

Occasional paper



Housing and support needs of older people with visual impairment – experiences and challenges.

Introduction

Rationale and methods of enquiry

In March 2001 Thomas Pocklington Trust (Pocklington) commissioned an 18 month study of the needs of older people with sight loss. The project brief called for a range of research methods of enquiry, in order to learn about older people's experiences of sight loss and coping strategies; support needs and preferences; home environments and views on supported housing; social contacts and inclusion, and information needs.

This work was seen as important both for the development of Pocklington's own portfolio of housing and services and also as a way of raising awareness among housing and service providers, and within society at large, about the needs of a group of whom very little is known in comparison with children and young adults with visual impairment. Pocklington considered that such a project should involve talking with and listening to a wide variety of older people living in different circumstances, and that the research would therefore be of interest to many other providers.

Researchers from University College London and the University of Bristol joined forces to work on the project. Between March 2001 and July 2002, interviews were conducted with 400 participants across three areas, Plymouth, Birmingham and London. Participants, aged 55 and over, came from diverse backgrounds and lived in a wide range of housing settings, from ordinary houses or flats, to sheltered accommodation and residential care. Some lived with a spouse or family member, many lived alone. Targets were set so that our sample included those who were and those who were not in touch with specialist services for older people with visual impairment, individuals with additional disabilities or health problems, and individuals from minority ethnic groups. Achieving this mix depended on the dedication of research time and ingenuity, as comprehensive lists of older people with visual impairment do not readily exist and there are no reliable national statistics on the incidence of late onset visual impairment.

Initial interviews involved use of a questionnaire that had been formulated and piloted with the assistance of older people with visual impairment. These interviews were carried out by specially trained lay interviewers, mostly older people with relevant life experience and empathy to draw upon. Subsequent in-depth interviews and focus groups were conducted by members of the research team. As a result, the study produced two main types of data: quantitative data deriving from questionnaire based interviews with 400 people, and qualitative data arising from detailed interviews with 75 of the sample, as well as three focus group

discussions. Additionally, questionnaires were completed by 34 fit, active and sighted older people, to provide a comparative dimension with regard certain questions. This combination of research methods was decided on following the success of a similar, though much smaller, Pocklington funded study of the social circumstances of younger people with visual impairment (Hanson *et al* , 1999).

The study held out the prospect of increasing knowledge and raising the profile of a population often absent from public policy considerations. Policy and other contextual points constitute an important backdrop to this important study and are summarised below.

Vision and older people

As the demographic profile of the UK shifts towards a greater proportion of elders within society at large, increasing numbers of people are set to experience failing eyesight in later life. Impaired vision affects more older people than any other sector of the population. It is estimated that there are nearly one million people in the UK today who have a registrable sight problem though at 31 March 1997 there were only 190,322 blind and 157,683 partially sighted people actually registered as such within the UK (RNIB, 2000). The estimated number of people with a registrable sight problem in the 60-74 age group was 104,830 for England alone in 1996 and 634,020 in the 75+ age range. Seventy per cent of all people with impaired vision are aged 75 or more.

Indeed, according to a recent study of the prevalence of visual impairment in a representative sample of 14, 600 people aged 75 and over (Evans *et al* , 2002), researchers found that 10% were visually impaired and 2% were blind. Three out of four women in the sample had developed serious eyesight difficulties by the age of 75 and almost 20% of the sample had such bad vision that they would not be permitted to drive. Significantly, Evans and colleagues point out that their findings, based on a conservative measure of visual impairment, suggest that many more people need expert eye care than are currently receiving it.

Policy has not kept pace with general demographic trends, nor with this incidence of visual impairment in later life. The numbers of people aged over 65 in 2020 is estimated to be 20% of the total population. The fastest growing sector of the population across most of the developed world is that of people aged over 85 (Shaw, 2000). Such trends are widely understood and have led to increased attention and funding with regard to the needs of older adults but application has been variable. Physical mobility difficulties, particularly those that affect older people's activities of daily living, have in recent years appeared prominently on the social policy agenda. Mental health problems, especially the dementias, have taken much longer to gain active recognition, while depression, frequently talked-of as a significant yet largely hidden concern for older people, is greatly neglected. Visual impairment has yet to reach even that status. It is neither talked of with any sense of priority nor the subject of concerted initiatives in research or practical support. As a response to questions of service delivery and practice posed by these demographic shifts, the government has developed the National Service Framework (NSF) to systematically raise the standards and quality of health and social services to a wide spectrum of the population. At the same time, the first Royal Commission for 20 years was set up to examine the subject of long term care of older people and in particular, how the costs should be met and by whom (Sutherland, 2000). One observable consequence of the Commission's report is a fresh reassertion in public policy that maintaining as many elderly persons at home

as is possible is the top priority. On July 23, 2002, the Secretary of State, Alan Milburn said in a statement to the House of Commons: 'Care Homes are a good option for some older people, but not for all. They are not and must not become the be all and end all of elderly care services in our country. Our objective is to broaden the spectrum of services, to widen choice and promote independence'.

Housing and support policy context

Government initiatives such as those outlined above have implications for housing provision for older people, especially those who have needs for additional support. Housing is a key element of community care for vulnerable people (Audit Commission, 1998). Supported housing in its increasing diversity is seen to be a suitable alternative to residential care homes.

Older people's views of what is appropriate housing have changed over time and will undoubtedly continue to do so. Though popular at its inception, recent evidence suggests that traditional sheltered housing is not as popular as it once was, particularly if accommodation is perceived as too small, inconveniently located and is difficult to let (Tinker *et al.*, 1995).

