Considerably more of the adults with sight loss who took part in our study were single compared with the general population, and the proportion living alone was correspondingly greater. This may worsen the feelings of isolation described earlier. Small numbers were living in a flat share with unrelated people, which suggests that younger adults with impaired vision are missing out on this important, emancipating life stage. This observation was borne out by the in-depth interviews.

Other pointers to social disadvantage included evidence that adults with sight loss enter relationships, whether marriage or a partnership, later in life and women with impaired vision are less likely to have children than their sighted counterparts. The employment rate for visually impaired adults is 44%, compared with 75% for the general population. Visually impaired adults of working age are also less likely to own their own home, or to live in more spacious housing. The informants in our study were quite averse to moving and tended to have lived longer at their current address than their counterparts in the population at large.

All these factors impact on the housing needs of visually impaired adults of working age including where they are likely to live, detailed design requirements and their expectations in respect of mainstream, affordable and specialist purpose-built housing.

Issues affecting the housing needs of adults with sight loss

Whilst most visually impaired adults of working age aspire to live a normal life within mainstream society, the majority need to be supported by a range of services and especially by adequate housing, in order to realise this goal. Unsurprisingly, people's housing choices are linked to their financial circumstances, which are in turn linked to their employment prospects. These three factors form a triangle that largely determines the housing options open to people of working age with impaired vision, whether they opt for mainstream or specialist housing.

Mainstream housing options

Younger people with sight loss weigh up housing options depending on affordability, choice and privacy.

Seven out of every ten informants we spoke to rented their home, whilst only three out of ten were owner-occupiers. In the mainstream population the figures are reversed, with seven in ten people owning their home.

Of the informants who were not working, only one in ten owned their own home. Home ownership is not an easy option for adults with sight loss. They see it as a heavy responsibility, particularly where, due to deteriorating sight, continuity of employment cannot be assumed. Many of those we spoke to would like to own their own homes, but felt that they could not realistically afford it.

For most visually impaired adults of working age, renting from the council was perceived to be the first port of call. However, the

points systems and weightings that are commonly used to allocate such housing do not recognise sight loss as an important criterion for access to social housing. Nominations to housing associations have led to greater uncertainty as to how and by whom people will be re-housed.

Typically, the process is experienced as a long, lonely wait, followed by the requirement to make a 'snap decision' to accept or reject the offer of accommodation. Half of those we interviewed had looked only at the property they were currently living in before their most recent move, and this was especially true of the social rented sector. Effectively, three-quarters of all council tenants and well over half of all housing association tenants had not exercised any choice as to their accommodation last time they moved.

Experiences of renting from a private landlord were very varied. Discrimination was found to be rife for people who were 'on benefits', anyone who had children or who owned a guide dog. Renting privately was perceived as a less secure option, and good housing near transport and facilities tended to be prohibitively expensive. Several individuals therefore felt that they were in an impossible position, as they could not afford to buy a home, were too low a priority to be considered for council housing and yet their welfare status excluded them from the private rented sector.

Shared ownership is an option to make home ownership accessible to people on low incomes living in mainstream housing⁶. This was thought of positively by interviewees compared to long term renting. However this was only the case if they were assured of a sufficient and reliable source of income to sustain this option. Negative aspects of shared ownership included the perception that it was beyond most people's means, that it was administratively more complicated than a conventional mortgage, and that it offered a reduced choice of accommodation in terms of location and access to transport and amenities. In addition, it was still associated with the 'stigma' of social housing.

More mature people with deteriorating eyesight were particularly worried that their future work prospects could not be guaranteed, and so they saw shared ownership as a risky venture not to be undertaken lightly. They were particularly concerned about repossession if they could not keep up the repayments on the mortgage element of the scheme.

⁶ The Government shared ownership scheme has been replaced by HomeBuy from 2005.

On the other hand, many young adults living in affordable social housing did not see shared ownership as good value for money, or a high priority at their stage of life. Nonetheless, if these obstacles can be overcome, shared ownership could be a way to help young people with sight loss to step on to the first rung of the housing ladder.

