

# Sight Loss and Minimum Income Standards: the additional costs of severity and age



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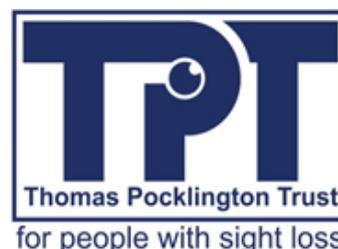
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### **Note on terminology**

In this report the terms ‘people who are sight impaired’ and ‘people who are severely sight impaired’ are used to describe those who are eligible for certification as sight impaired or severely sight impaired. Not all people who are eligible are actually certified. This study is based on people’s needs, however, the MIS budgets assume that someone claims all services and financial benefits that they are entitled to. The terms sight loss and visual impairment cover both of the above categories.

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# Executive Summary

## Introduction

This is the final report in a series of research looking at the additional needs and costs faced by people who are visually impaired, and how these costs vary by the degree of severity of sight loss and life stage. The research used the Minimum Income Standards (MIS) methodology to estimate how much more it costs for someone with visual impairment to achieve a minimum acceptable standard of living compared to someone in the same circumstances without sight loss. The report provides the detailed results of the final study – covering a single person of pension age who is severely sight impaired – and draws these findings together with previous studies. Together, these have shown that additional costs increase with more severe sight loss and with older age, and the final study shows the financial impact when these factors combine.

Understanding the cost of disability is important 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 or support. This research estimates such costs for people with sight loss using the Minimum Income Standard (MIS) as a baseline. 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 meeting basic needs, enables people to have the opportunities and choices necessary to participate in society.

## Methodology

The method looks at the additional needs and costs of living for visually impaired single adults by comparing four cases with the main MIS studies for a working age and a pension age person without visual impairment. As well as quantifiable evidence, this method of research provides description and reasoning about the range of different categories in which additional costs arise.

The research has been conducted in three waves. The earlier studies (Hill et al 2016; Hill et al 2015) looked first at the additional needs and costs of a single working age person who is sight impaired, and extended this to examine two further cases: working age severely sight impaired and pension age sight impaired. The final study, reported in detail here is the case of a single pension age person (aged 65 or over) who is severely sight impaired.

Overall the research comprised twelve groups – three for each case – of people with visual impairment discussing a ‘case study’ of a single person with impairments similar to their own to determine what needs to be different from the main MIS pension age budgets because someone is visually impaired. The method builds consensus within each group and across groups about what should change and why. These changes are costed to produce an additional weekly budget compared to the main MIS budgets for someone fully sighted. Some variations were noted where having no sight at all compared to very limited sight made a difference to costs. The additional needs and costs in the final study reported here were also compared to the budgets created in this way for the previous three cases to allow calculation of differences between

working age and pension age budgets across both sight impaired and severely sight impaired levels of visual impairment.

## **The Additional Needs of People of Pension Age who are Severely Sight Impaired**

A wide range of additional and different needs were identified for the case study of a single person of pension age with severe sight impairment. The main areas of goods and services that add to the budget for this group are as follows:

### **Paying for services and support in the home**

Groups included costs for formal services in the home which were seen as necessary to maintain independence and not be reliant on family or friends. This included regular support with cleaning, ironing, washing and dealing with paperwork – things which could be difficult and time consuming for an older person who is severely sight impaired. This was important to provide reassurance that their home was clean for themselves and to host visitors. The budget for home maintenance was higher than in other cases in recognition of a greater reliance on paid help for 'odd jobs' that they would not be able to carry out themselves.

### **Additional transport costs**

Groups emphasised the importance of 'getting out' but that an older person who is severely sight impaired would find it harder to use the bus or walk distances. Taxis were identified as a key means of transport especially if going somewhere unfamiliar, when door to door transport is

needed, after dark, and when carrying anything as at least one hand could be occupied with a cane or Guide Dog.

### **Additional costs of social participation and going on holiday**

Groups noted that the ability to take part in social and cultural activities was very important for older people who are severely sight impaired, especially for someone who lives alone. The budget was higher than for sighted pensioners to allow for some specialist leisure activities and to include money to allow reciprocity - paying for a meal or a drink - for someone who has accompanied them in activities outside the home. The holiday budget was also higher than for sighted pensioners to cover part of the cost of a companion's holiday who might provide assistance when away in unfamiliar surroundings.

### **Additional cost of household goods**

A need for additional items to feel safe and secure in their home was important for peace of mind. This included an intercom and bell alert to help identify visitors and guard against unwanted callers. A telecare system to summon help in an emergency and bathroom safety features reflected personal safety concerns that being both older and severely sight impaired contributed to a higher risk of slipping and falling. Additional and different types of lighting were viewed as vital to those with some residual sight to make the most of their remaining vision. Changes to kitchen and dining equipment added hardwearing items to prevent breakages and alternative or specialist equipment which was easier and safer to use. Options for hard flooring were added to help with cleaning and using a cane, and easier to clean covering on seating was also included.

### **The use of pre-prepared food**

Groups agreed that severe sight impairment presented challenges and safety concerns when preparing food or using the oven and included the cost of some pre-prepared food such as grated cheese and the option of some delivered microwaveable ready meals each week.

### **The use of technology**

Changes were made to a range of items to make them more accessible for someone of pension age who is severely sight impaired. This included: a television with audio menus; a specialist digital radio/CD player with the ability to easily use talking books – both items were an important form of ‘companionship’. Both landline and mobile phones were upgraded to models with more accessible features. Changes to the laptop included a wireless keyboard and mouse, a bigger screen size for those with some sight, and a printer/scanner to enable documents to be read with screen reading software. A cost was also added to cover IT training and support. Other specialist items included a penfriend labelling device plus a portable and stand magnifier for those with some sight. There was recognition of a divide among older people between those who make use of technology items which can have multiple functions, such as a smart phone and computer, and those who do not. Alternative items were costed to ensure ‘low tech’ options were within the budget.

### **Additional costs of personal goods and services**

The budget for clothing was increased to allow more frequent purchase of outerwear and higher quality footwear in recognition of extra wear and tear. The cost of more expensive glasses was included where people have some sight. More frequent hairdressing visits were added to

provide people with confidence in their appearance which they cannot see themselves.

## **The Additional Costs for People of Pension Age who are Severely Sight Impaired**

The total weekly budget for a single person of pension age who is severely sight impaired is £320.76 (excluding rent), which is £135.61 more than that for a single pension age person with no sight impairment. This represents a 73 per cent increase on the main MIS budget of £185.15. Half of these additional costs come from household services, 18 per cent from transport, and 12 per cent from social and leisure costs. The remaining 20 per cent is split between additional costs for household goods, food, technology, and personal goods and services. Severely sight impaired pensioners with no sight at all have a slightly lower minimum budget (£6.49 per week less) mostly because there is less spending required on glasses, additional lighting or magnification aids.

## **Differences in Additional Needs and Costs by Severity of Sight Loss and Age**

The previous studies in this series have shown that additional costs increase both with severity of sight loss and older age, and the new case reported here confirms that costs increase further when these factors combine.

- For a working age person who is sighted, the main MIS weekly budget is £197.63. For someone who is sight impaired this is

increased by £50.33 (around a quarter). In the severely sight impaired case, the budget is increased by a further £70.10 resulting in a total increase of £120.43 (around 60 per cent of the main MIS budget).

- For a pension age person who is sighted the main MIS weekly budget is £185.15. For someone who is sight impaired this is increased by £77.82 (around 40 per cent). In the severely sight impaired case, the budget is increased by another £57.79 resulting in a total increase of £135.61 (around 70 per cent of the main MIS budget).

Comparing additional costs across the four studies shows that:

- Severity of sight loss increases the additional cost of sight impairment across the working age and pension age cases.
- The overall additional costs are greater for someone of pension age than someone of working age across both cases.
- The difference between the cost of being sight impaired and severely sight impaired is greater for working age than pension age people.
- Greater needs can arise, even at a less severe level of impairment, for people of pension age who have acquired sight loss than for working age adults who have lost sight earlier in life. These include a greater need for regular human help and personal support which incur higher costs than the increased use of technology by younger groups. Costs related to home security and personal safety concerns were more prominent in pension age groups. Pension age groups noted issues around adjusting to sight loss coupled with poorer mobility which could contribute to loss of confidence and a sense of vulnerability.

Variation in the extent of additional costs across budget areas across the four cases highlights that:

- For working age, most of the difference between the sight impaired and severely sight impaired cases arises from the higher additional cost of household services and transport, followed by social activities, food, technology and personal goods. For pension age the extra additional costs associated with severity of impairment arise predominantly from household services, followed by social activities and to a lesser degree food, personal goods and household goods.
- In some categories, notably technology and social activities, additional costs are higher for working age than pension age cases at both degrees of impairment. Conversely the additional costs of household services are higher for pension age than working age at both degrees of impairment.
- The largest additional cost across all four cases is for services and support in the home and the level increases with severity of sight loss and age, as ability to carry out tasks in the home was felt to diminish.
- Transport costs increase by severity of visual impairment for working age, but older people's needs arise at a less severe degree of sight loss with the combination of decreased mobility and sight loss requiring more dependence on taxis for older people across levels of sight loss.
- The additional cost of technology is much greater for working age groups than for pension age groups across severity of impairment, and while the amount increases significantly from the working age sight impaired to severely sight impaired budgets, there is very little difference between the two pension age cases. This reflects that mainstream technology was seen by working age groups as a resource to draw on in a more wide-ranging way than by pensioner groups.

- Maintaining social participation to avoid the risk of isolation was important across groups with varying costs arising in different ways in the four cases. This reflected the greater costs required for activities, holidays, taxis to get to social events, money to pay towards a companion's holiday or treat them to a meal or drink or accessible communication and entertainment at home.

## **Conclusion**

This research looking at the additional costs of single people living with visual impairment underlines that the size of such costs varies by situation – in these studies by age and severity of impairment.

The scale of additional costs of visual impairment tends to be greatest where it involves regular human help, for example with help in the home or requiring a taxi, rather than the purchase of equipment. This means that people who feel the most vulnerable, and therefore require the reassurance and practical aid of more human assistance, can face particularly high costs. This helps to explain why an older person whose sight may have deteriorated relatively recently may face considerably higher costs than someone with a similar level of impairment acquired earlier in life that they have learnt to adapt to. Further implications of this vital human dimension are that people who have friends and family that can provide help may have far lower costs than those who do not and are therefore reliant on paid help. People's ability to adopt certain technological support can also make a vital difference.

The benefits system does recognise that there are extra costs associated with disability but can take a narrower view of how these costs arise than implied by this research. Visually impaired adults can

apply for PIP or Attendance Allowance, but whether these benefits cover the additional costs of sight loss identified in this research will depend on whether the eligibility criteria is met and they are successful in claiming the benefit, and what level of benefit is awarded. No benefits system will ever be able to come up with an accurate assessment of additional costs that include such things as how much an individual needs in order to treat a friend who has helped them out. Yet such costs are at the heart of what enables people who are visually impaired to participate in society, and need to be taken into account. These studies have given a broad guide of the scale of costs faced by people with sight loss, and how they change with the degree of sight impairment and age.

## Chapter 1 Introduction

This is the final report in a series of research looking at the additional amount that single adults who are visually impaired need to reach a minimum acceptable standard of living. How much more does it cost for someone to live with sight loss compared to someone in the same circumstances without sight loss? Visual impairment covers a broad spectrum of sight loss across a range of people in different circumstances. The research presented here is a culmination of a series of studies which have applied the methodology that defines Minimum Income Standards (MIS) to estimate the additional costs of visual impairment. They consider dimensions of difference in needs and costs for adults with sight loss and how they vary by the degree of severity and life stage. Research into the needs and additional costs of older people with sight loss is important as the majority of people with visual impairment in the UK are above eligible state pension age – one in five people aged 75 and one in two aged 90 and over are living with sight loss (RNIB, 2016). Furthermore, with an ageing population numbers are likely to continue to increase.

This report serves two main purposes. First, it provides the results of a study looking at the additional costs of living for one particular group – single people of pension age who are severely sight impaired. Second, it draws together these findings with those of two previous studies (Hill et al, 2015; Hill et al, 2016) which have already shown that the budget required to reach a minimum acceptable standard of living increases with the severity of sight loss, and with older age. This report shows the financial impact on people with sight loss when these factors combine

and contributes to understanding how needs and costs vary between different groups of people with visual impairment.

## **Background**

Understanding the cost of disability is important for any society that seeks to ensure that people do not have to live in undue hardship. It is particularly relevant in current times in the UK amid changes to disability benefits such as the move from Disability Living Allowance (DLA) to Personal Independence Payment (PIP) for working age people, and consultation about the future of Attendance Allowance (AA) for people aged 65 and over, plus continued concerns about how welfare spending cuts will affect services or support used by disabled people. Despite an understanding that disabled people do face additional costs, hence the existence of disability related benefits, the true effect of disability on everyday living costs remains poorly understood and hard to measure. Previous research has looked at spending (which does not capture unmet need) and has been hampered by the lack of a baseline from which to measure additionality (see Hill et al, 2016; Hirsch and Hill, 2016 for a more detailed discussion). In this context the Centre for Research in Social Policy (CRSP) has started to apply its Minimum Income Standard (MIS) methodology to consider the minimum costs required by different categories of disabled people, drawing on the MIS budgets as a baseline. Supported by Thomas Pocklington Trust, CRSP developed the method and since 2014 has been using it to calculate the additional costs of living for people with sight loss.