Developments are currently taking place that are widening the choices available to some older people. Retirement housing and extra care housing offer an alternative to sheltered housing and 'assisted living' is beginning to exert a similar impact on the residential care home and nursing home sectors. Though these options are likely to appeal to a relatively small proportion of all older people, and are more expensive than traditional forms of supported housing, they represent a drive to combine housing and care in a 'new preventative agenda for community care' (Oldman, 2000: 53).

The implementation of 'Supporting People' (Department of Social Security, 1998) should also widen choice in where to live in later life, since support and care will no longer be closely-coupled to the form of accommodation in which people are living. One of the explicit intentions of the programme is to help older people remain in their own home as long as they wish (or to return home after a stay in hospital) by funding visiting support services. Home Improvement Agencies, which provide advice and support to help older and disabled people make the necessary changes to their environment to enable independent living, have also been included in the programme. It will not, however, extend to the provision of long term care. Domiciliary home help and meals services will also be funded from other sources, such as local authority and social services mainstream budgets.

Additionally, 'smart homes' undoubtedly have a contribution to make to improving older people's independence and quality of life (Fisk, 2001), but even those who advocate the widespread adoption of IT qualify this with the view that technology should not replace face-to-face interactions between people. Most of these technological improvements are viewed as unacceptably expensive and completely unnecessary by developers and house builders but, if we set them in the context of the domestic technological revolution of the last century, this view is probably short sighted. The manufacturing costs of much modern technology are quite low, and the costs associated with installing it when the house is first built are far less than with its subsequent introduction. However, the costs of maintaining and servicing the new technologies needs to be born in mind from the outset. It is already clear that recurrent costs act as a deterrent to older people in taking advantage of more conventional assistive devices. Some smart items – such as sensors, tagging and surveillance equipment - also raise important ethical issues.

When viewing the economic and housing situations of those currently retired, it is necessary to see them as dynamic. In the upper age groups (the fastest growing part of our population) there is extensive poverty, increasing illness and disability and the greatest resistance to change or learning new coping skills. Again our data bear this out. Yet this group of the 'old' old make the greatest call on health and social services and present the greatest challenges in terms of the housing component of their care and support. They are the clientele. It is their needs which must be met. At the same time we must anticipate new cohorts of older people entering the need categories. They are better educated, have higher expectations and greater spending power. The next generation of elders will fall squarely into the 'haves' and the 'have nots'. The opportunity and service framework will have to reflect this economic dichotomy as well as the consequences of structural and family change.

The study's themes

The study set out to investigate a number of strategic issues that Pocklington had identified as key to ensuring that their policies (and those of housing and service providers generally) would be informed by the perceptions and preferences of clients. These issues were:

- the comparative merits of specialist and mainstream housing
- the appropriate size and layout of accommodation
- community care and home support needs and preferences for service delivery
- attitudes to resource targeting, whether to concentrate on frail/ less frail clients
- attitudes to and expectations of the concept of 'home for life'.

The report arising from this study, upon which this Occasional Paper is based, has been organised under five main headings, reflecting important themes that emerged in the data: the experience of sight loss, formal and informal support, the home environment, future housing, support and care, and, finally, social contact and inclusion. Like the full report, this Paper uses the same headings and similarly ends with conclusions and recommendations arising from the data.

Experiences of sight loss

General characteristics

The 400 interviewees who comprised the total sample were drawn almost equally from the three geographical areas. The gender balance for the sample as a whole reflected the balance for the older age groups within the population at large (1.85 :1). In gerontological research, it is generally recognised that there is a qualitative step change in the lives of those aged between 60/65 – 74, the 'young old', and those who are aged 75 and over, the 'old old'. A third category of those aged 85+, the 'oldest old', is sometimes also distinguished (Pilcher, 1995: 99). Our sample included 27% 'young old', 42% 'old old' and 31 % 'oldest old'. Far more 'old old' than 'young old' were included, compared with the population at large, where the respective proportions are 60%, 30% and 10% (Leather, 1999:1). This was justifiable, given that the focus of the study was upon meeting the housing, support and care needs of people whose sight (and health) was already failing. However, we also deliberately lowered the minimum age for inclusion within the sample to 55, in order to reflect the attitudes and requirements of those standing on the threshold of later life.

Nearly 60% of our sample were living alone, whilst just 28% were living within a relationship, either married or with a partner. Our sample therefore included a higher number of people living alone than would be expected, as national statistics indicate that 50% of those aged over 75 and 29% of those aged between 65 and 74 live alone (ONS, 2002). This divergence no doubt reflects the high proportion of oldest old in our sample and also the fact that nearly a third were living in sheltered housing, a setting largely populated by people living alone.

Overall, 20% of the sample were from black and minority ethnic groups. This is twice the national average (ONS, 2002) although the majority (51 out of 81 individuals) were concentrated in London, where 28% of the population are from black and minority ethnic backgrounds (ONS, 2002). A third of this sub sample lived in Birmingham and only 4% in Plymouth.

The vast majority (92.5%) of the respondents reported a late onset of visual impairment. Just over half reported having a serious visual impairment, and a further 13% as having no sight at all, while nearly a quarter described their impairment as moderate. Of the 400 informants, a total of 168 were registered as blind and 97 as partially sighted. However, 104 were not registered as either blind or partially sighted and a further 20 did not know if they had ever registered.

A very high proportion of informants, over twice as many as had been expected, were experiencing problems with their health, ranging from one or several long-standing chronic complaints (85.50%) to one or more seriously disabling problems (53.50%). When invited to rank their overall state of health on a scale from excellent to poor, the distribution was skewed towards the 'not very good' and 'poor'. The extent to which people felt that their lives were adversely affected by multiple health problems is worth stressing and, as we will document, exacerbated difficulties caused by sight loss.

