

Meeting the needs of older people with visual impairment: social care or social exclusion?

Introduction

This paper is based on the research study "Housing and support needs of older people with visual impairment – experiences and challenges" (Hanson *et al*, 2002).¹

The full findings of this study are reported in another occasional paper produced by Thomas Pocklington Trust.² It is, however, useful to state that this study found evidence that sight loss in later life has significant emotional consequences, often unacknowledged by professionals. It also showed how older people with vision impairment often have their own coping strategies, but are less able than sighted peers to carry out certain daily tasks.

The study suggested that professionals should offer sensitive and timely support, in a more collaborative manner, and that services have to be monitored and evaluated to avoid wide-ranging needs remaining unmet. In respect of the home environment, research indicated that adequate and accessible domestic space in which to do housework safely, low vision equipment and the provision of overnight accommodation for guests and carers was required.

Most participants in the study wished to stay in their homes and neighbourhoods. When asked about possible alternative options, participants emphasised the importance of location and sufficient space. If they were considering supported housing, they required full information about how it addressed their particular needs.

This paper focuses on whether older people with visual impairment are vulnerable to social exclusion if their social care needs are

¹ Hanson, J., Johnson, M., Percival, J. and Zako, R. (2002), *The Housing, care and support needs of older people with visual impairments living in a variety of settings*. Thomas Pocklington Trust, London.

² Thomas Pocklington Trust, (2002), *Occasional Paper: Housing and support needs of older people with visual impairment – experiences and challenges*. ISBN no. 0-9546199-1-9 Thomas Pocklington Trust, London.



unmet. In particular, this paper argues that:

- Greater professional collaboration is required to improve eye clinic and community support services.
- Relevant staff should aim to provide timely and holistic assessments of need.
- Older people with vision impairment have significant needs as regards home care support, access to information, psychological stress and social isolation.
- Initiatives such as peer support groups and resource centres offer opportunities to tackle social exclusion arising from unmet needs.

Defining social care and social exclusion

Social care and social exclusion are frequently used but often ill-defined terms. It is therefore useful to clarify how these phrases are interpreted and used within the context of this particular discussion.

‘Social care’ refers to the delivery or facilitation of appropriate support to people in their own homes and in the wider community, by statutory agencies, in particular the social services department (SSD), as well as specialist voluntary sector organisations. ‘Social exclusion’ refers to the subjective or objective perception that an individual, or collection of similar individuals, is socially disadvantaged because of a peripheral or marginalised position in society.

There is an obvious overlap of these two concepts in respect of outcomes. Good quality social care is likely to acknowledge and respect a wide range of personal and social needs, which confirms belonging and citizenship. Conversely, poor quality social care, which inadequately addresses or ignores important needs, may exacerbate difficulties and lead to social withdrawal or a sense of alienation.

Responsibilities of social service departments (SSDs)

Another fundamental introductory point is that although this paper concentrates heavily on responsibilities of SSDs in regard to the needs of older people with visual impairment, there are clear and important implications for other statutory agencies as well as specialist voluntary sector organisations. In fact, a significant theme running through our research is that greater cooperation between all relevant providers is the obvious way to target resources, so that more people with care and support needs are included in care

plans, and the responsibility for meeting needs is shared by providers.

This is particularly relevant given the varied nature of professional sensory impairment teams. SSD sensory impairment teams, where they exist, are typically made up of trained social workers, who provide care management functions (see below) and/or rehabilitation officers (who assess functional ability and equipment needs, discussed more fully later). However, some local authorities do not have designated sensory impairment teams and may only have social workers or rehabilitation officers operating within general adult care teams. Other local authorities contract out specialist services to voluntary sector organisations or societies.

Social service departments are the primary focus of this discussion because of their role as coordinators of the care management process, with responsibility for identification and assessment of needs, provision or commissioning of services, monitoring and evaluation of the overall care plan, and, if indicated, identification and assessment of further needs.

According to the Department of Health (DoH) this circular process, if it works properly, ensures that the client is an active participant whose views on their own independence and quality of life must be clearly heard (DoH, 2002).³

“Modernising Social Services” White Paper

Meeting the social care needs of vulnerable or disabled people is a complex task, a point acknowledged in the Government White Paper ‘Modernising Social Services’.⁴ This recommends more attention by social services departments to providing the kind of support that maintains an individual’s independence and prevents dependence, as well as delivering consistent services and services that fit individual needs. The White Paper also highlights the importance of reviewing services regularly as well as catering more explicitly for the needs of informal carers, often under great strain themselves.

In their response to this White Paper, the Royal National Institute for the Blind (RNIB) acknowledges these positive approaches and goes on to highlight the importance of good social work practice and its potential to enhance the choice, independence and social inclusion of visually impaired people of all ages. The RNIB also raises concerns

³ Department of Health (2002), *Fair access to care services: guidance on eligibility criteria for adults social care*. Department of Health, London.

⁴ Department of Health (1998), *Modernising Social Services*, White Paper, CM 4169. The Stationery Office, London.

about how low level support was insufficiently prioritised and how inconsistent application of registration and eligibility procedures could lead to discriminatory social care. The RNIB also argues that the social as well as the individual causes of disability should also be considered when planning services and provision. This implies a need to look at the obstacles to visually impaired people's participation and inclusion in society.⁵

The Social Services Inspectorate (SSI) identified further obstacles to providing visually impaired people with appropriate social care. In its report 'A Sharper Focus' the SSI defines good practice as, partly, that in which specialist staff are involved in assessment and provision of services.⁶ However, this was generally found not to be the case, and the inspectorate learned that nearly 50% of social services departments were not undertaking assessments that focused on needs arising from older people's sight impairment. The SSI also noted that there was a lack of internal and external collaboration with regard to services for visually impaired people. Furthermore, only two of the departments surveyed by the SSI were monitoring the ethnic identity of visually impaired older people, an important consideration given the propensity for African and African Caribbean people to suffer glaucoma.

Other reports on social care of visually impaired people

The question of focused social care assessments was also considered by Lovelock *et al*, who found that procedures were often unclear and differed widely across regions.⁷ This study additionally highlighted how Community Care Plans typically contained little mention of the needs of people with sight loss.

