Experiences of Living with Visual Impairment: Matching Income with Needs

Katherine Hill, Claire Shepherd and Donald Hirsch

Centre for Research in Social Policy
Loughborough University

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Terminology

In this publication, the terms ‘visual impairment’ and ‘sight loss’ are used interchangeably and refer to people who are eligible for certification as either sight impaired or severely sight impaired.

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Executive Summary

Introduction

In light of changes to disability benefits and concerns about cuts to services and support, this report explores the implications of living on a low income for visually impaired people in the UK. It presents research that followed on from a series of studies looking at Minimum Income Standards for visually impaired people (MIS VI) - what they require for a minimum acceptable standard of living that meets basic material needs, allows participation in society and covers the additional cost of disability (Hill *et. al* 2017). This new research, comprising interviews with visually impaired people on low incomes, provides an insight into the reality of their lives, how they meet their needs and how they draw on different resources.

The aim of this study was to describe the experiences of visually impaired single people who are living on an income around or below the MIS VI thresholds. It explores the extent to which people can meet material needs and social needs, as well as needs directly arising from sight loss, how they prioritise and make decisions about spending, and what other factors can help or make it more difficult to meet these needs.

The research comprised in-depth qualitative interviews with 26 participants living in different areas of England. Participants were single people living independently, split between working age (WA) (18-64) and pension age (PA) (65+), sight impaired (SI) and severely sight impaired (SSI), whose incomes were below or close to the MIS VI level.

Sources of income and meeting a minimum standard

Low disposable income (in relation to the MIS VI level) can be influenced by low gross income from earnings, pensions and benefits, and by high housing costs. A parallel study to the one reported here considered the adequacy of benefit and minimum wage levels in providing visually impaired people with a minimum acceptable income. It found that while

benefits to provide help with additional costs often full short of doing so, disability-related supplements to means-tested benefits can help fill the gap. On the other hand, for those of working age, general benefits fall well short of meeting needs not related to disability, and disability-related supplements are disappearing under Universal Credit, leaving many visually impaired people with incomes a long way short of the minimum.

Looking at the incomes of the individuals interviewed for this study, for those of working age, the most serious shortfalls occurred where their incomes fell below benefit ‘safety net’ levels. In most cases, earnings brought participants nearer to the MIS VI level than those without work. Factors influencing participants’ ability to find and sustain employment included negative experiences of looking for work and experiencing a sudden or drastic change in income when sight deteriorated. Factors that can help included in-work support from Access to Work; having a supportive employer; help from VI organisations; volunteering; and Permitted Work.

Access to benefits is crucial for visually impaired people on low incomes – especially because disability-cost benefits can bring additional income in premiums to those getting means-tested support. Working age participants raised issues around claiming benefits. This included receiving communication in inaccessible formats, having to think negatively about their visual impairment on an application, difficulties with the assessment and appeal process and the uncertainty of reassessment. Support from organisations in dealing with benefits was helpful.

It was rarer for pension age people to fall very far short of their income needs and their incomes tended to be more stable. Pensioners at most risk are those with a low pension but not receiving extra cost benefits such as Attendance Allowance. These are particularly important to those receiving Pension Credit, which attracts supplements for those on extra-cost benefits. Registration could bring financial, practical and social advantages through contact with social services and VI organisations, however, there was ambiguity about the process among pension age participants.

Housing costs can reduce disposable income where rent is not covered by Housing Benefit, people have a mortgage, and/or pay service charges. Issues relating to visual impairment that could affect housing options and costs include: the importance of familiarity meaning people are reluctant to move even if paying high costs, extra charges for services, paying more to live in convenient locations, ‘under occupying’ where Housing Benefit doesn’t cover the rent, instability in the private rented sector and constrained moving options.

Meeting needs and prioritising resources

Material necessities including housing costs, utility bills, basic clothing and basic food needs were generally met and prioritised by participants. Compromises were sometimes made, occasionally having to ‘stretch’ a food shop at the end of the month or sharing accommodation to keep housing costs down.

Socialising was important - getting out and meeting other people had a positive impact on well-being and helped limit seclusion. However, social participation can incur additional costs such as paying for transport or treating a friend as reciprocation for help received. Some participants had to restrict spending on socialising and most said that if their finances improved then social activities including holidays would be an area where they would spend more money.

Transport is closely linked to social participation. Taxis can be an important, but costly, means of getting out to socialise, shop or attend appointments - especially for some participants with little or no sight and those unable to access public transport or lifts. Spending on taxis was an area subject to restriction, deliberation and cutting back if money was short. Participants, especially those of working age, felt that if they had more money in their budget they would use taxis more often.

Technology and specialist equipment provides important support to maintain independence and help with daily tasks. However, the cost of some specialist items or technology can limit accessing or replacing and

updating equipment and be off-putting for people wanting to try it out, this restricts access to the internet or having to make do with limited functioning equipment.

Being without savings or flexibility in a budget could cause difficulty where unable to afford to buy or replace necessary high cost items, and also insecurity around the financial implications of future deterioration in sight or general health and changes to disability benefits or social care support.

Participants fell broadly into three groups. Those who felt ‘comfortable’ were content with their financial circumstances, they watched their budgets, but did not miss out on things and could cover a large expense if necessary. Some were ‘getting by’ and could cope with everyday living costs but had to be careful, facing restrictions for example, on support for social activities or specialist equipment. Others found it difficult to afford what they needed, they had had no leeway in their budgets which meant going without items, and being unable to do things, in particular social participation.

What makes a difference: resources and circumstances that can help or hinder meeting needs

Various forms of human support provided help with day to day tasks around the home, getting out and maintaining independence. Local authority funded social care that would have been hard or impossible to afford otherwise was crucial for some participants. Informal support from family, friends and neighbours can reduce the necessity to pay for formal support. Finding the money to pay for help was not always possible, and this was an area some participants would have liked to spend more money on if they had it. For those without access to (sufficient) human support, needs could be compromised or unmet which could limit access to social activities and allow tasks within the home to accumulate or mean having to get by without help.

National and local visual impairment (VI) charities and services, other third sector organisations and statutory services provided: items and

equipment; training and support ranging from employment skills, IT, braille to cooking skills and mobility training; information and advocacy, in particular help with benefit claims and appeals; support getting out; and opportunities to socialise and share information with others. However, knowledge about what is available is crucial and participants noted a need for better information sharing. Cuts or changes to services had affected some participants and there was concern that reduced funding would impact on services in the future.

It is important that companies communicate in accessible formats and have accessible websites to support financial independence and get best value, which wasn't always the case. While internet banking and billing could be helpful, those who do not use technology should not be penalised or charged more for communication.

Higher costs were associated with living in a rural area or location without major amenities and limited bus services. Trips to towns to access better facilities or cheaper shops could involve long bus journeys and the cost of taxis could inhibit people travelling which risks social isolation, and limits opportunities to meet other visually impaired people and gain useful information. In urban locations, taxis were necessary where people felt unsafe walking to a bus stop and where services were limited. In areas where disabled people received subsidised taxi journeys, they were widely used and incurred less cost.

Technology was a key resource, particularly for working age participants. The multi-functionality of smart phones including accessible features and VI apps provided independence including getting out and could save money on buying separate devices. Training provided valuable support where received but knowledge about what equipment or technology is available and how to access it was an issue, and there were also felt to be gaps in accessing IT training and local support.

Health conditions alongside visual impairment can make a difference to people's needs and costs. This includes: limited mobility meaning an increased use of taxis or relying on lifts; impaired hearing affecting use of audio, social interactions and confidence if unable to hear or see traffic;

other conditions requiring frequent appointments or spending on specific food or treatment; and loss or deterioration in vision and its impact on work, income and dealing with the benefit system affecting mental health.

Participants (in particular pension age who had become sight impaired in later life and working age who had become severely sight impaired) described a range of emotions and reactions to sight loss. which could present more challenges for some people who had recently lost their sight than for those who had developed strategies and confidence over a longer period. Support is most needed when people may be experiencing these emotional impacts.

Conclusion

Participants in this study prioritised meeting core material needs, although for those on the lowest incomes this could involve compromises. Social participation was extremely important, but for some this need was not met if they had to restrict spending on activities or the resources that could be a means to socialise.

Income is important, but a range of resources can also make a difference. Access to human support, services such as from VI organisations, and appropriate technology can also play a valuable role. Potential barriers that can impede meeting needs include: poor health; poor access to local facilities and public transport; and lacking knowledge of how to claim benefits, how to become registered with the local authority as visually impaired, where to find services and support or what technology may help. Some people face greater needs when they become visually impaired, especially in the early stages of sight loss.

Nonetheless, income remains crucial in accessing basic material needs and in oiling the wheels of social participation. Having enough income helps visually impaired people maintain independence and agency, and provides security or a buffer to protect them when things go wrong and cover the high cost of equipment or technology.

Visually impaired people can have personal concerns about the future, related to further sight deterioration, general health and work. Added to this are worries about the future in the context of austerity. This includes concerns about government support, particularly reassessment of disability and means-tested benefits, social care, and funding cuts to services including VI provision. Living under the shadow of potential changes to vital benefits and support can be a cause of anxiety, adding further uncertainty to visually impaired peoples' lives.

Key policy messages emerging from this study:

- Many visually impaired people, particularly those on working age benefits, need adequate and secure sources of income to help cope with the uncertainties of deteriorating sight and build savings to allow the purchase of expensive equipment. However, changes in the benefits system can bring precarity and stress.
- Lower income visually impaired people need good information about what benefits, services and support is available, advice and advocacy when things go wrong, help and training in the use of assistive technologies and less stressful pathways to claiming the benefits to which they are entitled.
- People need information and support when they first become visually impaired, when the challenges can be the greatest but knowledge of what is available the lowest. This includes access to VI networks and timely assistance especially for pension age people who become visually impaired, and a more joined up system to improve the sight loss pathway.

Chapter 1: Introduction

This study explores the experiences of visually impaired single people who are living on a low income and how they meet their needs. It follows on from a broader research programme that has looked at Minimum Income Standards for people with sight loss. That research identified a range of additional costs that groups of visually impaired people identified as being associated with maintaining an acceptable standard of living for those with sight loss and considered how these costs vary for different age groups and by degree of sight loss (Hill *et. al* 2017).

Understanding the cost of disability is important to inform policies aiming to ensure that people do not have to live in undue hardship and is particularly relevant in current times in the UK, amid changes to disability benefits and concerns about cuts to services and support. This includes, for working age people, the planned replacement of Employment and Support Allowance (ESA) with Universal Credit, the replacement of Disability Living Allowance (DLA) with Personal Independence Payment (PIP), and squeezed budgets affecting statutory and third sector provision. This new study aims to provide an insight into the reality of life for visually impaired people who are on low incomes, how they meet their needs and draw on different resources.

The Minimum Income Standard (MIS) calculates weekly budgets for different household types based on what members of the public think is needed, in order to reach a minimum socially acceptable standard of living which, as well as including the material essentials of life, enables people to have the opportunities and choices necessary to participate in society. These budgets were drawn on in research funded by Thomas Pocklington Trust to look at the additional needs of single visually impaired people and the extra costs this involves enabling someone to live independently with a minimum acceptable standard of living (Hill *et. al* 2017). This involved groups of people with experiences of sight loss going through the MIS budgets to identify what needed to change because of visual impairment, and acceptable thresholds were set variously for those at different life stages and degrees of sight loss. Additional needs and costs were identified associated with support in the

home, transport, social participation and holidays, household goods and technology. These additional requirements were added to the main baseline MIS budgets for people without disabilities to produce budgets for visually impaired people, referred to in this report as MIS VI.

The aim of this study is to describe the experiences of visually impaired single people who are living on an income, around or below the MIS VI thresholds. The research uses qualitative interviews to explore the extent to which people can meet material needs and social needs, as well as needs arising from sight loss. It examines how they prioritise and make decisions about spending, and what other factors can help or make it more difficult to meet these needs. This includes looking at, where relevant, the variation in experiences of working age and pension age people as well as those that are sight impaired (SI) and severely sight impaired (SSI). An earlier part of this current programme of work considered the adequacy of benefits and the National Living Wage in relation to MIS VI budgets (Hirsch, 2017). Reflections on this income analysis are presented alongside information on the actual incomes of people in this study in Chapter 2.

Recruitment and sample

We used a wide range of recruitment methods to contact visually impaired people who were working age, pension age, sight impaired and severely sight impaired to include a cross section of experiences in the study. The recruitment covered different areas of England. It was important to ensure that suitable methods were used to recruit different types of participants: for example, face to face recruitment at social groups was more helpful in recruiting those of pension age than via email or social media. Researchers used their network of contacts from previous research working with visually impaired individuals as a starting point. Recruitment techniques included sharing information about the study on VI organisations' social media including websites, Twitter and Facebook; sharing information through newsletters of a range of VI organisations; providing information for leaders of VI support groups to disseminate to members; researchers attending Macular Society groups in person to explain the research and broadcasting of information about

the study on an audio information service. There was also some snowball sampling as participants passed on details of the research to their own networks. The approach was based on practical considerations necessary to reach the required individuals and it should be noted that those included have had contact, albeit in some cases limited, with VI organisations.

To reflect the previous studies, the focus was on single people, split between working age (WA) (18-64) and pension age (PA) (65+); sight impaired (SI) and severely sight impaired (SSI) participants covering various dimensions such as employment status and location. The aim was to include participants with incomes below or around the MIS VI level (after housing costs – see Chapter 2). An estimate was made to assess how close to the MIS VI threshold each participant was and is referred to as a percentage of MIS VI. Information was provided by each participant to calculate this; however, there were some instances where estimates or proxies were used when participants were unsure or researchers were not able to collect precise information. As a result these categories should be considered a guide rather than an accurate representation of their income levels. Around three quarters of the sample (73%) had less income than required by MIS VI, and all but one of the other participants either had income within about 10% of MIS or had additional needs that would bring extra costs not measured in the MIS study. It is worth noting that some participants had medical conditions or issues with mobility, which can bring needs that are not measured within MIS VI (see Chapter 4).

Table 1 provides details of the study sample and participant demographics.

Table 1: Study sample

Age range	13 Working age				13 Pension age		
	25-34 3	35-44 2	45-54 4	55-64 4	65-74 5	75-84 4	85 + 4
Visual impairment	10 Sight impaired (including 2 not registered) 16 Severely sight impaired (of those SSI - 11 had no useable sight)						
Gender	16 female, 10 male						
Ethnicity	22 white British/European, 4 minority ethnic group						
Income % of MIS VI	under 50% 3	50-74% 5	75-99% 11	100%+ 7			
Work status (for working age)	8 not working 3 employed (non-Permitted Work). 2 full-time, 1 part-time. 2 working part-time in Permitted Work						
Benefits	17 receiving Means Tested benefits 22 receiving Disability Living Allowance, Personal Independence Payment or Attendance Allowance						
Type of area	8 urban/city, 13 suburb/large town/edge of city, 5 small town/village						
Region	15 Midlands, 5 South West, 4 South East, 2 East						
Guide dog	5 guide dog users						
Braille	4 braille users 5 with some limited knowledge of braille						

Method

The study included a total of 26 participants and took the form of 25 in-depth face to face interviews and one in-depth telephone interview. Interviews lasted between 90 and 120 minutes. Participants were advised they could have another person present during the interview which they did in two cases where a family member or Personal Assistant (PA) sat in. Researchers used a topic guide to steer the interviewees to describe their experiences of living with visual impairments and how they meet their needs. The interviews covered a wide range of topics including: income sources and experiences of work; housing and household bills; household goods and VI specific items; the

influence of technology; informal and paid support; social participation; accessibility of public and third sector services; experiences of becoming visually impaired and potential improvements for visually impaired people. Interviews were digitally recorded and transcribed along with the write up of detailed interview notes. Transcripts were inputted into NVivo (qualitative data analysis software), coded thematically and participants were classified by key characteristics to allow analysis across themes and demographics of participants. Participant information sheets and informed consent forms were made available in accessible formats (large print, braille, audio) and/or were emailed to participants if they preferred.

