## Faculty of Health & Social Care

# The Needs and Aspirations of Older People with Vision Impairment

## Report for Thomas Pocklington Trust

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# Contents

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In addition our thanks go to the members of the Advisory Group: Berni Warren, Mandy Smith, Pamela Lacy, Lynn Watson, Suzy England, Jane Minter, Marcus Green, and Nat Lievesley.

EXECUTIVE SUMMARY

- This report summarises the views of older people with vision impairment living in a variety of domestic environments across England. They were recruited through contacts in VI voluntary organisations including those supporting people from Black and Asian Minority Ethnic groups.

- Many participants lived with vision impairment[1] (VI) alongside other short and long term health conditions. This demands a combination of individual assertiveness, practical, social and environmental support;

- The experience of becoming vision impaired in later life can lead to learning new skills, accepting interdependency, learning to benefit from technology;

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[1] In this report, the terms 'vision/visual impairment', 'sight loss', 'sight impairment' and 'blind and partially sighted' are used interchangeably and by different participants.

- People's ability to access appropriate services depends on where they live and the availability of both statutory and voluntary organizations;

- For most participants ageing with VI staying in their own homes is key to their well-being. Spatial orientation is supported through familiarity and control even though a cherished home may not protect against isolation and loneliness;

- Being able to engage with other people locally including local and national organizations for vision impaired people can be a vital lifeline;

- Despite similar experiences of sight loss, people vary in the ways in which they are able to respond. These responses are mediated by practical knowledge and cultural approaches to life;

- For some people, the onset of VI had challenged their personal identity, for example through the loss of valued roles or activities. Most participants had incorporated VI as part of their identity and accepted it, along with ageing, through continuity balanced with adaptation;

- To retain their sense of self, some participants adopted 'responsible risk-taking', knowing their own limitations but working within them to maximize their independence.

# Introduction

Sight loss affects people of all ages but with increased age this is more likely: from midlife onwards many begin to develop age-related long sight (presbyopia) and wearing reading glasses becomes common. However this report focuses on the everyday experiences of those who live with more complex vision impairment alongside other health and welfare issues that can be disabling in later life; an area that is still under-researched (Zimdars et al, 2011).

How are people ageing with VI able to maintain a way of life that they judge as living well? How enabling is the environment in which people live? Do people with VI have access to the resources and information they need? What activities of daily living do people undertake and what are their coping strategies? What are the relationships that support their well-being? How do people maintain their identity?

These were some of the important questions that were to underpin the aims and objectives and guide a detailed qualitative study. But what is already known? In the following brief literature review concerning older people with vision impairment the aim is to contextualize this research.

## Understanding the literature

There is a growing body of national and international literature concerning vision impairment and growing older. In this report we consider the following areas: national demographic data; housing and living arrangements; health and well-being; quality of life and ways of living.

## Characteristics of older people with vision impairment

While it is reported that approximately 2 million people living in the UK have sight loss there is a definite relationship between growing older and vision impairment. Statistics from the Royal National Institute of Blind People (RNIB) show that whereas over 25,000 children aged between 0-16 years are severely visually impaired in later life this number is very different with far more people affected including those with lifelong conditions and those whose levels of sight loss have been acquired later in life:

- One in five people aged 75 and over are living with sight loss;
- One in two people aged 90 and over are living with sight loss;
- Nearly two-thirds of people living with sight loss are women;
- People from black and minority ethnic communities are at greater risk of some of the leading causes of sight loss;
- Adults with learning difficulties are 10 times more likely to be blind or partially sighted than the general population.

(Source: http://www.rnib.org.uk/aboutus/research/statistics/Pages/statistics.aspx accessed 17th December 2015)

These trends are supported by data from the 2011 Census (ONS, 2012). They indicate issues of risk of vision impairment relating to age, gender, cultural difference, and other health issues. In addition, through analyzing the English Longitudinal Survey on Ageing (ELSA) Nazroo et al (2015) show that the risk of vision impairment is greater for people from poorer financial backgrounds.

The registration of people with vision impairment does not necessarily reflect the overall numbers given here. Systems for obtaining a certificate of visual impairment and registration enabling access to

services and concessions have changed over time and currently people can be registered as:

- Sight impaired (known also as partially sighted);
- Severely sight impaired (known as Blind);

Statistics from Action for Blind People show that 360,000 people were registered as severely sight impaired (SSI) or sight impaired(SI) in 2009 ([www.actionforblindpeople.org.uk](http://www.actionforblindpeople.org.uk) accessed 20.12.15; RNIB,2009). Whereas further information for England from the Health and Social Care Information Centre (HSCIC accessed 20.12.15) indicates that the number of people 75 years and older registered in both categories has been going down over the past 10 years with figures for 2014 being 143,400 registered as SSI and 94,300 SI (HSCIC, accessed 20.12.15). While registration can lead to a needs assessment and access to certain concessions such as reduced council tax, not all people with vision impairment are registered or known by their local social services department.

Age-related macular degeneration (AMD) is the leading cause of sight impairment in adults. This condition is dominant alongside other significant complaints: glaucoma, cataracts and diabetic retinopathy. AgeUK have indicated that in the UK almost 50% of people over 75 years will have some symptoms of age-related macular degeneration (AMD) and 42% of people will develop cataracts. This increases to one in four people aged 90 years and over with AMD (AgeUK accessed December 16th, 2015).

While these conditions are experienced by many older people, those from Black and Asian Minority Ethnic groups (BAME) may be particularly at risk. In England black and minority ethnic groups form over 16% of the total population with VI and 8% of the population aged 60 years and over (AgeUK, 2015, p3). The UK Vision Strategy (VISION 2020, accessed online December 21$^{st}$ 2015) shows that:

- Black people are more at risk of developing age-related macular degeneration when aged under 60 years than white or Asian people;
- Asian people have a great risk of developing cataracts;
- Black and Asian people have a high risk of developing diabetic retinopathy;
- Black people have a high risk of developing glaucoma;
- People from black and minority ethnic communities are at risk of not taking up community based eye care services;

(Source: Thomas Pocklington Trust, personal communication Nov. 2014).

In addition, Johnson and Morjoria-Keval (2007) in a systematic review of published and grey material as well as action research, show that black and minority ethnic people with vision impairments have particular support needs due to issues such as language difficulties or social isolation. They have problems obtaining registration and access to rehabilitation, and show limited take-up of low visions aids, training and equipment. There are also higher rates of unmet need for carers and family members. For this reason, our study oversampled older black and minority ethnic respondents to gain further insight into their lives.

## Housing, living arrangements and lifestyle

The housing needs of people with sight loss vary across the life course. Blood (2015), in a UK study, focusing on housing opportunities for young to middle aged adults (16-44 years) considers the transition to living independently. Here consideration of tenure in the private rental sector highlights the importance of location in relation to services, education and employment; the interior design of properties; access to housing finance and advice, and the need for a basic recognition by all parties of the implications of sensory loss. While some of these issues remain in later life, there are generational differences and the housing experiences vary. Research concerning the housing and living arrangements of all older people in the UK shows that the vast majority (approximately 95%) of people 65 years and over live in mainstream housing across the range of types from detached to cottage, from terrace to flats (Peace et al, 2011). Currently, owner-occupation is prevalent and older people are more likely to be outright owners without a mortgage (AgeUK, 2015). In the main they either live alone or as a couple with only a relatively small percentage of people 65 years and over living in supportive housing, a proportion rising in extreme old age when some 16% of the over 85 year age group live in the care home sector (AgeUK, 2015).

A person's own home is often seen as a major financial asset should long term care needs lead to a move to alternative accommodation. Peace et al (2011) discuss the role of 'option recognition' as people may consider that their housing no longer meets their needs. The call for alternative styles of accommodation that older people would choose, move to and see as a life-time home is on-going with design, care and personal preference competing in a time of little new build (see DCLG, 2009; HAPPI, 2012).

Hanson et al's (2002) detailed study of the housing and support needs of 400 older people with vision impairment still provides baseline data with which to contextualize this study. Their work with people living in various types of housing indicated how many older 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' (Hanson et al, 2002, RF1 p1).

They also showed how adaptations can improve accommodation, and the importance of adequate and flexible space. The idea of supportive housing elicited mixed responses, positive and negative, about social aspects and enabling / disabling support.

Building on this research, Thomas Pocklington Trust (TPT) has developed Good Practice Guidance for home design, maintenance and refurbishment for people with sight loss in a variety of circumstances. Guides relate to interior design through improving lighting, colour contrast, avoiding clutter and ways of using accessible appliances (see TPT RF36, 2012; TPT GPG4, 2014; TPT RF42, 2014; TPT GPG5, 2015; TPT RF50, 2015). Changes to lighting can improve older people's ability to undertake everyday tasks but should be bespoke for different people in different contexts (Evans et al., 2010; Maguire et al, 2014). It is clear that many older people with VI proactively rearrange and structure their home environment in ways that enable them to retain everyday competence (Wahl, Oswald & Dimprich, 1999).

## Health, quality of Life and wellbeing

Relatively little is known about the effects of vision impairment on older people's health, quality of life and wellbeing. However, there are important indicators. Drawing again on the work of Nazroo et al's (2015) analysis of ELSA data, they show that over a two year period deteriorating eye conditions can lead to increasing levels of depression and decreasing signs of quality of life, social interaction and financial support (income levels).

Research shows that there are clear risks of depression and reduced mental wellbeing for this group which may reflect diverse experiences such as the incidence of sleep disorder (Zizi et al., 2002) or social isolation due to difficulties in getting out of the house (Evans, Fletcher & Wormald, 2007; Hodge, Barr & Knox, 2010; McManus & Lord, 2012). There is also growing evidence that people with vision impairment are more likely to experience falls (Dhital et al, 2010; TPT,2013). For example, there were an estimated 37,000 falls requiring hospital treatment in 2008 that were linked to sight loss for older people (Access Economics, 2009) and while falls have not been linked to specific vision conditions issues such as wearing multi-focal lenses or central / peripheral field loss may increase vulnerability.

Such research evidence is challenging and Zimdars et al (2011) argue from the ELSA data that:

"Self-reported vision [loss] is associated with multiple disadvantages, in particular with regards to other physical health functions, but also with regards to cognitive functions, economic well-being, social relationships and social participation, and emotional well-being".