The RNIB has produced a number of reports which identify additional issues that affect or potentially undermine the social care and inclusion of people with sight loss. There is a lack of accessible information about relevant services; variation in the provision of rehabilitation services and low vision equipment; poor liaison between key organisations at a local level; and a lack of emotional support when sight is first lost or impaired.⁸

⁵ RNIB (1998a) *Response by the RNIB to the Government White Paper "Modernising Social Services"*, Royal National Institute for the Blind, London.

⁶ Department of Health (1998b), *A sharper focus: inspection of Social Services for adults who are visually impaired on blind*, HMSO, Social Services Inspectorate, London.

⁷ Lovelock, R., Powell, J. and Craggs, S. (1995), *Shared territory: assessing the social support needs of visually impaired people*. Joseph Rowntree Foundation, York.

⁸ RNIB (2001), *Improving lives: priorities in health and social care for blind and partially sighted people*. Royal National Institute for the Blind.

Many people with sight loss face financial pressures, which particularly affects the wellbeing of older people, not least in respect of their ability to afford appropriate support and to remain active citizens. Older people with sight loss may also face extra costs because their difficulties are compounded by mobility problems or because they require specific low vision equipment.⁹ As a result of such shortcomings, visually impaired older people can often be marginalised from mainstream service. This particularly applies to the majority of the 900,000 older people with sight loss in the U.K. who may not have been identified or remain unknown to planners, commissioners and service providers. Specific processes may be needed to identify and reach out to this section of the older population'.¹⁰

So what can be done to ensure that older people with sight loss are less marginalised, better supported and more likely to feel socially included? This paper casts an enquiring eye over our research data and looks in detail at certain aspects of social care and social inclusion that are especially significant for older people with visual impairment. Given the areas of concern previously summarised, it would seem appropriate and useful to organise our discussion under three main headings. These are: identifying and assessing needs; acknowledging difficulties and priorities; and facilitating initiatives to improve social care and inclusion. Where individuals have been quoted, their names have been changed to safeguard confidentiality.

Identifying and assessing needs

Department of Health guidance on eligibility criteria for adult social care, appropriately titled 'Fair Access to Care Services', provides a useful benchmark against which we can consider two important themes: early detection and support at eye clinics, and formulating proactive and holistic assessments.¹¹

Early detection of support needs at eye clinics

According to the Department of Health (DoH), 'Appropriate assessment lies at the heart of effective service delivery for a whole range of health and social care provision. Its purpose is to identify

⁹ RNIB (2000), *Response by the RNIB to the Government Green Paper 'New ambitions for our country. A new contract for welfare'*, Royal National Institute for the Blind.

¹⁰ RNIB (1998b), *Response by the RNIB to the Government Discussion Document 'Partnership in action: new opportunities for joint working between Health & Social Services'*, Royal National Institute for the Blind, London.

¹¹ Department of Health (2002), *Fair access to care services: guidance on eligibility criteria for adult social care*, Department of Health, London.

and evaluate an individual's presenting needs'. This definition implies that the assessment process is dynamic and based on an individual's needs.¹² This is particularly important in the context of older people who are diagnosed with uncorrectable sight loss. This is because their emotional and information needs can be significant.

Sudden or worsening sight loss in later life was commonly reported by our interviewees to have been a 'devastating', 'shattering' or life-changing event. The ability to see was something intimately connected with the inner person. Individuals therefore grieved when they lost their sight. According to Sharpe (2002), visually impaired older people, like the 77 year old man who formed her case study, have feelings such as low morale, denial and a sense of bereavement that often remain difficult to observe.

As we have indicated elsewhere (Hanson *et al*, 2002), hospital eye clinics do not always recognise such feelings and offer limited counselling – if any – or information about community support services.¹³ As a result, older people with visual impairment not only receive unsatisfactory health and social care at the critical time of diagnosis, but are also left feeling that no-one understands what they are going through. This experience can compound depressive thoughts and a sense of exclusion. Mrs Hewitt poignantly summed up how this experience affected her when she said:

"It was like somebody had shut you up in a box and said, 'look, that's your place. Stay there. It is an awful feeling. It really is."

Eye clinics should have appropriately trained staff who are available to talk directly with patients about their worries and provide advice about possible sources of further help. This issue has also been identified by Barrick (2000), who found that only a third of ophthalmic nurses have received visual awareness training.¹⁴ However, this throws up implications concerning the availability of staff working in collaboration to provide information about support services and counsellors at eye hospitals. I return to this theme later.

There are also implications for better, more inclusive practice, in what Lovelock *et al* (1995) refer to as 'the medical/social interface' that determines an individual's registration as blind or partially sighted.¹⁵

¹² Ibid.

¹³ Hanson *et al* (2002) *op.cit.*

¹⁴ Barrick, A. (2000), *Informing and supporting: A review of support in UK eye clinics*. Royal National Institute for the Blind, London.

¹⁵ Hanson *et al* (2002), *op.cit.*

Stanford and Shepherd (2001) point out that the vicious circle in which visually impaired people with learning disabilities find themselves includes lack of recognition of their eligibility to be registered as blind or partially sighted.¹⁶ The same neglect, on a larger scale, applies to the two-thirds of older people with visual impairment who are not registered (RNIB, 2001).¹⁷ Of our 400 interviewees, a total of 42% were registered as blind and 24% were registered as partially sighted. However, 26% were not registered as either blind or partially sighted and a further 5.0% did not know if they had ever registered. This relatively high percentage of registered respondents, in comparison with the RNIB statistic cited above, probably results from our sampling method, which drew predominantly on people already in touch with specialist services and therefore more likely to be registered. However, it is important to stress that our interviewees presented very similar social care needs (which are discussed later), regardless of their registration status.