Report structure

Chapter 2 starts by considering how income from different sources helps visually impaired people to meet a minimum living standard, and how it can fall short of doing so. Chapter 3 then looks at the consequences of low income, in terms of what visually impaired people are and are not able to do when their income is low, how they prioritise spending, and what effect this has on their well-being. Chapter 4 looks at resources, other than level of income to explore, what other factors make a difference to visually impaired peoples' lives and what can help or make it more difficult to meet their needs with limited financial resources. Chapter 5 concludes the report by drawing together some key factors that this study has found are important in the lives of those who took part and highlighting some policy messages.

Chapter 2: Sources of income and meeting a minimum standard

In order for a visually impaired person to enjoy an adequate standard of living, they must have enough income to afford material essentials, to buy additional items related to their disability and to participate socially and costs can be greater for those who are visually impaired. These costs have been estimated in the MIS and MIS VI studies identifying both requirements of the population as a whole and the additional costs for (single) visually impaired people.

Similarly, visual impairment can have fundamental effects on income streams. On the one hand it can influence whether someone works and the level of their earnings – which may also in turn affect the eventual level of pension income. On the other, it can influence access to benefits, both those that help replace or supplement earnings, such as Employment and Support Allowance (ESA) and tax credits, and those that help to cover the additional cost of disability, such as Personal Independence Payment (PIP) (which is gradually replacing Disability Living Allowance (DLA)) and Attendance Allowance (AA).

How earnings and benefits compare to MIS VI

A perfectly functioning benefits system would ensure that visually impaired people are able to maintain at least a minimum living standard, by giving them adequate support taking account of labour market disadvantage and additional costs. The first stage of the present research looked at illustrative examples of how well income from benefits and low earnings measure up to the minimum requirements of a single visually impaired person, in various scenarios where they are out of work or on modest earnings. The results, written up in detail elsewhere (Hirsch, 2017), show that the system is a long way from providing adequate support, that this varies widely for people in different situations and that recent reforms have mainly widened the gap between income and need.

In summary, this first analysis showed that:

- Extra cost benefits, such as PIP and AA, often fall short of covering the additional cost of visual impairment, but this varies with the severity of the condition and the level of award.
- People getting extra cost benefits who are on low incomes may also be eligible for supplements to other benefits and tax credits that go further towards covering additional costs.
- Since general benefits for single working age people fall far short of covering minimum needs, so often do overall benefits for disabled people, even if disability-related additions match the additional cost of disability. This means that a visually impaired person on a low income receiving financial help to cover the extra cost of additional needs may have to decide whether to use it to cover such costs or to help meet general material needs not covered by the rest of their income.
- Changes in the benefits and tax credits system, including the introduction of Universal Credit, have in many cases worsened the prospects for working age disabled people. In particular, many who are not eligible to be in the ESA 'support group' may end up on reduced income either on a lower rate of ESA or on modest earnings with a reduced state top-up, linked to the abolition of various disability-related supplements. The resulting shortfalls in income relative to need can be very serious, in some cases leaving a single sight-impaired person with well over £100 a week below what they need.
- For visually impaired pensioners on low incomes, the safety net remains broadly adequate to cover minimum needs, provided they are eligible for AA. This does not however take account of the effect of having multiple conditions that can bring extra costs.

The above comparisons of how incomes on particular benefits and earnings are likely to compare to the benchmarks set by MIS VI is a starting point, showing to what extent the system is designed to meet minimum needs. But it is only a starting point, since people's lives are, in reality, more complex and varied than can be represented in such modelling. The qualitative research in this project considered the realities of individuals' income, spending and well-being. The remainder of this

chapter considers the determinants of the incomes of visually impaired people whose income is below or around the MIS VI benchmark.

An assessment of participants' incomes, used in selection for the study, considered how all income from earnings, pensions, benefits and tax credits, minus taxes and housing costs, compares to the disposable income required to meet the budget identified in the MIS studies. Participants in the study were those whose income fell short or just above this budget (see Chapter 1). The disposable income of people in this study was influenced by a range of factors. We start by considering their access to income to cover their main living costs, under the headings of earnings from work, income from working age benefits and pensioner income. We then consider the effect of housing costs and housing-related benefits on disposable income and finally what combination of circumstances produces particularly low disposable income.

Work and earnings

Visually impaired people with earnings from work should be better able to raise their living standards, and may be less vulnerable to benefit cuts, than those wholly dependent on out-of-work benefits. Of the 13 working age people in this study, five were working and for three earnings were their main income source, with the other two supplementing ESA by working fewer than 16 hours a week under the 'Permitted Work' rule. In the working age visually impaired population as a whole, only an estimated one in four are in work and over a third of these are in part-time work (Slade and Edwards, 2015). Participants in this study talked about a range of factors influencing their ability to find and sustain employment, and whether it was a worthwhile experience.

Some of the participants had had highly negative experiences of looking for paid work, causing them to give up doing so. Several had applied for hundreds of jobs, had undertaken numerous training courses and extensive voluntary work to equip them with skills and experience, but to no avail. Those who had had contact with the Jobcentre including Disability Employment Advisors had not always found them helpful.

“I mean I would love to go back out to work… and when I went to see a disability careers advisor at DWP she basically told me to go home and put my feet up, she just wasn’t interested.” (WA SSI)

Constant rejection was ‘disheartening’, and eventually seen as a waste of time and effort. Being unable to drive was also felt to be a disadvantage as participants had experienced long commutes by public transport in the past to maintain employment and felt that lack of transport narrowed down job opportunities. Visual impairment was felt by some to stack the odds against them, when it was hard for anyone to find work and they were concerned that employers would be less inclined to employ them against others without visual impairment:

“A lot, most of them are really not interested in employing someone like myself really, regardless of what qualifications you’ve got, or you get a feeling it is just a lot of hassle for them really as regarding providing the specialised equipment you need for doing the job.” (WA, SSI)

In contrast, one participant had been successful in only the second job applied for – she felt that the experience gained doing voluntary work had been crucial in securing work. Others had found jobs through links with VI and other organisations after doing training including updating IT skills, through placements leading to eventual employment, or through word of mouth. Participants who were working, or had in the past, discussed several factors that made a difference to their employment situation and income from work.

- **Employment stability.** Two participants welcomed the fact that they had steady jobs, compared to short-term contracts and temping jobs with less reliable income that they had experienced in the past which could cause uncertainty and make planning difficult.
- **In work disability-related support.** Access to Work was very helpful in terms of covering the cost of necessary and often expensive equipment such as desktop magnifiers or screen reading software. However, participants had experienced delays in applications being processed, sometimes for several months, which could be problematic when starting a job without support in place. Provision of

a support worker and payment of travel expenses was also helpful – in one case a participant welcomed this being provided directly by the employer rather than Access to Work, as there was no need to pay up front and avoided the delay in receiving money back.

- **Permitted work.** Permitted Work allows a certain amount of earnings to supplement ESA. One participant who was working up to the maximum eligible income / hours in a job she enjoyed felt it made a 'massive difference' to her finances and lifestyle – the extra money meant that life was less stressful and she was much happier. However, another participant who was working only a few hours a week had initially welcomed the opportunity, but now felt frustrated that after several years it was not leading anywhere.
- **Working for a 'supportive' employer.** Participants valued employers allowing work to be structured around time off for regular hospital appointments, being flexible with hours and pay to ensure they fell within Permitted Work limits, and being accommodating to visual impairment needs. In several cases workplaces already had equipment available and participants felt that the employer would be supportive if more help was required and/or their sight further deteriorated. This was contrasted to sometimes difficult experiences in jobs in the past related to visual impairment. The benefit of having a supportive employer was also noted by several (older working age / younger pension age) participants who had been in fairly long-term jobs during their working lives. This was sometimes linked to later financial benefits, such as receiving a work pension or redundancy payments and also the provision of support, equipping them with IT training and skills which they continued to draw on.
- **The role of visual impairment organisations.** Most directly this was as an employer but could also occur indirectly through providing information about a job or through gaining experience and skills while volunteering at a local VI organisation.
- **Opportunities to train or retrain.** A particular constraint on training opportunities was location, such as the location of RNIB colleges. There was a feeling that this limited opportunities to train or retrain unless people were living nearby or able to travel to or move to these locations. Accessible local IT training was also raised as an issue

(see Chapter 4). Another barrier to training was affordability where someone was interested in becoming a counsellor but could not fund the training themselves.

- **Volunteering as skill development.** Several working age participants felt volunteering with local VI organisations, third sector work programmes and internships helped develop skills in preparation for entering or re-joining the job market and provided examples of work experience. However, a few participants had felt unappreciated or disillusioned, for example, being regularly expected to do more hours on a voluntary basis rather than increase paid hours and lack of opportunity for voluntary experience to lead to paid roles.
- **Work beyond pension age.** Two pension age participants had part-time work – a few hours a week or on an occasional basis. They appreciated the extra money but were not reliant on it and working was about more than income, as it was helpful to get out and keep occupied after retirement.

Participants' finances were severely affected by whether they were working, and if so whether they were under-employed. This was felt directly in cases where there had been a sudden change in income – for example, participants who had had to stop work or change their type of work when they became visually impaired or their sight deteriorated to the degree it impacted on their work. This could result in a drastic drop in income and have long-lasting financial implications, for example losing a livelihood or using life savings to live on. One had taken low paid and short-term jobs in the past while trying to find more secure and better paid work, but with travel and living costs found it hard to break even. Some had been made redundant and been unable to find work again.

"I had got a budget before which was more than ample for payment for bills, the house, all outside things and then all of a sudden you got that safety net taken away and you find yourself in a real financial mess." (WA, SI)

On the other hand, a participant who had been a lone parent on a low income noticed less difference once disability benefits were awarded. For some of those working, the impact of earnings on their overall

financial situation was offset by the extent of other outgoings, particularly housing costs, which are considered below.

Nevertheless, in most but not all cases, earnings brought participants nearer to the MIS VI level than those without work, and several felt better off than in the past when not working or on lower or less stable wages. One participant, who had recently started work, thought that she was only very slightly better off financially, and balanced this against what she felt were positive aspects of working, but noted that she couldn't risk working if it wasn't financially viable.

"It is about the same if not a tiny bit more.…Well to be honest even if it was less I would still be doing what I am doing now, because I know some people because of getting more money would rather be on the benefits but for my like mental health and stuff as well I would rather sacrifice a bit of the money but be happier and just having that purpose in life. But it was a bit of a worry if I would, even though I still wanted the job and everything, I didn't know how much I would get on Housing Benefit or Working Tax [Credit], but even if I would get anything like that on the wage alone I wouldn't be able to manage, and I haven't really got any savings or any family to fall back on." (WA, SSI)

Income from benefits

For most participants in this study, means tested and/or disability cost-related benefits provided an essential component of their income. Of the working age participants, only those working full-time did not receive any means tested support (including Housing Benefit, Council Tax Reduction or Tax Credits). Most of the others were receiving ESA, with any rental costs at least partially covered by Housing Benefit. Nearly half of the pension age participants received Pension Credit, and where renting they also received Housing Benefit. All but one (ineligible on the basis of residency status) of the working age participants were receiving either DLA or PIP. However, four of the pension age participants were receiving neither DLA, PIP nor AA.

Access to benefits is crucial for visually impaired people on low incomes – especially because disability-cost benefits can bring additional income

in premiums to those getting means-tested support (Hirsch, 2017). Participants in the study talked about their experience of claiming benefits, and how they contributed to meeting various needs.

Experience of claiming working age benefits

The benefits system is supposed to help support disabled people but working age participants typically found the process of claiming far from supportive. They raised the following key issues.

- **Accessibility.** ESA and PIP communications being sent in inaccessible standard print was a recurring problem and people felt that government departments who should be aware of their needs were disregarding them, even where they had requested alternative formats (see Davies *et. al*, 2017). Several questioned why they could not use electronic communication or online forms. This could result in missed appointments for those unable to read post until a support worker or family/friends visited, and generally meant relying on others to read letters and complete forms, which was felt to inhibit privacy and independence. One participant had threatened legal action and another had resorted to responding in braille to try to get the message across.
- **Presenting disability on an application.** This involved applicants needing to explain in detail how visual impairment affected them. People talked about having to unpick their daily actions, think about their 'worst possible scenario' or 'lay it on thick' to justify their claim and were sometimes uncomfortable about how claims for ESA or PIP could involve stressing the negative. This could mean having to alter their way of thinking when presenting their disability on the application to focus on what visual impairment meant that they could not do. Having support with this process from someone who understood the system and how to answer the questions was deemed essential by some. Another explained how she had got used to it over the years and was now wise to what was required.

"You almost feel as if they think you are pretending to be blind…I don't understand really, when you have got a diagnosis of something that is

not going to improve, why you have to keep proving yourself over and over again.“ (WA, SSI)

“You have to abandon all pride and think really kind of outside, literally think of the worse possible scenarios …For example, if I was asked years ago can you dress yourself? I would be like of course I bloody can but then you think you break it down and I have been taught to think like this, well do I know if I have got a stain on my clothes? No. Can I match my clothes colour wise? Well no not all of the time, so do I need help with that? Well yes I do ... So that is why I suppose my ESA was quite smooth and they didn’t even have to see me I suppose because I knew all of the things that I had to say, but none of it was false, but I just knew what I had to include.” (WA, SSI)

- **Assessment process.** Some participants had experienced straightforward assessments, but others had encountered difficulties. This included issues with accessibility such as a badly lit and signposted venue and stressful experiences of assessment processes and decisions. This included a ‘battle’ to be put into the ESA support group, a ‘traumatic’ outcome when deemed ineligible for ESA but unable to work and refused JSA and going through an intimidating court hearing when refused PIP after being moved from DLA. As well as financial implications these experiences could have tremendous emotional impact and affect mental health.
- **Professional support.** From the third sector such as sight loss charities, Age Concern/ Age UK and Citizens’ Advice Bureau played an important role in benefit receipt. RNIB in particular had enabled a smooth transfer from DLA to PIP over the phone and had been a source of support in making applications – both with physical help filling in forms and knowing how to answer questions. When problems arose they had been instrumental in supporting appeals and participants felt this was crucial to successful decisions, as without such help they would not have had the expertise or money to pursue the case themselves.
- **Future uncertainty – the shadow of reassessment.** Concerns about the stability of benefits, in particular, the prospect of reassessment - ‘having to prove yourself over and over again’ – was a

worry, which some felt to be frustrating or unnecessary given that their sight will not improve. This related to staying in the ESA support group or concerns about an impending switch from DLA to PIP and fears that they may lose their award. Furthermore, there was a sense of unease about the current government's attitude to disability benefits and how this might affect future provision.