Our sample was representative of the general population of older people in terms of their education and employment backgrounds and achievements. Just over a quarter of those who were prepared to discuss finances explained that they had a weekly income of between £101-150; one in five had a slightly higher weekly income of between £151-200. A further 8% had an income of between £200-£300 per week. However, 69 people (17.25%) reported living on an income of less than £100 and one in five suffered some financial hardship. Although our study did not reveal such an unmitigated picture of financial hardship as did the RNIB Lost Vision study (RNIB, 1998), we did uncover serious pockets of poverty and deprivation, particularly in London.

Emotional consequences

At the time of interviews, nearly half the sample had a positive attitude to life, 38% thought life was alright, and 16% had a negative attitude. Findings indicate that a positive outlook was related to general health and not to visual impairment, which had been, and still was, keenly felt:

It changes your life, it really does, and there's no doubt about that.

I was absolutely devastated. I tell you straight, I know I'm laughing about it now, but I didn't know what to do when it first happened, when they told me. I couldn't see much point in it [life].

Sudden or worsening sight loss in later life is commonly reported by interviewees to have been a 'devastating', 'shattering' or life-changing event, experienced as a bereavement.

The most significant and commonly experienced feelings that followed onset of sight loss, according to in-depth interviews and focus group discussions, were grief, depression and self-doubt. These feelings accord with Cullinan's (1991) findings, that sight loss causes older people to critically examine their self-image and to feel stigmatised. The study also shows that interviewees' spouses were significantly affected by anxiety at what the future might hold.

The impact of visual impairment was undoubtedly affected by the fact that only one in five had been offered rehabilitation or support following onset of sight loss. In this regard, patient care at eye hospitals appears to be crucial. Interviewees reported that hospital specialists had been less than attentive to recognising the emotional consequences of sight loss and had bluntly added after diagnosis that nothing more, clinically, could be done. What could have been done at this critical time, according to interviewees, was to acknowledge their need for empathy, information and counselling. Without such proactive help, older people with visual impairment may internalise the notion that sight loss is a condition of old age that merits scant attention, and there is evidence elsewhere that such an attitude limits the motivation to ask for help (Hanson *et al*, 2001).

The aftermath of visual impairment was commonly said to have involved diminution of valued skills, interests and life-style, and reading, hobbies and outings were particularly missed. These and other significant losses, such as ill health, mobility problems or the death of a spouse, prominent in the lives of older people, present a cocktail of challenges to emotional well being. Our interviewees, like many of their generations, had personal characteristics, such as self-reliance, stoicism and self-determination, which helped them cope with such challenges. However, coming 'to terms' with sight loss takes time, and it was typically 6-12 months before interviewees had felt able to live life in a way that provided some confidence.

An overriding resolve to be independent may affect a willingness to accept help, which is one factor among others that informal and formal carers have to be aware of when considering the timing and appropriateness of offers of help.

Support needs

Activities of daily living

The study provided evidence that older people with sight loss are less able than their sighted peers to carry out activities of daily living independently or with as much confidence. The activity that most people had difficulty with was cooking, followed by dressing, washing, feeding themselves and using the toilet. The percentages of older visually impaired people who could manage these activities independently were in all cases much lower than the corresponding figures in the general population of older people, according to comparisons made with a recently published profile of Britain's older population (Jarvis *et al*, 1996).

Four mobility issues were targeted and the rank order of difficulty was manoeuvring in/ out of the bath, getting up and down the stairs, moving in and out of a chair and getting in and out of bed. In all cases, difficulties other than sight loss were far more likely to be the source of the problems people experienced in respect of these locomotive tasks. However, the sample had far lower levels of competence than the general population of older people. This suggests that sight loss may have an adverse effect on performance in areas of daily life such as locomotion. The apparent 'knock-on' effect of impaired vision on people's

competence and confidence when performing locomotive tasks would seem to require further research.

Data revealed that difficulty with domestic tasks was strongly related to sight loss, with problems experienced carrying out DIY, doing repairs, dealing with correspondence, and managing cleaning, laundry and washing up tasks, in that order. Ability to go out of doors or for a walk was more likely to result from other conditions but difficulties in shopping, going to the doctor or using taxis and public transport were mainly related to visual impairment. The proportion who had some difficulty with public transport because of their sight was nearly five times as high as those who attributed this to other conditions. Participants mentioned problems identifying bus numbers and buses that did not routinely stop as particular concerns, and there are implications here for maintenance of social contact, discussed later in this Paper.

Overall, the difficulties experienced by our sample indicated that older people with visual impairment in their 70s are performing activities of daily living at a level more commonly associated with people in their 90s. The difficulties that our older informants told us about implied that their need for support was likely to be far higher than that of the older population at large, which has important consequences for delivery of appropriate services.

Sources of and preferences for support

Given the above challenges, it was not surprising that our sample's self-assessed ability to manage daily life tended to be concentrated at the less able, fair/poor end of the scale. Our interviewees, in common with older people generally, looked first to informal carers for assistance with difficulties. Family members, most commonly daughters and sons, and their partners, as well as spouses, performed a range of tasks with or for interviewees, including: cleaning, shopping, escorting to appointments, dealing with correspondence, liaising with agencies, providing company, carrying out household repairs, chauffeuring, taking on holiday, helping with the laundry, helping in an emergency and providing emotional solace. Data shows that our sample found it easier to mobilise family help in an emergency than for regular low level support. Interviewees wished to reciprocate such help, and one way was to mind the grandchildren or host overnight stays by family members, a role that could be difficult to fulfil by those living in smaller housing settings.