Registration is not merely a medical nicety. It is a process that sets in motion rehabilitative work in the home and the wider community, the provision of low vision equipment, and an assessment of social care needs by social workers. Our study exposed significant gaps in provision of such services, not least because of the failure to register people. It also led to expressions of concern from our lay interviewees who were critical at the low level of rehabilitation and support received by many of their interviewees. One said: *"I think visually impaired old people are the forgotten people, with very little help available."* Another referred to people who she thought had been 'neglected'. Indeed, just over 51% of our respondents said they were not in touch with any support services, and a half of these were registered as blind or partially sighted. It is interesting to note that a DoH review of the registration procedures is currently taking place, and one explicit intention is to identify 'how people can access support services earlier' (Goodwin, 2003).¹⁸

Visually impaired older people have a tendency to feel a 'liability', a self-perception that expresses self-doubt and lack of self-worth which is an early indication of a visually impaired person's need for greater social confidence.

¹⁶ Stanford, P. and Shepherd, G. (2001) A vicious circle: visual impairment in people with learning disabilities. *Nursing Times*; 97:32, 36-38.

¹⁷ RNIB (2001), *op.cit.*

¹⁸ Goodwin, J. (2003), Personal correspondence from Janet Goodwin, Disability Policy Branch, Department of Health, London.

One reason for self-doubt is the perception that others view the visually impaired individual with less respect or tolerance. Mr Halliday, whose sight was deteriorating rapidly in both eyes, expressed unease about attending a pensioners' forum that he had been active in for several years. He was doubtful that others would really want him to be present, given the fact that he would not be able to read minutes or other documents. Mr Halliday was very depressed and evidently felt that he would be a burden to others because of his visual impairment.

This sense of no longer being accepted as somebody who would fit in was also expressed in one of the focus groups, For example, Mrs Jarvis said:

"Nobody would want [me] to get involved because I'd be a liability for them."

It would appear from these examples that early support of older people who have experienced sight loss has to take account of subjective feelings that may make individuals withdraw from social activities and interactions. Therefore, in addition to suggestions of good practice described above, there has to be a commitment to social care that extends beyond the boundary of the eye clinic and offers continuity. Any identified problems (for example, those that may affect social confidence) can then be followed up in the community. Indeed, Lovelock *et al* (1995) have identified good practice in eye clinics and found that it typically involved the visually impaired person having early contact with a social worker who provided information about diagnosis and its consequences.¹⁹ The social worker also liaised with area colleagues to develop longer term support. Information/advice workers can also carry out this role.

Of course, early detection of support needs at eye clinics depends on an assessment procedure that is appropriate, thorough and inclusive. This means that needs are expressed, well understood and properly evaluated. The hallmarks of such assessments are that they are proactive and holistic.

Proactive and holistic assessments

The DoH guidelines reinforce the importance of assessment that is both 'timely' and 'rounded' (2002:8) so that a proactive and holistic approach is developed.²⁰ Proactive assessment would pay attention to the type of presenting needs already described. This would be carried out by examining such needs at the time of diagnosis or

¹⁹ Lovelock *et al* (1995), *op. cit.*

²⁰ Department of Health (2002), *op. cit.*

soon after. Timely and proactive assessment would also address an older person's need for a rehabilitation service. This would normally include providing advice on the use of special equipment, help with orientation inside and outside the home, assistance with the development of compensatory skills with activities of daily living and, perhaps, attention to emotional support needs.

Such a service is likely to be needed soon after onset of sight loss. It is still the case, however, that relatively few older people with sight loss receive such a service. Despite the trauma that is associated with sight loss, only one in five of our sample had any rehabilitation as a consequence of impaired vision. Four fifths were not offered any rehabilitation or training whatsoever to help them cope with the consequences of failing sight. This finding is typical of other studies, such as those of Davis (1998) and Lovelock *et al*, (1995), which confirmed that the importance of rehabilitation work has often not been recognised or stated in social care plans.^{21 22} Consequently such work has been marginalised.

There are a number of reasons why the assessment of rehabilitation needs does not take place regularly. First, it may be that sensory impairment social services teams are insufficiently resourced and staff cannot meet demand. This is quite likely given the fact that teams are not able to offer regular monitoring of needs and evaluation of services. This theme is discussed later. Second, sensory impairment social work teams do not assess the needs of all older people who have significant sight loss, as they tend to focus attention on people who are formally registered blind or partially sighted. Third, staff may rely on carrying out only one assessment. This will not capture the subtleties and nuances of need that the client is struggling to convey or, perhaps, deny. One interviewee echoed others when he explained that, if he is not feeling well on the day of a visit by a professional, or does not want to appear 'inadequate', he may curtail or even cancel it, but expect to be contacted again at a future time. This becomes a problem if the assessor makes no further attempt to re-visit and assumes that the lack of expressed need or cancellation is a sign of disinterest in services. This is more likely to happen with teams that are overstretched.

Timing of assessment is an important issue. Professionals have to adopt a flexible approach that allows the visually impaired person some room to manoeuvre, to reveal levels of need when it is

²¹ Davis, M. (1998) Putting vision into Community Care. Royal National Institute for the Blind, London.

²² Lovelock *et al* (1995), *op. cit.*

comfortable to do so and to maintain maximum control of the process. We can understand therefore why the notion of timely assessment has to be linked to the idea of a proactive and sensitive approach to investigating need. Without this link needs that are difficult to articulate, accept or adapt to will remain hidden or ignored. Whether sight loss is acute or progresses more slowly, assessment often has to take account of a wide range of needs. These may emerge over time. The advantage of holistic assessment which takes account of these factors was implied by Mr Ward. He had recently been registered partially sighted and was aware that he would need practical help as well as support with regard to emotional and social aspects of his life:

"They're coming because I've been registered as partly blind... I'm hoping it's someone who's not just coming to see me because of the eyesight but is coming to see me because I have difficulties as a citizen."

Mr Ward was emphasising the importance of remaining a citizen rather than appearing, in others' eyes, simply a disabled person. He implied that a full and comprehensive assessment would help to make him feel as if he was a socially included person. Any such holistic assessment also has to include monitoring and follow-up. Mrs Martin said:

"I think the social services really could take a bit more interest in [visually impaired older] people. Perhaps they feel I don't need it [support] but it wouldn't hurt just to say 'How are you getting on. How are you coping?'... But they go and you think, what did she say? You can't take it in... I haven't seen the social worker now or heard from her, no contact at all, for eighteen months I suppose."