"I am concerned about the benefits system… I am lucky at the moment but it seems like a bit of a lottery as to whether you get put in the right group or wrong group or whatever way you look at it and I know that that could change at any time and if that were to change I would be buggered to put it bluntly. So yes that is a worry and you know, not to get political or anything, the government do seem intent on stopping or lessening your disability payments." (WA, SSI)

Drawing on disability benefits to meet needs

Some participants saw extra cost disability benefits as going towards a particular aspect of need and spending directly related to the additional needs associated with visual impairment. Several talked about it helping with travel – whether going towards the cost of support with getting to leisure activities, paying for a mobility car for a relative to provide lifts, or the extra cost of getting a taxi rather than the bus.

"My DLA has always just gone in to my household income and it is paid for everything that I need in the house, but when I have to pay for taxis and things I do think I justify it by saying that is what my DLA is for and I do use it. Without it I just would not be able to do those things, so I do use it for what it is meant for." (WA, SSI).

Others used it to pay for personal assistance, a cleaner or gardener, or felt that it helped to cover extra costs of equipment, or a more expensive phone than they would have otherwise. However, this was not always possible. Several working age participants with particularly low disposable income (in cases where we estimate this to be only around half of what is needed according to the MIS VI research) depended on their disability benefits to contribute to general living costs. One noted that she would love to be able to spend her DLA on support and taxis but

after paying bills (including a mortgage) “there is not much left of it to do what it is meant for”. Here disability benefits can be an important lifeline for people who find themselves in very tight financial circumstances. As well as the financial benefit, some participants highlighted a qualitative aspect of receiving disability benefits in relation to how they drew on family support. For example, receiving Attendance Allowance enabled a participant to give a set amount to a relative who was providing support – this arrangement legitimises her expectation of help, she feels more able to ask, and less indebted as it evens up the balance. Another, whose DLA mobility element provided a car which a family member used to drive her around, doesn’t feel bad about asking for lifts, which she might do otherwise.

An additional way that the benefits system helps people on low incomes cover additional costs is by associating other entitlements with the receipt of means-tested benefits, which made a difference for some participants. For example, those receiving such benefits were eligible to be reimbursed for the cost of travel to hospital appointments, which often entailed journeys to Moorfields hospital in London, as well as free prescriptions and dentistry, money towards glasses and in one case free access to a local gym.

Pensioner incomes

The incomes of visually impaired people of pension age came from varied sources. Some participants had no or very little pension other than State Pension. This made the receipt of the means-tested Pension Credit particularly important, in combination with Housing Benefit for those who were renting. Older women (aged over 75) in particular were less likely to have much in the way of their own work pensions, although for some who had been widowed, their husbands’ pensions supplemented their income. In contrast, other participants, including two women aged under 70 who had solid employment histories, were receiving more of their income from work pensions. A lump sum pay out upon retirement had also contributed to savings which were being used to supplement income in one case. A key feature is that pension incomes tended to be stable.

While pensioners' safety net through Pension Credit is more adequate relative to MIS than working age benefits, giving pensioners a better starting point, the availability or otherwise of disability-related benefits played a crucial role in how close a visually impaired person of pension age can get to meet their minimum needs. Only one person in this study was receiving neither Pension Credit nor a disability related benefit. The following further patterns emerged.

- Most of those on Pension Credit had been receiving it for some time or didn't remember applying. Only one participant recalled actively applying for Pension Credit - they had not been receiving means tested benefits but happened to see a notice about pension credit and the subsequent visit triggered a claim for Pension Credit, Housing Benefit, Council Tax Benefit (the last now replaced by multiple "localised" schemes), as well as Attendance Allowance which made a huge difference to their finances – they no longer "had to scratch and scrimp to last the week out".
- Some pension age participants received DLA and in one case PIP from claims made before reaching pension age. This included most severely sight impaired pensioners with long term sight loss and someone with an additional long-term health condition. They all received the mobility element (which is not included in Attendance Allowance) which, depending on the level received, can mean higher disability benefit income compared to Attendance Allowance.
- Access to Attendance Allowance varied, with very important consequences for overall incomes. Several participants had received Attendance Allowance following VI registration where a visit from social services or the local VI organisation had initiated the claim. However, four pension age participants were not receiving Attendance Allowance – these had some useable sight and were either more recently registered sight impaired or not registered. While one had been advised she was not yet eligible for Attendance Allowance, others were not aware of it or had not thought about applying. Those who received Pension Credit but not Attendance Allowance missed out, not just on the amount of extra benefit itself but on the supplement to Pension Credit that this would have triggered.

Three of these had much lower incomes than most other pensioners in the study, falling at least 25% short of the MIS level. They were managing to make ends meet, but this could mean living frugally, otherwise drawing heavily on additional informal support.

- Not everyone registered as visually impaired, even though it can bring substantial benefits. Two pension age participants were not certified or registered as visually impaired. Both were aged over 85 and had had sight loss for at least ten years, their sight was deteriorating and they were receiving regular treatment or check-ups. However, they had limited awareness of the process and it had not been suggested to them. Among other participants, some had been certified and registered on the suggestion of an optician or consultant, but others only because they happened to hear about it from other sources and had asked or initiated the process themselves, indicating some ambiguity about the process. Participants' experience demonstrated a range of financial, practical and social advantages of registration. It had triggered visits from social services and local VI organisations who performed benefits and needs assessments; this had led in some cases to Attendance Allowance receipt, free provision of basic low vision aids (see further in Chapter 4) and access to local VI networks and social groups – where all of these things had come together it could make a huge difference to someone's life.
- Pensioner income tended to be much more stable than it was for those of working age. They did not share the concern about reassessment or losing benefits once awarded. The positive impact of receiving regular income from pension and pension credit, as well as rent being covered by Housing Benefit was particularly noted as helpful where income had in the past been unpredictable for example from self-employment. Having a stable income made a 'gigantic difference'.

Housing costs and choices

Housing costs were taken into account when estimating participants' disposable incomes. For some participants on means-tested benefits, rent costs were covered largely or fully by Housing Benefit, so this housing cost was balanced in the income calculation. However, housing

costs could considerably lower the amount of disposable income for those who were renting where earnings or occupational pensions excluded or reduced Housing Benefit; or if they had private rents above the Housing Benefit 'Local Housing Allowance' (LHA) entitlement limit; or paid service charges; or those who were owner occupiers with a mortgage.

Working age participants generally faced the largest housing costs in this study. Highest costs were incurred by those paying mortgages. Two were working part-time in Permitted Work but their mortgages consumed a large proportion of their income which reduced their disposable income to below the MIS VI threshold. An issue in one case was a participant being obliged to have a parent on the mortgage which shortened the duration of the loan resulting in larger than planned monthly payments; another had originally shared a mortgage but was now paying it on their own. Although they realised that they might be entitled to Housing Benefit if renting (as both were on ESA) they valued the security of having their own home which they felt suited their needs – one commented that renting would most likely mean private sector accommodation with less stability and space for their guide dog. Pension age participants in this study had nearly all paid off their mortgages.

Several issues relating to visual impairment could affect housing options and costs.

- **Familiarity was important**, particularly for those who had little or no sight. In theory some participants might have been able to reduce costs if they moved to cheaper or smaller accommodation, but it was repeatedly stressed that their home was a safe environment, they knew where everything was and the thought of moving in this context would be very daunting. For example, being reluctant to move to a smaller property as unable to face the 'upheaval' and learning where everything was all over again. Learning new routes outside of the home was also raised as an issue for anyone relocating. Familiarity was a key reason for some pension age home owners to be resistant to the idea of moving.

- **The extra costs of accommodation** to meet needs with security, services or warden provision. Service charges could add to or incur housing costs which weren't covered by Housing Benefit. This included rented, shared occupancy or owner-occupied properties. Costs varied according to the extent of provision and whether it included extra services such as in-house services: sometimes including social opportunities; washing facilities; wardens; or emergency alarm services. A few pensioners had recently faced charges for their warden service which had previously been covered by subsidised funding schemes.
- **Location was important** and could affect or be affected by affordability. One participant was paying higher rent to live in a city centre as wanted to be near amenities and accessible public transport. Another, who was working, had moved but felt restricted by his income and could only find an affordable property on the outskirts of a city, as a consequence, is dependent on buses or taxi to get anywhere.
- **Housing costs and benefits.** In a few cases rents were not fully covered by Housing Benefit because participants were living in larger properties than deemed eligible by benefit rules. This meant LHA not covering rent in a private rented flat and being liable for 'bedroom tax' in social rented property. In both cases, adult children had moved out, so they had not actively chosen to 'under-occupy' their housing. However, living in a non-congested space was helpful and as mentioned above moving was not straightforward.
- **Stability**. Several participants living in the private rented sector did not feel very secure – in one case they had a one-year contract, were sharing and were dependent on their housemate staying or finding someone else to live with. In another they felt under threat of eviction from the letting agent as they thought the agent didn't want a visually impaired individual living in the property, and the landlord had also increased the rent.
- **Constrained moving options.** A couple of participants living in social rented accommodation wanted to move to more convenient locations with additional accessible facilities (see also Chapter 4). However, they faced difficulties, for example finding social rented properties in

their area suitable for a guide dog, and in another case they wanted to move to a different area and as such were not considered a priority, so had to look for alternative housing providers.

Conclusion on income patterns

The above discussion has shown that a wide range of factors affect visually impaired people's disposable incomes, with the potential for some having far less than they need, while others are better provided for.

Overall, for working age people, the most serious shortfalls occurred for those falling below the 'safety net' levels, in one case an asylum seeker and in another someone who was refused benefits on the basis of job search criteria. Other than these cases, the factor most commonly causing very low disposable income was housing costs. This was particularly true for those with mortgages, those working and not receiving any or only part Housing Benefit, and those out of work whose Housing Benefit fell short of covering their rent (because it was above the LHA limits or because of the bedroom tax) or who faced additional service charges. On the other hand, two people with jobs had incomes that just met the MIS VI level, but only because they limited their housing costs by sharing accommodation.

Among participants of pension age, low income was also sometimes associated with high housing costs – most notably for one person paying more than their entire income to live in expensive housing with care provided, whose savings meant there was no eligibility for Housing Benefit. Others who were renting were getting full Housing Benefit, although some with warden-serviced accommodation paid a service charge that was not covered by benefits. However, systematically the most important factor that can bring the income of visually impaired pensioners well below what they need is not having Attendance Allowance or other extra-cost benefits, along with the Pension Credit supplements that go with them. While pension age people in this study were generally not as badly off as the worst-off participants of working age, they could still fall more than 25% below the MIS VI level. This

contrasts to others of pension age who can get close to and above the MIS VI level, even when on means-tested Pension Credit, particularly if they have paid off their mortgages. Finally, pension age people can get closer to MIS VI if they have DLA or PIP with the mobility element than with Attendance Allowance, which has no such element. Since those who become disabled after pension age are eligible for Attendance Allowance rather than PIP, there is potentially a perverse income advantage associated with having become visually impaired before reaching pension age.

Chapter 3: Meeting needs and prioritising resources

Visually impaired people on lower incomes must often make tough decisions about what resources are most important to their daily lives, both in order to meet their basic needs and also to meet additional needs brought about by living with a visual impairment. This chapter starts by looking at how they prioritise and the extent to which they succeed in meeting needs, in four aspects of their lives: providing basic material necessities; maintaining social participation; purchasing specific goods related to visual impairment; incurring other additional costs and saving for contingencies. It goes on to consider the overall implications for people's living standards and concludes by making some observations about the pressures and implications of being on a low income when you are visually impaired.

Basic material needs

Within this study participants talked about the non-negotiable costs of meeting their basic material needs which included housing costs, utility bills, basic clothing and food. Participants generally stressed the importance of ensuring that these basic needs were met, and crucially paid for, before taking into consideration their other needs, which were often related to their visual impairment.

"Well I guess you know any gas and electricity and water like you have got no choice with those kinds of bills, so they are first and foremost… I have got to think about paying them every month, there is no two ways about it." (WA, SSI).

The participants were, in general, able to meet these basic needs. There were instances where these needs were being met at a minimum level, and compromises were sometimes made. For example, several participants reported occasionally needing to 'stretch' a food shop so it lasted longer at the end of the month. For two participants this was the result of living on a low income well below the MIS VI level, who were not able to claim means tested benefits, whilst for a third person, food costs were an area that could be reduced at times to prioritise spending on

social activities. Two other working age participants had their housing choices constrained by low income. They lived in multiple occupancy shared accommodation as a means of accessing affordable housing within central locations close to work. Housing costs for these individuals would be much higher to manage if they lived alone; effectively meaning the only choice open was to share with others.

There were several participants, particularly of pension age or older working age with a lack of informal support, who acknowledged the importance of insuring more expensive household items to provide peace of mind as a safety net to limit unexpected costs. For two participants this was prioritised as they now live alone and can't depend on a spouse or family member like they had previously. Despite the extra cost, insurance was cited as particularly important for those on a restricted income, as insurance payments could be made in manageable monthly increments whereas issues arising, for example a boiler breakdown, could incur large one-off costs.

"I need to have things repaired because things can break all of the time and to get somebody in, god it costs the earth … if you are covered by insurance that does help a lot you know." (PA, SI).

They realised it was a sizeable regular cost: one paid over £700 per year, in addition to excess for each call out, but felt it was necessary as they had no one they could call on to help, and their visual impairment made it difficult for them to quickly search and find a suitable person in an emergency, as they were unable to see a phone book or use the internet. There were examples of insurance for home care that went beyond standard building and contents but covered repairs on a range of household items and services. Other examples included personal accident cover, private medical insurance and mobile phone insurance. For most of the participants with these additional monthly costs, these were perceived as part of their non-negotiable living costs and as such a basic need to be met before other priorities.

The fact that overall, participants prioritised and met their basic material housing and food needs sometimes meant restrictions in other spending areas, which are now looked at in turn.

Social participation

In the standard MIS budgets there are allowances for leisure activities to allow individuals to socialise outside the home, eat out and take a holiday as a minimum for social participation. Similar provisions are made for the MIS VI budgets but with additional amounts to cover extra costs where these are incurred. Socialising was cited by many of the participants as the next priority after bills and food. This included activities such as taking part in sports, including VI specific sports; exercising and going to the gym; participating in social or drama clubs; attending lunch clubs; going to church and church activities; watching live sports; attending walking groups; going to the cinema and going out for meals. The cost of participating in these activities includes some elements common to the whole population (like the price of a cinema ticket) and others that are distinctive to VI people (like paying additional transport costs or treating a friend to a drink or a meal as reciprocation for practical help when going out).