The support offered by friends or neighbours was also wide-ranging and extensive. Substantial support from friends and neighbours was not taken for granted and several interviewees referred to payment in this respect. Many interviewees referred to the fact that they shared tasks such as cleaning, shopping and cooking with their informal helper. This way of operating may be a reason why the availability of informal support is so highly valued by older people, as formal care is often provided *for* people not *with* them.

The most often-used formal home services were those of a chiropodist, followed equally by the services of a hairdresser/barber and home help. The services that most people would like to have made more use of were those of their local social services department, chiropodist, physiotherapist, and occupational therapist. People's most urgent unmet needs were for more help generally around the home with housework, gardening and minor repairs and more help to enable them to '*get out and about*' through some kind of an '*escort service*'. The importance of an escort or guide is returned to later in the context of social contact and inclusion.

As far as experiences and perceptions of specific services are concerned, interviewees referred to the importance to them of having consistency in regard to the provision of a particular home help or home carer. It was important that they had a home help who they had got to know and were used to, someone consistent who could be confidently trusted to collect the pension and read personal correspondence for them. Such a consistent person is also more likely to be someone who gets to know an individual's routines and preferences, takes account of these and shows flexibility and sensitivity in this regard.

Although most interviewees did not often use the phrase 'sensory impairment team', this was what they were referring to when they talked of assessors and providers of specialist support for local people with visual impairment. Interviewees' comments and thoughts about this service most often centred on issues of assessment, follow-up, and unmet needs in regard to financial advice and counselling. Sensory impairment team members were clearly committed to their work, and were valued by those they visited regularly. Generally, however, workers appeared to have insufficient time to visit more than once or twice to carry out an assessment of need. This could be a serious limitation in cases where, on the day of the visit, the older person was not forthcoming about their support needs, perhaps because she or he was feeling depressed or because, as one person said, *'You don't want to feel so inadequate'*.

Most importantly, the research indicates that specialist workers should take account of needs that emerge over time and provide proper follow up and monitoring. A common complaint was that a social worker had visited once or twice, had been helpful and informative but had not returned. As a result, individuals felt abandoned, struggling to recall advice without the advantage of written prompts, lacking up-to-date information about low vision equipment (its efficacy, availability and cost) or entitlement to financial benefits, and desperate for someone to contact them to ask *'How are you getting on?'* and to *'see that I'm alright'*. Additionally, data indicates that the oldest old among our sample were less likely than others to choose technological support if this reduced personal contact with a professional helper, suggesting the importance of social interaction to less mobile visually impaired elders, an issue developed further in this Paper when considering social contact.

On the whole, interviewees were able to obtain the support they needed from a mixture of formal and informal sources. People tended to look to different parts of their 'support convoy' for different kinds of help and tried not to over-burden family members. However, there was unmet demand for professional care and support, for the reasons previously outlined. Given this, it would seem appropriate for services and resources to be targeted at both the younger old age group, as a preventative measure, and at the old and very old, in order to help them manage with greater confidence.

Other forms of support discussed by a significant minority were support groups and resource centres. Where mutual support groups exist, they are highly thought of by their members. Indeed, all the groups visited or heard about during the course of this research were attempting to provide a forum where members' information, social and recreational needs could be attended to. Groups were also valued as opportunities to remain active and to practise skills. For many older people who live alone and have had no rehabilitative support, this practical emphasis on support is valued. Although certain types of resource centre existed in each of the fieldwork areas, there were none that met people's aspirations to have access to a

truly holistic resource, one that would provide advice, equipment, support and befriending services under one roof. Existing resource centres were criticised for not being geographically central and difficult therefore to get to.

Managing the home environment

The sample's home settings were very varied and representative of the population at large. The highest percentage of participants lived either in a house (30%) or a purpose-built sheltered/retirement flat (29%). This was followed by people living in a purpose-built, low rise flat (14%). However, we spoke to people in all the main types of housing, including small numbers who lived in a bungalow, a converted flat or a modern purpose-built, high-rise flat. More unusual arrangements included living in a convent or a 'granny annexe'. Twenty-two individuals lived in a room in a residential care or in a nursing home. Just under 60 % lived alone, a quarter lived with a spouse and one in eight shared a home with extended family.

National statistics indicate that older people constitute the largest proportion of owner occupiers, with 73% of those aged 65-74 and 59% of those aged 75 and over owning their home, usually outright (ONS, 2002). A third of our sample were owner occupiers, a figure well below national average, which may be explained by the fact that nearly one in three lived in sheltered housing, although it has been noted elsewhere that people with visual impairment aged over 60 are less likely than their sighted peers to be owner occupiers (RNIB, 1998). The sample's mean length of residence was 17 years, indicating that visually impaired older people are inclined to stay put, an issue returned to later.

Modifications, layout, and space

The rank order for the changes people had either made, or planned to make to their homes in the future, was: lighting, furniture arrangements, decoration and use of lighter/ contrasting colours, floor finishes, planning and layout, changes to work surfaces, and other modifications. However, we discovered that the majority of our informants had done little or nothing to modify their homes to make them more suitable for someone with impaired vision. Lack of information, uncertainty about how to negotiate the 'benefits maze', concern about 'cowboy builders' and a determination to manage in 'tried and tested' ways all had a part to play in accounting for this low take up, but so too did familiarity with the current home and its locus as a repository of significant memories for the respondent.