The ability to retain information may be even more of an issue for those with sight loss who cannot rely on written reminders or prompts, as well as older people who have memory problems in addition to visual impairment and also those whose first language is not English. In regard to the latter, Mr Khan said:

"There is not enough support. People need to have more support and need to know where you can get it from."

Another minority ethnic interviewee, Mrs Begum, was prepared to pay for someone to take her out so that her daughter could have a break. However, she had only met her social worker once and did not know how to go about doing this. There was no-one to listen to her concerns or ideas.

As well as requiring information that they could understand, all minority-ethnic interviewees stressed the benefits if specialist teams

were better informed themselves specifically in regard to their cultural requirements. A meals on wheels service that provided appropriately prepared Halal dishes and a home help service that provided Punjabi speaking workers were two examples given.

Interviewees who experienced a lack of monitoring by specialist teams found it difficult to be kept up to date, to be told *'what is going on'* and to be helped in a preventative as well as supportive way. Monitoring social care needs therefore offers important opportunities for older people with sight loss to be kept informed. This, in turn, means they are more likely to be included as a more active participant in respect of the delivery of appropriate services.

Monitoring and follow-up are also important if we are not to fall into the trap of only assessing people who appear to present as high risk. Indeed, as Lovelock *et al* (1995) argue, complex needs do not neatly equate with high risk as complexity can involve simple but vital needs in combination.²³ This is the situation in which many older people with visual impairment find themselves. There is therefore a need to review social care arrangements so that changing situations and needs are included and can be incorporated in the holistic care planning of services. This is particularly important for those with sight loss. This is because eye conditions can change and affect independence or pose potential risks. Without assessment that pays adequate attention to monitoring and review, people with visual impairment may also find it difficult to re-access services (Lovelock *et al*, 1995).

Assessments that take account of visually impaired people's immediate and emerging needs, and monitor and review whatever support services are put in place, are instrumental in tackling disadvantage and marginalisation. In order to develop this argument, we move on to detail significant difficulties and priorities that emerge in the lives of older people with sight loss. Relevant social care initiatives are then explored.

Significant difficulties and priorities

A very high proportion of interviewees were experiencing problems with their health. These ranged from one or several long-standing chronic complaints (85%) to one or more seriously disabling problems (53%). Given the combination of these problems and visual impairment, it is not surprising that our interviewees experienced greater difficulty with regard to every day tasks such as cooking independently, bathing and getting out and about, in

²³ Ibid.

comparison with the abilities of older people generally, as described by Jarvis *et al* (1996).²⁴

The combination of visual impairment and these additional problems has significant consequences for the successful and confident management of daily life. The overall 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, which has implications for the delivery of a consistent and enabling home care support service (Hanson *et al*, 2002).²⁵

In the context of a discussion on social care and inclusion, it is important to focus on additional aspects of home care, before turning to consider difficulties and priorities in regard to financial pressures, access to information, psychological stress and social isolation.

Home care

Home care support tends to be targeted at people with high level support needs and discriminates against those with low level support needs (SPAIN, 2002).²⁶ A recent study of older people's views of what constitutes quality in home care services found that small tasks, such as changing bulbs and hanging curtains, were highly valued (Raynes *et al*, 2001).²⁷ Many older people with visual impairment require predominantly low level support in order to function at a level more normally associated with sighted peers of a similar age. Without low level support, there is an increased chance of premature admission to residential care (RNIB, 1998a).²⁸ This is not cost effective and does nothing to improve the social inclusion of blind or partially sighted older people.

Research carried out by Thomas Pocklington Trust (Thomas Pocklington Trust, 2000) concluded that people with sight problems value home carers who act as enablers.²⁹ This study also asks whether it may be better to have a specialist service for those who

²⁴ Jarvis, C., Hancock, R., Askham, J. and Tinker, A. (1996), *Getting around after 60: A profile of Britain's older population*. HMSO, London.

²⁵ Hanson *et al* (2002), *op. cit.*

²⁶ SPAIN (2002) *Press Release by the Social Policy Ageing and Information Network*. www.ageconcern.org.uk.

²⁷ Raynes, N., Temple, B., Glenister, C. and Coulthard, L. (2001) *Quality at home for older people: Involving service users in defining home care specifications*. Policy Press, Marston Books, Abingdon

²⁸ RNIB (1998a), *op. cit.*

²⁹ Thomas Pocklington Trust (2000), *Towards a new research policy: Review project report*. Thomas Pocklington Trust, London

are visually impaired or whether general home carers should be given visual awareness training. A more recent small survey in South West London (Thomas Pocklington Trust, 2003) further investigated this issue.³⁰ Our research indicates that a non-specialist service is viable. This is dependent upon factors such as sufficient time being available to individual home carers and carers having a positive attitude to working *with* rather than *for* the older person.

Although nearly eight out of ten interviewees received some sort of support from informal carers, as many as 30% looked to professionals for practical assistance with regard to domestic tasks. However, a home help service may not be provided at all if the potential client has a live-in carer. As has been discussed elsewhere (Hanson *et al*, 2002), family members themselves are often under great strain and their needs, together with the complexities of modern family life for many older people, require a more imaginative organisational response than is often provided.³¹

Nearly a quarter of interviewees indicated a preference for more frequent home help visits. This is not surprising given the regular assistance they required to read correspondence and to help with bills and other routine tasks. For many interviewees the cost of extra visits was prohibitive. However, few received any benefits advice that could have resulted in extra income to help with financial pressures.

Financial pressures

Findings of an earlier study of older visually impaired people (Baker and Winyard, 1998:3) uncovered 'extensive and deep seated poverty' within this particular group.³² In our study, just over one in five interviewees told us that they had no savings at all. There were also sharp regional variations in the cost of living. This made it particularly difficult for some older visually impaired people to meet their outgoings. Although our study did not reveal the levels of financial disadvantage showed by the RNIB study of Baker and Winyard, we uncovered serious pockets of poverty and deprivation, particularly in London.