Participants in the study, who lived alone, saw it as important that they should get out of their homes and meet people. Several noted the risk of isolation and need to keep occupied and appreciated having meals out (for pension age individuals this was sometimes subsidised through groups or lunch clubs). Many of the participants emphasised the positive impact that socialising had on their lives. For some, interacting with other individuals with visual impairment was important as it allowed them to discuss shared experiences as well as identify new equipment and gadgets that could improve their day to day lives. Social participation was clearly important for mental well-being and helping to limit seclusion and loneliness.

“If I had to prioritise it I would say that I will always make sure that my bills are paid first, probably it would be socialising would be my next big expenditure and important to me because without that I wouldn’t cope at

all, so for me to be able to get out you know … emotional wellbeing is really an important thing." (WA, SSI).

"It is very easy to become isolated, when you do your mood just like plummets and once you're in that mood you tend to want to stay in that mood so you don't want to go out, when you do go out you interact with people it is… it lifts your mood doesn't it?" (WA, SSI).

However, in one case where activities were provided in a housing complex, a participant felt unable to join in, for example as they couldn't see to play bingo. Most respondents, particularly those of working age, were dissatisfied with the amount of socialising they were able to do and stated that they did not go out as much as they would like to. There were multiple participants, with incomes below the MIS VI threshold that consistently restricted spending on social activities as they had to prioritise their limited budget to cover their basic needs rather than pursue their interests. Participants discussed how they would really like to do more of the same things, for example attend music concerts more frequently and go out more to socialise in the evening. There was an emphasis from some of the participants on the need for greater control and flexibility of their social interactions, for example wanting to try new hobbies and visit novel places and not have to rely on a friend but be able to choose where and when they go places (which would likely incur additional costs to cover a personal assistant (PA) to accompany them).

"I would just do more, so whether that would be with the support worker or getting out, you know being able to pay for taxis and stuff and not being as isolated, because even though I have got a job, the social side of it is still pretty rubbish." (WA, SSI).

There were examples where participants talked about the difficulty of reciprocity with friends, for example buying a round of drinks in a pub, and the emotional impact of wanting to join in but then having to severely limit spending until the following month.

"Q: So when you said that you sometimes have to cut back on say your social life, what difference does that make? What impact does that have on you?

R: Well I will sit back and sulk and say well that was bloody stupid…you shouldn't have spent that extra £15 yesterday, that was silly…I do curse myself if I do something stupid like over spending, I don't like doing that." (WA, SI).

The MIS budgets include a holiday as it has been established that individuals should be able to get away from their four walls and have a break from their routine and an opportunity to socialise with others. The MIS VI budgets recognise the same need but identify that individuals with a visual impairment, particularly if they have little or no sight, are likely to incur greater costs, for example they may have to subsidise a companion's trip. Holidays were discussed by participants as being beneficial, but not all participants were able to afford them. Several described how they saved up over several years to be able to afford to go abroad for a special occasion, such as a notable birthday. Others spoke of not being able to afford a holiday but budgeting for short weekend breaks to visit friends in the UK.

"I rarely go on holiday, I go away for the weekend you know I mean I have got friends in Manchester I go to see them down in London for the odd weekend but can't remember the last time I went on actual holiday, years ago…I just couldn't afford, the budget wouldn't allow it." (WA, SSI)

One participant limited her social activities throughout the year and put off home improvements such as a roof replacement, to save to go away for one week per year as she felt that she really benefited from having that break.

"Yes I mean I don't go out that much during the year and if I do it is very often for lunch rather than dinner in the evening so that I do have money to spare for holidays." (PA, SI)

For some participants, particularly of pension age, there were non-financial restrictions on their ability to be as socially active as they would like or go on holiday, such as not having an appropriate person to go with or limitations in their mobility. When discussing what they would include in their budget if finances were to improve, the majority

suggested that social activities, including holidays, would be a key area where they would spend more money.

Appearance

The ability to maintain and keep up a presentable appearance, including having regular hairdressing, is included in standard MIS budgets. This is intrinsically linked to social participation, as feeling confident in one's appearance can be important to be able to interact socially. For MIS VI, this includes wider aspects of personal care, as it is recognised that additional support is needed by those that are visually impaired. Several of the female participants emphasised the importance of investing in their appearance. This includes trips to the hairdressers and beauty salon to maintain hair styles, hair colour, facial waxing and manicures. Several participants described how eyebrow shaping and nail trimming were a definite cost resulting directly from being visually impaired because they could not see to do it themselves and wouldn't be an area that they would have to spend money on otherwise.

One participant described how she has her hair coloured in a specific shade that she had prior to the deterioration of her sight, as despite no longer being able to see it, she knows the colour looks good and suits her, which gives her greater confidence in her appearance. This was also linked to the importance of familiarity, as two participants described how going to the same place as they used to go, prior to the deterioration or onset of sight loss, made them feel like the same person as before. They both described how it was also comforting knowing that the hairdresser knows what they liked before and can replicate that.

"Well it makes you feel good if you can't see yourself how you look or how other people look you kind of go by stuff that maybe you used to do and I did. I used to kind of do my hair quite a lot and I used to be able to see it, I mean this colour I have had it for quite a few years now, and I used to get it done when I could see it, so now like I am sticking to the same colour…[the hairdresser] knows what I used to get when I could see it, what I liked." (WA, SSI)

Another talked about a feeling of guilt and explained that she was considering cutting back on spending money on having a manicure, despite not being able to trim or paint her nails herself, as she felt it is an unnecessary cost. All the participants that talked about the upkeep of their appearance identified it as integral to help them feel that they are looking good and key for their self-esteem.

“You want to feel that you look as good as anybody else…it is confidence boosting when people say that you look nice…well you must know yourself but you at least can look in the mirror and you can say to yourself well if nobody else likes it I do and blow the lot of them, well I can’t do that, so somebody says that looks really good on you, you think oh wow great I am doing it right.” (PA, SSI)

Transport

Within MIS there is a budget for taxi usage which is seen as an occasional supplement to public transport but in MIS VI this aspect is set at a higher rate (which varies depending on age and extent of sight loss), as it recognised that individuals with visual impairment will have a heavier reliance on taxis to support their day to day needs. Access to social participation was often heavily tied in with discussions about public transport and affordability of taxis. For many of the participants, taxis were inextricably linked with other areas of spending and as a result were a priority to support them to get out and about to socialise, go food shopping or attend appointments. Some of those with little or no sight, or those living in more isolated locations that were unable to access public transport, described how they had little choice but to use a taxi if they needed to get somewhere. This was most pertinent to those with limited access to other options, such as lifts via informal or paid support, meaning a significant monthly spend on taxis.

However, several participants described restricting taxis to once a week or even once a month (less than included in MIS VI budgets). One participant explained he had to weigh up whether he could justify spending money on a taxi when he could wait an hour and use his free

bus pass. For several participants this was also an outgoing that was curtailed when the budget needed to be spent elsewhere.

“It is the easiest one to make the adjustment with and the quickest whereas food bills keep going up, telephone bills will keep going up, equipment bills will still be there, so yes transport is the one that you would look at first.” (WA, SI)

There were others, particularly those with access to informal or paid support, who talked about only using taxis as a last resort due to their prohibitive cost, would make the decision to prioritise other areas of their budget and rely on planning outings with the support of a PA, friend or family member. Most participants, particularly those of working age, agreed that if they had more money it would give them the flexibility to use taxis more which would enable them to have a fuller social life and allow them to be more spontaneous with their activities rather than having to plan several days or weeks in advance.

“I suppose it would just save a lot of time and convenience really especially when you’re doing things at the weekends or later in the evening when the buses are starting to dry up a bit.” (WA, SSI)

VI specific items and technology

In the standard MIS budgets, it is recognised that individuals should be able to have access to a computer, their own basic smart phone and the internet within their household, as these are seen as important to being able to participate in society. Within MIS VI budgets it has been established that there are additional costs involved with meeting these needs to enable accessibility e.g. through screen reading or magnification software and a higher specification, more expensive laptop required to run accessibility software. Participants described how the specialist equipment, technology and software supported them in their daily tasks and interests and helped meet their VI needs, and what it meant when this was not fit for purpose or unavailable. There was much discussion about the value of smart phones, screen reading software, scanners, magnification equipment, specialist lighting and brailling

machines that could support visually impaired people to maintain independence and help with a wide range of daily tasks.

Several participants with little or no sight, talked about the prohibitive price of computer software, such as JAWS, Dragon, Dolphin and J-Say, which often have upfront costs of more than £700 with additional costs, usually over £100 for annual updates. For some this has meant making do with limited and slow functioning software, or for a limited time using free or trial versions which lack full functionality. Others described the great expense required to replace a laptop with one that had a decent specification, to ensure it could run software; this could involve spending two to three times as much as an entry level computer. Combined with buying and updating the accessibility software, this could mean having to spend significant sums of money in one go. As a result, some visually impaired individuals are going without access to the internet and other computer functions. Some that had a smart phone, were relying on it to carry out tasks they previously would have done on the computer, but this was not an adequate replacement for all functions. Not having enough money to immediately replace such integral items has extra significance for someone who is visually impaired; it can mean extra 'hassle', relying on others, or using credit, as one participant explained.

"I have been needing to for months now but because [the laptop] is just really, really slow and keeps crashing but it is just building money up for it…. it is quite essential so at the minute I am just doing everything on my phone so like replying to emails and stuff like that, I will just do it on that because I just can't be bothered waiting all of that time on the laptop." (WA, SSI)

Several participants said that whilst the range of features and apps on smart phones is extensive, there are certain tasks, such as completing online forms, that are often not compatible with mobile screen reading software, leading to unmet needs. Others were much less engaged with technology, and several talked about researching computer or tablet options, as well as training to use accessibility software, but were immediately put off by the price, and as such have no access to the benefits that such technology could bring.

“Well I would have one like I say but it is the price of them… RNIB do them, they do one that is easy for blind people…But that is a lot of money though… I asked about a computer once, oh yes, about £700…I was going to try the computer training but then when they told me the price of it [the computer] I thought oh cheerio.” (PA, SSI).

Others talked about not having access to the internet at home, either to save money or due to a lack of knowledge or device accessibility. One participant described how he relied on his phone data for all his online access in an attempt to cut down on monthly bills, but explained it would be easier for him to use the internet on his laptop as the screen is much larger than his phone. Another described teaching herself to touch type and exploring trial versions of screen reading software but the cost and her lack of experience using the laptop were barriers to using it to get online. She was unsure if she could perhaps access second hand software or pay monthly as the upfront cost was too high for her to consider. As a result she relied heavily on her landline to manage banking, pay bills and to communicate socially with friends and family, which accrued very high bills each month.

“Well just like just general socialising, ringing people but then like things you need to sort out like your bills, appointments so really getting on the internet and learning that is really what I need to do. I feel there is pressure on me to hurry up and do that because otherwise I am just going to get left behind you know, it would save a lot of time as well.” (WA, SSI).

Having access to appropriate software, and crucially receiving some training, would enable her to rely less on her expensive landline calls and explore the broader benefits of technology to support her VI needs. There were other participants with some useable sight who described the value of magnification and particularly video magnifying equipment and CCTVs. These are desktop devices that project a magnified image onto a monitor or handheld video camera that enable users to zoom into the text as necessary. Where someone had no sight and did not use other technology a scanner reader was invaluable. Several explained the significance of such equipment in terms of their independence as, for

example, it allowed them to read their own mail and not have to rely on others.

“It is something I couldn’t manage without because I can look at my post on it, and it means I don’t have to ask people….I would hate to have to ask people to read my letters and that and I think you need some kind of independence or keep things private . But also I am able to do like crosswords and puzzles and Sudoku and things like that which is a hobby I like.” (PA, SSI)

The prohibitive cost of such items, often over £1000, means not all who would benefit have access to them. There were examples where participants felt lucky that they received support from VI charities to source quality second hand equipment or in the case of one individual to receive one for free.

Knowledge of specialist equipment and technology was lacking for some participants, particularly for those of pension age (who account for the majority of people with sight loss) who could be missing out on potentially beneficial equipment which could support their daily tasks and help them to continue to pursue their interests. Some, often those individuals losing their sight in later life, described how their sight loss has led to them no longer being able to pursue hobbies such as reading for pleasure and craft activities such as knitting. Whilst there are audio books available these were not always seen as accessible or a true replacement to meet their needs. Several participants were unaware of what was available to support them and described struggling to read using very basic handheld magnifiers, which were not suitable for reading a large amount of text. This meant that reading and other hobbies like craft work were no longer enjoyable or even possible in some cases.

For a lot of participants VI specific items, such as magnifiers and screen reading software were identified as key resources which supported their daily tasks, but were an area that many were not able to use to the fullest as they lacked finances to buy or update items or didn’t have the knowledge of what was available or how they could get support with it.

The need for support

Some participants, particularly those with little or no sight felt that their need for support could be compromised or unmet due to a lack of financial resources to pay for help. This included help with day to day tasks such as cleaning, food preparation and shopping. Local authority funded support was welcomed by those who received it but for some the extent of provision limited how it could be utilised (as discussed further in Chapter 4). This was an area where people felt their lives could be enhanced if they could afford to pay for (more) help which would give more time for tasks and could include support with social activities.

“I would pay for more support, absolutely, definitely it would be for things that I could do at home, it would be for things like shopping in town … I have got a guide dog and I can get on a bus and I can go to town. When I get there I can’t find anything, you know, there is only so much assistance you can get in shops, it is not the same as having somebody you know with you constantly around town, it is not easy at all.” (WA, SSI)

Another unmet need concerned support with DIY. Several participants were no longer able to do jobs around the house, such as maintenance and painting, and instead having to rely on family or paying for a handy man. One participant had tried to fix an issue with his sink, despite finding it hard due to his sight loss, to avoid the cost of having to pay a plumber. Others described the need to update décor and not having anyone to ask and lacking the funds to pay a professional.

“So decorating…. you have got to pay for it to be done whereas as a sighted person I did all of my own garden, I did all my own decorating. Just last week my fence needed painting badly so I had to pay somebody to paint my fence. All of those little things that you could do yourself that I can’t do anymore…. that is one of the biggest outgoings I think DIY.” (WA, SSI)

Money for contingencies and savings

A final additional need was around the ability to save from a budget to cover contingencies and unexpected costs, as well as to build longer-term savings.

Some participants with incomes around the MIS VI threshold did have savings and felt reassured that they had access to some ‘rainy day’ money, whilst a few others described having a small ‘buffer’ to give short-term assurance that basic needs could be met. Savings were particularly important for those who were not working, where they were mindful that they could not be replenished once spent.

However, many participants in the study had no or very little savings, including most working age participants. The difficulty of having low income can therefore have a compounded effect on people’s finances by preventing them from saving money that gives a financial fall back. This is particularly relevant given the prohibitive cost of some specialist VI goods or technology that people draw on, and the extra difficulties caused by being unable to immediately replace even everyday items that visually impaired people rely on.