The importance of social relationships is central to well-being (Green & Miyahara, 2007; Cimarolli et al., 2011). A meta-synthesis of qualitative studies of the emotional well-being and adjustment to vision loss of older people found that an individual's ability to accept their condition and develop a positive attitude was an important factor in well-being, as was social support from family, friends, and peers (Nyman et al., 2012). However, they found that vision loss was not the only, or most important factor, leading to depression and low-wellbeing: poor health and economic status were also important (p29). Since most people in the UK in the 75+ age group have three or more long-term health conditions (Barnett et al, 2012), the complexity of living with co-morbidity needs further examination: at least 123,000 people in the UK, are thought to have both serious sight loss and dementia (TPT, 2007), and/or the complexity of dual sensory loss especially hearing and seeing (Roberts, et al, 2007).

Nyman et al (2012) concluded that self-reported poor vision appeared to be a good proxy for a person's lower propensity for other 'good fortunes' ranging from emotional and physical well-being to economic circumstances and networks, and that relatively simple interventions in any of these aspects have the potential for positive effects in other aspects of the person's well-being. Further comparable research between people with vision impairment aged 40-69, and 70-98 showed five important common needs: daily coping skills; affordability and access to technological aids, transport, information and access to the built environment, and personal attitudes towards sight loss by all parties (Duckett et al, 2010).

## Maintaining personal identity and control

How do people feel about themselves? Thurston (2010) set out to explore the emotional impact of sight loss in four core areas (mood, self-concept, social connectedness and loss), and the counselling experiences/needs of blind and partially sighted adults. She noted the recurring theme of the need for social support to combat social isolation and loneliness. It also appears that social support is best given in person and that many older people with visual impairments do not feel that online social connections are accessible or appropriate to them (Edwards, 2012).

While personal contact is central, the issue of 'perceived over-protection' is also important – older people with visual impairments may feel disempowered by well-meaning family and friends who especially fear that they will fall or injure themselves, and this may reduce the ability to adjust to vision loss and adapt their environment to suit them (Cimarolli, Reinhart & Horowitz, 2006). Negotiating the right balance between support and overprotection is often challenging for all involved. Where people suffer multiple forms of loss, both social (such as the death of a partner) and physical (such as the onset of hearing impairment), then maintaining personal autonomy may be threatened.

Good et al (2008) surveyed 560 older adults in New Zealand to look at any differences between visually impaired and sighted respondents relating to whether prediction of life satisfaction related to levels of activity, independence. Perhaps unsurprisingly, independence and frequency of activity were lower in the older age cohorts and those with visual impairments, but they also found higher scores for life satisfaction among the oldest cohort with VI (85 and older) reflecting: 'For the first time as older people, this oldest group with visual impairments may have

been able to compare themselves favorably to their sighted peers in terms of daily functioning, which may explain their higher levels of life satisfaction' (p524).

This short literature review shows a breadth of research that has begun to unpack the complexity of living with vision impairment in later life. It indicates cumulative disadvantage alongside positive coping strategies for those who in the main wish to live in their own community based homes. The present study seeks to add to this understanding comparing issues for people with different cultural histories.

# Research aims and objectives

In 2014, Thomas Pocklington Trust (TPT) asked The Open University researchers to consider the needs and aspirations of older people with vision impairment building on their earlier work concerning people with high support needs (Katz et al, 2011). In particular TPT was concerned with housing needs and 'staying put' in later life. The focus was to centre on the oldest age groups, except in relation to BAME groups.  The following were the aims and objectives:

**Primary aim:**

- To facilitate older people with vision impairments living in community environments to express their preferences for where and with what kinds of support they would like to live.

**Objectives**

- To understand choices over lifestyle and living arrangements;
- To understand issues of personal identity;
- To consider how control and autonomy can be maintained or delegated;
- To address issues of risk-taking and responsibility.

A detailed account of methodological development is given in Appendix A. Participants were accessed through organisations for people with vision impairment and for this reason generalisations cannot be made concerning all older people with VI.

# Findings

## Background characteristics of participants

This study is based on 50 older participants, of whom 36 (72%) were female and 14 (28%) were male. One participant was aged 54 (blind since birth, and from a minority ethnic group). Apart from that one person, the age range was 69 to 99 years: average 79 years; median 80 years. The current marital status of participants included 26 people widowed; 16 married; 4 divorced; 2 separated; 2 single.

The financial circumstances of participants were harder to establish, partly because a few participants did not want to discuss their finances, but more often because financial affairs were being handled by other family members and they were unsure about the sources of their income. However, we identified broad trends within the self-reported economic circumstances of those participants who handled their own affairs and were willing to disclose these.

Twelve participants described themselves as 'comfortably off' or 'comfortable' or stated that their monthly income was equivalent at least to the mid quintile of UK pensioner incomes (i.e. 3rd level of five, from lowest to highest). The division of incomes into quintiles was based on the most recent Department of Work and Pensions calculation of mean pensioner incomes for couples and single pensioners (DWP, 2014). These incomes typically included several sources including company pensions and other savings.

Nine participants fell within the second quintile, typically based on state and other small pensions and attendance allowance. Four of these participants had savings.

Eleven participants fell within the lowest quintile, with their incomes typically comprising state pension and pension credit. They tended not to have any savings, and were primarily widowed or divorced women, but also included 2 men (one single, one married).

Not all participants wanted to define themselves in terms of ethnicity: four participants whose place of birth was other than UK did not wish to define their ethnicity or rejected the concept. Of those (46) who did, the self-defined ethnicities included: White British [including White English] 32; Black British 2; Asian British 2; European 2; Black African 2; Asian 5 [excluding Asian British but including Asian (3), Indian (1) and East African Asian (1)]; Mixed race 1.

Figure 1 below illustrates, as a pie chart, these self-declared ethnicities: 64% as white British/English; 8% uncategorised; and 28% of the various minority ethnic groups.
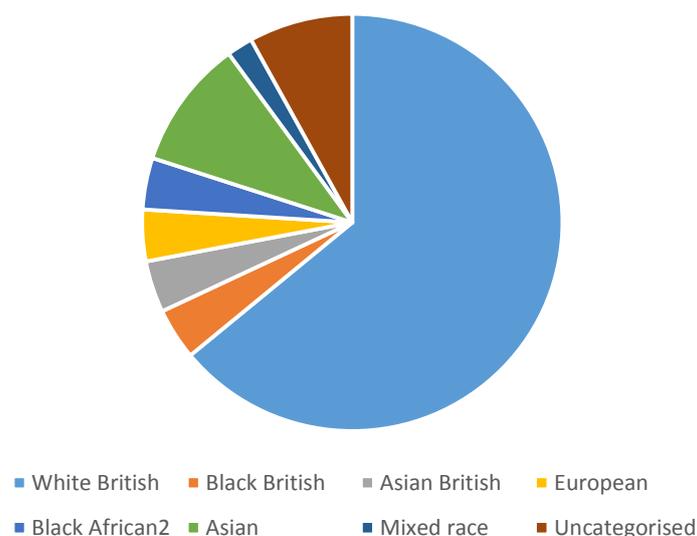


Figure 1: Self-reported ethnicity

We also asked participants about their place of birth. These included: 35 people born in the UK; 7 born in Asia (including 4 in India and 3 in Pakistan); 4 born in Africa (including 2 in Nigeria, 1 in Biafra (1) and 1 in East Africa); 3 born in Europe (Italy, Netherlands and Poland) and one person born in the West Indies. Of the 15 people born beyond the UK, the average length of continuous residence in the UK was 38 years.

## Range of vision impairments

The review of current literature indicates that vision impairment can be defined in different ways: clinical, administrative and self-reported. When discussing the onset of visual impairment with the participants, and when and how their sight condition had come to be identified/ diagnosed, it became apparent that participants varied in their understanding as to what they thought was 'wrong with their eyesight'.

Table 1 represents the complexity of this understanding. Some participants had had poor vision for much of their lives and in later life this had become a co-morbidity when age-related macular degeneration (AMD) also developed. So they may have already worn glasses for an on-going stigmatism or presbyopia before they developed AMD, or they may have developed cataracts and AMD.

The table below lists 17 people with AMD, 12 with multiple sight conditions, most with AMD, 10 with sudden loss, trauma or illness-related sight loss, and 5 other conditions including glaucoma with no other condition. Altogether 31 participants had some type of AMD, living with some form of peripheral vision.

| Condition | Number | Including |
| --- | --- | --- |
| Age related Macular Degeneration (AMD) | 17 | Wet, dry, and both: in one or both eyes. |
| Multiple sight conditions: most alongside AMD | 12 | Blind spot; cataracts; congenital cataracts blind from birth; degenerative myopia; dementia/glaucoma; detached retina; geographic macular atrophy; glaucoma/cataracts; glaucoma/diabetic retinopathy; glaucoma, hemorrhages, iritis; presbyopia. |
| Sudden loss/trauma/illness | 10 | Trauma; stroke/TIA; loss uveitis; not known; cerebral accident; encephalitic measles; sight loss in infancy |
| Other | 5 | Glaucoma; Retinitis Pigmentosa; Charles Bonnet Syndrome; Diabetic Retinopathy; Polypoidal choroidal vasculopathy; Cone dystrophy |

Table 1: Vision Impairment – Primary Sight Conditions reported by Participants

Some people were far more knowledgeable and confident as to how a condition had occurred and the treatment available than others. Participants who came from minority ethnic groups were much more likely to be unsure about the origin or type of their sight condition – this

applied to at least 5 of the BAME participants. 7 African and African Caribbean participants reported that they had glaucoma.

Some participants clearly knew when they had been registered as vision impaired and could report when this had changed from being a partially sighted registration to registration as severe sight loss, but this was not true of many participants. Only 1 person said they were not registered, 4 did not know whether or not they were registered, and 9 were uncertain of the type of registration. Of those who described their registration, 17 stated 'blind' and 7 as 'severe'; with 7 as 'partial'. Given the recency of definitions as SI and SSI and the length of time of their conditions, this lack of clarity is understandable.

## Adding health conditions to vision impairment

While vision impairment often had a complex history, living with sight loss was often compounded by living with other health condition(s) either short or long term. Poor hearing was noted alongside a wide range of ailments that could be more or less debilitating. The most common conditions mentioned were those related to mobility (e.g. arthritis), heart or circulatory illness, diabetes or thyroid. Four participants had had strokes and two had vascular dementia. Almost a quarter of the participants had a form of arthritis or rheumatic condition that affected their mobility.

Some of these conditions were limiting especially in terms of going out – for example a man with serious prostate problems was more restricted by this than his sight loss. Other participants were wheelchair users or needed a walker inside and/or outside the house.