Additionally, significant numbers of our interviewees were managing by going without any luxury items and some were even denying themselves what most people would consider to be life's necessities.

³⁰ Thomas Pocklington Trust (2003), *Domiciliary support for people with sight loss*. (Research Findings no. 2) Thomas Pocklington Trust, London.

³¹ Lovelock *et al* (1995), *op. cit.*

³² Baker, M. and Winyard, S. (1998), *Lost Vision: Older visually impaired people in the UK*. Royal National Institute for the Blind, London.

For example, within the previous five years a third of our sample had not bought a new coat, one in ten had not purchased new glasses and one in twelve had not bought new shoes.

The extra costs of sight loss are likely to add to the problems faced by those with little, if any, disposable income or savings. Older people with sight loss incur extra costs because of a greater need for additional home care services, as already mentioned, and also because of their need for low vision or specially adapted equipment, for alternatives to public transport (as we later see, public transport is often unsuitable), and for accessible formats of information, such as talking books (for which there is a charge in some areas). Help to meet these costs is likely to encourage independence, social connectedness and involvement with the outside world. These are all factors that promote dignity and greater social inclusion. However, such help may well depend on the availability of relevant financial state benefits. Unfortunately, older people with visual impairment do not routinely receive professional advice which could promote their greater take-up of such benefits.

Interviewees often reported having had little or no advice about state benefits they would probably have been entitled to. Lack of financial advice had been a concern for Mrs Begum, who, in the course of two interviews, repeatedly raised her need for a winter coat. Mrs Begum had only recently begun the process of applying for attendance allowance after the existence of the benefit was brought to her attention by an Asian social worker. Before that *“I didn’t get disability allowance because no one gave me the appropriate guidance”*, she said.

Mrs Begum’s account may also highlight the need of older people from minority ethnic groups to have holistic assessments carried out by specialist teams that include staff who reflect the local population.

For the very small minority of interviewees who had lost their sight at working age, the additional loss of income had been a severe blow. The emotional impact of visual impairment, described earlier, must have been considerable in such cases. As Mr White, aged 56, implied, this was exacerbated by the demeaning level of basic benefit upon which he relied. This does not appear to have been supplemented by special allowances for those with a disability:

“I am getting £91.18 a fortnight, £45.59 a week. That is not enough to pay my bills, to pay my little rent, to feed me. It is not enough. And that’s the only source of income I have. There is nothing else.”

From the above points it is clear that visually impaired people can be disadvantaged by lack of information that targets their specific

needs. Access to up-to-date information was also a problem commonly raised by interviewees.

Access to information

Lack of information about social care services appeared to be widespread throughout our sample. This indicates a need for strategies that would provide accessible and wide-ranging information to the maximum number of people. This theme is discussed more fully later in the context of initiatives to improve social care and inclusion. One relevant point to make at this stage is that interviewees commonly highlighted a general lack of up to date and impartial (non commercial) information about low vision equipment, its efficacy, availability and cost. This particular problem, in conjunction with the low levels of rehabilitation received by older people mentioned earlier, suggests further disadvantage and exclusion of those with sight loss.

This is especially true when we consider that many interviewees required information in response to a range of problems. One basic but important difficulty is the reduced ability to read. This was a concern for 23% of our sample. This factor appears to influence quality of life. It is therefore regrettable that so many older people with visual impairment do not receive offer appropriate advice and information on assistive technology. For example, Mrs Burton had bought a second-hand “Ezee-reader”, but she had no idea how to use it properly, or whether it actually worked. This added to her sense of frustration. Another example was Mrs McCourt. Without proper information she had made expensive mistakes buying different aids even though she could not afford to do so. She felt strongly that visually impaired people were discriminated against:

“I know it’s rather mercenary to look at it like this, but – when you think about it – anybody who needs a limb, they get one. Any prosthetics, they get them and they’re all paid for by the National Health. But for your eyes, there is very little aid at all.”

Older people’s quality of life is strongly associated with the simple pleasures such as reading. The lack of information that would enable them to take part in such activities seriously affects their ability to lead fulfilling and independent lives. This, in turn, exacerbates a sense of exclusion or alienation.

Psychological stress

Several interviewees were able to generalise from their own experiences. They suggested that a need to express problems and difficult feelings might be widespread among older people with visual impairment: Mr Armstrong said.

"It's hard for them [fellow group members] to accept that they've lost their sight and they just can't handle it. They need someone to go in and talk to them."

Mrs Troughton said:

"Old people have got to feel that they can confide and trust people with their problems. Some people can't carry their problems around with them; it makes them ill, mentally ill. That's why you need someone."

As Mrs Troughton suggests, the mental health of older people attempting to deal with their visual impairment is likely to be affected if pressures and anxieties build up. Individuals may not want to burden their family with all their problems. A number of people commented that they would prefer to talk to someone outside their immediate family. This was because 'there are some things you don't want to tell your family'.

Family carers themselves can be under considerable pressure and Mr Khan was not alone when he said that he did not want to put any more responsibility on family members. He wanted someone with whom he could discuss 'what is in my heart'. Of course, people did turn to family in times of emergency and most often this was a son or daughter (in the case of 52% of our sample) or a spouse (which applied to 80 out of the 111 interviewees who were married). The next most important source of emergency help was health-care professionals (mentioned by 36%).

People were less reliant on family members if they had someone else to talk to about their worries. Only 43% of our sample turned to sons or daughters at such times, and only 19% thought to contact health-care workers. Nearly one in ten of the sample could think of no-one at all to whom they could take their troubles.

Inability to express feelings and problems can affect mental health. This may have been the experience of Mr Fulton. He appeared to be extremely depressed, spending most of his time in bed in a very sparsely furnished sheltered housing flat. He admitted he had become 'withdrawn' and said that 'after you're blind you've had it'. He regretted the move to sheltered housing, away from people he once knew but now rarely saw. His only company was his home help. His coping strategy, 'I just give up', was an entirely negative one. Mr Fulton's feelings of isolation and worthlessness were poignantly summed up when he said: "I'm like a tree a million miles from the water's edge". He continued with this metaphor of lack of psychological nourishment by adding that he needed to 'get some water by my roots'.