Two out of five interviewees had made changes in the kitchen, the highest incidence in our sample. These changes were minor and included installing a smoke detector, adding tactile information to white goods, and purchasing special gadgets. Other features were more difficult to change. A preference was raised for kitchens to be positioned so that they lead directly off the living room, and generally for design that minimized 'zigzagging' between rooms. Accessibility of certain domestic spaces was important to interviewees and some expressed their difficulties, particularly in respect of the kitchen. One man, who lived in a sheltered scheme for older people with visual impairment, reflected on problems accessing cupboards that were 'too high'. A number of interviewees, mainly sheltered housing tenants, were critical of kitchen cupboards that were too high and the associated risks if they stood on stools to reach them.

Domestic lighting was a concern that interviewees had thought about, even if changes had not been made. One person found that in order to adequately manage

household activities she needed bright lights, not so attractive as her previous soft tone, lantern effect lighting, but more serviceable. Reluctance to dispose of aesthetically pleasing light fixtures may be one reason why the majority of our interviewees had not made similar changes. Another person had given thought to the best location of lighting as well as the preferred types, potential improvements with which, unfortunately, his housing association landlord was not prepared to assist:

But the lighting itself is inadequate..it would be better to have maybe round lighting, maybe less of the glare lighting, lighting which could be turned off or dimmed down as the person required it. In the hallway you've got two lights and they're in the wrong position.

Lighting was also discussed in terms of availability of natural light. One tenant in sheltered housing regretted the lack of windows in corridors and the resulting gloomy, 'oppressive' atmosphere.

Modifications were most often discussed during the in-depth interviews in respect of the bathroom. A third of the sample had made changes, which tended to be low cost interventions such as grab rails or bath boards. Interviewees often stated a preference for a shower, and those that had them thought highly of their value. In several cases, showers were preferred to baths because they released space within bathrooms and because they were easier to get in and out of, factors that may be particularly important to older people with visual impairment. The delay in obtaining adaptations for bathrooms was pointed out repeatedly by interviewees. The waiting period for relevant adaptations could extend for many months.

An area where a significant minority of the sample had made changes was in the approach to their home, to improve accessibility. There is an overlap here with concerns and recommendations regarding security and safety matters in the home environment. These included lack of railings forming a protective burglar-preventative barrier around a sheltered housing scheme, and poor outside lighting in the immediate vicinity, a concern shared by a number of interviewees living in sheltered accommodation. One man talked of his nine-year struggle to get white edgings painted onto steps in the communal staircase leading to his second floor flat. Steps were also a safety issue in one of the specialist schemes for older people with visual impairment, where tenants referred to the fact that there were 'so many steps' around the scheme. This particular feature had put off a prospective tenant moving to the same scheme and she said: *'I think it's the most hideous building ever built for blind people. For one thing, [there are] all the steps and the stairs'*.

Maintenance of the home and upkeep of gardens is also important to the morale of older people with visual impairment, especially those who live alone. Sight loss not only makes it difficult to carry out necessary repairs and gardening but also confounds householders when they wish to check the quality of work completed by professionals.

Older people with visual impairment, whether living in mainstream or supported housing, have strong views, as well as aspirations, in regard to the flexibility and adequacy of domestic space. This is not surprising, as recent studies have suggested that the configuration and adequacy of space are central to older people's identity with and continued enjoyment and management of their homes (Percival, 2002). Flexibility in terms of making different uses of rooms and spaces can be important to older people as changes in their health and mobility present challenges within the home environment. Where flexibility permits, the use of

certain rooms can be adapted so that older people with visual impairment are better able to make use of low vision equipment. In flats, particularly those that are relatively small, the positioning of low vision equipment is a major difficulty, and there is less scope to be flexible in the use of space, as one interviewee explained:

Apart from the study computer I've got a CCTV and I've got a reading machine which is this gadget on the end and it takes up space... if I didn't have a sight loss I wouldn't have three quarters of that stuff there.

Eight out of ten said they were satisfied with the amount of space they had and only 15% complained of insufficient space. However, the majority would have liked to have an extra bedroom or a spare room for hobbies and equipment. Adequacy of space was most often raised in relation to the kitchen. Difficulties confronted by older people with visual impairment may be particularly challenging, with concerns ranging from the 'very small working surface' to the potential 'danger' of badly appointed cupboards and doors.

Space standards in sheltered housing are relatively low, and older people, including those with visual impairment, can be very critical of this fact. A number of individuals who had visited relatives or friends in sheltered housing, or who had been to view sheltered flats in preparation for a possible move, were critical or put off by the limitations of space. Space to entertain guests or put them up overnight is important to many older people with family or friends who visit, as it allows the opportunity to continue to practice skills and roles that are part of their self-identity. Lack of adequate space in sheltered housing can restrict the ability to continue as host for family and be 'a social person'.

Generally, interviewees living in sheltered housing were less satisfied with levels of space and storage, while those in mainstream housing tended to be concerned about the upkeep of the home and garden. Developments are currently taking place that are widening the choices available to older people and the flexibility that can be incorporated into the home at the design stage (Robson *et al*, 1997). Many of these innovations could improve choice for older visually impaired people, particularly if it were possible gradually to adapt the home whilst preserving its essential characteristics.

Future housing, support and care needs

Attitudes to moving and 'home for life'

The overwhelming majority of the sample (81%) had no plans to move home for the foreseeable future, and comments such as *'I've always said that I'd cross that bridge when I come to it'* were commonplace. Although lack of information about suitable alternatives may be a factor, there are also positive reasons why interviewees indicate a preference for staying put. A very commonly heard reason for staying put was identification with a familiar home environment and location. Familiarity assists control and management of daily life, in *'surroundings that you're used to... you get about by memory'*. A familiar home is also one where there are opportunities for continuity of significant local relationships, and where familiarity of location helps the individual remain as independent as possible with regard to shopping and visiting community venues with confidence.