When asked how they would assess their health in general, the response was relatively positive. Figure 2 below shows as a pie chart the self-assessed health of 40 participants: very good 7; good 11; good-fair 3; fair 8; fair-poor 2; poor 3; poor-very poor 3; very poor 3.



vg ■ good ■ gd-fr ■ fair ■ fa-pr ■ pr ■ pr-vr ■ v pr
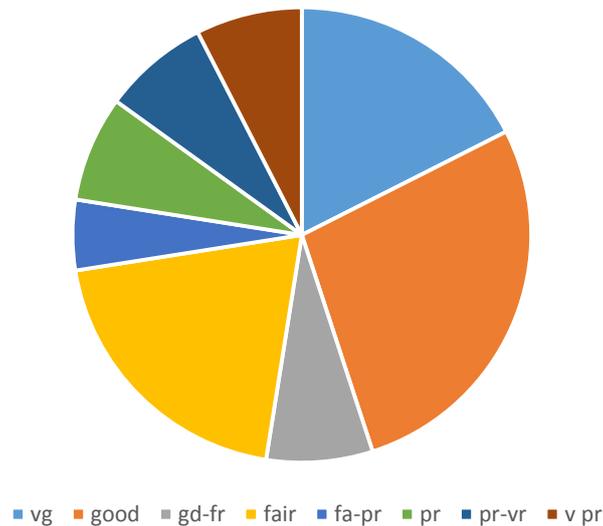
Figure 2: Self-reported health status.

Not surprisingly, the older participants graded their health as poorer, although there were some notable exceptions.

# Housing, living arrangements and creating an enabling environment

Most participants lived alone, with the next largest group living with their spouse and a smaller number having other living arrangements.



alone ▪ spouse ▪ spouse + child ▪ child ▪ sibling ▪ other
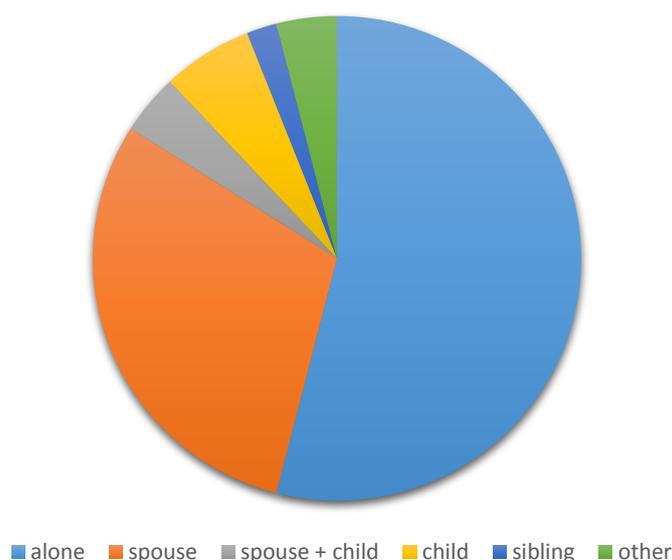
Figure 3: Co-residence arrangements

Figure 3 above shows the breakdown of living arrangements with 54% living alone; 30% with their spouse; 4% with spouse and adult child(ren); 6% with adult children but no spouse; 2% with a sibling; and 4% with other family or a friend.

The housing profile for these participants very broadly reflects that of the general older population as at the 2011 Census, with some variation, partly reflecting local conditions and the nature of the sample (not selected for housing characteristics). A large majority (34) were owner–occupiers, with just three still having a mortgage or having re-mortgaged. Figure 4 below shows as a pie chart the breakdown of tenure among the participants, with 68% owner-occupiers; 14% social

renters and 2% renting privately; 8% living in accommodation owned by othe family members. The remainder were uncertain or not disclosed.



owner-occupiers ■ social rent ■ private rent ■ rent ■ family ■ ?
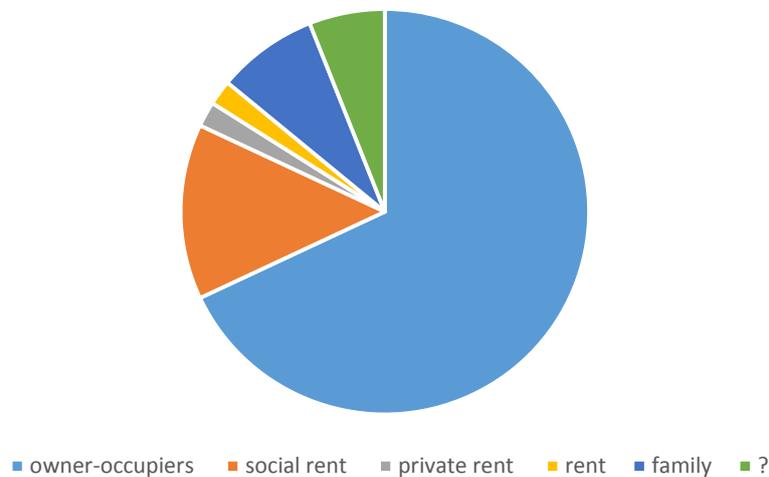
Figure 4: Housing tenure of participants

They were living in a range of housing types, from large houses with multiple rooms, to flats with a single bedroom. Most lived in houses (the majority in terraced housing or semi-detached, with just two living in detached housing); nine lived in flats (including retirement flats); and seven lived in bungalows.

The length of time that people had lived in their current residences varied from 1 month to 60 years or more. Most participants (64%) had lived in their present home for over 20 years. Figure 5 below shows a breakdown of the length of residence: 14% for over 50 years; 16% over 40 years; 18% over 30 years and 16% over 20 years. A further 12% had lived in the same house for over 10 years and 19% between 1 and 10 years. Just 5% had moved within the previous year. These long residences are probably related to the high level of owner-occupation, and have an influence on participant's sense of familiarity and attachment to their home.

50+ ■ 40+ ■ 30+ ■ 20+ ■ 10+ ■ 1+ ■ under a year
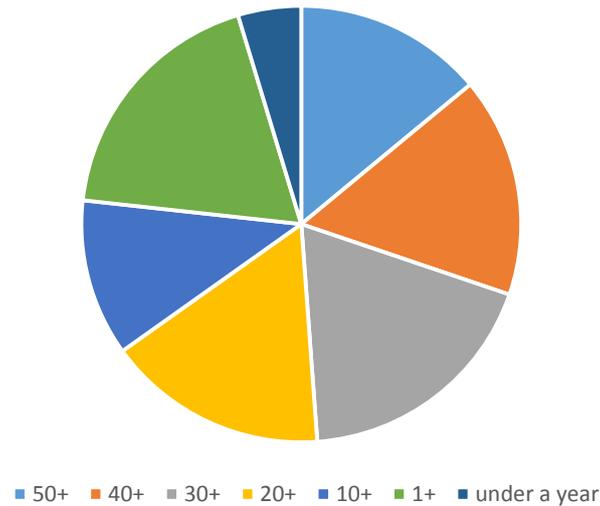
Figure 5: Length of current residence

Participants' housing histories varied considerably. For most it was previous life events that had led them to living where they still lived now, generating the motivation to remain in the same home and place.

The original motivations to move to their current accommodation included marital issues (marriage, divorce, separation); moving for work and to accommodate children or on retirement. For several participants this led to a desire to stay put if they could, but in some cases participants acknowledged that this was only viable because of their mutual support with their spouse or with other family members.

Participants differed in their preference for type of home - for some it was the nature of the accommodation and/or whether the dwelling itself suited their physical health and mobility; for others it was about the ability to buy a property, or downsize. Many cited 'location' as central, for example some Muslim male participants identified proximity to their mosque as important. Many participants cited convenience (bus routes, local schools), and physical beauty and quietness. One participant who

had moved into supported housing three years previously had done so for security (moving from an end-terrace house which had been vandalised by local children).

Yet life changes had influenced some participants' decisions to move rather than stay put, with motivations including retirement, and to maintain their autonomy and independence from family in later life. For the minority of participants who had relocated relatively recently, the motivation for choosing their current residence related to their need for care. This had meant moving in with, or close to, family members (especially daughters) avoiding the need for more formal care.

Participants were asked whether they had thought about their future housing needs, and the possibility of living somewhere else. Several participants said that they had not really thought about this or had decided not to worry about it, but most had given some consideration to this issue even though they weren't actively looking to move yet. The possible alternatives included moving to a bungalow or small flat; moving into sheltered housing, extra care or residential care; or moving to be closer to family. However, in most cases these options had either been rejected for various reasons (including unsuitability and costs) or suppressed until 'when really needed and not before'.

Many participants had thought about it, and rejected it.

'I hope and pray that I never have to go into a home – I know a very nice home,…I've been in there for respite a couple of times when my family had booked holidays…but its £800 or £900 a week and I have no property to sell.  I can't afford that. And there's no way the council are going to pay that sort of money.  And that's the only place I'd really want to go, so I'm hoping I can manage…..' *(Barbara from the Midlands)[2]*

The idea of a bungalow (to avoid stairs) or small flat (e.g. to avoid sleeping downstairs) was very much more attractive because of the perceived greater independence and potential space for visiting family and friends compared to age-related housing. For a small number of participants, ideally they would prefer to move to larger accommodation to gain an extra room or more space for visiting family:

'I mean it's silly to say this when my sight's gone, but I regret now that I didn't buy a three bedroom house…Because when my children come I would have more space. But when I bought that house I thought the two bedroom house is quite big…but if I had a three bedroom, you know, I'd have my children more' (anonymous)

However, most participants thought that even though they didn't want to move (and some said that they would never do so) they could envisage circumstances where they would have to, either because of declining health or because their spouse died affecting their support system. In one case, in addition, a husband and wife renting a house from a local authority were very worried that if one of them died, the other would be required to move out because of the 'bedroom tax'. Notably no

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[2] Participants elected to be known by their full names, or partly or fully anonymised

participant talked about the potential social aspects of living in sheltered/extra care housing as a positive 'pull' factor, emphasising instead their desire for independence and family ties.

## Adaptations to the accommodation

Most participants reported that their home was adequately comfortable or very comfortable. In response to our question 'whether they had made any alterations or adaptations to their current accommodation to make it more suitable for the vision impairment', they described three kinds of alterations or improvements. In many cases people had undertaken more than one kind of adaptation, not necessarily at the same time.