In the case of Mr Lomax, who had become so severely depressed that he was eventually referred by his GP for psychiatric help, he inferred that a 'stiff upper lip' approach was often expected by professionals and that he would have welcomed some sort of counselling at a much earlier stage.

Baker and Winyard (1998) conducted questionnaire interviews with over 500 older people with visual impairment.³³ They found that 40 % were worried about having no one to talk to. On the evidence of our research, many of these worried people would have expressed an interest in a counselling service. Others may simply have been expressing concern that they did not have a friend or confidante and were socially isolated, another difficulty highlighted by interviewees.

Social isolation.

Our research identified a significant need for greater social contact. Over a quarter of interviewees said that they were not sufficiently in touch with other people and as many as a half wanted to go out more. Six out of ten acknowledged that they did not feel engaged with their local community. As we have discussed elsewhere, poor health, declining mobility and impaired vision limit social contact outside the home (Hanson *et al*, 2002).³⁴

What are the effects and implications of limits to social interaction for those who experience sight loss in later life? There may be a stoic acceptance that the social world necessarily contracts. This point was illustrated by Mrs Zabel when she said: "Oh, I think every blind person gets isolated". However, the majority were far less stoic. Mrs Parsons was one of many who expressed how difficult it was to live with insufficient contact, especially in the evenings and at weekends, when 'I'm longing to hear a human voice'. Of course, for those like Mrs Parsons who do not have family living nearby and whose social interaction centres on contact with neighbours or professionals who provide practical support, the need for informal social contact is often unmet and difficult to bear.

Lack of 'another voice' was upsetting not only because of the isolation experienced but also because individuals felt that their social or basic human skills were diminishing as a result. Mr Chapple told of his trip every Monday to Sainsbury's on the special bus, when he could 'have a little natter with the people' but that the rest of the week he was on his own at home. Lack of sufficient social

³³ Ibid.

³⁴ Hanson *et al* (2002), *op. cit.*

contact was a concern to Mr Chapple because:

"I'm finding that my vocabulary is nearly nil. You are not speaking to people."

The mental stimulation of regular social contact was important to interviewees. Several spoke of the lack of 'exercise of the mind'. Interviewees indicated that they could become depressed by lack of sufficient social interaction. This concern repeatedly surfaced throughout the in-depth interview with Mrs Burns who, interestingly, also used the word 'human' to describe necessary social interaction:

"I feel I want to scream just for human conversation... I feel that I'm deteriorating so much because I have no stimulant, I suppose. I hardly sleep at all."

The basic need for contact and the human capacity to compensate when it is in short supply was poignantly illustrated by Mrs Wisden, who had helium balloons tied to her little balcony, originally bought to commemorate the Queen's golden jubilee. These balloons represented 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 is the worst illness a person can have."

Mrs Wisden went on to speculate that she may be going a little 'crazy' because of social isolation, a perception well understood by Mr Walker who said that his main problem was not his sight loss but rather the ensuing loneliness. Sitting in a silent room with no one to talk to made him feel that he was not far removed from 'the nuthouse'.

All these comments confirm the importance of social contact for those with sight loss. They profoundly feel its absence from their lives. They have a strong need for human contact to help maintain their well-being and to give them a foothold in the world of the socially included.

Discussion so far has emphasised shortcomings in assessment of the social care needs of older people with visual impairment and has illustrated significant difficulties and priorities that affect social inclusion. The penultimate section of this paper will discuss the ways in which support can be delivered to improve opportunities for inclusive social care.

Facilitating initiatives to improve social care and inclusion

In addition to earlier detection and more comprehensive assessment of needs, our research indicates that there are four significant initiatives that would improve social care and inclusion of older people with visual impairment. These are: peer support groups, resource centres, befriending services and availability of community guides.

Peer support groups

When Mrs Leeson first lost her sight, she felt 'cut off' and depressed. Our research has shown that these feelings are commonplace among older people with visual impairment. However, Mrs Leeson felt more positive when she became involved in a local peer support group for people with sight loss.

This group consists of about a dozen people, mostly over the age of 60 and all registered as blind or partially sighted. Each weekly session begins with gentle exercise. There are invited speakers, such as police, fire-fighters, officers from the Royal National Institute for the Blind and local authority occupational therapists, who, respectively, provide information and advice on security, safety, financial benefits and useful equipment such as talking microwaves. For the majority who find it difficult to get out unaided, there are organised outings with transport and volunteer guides. And there are activities to bolster existing and new skills, such as safe meal preparation and using assistive technology. As Mrs Leeson says, "We don't just sit there like lumps, we do things."

Peer support groups for visually impaired older people can also provide a much needed monitoring role, with members being contacted if they are absent for more than a week. This is to check whether they are ill or have a problem. Mr White, who is 69 and one of the regulars at Mrs Leeson's group, discovered how supportive his peers could be after he was attacked by burglars in his flat. When the group learned what had happened, as well as offering a great deal of empathy, they had a collection and were able to replace Mr White's beloved radio/audio tape recorder. Mrs Leeson, who now chairs her group, was obviously proud of members' responses and explained, "We've built up quite a nice group, and a group that feels for one another."

As well as providing people with information, advice, skills training and monitoring, peer support groups provide people with an opportunity to socialise and to leave behind the isolation of home and have some human contact. Mrs Pick, who lives alone and has

no family left alive, referred to the group as *'my only connection with life'*. In fact, the social interaction that takes place is so important that members of a visual impairment peer support group in Birmingham, chaired by Mr Carter, have been known to change doctors' and hospital appointments so they do not miss a meeting. Mr Carter is well aware of the personal isolation that grinds down social confidence but still finds this commitment to the group surprising. He said, "It's quite amazing just how much people cling on to these groups." Mr Carter also mentioned how his group, and others like it, provide advice and advocacy on issues like an individual member's consumer problems or problematic communication with a council department.