## **The Minimum Income Standard**

The Centre for Research in Social Policy has since 2008 produced Minimum Income Standard (MIS) budgets for different household types which are regularly updated (Bradshaw et al., 2008; Davis et al., 2016). These are based on detailed research with members of the public specifying what goods and services households need in order to reach a minimum socially acceptable standard of living. The central features of MIS that are important for this body of research are that it provides a baseline against which to measure additional costs, the method is based on social consensus, meaning that decisions about need are made by groups of members of the public, and it provides a clear definition of what is meant by a socially acceptable minimum need.

‘A minimum standard of living in Britain today includes, but is more than just, food, clothes and shelter. It is about having what you need in order to have the opportunities and choices necessary to participate in society’.

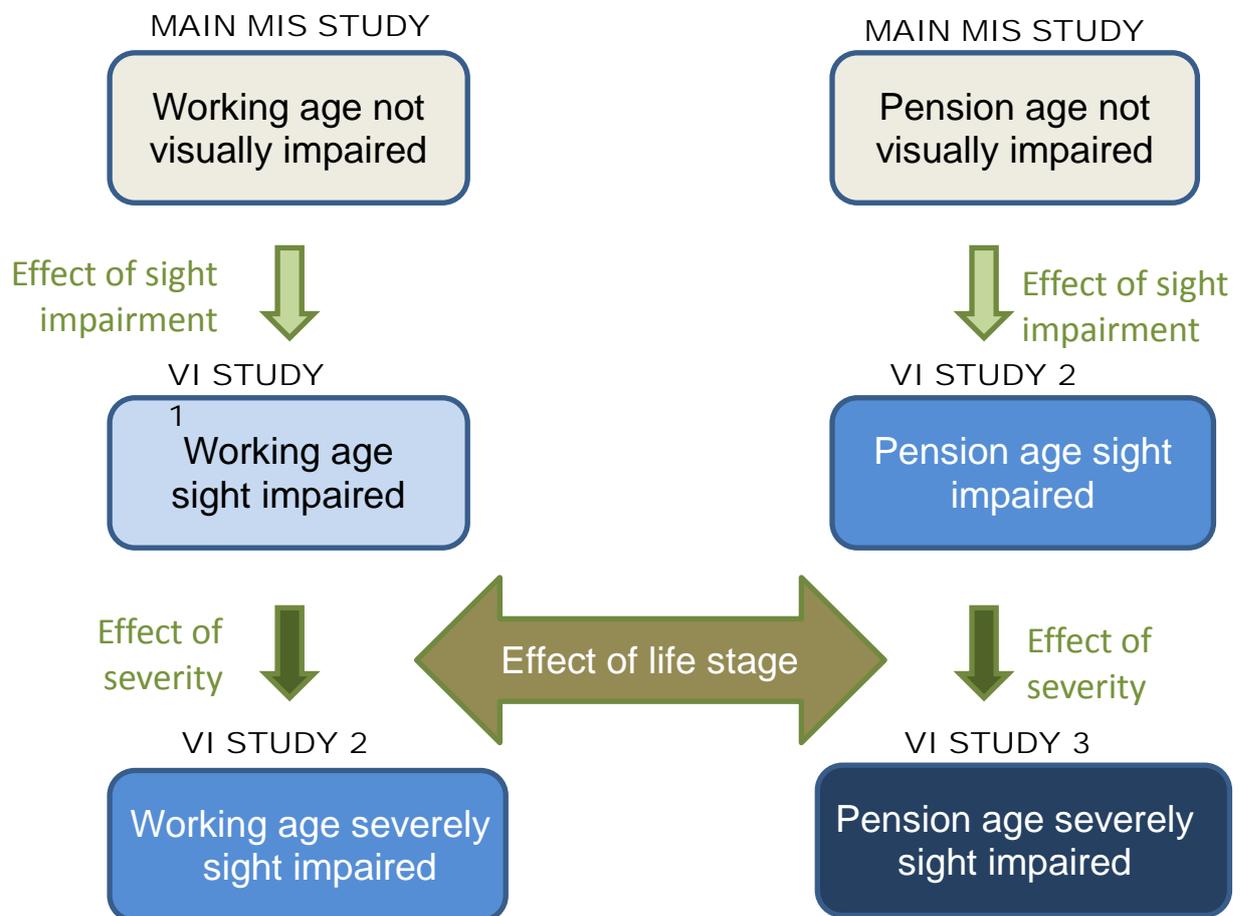
This definition allows MIS to be used to look at the additional needs of disabled people in a way that does not start with the premise that they must be enabled to live identical lives to non-disabled people, but rather that they should have equivalent access to a minimum acceptable level of choices and opportunities, as well as meeting physical needs.

Moreover, like the rest of MIS, it involves giving responsibility for judging the acceptable threshold to groups of people with experience of living in the type of household whose needs are being researched – in this context people who have sight loss. A Background Note at the end of this chapter summarises the MIS approach.

## **Investigating the Additional Costs of Sight Loss**

Figure 1 and the explanation below summarises how this series of studies have built up a picture of the additional costs of living for visually impaired single adults. It shows how the main MIS studies for a working age and a pension age person without visual impairment are used as a baseline to consider over the course of three studies the effect of sight loss on costs of living and how this varies by severity of impairment and life stage.

**Figure 1 Summary of MIS visual impairment studies and the additional costs that they identify**



The first study in this series calculated additional costs of living for a single person of working age who is eligible to be certified as sight impaired and has some useable sight. It showed that the budget needed to reach a minimum acceptable standard of living was a quarter more than for someone without sight loss (Hill et al., 2015). The study was extended in 2015 to consider two further cases looking at the effect of severity of sight impairment and life stage. The findings showed that both being severely sight impaired or being of pension age further increased the budget required. The budget for a single working age person who is severely sight impaired, with little or no sight is 60 per cent more than for someone without that impairment, and for a single

person of pension age who is sight impaired, with some useable sight the budget is 41 per cent more than for someone without such impairment (Hill et al., 2016).

The findings so far demonstrate that there are substantial additional costs in all three cases considered, and the difference made when one factor is changed from the original case. The aim of the further, third study reported on here is to 'round off' this body of evidence to examine what difference is made when both of these factors are taken into account – being severely sight impaired at pension age – and whether they combine to add further to costs. Being able to identify additional costs enables comparison with current benefit levels (such as PIP and Attendance Allowance), which recognise the presence of additional costs for people with impairments, but not necessarily the extent or breadth of the costs involved.

As well as quantifiable evidence, this method of research provides description and reasoning about the range of different categories in which additional costs arise. These include direct aids to help compensate for sight loss, services at home and additional lifestyle related costs outside of the home, such as for social interaction and travel. This is important, as a crucial element of the MIS definition relates to social participation, which is relevant given that people who are visually impaired can feel that their social activities are limited and risk isolation or loneliness, particularly in older age (Slade and Edwards, 2015; Hodge and Eccles, 2013).

The first two studies highlight that there are both similarities and differences in needs and costs when severity of impairment and age are

taken into account. For example, both severity and older age added to the need for help in the home, use of taxis and the inclusion of some ready meals. On the other hand there were differences in how some needs were met across life stage, in particular through greater use of technology by working age compared to pension age groups even with similar levels of sight loss (sight impaired). This further study enables comparison between various categories of additional cost to explore how needs are affected by sight loss in different situations, the various ways in which these are met and the cost implications.

## **Structure of the Report**

Chapter Two outlines the research method and how the MIS approach was applied to this study. Chapters Three and Four focus on the findings of the final study in this series, looking at the needs and costs of a pension age person who is severely sight impaired, compared to someone who does not have sight loss (the pension age case in the Main MIS research). They respectively provide a qualitative account of the discussion of additional needs, followed by budgets that quantify the additional weekly costs in this case. These findings are drawn together in Chapter Five with those of the previous three cases in the series to examine dimensions of difference by severity of sight loss and age, in isolation and when combined. Conclusions and implications of the research are reported in Chapter Six.

## **Background Note: The Minimum Income Standard (MIS)**

**What is MIS?** The Minimum Income Standard is the income that people need in order to reach a minimum socially acceptable standard of living in the United Kingdom today, based on what members of the public think. It is calculated by specifying baskets of goods and services required by different types of household in order to meet these needs and to participate in society.

**How is it arrived at?** A sequence of groups have detailed negotiations about everything a household would have to be able to afford in order to achieve an acceptable living standard. In certain areas of household requirements experts check that the specifications given by groups meet basic criteria such as nutritional adequacy. Each group typically comprises six to eight people from a mixture of socio-economic backgrounds, and is composed of people from the particular demographic category under discussion - for example, pensioner groups decide the minimum for pensioners.

**What does it include?** The MIS definition is about more than survival. It covers needs, not wants; necessities, not luxuries: items that the public think people need in order to be part of society. In identifying things that everyone should be able to afford, it does not attempt to specify extra requirements for every particular individual or group - for example, disabled people or those with long-standing health problems. So not everybody who has the minimum income is guaranteed to achieve an acceptable living standard. However, anyone falling below the minimum is unlikely to achieve such a standard.

**To whom does it apply?** MIS applies to families comprising a single adult or couple with or without dependent children. It covers most such households, with its level adjusted to reflect their makeup. It does not cover families living with other adults, such as households with grown-up children.

**Where does it apply?** The main budget standard applies to the whole of the United Kingdom outside London. The main MIS is based on research with households living in urban areas. In 2010, 'MIS Rural' was published, which includes the additional costs associated with living in rural areas, and in 2015 'MIS London' looked at costs arising from living in the capital.

**When was it produced and how is it being updated?** The original research was carried out in 2007 and the findings presented and costed in 2008. Every July, new MIS figures for the main budgets are published, updated to April of the same year. Annual updates take inflation into account. In addition, every other year new groups are convened to review or rebase selected budgets.

Further information and publications available at  
[www.minimumincomestandard.org](http://www.minimumincomestandard.org)

## Chapter 2 Methodology

This series of research has used the Minimum Income Standard (MIS) approach to calculate the additional needs and costs associated with having a certain impairment. The method for researching additional needs of disabled people under the MIS approach is structured as follows:

- Identifying which type of household's additional needs are being specified, in terms of who is in the household and the disability under consideration. The needs of a household in which someone has a disability is compared to an otherwise identical household where nobody has a disability.
- Holding a series of discussion groups, each lasting several hours, involving individuals with the same or similar living situations and disabilities as in the case being investigated. Each group is asked in detail to review the minimum 'baskets' of goods and services drawn up by non-disabled people and to come to agreement about what needs to change for an imaginary 'case study' household with the specified disability. In each group the idea is to reach consensus as far as possible, with successive groups confirming or amending prior groups' decisions and adjudicating any areas of disagreement or ambiguity. After three groups of this kind for each case, the researchers identify where the overall consensus or balance of opinion lie, in terms of which additional or different items are needed compared to the original MIS budgets. Throughout this process, the emphasis is on 'needs, not wants': any 'nice to have' items that are not essential to meet the MIS definition of the minimum are not included.

- Researchers costing additional items (factoring in how long groups say they will last) and identifying how much this would add overall to the weekly minimum household budgets.

Overall this project implemented this method for four types of household with visual impairment. This Chapter covers some general points on methodology across the studies and reports specifically on the research process of the final case in the series. Detailed accounts of the method in practice for the first three cases can be found in previous research reports (Hill et al, 2015; Hill et al, 2016). In each case, the research team had to ensure that the method was suitably applied to the situation of the people whose needs are under review, in ways set out below.

## **Specifying the Cases**

A key issue in identifying additional costs associated with a particular impairment is to ensure that it is defined in clear terms, and is understandable to participants in the focus groups who themselves have experience of what it is like to live with such an impairment. In MIS, an imaginary person is specified as a 'case study', described in terms of where and with whom they live and, in the case of studies of disability, what impairment they are living with.

After consultation with specialists in the field including Thomas Pocklington Trust, the initial study in this series used the case study of a person of working age, certified as sight impaired, and who has some usable sight (Hill et al, 2015). It was decided that the case studies to be used in the initial follow up research (the second study) should be a person in the same age category but certified as severely sight impaired

with little or no useable sight, and an older person, of pension age (65 or over), certified as sight impaired with sight loss acquired in adult life (Hill et al, 2016). The fourth case reported in more detail below draws the previous two cases together to look at a person of pension age who is certified as severely sight impaired with little or no useable sight. These descriptions were thought to be generally meaningful to people, and relate to the needs of people eligible to be covered by the Certificate of Vision Impairment definitions of 'severely sight impaired' (blind) and 'sight impaired' (partially sighted), without narrowing the case studies to a specific condition or functionality.