“If the washing machine breaks down tomorrow, I have got to think do I just go on the credit card, well I have still got to pay it back … Can I really afford it?… Or do I then think well I take or get someone to take my clothes to the laundry which wouldn’t be practical because you have got to feel the machine… I am not saying you couldn’t do it as a blind person, but it would be a bleeding hassle.… it wouldn’t be a case of the washing machine goes wrong oh I will just replace it. But if I had that buffer, because it is always them things that come up that you don’t expect that you just can’t budget for. If you had that little bit of extra money, I wouldn’t call it savings but you put it away or have it to hand for them times.” (WA, SSI).

Having no savings and a lack of flexibility in their budget for the short term, also brought concerns about the impact this would have on the long term for example, building up credit card debts. A few participants had credit card balances or debts that they were trying to pay off which

added to monthly outgoings, leaving even less disposable income. These were either historical debts from losing a job or reduced earnings after becoming visually impaired or from ongoing use of credit cards to pay for larger cost items which couldn't be paid for outright. However, many participants were very conscious of the need to avoid debt, whether because of a lifetime attitude especially among those of pension age, or through knowing that with limited income it could be hard to pay back.

Looking ahead to future needs, some participants mentioned the impact of a deterioration in their sight, general health or age-related mobility issues and the need to plan for such eventualities. Some participants talked about savings for the future in relation to the precariousness of disability benefits and social care support, and how having some savings would provide greater peace of mind in case personal circumstances or government policies were to change in the future.

"How am I going to stay financially stable?....And make sure I have got enough money to live off because I need money to survive, we all need money to survive. And again with my direct payments, that is not forever, they come and review that every year, that money could go and then I am going to be stuck as well, it is just a stress every year." (WA, SSI)

Potential costs were a concern especially where people didn't have family around and they would be dependent on paying for formal support. Indeed, one participant had moved to a retirement village where the housing with support costs outweighed his income and was quickly depleting his savings. A few participants (working and pension age) had seen larger levels of savings deplete over the years, when they were out of work and outgoings outweighed their income, or they had additional spending on housing or health related costs. This could bring savings down to the eligibility level for means tested benefits, which would provide an additional income stream that could reduce the need to draw on savings.

Overall perceptions of living standards

Participants' perceptions of their financial situation and the extent to which their needs are met varied across the sample. They fell broadly into three groups which generally but not always reflected the financial resources, levels of informal and paid support and social participation available to them:

A first group report, **feeling comfortable***:* those who felt quite content with their financial circumstances. While not having to worry about their finances, they still watched their budgets but didn't feel that they were missing out on things. Most of these participants had incomes over 75% of the MIS VI level and had some savings that they could fall back on, so for example were able to cover a large expense if necessary. There were more pension age than working age participants in this group. A few of these participants noted that their financial situation had improved in recent years, so they felt comparatively better off; this was where incomes had increased, for example where they had received disability or means tested benefits or had started doing permitted work. Several talked about feeling 'lucky' that they were in this position, though some noted that this could change in the future.

"R:…reasonably comfortable, I am not a bit worried ... I manage with what I have got but I don't feel poor about it…

Q: Is there anything that you think you would spend more on if you had more money?

R: Not just for the sake of no, no. I wouldn't spend money just because I had got it." (PA, SI)

Some in this group with incomes close to or below the MIS VI threshold felt secure as they had access to a stable informal support network which enables them to save money in certain areas of spending, for example transport, and can help meet social needs (see Chapter 4).

The second group include those that were **getting by.** They felt that they were 'coping' or 'breaking even' and could 'keep afloat' without having to

struggle to pay everyday living costs. Participants talked about the need to be ‘careful’ or ‘not go mad’ with their budgets but could make ends meet without too much difficulty. However, they generally faced restrictions in their spending, and there were often things that they said they would spend more on if they had more income, for example on additional support to participate in more social activities or update specialist equipment. All had incomes of 50-99% MIS VI and were a mix of working and pension age participants. Most, but not all, had some savings, but lower amounts than the ‘comfortable’ group, and sometimes viewed these as being kept aside for emergencies, or as a ‘buffer’, rather than for everyday spending, and for several these had depleted over the years.

“I have got my head above water I am not worrying about not paying the bills but you know obviously I don’t have the spare cash to improve things so that can get you down. But I know that I am lucky in the sense that I have got a roof over my head and I can pay the mortgage and my bills so the fact that there is not a great deal more left after that is you know it is a sad… but it is not the end of the world.” (WA, SSI)

The final group consists of those who **found it difficult** to afford what they needed, although their circumstances and the nature of their financial situations varied considerably. A few participants were on very low incomes under 50% of MIS VI, as they were not able to claim means tested benefits. Without savings this meant very limited financial resources and restricted spending, at the extreme depending on friends and charity for essentials. These participants were waiting for their financial situation to improve; through reaching state pension age in one case, or through being granted UK residency in another. One pensioner had savings, but outgoings including rent outweighed income, so these were being used to pay for living costs. Others with incomes that were not as low, at over 75% of MIS VI, still found finances very tight and had no savings, and a few had debts or credit card balances that they were repaying. These participants talked about having to tightly control their money, were constantly aware of finances and had no leeway in their budget which could involve ‘juggling to afford to pay everything’ or ‘getting nervous at the end of the month’. This meant going without or

not replacing items or being unable to do things that they would like to do such as travel. Participants in this group tended to more heavily restrict their social participation and some cited feelings of isolation and loneliness. Some of these participants had been in better financial situations in the past, for example when earning (more) money from work – this could act as a reminder of more affluent times, as one participant noted:

“It is a big come down when you used to have money and you couldn’t care less and go out and go where you wanted, do what you wanted where you went, but I know now those days are gone.” (WA, SI)

Conclusion

This chapter has highlighted the key spending areas prioritised by visually impaired people and has identified the often difficult decisions that must be made to meet the additional needs brought about through sight loss. In general, it has shown the prioritising of resources according to a hierarchy that privileges first the meeting of basic material needs, then a range of interrelated needs which include social participation, buying equipment and meeting other needs such as paying for additional support and services.

The extent to which people have to forego requirements in these categories varies considerably for different visually impaired people on low incomes. However, a general theme is the need to put considerable effort into careful budgeting. Many of the participants within the study acknowledged that they must be organised; precisely manage their budget and be money ‘savvy’ when planning their outgoings in order to best meet their needs. The process of having to make decisions about what they can or cannot afford can itself be a source of stress. Thus, the personal well-being of visually impaired people can be affected both by having incomes too low to be able to afford to meet all their needs and participate fully in society; and also by the daily experience of having to make tough choices.

Chapter 4: What makes a difference: resources and circumstances that can help or hinder meeting needs

The previous chapters have looked at economic resources and the extent to which participants in this study were meeting and prioritising their needs across different areas of life. This chapter looks further at some of the drivers of these outcomes for visually impaired people: other than the level of their income itself, considered in Chapter 2, what other factors make a difference to their lives and to their ability to cope within limited financial resources. While overall income is important, so are a range of other influences on the lives of individuals.

This chapter considers five broad influences that can make it harder or easier to cope on a given income.

- The **support** to which visually impaired people have access, including support provided by public authorities, informally from family and friends, paid for by individuals, and received from services and organisations.
- The extent to which individuals are able to **make the most of their money**.
- People's **location** and how it affects individuals' access to facilities and public transport.
- How well they are able to interact with **technology**.
- People's **health** including both physical and mental health.
- **Responses to sight loss**.

Access to support, services and organisations

In order to enjoy an acceptable living standard, visually impaired people can require various forms of support from society to help them meet their needs. Support of various kinds may be supplied or financed by the state, third sector or charities or provided by friends and family. This section looks first at access to human support, which is particularly important to visually impaired people in assisting them to participate in society. It then goes on to consider the significance of access to services.

Access to human support

The MIS VI groups recognised the need for various forms of human support and their cost implications, which increased with severity of visual impairment and with age (where the impact of sight loss can be combined with deteriorating mobility). Payment for some services such as help with cleaning or more general assistance was included in the MIS VI budgets, as was the indirect cost of having help from a friend, identified as being able to reciprocate by buying them a drink or occasional meal. However the MIS VI budgets did not include the cost of social care support where the cost is supported by local authorities which will depend on the individual circumstances. The majority of participants in this study had some form of paid-for support (from cleaning and gardening to PA support). In seven cases PA support was financed or part-financed by a local authority.

Local authority supported social care

Those receiving social care support viewed it as essential to maintaining independence, and generally used it for help with everyday living tasks such as cooking, admin, help around the home, for example finding things, labelling, or getting out to do shopping or to attend appointments. Importantly it provided formal support without cost (or with a contribution in some cases and petrol costs where it included travel) which would have been hard or impossible to manage from their budgets otherwise - the cost of which could amount to well over £100 per week for the extent of support provided in some cases. This model contrasted to the one envisaged by MIS VI groups where a visually impaired person who did not qualify for social care, would have to incur some costs, such as paid-for help and reciprocation for practical assistance. People getting such packages therefore had to find less of such costs from their income.

In most but not all cases, participants receiving formal social care had little or no regular informal support, for example from family, so their support workers played a key role in their lives. As one participant explained:

“I wouldn’t eat properly, forms wouldn’t get done and I wouldn’t be able to get some of the things that I am entitled to or the place would be in a bit of a mess, so … I hate to think you know.” (WA, SSI)

The amount of support received varied considerably (from 3 hours a fortnight to 16 hours a week), as did the way it was provided - either through the direct provision of a support worker for a certain number of hours or via direct payments where the participant had more flexibility to organise the hours or employ someone themselves. Two participants receiving local authority contracted support had a visit for set hours at a specific time. In both cases the time allocated (2 hours a week / 3 hours a fortnight) was felt to be insufficient and having to wait a week or two between visits could be problematic, for example for help to read post or shop at a large supermarket, and there was no flexibility with the time or hours. The difficulty was that they could not afford to pay for more support from their own budgets and hence had to ‘cram everything in’ to the set hours. Others, mostly with additional health conditions, had higher personal budgets and used direct payments which allowed the provision of more flexible support of between 6 and 16 hours a week. Two of these participants had to pay a contribution towards their care provision, though this was a small proportion of the overall value of support received. One working age severely sight impaired participant had cancelled direct payments in the past because the contribution demanded was unaffordable and now has a private arrangement for fewer hours which costs less.

Although in most cases direct payment provision helped with general daily living tasks, one participant specifically used her support worker to take and accompany her to leisure or voluntary activities. She felt this was important so she was ‘not socially isolated’ – what helped was that she had informal help with tasks like cleaning and shopping which left more leeway in how she was able to allocate her direct payment resources. The need for funding to enable social activity was reiterated by several participants who, spoke of how, if they had more funded hours allocated, or money to enable buying support, they would spend it on social activity:

“Cleaning and going to events because the support I have just doesn’t cover any of that stuff, it is just basic organised stuff but yes just accessing events, museums anything like that you know there is so many things that I should want to do but then I do think twice well how am I going to do that?” (WA, SSI)

“I am not as active as I should be, I try but getting one hour a day with the support worker it means you can’t… there are days I can’t go out because it is only one hour, if want to cook something the one hour is gone yes? I have talked to social services about if they could increase my hours, even by two hours so I can go swimming... I could walk from here to town and back when I could see, even when I had partial sight I would walk to town and back, good enough exercise yes? But now because I can’t see, it makes it harder.” (WA, SSI)

A salient issue with social care funding was that annual reassessment could mean future changes in support. Some participants worried that their support levels could be cut, and others who received only a few hours social care a week and felt that they needed more had little hope of increased provision in this economic climate.

“I think I am lucky to get what I have because resources are so limited now”. (WA, SSI)

“And again with my direct payments, that is not forever, they come and review that every year, that money could go and then I am going to be stuck as well, it is just a stress every year… That would be a big knock on effect for obviously my social life as well….because I know a lot of visually impaired people don’t qualify for direct payment.” (WA, SSI)

Informal support

The availability of support, in particular from family (parents, adult children and grandchildren, and siblings) but also from friends and neighbours could make a huge difference to how participants manage. It was especially important to those not receiving formal social care. Practical support around the home and with getting out was instrumental for a number of these participants in meeting their everyday needs and can reduce the expense of paying for (so much) formal support or

services. It could thus play a vital part in their ability to cope on low incomes. However, the study illustrated how unequally the availability of such support is distributed, with some participants receiving a very high level of daily support, others drawing on it from time to time, and some receiving none at all. Support covered a wide range of areas, including:

- **Administrative tasks** such as reading post, filling in forms, dealing with benefit applications, shopping around for better deals, provided both practical help and enabled participants to get the best out of their money. Most really welcomed such support, though some noted the need to maintain privacy and independence.
- **Help with cooking and food preparation,** which could bring benefits including social contact and the opportunity to eat home cooked rather than ready-meals.
- **The provision of lifts** to appointments, shopping and social trips. This made a real difference to some participants, especially where using public transport was difficult and/or they felt unconfident going out on their own, while saving money on taxis (see mobility, below). Lifts also often provided more than just transport – it generally meant being accompanied when out and could be a means of doing necessary tasks but also social participation.
- **Accompanying them on holiday** – a form of support greatly appreciated even by some who were used to travelling independently to visit friends. This helped them get around in less familiar environments, and was cheaper than using a specialist VI holiday company. Sometimes family or friends had subsidised the holiday costs, sometimes they were split and a few (pension age participants) contributed to the cost of those accompanying them. However, travelling with others could mean falling in with where they wanted to go, and a potential cause of tension if a companion was ‘overprotective’.
- **Emotional support.** This could be tremendously valuable, particularly for some participants who had developed visual impairment later in life (see further below).
- **Material or financial support.** A few participants had saved money where items such as laptops, an iPhone or a new television had been

passed on or paid for by family members. Others had been helped by with funding for a deposit or advance rent when moving house – finding such large sums of money would have been impossible otherwise – or to subsidise a holiday, or just to fall back on if they had financial difficulties.

Participants in general had very positive attitudes towards receiving informal support, appreciating an 'extra bit of help' that could make life easier, such as setting up a laptop, mending something, changing a light bulb or finding things they might have mislaid. Having regular visits and knowing that they could depend on someone to help with such things could provide a sense of security. Those who did not have such support had more need for paid-for assistance. Some pensioners who were sight impaired were sometimes limited without someone around to help if they had a problem. While some made up for this by paying for assistance (see below) for others, it limited what they could do:

"Q: You have talked about reading and magnifying, do you ever use audio books?

R: No, do you know why? Because I don't know how to use them. Who is going to show me? I cannot go through all of that performance and palaver. If there is somebody here, like if [husband] was here he would be like oh yes come here, there you go, now you are OK, no there is nobody to show me … sometimes when there is a programme on the television and you can get it [on catch up], I don't know how to do it or what to do so I never use it." (PA, SI)

Participants who had strong regular support from family, friends or neighbours sometimes talked about feeling 'lucky' to have the extent of help they did. One described her neighbour as a "guardian angel". They could not imagine managing without such help – life would be more of an "existence".

"They are just such a good family to me that I don't know where I would be without them. Because they do things automatically that you don't even recognise you know what I mean? You don't think about what it will cost … like taking me shopping, if I had to get a taxi to Asda to do my big

shop once a fortnight it would cost me I would say something like £14 …. it is the little things like now and again if my daughter, if it's her day off she will take me to the dentist which saves £6 or £7 …I certainly wouldn't have all of the perks, god knows I wouldn't be going places you know?... I would sit here go to town on the bus, go to church if they weren't there, that would be the sum total of my existence." (PA, SI)

Those without regular informal support, limited social care support and unable to afford extra paid help also noted the difficulty of having tasks accumulate.