Both Mrs Leeson and Mr Carter are concerned, however, at the long term viability of their groups. They were originally set up by social services personnel but are now left to fend for themselves. This creates financial instability. Both groups rely on voluntary effort to raise money for running costs. Mrs Leeson regularly requests donations from shops and traders but also has to depend on raffles and jumble sales. As she explains, *"If it's a case of begging, then I'll take the begging bowl out, because I think these people need the interaction."*

Peer support groups for older people with sight loss clearly have the potential to meet many important social care and inclusion needs. This is because they offer wide-ranging and preventative help. Such groups are also settings where members' individual rights and advocacy skills are potentially strengthened. The Better Government for Older People strategy considers people who are marginalised or disadvantaged to be of special importance (Dunning, 2000).³⁵

Peer groups are also cost effective. This is because services which would be expensive to provide on a one-to-one basis can be made available to a group of peers with similar needs at the same time. This rationale, together with the broad scope of peer support groups, is also endorsed in the National Service Framework for Older People (NSF), which refers to the need for 'wider initiatives involving [promotion of] health, independence and well-being in old age' (DoH, 2001: 22).³⁶

As well as peer support groups, interviewees emphasised the potential benefits accruing from joining some sort of town/city-wide 'association', which we have chosen to refer to as a resource centre.

³⁵ Dunning, A. (2000), *Power to the People: The role of forums and advocacy schemes in hearing the voices of older people*. www.bettergovernmentforolderpeople.gov.uk

³⁶ Department of Health (2001), *National service framework for older people: executive summary*. Department of Health, London.

Resource centres

Time and again, our interviewees, as well as respondents in other studies, have called for a resource that provides professionally staffed services for people with sight loss under one roof. In many ways such a resource centre, or one-stop-shop, offers the potential for fair access to care services recommended by the Department of Health, in that it would be holistic, in terms of the range of needs it would be equipped to meet, and yet capable of delivering a personal service.³⁷ To this end, a resource centre would be centrally located and have meeting rooms and facilities for groups. It would be staffed by knowledgeable people who could offer appropriate advice and advocacy and have equipment for loan, as well as being a base for support workers and members of the local sensory impairment team. It could also accommodate a volunteer coordinator who would recruit and supervise a network of home visitors.

Interviewees considered that a *'one-stop-shop', 'all singing, all dancing'* enterprise such as this could, in time, become a catalyst for development of well publicised and supported initiatives in local areas. Although certain types of resource centre existed in each of the fieldwork areas, there were none that met such a range of needs under one roof and therefore provided maximum accessibility to social care services. Such initiatives are gaining credence and encouragement from voluntary sector organisations, as indicated by applications recently made to funding bodies such as the Nuffield Phoenix Fund. The author has seen some of these applications. It is noticeable that they identify positive service development as promoting a comprehensive package of social care, coordinated from a centre.

Interviewees at two of the focus groups raised the prospect of 'outreach' workers operating from resource centres. Outreach workers would be available to visit and advise on small but often extremely troublesome problems within the home, such as use of new appliances. Interviewees suggested that outreach workers could also deliver equipment to an individual's home and demonstrate their proper use. Resource centres could also make equipment available on a loan basis for home trial.

Interviewees were generally supportive of resource centres as places where support would be coordinated, accessible, socially oriented and individually tailored. Interestingly, interviewees also suggest that if such an enterprise is to deliver the preferred range of support, it

³⁷ Department of Health (2002), *op.cit.*

will need to be backed by local authorities in partnership with other agencies and organizations. Similar conclusions are reached by the RNIB (1998a:6),³⁸ when it refers to quality services providing 'holistic and user-centred support' to the individual as a 'whole person rather than a collection of isolated needs'. Resource centres would also reduce the maze of services and systems that were identified by the Social Services Inspectorate (DoH, 1998b) and promote support networks, which help tackle social exclusion (Barr *et al*, 2001).^{39 40}

Befriending services

Although we have noted the need for social care that offers counselling, it is clear from our research that many older people with visual impairment welcome the opportunity to have a more informal form of social contact which is psychologically beneficial. The need for a confidante, or befriender, was evident during the interview with Mrs Burns, who had moved away from her family in order to live in special accommodation for older people with visual impairment. She felt a strong need for one to one friendship. Mrs Burns 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 Mrs Burns 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 had a regular monthly home visiting service provided by the Metropolitan Society for the Blind. This service met some of these befriending needs. However, the time available during these visits was necessarily limited and the resource was clearly rationed, as many who could have benefited were not receiving visits. One possible source of a larger pool of benders was suggested by Mr Sutcliffe, who had reflected on this matter prior to the planned in-depth interview and who supplied the interviewer with a hand-written series of suggestions. These included the use of volunteers who may be interested in pursuing careers in the social care or medical professions, and who would use their experience of befriending as a sign of their caring capabilities.

³⁸ RNIB (1998a), *op. cit.*

³⁹ DoH (1998b) *A sharper focus: inspection of social services for adults who are visually impaired or blind*. HMSO, Social Services Inspectorate, London.

⁴⁰ Barr, A., Stenhouse, C. and Henderson, P. (2001), *Caring communities: A challenge for social inclusion*. York Publishing Services, York.

Volunteers are, of course, used by befriending agencies. Perhaps a pool of prospective vocational students would be of interest, although agencies would have to be sure that volunteers were sufficiently mature and appropriately aware in order to provide a sensitive service. Interviewees indicated, however, that any expansion of a befriender service would most likely start from a very low base, as neighbourhoods often lacked resources to appoint, train and coordinate volunteers. Nevertheless, there was a great deal of enthusiasm for such development.

Community guides

As we have already discussed, with a significant number unable to go out as regularly as they would have wished, the need for increased social interaction was very important to many interviewees. Stokes-Roberts (1991) suggests that poor self-image and problematic emotional reactions to sight loss affect older people's motivation to go out, increasing the prospect of social isolation.⁴¹ Our research suggests that these feelings were heavily outweighed by the need to go out, which helped people feel socially included. This was well summed up by Mr Harrison, who said, "When I go out and mingle with people, I come back home in a happy mood. I feel that I'm part of society."