Another stated reason for staying put was that alternatives such as sheltered housing (which we discuss more fully below) were not necessarily seen as good value for money. A perception was held that ordinary sheltered housing provides

limited or merely crisis levels of support from the one worker, the warden, and that a move there was not worth the disturbance or possible extra financial costs. Interviewees indicated that if they were to go to the trouble of moving it would only be worthwhile if the support available was extensive, thereby reducing the need for another move at a later stage. On the other hand, the majority of the sample (69%) said they would definitely or possibly accept help from professionals if that enabled them to stay out. These views indicate how support is perceived as pivotal to housing preference and choice.

For those who were considering a move, principal reasons included: declining health, financial reasons, difficulty with stairs, need for company, to be nearer to family or friends, and to receive more support. Interviewees from ethnic minority groups tended to live in overcrowded accommodation, and indicated a desire to move with their existing extended family to larger accommodation. The rank order for what people were definitely prepared to consider if they had to move shows that the most popular option, by a factor of two (28% of the sample), would be to move to sheltered accommodation for people with a visual impairment, closely followed by sheltered housing for those of mixed age/ ability (22%) and age-specific sheltered housing (20%). The majority expressed mixed feelings about moving to an age-specific or disability-specific housing scheme. About one in five were prepared to consider nursing or residential care homes, but there was great reluctance, indicated by 72%, to accept the prospect of moving in with family, although this was a popular option with individuals from black and minority ethnic groups.

Perceptions and preferences in regard to sheltered housing

Although less than a third of the sample lived in sheltered housing, the majority had strong views and firmly held opinions, which drew attention to both positive and negative aspects. These tended to centre on the consequences of this environment as an age-specific setting. In this respect, interviewees' accounts focused on two main themes: proximity to people who were very frail or confused, and social interactions.

A number of interviewees who were resident in sheltered housing regretted that they lived in such close proximity to people who were confused, and recalled troublesome events, such as being disturbed by neighbours knocking on the door at night or rattling the letter-box. In addition, there were references to large lounges that were rarely used and an atmosphere of deathly quietness. This atmosphere could be difficult to live with. One tenant said that she went out frequently, preferring this to spending time in a setting that emphasises old age and mortality: *'The thing is if I'm here I think of nothing but death'*. Another tenant was a wheel chair user and was less able to go out regularly, so for her an eerily quiet atmosphere was particularly hard to bear:

I sometimes feel that I'm going crazy, simply from the stillness of the place, do you know what I mean?

The quietness of hushed corridors produces a feeling of detachment from a living street and outside world, which can affect morale, a feature of age-specific housing noted and discussed fully in other studies (Percival 2001).

Recent studies have also examined in detail the social interactions that commonly take place in sheltered housing and have concluded that these can be both beneficial and alienating, and that careful negotiation of social norms and

expectations is required (Percival, 2000). Certainly, interviewees in our study indicated the positive and negative aspects of social life that can characterise daily life within schemes. For some, the scheme as a social venue was very attractive and heartening, and people described how they felt a part of *'one big happy family'*. For others, however, it could be the antithesis to this if they felt pressured to be involved, or did not feel included because of cliques or gossip. Interviewees referred to how confidences were shared and then gossiped about by residents, to a neighbour's detriment, and there was unhappiness at such talk. Tenants also referred to cliques that were socially exclusive.

Black and minority ethnic interviewees emphasised the more inclusive element they experienced, or would have expected, in culturally specific sheltered housing, and stressed the potential usefulness of care being offered by workers who speak their language, respect their customs and habits, and are part of their community.

Given the range of positive and negative experiences revealed during interviews, it was not surprising to hear comments such as *'This communal living is difficult, I find it very difficult'*. The complexities of life in age-specific housing settings are also likely to feature as important considerations by those contemplating a move to or living in specialist accommodation.

Perspectives on specialist accommodation

The concept of ordinary sheltered housing is not clearly understood by many older people, and it was certainly clear from interviews and focus group discussions that those who have visual impairment commonly confuse sheltered housing with residential care, or 'old people's' homes. Unsurprisingly, interviewees' knowledge of specialist sheltered or residential care schemes for those with visual impairment was minimal, and interest in the idea of possibly living in such settings was therefore not something that many had previously considered. Nonetheless, these interviewees offered a range of thoughts and opinions that probably reflect positive and negative assumptions that older people generally may put forward. In addition, interviewees who live in special accommodation for older people with visual impairment made useful observations and suggestions.

Positive perceptions included an expectation that schemes would have staff on site who understood the practical and emotional needs of older people with visual impairment. There was also a view that the proximity to other older people with visual impairment would increase the opportunity for greater understanding and sensitivity between neighbours, which would assist communication.

Negative perceptions included a concern that this form of specialist accommodation would be institutional or disabling. There was concern at the prospect of living alongside people who could not help each other and would become a helpless group characterized by their vulnerability.

An imaginative strategy to convey the reality of life in specialist settings (and perhaps sheltered housing generally) was put forward by one interviewee, who advocated *'drop-ins'* attached to specialist housing schemes, *'where people could see what it was like, come in and have a day'* and therefore know what they were 'coming into', which would make any subsequent move less traumatic.

Given these perspectives and preferences in regard to sheltered and specialist housing, and in the light of interviewees' expressed wishes to manage as independently as possible, it would seem advisable to target supported housing at those visually impaired older people who are already frail, rather than those who

are not so old or infirm. Older people with visual impairment are no different from anyone else in their desire to stay put for as long as possible, with appropriate home support when needed.