The interviewees were very keen on the idea that a specialist housing provider with knowledge of their needs could purchase an ordinary house on an ordinary street and convert it to flats of various sizes for occupation by people with sight loss and their families, with or without support. This idea seems to allow for personalisation of the accommodation, avoiding the institutionalisation that can result from measures to make the home and the communal environment more suited to people with sight loss. Also, there is a greater opportunity to provide a range of flat sizes rather than the standard one-bedroom option found in the social rented sector, perhaps extending to a flat share as previously discussed.

Housing providers, on the other hand, were keen to explore novel funding mechanisms, such as raising a loan on the parental home, so that young adults with sight loss could use the equity released to secure independent housing.

Specialist housing options for people with sight loss

Although most of our informants were aware that specialist housing exists for people with sight loss, their perceptions were that the current choice is very limited. Provision was described as patchy in some areas, and was totally absent in some parts of the country. In other regions, purpose-built schemes for people with sight loss were limited to particular categories of people, such as older people or guide dog users.

Many of the visually impaired adults who participated in this study thought that the main advantage of living in a special purpose-built setting would be that their support needs would be met, rather than that the housing itself would be physically well designed and better adapted to their impaired vision. They look to such settings to provide generous levels of support by well trained and sympathetic staff, so that they could achieve their potential for living independently.

Purpose-built settings were also perceived to offer good value for money. However, the respondents had reservations about location, in that specialist housing schemes tended to be built on less

expensive, isolated sites far from public transport and amenities. They were worried that being set apart from mainstream society in this way might lead to a slide into dependency.

In addition to the tried and tested solution of sheltered housing, our informants suggested a variety of new housing solutions, some of which are available now and others which are more innovative, even radical. These included:

- 'extra-care' housing for older people with sight loss
- 'transitional' housing as a springboard to independence
- 'supported' housing for visually impaired parents with young children
- 'intermediate care' housing that offers rehabilitation
- housing for a mixed-ability community, or for a mix of sighted and visually impaired people.

The informants also gave their opinions of residential care and more mainstream alternatives, such as shared ownership and designated housing in the community.

Extra care housing for older people

The most common stereotype associated with specialist housing is 'sheltered' housing for older people, the most widespread form of purpose-built accommodation in the UK. Introduced after the Second World War, this type of housing is generally seen as outdated⁷ and has largely been replaced by the concept of 'extra care' housing.⁸

Many younger interviewees acknowledged that, while they were not prepared to consider this option at present, there are probably a number of older people with impaired vision for whom 'extra care' will remain an attractive proposition, given the fast pace of modern society. Even at a younger age, some adults with sight loss may find they value the security and support that this housing option can provide more highly than their personal freedom, independence and autonomy.

Though the absolute numbers are small, it is likely that some visually impaired home owners will consider buying or renting from a specialist provider in future, to reduce the burden of home

⁷ Robson D, Nicholson AM and Barker N (1997) *Homes for the Third Age: a design guide for extra care sheltered housing*, Spon Press, London.

⁸ Baker T (2000) *Promoting inclusion using very sheltered housing, education and ageing*, Volume 15, Number 3.

maintenance, gardening and household repairs. As retirement housing becomes more popular within mainstream society, there may be a need for more specialised alternatives, leading to the emergence of an up-market version of extra care living.

People in the social rented sector, on the other hand, were more concerned about the swingeing cuts they see being made to services, as a result of which they feel that even the current levels of support in extra care settings cannot be taken for granted.

Whether affluent or affordable, there was widespread agreement that alongside the higher space standards and enhanced facilities that extra care provides, there also need to be management changes to make such schemes more user-led and less institutional.

Specialist housing options for working-age adults

Respondents generally agreed that transitional housing can help young people with sight loss loosen their family ties, by offering independence in a secure and supported environment. Besides younger adults with sight loss moving to the city, this form of housing may also be suitable for those in rural areas where there is a shortage of housing and few other affordable options.

The idea of a 'flat share' might also be appropriate at this stage of life, as not everyone leaving the family home aspires to live alone. Setting a time limit of about five years on this form of accommodation was generally considered to be a good idea, to encourage a move on to independent living. This could be linked to novel forms of tenure that encourage tenants to build up deposits for homes of their own.

Although most people believed that current forms of specialist housing for people with sight loss are not really suitable for families with young children, some suggested that living in a supported, specialist setting could prove invaluable for younger parents, especially lone parents, with sight loss. It was felt that many people struggling to bring up a family would welcome a supportive community that understood their position.