However, going out was not necessarily a straightforward proposition. The proportion of our interviewees 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. The problem for many was identifying bus numbers and making their presence known in time to make buses routinely stop. A number had access to Dial-a-Ride or similar schemes operating in their area. Where they existed they were often spoken of favourably. However, the vast majority of interviewees either did not know of any comparable local provision or found it too inflexible to meet their particular needs.

Statements about the benefits of having a guide or escort to assist them to get out were commonplace. For example, in regard to travelling to a new venue, the following comments were made at one focus: "It's inaccessible to you because you aren't familiar with how to get there. This is where a guide is essential to get you from A to B. They can show you the route and teach you the route so you can become independent'. Another person advocated a system whereby "if I need to go somewhere on such a day, then somebody could be brought in as a helper, be paid for that job and say 'right, you've got

⁴¹ Stokes-Roberts, A. (1991) Maintaining activities and interests. In: Redfern, S.J. (ed) *Nursing elderly people*. Churchill Livingstone, Edinburgh.

two hours of my time today, I can take you here, there and do that'."

Interviewees advocated a scheme that would ideally provide 'assistants' who could be booked in advance for the time required to accompany individuals to a venue, help them orientate themselves and guide them onto public transport. A number of interviewees made the point that spouses or other family members need relieving from the task of always acting as guide and escort, a particular worry for Mr Cherry, whose wife was suffering from respiratory problems. During our interview Mr Cherry rehearsed what he would say to those agencies that could potentially provide him with a resource, when he said

"I'm a blind person. I'm 75 and totally blind. I'd like somebody to walk me once or twice a week."

Without escorts, many older people with visual impairment simply cannot envisage going out and being part of wider society. The need for an escort is not limited to having someone to help orientate and guide the individual. An escort helps the individual develop much needed confidence to face the challenges and obstacles presented by uneven pavements and other hidden hazards, such as the problem of encroachment of pavements by cars and a general lack of confidence in negotiating busy roads. This lack of confidence is understandable when we recall that the majority of older people with visual impairment are not registered as blind or partially sighted and do not receive rehabilitation services following sight loss. Lack of someone to escort individuals resulted in a reluctance to *'take a chance'* in going out, reducing an individual's potential social interactions.

Conclusions and Recommendations

This paper has focused on ways in which social care provision affects the social inclusion of blind or partially sighted older people. It was thought important to adopt this focus, partly because of the range of issues that emerged throughout interviews and partly because of people's responses to certain statements which were included in our questionnaire. This sought to establish their perception of society's attitudes to older people who are visually impaired. In regard to the latter, nearly two thirds of interviewees agreed with the statement that *'many older people with impaired vision feel left out of society'* and over half disagreed that *'people generally are aware of the problems faced by people with sight loss'*. Four fifths agreed that *'blind and partially sighted people need more help than is currently provided'*.

This paper has sought to show that the ways in which organisations

identify and assess social care needs, and the nature of interviewees' difficulties and priorities, affect people's feelings and experiences of social inclusion or exclusion. The paper has suggested initiatives that could assist organisations to deliver the type of social care that would improve prospects for social inclusion. A number of recommendations are now made to prompt further discussion about how best to develop good social care practice and forward-looking initiatives.

Early detection of support needs

Social workers, rehabilitation officers and voluntary sector organisations should collaborate to provide outreach advice and awareness training to staff in hospital eye clinics, and, where appropriate, an information/advice service within eye clinics. Additionally, social care workers should seek opportunities to make case study presentations at clinical meetings, and to emphasise the benefits of registration and rehabilitation services. All social care staff should ensure that staff training includes attention to the emotional aspects of loss of sight. They should also consider co-opting service users to help design such training components.

Assessments

SSDs need to be more proactive in identifying social care needs and priorities of this population. To this end, sensory impairment team staff should be prepared, for example, to visit and become more familiar with voluntary sector services and the resources of local societies. They should also hold 'surgeries' within a range of settings frequented by older people and provide information in accessible formats about social services to GPs, housing offices and community groups.

SSDs also need to increase the availability of rehabilitation and mobility training. At the same time, relevant social work teams need to make the case to central and local government that greater levels of funding are needed if they are to fulfil their statutory obligations to the growing numbers of older people with visual impairment.

Difficulties and priorities

All relevant social care agencies should ensure that teams are sufficiently well resourced to work in partnership with clients and their informal carers, and to acknowledge complex but possibly low level home support needs. Social care staff should make the case to central government that visually impaired older people require more accessible information about financial benefits and low vision equipment. At the same time, sensory impairment teams, as well as specialist voluntary sector organisations, should develop strategies

for providing advice and advocacy in regard to financial benefits applicable to older people with visual impairment. Social care agencies need to collaborate in order to develop counselling services dedicated to the needs of older visually impaired people, including those who are not registered blind or partially sighted.

Facilitating initiative to improve social care

SSDs need to collaborate with relevant agencies to provide venue, transport, administrative back-up, and all necessary equipment to facilitate peer support groups. Similarly, statutory and voluntary sector organisations should collaborate to establish resource centres that benefit from the expertise of various personnel in what amounts to multi-agency enterprises. SSDs and voluntary sector organisations should join forces to investigate the possibilities for establishing and expanding befriending services. This collaborative venture could include making useful contacts with sources of potential befrienders such as University of the Third Age groups and younger people who are undertaking relevant vocational training. SSDs should consider providing or commissioning personnel to act as community guides, so that visually impaired older people can go out with confidence and participate fully as social citizens.

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How to get further information

A Research Findings summary of this work, and the full report entitled "*Assistive Technology*" by Keith Ross of BRE are available from:

Thomas Pocklington Trust,
5 Castle Row,
Horticultural Place,
London W4 4JQ

Telephone: 020 8995 0880

Email: info@pocklington-trust.org.uk

Background on Thomas Pocklington Trust

Thomas Pocklington Trust is the largest specialist provider of housing and support services for people with sight loss in England. In addition to promoting services, Pocklington also funds a £750,000 social and public health research budget over a three year period.

Pocklington's centres offer a range of sheltered and supported 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.

Email: info@pocklington-trust.org.uk

Web: www.pocklington-trust.org.uk