It is important to recognise the heterogeneity of visual impairment. The categories of 'sight impaired' and 'severely sight impaired' cover a range of different conditions that can vary and fluctuate, some of which have implications for needs. Reflecting this, groups in some instances mentioned more than one possibility (e.g. for lighting). So rather than specify specific items, an amount of money was budgeted for that could provide the necessary flexibility to allow someone various options to meet such a need. In a few areas of the budget the groups discussing the needs of a person who is severely sight impaired made clear distinctions between items required by people with a little usable sight and those needed by people with no usable sight or light/dark perception. A further issue that emerged, particularly in the pension age groups, was differing familiarity and engagement with technology as a means of meeting needs. These variations are recorded and reported in Chapters Three and Four. Differences in needs and costs for visually impaired people who are Braille or Guide Dog users were discussed and quantified in the working age severely sight impaired case in phase two of the research (Hill et al., 2016).

The case studies used in this research specify that the person concerned does not have any other significant impairments or health conditions. Although some people who are visually impaired have additional conditions that may or may not be related to their sight loss, the focus of this research is specifically on the additional needs associated with visual impairment. In the pension age case it is recognised that older people do not typically have the levels of general fitness or mobility that younger people have, and that this can be relevant for the way in which sight loss affects them. Therefore, certain assumptions about physical limitations, such as some loss of mobility, were made in looking at the needs of someone in 'generally good health for their age', but with sight loss as their primary impairment.

This research focuses on the needs of people who are living on their own, and are not in supported housing. While a large proportion of people with visual impairment live with other people, this case study enables the research to most clearly distinguish additional needs associated with visual impairment, and to measure the cost of living independently.

These criteria were used to develop the case studies used throughout this research. The first three cases (outlined in previous reports) were drawn on for the case study used in the final focus groups:

*Janet (or Jim) is of state pension age (65+) and is certified as severely sight impaired and has little or no useable sight. Her sight loss has been acquired in adult life, and is her primary impairment. She is in generally*

*good health for her age, and lives alone in the community in a one bedroom rented flat.*

## **Recruitment**

A key aspect of the Minimum Income Standards research is that participants are recruited across a range of backgrounds, but that they should match the category of household whose needs are under consideration. A purposive approach was necessary to find people of the correct age and severity of sight loss, living independently or with experience of living alone who were able to attend a focus group in a certain area. Various recruitment methods were used throughout the research (outlined in previous reports). In general, advertising via online Visual Impairment (VI) networks was more successful in reaching working age groups, and direct contact with local VI organisations worked better to access older age groups. These experiences were drawn on for recruiting participants - people aged 65 or over and severely sight impaired - to the final groups. Most participants were recruited through local VI networks such as groups and contacts working with older people who were visually impaired in the particular area where a group was being held. Key to this was the involvement of an intermediary who distributed information about the research to people who might be eligible to take part, mostly verbally but also through email newsletter. Visits were also made to VI group meetings by a member of the research team. National VI networks were also used, such as advertising the project on email forums and VI radio stations, which did lead to the recruitment of several participants. Contacting people through a person or organisation that they were familiar with and trusted helped provide reassurance to potential participants. While remote or

email recruiting, as expected, was not so successful in reaching older people, who were less likely to be 'online' than younger age groups, it did prove more fruitful than in the previous study when looking for pension age sight impaired people. The success in recruiting some participants by this means was helpful, as it was important to include people in the study who were computer literate, and also not necessarily attending regular support group meetings.

The groups for the study reported in the following two chapters comprised:

- 23 individuals across three groups
- 7 men and 16 women
- 6 aged 65-74, 12 aged 75-84, and 5 aged 85 and over
- 17 who lived alone, 1 living with a partner who was also visually impaired, 4 living with a sighted partner and one with another family member.
- 18 owner occupiers and 5 living in social rented housing

## **Running Groups**

Taking account of accessibility needs was a prime consideration when setting up and running the groups. The research team had telephone discussions with participants before focus groups took place about what was involved in the research and to check their communication and accessibility requirements. Project information was made available in large print, audio, Braille and email to help meet the needs of potential participants. Groups were generally held in VI organisation premises to help meet the needs of people with sight loss, for example, accessible facilities or provision for Guide Dogs, and also participants were often

familiar with the venues. Support with transport and meeting participants from train stations was provided where required. During the groups, information that would normally be shown on a flip chart in the MIS methodology was talked through by facilitators. In recognition that lack of visual aids can place more demands on people's concentration, and to allow more time for breaks and completing paperwork, the groups were of a longer duration than the usual main MIS groups.

The aim was to build consensus across three groups in each case through the review technique used in previous MIS studies looking at difference and any corresponding additional needs. The first group in each sequence started by considering and amending the relevant MIS budget for a fully sighted single person of working or pension age – what needs to be different because someone is sight impaired / severely sight impaired. Subsequent groups were asked to confirm or revise decisions, and to clear up areas of ambiguity. The second and third groups were also informed, where relevant, of revisions made to budgets in the previous studies for working age sight impaired, severely sight impaired, and pension age sight impaired cases. This was to explore whether any differences were based on different needs related to severity of sight impairment or age, rather than differences in knowledge about what might be available, for example, in the area of specialist equipment, or technology. Groups generally came to consensus about additional needs, even where the specification of the precise items required could not always be agreed on exactly across groups to bring an iterative move towards consensus. Decisions reached within groups were looked at as a whole, and the budgets produced are based on the overall outcome of decisions and rooted in reasoning and justification outlined by participants.

## **Analysis and Costing**

The costing of the MIS budgets for people with sight loss assumes that they are certified as sight impaired or severely sight impaired according to their condition, and are registered as such with their local authority. Certain goods and services that are universally provided to people that are registered are removed or reduced in the budget. For example, the cost of eye tests or off peak bus travel, and a half price TV license for anyone registered severely sight impaired. If someone is eligible but not certified or registered they may therefore face higher costs, despite having the same needs. Other items that might be available to some households, but not others, such as where there is variation by local authority or another provider, are costed into the budgets as it cannot be assumed that everyone who needs them will be able to access them for free. In costing the budgets VAT has been excluded where goods are eligible for VAT relief because they are designed for disabled people.

Analysis for the final study reported in the following chapters produced calculations to compare with the equivalent MIS budgets for someone of pension age who is not visually impaired to establish the additional costs of someone of that age who is severely sight impaired. Variations are noted in a few budget areas relating to if someone has any sight or light / dark perception. This case is compared to the three cases in the previous studies to examine where there are differences in needs and costs related to severity of impairment and age. In making comparisons between the three studies produced in consecutive years, this report expresses all results inflation-adjusted to 2016 prices, which creates small differences with the numbers reported in the previous two studies,

although not in the percentage that visual impairment adds to costs.  
Throughout this report the term 'main MIS' is used to refer to the original MIS budgets for people who are not visually impaired.

## **Chapter 3 The Additional Needs of People of Pension Age who are Severely Sight Impaired**

This chapter looks at the additional and different needs our participants identified for the case study of a single person of pension age (aged 65 and over) with severe sight impairment. It explores the key goods and services that mark the differences between the budget for this group and the main MIS budget for people who are pension age and fully sighted. Previous research with people of working age who are severely sight impaired and those of pension age with a lower level of sight impairment allows for comparisons to be drawn across life stages and levels of impairment severity. This analysis is presented in Chapter 5.

### **Security and Safety**

The main MIS budget for a fully sighted person of pension age includes a door chain for added security. Participants in this study felt that someone with severe sight impairment would need additional items to feel safe and secure in their home. The need to identify expected or unexpected visitors was raised as it was felt that pensioners may be targeted by bogus callers and severe sight impairment might mean that 'once the door has been opened for visitor number one, visitor number two could slip straight through'. Two further items of an intercom and a bell alert were therefore added to the budget. In being able to use an intercom system to determine who is approaching their home and a bell that sounded when an electronic sensor detected someone crossing the threshold, people in this demographic felt able to achieve the peace of

mind that their fully sighted counterparts got from using a door chain and their ability to inspect a visitor.

Personal safety was also a concern for the groups as being both older and severely sight impaired contributed to a higher risk of slipping and falling. This was said to be exacerbated by dealing with sight loss in later life when one would be used to being able to 'see where things are to break your fall and stop it', and adjusting to a lack of this perception means 'we don't, we just go bang'. The need for 'telecare' was therefore raised as advanced age and severe sight impairment combined to make people feel more vulnerable and a Careline system was added to the budget as a way of summoning help in an emergency:

'W: It's good if you fall down, if you fall in the bathroom or kitchen, if you've got a [Careline] pendant on and you might not be able to get up and then there will be help coming.

Q: ... is there something about being older and more severely sight impaired that would make it more important?

M: If you're living on your own and anything happens to you the one thing you need to know is that I've told somebody and they're coming.

W: Yes.

M: And that's a guaranteed way of doing it.'

This was said to be a particular need for people with no sight because 'as soon as you lose your sight altogether, well it makes a difference to your balance'. The need for peace of mind in navigating the home safely led groups to decide on changes in the bathroom as additional items were required in order to safely use the shower. Grab rails were said to be 'essential' for getting in and out of the shower and a sturdy shower screen that is clearly visible (patterned) as an alternative to the

main MIS shower curtain was added as, in the event of slipping in the shower:

‘... if you grab something it’d fall, wouldn’t it, or wrap round you or something. I don’t think it would be very safe.’

## **Flooring**

Choice of flooring was considered to be an important issue for older people with severe sight loss as the wrong kind of flooring could adversely affect their mobility. The main MIS budget is based on carpet in the hall and living and dining areas. This study found that there was a need to provide for a choice of flooring types to reflect the different ways older people might experience severe sight impairment. For example, hard floors can be easier to negotiate when using a cane:

‘... it’s a surface that if I’m using a cane in the house as opposed to the dog I can figure out what I’m doing. With carpeting I can’t, I struggle with carpeting. In the bedroom, I literally have to walk round the room I can’t use a cane on carpet at all.’

In addition, budgeting to allow for variation in flooring throughout the home was thought to be a useful way of enabling freedom of movement around the home:

‘Well it helps to have a different flooring because it helps you to find out where you are.’

Hard flooring was also considered easier to clean, particularly for anyone with a Guide Dog, however, it was recognised that people will

have different preferences. The budget therefore includes laminate in the hall and the living and dining areas so that there is the option to fit hard flooring or carpet (which is less expensive), depending on what best serves the individual's needs 'because of their particular sight loss'.

## **Lighting**

Effective lighting was said to be extremely important to severely sight impaired older people with some residual sight, who would rely on a range of equipment to make the most of their sight and retain some of the independence that a degree of vision facilitates. It was acknowledged that a variety of needs may arise from the different conditions that cause sight loss and addressing these needs requires investment in brighter, dimmable, flexible bulbs, fixtures and task lighting, which also incurs costs of fitting and replacement as needs change. The minimum standard of lighting in the main MIS budget, which includes a basic ceiling light in each room as well as low cost table lamps in the bedroom and living dining area, was agreed across the groups to be inadequate for fulfilling the needs of someone with severe sight impairment.

Significant variation in the ways in which people are affected by their sight loss led the groups to stress the need for a substantial increase in the budget for lighting without specifying particular items so as to enable flexibility in choosing products that meet individual needs. It was decided that £103.50 per room every five years was the minimum budget that would allow people to purchase lighting that would adequately compensate for the effects of having little or no sight in later life. This budget provides for a range of needs as:

‘Someone who has some sight might well want to go to LED type lighting because it’s very bright and it casts very good shadows so you can figure out where you are ... but just having up-lighters, having side lighters; again different conditions need different things but there is a need for some money in the budget for an upgrade of lighting.’

In this way, individual safety needs could also be addressed, such as the need for cooler bulbs like LED:

‘Another bonus with them is they run very cool ... because if I reach out for the lamp to turn it off or not careful where I put my hand then you burn yourself. It’s not so much a problem now because the old incandescent light bulbs or whatever you call them have virtually disappeared but even the traditional power saving bulbs do throw off a significant amount of heat. If you’re using them as some sort of task lamp I suppose it can get a bit uncomfortable being near them but you don’t have that problem with LEDs at all.’

Participants were also vocal about a shortage of sources of reliable advice on lighting, which meant they were often unsure of what was available, what would suit them best and whether they were paying a reasonable price.

For those with no sight, these increases do not apply, instead the additional items of timer switches to control lighting for security purposes and a daylight floor lamp for visually impaired visitors were added to the budget.

## **Curtains, Nets and Blinds**

Related to the issue of lighting, discussion of the adequacy of the curtains provided in the main MIS budget centred around the range of needs experienced by those with severe sight impairment. In particular, the need to have control over directing natural light and cutting out glare was said to be crucial for those with some residual sight.

‘It depends on the level of sight loss. If you’ve got residual sight you may want to shut out some bright light and therefore you may need blackout type linings or you may need blinds just for your own comfort. When I had residual sight first thing in the morning in the summer my bedroom was bathed in sunlight even with heavy curtains on it and it was a nightmare because it’s very uncomfortable. Bright light can be uncomfortable to some conditions.’

The net curtains in the main MIS budgets were replaced with blinds. The cost for blinds reflects the price of venetian blinds as these were reported to be useful because ‘you can control sunlight to an extent and you get a useful amount of light coming in if you have some useful residual vision’. This type of blind was also said to be suitable as ‘when you need to cut the light out a bit you need something that lets the air in at the same time’. The budget allows for the alternative of roller blinds if these are preferred as they can be purchased at a slightly lower cost.