Some service providers pointed out that parental support is particularly important in the early years, as the developmental progress of the child may be adversely affected by limitations on parenting skills that can occur where parents with sight loss are inexperienced and lack guidance. As it would be unhealthy to bring up young children in an institutional atmosphere, this housing concept would need to be carefully considered in terms not only of architecture but also how it is managed.

Interviewees came up with other suggestions for community living that are currently not widely available. One idea was for accommodation aimed at more mature single adults who had recently lost their sight. In this case supported housing might supplement rehabilitation and retraining in life skills.

Housing in a community of mixed abilities, whether this be a mix of sighted and visually impaired people or people with different forms of disability including physical, sensory and cognitive impairments, was also thought to be a good idea. The reasoning behind this is that, where people's abilities and impairments are different, they can build on each other's strengths and compensate for one another's weaknesses. Again, new forms of management would be required.

Residential care was not at all popular with the respondents in this survey. Previous research⁹ confirms that most older people with impaired sight prefer to live independently for as long as possible. They draw a firm distinction between support and responsibility. People could imagine situations in which they might need support, but most said they would never be prepared to relinquish responsibility and self-determination, as was seen to be the case with residential care.

However, experience with older people with sight loss suggests that there will continue to be a small minority of older people with sight loss, especially those who are also physically frail or confused, who will benefit from residential care. In this respect, residential care may be another option that requires reinventing, into a more therapeutic and life-enriching housing option for later life.

Inclusive design of housing for people with sight loss

The detailed design of housing for people with impaired vision need not be very different from mainstream housing. However, designers and house builders need to embrace inclusive design principles so that an increasing proportion of the general housing stock is suitable for people with disabilities, including those with sight loss. Our informants were very anxious indeed to stress how important adequate housing is to their quality of life. Three issues in particular are central to this: location, space, and safety and security.

⁹ Hanson J, Johnson M, Percival J and Zako R (2002) *Housing and support needs of older people with visual impairment – experiences and challenges*. Occasional Paper 1, Thomas Pocklington Trust, London.

Location

Location is the biggest issue for younger adults with sight loss where housing is concerned. A good location is one close to important amenities, people and public transport links. Visually impaired adults need to live in an area that is central, close to the town centre, to employment and leisure opportunities.

Location of housing can be crucial in helping people with sight loss develop a greater sense of independence, security, social inclusion and belonging. Housing providers should therefore consider location very carefully when offering housing to such applicants.

Space

Adults with sight loss need a lot of space, and flexible space, to balance competing needs for entertainment, support, hobbies and special equipment. Their home must be free from impediments and hazards and the layout should be as simple as possible.

Nearly half of our informants reported that they did not have enough space in their current home. Three in ten said that they had insufficient privacy in their home.

Space requirements and preferences centred on six important themes:

- space for equipment and storage
- space to accommodate carers or guests
- space to be sociable
- space to be free from danger
- income-generating space
- garden space, including guide dog needs.

The problem of insufficient space is particularly acute for single people living in the social rented sector, as the official view is that these people only require a one-bedroom flat.

Flexibility is important when it comes to living space, as it makes it possible for a property to be adapted to individual needs or to be altered as the occupant's sight or health needs change. A garden is of particular value to adults with sight loss in terms of safety, amenity and enjoyment, provided that it is not too difficult to maintain.

Only half of the informants had made any physical alterations or adaptation to their home to help them cope better with impaired vision. The rank order of the physical changes made to people's homes was to furniture, lighting, decoration, floor finishes, fixtures and fittings, and space layout.

Seven in ten of those interviewed had aids and equipment to help them at home. The rank order of popularity of assistive technology was for talking gadgets, ICT solutions, textural information, extra security, adapted telephone, and bath aids. Unlike older adults with sight loss, these respondents had more use for 'high-tech' solutions and were less attracted to low-level interventions. Demand for a guide dog is high in the younger age groups: 14% had a dog and another 22% would like one.

The question of adaptations and modifications is a thorny issue in many studies of housing and disability. This is probably partly to do with the fact that it would be impossible to draw up a detailed blueprint for inclusive design. The important principles of interior design here are simple to remember and implement: make things bigger, bolder and brighter. Three more things that will make a difference are:

- keep the layout simple
- accentuate the physical features of the environment to make them clearer
- provide good colour and tonal contrast.