Social contact and inclusion

Social contact and inclusion was an important theme arising and recurring in this study. Interviewees placed great value on their local surroundings, and easy, comfortable and safe access to local facilities contributed a great deal to their quality of life. However, just under half the sample could not reach any of their local amenities easily or independently, and six out of ten felt they were disengaged from local community life. Nearly a quarter of the participants never or very rarely went out to local shops, while three quarters said they would like to get out more.

Poor health, declining mobility and especially impaired vision limited social contact outside the home. A particular obstacle to getting out more was difficulty accessing public transport. Over three quarters (78%) of interviewees raised this problem, and emphasised difficulties identifying bus numbers, signalling in time to stop a bus, and being noticed by bus drivers. Additionally, interviewees could not envisage going out and being part of wider society without the assistance of a guide or escort. The need for an escort was not limited to having someone help orientate and guide the individual. An escort also helped the individual develop much needed confidence to face the challenges presented by uneven pavements, vehicle encroachment on pavements, and other hidden hazards. For those who could get out, mutual support groups offered a highly valued social reference point, where members could share experiences and coping strategies, and 'connect with life... connect with the outside world'. But availability of mutual support groups was patchy across the three cities studied, and most struggled to survive on jumble sale proceeds or hand-outs for good causes. Furthermore, attendance at such groups was dependent on availability of community transport and escorts, provision said to be under-resourced and under threat of being withdrawn.

Interaction was very limited for those who lived alone with few visitors, and many talked touchingly of their need for greater contact and the negative consequences of remaining too isolated. One woman described a '*longing to hear a human voice*' and another said, '*I want to scream, just for human conversation*'. This profound lack of interaction was poignantly illustrated by an interviewee who had balloons tied to her balcony, originally bought to commemorate the Queen's golden jubilee, which now represented in her mind the heads of imaginary visitors:

It's strange you know because I'm here on my own twenty-four hours a day... but as soon as the wind blows it's like somebody else coming in... To me it's company... They [the balloons] come and they poke their heads in... Sometimes I feel very lonely which I think myself is the worst illness a person can have.

The need for a befriender to talk to so that feelings could be expressed was evident during in-depth interviews. One interviewee had moved away from her family in order to live in special accommodation for older people with visual impairment, and subsequently felt a strong need for one to one friendship. This person talked with regret of a now defunct service that once provided residents at the scheme with someone to talk with and '*have a weep with if you wanted, or [have] a general conversation*'. Lack of this befriending service made the interviewee feel '*uncared for and unwanted*'. Others said that it would be good '*to get things out*' and have someone outside the family who could become a companion and confidante.

A number of interviewees were in receipt of a regular monthly home visiting service provided by the Metropolitan Society for the Blind, and some of these befriending needs were met by this service. However, the time available during these visits was necessarily limited and resources did not allow time for going out for a walk or visiting a social venue with the visually impaired person, activities that would complement the opportunity to talk and perhaps allow talk to take place more easily, away from the home and in a more neutral setting such as a café or park. Befriending agencies typically rely on volunteers but interviewees spoke from bitter experience that availability of volunteers to work with older people was severely limited in their neighbourhoods, although some put forward imaginative ideas about possible recruitment.

Social inclusion also depends on availability of adequate and accessible information. Participants appeared to have little up-to-date information about equipment, housing options, sources of support or financial benefits. Researchers additionally encountered widespread ignorance about the effects of late onset visual impairment and the factors that might affect people's experiences and relationships. Professionals too were in some cases insufficiently informed about developments of potential benefit to their visually impaired clients.

Conclusions and Recommendations

Experience of sight loss

Sight loss in later life has significant emotional consequences, including depression, feelings of bereavement and self-doubt, as life significantly changes. Furthermore, there is often anxiety about what the future holds.

The diagnostic consultation with medical specialists may be limited to clinical facts, with no recognition of these often unarticulated raw emotions.

The aftermath of sight loss commonly includes diminution of valued skills, interests and life-style, which cause frustration and great regret.

The emotional effects of sight loss also impact on those living alongside the visually impaired person. Spouses have to deal with changes in their life and relationship, as complex, unwanted and sometimes frightening feelings present themselves, which they are ill prepared for.

The study recommends that:

- health and social care services offer better patient care following diagnosis, to include provision of information about support services and the benefits of low vision equipment, as well as the availability of counsellors.
- voluntary sector organisations and sensory impairment teams develop rehabilitation strategies that take account of a wide variety of preferred activities, interests, and life skills.
- the needs and feelings of informal carers are taken into account by service providers.

Support needs

This research provides evidence that older people with visual impairment are less able than their sighted peers to carry out activities of daily living independently or with as much confidence. Interviewees did, however, draw on inner reserves such as self-reliance, stoicism and self-determination to meet these associated challenges.

The wish to maximise control in daily life influenced preferences in regard to delivery of support. Informal help, the first choice for most people when in need of assistance, was particularly valued by these older people, as such help usually enabled the individual to work with the helper and be an active participant in the support process.

There were also examples of professional carers, such as home helps, trying to be sensitive to this need for partnership. However, the limitations on home help services, in respect of time available but also in terms of resources ensuring consistency of personnel, made it less likely that a shared approach to the delivery of support was possible.

The study also revealed that sensory impairment teams, already proscribed by their remit to work exclusively with those registered as blind or partially sighted, are under resourced and typically assess needs on only one occasion, when the individual may not be receptive to offers of help. Such teams are often unable to offer a regular monitoring and follow up service, and there is evidence that financial and counselling needs, as well as the support needs of informal carers, are unmet as a result.

Other forms of help with potential significance for many older people with visual impairment are groups offering mutual support, information, social contact and participation in activities. These groups are often poorly resourced and in short supply but can be vital life-lines to the outside world.

