

Research findings

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The housing and support needs of older people with visual impairment

This publication summarises findings from research conducted by Professor Julienne Hanson, Dr John Percival and Reem Zako, University College London, and Professor Malcolm Johnson, University of Bristol, on behalf of Thomas Pocklington Trust.

Visual impairment is one of the most prevalent and disabling conditions among older people, and yet very little research has been conducted that could inform the development of appropriate public services. In order to address this deficiency, Thomas Pocklington Trust funded research to examine the housing and support needs of 400 visually impaired people aged over 55.

The study found that:

- There is little professional recognition, or offers of help and advice for the anxiety, depression, and sense of profound loss that people experience with late onset of visual impairment.
- Both blind and partially sighted people need timely and holistic assessment, rehabilitation, affordable equipment and regular review.
- People with sight loss do not wish to leave their homes. Home is the epicentre of a mental map that assists orientation and continuity following sight loss.
- Social isolation and lack of human contact are major problems for people with sight loss.
- People with sight loss have poor knowledge of support groups, community services and/or specialist housing options for older people with visual impairment.

The housing and support needs of older people with visual impairment

Introduction

In March 2001 Thomas Pocklington Trust, a charitable organisation providing housing and support services for visually impaired people of all ages, commissioned an 18-month study of the needs of older people with sight loss. The project brief called for both quantitative and qualitative methods of enquiry, in order to learn about people's

- experiences of sight loss and coping strategies;
- support needs and preferences;
- home environments and views on supported housing;
- social contacts and inclusion;
- information needs.

400 people aged over 55, living in various types of housing in three cities, Plymouth, Birmingham and London, participated in the research. Targets were set so that our sample included those who were not in touch with specialist services for older people with visual impairment, as well as those who were, individuals with additional disabilities or health problems, and individuals from minority ethnic groups.

Initial interviews involved use of a questionnaire and 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.

Emotional effects of sight loss

Sight loss in later life has significant emotional consequences, including anxiety, depression and feelings of bereavement, 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. Several participants described the rather blunt way in which they were told of their diagnosis and how they had left the consultation more depressed than when they had arrived:

“The very, very first thing ever said to me (by the eye infirmary) was ‘there’s nothing we can do, there’s no treatment, there’s no cure’, and that was it, good-bye. No counselling, no nothing... They didn’t prepare me for this at all... Three o’clock in the morning (I am thinking) oh God, what am I going to do if I go blind, I’m on my own. It’s a terrible thing it really is.”

The aftermath of sight loss may commonly include diminishment of valued skills, interests and life-style. People’s identity can be undermined and feelings of frustration, depression and self-doubt develop, which, without attention, weaken self-esteem and confidence.

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

The study recommends that:

- health and social care services offer practical and emotional support when visual impairment is diagnosed.
- rehabilitation and activities are available to enable maintenance of leisure interests, relevant skills and an active mind.
- the needs and feelings of informal carers feature prominently in the care management of older people with sight loss.

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. As with loss of sight, participants 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 after considerable delay, or 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, as one participant suggested when she said:

“This (group) is my only connection with life.”

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 in partnership, and offer time and consistency to individuals.
- sensory impairment teams be sufficiently resourced, so that they may conduct assessment and review over time and in a holistic way.
- voluntary and statutory sector agencies raise and pool funds so that community-based groups and centres are given increased status and standing, alongside more mainstream services.

- resources should be targeted at both active, fitter older people with visual impairment, as a preventative measure, and at those who are frail, as a way to help rebuild confidence.

Current housing environment

Participants 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 most participants had not made any changes to their home environment, those who had or desired adaptations spoke with conviction about the benefits. Adaptations to the bathroom were popular but the delay in obtaining these and other adaptations was a particular concern. 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.

Perspectives on future housing

Whatever limitations there may have been in their home settings, participants were by and large reluctant to think about moving. Most 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.

Those from ethnic minority groups tended to live in overcrowded housing and wished to move with existing extended family members to larger accommodation.

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.

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 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 could 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. The study recommends that housing providers:

- carefully consider the location of supported housing developments.
- target such resources at those who are frail and more likely to need supported housing.

- 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 sheltered schemes to socialise in the wider community.
- 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

Nearly a quarter of the participants in our research never or very rarely went out to local shops, while 75% said they would like to get out more. Poor health, declining mobility and especially impaired vision reduced social contact. Many found it very difficult or impossible to use public transport, especially if unaided.

An escort could help orientate and guide the individual so that uneven pavements and other hidden hazards were confidently managed. An escort was also valued as someone who could advise on clothes shopping and offer companionship when outside the home.

Social interaction was very limited for those living alone with few visitors.

Participants talked touchingly of their need for greater human contact and the negative consequences of remaining too isolated:

“Every evening I’m on my own... I’m longing to hear a human voice.”

“I feel I want to scream, just for human conversation.”

This study indicates that many older people with visual impairment may have a largely unmet need to talk informally with a trusted person outside the immediate family, about the emotional and social consequences of their sight loss, and to act as a befriender. This study recommends that:

- national and local government make available resources that enable older people with sight loss to be socially included 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 consider the development of a more comprehensive befriending service.

How to reach vulnerable clients:

Research highlighted the needs of older people with visual impairment for greater and more accessible information. Indeed, this issue ran through all aspects of life and surfaced throughout interviews. 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.

Significant numbers of older people have dual sensory impairment, so the use of audio tape to provide information cannot be exclusively relied upon.

In many respects, recommendations arising from all aspects of this study would, if acted upon, improve the availability of relevant information. In addition, there should be:

- more consideration, by all health and social care agencies, of the particular communication needs of people with impaired vision.
- greater efforts to provide publicity in as many varied formats as possible.
- regular top-up training for key specialist professionals, to meet their needs for information about resources.

How to get further information

A short report, in the form of an '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

Background on Pocklington

Thomas Pocklington Trust is the leading specialist provider of housing, care and support services for people with sight loss in the UK. In addition to promoting services, Pocklington also funds a £700,000 social and public health research budget over a three year period.

Pocklington centres offer a range of sheltered housing, residential care, respite care, day services and home care services, together with community based support services. A Positive about Disability and an Investor in People organisation, with quality assurance systems for its services, Pocklington is fast becoming a best practice organisation in its sector.

Pocklington has centres in Birmingham, Wolverhampton, Plymouth, Middlesex, and two in London. The charity also manages a day service and a community support service in the West Midlands and a Resource Centre in South London. Pocklington is increasingly working with partners to bring new services to people with sight loss living in the local community.

Notes

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