Safety and security

Most visually impaired people make a trade off between perceived security and their need for social stimulation. The type of balance they strike will depend on their stage of life. Adults with impaired vision are no different from the population at large in how they perceive and assess risk, but they have particular needs when it comes to keeping safe.

One in ten felt fairly or very unsafe because of the way their home was designed, and nearly a quarter felt vulnerable to crime or harassment. About one in four also felt fairly or very unsafe in their local neighbourhood due to poor design or antisocial behaviour.

The things that make people with impaired vision feel safer in the home include perimeter fencing accessed by a locked security gate, sensor-activated external security lighting, porch lighting, CCTV, entry phone or intercom, secure doors, locks and window catches, a burglar alarm and a smoke alarm.

Matters of safety and security can be improved with thoughtful intervention and modest adjustments.

Widening housing choices

The 18-55 age band encompasses a wide range of life stages, from young people on the threshold of independence to more mature adults who are beginning to consider their options for later life, as well as people in their twenties and thirties who are forming stable relationships, meeting a partner and settling down to raise a family.

The findings from this study suggest that the current model of specialist housing for people with sight loss is too one-dimensional in its present form, with schemes attempting to cater for too wide a range of tenants living under one roof. Service users were concerned that, under the present arrangements, support staff would find that pressure of work forced them to focus on high dependency tenants at the expense of those with lower level but equally important support needs.

However, people of working age with impaired vision are looking forward to the time when there will be a lot more choice of accommodation available to them throughout the country.

They want to see new forms of housing that will bring different sections of society together on the basis of mutual support, rather than setting people with impaired vision apart from the mainstream.

Issues affecting stakeholders and service providers

Despite their expressed wish to lead an 'independent life', three-quarters of the visually impaired adults we interviewed needed support in three or more areas of their home life. Over half said they would like to receive more help, but were not currently receiving it.

Most of this unmet need was for practical support. Nearly half needed help from a home handyman and about a third reported an unmet need for a cleaner. So far as activities of daily living were concerned, the most difficult area was home maintenance, which nearly three-quarters of the sample found difficult. However, almost as many people reported difficulty in getting about out of doors or carrying out domestic tasks.

The problem for service providers is that this kind of ongoing, low-level support does not receive priority funding. On the contrary, in some areas of the country essential, more intensive, support services for adults of working age with sight loss have been withdrawn due to resource prioritisation.

Generic issues

Service providers and service users share a number of concerns about the current provision for people with sight loss.

A major shared concern is that there seems to be a 'hierarchy of disability' in the way services are prioritised, whereby people with visible disability, such as wheelchair users, are assumed to have greater needs than those with a hidden disability such as impaired sight or hearing. This results in inequitable social care and housing services for adults with impaired vision.

Another important issue for adults with impaired vision is their great need for access to information to enable them to make informed choices about employment, education and housing options, as well as access to services.

Information is no good, however, unless it reaches the people it is meant for. When it comes to communicating with their visually impaired service users, stakeholders can usually provide a wide range of formats if requested. Service users say that providers need to be better and more proactive when communicating with visually impaired adults, especially black and minority ethnic service users. Telephone contact is thought to be especially useful in the early stages of information gathering.

Adults with impaired vision may be losing out on support as they are sometimes reluctant to contact social services departments or specialist services for fear of being 'labelled', or because of the perceived stigma that is still associated with disability within mainstream society. Stakeholders recognised that adults with impaired vision may also require support to identify opportunities to participate in ordinary activities of daily life, to receive emotional support, to deal with correspondence and to manage family matters such as childcare.

Service providers also need to collaborate more to consider the needs of visually impaired service users holistically, especially when it comes to housing and support services. Both groups called for the development of more 'tailored' services, such as transitional support for young people leaving home for the first time and more precise targeting of resources to meet clearly identified needs - such as a specialist rehabilitation worker or key worker to help young people find work.

Everyone in the sector also agreed that there is a pressing need for stakeholders to introduce a structured, ongoing, in-service programme of disability awareness and diversity and equality training, not only for frontline workers but for senior management.