The first group of adaptations comprised the kind of changes that householders undertake from time to time to make their home more comfortable, or more spacious, or more modern. This includes the refitting of kitchens and bathrooms to refresh them, rather than to install assistive aspects; knocking rooms through or building conservatories to increase space; renewing windows and doors and installing solar panels. While participants did not identify these improvements as relating to their sight, they nevertheless contributed to their general well-being and feeling of homeliness and control.

The second group of adaptations were attributed to physical impairments or 'ageing' generally: sometimes for the participant's own benefit, either now or thinking ahead to potential future needs; and sometimes for the benefit of their partner or a previous resident. Frank Norman talked about a number of changes made to their house to enable his late wife to be discharged from hospital:

FN: '[Occupational Therapist] suggested putting a rail up there, she said if my wife was going to be discharged…She put a grab rail by the bath. There was a handle at the top of the stairs, on the landing there, so when you got towards the top you've got something to hold onto to pull you up. What else did they do? Oh they put a half step outside the front door…Also the chappie and his assistant, they, all these thresholds on it between rooms, all wood, and they had a sharp edge, so they chamfered off the edges on all the doors, so that she wouldn't trip over them'.

Interviewer: 'So a lot of those things have been useful for you?'

FN: 'Well they have been yes, but they weren't done for me, they were done for my wife'

These kinds of adaptations included stair lifts, indoor rails particularly upstairs, ramps to front and rear doors, higher WC pans to assist sitting and rising, and bath and shower arrangements adapted to help with mobility difficulties. For some participants their own mobility and other health issues were more significant than their sight problems in limiting their activities, therefore requiring adaptations in the home.

The third group were adaptations undertaken specifically for vision problems (or, in the case of one totally blind participant, for their partner's vision impairment). These included the installation of wet rooms and shower rooms, especially downstairs; and indoor and outdoor guide rails. Some participants described kitchen improvements such as better lighting, colour contrasts, and installing window blinds to reduce dazzle.

Gaining advice about possible adaptions was hard to access and coupled with long waiting times for occupational therapy assessments or issues concerning funding. In a few cases, the local authority had funded adaptations, but more often they were self-funded or in some cases by a local sight loss charity. One participant described funding her own wet room after an OT decided she did not qualify for one. Another family converted an integral garage into a multi-purpose room so that the older person with vision and mobility problems would not have to go upstairs.

Many participants had adaptations on their 'wish list'. One hoped to convert a downstairs office to a bedroom (though she had not yet discussed this with her resident child); others expressed an interest in getting a wet room / shower room or a downstairs WC installed.

## Use of assistive technology

In contrast to participants' apparent difficulties in locating the appropriate statutory organisation to assess their homes for adaptations, most interviewees were well versed about the latest types of aids and assistive technology available varying in sophistication and complexity. In many cases relatives or friends had scoured the internet looking for devices and priced them; sometimes participants had done this themselves or asked local vision organisations for advice. The most commonly used assistive devices were, in order of prevalence: various magnifiers (often several, in different rooms, and for image enhancement reader devices including Optelec); liquid level indicators; various labels and markers on domestic equipment; dedicated/ specialised lighting; talking clocks; talking watches and computers. Several also used personal alarms and one with poor hearing a vibrating pillow fire alarm. It is worth remembering that this analysis relies on

participants' recall during interview, and they may have forgotten other devices.

Among participants using a computer, a few had special large character keyboards, and several regularly used specialist computer software which included proprietary speech outputs - Supernova, Sonata, Calibre, DAISY, Skype and Guide (Dolphin). In addition, 'everyday' technologies were used by some participants for dealing with their vision impairment. For example - pre-set numbers on mobile phones; tape recorder; LED torches. Several participants used the PenFriend, an audio labeller, to have the cooking instructions on purchases recorded by shop assistants. However, some participants described how either they had tried various devices and given up on them, or else had found them to become less useful as their vision deteriorated. One person described how she did not use talking devices because she did not like synthetic voices. One participant had become unable to use most devices after developing dementia.

Beyond these commonly used technologies, there were others used by fewer people. One person used a braille clock and watch and made her own braille diaries. 'Talking' devices and services included talking books/news (one using Gujerati services); microwave ovens; and talking phones, keyboards, calculators and kitchen scales. However, some participants also had hearing problems, so for them talking technologies were not (or were no longer) useful. Instead they tended to use alternatives such as big number phones and clocks, alongside hearing aids. Smart Phones also enabled enlargement of images on the go, whether or not participants had hearing problems. Individual participants

reported also using simpler kinds of aids, such as a signature guide or a monocular, and some used coloured over-glasses.

The prevalence and type of devices at all levels is linked to accessibility through information sharing and communication. When some participants were initially diagnosed with a specific sight condition they could be referred to a local group for vision impairment, a low vision centre or specific worker – the Eye Clinic Liaison Officer (ECLOs) or Independent Living Co-ordinator (ILCOs). Other participants made these contacts themselves in which case they needed to be more assertive.

Knowing who to contact and gain advice from in relation to housing adaptations or useful devices needs to be on-going in later life. Links between statutory services, ECLOs, ILCOs, local vision organisations and OTs are important especially when people have different abilities, contacts and resources.

## Coping with activities of daily living and spending the day at home

 'Home is where you're happy and content, and you're proud to bring your family and friends to […] Yeah, you're proud to bring your family and friends into your home, and make them comfortable, so they're comfortable and they enjoy the environment' (Lyn B from Hatfield).

When asked about the meaning of home, many participants replied along the lines of somewhere that you felt secure, somewhere that you could retreat to, or somewhere where you could do what you liked: some characterised home as a place where you knew where everything was,

in contrast to experiences outside the house. Many participants spent much of their day at home alongside specific trips in the community. Most felt safe within their homes although some were worried about the possibility of falling or tripping. This concern impacted on how they spent their days at home to which we now turn.

People described their activities of daily living (ADLs). How active they were related to their level of mobility, their vision, their feelings of well-being and how support was provided.

Most participants were able to get in and out of chairs, wash themselves, put themselves to bed and go to the toilet. A small number (n=6) needed support to get in and out of bed and could not carry out basic washing or showering, or needed help at particular times:

'At night wife has to help me to go to the toilet' (Hindu man in Coventry).

In some cases participants could undertake their personal care, but had serious mobility difficulties (including getting around the house). They had mobility aids such as a stair lift plus wheelchairs / walking sticks / walkers placed strategically.

For some participants getting in and out of baths had become a source of anxiety and difficulty. A few had replaced their baths with showers. Additionally several had installed a downstairs shower room and toilet. Other wanted to, but found the cost prohibitive.

Getting dressed posed difficulties for a number of participants. Several talked about choosing clothes and being unsure of whether they were clean and matching. Some had devised strategies for ensuring that they wore appropriate combinations such as the couple of respondents who said that they only bought particular colours or styles.

A majority of participants could move around their homes with little difficulty, mostly because they were very familiar with the layout. A few participants acknowledged that they did occasionally have problems: the wife of Peter from East Anglia said:

'Everyone with eyesight problems gets lost even in their own home'

Participants described their primary activities at home as sitting in their gardens, or listening to the radio, talking books or the television. Many people sat in the same chair in their living room. They had memorised how to get to and from this chair, and to, for example the bathroom, the kitchen or the 'reading' machine. If someone moved an object, this could throw the VI person into great disarray and create a sense of great insecurity.

Most women participants prided themselves on continuing to keep their homes clean.  Some emphasised the importance of retaining control of all or some tasks:

'Can load and unload dishwasher - knows where things go - doesn't want other people doing and putting things in wrong place' (Mary from Oxfordshire fieldnote).

A number had employed paid cleaners and others had delegated tasks to spouses and children.

However, eating and cooking both posed challenges – Amy from the Midlands said 'you can't see if it is cooked or not'; several others spoke about sometimes piling food on to their plate, rather than spreading it around; one talked about eating a pot of butter thinking it was cheese, and others described putting inedible things into their mouths. Many participants who lived alone had changed their eating habits as their eyesight worsened, some had completely stopped preparing food,

buying ready-made meals to either prepare themselves or by relatives or carers.

A number of men spoke about eating out as much as possible even where they had cooked previously. Cooking a meal posed a number of challenges and participants varied from preparing their meals from scratch, to buying ready-made dinners from Marks & Spencer and elsewhere.  Many employed different aids to support them with cooking from strip lights over the hob; to raised nobs on their cookers / microwaves indicating temperatures on heating dials to talking microwaves, and almost all used liquid level indicators. The husband of one prospective participant commented:

'She is keen to talk about technology that helps her, she has got talking kitchen scales, a talking measuring jug, a talking alarm clock and a talking calculator. She has also devices to tell her when her cup is full, and when a pan is boiling' (anonymous)

In contrast to instrumental tasks when talking about activities as pastimes several of the women had previously been very keen on handiwork (e.g. making greetings cards, crocheting, knitting, pottery, porcelain dolls (see above)) as well as pursuits such as jigsaws or gardening and for them VI brought a great sense of loss. This had led them to do other things. For many people, talking books and listening to different radio programmes were an enjoyment while other people found themselves going out more:

'Talking books are my lifeline, (and the radio). I don't know what I'd do without them.' (Daphne Palmer from Coventry).

'I listen to the radio very much in my spare time.  I love the radio, because I'm very sport orientated and (so) there's a lot of sport on the

radio.' (Peter from East Anglia).

Looking at everyday tasks suggests that people with family carers are interdependent with them but those living alone need the support of others. Participants from minority ethnic groups were less likely to go out but were more likely to have family members carrying out their everyday tasks.

## Getting out and about

Going outside the house can be a much more challenging experience than moving around your own home. However, most participants did venture out regularly though some went only with company.

As the participants in this study were almost exclusively accessed through vision impairment groups, they were more likely to attend some regular meetings specifically for people with VI. A number of people went out frequently, at least five times a week, to shop or attend a range of meetings and many participants even in their high nineties ensured that they often went out even if it meant taking taxis or asking friends for lifts.

In contrast others, particularly participants from minority ethnic groups went out rarely except to undertake essential tasks such as shopping or attending medical appointments; their primary social activities outside the house were to attend religious services or to attend meetings of their VI groups. But there were exceptions and Mr. Jamail from Coventry explained his regular activities:

Interviewer: 'Do you get out and about at all; do you go out at all'?

M: 'I go out on my own some days of the week. Like Friday I go to the

mosque, other days I just go out to the city centre and back again. I go to the gym for the cardiac exercises once a week, so I do get out and move about'.