## **Living Area Furniture**

The main MIS budgets include low-cost fabric seating. All groups in this study expressed the view that a severely sight impaired person would be more likely to have to deal with spills and so felt that a fabric covered sofa would be difficult and expensive to keep clean:

‘Well we’re more prone to spills than other people are because of the balance issues and missing tables and things when you put things down.’

The suite from the main MIS was therefore replaced with reasonably priced leather-type furniture, which is easier to wipe clean. The additional cost could alternatively be used to add stain protection to fabric furniture if this was someone’s preference.

## **Household Goods and Equipment**

In the main MIS, dining items comprise china plates, bowls and mugs and inexpensive glasses. Changes and additions were made to dining-ware following discussions about the difficulties severely sight impaired people face in using mainstream crockery and glassware, which result in breakages and spillages. Groups proposed a balance between dining-ware that would be more resilient and easier to use and being able to cater for sighted guests in a way that reflects more mainstream presentation standards. A selection of plates, bowls and glasses made from more hardwearing material than in the main MIS’s were added and the lifespan of china mugs was reduced as breakages were said to be more commonplace. A set of high sided plates was also included. The

budget therefore promotes confidence in being able to eat without worrying about mess ('he wears his dinner') as well as fulfilling the social role of being able to entertain a visitor. The resulting mix of items allows choice:

'What I've got in my everyday cupboard, I've got two sets of normal crockery for if anyone comes and I have my set.'

Decisions regarding kitchen equipment tended to be guided by additional needs relating to ease of use and safety, as well as independence in the preparation of meals. Specialist models of equipment and appliances were then added to the basic items that equip the main MIS kitchen to replace items whose use depends on sight. For example, kitchen scales and measuring jugs 'have to be talking, I can't use them otherwise'. This was seen as highly important because:

'We're talking about independence and quality of life here and if you're denying the person the opportunity to cook something you're condemning them to takeaway meals and prepared meals from other sources.'

As well as the talking scales and jug, a talking microwave was included as it was felt that some severely sight impaired people would find this easier to use than the main MIS standard microwave. There was strong support for the inclusion of a small slow cooker as a low-cost addition that would offer an easier method of cooking that was not labour-intensive or time consuming and so promote independence. It was also said to be safer in its simplicity:

'W: It's easy cooking.'

W: It's a one pot meal and it's easy to serve and you can serve straight from the pot without straining pans. You know it's so much safer.

M: And less washing up.

W: Less saucepans.

W: Less complicated.

Q: And is that helpful because of her sight loss?

W: Yes definitely.'

A water level indicator, a boil alert and a non-slip place mat were also added to the budget for safety and to reduce spills. In addition to these specially designed items, groups provided different specifications for everyday items such as the kettle and toaster, which allowed for easier pouring of boiling water and easier extraction of hot toast to reduce risks of scalding and burning, and an automatic tin opener, which would be safer and less messy than a basic model. For those with some sight, a set of brightly coloured chopping mats replaced the standard chopping board to provide a contrast coloured surface and enable safer food preparation.

The main MIS includes a basic, corded vacuum cleaner. There was a consensus among groups that the budget should provide for a cordless vacuum cleaner, with a smaller hand-held cleaning attachment, that would eliminate the trip hazard of the corded vacuum cleaner in the main MIS and allow for easier cleaning. Help with cleaning was a significant issue in this study, which will be discussed later on.

## Technology

### Clock

Some mainstream items were replaced with accessible alternatives, like the Communiclock talking alarm clock, which announces the time at the push of a button instead of requiring the user to read a visual display.

### Radio

The medium of radio was said to be ‘very, very important’ as a source of companionship and contact with the wider world for single people over 65 who are severely sight impaired. The basic radio in the main MIS budget was thought to be inadequate for the needs of those with visual impairment as its design assumes the user’s ability to use a visual display and it lacks accessible controls such as ‘easily locatable and settable presets [which are] very important’.

Groups therefore decided to add a specialist digital radio with accessible features, a CD player and USB port. These additional sources of input would enable the user to play audio in all the forms they are likely to receive information and entertainment, including RNIB’s free talking books services, which now uses USB drives. This model of radio is portable so the ‘companionship’ role of radio can be enjoyed from room to room. It was also acknowledged that digital radio might be accessed via the television (see below). This model of radio would allow an important medium of social and cultural participation to remain open to those with severely impaired sight, as one participant commented:

‘... so many digital radios, radios in general seem to assume that you can interact with a visual display and that’s the biggest drawback with a

lot of radios. You want one that's far more friendly to somebody who is using touch alone because if you've got a small amount of sight you won't see those displays as a rule. They're just too indistinct and too small.'

## **Television**

The main MIS includes a low-cost 32-inch television and an annual television licence. People who are certified as severely sight impaired can purchase a television licence at half price. Along with radio, television was said to be an important means of staying involved in social and cultural life for older severely sight impaired people. Groups noted that their use of television would be different from people who were not sight impaired as they relied more on the audio element of programmes and audio description and were less able to access controls and menus. When groups discussed televisions there was a clear market leader in catering to visually impaired people as Panasonic televisions include the option of spoken controls, which allow users to navigate channels and menus:

'There's only one television that blind people ought to buy and it's made by Panasonic and they talk to you.'

For those with some sight, groups thought that an increase in screen size would help them to make use of their residual sight and benefit from the picture as well as the audio. At the time of the research, 32" and 40" models were available at the same price. People who are certified as severely sight impaired are entitled to a half price 'blind concession television licence'. However, this saving is negated to a degree by the

higher cost of purchasing a television set that meets the minimum need of a severely sight impaired older person.

### **Computer Use**

Upgrading aspects of computer use factored in to the main MIS was considered to be essential to enable people of pension age who are severely sight impaired to participate in society using this technology. Registering to vote online was one example given of why it was important to ensure that the budget provided IT items that were as accessible as possible. Several participants advocated free accessibility software as a fundamental necessity for computer use. A number of changes to hardware were also considered vital. A wireless keyboard and mouse were included to minimise the number of wires that might cause problems for someone severely sight impaired with little or no sight, and to give a bigger typing area for ease of use. For those with some sight, the screen size was increased to make it easier to see.

In the main MIS there is an annual cost for printing using a local service such as a post office but in this study groups felt it was important to be able to print reliably at home. A scanner was also necessary to allow paper documents to be scanned and read by screen reading software and so a wireless scanner/printer and ink cartridges were added.

### **Telephones**

Participants talked about the difficulties that their lack of sight, together with their advanced age, presented when they tried to move at speed to reach a ringing telephone. For this reason, the main MIS's single corded telephone was replaced with twin cordless handsets, one for the living area and one for the bedroom. Talking caller ID was also included as an

essential function to allow severely sight impaired people the same benefit of choosing whether to answer a call as in the main MIS. For peace of mind, a basic corded telephone with big buttons that would work without power was added for use in emergencies.

‘... whilst the big button is fine for someone who has some sight it’s marginal any benefit I get from it having no sight: I need a talking phone.’

When discussing the additional needs an older person with severe sight impairment would require a mobile phone to fulfil, there was acknowledgement that there would be a marked divide in those who were in the habit of making use of technology and those who were not. In the main MIS for people of pension age, this divide does not affect the budget as a basic smartphone costs the same as a non-smart mobile phone. However, our groups were of the opinion that, if a severely sight impaired person needed to use a smartphone, their accessibility requirements would be beyond the specification of a basic smartphone and they would need to be able to purchase a smartphone that had features specifically designed for visually impaired people, such as voice control, a screen reader and a screen magnifier. The Apple iPhone was universally advocated as a mainstream device offering these accessible features, together with free apps and the KNFB Reader app, which uses the phone’s camera to capture text and read it to the user. This study’s baseline budget therefore provides for an iPhone but also notes the alternative cost for someone with a ‘low-tech’ lifestyle. As can be seen from the following sections, the increase in cost for this item is actually associated with savings elsewhere in the budget, as a number of the iPhone’s functions and associated apps render discrete low-tech devices

unnecessary. One participant gave the following example of a barcode reader app:

‘... but with the phone and the app you can scan what you've got in your cupboard, it will check the barcode and then it will come back and it will tell you that it's tinned tomatoes, tinned beans, tinned soup, whatever, so you'll be able to use your phone.’

Those who opted for low-tech mobile phones also favoured a change from the main MIS to provide a specialist model that was more accessible than the most basic handset and featured audio feedback and text reading:

‘Mine talks to you, it tells you what number button you're pressing so if you make a mistake you know. It does that, a text comes through and it reads it to you.’

The importance of both larger buttons and a talking function led to the Alto 2 handset as a non-smart phone alternative, which comes within the cost of an iPhone.

It was recognised that lifestyle choices may vary considerably in a population ranging from 65 to over 100 years old and with a range of eye conditions. While it was considered vital that the case study budget should provide the choice to use a laptop and a smartphone in the way that the main MIS pension age budget allows, groups sought to ensure that those who were not familiar with such mainstream technology had their needs provided for without those items that require computer literacy.

## **Specialist technology**

This study found that some items needed to be included in a minimum income standard budget for older people with severe sight impairment to allow the recipient to maintain a decent level of independence through the ability to respond to their surroundings, and particularly to engage with text, without having to depend on someone else's interpretation. This necessitates the use of technology specially designed for people with visual impairment to identify items, magnify images and text and read text aloud.

Specialist technology added to the budget included a Penfriend labelling device that allows the user to create descriptive labels for items that the device then reads back to them, which was said to be 'worth [its] weight in gold'. Bumpons – adhesive rubber bumpers that serve as markers on household appliances were also added to make mainstream items easier to use. For those with no light perception, a light detector was included to help the user keep track of the appearance of their home and the energy they are using:

'[It is] essential, absolutely ... They work like a charm, you walk around your house, press the button and if it goes buzz there's lights on, if it doesn't buzz, lights off.'

A portable illuminated magnifier and a magnifier that connects to the television were also included for those with some sight. Within this budget, an illuminated stand magnifier may be chosen if preferred to the television type.

For those with not enough residual sight to benefit from magnification the KNFB Reader app on the iPhone and using the scanner printer with the laptop and free screen reader software would meet this need. As an alternative for those who are not comfortable with using an iPhone or computer, an Optelec reader was suggested, which 'takes a photograph of say a bill and then it reads it out to you' using scanning, text recognition and audio functions that someone who prefers a low-tech approach could easily use. This was said to be invaluable because higher levels of personal support would otherwise be required, which might diminish someone's independence, and so 'I'm not having to ask people to do this, that and the other'.

Another item that was added for those not choosing a smartphone was a dictaphone, which was said to be useful for making everyday 'notes'.

## **Food**

The food included in the main MIS budgets is based on weekly household menus, which are decided by groups and analysed to ensure nutritional adequacy, before being converted into shopping lists. It is assumed that people cook themselves, using some ready-made ingredients for convenience.

Groups agreed that severe sight impairment presented challenges when cooking and one participant reflected on her need for more prepared ingredients:

'Well grating cheese can be quite dicey, so I have to buy my cheese grated now and that's much more expensive.'

Grated cheese was therefore added to the budget. The most significant change to the budget was driven by groups' view that, because of difficulties in using kitchen equipment discussed above, some delivered ready meals should be included.

'Well I can't use the oven ... so the man comes, brings them and then he puts in big letters how long it's got to be in the microwave.'

This personal service was said to be invaluable for those who could not confidently cook for themselves every day, with some participants saying they 'relied' on it, and groups agreed that the budget should allow for four of these meals a week. It was noted, however, that the activity of shopping for food provided older, severely sight impaired people with a valued reason to get out of the home. Many participants gave this reason for eschewing the convenience of supermarkets' delivery services and expressed their satisfaction with the help provided by staff when they visited shops.

## **Clothing and Footwear**

Groups talked about the wear and tear their clothes were subjected to because of their low vision. A potential need for higher quality outerwear was discussed but it was agreed that 'if you catch it somewhere, it doesn't matter where you've bought it from' and so the appropriate change to the budget was to reduce the lifespan expected of coats and jackets to reflect the need to replace damaged clothing more regularly than in the main MIS. Items that would otherwise endure for three years were therefore re-costed for replacement every two years.

Similarly, shoes were said to face testing conditions:

‘And you do tend to kick, you know as you’re going up, I found when I was walking when you’re going up curbs, you catch the toes. So as much as you polish them on a regular basis, you do scuff the leather, so therefore once you’ve scuffed the leather and it doesn’t keep, and if they’re not leather then they’ll go to a hole much quicker.’

The budget was therefore adjusted to include shoes of a higher quality. Groups discussed the kind of retailers that severely sight impaired older people would purchase clothing from and whether these might differ from the supermarkets and chain stores of the main MIS budget.

Participants were largely satisfied that the case study person would be able to shop in the same places as, although they might need some extra help, they were confident that this would be offered:

‘... [in large supermarket] they said “well try this one on” and I said “well I can’t see what it looks like”. She said “try it on, we’ll help you”. They’re ever so kind.’

A cap was added for protection from low branches and other unseen obstructions.