Challenges facing housing providers

Stakeholders highlighted a number of issues that currently hamper better service delivery. The first of these is the difficulty in estimating accurately just how many visually impaired adults of working age there are. We found that housing sector stakeholders have particular trouble in extrapolating data about adults with sight loss. Reasons for this include the relatively small proportion of visually impaired service users who are below retirement age, inadequate information retrieval systems and the lack of awareness of needs arising from sight loss.

Many housing providers have very little contact with visually impaired adults of working age, and are more comfortable responding to the needs of older people. Lack of awareness about the housing needs of working-age adults with sight loss, such as the importance of living in a familiar neighbourhood or the need for space to accommodate low vision aids, equipment and assistive technology, also hampers service delivery.

If working-age adults with impaired vision in general are not adequately consulted by housing providers about their needs and wishes, then several sub-groups among them are doubly disadvantaged. Stakeholders admit to even less awareness of the needs of those with additional disabilities, those living in rural areas, vulnerable adults or people from ethnic minority communities.

Throughout the sector there are few clear policies to guide the allocation process, as compared with other groups such as people with limited physical mobility. Furthermore, the relative inaccessibility of new 'choice-based lettings' systems to people with sight loss, due to the fact that information is often web-based or text-based but in regular print, prevents service users with impaired sight from competing on an equal basis to their sighted peers.

All these issues are compounded by problems of supply and demand, in that demand vastly outstrips the supply of affordable housing in most parts of the country. The 'right to buy', coupled to the requirements placed on local authorities to re-house people who are homeless or asylum seekers, means that even where adults with sight loss are given special consideration, there is not enough housing to meet even the most urgent cases in need of accommodation. However, once it is drawn to their attention, most housing providers can appreciate the importance of appropriate housing that takes account of location, space requirements, floor level and adaptations.

Challenges facing support services

Many of the issues mentioned by housing providers also affected support services.

Service providers broadly agreed that local authority registers are slightly underestimating the number of people of working age with sight loss, so accurate and up-to-date numbers would be welcomed. From a service planning perspective, a lack of understanding of needs means that issues relevant to sight loss are often ignored when resources are prioritised.

There was concern that poor transport, coupled with poor location and inadequate housing, excludes working-age adults with sight loss from social and service networks, such as support groups. It was felt that stakeholders had a responsibility to offer these clients and their families a more comprehensive service; they should also respond to a wider variety of circumstances than is catered for at present.

The most popular idea among stakeholders for improving service delivery was to make needs assessment more holistic. In this respect, appointing an eye clinic liaison officer to act as an advocate for clients at the point of diagnosis was seen to be beneficial.

Service providers from all four regions wanted to see improved case working practices, holistic assessment, active leadership by the sensory impairment team, and a client-centred approach.

Perhaps the most challenging suggestion to emerge from consultations with service delivery organisations was the need to bring about change through improved public awareness and understanding of sight loss, thereby 'mainstreaming' sensory impairment as an aspect of equality and diversity.

When it comes to liaison, statutory agencies liaise regularly with their internal departments, although not all have a specific remit to work with sight loss and some place more emphasis on work with physical disability than with vision impairment. In terms of external liaison, there appears to be a close link between social services departments and voluntary sector organisations. Housing sector organisations also value liaison with voluntary sector organisations on policy and practice issues.

The stakeholders came up with several ways of improving service delivery through organisational change. These included awareness training (by far the most popular initiative), as well as more effective networking, inter-agency working, partnering and general collaboration between agencies providing services for people of working age with sight loss. Good practice examples included joint,

client-centred casework based on holistic assessment, measures to audit and evaluate the organisation's own systems for service delivery, and targeting resources to give adults with sight loss information and help with daily living skills.

In return, it was suggested that organisations and agencies which offer inclusive services for people with sight loss should be given more external recognition and reward. Organisations in different parts of the country also advocated appointing a local 'champion' to give people with sight loss a voice in improving the standard of services.

A changing climate for service delivery

For the past 50 years, services for people with sight loss have been heavily influenced by the 'medical' model of disability¹⁰ that gave rise to the concept of 'special needs'. People with sight loss have been portrayed as vulnerable and needy people, with problems that service providers have a duty to resolve. Residual pockets of this unflattering and demeaning attitude can still be found in service delivery organisations, but this is not at all how adults of working age with sight loss see themselves.