[…..]

F: 'Sometimes he goes and sits in the library' (wife)

Interviewer: 'And how do you go when you go?'

M: 'I use the bus generally'

Interviewer: 'Have you got a bus near here?'

M: Yes, just one you get out of this place where the properties are, and just on the main road you can get a bus."

## A vision friendly environment

Whether accompanied or unaccompanied, going outdoors and walking in the wider community could be problematic and may require using a stick. Nine participants used ordinary walking sticks whilst eighteen used white sticks. The type of stick used was a subject for debate, the short white stick (18 people) which supported them when walking or the folding 'symbol cane' (9 people). The 'symbol cane' is used additionally to alert others to the loss of vision and users need to have training:

'The sight impairment team at the hospital put me in touch with the people who issue all this equipment.  I asked for training for the long cane… and she explained to me how it works – I was taught how to use it and not to swish it around. I haven't resorted to using it yet, but I wanted to get an idea of what it was like whilst I'd still had some eyesight to judge what she was saying.' (Edward from Warwickshire).

Other participants may have had a white stick - either long or short – but not always wish to use it.

Local journeys on foot posed considerable challenges for participants – narrow pedestrian walkways could be particularly disabling. Pavements may not exist on some stretches of road, or be wide enough for easy passing. Indeed, for many the state of local pavements was a cause for considerable alarm. The following three quotes are typical of urban environments:

'It can be a little bit frightening. And pavements I find a great problem because they are uneven and I fall if I'm not careful.' (Shirley from Herts).

'The pavements are vile but I get by… the paving slabs are all crap; the council say they have no money to do repairs' (Arthur Mathieson from Coventry).

'Some pavements are not okay because at times (it's hard to judge) the level of the pavement' (Raymond from Liverpool).

The local environment could be more or less enabling. Disability Discrimination legislation from 1995 onwards has led to greater accessibility and visibility in public spaces through paving markers and zebra crossing timers to control traffic flow. Yet, several participants were unaware of these and they were not common throughout the research locations. In Warwickshire participants were particularly worried about the removal of pedestrian crossings to create shared spaces (see Coventry Telegraph,2013)

The scarcity of public toilets deterred some older people from getting out and about. No audible signage in relation to public toilets for people who are vision impaired was noted. Some participants spoke about difficulties in relation to unfamiliar surroundings. For example, with a toilet - finding out where the flush was, how to lock the door, or to familiarize themselves with washing facilities.

Through future development of assistive technology and accessible street design people with VI could feel more integrated in their local community. Such facilities would also be a part of inclusive design for all.

Nevertheless, in order to preserve their independence, many participants persevered in navigating their local areas. Managing to go out alone indicated a determination for independence; to do this participants memorised specific routes and navigable pedestrian crossings. Local shops with familiar and helpful staff were particularly important as were access to a seat and staff prepared to fetch or deliver. Other than going to the shops, many respondents often met friends or attended clubs. Some of these were VI groups but more frequently were local groups which they attended regularly. Some people had found their religious faith can keep them part of the community alongside a determination to stay active.

Some participants relied on neighbours as guides and three participants all living in rural areas, currently had a trained guide dog. However, one participant spoke about the hurdles to pass the vetting system from the Guide dogs for the Blind :

'I tell you it's a real challenge for anybody who's got sight problems to actually get through their system… you have to come up to a certain

level of competence, intelligence I guess, to actually manage a dog like this' (Peter from East Anglia).

Public transport, especially a local bus service, is essential. Even in more urban areas, participants bemoaned the paucity of bus services, and the fact that many did not run at night. Even when they do operate how do you know when the bus is on its way? And when it does arrive how do you gain access? Although a few participants knew about the bus 'Hailer' – only one person used it. Again there is a need for audible signage, somewhere comfortable to wait and support from transport staff.

One participant has been actively lobbying the council over bus shelters:

'They've got an older shopping area called the [     ]. So they're pulling that down, rebuilding the whole area, but they haven't considered buses. Because that's the stopping place for buses to turn round and go back down into town.  So there are seven routes, and the shelter they've got at the moment is a covered shelter where people can sit inside out of the rain.  The proposal is cantilevered ones where there's no seats or no covering from the rain and so on' (anonymous)

Because of these issues, being informed and receiving communications via organisations can be vital so that participation in social relations is maintained. The local mini-bus that comes and fetches people; the coach trips that take people on regular outings, the personal assistants that may be able to take individuals out have all been recognised by participants in this study. They are all part of a 'vision-friendly community' yet one participant noted many people are denied the

opportunity to continue with previous activities leading to social isolation and loneliness. Some activities need a facilitator:

'I would like more of a social life beyond meetings – especially walking and swimming which I can't do solo' (anonymous)

In contrast, Mary from Oxfordshire regularly participated in a rowing club which included people with a wide range of abilities.

# Support - informal and formal

For people with vision impairment community living can depend on different levels of support discussed here as 'informal' and' formal'.

## Informal support

Participants varied considerably in terms of the quantity or quality of family or neighbourly support that they received. Unsurprisingly, those who lived with family reported the greatest degree of informal support, especially from their partner (n=15), with many couples being mutually supportive where both had some degree of health difficulty.

Other than four, all of those interviewed had children and a majority living nearby, including step-children, who provided some degree of support. Unsurprisingly, those living closest or in the same house generally provided greater support than those who lived further away. Some respondents had moved specifically to be closer to their children especially when widowed; in these cases they often felt extremely well supported.  In contrast, moving could be detrimental - in order to get a council bungalow a respondent had to move far away from her daughter:

'You see, what's happened where I live now, I'm away from where my daughter is, and I feel very lonely, it's a terrible feeling' (Amy from the Midlands)

Adult daughters were perceived to provide more everyday support than adult sons:

'Daughters will be in touch with you all the time. If I rang my son, could you come and help me to do so and so, he would come. But he doesn't ring up and say how are you fixed, Dad, are you doing so and so all right? Boys don't think about that' (Edward from Warwickshire).

For example help with paperwork and shopping were the forms of support mentioned most often. In many cases children helped specifically with this task. Paperwork was one area in which participants living alone often had help, although quite a number spoke about transferring all financial accounts to direct debit. Participants generally were philosophical about their inability to do paperwork, and although some regretted ceding control, this was far less of a loss, especially to the women, than having to give up housework or cooking.

Several also mentioned a regular arrangement of weekly meals at the adult child's house.

'I go to my daughter's for Sunday dinner, just that once, and then when I come back I've got another dinner for Monday – I have to warm it up; she gives me some just for the Monday'. (James, aged 99 years from the Midlands).

Participants from BAME backgrounds were more likely to receive or attend meals cooked by adult children (almost always daughters and daughters-in-law) than participants from White British backgrounds.

Where there was relatively little contact with local children, respondents often felt the need to explain this. Several also spoke about children who were divorced or separated from their partners and said they did not want to aggravate what was already a fraught life for their children. Most respondents acknowledged the competing demands on their children's lives and did not want to be a burden:

'It's me having to walk. I have to go through the garage because she's got a big step at the front door. And I thought I'm giving them too much bother to watch me every step, and that's why when she said, 'Mum, what about coming to my house for dinner tomorrow', I say, 'no thank you'. It's because I don't want them to have to look after me… when you were very independent you never can change'. (Eda from Wolverhampton).

A few participants were estranged from their adult children or their children had died, and some lived far away from their children and had little contact.

Informal support beyond the family came, in one case, from the warden in a participant's housing association, but mostly from neighbours or local friends who took respondents shopping or met them for meals in local cafes (especially in smaller villages or suburbs). For some participants, particularly, but not exclusively those from BAME, places of worship provided community and support. Others were active in a variety of local organisations which provided them with company, informal support and a sense of worth. However, for many respondents, their personal social network was diminishing as they found it more difficult to get out of the house and as friends themselves became physically and mentally frailer, or died.

However, shared care was also an option where family members lived at a distance. One daughter (Joan, 37 years old) living in Milton Keynes made weekend visits to her father who lived in Shropshire and stayed a couple of days. At 93 years, he had been a long term carer for his wife who died three years previously. He had driven until aged 90 years but had developed wet AMD and having fallen a number of times at home ending up in hospital and now with shared care between agency staff and his two daughters. The informal and formal carers all do different things, e.g. shopping is done in Milton Keynes because there is an M&S and he likes the meals. But while, as seen above, some neighbours do get involved she made this comment about being distant and local contact:

'He has a visit from a Health Service ECLO and some support for machinery but the one thing missing is a neighbour.  There is no-one who would pop in. They are friendly but would only do emergencies. It's very disappointing. If he could ring up and say can you pop in but they are not willing to get involved.'

Also, there are levels of formality. This gentleman was happy to have a TPT volunteer who would read to him and whom he could help with his cross-word but he did not want a woman living up the road to have the number to the key safe so she could come into the house. He said 'it could be anybody'.

## Formal support

Establishing how people initially found out about the formal support services they used was difficult as many participants could not remember. Relatively few recalled receiving home assessments from Occupational Therapists related to their vision loss at, or after,

diagnosis. A few did remember visits by social workers / care managers. A minority had home carers visiting daily helping them with personal care which were arranged through social services or independently. Several paid for cleaning services and/or help in the garden, from weekly to twice a year, depending on their needs and priorities.

Many respondents were connected to organisations which provided support for specific types of vision impairment such as The Macular Society which focuses on a particular condition. The nature of this support varied, from advice to attending regular local support groups to hear talks from external speakers. For some respondents attending these meetings posed difficulties in terms of transport, with either practical or cost problems; but for many this was a lifeline and transport was organised through the members. Meetings often addressed a particular issue with an appropriate professional attending to provide advice and information. Most respondents were in touch with more than one organisation supporting people with VI and some attended specialist centres such as those whose work is outlined in Appendix C alongside other issues identified by professionals and volunteers working in the area of VI.

Generic vision impairment organisations (such as the Blind Veterans UK, Action for Blind People, RNIB, and local sight-loss groups) provided similar support as well as additional help such as holidays, trips to local attractions and meals out. Several respondents saw the RNIB as geared towards the 'posher people'. Yet most used them for telephone support or advice with regard to equipment and, in many cases, used their talking books services which many described as reducing their loneliness.  However, changes in how these were delivered (i.e. USB sticks for computers as opposed to cassettes) impacted on their

perceived competence, and caused concern.  RNIB also facilitated informal support amongst people with VI - for example one participant enjoyed a mutual support network:

'Talk and Support' telephone connection: The RNIB connect six of us together on the phone every Thursday morning' (Marie Freeman).