Reciprocation was important to participants in this study. For those who received a lot of support being able to pay for things or buy a treat could act as a way of redressing the balance – 'making it a bit more even', recognising that the helper was giving up their time, or just wanting to show appreciation. This included regularly contributing to food and motoring costs where meals or lifts were provided, paying for travel costs or a holiday or buying dinner, flowers or a gift – it gave pleasure to be able to do this. Having money in their budget to allow them to reciprocate in a meaningful way was important to people's feelings; conversely those on a more restricted budget wished that they could buy more than just a coffee when being taken out.

Some who had more occasional help, or help from friends rather than close family or neighbours were conscious there was a balance to be struck in the extent of help they accepted. As one participant noted "I try not to take the micky". Even if friends insisted that they didn't mind helping, participants were conscious of overstepping the mark.

"I am quite happy to accept help, but on a regular basis I don't like to ask friends to do it because in the end to be honest you become… however much they don't mind, you become a pain in the neck." (PA, SSI)

Some participants even made receiving help conditional on the helper accepting reciprocation – such as one who said she would rather get a taxi than have a lift where a friend won't take petrol money. Participants did not want to feel 'beholden' to others, seeing it as a matter of independence and 'pride':

“I mean I rarely unless I am really, really, really pushed or stuck that I might knock on a neighbour’s door, I don’t… I have got to be really desperate because I just… I don’t want to be a burden … it is like this thing when you have friends round yes, why should you have a friend around and then you say ‘can you do this for me? Can you do that for me?’ And then if you do that every time they come they are not really being normal friends are they?” (WA, SSI)

Another issue was the potential instability of informal support as the dynamics of family relationships and demands on their time can change. This related to participants’ parents ageing and being less able to provide physical help. One anticipated that she would have to start paying for formal help cleaning soon. Another noted that she should be helping her elderly parent rather than them being a source of support. The extent of contact with family members could also change when participants’ adult children had their own families, were looking after young children, caring for partners with serious illness or had very demanding jobs – participants felt they had enough stress and demands on their time so didn’t want to put them under more pressure. Some participants noted that their sources of support had ‘dried up’, when close relatives, peers, friends or neighbours had become ill or died. Furthermore, it cannot be assumed that family are an automatic source of support even where close by – for example they may be estranged or have a difficult relationship. In one case a participant’s relationship with his relatives had broken down after a bad experience in the past which left him feeling taken advantage of. Another had found the intervention of family when they became visually impaired difficult to manage.

“When I first lost my sight, people like my parents literally took over, and I just fell in to line with what they said and I was bullied a little bit and I went along. They opened my post and I found it really difficult to carry on staying independent. And it was a horrible time and I really had to like fight to say ‘look you know this is nothing to do with you, the post is my business’, and it took ages for them to back off.” (WA, SSI)

Self-funded paid help

The greatest financial costs for human support fell on those participants who neither had sufficient funded social care nor sufficient informal support to meet their needs. Often, paid-for services complemented informal support, with all but two pension age participants, and all the working age participants with no useable sight who did not receive social care funding, paying something for services such as cleaning, gardening, general home help, lifts or help with shopping. They were mostly paying £20-30 per week from their own budgets for such help; sometimes less, but in one case over £80 a week. However, finding such income from stretched budgets was not always possible, and this was an area where some participants would have liked to spend more money if they had it.

Although sometimes participants employed people for a specific job, for example gardening, dog walking or cleaning, others had a ‘cleaner’ who helped with a multitude of other tasks and some had a PA or support worker who also took them out. Key positive factors were having someone who was flexible. This related to the tasks they helped with, such as cleaning and shopping as well as help with paperwork, technology, making phone calls, checking food dates and also being flexible in the time provided. Several really valued knowing that they could ask their PA or cleaner to do extra hours if necessary, if a specific job needed doing like changing curtains or they were having trouble with their TV, or needed some shopping picking up. This flexibility of task and time was especially helpful to those who were severely sight impaired or who had additional mobility problems, in one case extending to accompanying on holiday. Finding the ‘right person’ and someone they could trust was also paramount and was particularly emphasised by some of the pension age participants – opening up your home and your life to a stranger could be hard, and not being able to see what they were doing or if something was missing could make trust very important. This was reflected in how people had found someone, for example, through word of mouth, arranged by a relative, or they had originally been employed via an agency but now on a private basis, and for some had been a long-standing arrangement.

“It is fantastic, it just makes such a difference because when you have got no family and sometimes it is just all of the little things, all the little extra bits, you know things that crop up and you can’t see, you can’t just make out something, just all of the little extras…. It is security. She always says if you want anything in-between give me a ring and I try not to, but I always know she would if she could.” (PA, SSI)

There was some overlap between paid-for help and informal support, where participants paid set amounts to a family member or neighbour to recognise the extent of help provided where someone had taken on additional roles (for example gardening) or to formalise an existing arrangement (made possible through receipt of Attendance Allowance).

Human support – summing up

These findings show that visually impaired people consider human help to be essential in their lives and are drawing on it from a range of sources – informal, self-funded and local authority funded. Yet access to such resources can be constrained, leaving some needs unmet. For example, when it came to doing things outside the home, any social care time provided was often squeezed or limited to more essential trips, and social activities would require paying a PA, adding significant costs to a limited budget, or having to rely on family or friends. In practice, this meant that paid-for support mainly addressed practical needs, but where people needed support to take part in social participation outside the home this was more likely to be dependent on the extent of informal support (if any) that people could draw on. This depended on the strength of people’s networks and the availability of family, as well as on participants’ attitudes to asking for help, since many felt constrained in how much they could ask for.

Access to support from services and organisations

Participants in this study highlighted the importance of a range of support received from various organisations and services, in particular, national and local VI charities and services, but also other third sector organisations and statutory services. These resources could make a tremendous difference, practically, financially as well as socially,

although people's access to and experience of services varied. They included:

- **The provision of items and equipment.** Local VI organisations and social services were key sources of free basic equipment for most of the pension age participants in the study who had become sight impaired in later life. Provision of these items not only avoided having to pay for equipment, but also made people aware of what was available, which was especially important in the early stages of sight loss. Supply of equipment was often linked to registration, which triggered visits from staff who provided items such as a magnifier, liquid level indicator, talking clock, large button remote control, a cane, and organised the installation of additional lighting or helped activate the audio description on a TV (people weren't always sure what was supplied by whom). For some of these participants these items or equipment were all that they had, and they had limited knowledge of what else might be helpful to their situation. A few working age severely sight impaired participants had been supplied with expensive vital equipment – a brailler or scanner reader – to replace broken items that they would not have been able to afford otherwise.

  "The print reader I was very lucky that the [local VI organisation] paid for that… when it broke oh I was gutted, I just didn't know what I was going to do because it was a case of I was losing a bit of my independence ... I don't want people reading my post you know it is private and they had to because I had got no way of doing it myself so [local VI organisation] got in touch with the rehab team and they just said we will buy it for you…. I mean I would never in a million years would have thought that because they kept saying to me it is like over £1000 I thought well I am never going to save that." (WA, SSI)

  Some participants also received free audio resources: audio books (via RNIB, Calibre, the library), as well as talking newspapers, RNIB Connect radio services, and audio information services.

- **The provision of training and support services** which could make a difference to participants' ability to fulfil their potential. These included specialist training and courses provided by local VI organisations or national sight loss organisations and colleges - such as mobility training, providing crucial support by helping some severely sight impaired participants to learn new routes or to use a cane to enable getting around independently. Pension age participants who had become sight impaired had received less support with mobility, some of whom were reluctant to use their canes (see below) – those who had received fuller explanations at the time of provision had a better understanding of its benefits. Other courses that had helped people in everyday life included cooking courses, the teaching of braille and IT skills and employment-related training. As discussed below, there was a contrast in the capabilities of participants who felt confident accessing technology and those who did not, in which training could make a huge difference.
- **Information and advocacy** from VI organisations, providing valuable support, in particular with benefits (see Chapter 2). This included assisting and advising on benefits claims and additional entitlements, appeals or representation at a tribunal hearing. Other charities such as local Age Concern, CAB and Red Cross had also provided help with filling in forms, benefits queries, help with housing and signposting to other services.
- **Services that support getting out and about.** Those with guide dogs stressed the difference this made to their lives, helping with confidence and independence. It could make the difference between going out or not which was important to combat the risk of isolation.

  "I couldn't be without him… before getting him I didn't go out anywhere by myself at all… but yes I mean we have learnt everything, from walking around the block, to then being able to walk two and a half miles back to my parents… [my dog] is great and I love him, I wouldn't live by myself if I didn't have him either." (WA, SSI)

  A few participants had received help from local guiding services, a partner scheme or volunteer. These free services varied from specific help with travel (meeting and finding a destination), taking shopping or

to an appointment when required, to regular social trips and activities with a volunteer. The latter was particularly valued by one participant as it enabled her to take part in classes or try out new interests. This was something that others said they would like to do but did not think was available in their area.

- **Access to activities and groups**, providing crucial opportunities to socialise and to share information. A key resource, especially for pension age participants, were group meetings organised by a local VI organisation or the Macular Society. For some, these meetings were the only contact with VI organisations or networks – this included those who were not registered. People valued the social aspect including activities, talks, trips out and chatting with others who were in a similar situation to themselves. This shared sense of understanding the experience of visual impairment seemed especially supportive for some older people who were experiencing sight loss in later life.

  “I like the Macular Club, without the Macular Club I think I would be ever so frightened, yes because who would I go to? Who could I talk to?… They know what you’re talking about you know they’ve mainly been through it … it is just someone to talk to that knows what you’re talking about.” (PA, SI)

  These meetings could also be an important source of information about various aspects of VI and what can help, whether shared from other members, from guest speakers or the VI organisation. Participants talked about being spurred on to ask about registration, finding out about different low vision aids or services such as audio books and other social groups in the area. But some participants missed out on their benefits, such as one who lived in a rural area could not travel to the nearest VI group meeting. Despite receiving a home visit from her local VI organisation, she missed the social aspect of attending group meetings and potential information sharing. Working age participants (especially aged under 50) were less likely to attend these groups. Several felt that they were mainly for older people and noted a lack of social provision for ‘middle aged’ people

who are visually impaired. On the other hand, those of working age were more likely to be involved in VI-oriented sports, drama, holiday and other activities but there was variation in what was available in different areas, and those living in areas without such provision sometimes noted it was lacking. Several severely sight impaired participants noted difficulties in accessing some non-VI facilities without additional assistance, limiting their capacity to take part in sporting and cultural activities if they did not have a friend or personal assistant to help them (Harris and Gregory, 2018). Where provided, measures such as an extra ticket for a companion, a guide or live commentary were helpful with access to trips out to attractions or events.

An underlying issue affecting people's access to services is knowing what is available. The participants' experiences in this study highlight the wide variation in knowledge, from those who were very well networked to others who knew very little about what services or provision might be available. Factors that seemed to make a difference were:

- **Length of time of visual impairment**, with some who had been visually impaired early in life being very well networked in to various VI resources (including online forums, audio information services), conversely some experiencing sight loss in older age feeling unsupported. Where not attending hospital appointments (as told no more could be done for their vision) they can feel 'left to get on with it'.
- **Involvement with organisations**: working for or volunteering with a VI organisation (national or local) provided additional contacts and sources of information.
- **Registration** (for pensioners in this study), which had led to visits from social services and local VI organisations. Experience of support received was mixed, it generally provided some low vision aids and for some it had opened the door to social groups, signposting to other services and courses. Those not registered in this study had not had such dealings with these services. It is important therefore that people are aware of and able to access VI groups and resources before registration, and that opportunities to register are made more systematic.

- **Attending VI meetings or social groups** could be a source of information sharing about other groups, services or equipment.
- **Contact with other services** – for example a warden had provided information about a service in one case.
- **Having the confidence to ask** – whether phoning up a local VI organisation when needing help or equipment, or asking staff for help to use a gym.

What is clear is that being involved in one thing could lead to another - for example, hearing about Myguide via Infosound, finding out about Blind Veterans or Wireless for the Blind from the local VI organisation, and finding out about the local VI organisation from the local Macular Society group. These further links are essential as while initial provision at the point of registration can provide basic equipment, it was often these further services that could provide really valuable moral and practical support. For example, enrolling on a cookery course after information received via RNIB Connect, being provided with a range of technology equipment and support to use it from Blind Veterans.

“I have found in my experience if you join one thing you often get to hear about another thing so it is like you know if you want to start to get out a bit and often it does lead to something else.” (PA, SSI)

However, a view among many participants, even those that were well networked into various organisations, was that there was a need for better information sharing. It should be noted that participants in this study were recruited via VI organisations, and experiences of people who become visually impaired and do not have such contact will vary, especially if they are not registered.

“Q: is there anything that you think could improve things for people in your situation?

R: just maybe more information on things that are available, regarding help you know with everything really, finances and home help and there is a lot of things I mean there is a lot more things that are

available that a lot of people just don't know about really." (WA, SSI)

Visually impaired people as a source of support

While we have outlined the use of services and support, it is also important to note the role of visually impaired people as a source of support for services and their communities. Most of the participants in this study discussed experiences of volunteering. Volunteering roles varied widely and included: helping to fundraise for charities, organising events, running sports clubs or group activities, helping at Brownies, giving motivational talks, supporting refugees, providing administrative and reception support, monitoring online VI discussion boards, volunteering at church activities and helping at a gym. One had secured funding for a club, whilst two others were trustees of local charities and another advised their housing association. Participants felt that their voluntary roles had provided work related skills (though not necessarily leading to paid work - see Chapter 2), boosted self-esteem and confidence and provided a sense of satisfaction from helping others. Some valued that it gave them a purpose or structure – 'getting out and doing something'. Where volunteering for VI charities it provided networking opportunities and sharing of information. What is very clear is that these volunteers contributed a great deal to their local communities and were a tremendous resource to society.

"I do some voluntary work… I did a course to learn to facilitate workshops for newly diagnosed blind people and when I did the course I was thinking I am not going to have the confidence to do this, but I thought I will do the course and see how I feel about it but gradually I started working with two other visually impaired people who run the courses in this area…and I really, really enjoyed it." (WA, SSI).

Cuts in provision

The ramifications of reduced funding and cuts to provision in the current economic climate came through from participants' experiences of dealings with services. This ranged from cuts to statutory services such as reduction in warden cover in some sheltered housing and loss of subsidy for warden charges (see Chapter 2), the withdrawal of a mobile

library service meaning someone could no longer choose her own books (as large print books were too heavy to carry home from a more distant library). Cuts to NHS chiropody was also a concern where they were no longer providing basic toenail cutting - which was hard for participants to do themselves when unable to see their feet (and in cases get to them or feel them) – the alternative being to pay for private chiropody or rely on informal support (however some felt uncomfortable asking for such help even from close family members).