This disparity in attitudes has profound implications for the way services are delivered. Those who provide support services for people with sight loss should be aware that young people may have a sense of stigma as well as a natural disinclination to seek help, and provide necessary information, advice and support that is proactive, comprehensive and rationalised.

In the past few years the Government has been pushing hard for 'joined up' thinking. Amongst the measures that are reshaping the support context are changes to legislation and benefits, measures to ensure a more inclusive built environment, developments in assistive technology and telecare, and changing social attitudes. This is putting an enormous strain on service providers, who are struggling to deliver a better service to more people with fewer resources.

We found some stakeholder organisations that were working hard to improve and innovate in service delivery. These were mainly in the voluntary sector. Where there was stronger integration between the voluntary, statutory and health sectors, there were more opportunities to be bold in service delivery. However, it seems that the model for the delivery of statutory services is still predominantly 'service led' and focused on resource prioritisation to meet

¹⁰ Imrie R and Hall P (2001) *Inclusive design: designing and developing accessible environments*, Spon Press, London and New York.

government targets. In the voluntary sector, the model for service delivery is more 'client led' and orientated to the lifetime needs of the clients. The opportunities for change may ultimately lie in more flexible and effective procurement, coupled to the recognition that a 'one size fits all' service delivery does not quite work for visually impaired adults of working age.

Recommendations

We have identified 30 generic recommendations that apply to all stakeholders and service users, and which fall into eight groups, relating to:

- prevalence
- policy frameworks
- hierarchy of disability and countering disadvantage
- holistic and ongoing needs assessment
- communication needs
- partnership working
- in-service training
- design of the built environment.

These generic recommendations have been phrased broadly to give them the widest possible scope and applicability. It is therefore assumed that, when interpreting these recommendations in real situations, stakeholders and service users will draw on relevant, detailed guidance.

Prevalence

Detailed information should be gathered about the prevalence of sight loss among people of working age and their associated health, housing and support needs.

Policy

Policy on housing and services for visually impaired adults should be standardised within a national service delivery framework, to eliminate the 'postcode lottery'.

Housing and service providers should raise their need for additional resources and more 'joined up' funding with the relevant government agencies, to promote better housing and services for adults with sight loss.

Service providers should respond to service users' demand for a single entry point to access housing and services.

Countering disadvantage

Attention needs to be paid to ensuring that impaired vision is not sidelined as of lesser importance than more visible disabilities. Service users' preferences should be taken into account when prioritising the complex needs of people with sight loss.

People with sight loss are disadvantaged in many areas of life, so stakeholders should work together to counter this by putting in place the necessary measures to allow people living in all circumstances to reach their full potential.

Support offered should be appropriate to an adult lifestyle and not seek to replicate or emulate services designed for older age groups.

All providers should embrace good practice guidelines on gender equality, disability mainstreaming, social diversity and inclusion, as well as legislation such as the Disability Discrimination Act, in a way that reflects the particular needs of minority ethnic people with sight loss, and those with additional disabilities.

Particular effort (including skills training and ICT support) needs to be put into supporting visually impaired adults seeking fulfilling and well-paid work.

Assessment

Stakeholders should work together to provide holistic assessments of need in relation to the housing and support needs of visually impaired adults.

Hospital eye clinics in particular should develop a more holistic appraisal of needs, including psychological and emotional needs and the need for practical, everyday support, rather than simply concentrating on the clinical diagnosis.

In this respect, all organisations involved in service delivery should take advantage of the opportunities offered by integrated IT and information retrieval systems, which should be kept up to date and regularly monitored.

Needs should be regularly reassessed as people pass through the important stages of life, to ensure that housing and support match their changing expectations and aspirations. In this respect, all stakeholders should be aware of their particular contribution to effective transitional work with young people with sight loss, and be committed to improving collaborative practice.

Stakeholders should try to be flexible when it comes to application and allocation procedures for both housing and support services, to take account of people's particular and urgent needs.

Thought needs to be given to how services can be redesigned and repackaged to appeal to younger age groups.

Where service users require it, supported access to Direct Payments should be introduced, to enable visually impaired adults to determine and resource their support needs, including low-level interventions such as a 'handyperson' service, a confidential 'reading' service, home help, or an 'escort' service, to enable people with sight loss to achieve greater autonomy.