In general the very many local VI groups were perceived as supportive, informative and helpful. However, people from minority ethnic groups tended only to attend those specifically geared to their own communities; even though these organisations did liaise regularly with local and national statutory and VI services. One BAME organisation had arranged for stair rails to be installed for two participants.

Where participants were not recruited through organisational networks they could feel very isolated as their contacts were limited to GPs and hospital clinics rather than support groups. These participants did not know how or who to challenge about changes in treatment for Macular degeneration. Other participants particularly from BAME groups were also unaware of the existence of organisations providing support for their specific sight impairment, although their pressure groups – as seen in Coventry and Liverpool - would invite people from national groups ( e.g. RNIB and Action for Blind People) and manufacturers to give talks and demonstrate products. In contrast to these experiences, a couple of participants who had previously been very active in running national or local branches of local vision impairment organisations were now critical of their services and had sought other avenues of support.

This picture of the everyday life of older participants with VI indicates the interdependency of social, material and psychological factors and forms a basis for addressing how people maintain their personal identity.

# Present experience and looking forwards

In terms of their self-rated current Quality of Life (QoL), participants' experience ranged from very good ('the most content I've ever been') to poor, with most people describing their current QoL as good or fair / adequate. Participants stating very good or good quality of life tended also to report very good or good health. The very few describing their QoL as poor were either in very poor health in addition to their sight loss, or were financially poor, and living alone: they expressed feelings of loneliness, 'uselessness', and needing more support. These participants gave very negative accounts of their lives, emphasising their loss of control and independence.

Asked whether they got anxious or low spirited, many participants reported some degree of low mood, but most emphasised that it was periodic and that they worked hard to not dwell on their difficulties. For example, one person said 'from time to time I get very depressed and have a little weep. And then I pick myself up' (anonymous).

Participants were offered a choice of ways to describe the amount of control they felt they had over their lives: 'as much control over your daily life as you want, adequate control, some control, no control over your daily life'. Most chose 'adequate' or 'some' with only a few choosing 'complete'. In comments, several participants described their sense of control as good, given the limitations of what they could do and their occasional frustration at being unable to do things independently. Some were very aware that their current high level of control was dependent on factors which might change, such as the death of their partner or if their partner became unable to drive or carry out other tasks. Elizabeth from Suffolk said:

'As [husband] is there I have quite a lot of control, but if he weren't there I'd have no control. I wouldn't be able to run my computer system.  I wouldn't be able to look up telephone numbers. […] It wouldn't work without him.'

A greater personal experience of loss is seen in comments by one of the very few participants who was very despondent. She said:

'I haven't got that much control…Because it's a very bad thing to lose, it's a terrible thing to lose your sight isn't it? I mean it's a terrible thing to see blank all the time isn't it. Terrible' (anonymous).

Participants were asked about what gave them pleasure now, and about activities that used to give them pleasure in the past but which their sight impairment now prevented. Being able to get out of the house, both to see friends and family and to go on excursions to particular places was very important for most people in their current lives, and where these trips had become less frequent than they would want, they were missed. Some participants still enjoyed trips to the theatre with friends despite not being able to see the stage and a small number attended audio-described sessions at local cinemas and museums. These trips mostly relied on lifts in cars from friends or partners rather than public transport. For those participants who had been drivers, loss of the freedom and pleasure of driving was a regret:

'How important is your independence? Oh gosh, you can't say how important it is. That's been the hardest thing, is having to give up driving a year ago'. (Shirley from Herts).

Those participants who had partners or family members living with them often emphasised the crucial role that these people played in helping them to maintain their quality of life and take part in activities that gave

them pleasure, and some also described their great pleasure in these close relationships for their own sake: As this participant said about life with her husband:

'We're very compatible with each other. And just sitting in those chairs sometimes reading the paper and not saying anything, we both enjoy doing puzzles…No, we have a good sense of humor with each other. And as I said earlier the pleasure is that we try and do things that both of us enjoy '(anonymous)

Some participants stressed the emotional support they received from family members at a distance, sometimes in the absence of practical support. For example Lyn B said of one of her sons:

'He's just my brick, he really is. He's the most wonderful person. He's a really lovely guy […]  he's very much a part of my life, and we're on the phone to each other every second day. He's an absolutely wonderful son to have, and I wish everybody had the same experience'

Curently, only three participants had guide dogs (three), but those that did felt that their dog added hugely to their quality of life and autonomy. For example:

'It's brilliant because she's a dog - she needs to go out; she needs to be exercised.  And so always we're out and about and independently, which to me is very valuable and gives you the confidence to go out and do more things' (Mary from Oxfordshire)

Another pleasurable activity which was often missed was the ability to read, and several participants did not find talking books an adequate substitute for them (for example because of hearing problems, or a dislike of 'artificial voices'). Hobbies such as gardening, crafts and

sewing were also often mentioned as past pleasures now denied. One participant spoke about loving to do jigsaw puzzles and how her husband had spent a lot of time on the internet tracking down jigsaws with big pieces that she could try to put together. It was a great joy to her that he had found these.

Several participants had become active volunteers with vision impairment charities and other voluntary organisations, and reported that these contacts and activities gave them great satisfaction and provided structure and meaning for their lives now.

When asked to describe what would make their lives easier, many immediately replied that regaining their vision, or a greater degree of it, would be the true answer, but other more tractable things included specific aids and adaptions, such as downstairs toilets or shower rooms, and, again, the ability to get out of the house more often.

These findings are consistent with those of previous investigations of what underpins well-being - for example the Nyman et al (2012) meta-synthesis findings regarding acceptance and positive attitude along with social support from family, friends, and peers is reflected in the resilience of participants in this study. Likewise our findings regarding what support participants value and want to maintain or improve are reflected in the findings of the TPT report from over a decade ago: 'The housing and support needs of people with vision impairments' which also found that family members gave much practical support, but that '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' (Hanson et al, 2002 p7).

These are essential elements in helping people with vision impairments

to remain living in the places they value and to which they are socially connected. While recognizing that should their support systems fail, sheltered housing or residential care might become a necessity, for the participants in this study their strong preference for future support was for practical support to remain in place – i.e. both in their own home, and within the wider community.

# Conclusions

In this research fifty older people living with VI and some family members addressed the experience of going through the physical and emotional transition of sight loss, which for many people occurs across the last forty years of life and may be either gradual or accelerated. Only three people had been vision impaired since birth or from early childhood. The participants included the 'oldest old' aged in their high eighties and nineties; and older people from Black and Asian Minority Ethnic groups, whose voices are rarely heard. For all participants it permitted an in-depth view of what it is like to try to maintain personal autonomy when circumstances may undermine your ability and there were some similarities with the wider literature especially in relation to housing needs and social relationships. Interviews with those who work alongside older people show how complex the service  system can be but also the value of local and national organisations for people with VI.

The aim was to consider where and with what kinds of support they would like to live, acknowledging that this would need them to draw upon issues of choice and control that would impact on their personal identity, often through recognised risk-taking.

The research team's experience of studying the needs and aspirations of older people with high support needs[3] - some with dual sensory loss - underpinned this study (Appendix A; Katz et al, 2011). Here the post-analysis model from the earlier study for the Joseph Rowntree Foundation (JRF) (see Appendix B) is reconsidered to see whether there

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[3] In earlier research the participants with high support needs were identified by professionals. In this research people were accessed mainly through VI organisations that they had contacted indicating an element of initiative.

are comparable similarities and differences in terms of the issues that were valued by people and those that hindered or helped them. These were seen as social, physical and psychological factors and comparison is made between older people identified as having high support needs, and current participants identified primarily with vision impairments while addressing issues of cultural differences.

## Social factors

Not wanting to impose on others was a central concern for the research respondents with high support needs (Katz et al, 2011 p.7) alongside the value of reciprocity in relationships, and being able to make a contribution themselves whilst valuing social interaction with others. In this study, the balance of control within interdependent relationships was slightly different. Shared care including spouses or family members can lead the older person with VI to delegate autonomy in certain situations and contexts. If the person with VI wanted to stay in their own home supportive relationships – informal or formal – were essential, and this was especially true of those from BAME groups.

In the JRF study, getting to meet new people was especially important for many with high support needs. Their lack of association with other people was also common to some of those involved in this study, emphasising the importance of voluntary groups for people with VI, particularly for people who may be isolated or lonely. These groups were also essential for informing people about new equipment and advocating on their behalf, especially where service delivery was confusing – and this was more applicable in some locations than others.

## Physical factors

In both the JRF findings and this study participants experienced co-morbidities, but the association of health problems with sight loss may be experienced differently. There are similarities in patterns of coping, yet in examining activities of daily living in detail it is clear how demanding it can be for people with VI to learn new skills and benefit from technological support. There was an acceptance of interdependency with others which participants from both studies shared: a combination of individual assertiveness alongside practical, social and environmental support was essential.

Ways of living inside and outside the home indicated the importance of mobility, accessibility, routine and orientation for older people with VI. A majority of participants wished to stay in their own homes, with an acceptance of more limited routines, some adaptation to maintain continuity, and support from others - especially by those in the BAME groups. This had also been reported by people with dual sensory loss in the JRF study.

Some participants recognised that they would probably need to move at some stage, probably if their house became too big to manage or there was further deterioration in their sight. Bungalows and sheltered housing complexes were the options that most people considered, while few participants preferred a care home.

## Psychological factors

There were many similarities between the JRF study and this research regarding the maintenance of psychological well-being, but the onset of

VI does mean an acceptance of sight loss as part of personal identity, which was a particular challenge for many. While people were no longer able to take part in some of the pleasurable activities they had cherished, and knowing their own limitations, they did adopt 'responsible risk-taking' to maximize their independence as far as possible. This form of resilience and self-determination was a common denominator in both pieces of research. In this study, the onset of VI had challenged personal identity, but most participants had incorporated VI as part of their identity and accepted it, along with, in due course, their ageing. If this meant a level of responsible risk, so be it to retain their sense of self and maximize their independence.

While these three factors are important for all participants some differences do exist for the BAME participants. They were less likely to to know the nature of their eye condition or what could be done to help them medically and how to access services. They had a greater sense of living in a time of 'austerity' and they were less likely to have up to date technological devices. Nevertheless, all participants demonstrated a combination of individual assertiveness, practical, social and environmental support, learning new skills, accepting interdependency, and learning to benefit from technology. Access to appropriate services depends on where people live and individual drive; staying in their own homes is often key to their well-being.