The main MIS includes a watch and groups agreed that this needed to be substituted with a talking watch so that severely sight impaired people could check the time themselves.

A rucksack was also added as a hands-free way of carrying items.

## **Opticians**

The main MIS includes a cost of £118 every two years for glasses. Groups said it was necessary to increase the cost for older people who are severely sight impaired with some sight. Where someone has some sight, it was recognised that there could be wide variation and frequent changes in their needs for eye care. To account for this, the glasses budget was increased to £300 every two years to cover more complex and changing prescriptions. Where someone has no sight, the main MIS figure of £118 every two years was reduced to £25 a year to cover eye shields for protection from wind and glare and general eye care.

## **Hairdressing**

The minimum need for hairdressing for both men and women was debated in some detail, with groups agreeing its significance for older people who are severely sight impaired was that 'it's a confidence thing':

'You tend to have lower esteem because of your sight loss. You are separated out as different. So anything you can do, whether it's having your hair done, buying a new tie, whatever, you do just to cheer yourself up. So is there a clinical need: no. Is there an emotional need: yes.'

Together with the practical consideration that 'you can't see yourself in the mirror', this led groups to add the cost of a wash and set between cuts for women, and to increase the frequency of men's cuts from every six weeks to every five weeks. It was felt that this increase in personal care would afford the case study person a degree of confidence that

would allow them to participate socially, as is fundamental to the definition of the Minimum Income Standard.

## **Services and Support in the Home**

Groups felt strongly that there were a number of domestic tasks that an older person with severe sight impairment would need help with if they are living alone independently and not reliant on help from family or friends. Many used the services of a 'home help' for 'cleaning, ironing, washing, stuff like that'. Having the time and energy for social participation, as well as undertaking all their own housework was thought to be difficult for this demographic and there were also concerns about being able to maintain cleanliness when a person is severely sight impaired with little or no sight, as well as the safety of operating appliances such as irons. Additional benefits to using the services of a professional included being able to take pride in one's home and feel comfortable having visitors, and having a regular source of support with small tasks that arose, such as reading energy meters.

Paperwork was also recognised as a regular task that older visually impaired people would need support with. Occasional assistance in dealing with bills and correspondence was therefore included in an overall total of five hours a week of home help.

The home maintenance budget was also increased from the main MIS figure of £100 a year to £350. Groups felt that it would be impossible for the case study person to carry out the less skilled elements of decorating and repair that keep the cost down in the main MIS and that they would therefore incur the labour costs of employing an 'odd-job'

person. This was thought to be a difficult cost to manage: 'some charge £50 and they haven't done a thing, they've come to have a look'.

Finally, in the case of computer users, it was said that an annual cost for technical support should be included. Groups suggested £80 a year would cover additional training to use accessible software and troubleshooting needs arising from using a laptop and associated technology, including specialist software.

## **Energy Costs**

The main MIS uses a calculation of the cost of the energy a person of pension age would be expected to use in a one-bedroom flat. This study found that there were additional needs that would increase this budget as a severely sight impaired person uses household appliances and lighting differently. As described above, extra lighting would be necessary and it would also be used for longer periods to avoid having to locate switches in the dark, thus consuming more energy. The companionship function of radio and television was said to mean one of these devices would be used most of the day. Groups noted that additional electricity costs related to lighting do not apply to someone who has no light perception.

## **Transport**

A key message from groups was that it was 'important to get out', whether for shopping, keeping appointments, or for social activities, and to not be excluded from participating by issues of time or location.

Hence transport is clearly vital to severely sight impaired older people's sense of freedom.

The main MIS provides for a bicycle for someone of pension age, which groups agreed should be removed as it would not be practical or safe for someone with severe sight impairment. All MIS studies make the assumption that people over 65 will utilise their free bus pass, which is supported by groups. Participants acknowledged, however, that an older person who is severely sight impaired would find it harder to use the bus or walk distances and taxis were identified as a key means of transport. There were some journeys that could not always be made by bus. 'Ring-and-ride' minibus services were discussed but their availability was said to be limited. Taxis were said to be a necessary cost at times when bus services were not running, as well as on the occasion of going somewhere new and unfamiliar, when someone would not be confident about which bus stop to get off at. It was also noted that severely sight impaired older people might be more comfortable with door-to-door transportation when it is dark:

'... when I'm doing a lot of voluntary work, especially in the winter, at least getting home in the dark because my sight just disappears in the dark. So after 6pm, 5pm even, in the dead of winter, taxis really come into their own. I will mix and ride taxis and public transport if I can, but [taxi journeys are necessary] certainly going somewhere new and in the voluntary work I do.'

Taxis were also helpful when carrying anything, for example shopping, as someone who is severely sight impaired would have at least one hand occupied with a cane or Guide Dog.

‘Well I have to go out and shop and there isn't a shop near me, so before I start I have to pay £10 for the taxi ... So it's £10 in a taxi before I even buy anything.’

The budget for taxis was therefore increased from the main MIS figure of £12 a week to £35 a week.

Groups also agreed that a severely sight impaired person would need a cane and this was added to the budget along with replacement tips.

## **Leisure and Social Activities**

The main MIS budget for a single pension age person includes £14 per week to cover leisure activities, as well as a modest amount for a fortnightly meal out. Groups noted that the ability to take part in social and cultural activities was very important for older people who are severely sight impaired, especially as the case study in this study is someone who lives alone.

‘W: It gets you out.

W: It gets you out go out meeting people.

W: Have a chat, cup of tea and a talk.

W: Actually with the Macular our Macular is all the same things wrong with us, that's the only thing that's wrong so we can all talk about the Macular.’

Examples of activities that they might engage in included those run by local VI organisations or Macular Society groups and various sporting

clubs that provide opportunities for visually impaired people to take part in activities. This study found severely sight impaired older people expected to incur higher costs for some of these leisure and social pursuits:

‘If she wanted to go to acoustic shooting, archery, fishing, any kind of mainstream, bowling, they have to have special equipment, they have to go on special days. They can’t just go ‘oh I’ll go bowling tomorrow’ – is it a VI bowling day or not? If it’s not, then you can’t go. So there is a cost involved in that because you have to rearrange things. So just to say £14 a week, because it tends to cost more. If I go acoustic shooting it costs me £20 a session. A normal person going who goes shooting on the range, pays £10, but because I’ve got to have extra safety people there and so on...’

In light of their leisure choices being more restricted and not being able to take advantage of the lowest priced activities, groups agreed on a £4 increase in the weekly budget. A CEA cinema card that allows a carer to accompany a visually impaired person to the cinema for free was also added at a cost of £6 a year.

Groups also said that being accompanied by a friend or helper often enabled people to participate in activities outside the home. In these instances, groups agreed that they felt more comfortable accepting help if they could reciprocate by paying for a meal or a drink while out with their friend or helper. ‘They’re so kind to you, you feel you’ve got to say “No, I’ll pay for it”.’ It was decided that £10 should be added to the budget to cover this cost.

## Holidays

The main MIS for a single pension age person provides for holidays in the UK – one week and one weekend break a year. This study looked at whether the minimum standard of half-board coach holidays would meet the needs of someone with severe sight impairment. Groups agreed that the holiday itself would be suitable for an older person with severe sight impairment but thought that they would need someone to accompany them in order to feel confident about going somewhere new. As with the reciprocity cost above, it was decided that offering payment was the only way to ‘guarantee’ the appropriate assistance would be available to allow someone to relax and enjoy their holiday:

‘M: ... If you are going on a holiday and you are severely sight impaired you have to take somebody with you to be your guide. You can’t walk around in strange places, even with a guide dog, unless you have someone else with you.

Q: Because you are going to unfamiliar places?

M: Unfamiliar territory.

M: And it is unfamiliar to the dog as well.’

Groups agreed that adding an extra third to the holiday budget to cover some of the cost of the companions holiday was a pragmatic way for them to feel confident that they would be adequately assisted, ‘and then you are paying for them to come and you can ask them to do things and you don’t feel embarrassed’.

## **Chapter 4 The Additional Costs for People of Pension Age who are Severely Sight Impaired**

The changes to the budgets discussed above for people of pension age who are severely sight impaired have been calculated by accounting for the price of items added or changed from the main MIS budgets and removing any costs that do not apply. In some areas of the budgets these additions and differences have had a significant impact on the weekly cost of this minimum basket of goods and services. In other areas the implications for overall costs are less significant, although there may be notable differences in the items that comprise the budget. This chapter details the additional costs of a minimum, socially acceptable standard of living for a single pension age person who is severely sight impaired. The categories are discussed in descending order of additional cost per week. There then follows a discussion of areas of the budget where having no residual sight or light perception makes a difference to costs. Note that some of the figures used in the tables below have been rounded.

### **Additional Cost of Household Services: £67.27**

The category that adds the most to the weekly budget is household services. Whereas a single person of pension age without sight impairment has no money in the MIS budget allocated to paying for help in the home, for those with severe sight impairment £62.51 has been added for five hours a week of domestic work and help with paperwork based on an hourly rate of £12.50. The cost of home maintenance also

increases by £4.76 a week for the additional ‘DIY’ that severely sight impaired older people would need help with.

**Table 1 The additional cost of household services for a pension age person who is severely sight impaired**

£ per week (April 2016 prices)	Single pension age person without sight impairment	Single pension age person who is severely sight impaired	Cost of additional and/or different items
Formal home help - cleaning / paperwork	0	62.51	62.51
Home maintenance costs	1.95	6.71	4.76
<b>Total</b>	<b>1.95</b>	<b>69.22</b>	<b>67.27</b>

### **Additional Cost of Transport: £24.30**

The weekly amount that transport costs contribute to the budget more than triples for a severely sight impaired person of pension age, from £10.70 to £35 and relates to a greater number of taxi journeys required. Groups said that this would increase as people relied on taxis rather than being able to cycle or use bus services. Costs associated with bicycle use (54 pence) have been removed from the budget.

## **Additional Cost of Social and Cultural Participation: £15.81**

The cost of regular social activities increases the budget by £13.94, most of which is accounted for by the addition of £10 for the cost of reciprocity when receiving help. A further £1.87 increase in the cost for holidays also adds to this category of the budget.

**Table 2 The additional cost of social and cultural participation for a pension age person who is severely sight impaired**

£ per week (April 2016 prices)	Single pension age person without sight impairment	Single pension age person who is severely sight impaired	Cost of additional and/or different items
Regular social activities and hobbies	14.57	28.51	13.94
Holidays	11.24	13.11	1.87
<b>Total</b>	<b>25.81</b>	<b>41.62</b>	<b>15.81</b>

## **Additional Cost of Household Fittings and Goods: £8.25 a week**

The addition of items for extra security and personal safety for older people with severe sight impairment makes the biggest difference to the weekly cost of household fittings and goods, adding £3.03 to the weekly budget. This is largely due to the ongoing weekly cost of the Careline telecare system. The specialist lighting needed by severely sight impaired older people adds £2.14. Kitchen and dining equipment

accounts for an additional £1.21. Flooring adds £1.05. Living room furniture adds 72 pence. The addition of a cordless vacuum cleaner adds 10 pence a week. The change from net curtains to blinds made no difference to the budget.

**Table 3 The additional cost of household goods and fittings for a pension age person who is severely sight impaired**

£ per week (April 2016 prices)	Single pension age person without sight impairment	Single pension age person who is severely sight impaired	Cost of additional and/or different items
Security items	0.00	3.03	3.03
Lighting	0.25	2.39	2.14
Kitchen, dining equipment	1.40	2.61	1.21
Flooring	1.97	3.02	1.05
Living room furniture	1.25	1.97	0.72
Vacuum cleaner	0.11	0.21	0.10
<b>Total</b>	<b>5.92</b>	<b>14.17</b>	<b>8.25</b>

### **Additional Cost of Food: £7.97**

The food budget for older people with severe sight impairment is £7.97 more than that of the main MIS after the addition of delivered ready meals and grated cheese.

## **Additional Cost of Technology: £6.51 a week**

The inclusion of various items of accessible technology increases the weekly budget for older people with severe sight impairment from that of the main MIS, with each single item adding less than £2 per week. The upgrading of the mobile phone to an iPhone on a low-cost tariff and inclusion of a KNFB reader app adds £1.80 a week. Magnification devices add £1.56 a week. The inclusion of support for using technology brings a cost of £1.54. Using a printer and scanner in the home rather than relying on printing services adds £1.29. Replacing the main MIS radio with a more accessible model adds 36 pence a week. Items for labelling things in the home cost an additional 32 pence. Changes to the laptop computer itself adds 31 pence. Having easier to use landline telephone handsets also adds 31 pence. The talking alarm clock adds 5 pence a week. This budget also requires an extra 11 pence for batteries. An upgraded television and remote control adds to the budget, but this is more than offset by the discount that someone certified as severely sight impaired is entitled to on the TV license, bringing an overall reduction of £1.13 a week.