Resource centres are also valued, and would be more so if they provided a base for advice workers, home visitors, group facilitators and low vision equipment for loan, all under one roof.

The study recommends that:

- home help services work consistently and in partnership with clients, in order to help sustain coping strategies.
- sensory impairment teams be sufficiently resourced, so that they may conduct assessment over time and in a holistic way, as well as provide regular review.
- voluntary and statutory sector agencies raise and pool funds so that community-based initiatives are given increased status and standing, alongside more mainstream social services.

Managing the home environment

Interviewees lived in a variety of housing types and of various tenures. However, certain themes emerged that were commonly perceived as important and which are indicative of preferences and priorities that older people with visual impairment hold in regard to domestic spaces. Two particular themes were especially significant.

First, although interviewees had not made many changes to their home environment, those who had or desired modifications spoke with conviction about the benefits. Adaptations to the bathroom were popular but the delay in obtaining these and other modifications was a particular concern. Homes need to allow for changes in people's needs as they age in place, so that choice and flexibility, in regard to self-care tasks, uses of lighting and safety and security, are maximised.

Second, it is quite clear from this research that older people with visual impairment have strong views and aspirations in regard to the flexibility and adequacy of domestic spaces. This is not surprising, given the need to house low vision equipment and to confidently manage busy, often small kitchen areas, as

well as the desire to entertain guests and accommodate them overnight, thereby reciprocating the help visitors often provided.

This study recommends that:

- features regarded as helpful by older people with visual impairment should become the basis of a Best Practice standard for architects and the commissioners of new residential facilities.
- a standard checklist and package of home improvements be made available, on the basis of a standard professional needs assessment.
- space standards be revisited and issues of adaptability and flexibility be addressed by the design professions.

Perspectives on alternative/ future housing

Whatever limitations there may have been in their home settings, participants were by and large reluctant to think about moving, although those from black and minority ethnic groups were keen to move, with their extended families, to larger accommodation. Most interviewees considered their current home to be their preferred home for life. One reason for this was the importance to participants of the familiarity of their home, and the mental map it provided, which allowed people to get about easily indoors, despite lack of full vision.

Other reasons for wishing to stay put were the convenience of the home and its location, particularly if it was near to shops and other significant places, as well as the home's social connections in people's lives.

Participants were asked for their thoughts about alternative accommodation, such as sheltered housing. Many who lived in sheltered accommodation were pleased with its accessibility, the nearness of a warden if help was needed, and the social life of the place. Others were rather more ambivalent. Some voiced unease living in an age-specific setting, which seemed to emphasise old age and frailty and could feel too quiet and detached from the outside world. There was also concern about cliques and gossip, characteristics that could be rather alienating.

The study also sought views about specialist housing for older people with sight loss. Although this type of accommodation is not as plentiful as general sheltered housing, and is therefore not so well understood, participants did offer thoughts and reflections, both positive and negative.

The study recommends that housing providers:

- ensure sufficiently large flats and houses are designed to meet the needs of multi-generational families from minority ethnic communities
- carefully consider the location of supported housing developments.
- inform prospective residents of the positive and negative aspects of life in sheltered housing.
- help those who are resident in sheltered accommodation, and experiencing difficult feelings and social interactions, to express their concerns in confidence.
- develop strategies that enable residents of supported housing schemes to socialise in the wider community, and, where appropriate, enable the wider community to learn about life in such schemes.
- devise ways in which specialist settings are made known to a greater number of potential residents, and address the negative connotations noted.

Social contact and inclusion

Throughout this research we learned of the importance to older people with visual

impairment of the maintenance of social contacts, as well as the reasons why their social inclusion may be limited. Significant numbers found it difficult to go out unaided but had insufficient recourse to accessible public transport and guides/escorts.

In addition, interviewees talked touchingly of their need for greater human contact and the negative consequences of remaining too isolated. Older people with visual impairment appear to have a largely unmet need to talk informally with a trusted person outside the immediate family, about the emotional consequences of their sight loss, to reduce loneliness and boredom, and to go out with that person to local social venues and so maintain social confidence.

Additionally, research highlighted a significant need for greater and more accessible information. Many participants had little knowledge of supported housing options and there was widespread ignorance about sources of potentially useful advice and information. Specialist professionals also lacked knowledge of important resources and developments, indicating their need for top-up training.

The study recommends that:

- national and local government give urgent consideration to resources that enable older people with sight loss to be social citizens, able to make social and shopping trips more readily and to keep in touch with the outside world.
- social services departments and voluntary sector organisations seriously consider the development of a more comprehensive befriending service and a drive to recruit retired and vocational student volunteers.
- more consideration be given by all health and social care agencies to the particular communication needs of people with impaired vision.
- greater efforts are made to provide publicity in as many varied formats as possible.
- regular top-up training of key specialist professionals takes place, to meet their needs for information about resources and the wide-ranging, complex needs of this population.

Further research

The study identified but could not explore in detail certain issues that would benefit from further research. In particular, the study recommends that:

- detailed studies are undertaken that clarify the needs of older visually impaired people who additionally have dementia or a learning disability.
- studies are carried out that are sensitive to the diversity within black and ethnic minority populations.
- further enquiry is made into the relationship between people's physical competence and confidence.
- similar studies explore the needs of older people with visual impairment who live in rural areas.

How to get further information

This 'Occasional Paper', and the full report, both titled *The housing and support needs of older people with visual impairment* by Julienne Hanson, John Percival, Reem Zako and Malcolm Johnson, are available in a variety of formats from: Thomas Pocklington Trust, 5 Castle Row, Horticultural Place, London W4 4JQ
Tel: 020 8995 0880.

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