# Appendix A – Methodological development

In developing an in-depth qualitative research study there were a number of stages in methodological development: establishing an advisory group, developing new skills, ethical approval, questionnaire design, gaining access, recruiting a purposive sample; location (macro / micro), piloting/interviews, analysis.

## Working with an advisory group

An advisory group was set up at the beginning of the project to benefit from the expertise of people with vision impairment; key stakeholders with skills concerning housing issues and later life from AgeUK, Care & Repair and the Centre for Policy on Ageing, and members of TPT's research management. This was especially important as the research team had not worked solely with older people with vision impairment before. The group met three times during the project: October 2014, March 2015 and September 2015.

All discussions were tape-recorded and minuted. Issues raised concerned: focus, location and reach, the range of organizations for people with vision impairment and key contacts, reaching BAME people, communication and the need for special training, ethical issues, and dissemination. It was agreed that this research would be based in England and begin by focusing on locations within a 50 mile radius of Milton Keynes where The Open University has its central campus. At a

later stage boundaries were extended.

## Networking for access to participants

Given the limited time for fieldwork in a 12 month study period, participants were not accessed through the NHS or social services due to potential delays due to gaining ethical approval. Instead access was through recommended national VI organizations and supplemented with local vision charities. Research team members made early contact with and visits to RNIB/Action in Bristol, London and Birmingham and the HQ of The Macular Society in Andover. An information sheet outlining the study was distributed. In addition, researchers spoke at local meetings of the Macular Society and RNIB in Milton Keynes and the national Macular Society advertised the research through their newsletter asking volunteers to participate and distributed information to certain local associations.

A purposive sample of participants was sought to ensure:

- focus on participants in late old age (over 85yrs)
- participants with a range of eye conditions
- a substantial number of people from minority ethnic groups

In order to ensure adequate representation from minority ethnic groups (many of whose members have a shorter life expectancy than the average white Briton and a higher incidence of VI) a small number of people under the age of 70 as well as a substantial number under 85 were included.

## Training and Gaining Ethical Approval

During March 2015, the research team participated in a one day training

course run by members of East London Vision (ELVis) for TPT to consider communication with people with vision impairment taking part in research.

At this time, a proforma including aims and objectives, methodology, recruitment, informed consent, anonymity, schedule, dissemination and data protection was submitted to The Open University Research Ethics Committee (REC). The REC were very supportive of the project and made useful comments concerning oral/recorded consent, similar to issues raised on the ELVis course.

## Questionnaire development

Guided by the aims and objectives, the research team reconsidered topics outlined in the post analysis model developed in the JRF Research relating to the lives of people with high support needs (Katz et al 2011) (see Appendix B) involving aspects of physical, social and psychological well-being. This research had adapted the 'Life of Quality' tool devised by two of the current researchers in a study of 'environment and identity in later Life' (Peace et al, 2006). As a visual tool this instrument was inappropriate for this audience but the central topics were turned into a semi-structured questionnaire. The resulting conversation encouraged participants to discuss a range of health, housing and social care issues and considered the following:

- visual and general health
- housing
- support and interaction
- living at home
- activities of daily living

- spending the day

- going out

- social isolation & loneliness

- self-worth, pleasure and meaning of living well

In addition, participants were asked to estimate their current income; indicate their financial assets (excluding their house if owner-occupied); and give their ethnicity based on the categories used in the current national census.

## Fieldwork – pilot and main

The Macular Society advertised the study and encouraged local societies to take part and potential participants were contacted directly or through a local society. Initial interviewees were contacted primarily by telephone followed by a letter explaining the interview process where appropriate. The first six interviews took place in Oxfordshire, Bedfordshire, Buckinghamshire and London during February / March 2015 acting as pilot interviews to enable any revisions. Some questions asked participants to respond by choosing a category from a SHOW CARD given as black on yellow paper in 72pt font size: for example the show card in relation to Activities of Daily Living asked if you:

1. Do this easily
2. Have difficulty doing this yourself
3. Really can't do it yourself

While some people coped well with these cards others needed the categories to be read and re-read.

At this point, while further participants continued to contact the research team, a decision was made to extend the geographical area to attract people from different ethnicities and age groups and capture different types of vision impairment as well as a wider range of experience of urban/rural living.

Through contacts from National organisations, the researchers visited two centres for people with VI in the East and West Midlands (Centre A and Centre B); where staff agreed to approach members who fulfilled the criteria and be interviewed themselves. Interestingly, despite these two centres for 'The Blind' being in cities with large ethnic populations, centre attendees reflected the white British population rather than the local urban population, consequently, we contacted two further voluntary organisations providing services for BAME groups in two different localities. Finally, recognising the lack of rural participants we enlisted the help of a longstanding local organisation in East Anglia who approached participants on our behalf.

Most local organisations facilitated interviews with their members as well as permitting interviews with managers, workers and volunteers. These provided contextual information about the participants and their lives, and particularly the services (un) available in different localities. People associated with 9 organisations were interviewed. Most were funded through national or local fundraising or legacies and operated in the context of a variety of local, municipal, health, social and other voluntary organisations providing a raft of different types of services. Despite their local bases, many had strong connections with national organisations for VI people.

The final purposive sample comprised 50 older people including some pilot participants and a smaller number of family members/volunteers

and professionals. They lived and worked across England from Liverpool to Norfolk from Oxfordshire to Coventry from Dudley to London; a widespread group in rural and urban areas. A small number (3) had been vision impaired since birth or a very young age. This research explored issues with people living predominantly in mainstream community settings, who are living alone, living as couples who may support each other, and a small number living with other family members.

## Site of interview & procedure

The interview aimed to last approximately an hour to 90 minutes and the majority took place either in the person's home, or in an agreed 'public place', negotiated in advance. Two were conducted on the phone and one in a library, one in a relative's home, one a church hall, and seven in 'centres for the blind'. In both centres staff introduced potential participants and interviews took place either on the premises or in the participant's home. Interviewing at home was preferable as this enabled an understanding of the participant's environment.

Even when researchers interviewed participants at home, it was not always appropriate to ask to see certain rooms, such as kitchens and bathrooms, as doors were shut and interviewees preferred to describe them. Occasionally interviewees forgot to describe certain aids - for example a stair lift or a talking phone that were noted by the interviewers.

Eight participants were interviewed with relatives present (usually spouses) who contributed information. Several others chose to be interviewed alone, even when spouses were in the building.

The majority of interviews were tape recorded in agreement with participants and where appropriate photographs of equipment or housing adaptations were taken with the participants' approval. Informed consent was discussed at the beginning of the interview with participants signing a consent form at the end which was read or re-read to them if appropriate. The interviews were later transcribed for analysis and sent to the participant if requested.  Participants were provided with a £20 shopping voucher for their time.

## Interviews with relatives, workers, volunteers and observations at centres

When researchers attended sessions for people with VI held in 'public' premises by different voluntary organisations in some cases relatives were present and expressed an interest in the research. They were followed up and contacted separately. Three interviews with relatives took place on the phone whereas other relatives (8) were present at the interview with the person with VI and contributed where appropriate.

Most interviews with paid workers took place at their workplace - one was in a community worker's home which doubled as her office; another took place jointly with the person with VI. These interviews contributed to understanding both the context of peoples' lives as well as obstacles faced by providers of services (including relatives) (see Appendix C). Researchers also observed activities at centres for blind people, including manufacturer's exhibits, computer lessons, exercise classes, cooking demonstrations, and so forth. Additionally researchers observed meetings for people from BAME with vision impairment in two different localities.

# Analysis

All interviews were tape recorded and then transcribed according to data protection regulations. Data analysis was undertaken through framework analysis following (Spencer et al, 2003) utilizing a template so that all four researchers could contribute. The areas covered in the template relate to the original interview schedule.

- Demographics
- Vision
- Health
- Housing & Living arrangements
- Spending the day
- ADL
- Support
- Being at Home
- Getting out and about
- Pleasure, autonomy, quality of life

# Appendix B - Model from A Better Life (Katz et al, 2011)
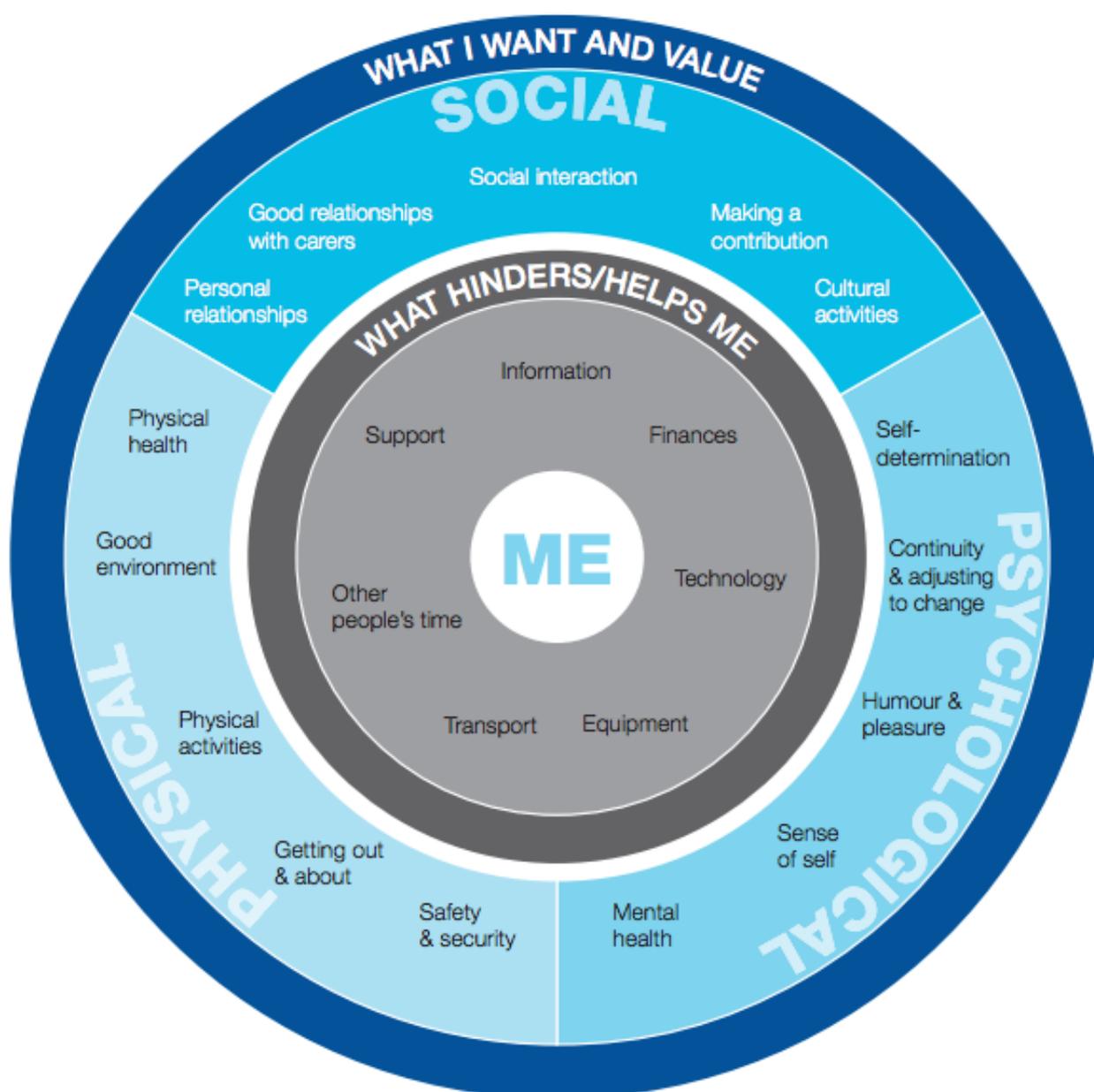


(Katz et al, 2011, p 41)