**Table 4 The additional cost of technology for a pension age person who is severely sight impaired**

£ per week (April 2016 prices)	Single pension age person without sight impairment	Single pension age person who is severely sight impaired	Cost of additional and/or different items
Mobile phone (including app)	2.49	4.28	1.80
Magnification	0.00	1.56	1.56
IT and technical support	0.00	1.54	1.54
Printing costs	0.10	1.39	1.29
CD / radio etc.	0.02	0.39	0.36
Labelling	0.00	0.32	0.32
Laptop or PC	0.74	1.05	0.31
Landline (including cost of phone) and Broadband	6.26	6.57	0.31
Batteries	0.06	0.17	0.11
Alarm clock	0.01	0.06	0.05
Television / remote control (including TV licence)	3.24	2.10	-1.13
<b>Total</b>	<b>12.92</b>	<b>19.43</b>	<b>6.51</b>

As noted in the previous chapter, discussions around the need for some of the above items highlighted that some older people are not familiar or

comfortable with certain mainstream technologies. Recognising differences in lifestyles and incorporating choice in the level of technology older people might wish to adopt can have cost implications. An alternative budget without items that require computer literacy or the ability to use a smart phone was therefore costed to ensure that any alternative additional items for reading, note taking and communication would be available within this minimum income. The overall cost of certain 'high tech' items in the additional budget outlined above - a laptop, accessories and printing, IT support, and an iPhone plus KNFB app - covers that of alternative items such as an Optelec reader, Dictaphone and an accessible standard mobile phone. This might vary if some rather than the total of these items were replaced.

### **Additional Cost of Personal Goods and Services: £4.78**

The additional cost of glasses adds £1.72 to the budget for personal goods. The changes made to the duration of clothing and the higher price for shoes adds £1.46. More frequent hairdressing costs an additional £1.12 a week. The addition of a long cane and a talking watch add 29 pence and six pence respectively.

**Table 5 The additional cost of personal goods and services for a pension age person who is severely sight impaired**

£ per week (April 2016 prices)	Single pension age person without sight impairment	Single pension age person who is severely sight impaired	Cost of additional and/or different items
Glasses	1.15	2.87	1.72
Clothing and footwear	6.55	8.01	1.46
Hairdressing	2.64	3.76	1.12
Cane	0.00	0.29	0.29
Rucksack	0.00	0.13	0.13
Watch	0.05	0.11	0.06
<b>Total</b>	<b>10.39</b>	<b>15.17</b>	<b>4.78</b>

### **Additional Cost of Household Bills: £0.72**

A calculation for this project by a fuel expert estimates that the additional electricity costs to cover extra lighting being used for longer periods, additional technology usage and greater radio and television use adds 72 pence a week to the budget for someone of pension age who is severely sight impaired. Note that this calculation is based on LED bulbs for the main lights which are more efficient and longer lasting than other types. The use of halogen bulbs, for example, would increase this figure. Difference in the budget for lighting energy consumption for someone with no sight or light perception is discussed below.

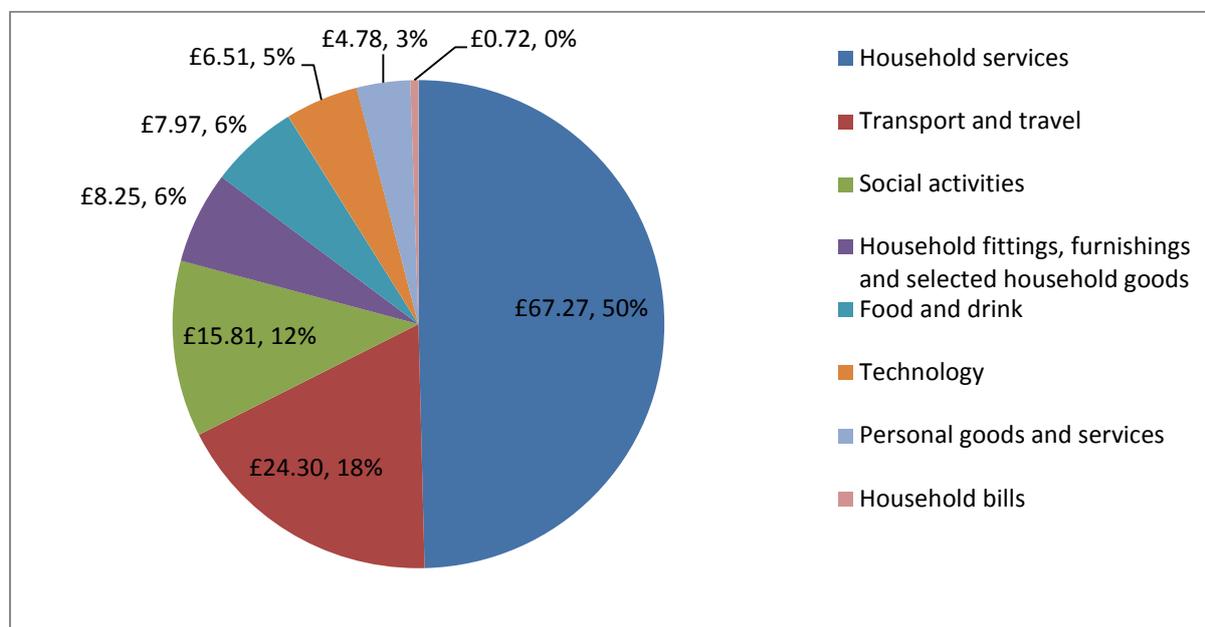
## **Overall Impact of Additional Needs on the Weekly Budget for a Single Pension Age Person who is Severely Sight Impaired**

The total weekly budget for a single person of pension age who is severely sight impaired is £320.76 (excluding rent), which is £135.61 more than that for a single pension age person with no sight impairment. This represents a 73 per cent increase on the main MIS budget of £185.15.

Figure 2 below shows how each budget area contributes to the total additional cost. Changes to household services make the most significant impact, adding £67.27 a week and accounting for half the total increase mostly due to the inclusion of regular formal domestic and home help.

Transport costs are the second biggest addition to the budget as an extra £24.30 a week for taxi journeys represents 18 per cent of the total additional cost. An extra £15.81 for expenditure relating to social activities, which is mostly for reciprocity but also includes a slight increase in the cost of holidays, makes up 12 per cent of the additional cost. Six per cent of the increase results from a rise of £8.25 for household fittings, furnishings and goods; mainly items for security, safety and lighting. Changes to the budget for food add £7.97 after the inclusion of more prepared food, and account for a further 6 per cent of additional costs. Five per cent of additional costs result from an extra investment in technology of £6.51. Personal goods and services, including clothing, glasses and hairdressing, add £4.78 to the budget; three per cent of the increase. Fuel bills account for the remaining 72 pence rise, less than one per cent of the total increase.

**Figure 2 Components of additional costs for a single pension age person who is severely sight impaired**



**Differences in the Budget for a Single Pension Age Person who is Severely Sight Impaired with No Usable Sight or Light/Dark Perception: £6.49 per week less**

In the case of a severely sight impaired older person with no usable sight there are reductions in the budget in the areas of personal goods, household goods and fittings, technology and leisure goods.

Groups said that someone who is severely sight impaired with no sight would not need an increased budget for glasses and reduced the main MIS budget, saving £2.35 per week.

It was also agreed that someone with no sight or light/dark perception would not need an increased budget for additional specialist lighting,

although a daylight lamp was included for the benefit of visually impaired visitors. These adjustments save the lighting budget £1.92 a week.

There is also less additional cost for electricity consumption because someone with no sight or light/dark perception does not have the need for the extra lighting, which is on more often. This reduces the additional budget for energy use by 48 pence per week.

Groups added a talking light detector to the budget for a pension age person who is severely sight impaired and has no sight or light/dark perception but removed magnification aids. These changes reduce the amount allocated to specialist technology by £1.47 per week.

The laptop for someone with no sight was kept to the same specifications as for the main MIS as there was no need to upgrade to the larger screen needed by someone with some sight and a separate larger keyboard is included for ease of use. This represents a saving of 27 pence per week.

**Table 6 Variations in additional costs for a single working age person who is severely sight impaired and has no usable sight**

£ per week (April 2014 prices)	Variation in additional weekly cost compared to the core budget for a single pension age person who is severely sight impaired and has no usable sight
Glasses	-2.35
Lighting	-1.92
Specialist technology	-1.47
Electricity costs	-0.48
Laptop	-0.27
<b>Total</b>	<b>-6.49</b>

## **Chapter 5 Differences in Additional Needs and Costs by Severity of Sight Loss and Age**

The previous chapters provide details of the needs of a severely sight impaired person of pension age and how much this adds to the budget of someone of pension age who is not visually impaired. Now that these figures are available it allows comparison with the results of the previous three case studies in this series to illuminate how severity of sight loss and life stage make a difference to the needs and costs for people who are visually impaired. The previous study has already reported differences between, on the one hand, people of working age who are sight impaired compared to severely sight impaired; and on the other, sight impaired people who are of working age compared to pension age (Hill et al, 2016). This chapter will focus on what further can be learnt with the inclusion of the severely sight impaired pension age case which allows us to draw out overall conclusions across the four cases. We know from our previous studies that additional costs increase both with severity of sight loss and older age, and the new case reported in the previous two chapters now confirms that costs increase further when these factors combine.

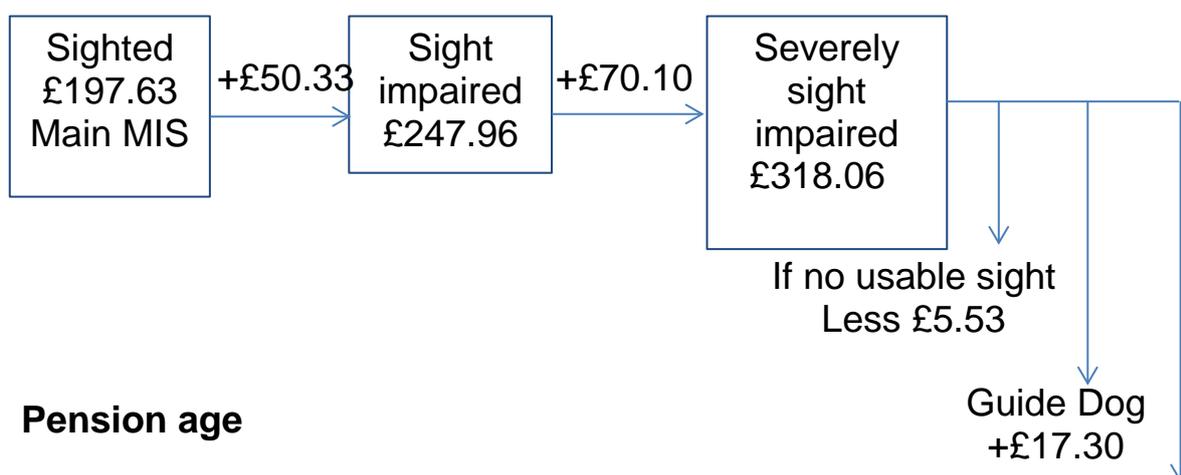
The overall weekly costs for single working age and pension age people who are sighted (main MIS) and visually impaired are set out in a flow diagram (Figure 3). As noted above, the figures used in this chapter have been inflated to 2016 prices to allow comparison, and as such the amounts for the three cases previously studied differ slightly from the 2014 based figures used in previous reports.

The diagram below shows that:

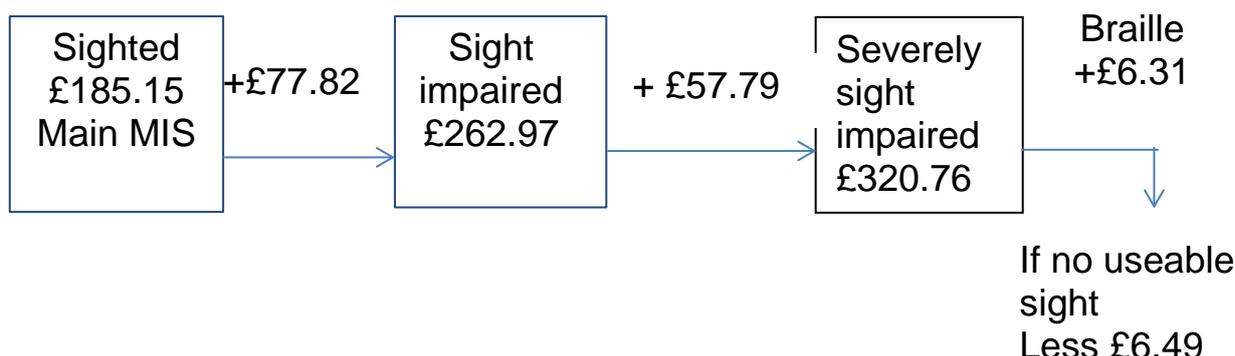
- For a working age person, the main MIS weekly budget of £197.63 for someone who is sighted is increased by £50.33 (around a quarter), to £247.96, for someone who is sight impaired.
- For a working age person who is severely sight impaired it increases by a further £70.10, resulting in a total increase of £120.43, bringing it to £318.06, around 60 per cent more than the budget for a sighted person.
- In the case of a pension age person the main MIS weekly budget of £185.15 for someone who is sighted is increased by £77.82 (around 40 per cent) to £262.97 for someone who is sight impaired.
- For a pension age person who is severely sight impaired it increases by another £57.79, resulting in a total increase of £135.61, bringing it to £320.76, around 70 per cent more than the main MIS budget of a sighted person of pension age.
- In addition, as outlined in Chapter 4 and the previous study (Hill et al, 2016), there are a few areas of costs where there are small variations particular to people who are severely sight impaired and have no usable sight or light / dark perception. In the working age severely sight impaired case variations are also noted for people who are a Guide Dog or Braille user.