"R: I can't see my feet … the only way I know where my toes are is because I feel it…But last time I went she said we weren't doing it anymore and that is one thing that I really need ….. she said you will have to get somebody in to cut your nails.. Well I don't think for people with a sight problem who can't see their own nails to do them, because you can't even see where to put the file to do inside the nail, so that is going to be a real problem.

Q: So what do you think your options are?

R: Well I am certainly not going to ask [neighbour] to do it. I mean [daughter] could but when she comes she usually does quite a few things yes." (PA, SI)

Other cuts mentioned included a local CAB office, a hospital VI equipment centre, and one participant noted that the foodbank she had accessed in the past no longer had the resources to deliver and she could not get to it herself. There was concern that dwindling day centre and lunch club provision or reducing access to activities would limit social opportunities for people who could be vulnerable to isolation.

"We are going through austerity and… funding is being cut, but I think they need to realise though like there is lots of things that benefit your health through like taking part in things, like getting out, leisure activities so we're cutting them down but maybe it is not improving people's mental health or health …it means a lot to people, it is an interest and it gets you out." (PA, SSI)

In regard to visual impairment, a local organisation had cut its opening hours, a VI social group was threatened with closure due to lack of funding and someone who was not a big technology user had stopped accessing Infosound after it changed from CD to internet access. Several participants noted that there were either now limits to the amount of mobility training provided in their area, or there were long waits to access it.

“My local society for the blind, they have come out and given me mobility training, that has been generally very good over the years but they are getting cuts from the council so now it is going to be… if I want to learn a new route, they are only going to give me so many sessions, so before it used to keep coming until I have learnt the route and I am confident with it, but now it is going to be well you have got three sessions to learn this route because that is all we have got funding for. Which is kind of bad.” (WA, SSI*)*

Making the most of a low income: managing finances, access to banking, shopping around and getting best value

When on a restricted budget, it is important to be able to get the best out of the income that is available. The research highlighted that some factors can help and others hinder this for visually impaired people, particularly in terms of accessibility, which can impinge on peoples’ independence as well as their ability to shop around for the best deals.

Financial management

Two participants had support from family to manage their finances, but most were in tight control of their own budgets. There was a feeling that being on a limited income meant it was essential to keep on top of it - some knew to the penny their income and outgoings. Strategies included keeping meticulous written records or a spreadsheet, closely monitoring accounts online or using phone banking.

Accessibility provision from banks and utility companies was viewed as better than that of statutory organisations. Banks were generally praised for being aware of VI needs and communicating in accessible formats. There were mixed experiences of utility companies with some

participants receiving bills and letters in their chosen format, but others not. As well as being essential to managing a household budget, accessible communication is important for financial independence and also to protect privacy. As one participant who had no sight and received audio bills and statements and used telephone banking noted “I wouldn’t want anyone else doing my money”.

Skills in using technology, discussed below, could greatly affect people’s capabilities in managing their money. In particular, those who used online banking found it a helpful way to keep track of their finances using a mobile or computer and magnification or screen reader. Several participants with no sight managed their budgeting this way for gas/electric, internet provision and TV licence, but noted that it would be helpful if all service providers could email bills or statements - large print or braille was not useful if someone with no sight is not a proficient braille user. Conversely one participant who had not been able to get online since losing her sight felt penalised as she didn’t receive the ‘discount’ offered to direct debit users and was charged for being sent (audio) bills rather than being ‘paperless’. Phone or internet banking also lessened the need to visit banks in person – especially helpful where living in an area without a local bank branch.

Shopping around

Getting the best deal on utilities, in particular switching energy companies, could be problematic. A few older participants had a sense of loyalty or trust towards a provider, others felt that changing suppliers was just too much hassle and were worried it could go wrong, but often the whole process of different rates and tariffs was just seen as very complex. Some participants had used comparison sites to find better deals but there were barriers for others who were not online, no longer able to see to use a computer or found company or comparison websites hard or impossible to navigate with screen readers, particularly if accessed on a mobile or tablet. Several felt that it was difficult to do this over the phone, for example, being asked for information that they couldn’t see and juggle a magnifier at the same time. However, for annual home insurance, telephone / broadband or mobile suppliers it was easier to phone companies to compare a quote or negotiate a

cheaper deal. This was an area where sometimes family members or a support worker provided help or did this on participants' behalf. Another frustration with financial implications is where websites are not accessible but extra charges are incurred when booking tickets for events or travel via telephone compared to online booking prices.

In the case of physical shopping (in stores rather than online) barriers to price comparison included not being able to see prices clearly and having restricted capacity to go round several shops, especially with a support worker whose time is limited and limited control over shopping if someone does it on your behalf.

Location: access to facilities and public transport

The study covered people living in a range of areas– from city centre to rural locations - and highlights differences location and living environment can make to people with visual impairment meeting their needs as well as financial implications. This includes access to and variation in transport and other services.

The importance of where you live

A range of practical and financial issues were associated with living in a rural area or location without major facilities. Limited amenities in the immediate area restricted what people could do locally, for example access large supermarkets, go to a gym, or take part in a VI social group which limits opportunities to meet other visually impaired people and gain useful information. To get to a destination with more amenities involved transport, and limited bus services meant an increased need for taxis which could eat into a restricted budget, for example where no buses run on a Sunday or in the evenings. Several participants wanted to move to bigger towns to limit the need to travel, and the amount being spent on taxis.

"There is not a lot of amenities in [village] so anything that I want to access I have to travel so you have always got travel costs… if I want to go out and I want to be out after 6 pm I have to taxi everywhere because of the bus service so that is one of my major reasons for wanting to move, so it is a financial reason." (WA, SSI)

Being close to a good range of local shops or other local amenities made a big difference – not only did this mean being able to walk, where they were able, but some also valued that people knew them in the shops. This could help in terms of assistance, and some participants also valued the familiarity, social contact and sense of 'community'. Being able to access large supermarkets and cheaper food shopping could be an issue if this was inaccessible by bus. Where people did not have informal support for lifts, or sufficient PA time, this meant using a taxi, which for one person living in a more rural area cost £12 a time. The alternative was shopping at a smaller local shop, but this meant higher shopping costs.

Having to make sometimes long or arduous bus journeys to towns with better facilities for shopping or a bigger library or for onward travel links to visit friends or family members was another issue for people in smaller towns or villages. For example, to get to a bigger town could take over an hour bus journey in one case, which was becoming more difficult for one pensioner. Another had stopped using the bus due to a combination of deteriorating mobility and sight and she was no longer able to get to the nearest local VI social group in a town some miles away. Because of the distance she felt that a taxi would be too expensive to justify.

Even where living in urban locations, some participants had difficulty accessing buses, for example where they felt unsafe walking to a stop because of crossing a road or a road had no pavement, and limited evening services to the suburbs meant using taxis sometimes. For those who were mobile and confident using buses, living on or near a good bus route was very important, and meant less reliance on taxis, hence saved money. Several described how their decisions to move to their present homes were based on being near local amenities and transport links.

Aspects of public transport that make a difference

Participants mentioned various aspects of public transport that affected their ability to use it effectively, including:

- **The provision of talking announcements** on buses or trams. Several found the lack of such announcements problematic, including

one person whose deteriorating vision meant that they became reliant on taxis to avoid the risk of missing their stop on a bus trip.

- **Whether travel concessions were valid at peak times**, which varied by area. Where they were not, this caused problems for those needing to travel before 9.30am, or just after, when buses could be crowded so they could not get a seat. Participants living in London felt well served as were able to use their passes anytime on bus, train or tube. They also received a Taxicard allowing a set number of local subsidised taxi journeys per year, which was well used by participants in this study.

Overall, an important outcome of how accessible participants found public transport was the cost of using taxis as an alternative. There was a clear distinction between those using taxis as a 'last resort' due to the cost involved, and those using them more regularly. This depended partly on the public transport alternatives discussed above, but also on:

- **Other human help**: Having informal help with lifts or a PA (with sufficient time to allow being taken shopping or to an appointment) could lessen the need for taxis.
- **Confidence in using public transport.** Some participants who had lost sight in adulthood had lost confidence in using buses, or walking to and from the bus stop, so taxis became a greater need.
- **Subsidies for using taxis**. Costs were reduced for participants living in London who received a set amount of subsidised taxi journeys per year or month which provided substantial savings.
- **Attitudes to taxi use.** Overall in this study, working age participants seemed to be spending more on taxis than pension age. While this was associated with the type and amount of journeys made, a few older participants noted that they almost had to justify using a taxi because they had not been brought up to do so.

"R: I consider alternatives before I would have one and I would rather walk or get the bus… I only go when I really feel I have to in a taxi.

Q: And if you did have a bit more money in the budget is that something you would get more often if you could?

R: No I don't think so … my granddaughter she gets a taxi when she could get the bus, you know she is just taxi conscious where as I… I was brought up in a different era." (SSI, PA)

Use of technology

Technology is a key resource that provides a lot of support on a day to day basis to visually impaired people and makes a significant difference to their lives through supporting everyday tasks in the home, helping them to get out and about and connecting them online to family and friends.

Working age participants that were registered severely sight impaired with little or no sight tended to describe the greatest impact and advantages of technology, with pension age participants generally less engaged. This reflects differences in expectations of technology use identified in the MIS VI budgets, and that the use of new technologies reduces with age (Slade and Edwards, 2015), though this is likely to change as younger generations age. However, there were several examples of pension age individuals in the study using different forms of technology – some were supported in doing so through third sector organisations, or relied on regular support from a PA or family members. They used their devices for email, online banking, photos, video calling with family abroad and for entertainment when no longer able to read books. Using it to keep up to date and in touch with friends and family could help to limit social isolation.

"It is just really emails and Facebook and I look at all of my family's… find out all of my family's business you see, every morning I look at my mail and I look at Facebook … …I think it is important because it has kept me in touch with the world hasn't it? And instead of feeling alone, you feel as if you're quite close to your family… I know what she is doing. It is interesting, you are living their lives with them aren't you?" (PA, SI)

Multi-functionality of smart phones

A lot of the visually impaired individuals within this study, particularly those with little or no sight, talked at length about the value of smart

phones. Apple iPhones were by far the most common phone owned by participants. Benefits were felt to be its ‘accessibility out of the box’ as there are in-built functions of VoiceOver audio description, zoom, larger text and magnification options available as standard. The iPhone also enables access to a wide range of applications; some free of charge, others that incurred costs. The multi-functionality of smart phones, allowing standard phone communication via calls, texts and emails as well as video calling; social media; listening to music or radio shows; transport information; reading apps; online banking; games etc. and a large number of VI specific apps such as ‘Be My Eyes’ or ‘Colour ID’ means that they can perform many roles.

“It is almost like having ten pieces of equipment in one really with that... I use that all day every day for so many different things.” (WA, SSI).

The multi-functionality of smart phones also allowed some visually impaired people to save money where they did not need to use a separate device, such as a GPS or colour detector for example, as they could use the app versions on their phone. Participants who heavily relied on them emphasised the need to replace their phone if it broke. This was seen as a very high priority, even for some of those whose incomes were below the MIS VI threshold, as the thought of managing without their phone could be hard to imagine. The importance of such devices was heavily linked to discussions about independence and several participants noted that technology enabled them to carry out simple tasks, such as looking up a website or checking the weather easily without assistance.

“If my phone broke today I wouldn’t hesitate in buying a new one tomorrow, it is that important, it is that necessary …it is not just in terms of the reading apps, the being able to access your banking, it is the knowledge, if I want to find something out you know I don’t have to read a book I can just go online like everybody else and do it quickly. I can set timers quickly, I can do all of the things that were just a pain in the arse before, I think they are a lot more easy, doable.” (WA, SSI).

Specific apps enabled people to carry out tasks that they would never have thought possible in the past. For example, one participant talked about the benefit of the 'Be My Eyes' app which connects blind and visually impaired people with sighted volunteers via live video call:

"I love it, I fixed my washing machine once with it because… I couldn't find the filter and I needed to empty it, for it to actually work … this person went on Google, put all the details in and came up with a manual, read the manual and then told me what to do." (WA, SSI)

Technology as an aid to getting out and about

Several participants described the importance of their phone or separate GPS system for getting around outside their home, how it enabled them to be more independent, and, go out alone. Technology could also be helpful when travelling for example, to check bus or train times and use apps which alert you when you reach your destination and get clear instructions to direct walking routes.

"There is a wonderful app that not only does it tell you bus times when they are due to arrive at the stop, but if you are actually on the bus [or train] this will tell you before you get there. …That is crucial because if you aren't aware you are coming into a station, more often than not you end up missing getting off at that station unless you have booked the passenger assist. It has also got built in to it a satellite navigation system. So I could say I want to walk from here to home and it will tell me the route and it is all in one app." (WA, SI)

Training

Some participants had attended courses or received home visits to learn how to use a computer, including touch typing skills, the internet, accessibility software and support with their iPhone; this included local authority provision, local VI organisations and other local charities. One pension age participant had received intensive free residential training and support which had enabled him to engage with technology for the first time. The amount and level of support he received was crucial but he felt that he was lucky to access this service from a charity for ex-service personnel which was not open to all. Other sources of support

included tapping into informal knowledge sharing through visually impaired work colleagues and paying for lessons and follow up support at an Apple store. However, there were felt to be gaps in accessing training, in particular for IT training where some participants expressed a need for more local face to face provision. Issues included knowing what was available, especially where people did not have strong links with local VI networks, lack of provision, and also location.

“There is not a lot of opportunity for training here …for me to go and really do a computer course would mean me going to Loughborough or Hereford …. And the local college had nothing … I phoned last summer holiday to say is there anything accessible to me or any sort of IT training that I could have and there wasn’t anything.” (WA, SSI)

Others talked about having to ‘muddle through’ and teach themselves how to use their devices. Lack of knowledge about the capabilities of technology meant being unable to make full use of their devices. As one participant explained:

”There is so many short cuts you know… like typing, learning how to type with a touch screen that took time. No one tells you how to do that when you can’t see, sort of double tapping things and how to get to things quicker on the phone, and same with supernova on my laptop, I don’t know all of my shortcut keys when I am accessing the internet”. (WA, SSI)

Limitations

Whilst there was an emphasis on the positive difference made by technology, there were also discussions about what could improve, limitations to current devices and barriers to access.

The voiceover functions and screen reading software used on smart phones enable great accessibility but have the knock-on effect of slowing the functionality of the phone down and limiting memory space meaning apps would not run efficiently. As a result participants talked about needing to update and replace their phones more frequently than sighted individuals, for example, every year or eighteen months (rather than the two or more years that standard phone contracts last). Other limitations

included apps or websites not being fully accessible to the screen reading software:

“It is still frustrating because apps rely on the developers and if the developers don’t code an app correctly then your screen reader, the voiceover, can’t read it and that is frustrating when you come across that which you do quite a lot.” (WA, SSI).

Whilst there are some very useful apps that can be downloaded for free or for minimal costs, participants also noted that there are a number of high cost apps targeted at improving the lives of those with visual impairments. It was suggested that free trial periods would allow people to try out new apps to see if they meet their individual needs before having to pay upfront and risk spending money on something that may not help them. For example, one participant had heard good reviews of a GPS app that specifically catered for VI needs, but at over £60 plus annual update costs, she was reluctant to buy it if she could not be sure it was an improvement on her current app.