The Model above is from previous research undertaken by the authors for the Joseph Rowntree Foundation and is based on analysis of

conversations with older people with high support needs in relation to three areas of well-being – social, physical and psychological. The researchers described the model which is drawn as three interlocking circles in this way:

"The new model distinguishes between the things that older people want and value (shown in the outer circle) and the factors that hinder or help them to access these things (shown in the inner circle). It focuses attention on what can be done differently to help older people with high support needs achieve and retain the things they value in life, rather than simply assuming that their individual social and/or medical conditions will inevitably place many experiences out of reach.

The older person is at the centre of this circle – a reminder that this is about people and what they want from their lives, not about what services and policies say they can have. The individual person (rather than the broader group of older people with high support needs) is at the centre, since one size will not fit all. Each individual will have different needs, values and aspirations; different assets and resources at their disposal to achieve these; and will encounter different barriers.

This person is represented as 'me', partly to give ownership of the model to the individual (rather than it forming part of an assessment being done to people) and partly as a reminder that this is – or will be – about all of us (not about 'them')."  (Katz et al, 2011,p40/41)

# Appendix C - Hearing from local organisations, service providers and volunteers

## Who does what?

Regardless of their role, all workers spoke about the confusion people with VI face in relation to who provides supports for people with VI, as well as services available to them, let alone very confusing terminology. The head of a centre for people with vision impairment (Centre A) explained:

'What is an ECLO, what is a nicely written out answer? What's an ECLO, [and/or] independent living coordinator, [and/or] what's the rehab team?... people that deliver services to people with sight loss are usually rehabilitation officers for people with sight loss, or assistants; however the rehabilitation officer often works for a sensory team. They may also work for a support service. So you've got rehab sensory support, there's complete confusion'

Additionally, all the 'workers' described the process of registration as also confusing for people with VI:

'Certification is what the consultant does, that's the process. Registration is local authorities registering it. That in itself causes so much confusion…partially sighted, severely sighted, impaired, blind'

During the course of this research it became evident that many local VI charities and organisations exist, with varying agendas. Interviews were

conducted with four heads of voluntary services (two heads of large centres for VI people (Centres A & B), and two heads of local voluntary organisations); additionally we interviewed four people who worked in different capacities at Centre A; two community workers in a rural area, and the volunteer manager of a group serving an ethnic minority. As noted in Appendix A other workers and volunteers were observed.

## Referrals

Organisations received referrals in a variety of ways and acknowledged that many people with VI were not picked up.  In one case a (rural) organisation was co-terminus with others serving (different numbers of) people with VI across the county where there was cross referral. The director explained the two primary routes of referral. Either:

'When they are filling in this CVI form as it's called, one of the boxes on there says to them, are you happy for us to notify, well, two questions, the first question is the social services and the second is the local voluntary organisations and they can only deal with it depending on what answer the client gives'.

Or:

'We try and get these (leaflets) into opticians, GP surgeries primarily and obviously the hospital eye clinics and people do pick them up and they do self-refer.  I would guess the majority of our referrals come from word of mouth, recommendation, people who know and then say, have you thought about, have you contacted, why don't you'.

Most other workers described the haphazard nature of referrals to their services – this often depended on relationships with ECLOs (Eye Clinic Liaison Officer), low vision clinics and so forth. For example, one

community worker got most of her referrals via the low vision clinic at the closest hospital with an eye clinic where they'd recently replaced volunteers with an employed ECLO:

'We don't get many from Social Services not really because they've got their own department on that area. I suppose the only referrals we really get for that is socials because we run socials in all areas throughout (region) for visually impaired people. They all get together once a month and there's some sort of form of entertainment: music or a quiz or whatever. So basically my job is pointing people in the right direction because you come out of the hospital, some people don't even know what their eye condition is even all about or what they've got because, you know, you're in and out, in and out and it's just not always explained to you'.

Being an advocate and enabler particularly applied to organisations serving people from minority ethnic groups as described by the founder of one, herself VI:

'If it's hard for me, how about people, like [   ], they can't talk English, they don't know where to go… At least I could ring people and say, look, I need help and support. This is what I did. I went to hospital, and they just… say, you're blind, and that's it…They don't tell you what it means or nothing…

The sensory impairment team…I wouldn't say they work well in (city). They should put more effort into it, more work into it… after four or six weeks, they close the case'.

# Aims of organisations

One rural organisation founded in 1914, amongst other activities, inter alia aimed to work :

'In local hospital eye clinics, providing information to all patients on services, and signposting to other agencies.

Visiting all new members in their homes, where requested, to assess their circumstances, offer advice, agree an action plan of changes and involve other agencies where necessary'

This organisation did not have a 'base' for activities, but did have an office where equipment was displayed. It provided a large, extensive information pack for people who are visually impaired together with their Family, Friends and Carers.

In contrast, on the outskirts of a large city in the Midlands, a recently rebuilt centre (known here as Centre A), a charity that had been operating since the nineteenth century, provides services for people from two local authorities, who have different criteria for financing their residents to attend causing some ill-feeling. From talking to local attendees at this centre, it became apparently that 'it is pretty hit and miss if people get services, in most cases it relates to their connections with SS - most people are unaware who is funding their care package - they simply don't know'. The discrepancy between different attendees at this centre created distress amongst participants as well as placing workers in a difficult position.

Another more recently opened centre (in another city) (known here as Centre B) has as its mission statement:

'…Provides specialist support services and activities for blind and partially sighted people and their carers …encourages active participation to reduce the impact of isolation felt by many who suffer sight lose.'

## Outreach

Centre A as noted had been in existence a long time but the new facility provided a variety of activities for VI people each weekday; the second, Centre B had been 'revived' 5 years previously by two women, one of whom is VI, in a building owned by another charity.  Both organisations had a variety of outreach services, for example, Centre B had a radio station:

'This is Community Broadcast Service and this is where they do their recording each week, which is an outlook tape which goes out to over 400 people (locally)…This would include articles that are in the local press, also articles that are in magazines. There will be a piece on sport, of the local sport and the national sport. There will be some sort of representation of what's on in the local area, which will tell you about the theatres and the cinemas and things and just general information. Also about the events that are happening at the Centre each week. So this goes out every single week to blind and partially sighted in (city)'

Both centres were in conurbations with large minority ethnic groups. However, most of their clients were white British. Many attendees at Centre B came weekly, but for some transport was a problem and costly as there was no transport provided. This might partially explain the relatively low proportion of attendees from Minority Ethnic groups.

While at Centre A one worker said:

'We've tried various routes. We've gone on local Asian radio and we've got a couple of Asian care workers. We've gone on local radio stations. We've been to the local temples. It's very much making the services accessible but making them relevant. And a lot of people in those particular communities, I understand the afro-Caribbean communities, the community tends to be very…they look after their own, they look after themselves, and it's almost an admission of failure if they seek help elsewhere. And we've found it very difficult to…we offer our services to everybody, obviously, but it's very difficult to try and keep involvement and to make it available so they can, you know, it is for them, for everybody. It is very difficult to get those communities involved.  We've been to various foreign shows and festivals with some equipment, and they're very welcoming, very absolutely fantastic, but it doesn't go any further than that'.

## Giving Advice

We interviewed workers with different roles; the low vision expert at one centre explained how he advised people with VI which types of aids (some of which he supplied) would suit them best:

'We range from very basic tactile market through every aspect of daily living, kitchen equipment that speak, tactile marked colour contrast equipment, through to leisure, which is playing cards, tactile dominoes, big print cards, time pieces, navigation aids, calculators up to all filter glasses, lighting, computer equipment, magnification.  So we try and cover every aspect of daily life and try and find strategies to maintain independence, but the equipment will support the strategies as well.  So

it's not always about the equipment, it's also about how the people approach doing things, how they're using their sight effectively. We do a low vision assessment scheme where we'll assess for absolutely everything, anything that person's having problems with, we'll try and look at finding solutions to make, maintain independence; keep them doing what they want to do for as long as they possibly can'

If based in a physical centre they arranged demonstrations by suppliers of equipment and some organisations 'lent' some of this equipment as well as ensured that they had brochures of the most recent equipment for relatives to read.

## Volunteers

Most organisations spoke about the centrality of the role of volunteers who were involved in organising fundraisers, helping with regular meetings for people with VI or supporting them in different ways. One volunteer who supported a minority ethnic group described her usual tasks:-

'…tomorrow I will take a lady shopping. I'll go and pick her up and take her shopping and do her weekly shopping, but we do it every two weeks. Then another lady will phone us and say, she wants to go into town to do some clothes shopping, or she wants to do some shopping'.

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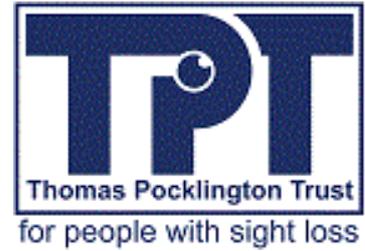
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