**Figure 3 Overall weekly budgets for single people who are sighted and visually impaired**

**Working age**



**Pension age**



These figures show several things.

First, greater severity of sight loss increases the additional cost of sight impairment across the working age and pension age cases.

Second, at both the level of sight impaired and severely sight impaired, overall additional costs are greater for someone of pension age than someone of working age.

Third, the results highlight that the relative size of additional costs associated with each level of sight impairment differs at different life

stages. At working age, the initial increase between the Main MIS (sighted) budget and the sight impaired case is outweighed by a larger increase between this and the severely sight impaired budget.

Conversely when looking at pension age, most increase in the budget is observed between the Main MIS (sighted) and the sight impaired case, with a further but not so large increase between being sight impaired and severely sight impaired. This suggests that in some respects, a lower level of impairment can trigger more substantial costs for people of pension age who acquired sight loss in later adult life than for working age people who are experiencing being sight impaired at an earlier age (£27.49 difference), but that the gap between the cost of additional needs of these two groups is less at the more severe level of impairment (£15.18 difference).

Figure 4 (below), shows in a graph that overall additional costs are greater for pension age than for working age in both sight impaired and severely sight impaired cases, but the difference between the cost of being sight impaired and severely sight impaired is greater for working age people.

**Figure 4 Total weekly additional costs of sight impairment and severe sight impairment for people of working age and pension age**

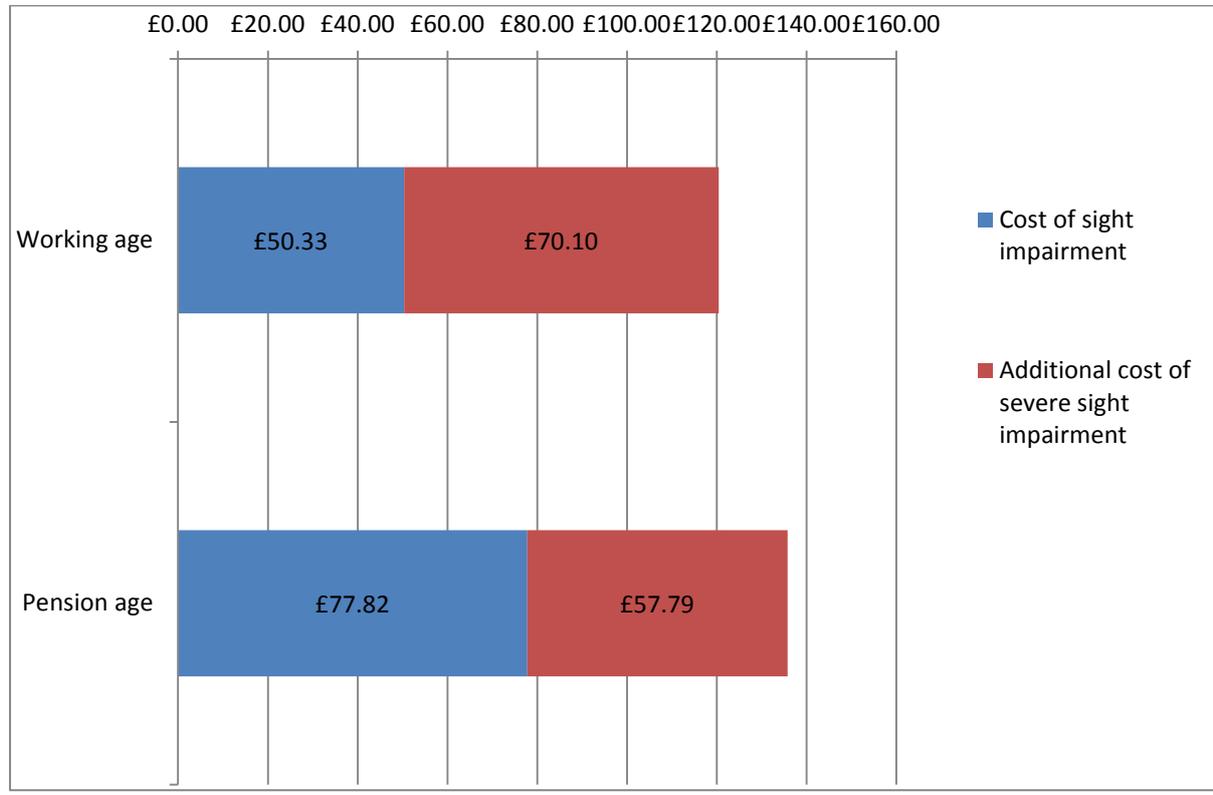


Table 7 (below) elaborates the overall figures reported above by showing breakdowns of the main categories in which additional costs arise among all the cases under review.

**Table 7 Additional weekly costs by category**

£ per week, April 2016	Sight impaired working age adult	Severely sight impaired working age adult	Sight impaired pension age adult	Severely sight impaired pension age adult
Household services	13.46	32.62	27.96	67.27
Transport and travel	6.61	27.96	24.57	24.30
Social activities including holiday and reciprocation	9.35	20.07	6.15	15.81
Technology	12.97	19.00	6.36	6.51
Food	0.00	9.02	5.57	7.97
Personal goods and services including clothing	3.33	7.04	2.08	4.78
Household fittings, furnishings and selected household goods	3.26	4.05	4.84	8.25
Household bills	0.52	0.67	0.29	0.72
Total	50.33	120.43	77.82	135.61

Note that some of the figures used in the table above have been rounded.

Severity of impairment increases additional costs in both age groups, but there is variation in how the difference is explained. Table 7 (above) highlights where there are similarities and differences in the extent and nature of additional costs associated with different degrees of impairment at different times of life.

- For working age, most of the difference between the sight impaired and severely sight impaired cases arises from the higher additional cost of household services and transport, followed by social activities, food, technology and personal goods. For pension age the extra additional costs associated with severity of impairment arise predominantly from household services, followed by social activities and to a lesser degree food, personal goods and household goods.
- In some categories, notably technology and social activities, additional costs are higher for working age than pension age cases at both degrees of impairment. Conversely the additional costs of household services are higher for pension age than working age at both degrees of impairment.

Some of these differences are discussed in more detail below.

### **The Need for Services and Support in the Home Increases with Both Severity of Sight Loss and Age**

The single largest additional cost incurred across all four cases is for services and support in the home and the level increases with both severity of sight loss and age, as ability to carry out tasks in the home

was felt to diminish. Figure 5 shows that this addition is particularly great for people of pension age, and that severe sight impairment for pensioners brings the biggest increase. This accounts for around two thirds of the difference in the additional budget between the pension age sight impaired and severely sight impaired case.

**Figure 5 Additional weekly costs of household services**



While help at home had been included by working age sight impaired groups, it was for two hours a fortnight to provide a supplementary cleaning, but with an expectation that most tasks would be manageable in this case. This level of regular domestic help was maintained by working age severely sight impaired and pension age sight impaired groups but they also included additional help with extra or heavy jobs around the home, deep cleaning from time to time, and with fiddly tasks

or paperwork that were more difficult with severe sight impairment for working age, and the joint impact of some sight loss and lower mobility in older age. This combination of sight loss and older age was even greater for the pension age severely sight impaired case where the need for a much higher level of formal support was demanded and the level increased substantially to five hours a week. Groups felt that the role should be broadened to include regular help with laundry, ironing, paperwork and general tasks around the home which were no longer possible without formal support or relying on family or friends. Costs associated with home maintenance or DIY are also included in this budget category and although these were increased by working age sight impaired groups to account for some need for buying in services, they were much higher for pension age and both ages of severe sight impaired cases. Again this was associated with being more reliant on paid for services to carry out even small jobs that others with less severe sight loss or who were younger might be able to do themselves.

### **Transport Costs Increase by Severity of Visual Impairment for Working Age, but Older People's Needs Arise at a Less Severe Degree of Sight Loss.**

The transport budget is complicated by different main MIS baselines, and modes of fulfilling travel needs vary by age. For example, working age visually impaired people have additional transport costs partially offset by concessionary bus travel, but since pensioners get free off peak local bus travel anyway, they do not experience this as a 'saving'. Nonetheless, the level of additional transport costs, shown in Figure 6 (below), is dominated by how much money each of the four visually

impaired cases need to spend on taxis. In the working age case a relatively small increase in the budget for people who are sight impaired contrasts with a large increase in the budget for people who are severely sight impaired. Conversely, at pension age a large additional cost for transport is included in the sight impaired case but this does not rise with severity of sight impairment.

**Figure 6 Additional weekly costs of transport**



For the sight impaired working age case the bus was still seen as the main form of local transport, with only one additional taxi journey per week. However, all other groups felt that there was a greater need for more taxi journeys to include up to five per week. For pensioners, this need was already great with sight impairment, and hence there was no additional requirement associated with severe sight impairment,

whereas for working age people the higher cost was only experienced at the severe level of sight loss. Reasons for more dependence on taxis than buses outlined in Chapter 3 for severely sight impaired pensioners, reflect those reported previously for sight impaired pensioners and for severely sight impaired people of working age. They include travelling to unfamiliar destinations, going to places not on a (straightforward) bus route or after dark when door to door transport is more of a requirement. Also for practical reasons such as when carrying things, and relate to confidence in using the bus when unable to see it coming and for older people in particular, feeling less steady on their feet. For older people, age and mobility combined with sight loss brought these reasons to the fore at the less severe degree of sight loss than for working age people.

## **Technology and Age Related Differences in Meeting Additional Needs**

The additional cost of technology is much greater for working age groups than for pension age groups across severity of impairment – more than double in each case. While the amount increases significantly from the working age sight impaired to severely sight impaired budgets, there is very little difference between the two pension age cases as shown in Figure 7 below.

**Figure 7 Additional weekly costs of technology**



The higher additional costs of technology in the working age compared to pension age budgets reflects clear differences in how the two age groups drew on technology. While certain specialist items were valued across groups, such as magnification aids and labelling devices, engagement with mainstream equipment that can run accessible apps and software was a key issue. The accessible use of mainstream technology, specifically a smartphone and computer, was paramount in the lives of both working age groups as a main means of communication, keeping in touch, access to information and in dealing with sight loss. While both items are included in main MIS (working age and pension age) budgets, they are at a basic level. Both working age budgets were increased to cover the additional cost of a more advanced mobile phone (iPhone) with more accessible features, a more expensive monthly plan to include larger amounts of data and calls, and a bigger computer or

laptop with paid for accessibility software. The additional costs for the severely sight impaired working age case were further increased reflecting even greater dependence on these items, to allow heavier use/shorter lifespan of the smartphone and additional paid for apps, as well as higher specification computing equipment and more expensive software. The pension age groups made changes to the mobile to a more accessible type, but only included a higher grade smart phone in the severely sight impaired budgets. The size of the computer / laptop was increased but pension age groups felt that free accessibility software was sufficient for needs. While there was more recognition in the severely sight impaired than sight impaired pension age groups that IT and smartphone technology, such as specific apps could be helpful resources for dealing with sight loss, the assumed use of mainstream technology did not match that of the severely sight impaired working age groups.

The overall result of these differences is shown in Figure 7, showing much greater technology costs for working age groups, reflecting that mainstream technology was seen by those age groups as a resource to draw on in a far more wide-ranging way than by pensioner groups. An iPhone was really valued as a 'multi-use' device by both working age groups, and while this potential was recognised in the severely sight impaired pension age budget, there was a greater tendency among older age groups to see the mobile phone as principally for making calls, or even just to use in emergencies and in contrast to working age groups more emphasis was placed on having accessible landline handsets. Similarly, working age groups placed great importance on the computer/laptop for communication, information and entertainment whereas while pension age groups noted the need for someone to be

able to be online, it was not seen as such a heavily used item, with more emphasis than in working age groups placed on having an accessible radio/CD player to enable listening to audio books. It should be noted that in both pension age groups there was a divide in participants' experience of technology, as one might expect in people that ranged from in their sixties to well over ninety, and given that the use of new technologies reduces with age (Slade and Edwards, 2015). This is an area where views are likely to change over time as technology use spreads and more 'tech-savvy' generations age. Furthermore, this is a fast moving area with new products being introduced including mainstream devices with better accessibility for people with sight loss (Thomas Pocklington Trust, 2016).

One important caveat to this finding about working age groups specifying wider use of technology is that some additional items that use technology but not included in this category were specified by severely sight impaired pensioners. These included household goods such as a talking microwave, jug, scales, and a telecare service. This shows that while some may not use mainstream communications technologies, such as computers and smart phones as extensively, pensioners with severe sight impairment can still benefit from particular resources made possible by technological advance, especially those using audio.