Communications

Stakeholders should be more proactive in anticipating and meeting all the communication needs of people with sight loss. Better database management systems could help achieve this.

Information should routinely be provided for people with sight loss in a wide range of formats, and should be more readily available in mainstream locations that are well used by visually impaired adults. Information in different languages should be routinely provided as part of a proactive service for minority ethnic communities.

Partnership working

All providers should maximise opportunities for partnership working, particularly with service users so that their needs and expectations can be more clearly understood.

The role of occupational therapists, rehabilitation officers and support workers should be strengthened, so that they work more closely within sensory impairment teams to deliver appropriate and timely services to adults with sight loss.

Training

Appropriate in-service training should be implemented by all stakeholders, through a structured, cumulative, accredited and ongoing programme involving people with sight loss as expert clients and mentors.

Front line staff, domiciliary workers and service providers in the community should receive sight loss awareness training to help them deliver a better service to clients with sight loss.

Built environment

In line with the requirements of the Disability Discrimination Act, planners, architects and designers should adopt inclusive design principles, not only when designing new housing specifically for people with sight loss, but also when designing general needs housing and public and community spaces.

Public transport systems need to be accessible for people with sight loss.

All housing providers, including private sector house builders, should develop a portfolio of housing that is suitable for people with sight loss and offers a choice of residential scales and settings.

Specialist housing for young people with sight loss can usefully be packaged to reflect diverse needs, abilities and levels of independence. New forms of specialist housing should be explored that bring different sections of society together on a basis of interdependence and mutual support rather than setting them apart from mainstream society.

Housing providers should locate housing for visually impaired people in safe, integrated locations well served by public transport, with good local shops and amenities.

Housing intended for people with sight loss should be spacious and designed with flexibility in mind. A clear and logical plan will assist orientation indoors.

A greater proportion of two-bedroom units for single people with sight loss should be provided by the social rented sector.

Existing and new homes should be individually tailored to visually impaired people's requirements, using evidence-based design guidance and checklists developed for this purpose. A home visit from a vision impairment consultant should be offered as standard at the time of a move, to help people with residual vision tailor the lighting and colour contrast in their home to their individual requirements.

However, these recommendations will only go so far in addressing the challenges identified by all the participants in the study. Service providers are constrained by the current environment in which they must demonstrate that they are allocating their resources effectively by achieving the Government's many targets and performance indicators. Whilst this need to measure performance may be laudable in promoting accountability and transparency, it may also have desirable, unforeseen effects.

In this respect, despite a commitment by most stakeholders to follow the 'social' model of disability, the language, procedures and practices that regulate day-to-day contact with clients and service users still tend to emphasise their disability and neediness, rather than their rights and entitlements. This, in turn, may impair attempts to provide a holistic and client-centred approach. Service providers need to be aware of this so they can ensure that their services empower users rather than promoting dependency.

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How to get further information

A full research findings report, a Good Practice Guide that includes a Needs Assessment Checklist for use in determining the housing needs of people with sight loss and a Housing Needs Checklist for housing providers to use when assessing properties as to their suitability for someone with sight loss, are available on the UCL website at:

<http://www.bartlett.ucl.ac.uk/research/space/housingfutures/ypiv.htm>

A summary report, in the form of a 'Research Findings', entitled *The Housing and Support Needs of People Aged 18-55 with sight loss* by Professor Julienne Hanson is available from:

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Background on Thomas Pocklington Trust

Thomas Pocklington Trust is the leading provider of housing, care and support services for people with sight loss in the UK. Each year we also commit around £300,000 to fund social and public health research and development projects.

Pocklington's operations offer a range of sheltered and supported housing, residential care, respite care, day services, home care services, resource centres and community based support services.

A Positive about Disability and an Investor in People organisation, we are adopting quality assurance systems for all our services to ensure we not only maintain our quality standards, but also seek continuous improvement in line with the changing needs and expectations of our current and future service users.

We are working in partnership with local authorities, registered social landlords and other voluntary organisations to expand our range of services.

Our research and development programme aims to identify practical ways to improve the lives of people with sight loss, by improving social inclusion, independence and quality of life, improving and developing service outcomes as well as focusing on public health issues.

We are also applying our research findings by way of pilot service developments to test new service models and develop best practice.



Thomas Pocklington Trust

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