Some participants were aware of new developments in technology and new gadgets on the market aimed at visually impaired people. However, it was felt that the costs of such innovative gadgets, such as face recognition glasses, were very high. Whilst the significance of smart phones could be balanced against their cost, these other more experimental and higher cost items were not considered a priority.

“I don’t have all of the latest gadgets, there is probably a lot more things that I could have to help me with my visual impairment…. but unfortunately because the market for visual impaired is so small they have to make the things expensive otherwise they are not getting their money are they?” (WA, SSI).

Health and interaction with visual impairment

MIS budgets are based on the needs of people who are in relatively good health (for their age) and while the MIS VI studies focussed on the additional needs and costs associated with visual impairment, they did not take account of any other health conditions. However, people who

are visually impaired are more likely to have poor health than those without an impairment (Flynn and Lord, 2015) and the likelihood of having other conditions increases with older age (Slade and Edwards, 2015). In this study around half of the working age and most of the pension age participants had other health conditions, including several with diabetes. For those of pension age this included arthritis, mobility and hearing difficulties which were often associated with 'old age', especially among those in their 80s and above. The findings highlight how the presence of health conditions can go alongside or interact with visual impairment to make a difference to people's needs and ability to deal with visual impairment, and can impact on spending or the ability to meet other costs:

- **The impact of limited mobility.** Where participants had conditions such as back problems, joint pain, leg ulcers, neuropathy, difficulty standing or with walking very far or conditions that affect the need to quickly access toilet facilities, it combined with visual impairment to make it harder to get out and about or to use the bus. This meant an increased use of taxis, relying on someone to provide lifts (through formal or informal support), or not going out as much as they would like to. Conversely good physical mobility, especially for participants with some useable sight or who were longer term visually impaired and confident at getting around, helped maintain independence and involved less spending on taxis (especially where they lived in areas with nearby facilities and/or good public transport links – see above).
- **Being unable to rely on hearing.** Several participants had hearing difficulties (hearing loss or tinnitus) which could further add to the impact of visual impairment because hearing can be an important coping mechanism. For example, being unable to use audio books, or use audio description on the television could limit entertainment, and one participant had given up attending a social group as they could no longer see to take part in craft activities or hear the talks. When out and about, difficulty in hearing as well as seeing traffic affected confidence in crossing roads for a few pension age participants who had become sight impaired, while another noted difficulty travelling as they couldn't see information on monitors or hear announcements.

- **The additional impact of other health conditions**. The need to attend frequent appointments (for example for diabetes or heart related conditions) incurred additional travel costs if this required a taxi to reach a hospital or clinic. The need to consider food and dietary requirements was relevant where people had diabetes or another condition affected by diet. This meant having to be aware of the content of food or drink, for example, having a PA help with shopping around and reading labels, trying to use fresh food, not being able to rely on standard ready meals, or having to pay more for gluten free foods. Occasionally participants had spent money on their health, such as private physio or alternative treatments, or were allowing for potential future private costs through health insurance or keeping savings to enable them to access treatment more quickly. A condition causing fatigue was compounded by visual impairment and restricted going to different places where absorbing new information with limited sight had become too overwhelming.
- **Mental health.** The emotional impact of visual impairment was discussed by some participants, reflecting documented links between sight loss and lower levels of wellbeing (Flynn and Lord, 2015; Nazroo *et. al*, 2015). A few working age participants linked experiences of depression to their visual impairment. Having to deal with the onset of sight loss or deterioration of vision, the 'constant reminders' of what they could once see or do, the risk of isolation, as well as pressures from financial repercussions related to the loss of income and livelihood, not being able to find work, and difficulties in dealing with the benefit system were all seen as adversely affecting mental health. One participant had found therapy helpful in coming to terms with their deteriorating sight.

  "Well I think anything that happens to us physically does affect us emotionally doesn't it? I mean it affects our sense of how people are perceiving us for instance, it affects our sense of our own vulnerability." (PA, SI)

  "When I lost kind of quite a chunk of my sight again you know going from still being able to see colour and stuff like that to just light perception so it kind of hit me quite hard so it was for a couple of

years I was kind of battling depression trying to get out there and do whatever because, it is like a vicious circle, you kind of need to get out there and do something to kind of prevent the isolation, not just because you are a bit depressed but because of all of your issues that you're having anyway because of like sight loss, and it just kind of doubles it all up. Because somebody who doesn't have sight loss issues, you know experiencing depression and stuff like that, they haven't really got the disability side of the equation that is bringing them down as well." (WA, SSI)

Responses to sight loss

An important factor influencing how people coped with sight loss was how they reacted to deteriorating vision, including on an emotional level. Some participants, including working and pension age, had become visually impaired in adult life, between 6 and 20 years ago. This was often a process of deterioration over time, which for some was ongoing. Others had been visually impaired since childhood. Participants (in particular pension age who had become sight impaired and working age who had become severely sight impaired) reflected on a range of emotions and reactions to experiencing sight loss:

- **Shock or confusion.** This included where sight loss had occurred very suddenly and out of the blue but was also a reaction to receiving a diagnosis or the news that they were losing their sight.
- **Difficulty coming to terms with loss or deterioration of sight**. This could include feeling traumatised, 'mourning' what they had lost, shutting themselves off, being in denial, finding it hard to accept and not wanting to be helped.

  "I was awful for about four months …I just sat, well I was crying, and when every time somebody took me out, and someone said hello…. It was awful." (PA, SI)

  "I did fight against it, I did I mean if anybody said to me are you coping? I just said yes I am fine thanks you know… I wasn't very honest about how I was dealing with it." (WA, SSI)

- **Having to stop or give up certain things** were markers of sight loss but also part of identity – driving, gardening, reading, crafts or hobbies which they loved and were an important part of their lives.

  *"*I was a big knitter, I loved to knit, I think that is the one time I cried about it was when I threw out my patterns and my knitting needles. I really miss that….but I just couldn't read the pattern so you know." (PA, SI)

- **Loss of spontaneity** where going out now often entailed planning, booking a taxi, arranging for someone to meet them, or getting a lift. For those who tended to go out only with other people this sometimes signified a loss of independence.
- **Experiencing role reversal.** Several participants talked about the emotional difficulty of changing roles when they had to rely on others for help. Going from being a driver to being driven, changing dynamics in family relationships.

  "I rely on other people all the time, and I say to my daughters no …. I don't like being reliant on people that is the thing… because I am independent I suppose because I never have done, because I have always done for them haven't I really?" (PA, SI)

- **Loss of confidence outside the home**. This was an issue for some pension age participants who had become sight impaired, and two working age participants who had gone from being sighted to having no useable sight in a fairly short space of time and who did not have a guide dog or use GPS technology. This related in particular to going out, concerns about safety, getting lost or finding their way around especially in unfamiliar places, and meant feeling nervous when out or not going out alone.

  "I am always a bit wary, crossing over as there is a car there and will they see me? Will I see them in time? Yes scary you know. And like I won't go anywhere new now that I don't know you know, because I will panic … you don't know where you're going because you are lost and your eyes aren't good enough to pick up signs." (PA, SI)

- **Feeling vulnerable and not wanting to feel conspicuous.** Some participants felt very ‘wary’ when using money or magnifiers when out for fear of being seen as a ‘target’. A few were reluctant to use a white cane, because of how they felt they might be viewed by others while at the same time being worried about drivers not realising that they could not see traffic. A key issue is how people are provided with a cane and the explanation of its benefits and how to use it.

  “Q: What puts you off using it [cane]?

  R: Well I feel a bit vulnerable that people could take advantage of you ….I fear maybe someone would come and take my handbag or try, stuff like that”. (PA, SI)

  ”When I had the white stick … I said ‘I don’t need a white stick’, and they said’ use it because it is not for you, it is to let them know you have got a problem’, and when I said that about the buses she said ‘that is why you need the white stick because if you have got a white stick the driver gives you time to sit down’, and I have found that that happens.” (PA, SI)

- **Being at risk of isolation**. Issues curtailing social contact such as no longer being able to recognise people when they were out, or the need for intense concentration making it hard to engage with others when walking, can impact on people’s feelings about going out and social activity.

These factors combined could present more challenges for some people who had recently lost their sight than for those who had developed strategies and confidence over a longer period. Some participants talked about what helped them cope. This included acceptance, though this can come gradually, learning different ways to do things, having to be patient, ‘getting on with it’, having to make themselves get out and about to avoid social isolation.

“You have got to accept it…, I wouldn’t accept it at first, you think well come on there is a jolly sight worse than that… I have got used to it you see, you have to.” (PA, SI)

“When I lost my sight it changed everything… there is a time to mourn, there is a time to stand up, dust yourself off and say where do I go now? If you can’t go the same place where you intended, how do I go to the same place but taking a different route?” (WA, SSI)

These experiences of becoming visually impaired reflect findings in previous studies (Stevelink *et. al*, 2015; Thurston *et. al*, 2010). While there was general agreement that things can become easier over time, this highlights additional needs at the time when someone becomes visually impaired or their sight deteriorates further, when they may be experiencing these emotional impacts. As this chapter demonstrates, issues such as loss of confidence can incur additional costs through the need for additional support, especially where people have fewer non-financial resources to draw on such as informal support, they cannot access public transport, or they have additional health or mobility problems.

There is also a clear need for emotional support when experiencing sight loss - the need for positive and encouraging support and the difference this can make was often reiterated.

“You don’t want sympathy…Some encouragement to say, you know it is not the end of the world, and it isn’t.” (PA, SI).

Practical support from VI organisations, especially mobility training for those with severe sight impairment, can be vital. While a few pension age participants who had become sight impaired in later life had really benefited from a rehabilitation course, IT, or a cookery course there were only limited examples of this level of support for people in this situation in this study – for others, involvement with VI organisations was often through social VI groups and an initial registration visit (if they were registered). This highlights a gap in support, especially for pension age people who become visually impaired: the need to give timely assistance to those trying to cope with the early stages of sight loss.

Chapter 5: Conclusion

This study has examined the experiences of visually impaired people living on their own on low incomes. It has explored how they meet their needs, including additional needs related to visual impairment. The qualitative research considered what resources are most important to help individuals to attain minimum living standards; how difficult decisions are made that prioritise certain needs above others; and what factors make meeting needs easier or harder on a low income.

The participants in this study prioritised meeting core material needs, although for some of those of working age, in particular those on the lowest incomes, this could involve compromises. They also considered social participation to be extremely important, but varied in terms of how well they could meet this need. Some did not feel that they could use their incomes to pay for taxis or human support where this was required to enable them to socialise adequately outside the home, and those receiving social care support tended to use it principally to meet practical requirements. On the other hand, many participants in this study benefited greatly from unpaid help from family and friends.

The study highlights that a range of resources can make a difference to how well visually impaired people are able to meet their material and social needs. Income is very important, but is not the only factor. Access to human support, whether from friends and family or paid for with or without help from the state, services such as those from VI organisations and appropriate technology can also play a valuable role.

Potential barriers that can impede or force compromises in meeting needs include: poor health and its interactions with visual impairment; poor access to local facilities and public transport; and lacking knowledge about what could help. Some people face greater needs when they become visually impaired (especially in older age, and those who go from sighted to having little or no useable sight in adult life) and can be dealing with the emotional impact this brings, especially in the early stages of sight loss.

Knowledge seemed to be a key resource to which access was variable. This included knowledge of how to claim benefits, how to become registered with the local authority as visually impaired, where to find services, training and support, what technology may help and what social activities are available locally. It was clear that one form of contact with supporting services could lead on to others.

The presence or absence of such resources can depend on many factors apart from income, but income remains crucial in accessing basic material needs, addressing the extra costs of disability and oiling the wheels of social participation. Money cannot buy an adequate social network, but having enough to be able to reciprocate the help that friends give you, or to take taxis where needed to get out and about, helps determine how much visually impaired people feel that they can interact socially. Use of technology depends partly on skills, confidence and help from others, but also on being able to afford expensive equipment. Having enough income helps visually impaired people to achieve two crucial things that they value – a measure of independence and agency, and a measure of security, which requires them to build up a savings buffer to protect them when things go wrong. A further essential reason for building up savings to a greater degree than if they were not visually impaired was the need to be able to make large one-off payments for specialist equipment.

Instability and apprehension about the future featured heavily in discussions with participants. This included personal concerns related to further sight deterioration, general health, work or changes to informal support networks and the implications this would have. Added to this were concerns about the re-assessment of disability and means tested benefits and how those particularly living below the MIS VI threshold would manage if income were reduced. Similarly, for some there were fears about whether the annual assessment of social care needs could result in a loss or reduction in support and what this would mean in terms of having to pay for extra help or going without. There were also worries about funding cuts to services including VI provision. These concerns were often voiced in the context of current austerity measures and benefit changes which can seem to further put the needs of disabled

people under siege – and was something that was out of their control. This sense of precarity in income and support can be a cause of anxiety, adding further uncertainty to visually impaired people's lives.

"I just think that the more cuts and the more scrutiny that they do, it could all fall down, it would only take, you know when they do a reassessment of the PIP or the ESA for me to fall through that hole and I could be losing everything … I get zero council tax … if they said they couldn't cover that you know what I mean? And let's say they put up my care contribution, and my PIP changed to a lower rate of care or whatever I can just see me falling through this hole and through the cracks. And that is my fear, you sit here worrying. You have got enough problems with your sight problem and how much of a struggle it is and what help you can get and the health, and then they are trying to chop your legs off at the same time, and that is my big fear of the way that things are going." (WA, SSI)

Three key policy messages emerge from this study.

First, that many visually impaired people, particularly those depending on working age benefits, need more adequate and secure sources of income than is offered by the present system. Many of those interviewed were just managing, but there were concerns about the future, and the additional need of visually impaired people to cope with the uncertainties of deteriorating sight and to build up savings that allowed the purchase of expensive equipment when needed. Constant changes in the benefits system have made it difficult to know what income will be available from one year to the next, bringing precarity rather than stability and can be the source of considerable stress.

Second, there are many ways of helping lower income visually impaired people build the capabilities that help them cope with the challenges of life. These include providing good information about what benefits, services and support is available, advice and advocacy when things go wrong, help and training in the use of assistive technologies and less stressful pathways to claiming the benefits to which they are entitled.

Finally, the study underlined the importance of getting such information and support to people when they first become visually impaired, a time when the challenges can be the greatest but knowledge of what is available the lowest. A crucial factor is being well linked in to VI networks, a process in which registration and its follow-up can be crucial. But access to VI groups before registration can also be valuable. This research suggests that there is a gap in support, especially for pension age people who become visually impaired, and a need to give timely assistance to those trying to cope with the early stages of sight loss. A more joined up system for ensuring that people are linked in to the support they need would be a good start in improving the sight loss pathway and life in general for people at this critical time.

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Centre for Research in Social Policy
Department of Social Sciences
Loughborough University
Leicestershire
LE11 3TU

Tel: +44 (0)1509 223372
www.crsp.ac.uk

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