## **The Importance of Social Participation and Differences in Costs**

Social participation is a key element of the minimum acceptable standard of living definition upon which this research is based. However,

people who are visually impaired can feel cut off from society, as deteriorating vision risks greater isolation, depression, and decline in quality of life and social engagement particularly among older people (Nazroo, Whillans and Matthews, 2015; RNIB, 2015; Slade and Edwards, 2015; Hodge and Eccles, 2013). The additional costs identified in this study recognise a need to avoid this danger and groups felt it important that the budgets should enable someone with sight loss the opportunity to participate in society.

As shown in Table 7 (above) the additional cost of social activities is greater for working age than for pension age groups, across severity of impairment, and the additional cost increases by severity of impairment in both cases. One reason is because both severely sight impaired groups increased this area of the budget to cover more or specialist activities to reflect the growing risk of isolation and a greater need for supported activities for someone with little or no sight. The amount was increased more by severely sight impaired working age, than pension age groups. Another reason is additional holiday costs. Differences here are partly attributable to different baselines. The main MIS working age holiday assumes a self-catering model, that groups felt should be changed to hotel accommodation to better suit the needs of someone with sight loss, which incurs extra cost in both cases. On the other hand the coach holiday in the main MIS pension age case was thought to be acceptable by pension age groups, and an additional cost was only added in the severely sight impaired pension age case to cover part of the cost of the holiday for a companion. All groups included an amount within this area of the budget to enable someone with sight loss to treat a family member or friend who has helped them as it was important to be able to buy someone a drink, meal or gift by way of reciprocation to

show their thanks. Both working age groups and sight impaired pensioners included £5 per week for this purpose, however, this budget was doubled in the severely sight impaired pension age case.

It should be noted that being able to participate in society is often intertwined with being able to get out and about, hence the additional need and cost of transport was also a significant factor in discussions about social activities. Some of the relatively high additional cost for taxis required in the pension age sight impaired case is to enable participation in VI groups and activities that in themselves may not necessarily bring large weekly costs, but cannot be separated from the cost of getting there. Furthermore, extra taxi costs were required in order to access the additional provision thought so important by severely sight impaired groups to engage in social activity, as a means of maintaining this level of participation. This highlights how costs in different areas of the budget arise in conjunction, meaning people with sight loss can face multiple outlays in order to do something that people without sight loss might take for granted.

Avoiding the risk of isolation in the home was also important and feeling connected can be achieved in different ways. As outlined above, for working age groups in particular, mainstream technologies such as the laptop and iPhone were important for communication and finding out information. The landline phone and a decent radio/cd player was vital to pension age groups and a television with audio menus was included by all groups. All of these involved budget adjustments to make them more accessible but were important to enable people with sight loss to feel included and connected to those close to them and society in general.

## **General Factors that Affect Additional Costs Associated with Sight Loss and Older Age**

At the beginning of this chapter we noted that while overall additional costs are greater for pension age than working age at both the sight impaired and severely sight impaired level of sight loss, there is also a difference in the relative size of these costs at different life stages. This section explores a few cross-cutting factors to further illuminate these differences, including why, when compared to the working age case, people of pension age might experience more substantial needs and costs associated with sight loss at the lower level of sight impairment, with a relatively smaller increase between this and the severely sight impaired case.

### **The need and cost implications of human help / personal support**

All groups referred to quality of life and the importance of independence. While younger groups felt that their familiarity with and increased use of technology would go some way to helping a working age person with visual impairment retain independence, older people stressed a greater need for human help. Much of the difference in the greater amount of additional costs for pension age than for working age cases is explained because the type of needs identified are those that require personal service or labour. For example, the inclusion of more hours of formal help in the home or a few extra taxi journeys each week adds a relatively high amount to the weekly budget, compared to the additional costs of technology included by working age groups.

The inclusion of an amount to allow reciprocation enables recognition of help provided by others to people with sight loss on a more informal basis. As noted above, the cost included for reciprocation to support social participation was highest in the severely sight impaired pension age case where the budget also includes a contribution towards the costs of a companion's holiday. The sight impaired pension age case budget for support in the home comprises much lower formal support levels than that of the severely sight impaired pensioner but includes an additional £5 per week reciprocation budget to help recognise informal support received in the home. In reality, the type of help recognised in this way is varied and might be difficult to divide into particular categories as they can be blurred. Nonetheless, overall the pension age budgets for reciprocation are higher than those of working age at both degrees of impairment. These higher levels of reciprocation included by pension age groups, suggest more of a reliance on human help, as groups, particularly those with severe sight impairment, outlined a greater need to be accompanied, to get around and for assistance when they are out, and noted that in such situations the role of a friend or companion can become more of helper or guide because of their sight loss. Being able to recognise this additional need for human help is important for self esteem which can be undermined when having to rely on and feel indebted to other people, and can perhaps help in some part to redress the potential imbalance in the relationship that people expressed.

There were several issues which combined together could contribute to a sense of vulnerability associated with sight loss, and appeared of particular relevance in the older age groups.

## **Security and safety concerns**

The need for additional security in the home increased both with severity of sight loss and with age. No extra security items were added to the budget for the working age sight impaired case; however, an intercom system was included for both working age severely sight impaired and pension age sight impaired cases. Security needs were increased still further when age and severity of sight loss combined. Like the previous cases there was a practical issue of not being able to see who is at the door, coupled with a heightened sense of vulnerability to intruders or unwanted visitors, thus a door bell/alert was added. The inclusion of a telecare system highlights that being older and severely sight impaired also brings concerns of personal vulnerability, particularly for someone living alone, associated with the fear of falling or having an accident in the home. Increases in the food budgets to include more pre-prepared food and ready meals were also linked to severity of sight loss and older age as groups discussed the need for safer as well as easier to use cooking options.

## **Adjusting to sight loss**

Issues around adjusting to sight loss were particularly relevant in the sight impaired pension age case, and may help explain why certain areas of the budget (services in the home, transport, food) were higher for the pension age compared to the working age case with a similar degree of sight loss. The pension age 'case study' under discussion in groups for both sight impaired and severely sight impaired was for someone who had acquired sight loss in adult life, recognising that older people are at greater risk of sight loss. Indeed many of the participants in these groups drew on their recent and ongoing experiences of deteriorating sight, whereas working age participants are experiencing

sight loss at an earlier stage in their lives. As outlined in more detail in our previous report (Hill et al, 2016), **becoming** sight impaired brings a range of issues that impact on people's needs alongside or intertwined with age. These include: having to adapt and learn new ways of doing things; relying more on others to do tasks that they previously did; loss of confidence and feelings of vulnerability for example in the home, to do cooking, or using public transport; feeling isolated and not knowing what equipment or services might be available to help. It is in this context that groups included additional costs in areas such as help with cleaning or paperwork, security, food, and taxis.

### **Deteriorating sight and poorer mobility**

Issues of sight loss affecting balance and depth perception were raised by sight impaired pensioners, and were coupled with having lower levels of mobility that comes with ageing which for example related to concerns about getting on and off buses, or being able to see and physically carry out heavy housework. These led to the inclusion of higher additional costs for help in the home and for taxis for sight impaired pension age than in the working age budgets. These difficulties associated with the combination of old age and sight loss led to further concerns in the severely sight impaired pension age groups, particularly related to problems with balance, who talked much more about the dangers of falling, which is an issue for older people who are visually impaired (Wood et al, 2011; Thomas Pocklington Trust, 2013). Discussions related in particular to safety in the home, for example, fear of tripping on flooring or over obstacles or the need for extra phones to avoid falling in the process of rushing to get to a handset. The telecare service was included in the pension age severely sight impaired budget in acknowledgement of the possibility of trips or falls, and was a way of

restoring confidence, minimising the risk of being 'alone' in an emergency and provided peace of mind.

In each of the above four categories – the need for human help, safety concerns, adjusting to sight loss and mobility issues – there are ways in which greater needs can arise, even at a less severe level of impairment, for people of pension age who have acquired sight loss than for working age adults who have lost sight earlier in life. This helps explain why costs can increase more for the pension age case with any form of sight impairment, and conversely why the additional effect of severe impairment is in some respects smaller.

## Chapter 6 Conclusion

This final report in a three part series looking at the additional costs of single people living with visual impairment underlines that the size of such costs varies by situation. Of the cases examined, the minimum cost of living ranges between 25 and 70 per cent higher for a visually impaired person than for someone with no such impairment.

These studies have considered the difference that it makes to be sight impaired compared to severely sight impaired, and the difference it makes to be of working age compared to being of pension age. These are just some of the variables that can affect the size of additional costs. As noted in RNIB's My Voice study, other variables include the timing and process of sight loss and the existence or otherwise of other disabilities (Slade and Edwards, 2015). Moreover, in taking the simplest case of a single person living on their own, these studies still leave room for further research on the additional costs of people living with partners or dependent children.

Such studies of the additional cost of disability will never capture every case, and this is not their intention. Rather, they have set out to create greater understanding of where costs tend to be the greatest, and how this can vary as people's circumstances change.

A central finding has been that the scale of additional costs of visual impairment tends to be greatest where it involves regular human help, rather than the purchase of equipment. Depending on someone to come and clean your house every week, or having to use a taxi regularly

to meet key transport needs costs many times more than, say, purchasing a speaking clock or paying a higher electricity bill for additional lighting. The knock-on effect of this finding is that people who feel the most vulnerable, and therefore require the reassurance and practical aid of more human assistance, can face particularly high costs. This helps explain why an older person whose sight may have deteriorated relatively late in life, possibly combined with reduced mobility, may face considerably higher costs than someone with a similar level of impairment acquired earlier in life that they have learnt to adapt to.

We can also note two other important implications of this vital human dimension. One is that people who have friends and family that can provide help may have far lower costs than those who do not and are reliant on paid help. The other is that people's ability to adopt certain technological support can also make a vital difference. As voice-enabled technologies become ever more mainstream, they are no longer necessarily particularly expensive, and visually impaired people may simply require an enhanced version of technologies that everybody is using.

This creates an ever-widening gap between people who need to pay others for assistance and those who get informal help or can meet certain needs through technology. However, this is often a matter of degree, and all visually impaired people have at least some significant extra costs. An iPhone will never be able to clean your home. And while visually impaired people find it a godsend to have a friend to help them out in social situations, the obligation to reciprocate means that such support can never be considered cost-free.

The individual nature of different needs means that public support to help cover additional costs will never be perfect. While the benefits system does recognise that there are extra costs associated with disability through Personal Independence Payments (PIP) for working age and Attendance Allowance for pension age claimants, it can take a narrower view of how they arise than implied by this research. Research with visually impaired PIP claimants notes some issues with the process including accessibility, difficulties identifying less obvious costs and tension between the focus of the assessment (on what people cannot do) and the independence that people strive to achieve (Ellis, Douglas and Clarke, 2015; Davies et al, forthcoming).

It is in this context that the overall findings of this research can be used to reflect on the extent of the additional costs of sight loss identified in the four cases under review alongside the current levels of PIP and Attendance Allowance. Adding to previous conclusions (Hill et al, 2015: Hill et al, 2016), visually impaired adults can apply for PIP or Attendance Allowance, but whether these benefits are able to cover the additional costs identified in this research will depend on a) whether they meet eligibility criteria and are successful in claiming the benefit, and b) what level of benefit is awarded. The following is a comparison of PIP/Attendance Allowance rates and the additional costs of visual impairment identified in this research (note that it does not take account of other impairments or disabilities which can also impact on needs, costs and disability benefits):

**Working age:**

Additional costs per week (not including housing costs):

£50.33 for sight impaired; £120.43 for severely sight impaired.

PIP weekly rates:

Daily living: £55.10 standard; £82.30 enhanced.

Mobility: £21.80 standard, £57.45 enhanced.

For working age people, therefore, a PIP award covers the basic cost of sight impairment when it is not severe, if someone who is sight impaired is able to successfully claim the daily living component. In the severely sight impaired case, however, only receipt of both the daily living and the mobility component at the enhanced rates will cover the identified additional costs of sight loss. Receipt of both components, with only one at the enhanced level, would still leave someone with sight loss £8 to £16 short of the additional costs identified.

### **Pension age:**

Additional costs per week (not including housing costs):

£77.82 for sight impaired; £135.61 for severely sight impaired.

Attendance Allowance weekly rates: £55.10 lower; or £82.30 higher.

This shows that in the pension age case, the benefit will only cover the extra cost in the case of a sight impaired person being awarded the higher rate. The lower level payment is more than £20 short of the additional costs in the sight impaired case. The difference is even greater in the severely sight impaired case, where even the higher level benefit award is over £50 short of the additional costs identified in this research.

The Attendance Allowance system, which accepts a relatively loose link between eligibility criteria and the amount of money people need to spend is now under review. Despite the imperfections of this system (in particular the absence of the mobility component that exists for DLA and

PIP), a reform that undermined its level or tried to direct support more explicitly to meeting certain needs is likely to be problematic.

No benefits system will ever be able to come up with an accurate assessment of additional costs that include such things as how much an individual needs in order to treat a friend who has helped them out – yet such costs as these are at the heart of what enables people who are visually impaired to participate in society, and need to be taken into account. Rather, these studies have given a broad guide of the scale of costs faced by people with sight loss, and how they change with the degree of sight impairment and age. It is against such broad-brush estimates of costs, rather than precise calculations of the cost of living for each individual, that the sufficiency of benefits to compensate for the cost of disability should be judged.

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