DISABILITY AND MINIMUM LIVING STANDARDS: *The additional costs of living for people who are sight impaired and people who are Deaf*

Loughborough University

Centre for Research in Social Policy

Katherine Hill, Abigail Davis, Donald Hirsch, Matt Padley and Dr Noel Smith
Centre for Research in Social Policy
and University Campus, Suffolk

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The research reported here is independent research commissioned by Thomas Pocklington Trust. The views expressed in this publication are those of the authors and not necessarily those of Thomas Pocklington Trust.

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Note on terminology

In this report ‘people who are sight impaired’ is used to describe those who are eligible to be certified as sight impaired. As set out in the text, the additional needs measured here apply to people whose condition would meet the criteria for such certification and who have some useable sight.

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Executive Summary

Introduction

This report gives the results of a research study into the additional amount that it costs people who are sight impaired and people who are Deaf to reach a minimum acceptable standard of living. The research was undertaken to trial a new application of an accepted methodology that defines Minimum Income Standards (MIS) for certain population groups. It applied the methodology to single people of working age, living alone who are eligible to be certified as sight impaired (with some useable sight) or who are Deaf and use British Sign Language. The findings estimated additional costs of living and defined a Minimum Income Standard for each population group.

An understanding of the additional cost of disability is especially salient in the UK with the introduction of Personal Independence Payments, and can help show what would be a fair way of helping different groups to afford these extra costs.

Previous research on this topic has either looked at what disabled people actually spend (ignoring unmet need) or made broad assessments of the relative well-being of disabled and non-disabled people on different incomes, without pinpointing the actual source of additional costs associated with particular conditions. Research looking more directly at disabled people's costs has found it hard to distinguish which are 'additional' to what non-disabled people require. The present research is able to address this by building on Minimum Income

Standard (MIS) research for non-disabled households and using the same method to explore additional requirements for people with certain disabilities. The MIS method involves asking groups of members of the public to agree detailed lists of items that households need in order to reach a minimum acceptable standard of living.

The present study is carried out by the same team at the Centre for Research in Social Policy that conducted the main MIS research. For the first time this method is applied to establish minimum budgets for two disabled household types: single working age people, living alone, who are, respectively, eligible to be certified as sight impaired (with some useable sight); and profoundly deaf who use British Sign Language (BSL). Many deaf people whose first or preferred language is BSL consider themselves part of the Deaf community. They may describe themselves as Deaf with a capital D to emphasise their Deaf identity.

This report serves a dual purpose. It identifies a minimum income standard for people with certain sensory impairments and demonstrates the scope for doing similar research with people who have different types of impairment or disability. Its calculations have selected two types of sensory impairment to measure in a first study. In the case of sight impairment, the calculation is for someone with some usable sight, whereas in the case of deafness, it looks at the needs of someone with no hearing. The results of each of these calculations should therefore be considered separately, and do not comprise a comparison between the cost of sight and hearing loss in general. It is also recognised that the needs of people with other levels of sight or hearing loss are likely to be different and require a separate study to identify properly.

Methodology

The research asked three groups of people who are sight impaired and three groups of people who are Deaf, each to reflect on the additional things that households with impairments similar to their own would require in order to reach a minimum standard of living. Participants discussed in detail whether MIS budgets covering different aspects of a single person's life would be adequate or needed to be supplemented. The method built consensus both within each group and across groups about what should change and why. Those items that commanded wide agreement as additional requirements were costed to create a disabled person's budget for each case under consideration. In line with the original research, the emphasis was on 'needs and not wants': only those items essential in order to meet physical needs and to have the 'opportunities and choices required to participate in society' were included. 'Nice to have' items were explicitly omitted.

In each case, needs were specified for an imaginary 'case study' person, of working age, living alone with a particular type of disability. For people with sight loss it was decided to make the case study someone who was certified sight impaired, with some useable sight. In the case of hearing loss the case in question was someone who is profoundly deaf and uses British Sign Language (BSL). These cases were chosen after consultation with an advisory group as readily recognisable categories, and while acknowledging that within each of them not everybody's needs are identical, they provide a starting point in showing the minimum needs of someone covered by a given set of characteristics.

Participants were purposively recruited through networks and service centres used by the relevant groups and was carried out by organisations working within the relevant communities, with recruitment materials designed to be appropriate for people with sensory impairments. The standard MIS method was used when running the groups with additional attention given to communication. This involved talking through information and verbally recording decisions (rather than using flipcharts) in the sight impaired groups, and using BSL interpretation in the Deaf groups.

The minimum cost of living for a single person who is sight impaired

Groups identified a wide range of additional needs that would require extra spending for a single working age person, living alone, who is eligible to be certified as sight impaired (with some useable sight). No one of these was very expensive, but between them they added a quarter to a minimum budget for a single person.

The main categories incurring extra costs were as follows:

Paying for various technological equipment. This was required to enable communication, facilitate access to written materials, and make the best use of the sight that people have. Some of these would be one-off purchases such as a larger laptop, scanner, video magnifier, specialist software and IT training, whose cost would be spread across a long period. The cost of a higher grade mobile phone (to provide good quality accessibility features) than is included in the budget for a fully

sighted person adds a greater cost on a recurring basis.

Domestic help every two weeks for two hours. Groups agreed that having regular help with cleaning or to deal with particular jobs in the home would support someone who is sight impaired in keeping their home presentable.

Additional travel costs. People who are sight impaired can require additional taxi journeys to some local medical appointments and a certain number of train trips further afield. Total travel costs take account of free off-peak bus travel (with a concessionary pass), but also assume that some peak-time journeys need to be paid for.

Additional costs of socialising and going on holiday. These include the cost of treating a friend, who accompanies them in social activities that may otherwise be difficult, and using hotel rather than self-catering accommodation on holiday.

Additional costs of household goods. This includes better lighting throughout the home and differences to standard goods such as the type of floor covering or sofa material which were changed for safety and maintenance reasons. Also, paying for someone to help with home maintenance adds a small amount.

Additional health care costs. This covers an increase in the number of prescriptions, for example for eye drops, and a higher budget for the cost of glasses.

Electricity. A small weekly addition to bills to cover the cost of running

additional lighting and appliances.

Overall, additional costs for someone who is sight impaired (with some useable sight) add £50.49 to a £198.60 minimum household budget for a single working age person, excluding rent. A quarter of the additions come from technology, a quarter from domestic help, and the rest are spread across the other categories.

The minimum cost of living for a single person who is Deaf

Groups were able to agree substantial costs for a single working age person who is Deaf, adding 82 per cent to a weekly budget, but these were concentrated in fewer categories than was the case for sight impairment:

Interpretation. By far the most significant additional cost for Deaf people is paying for interpreter services. Service providers have a legal requirement to make reasonable adjustments to ensure that their service is accessible to people with a disability, for example by providing an interpreter. However, many services fail to meet this legal duty and in some cases it may not be considered a reasonable adjustment to require the service to pay for an interpreter. Groups agreed that there are circumstances where an interpreter is not provided and Deaf people need to arrange and pay for an interpreter themselves. The minimum amount needed is not easy to specify, but groups felt that a modest baseline would be an average of 10 hours a month, costing £127 a week. This in itself adds more than 60 per cent to a single person's household budget.

Social activities. Groups agreed that a Deaf person will need to carry out more social activities outside the home, as a minimum, than a hearing person. This was in order to combat the risk of social isolation, and the budget for social activities was doubled. Holidays were also costed for hotel rather than self-catering accommodation.

Technology. Technological items incur a relatively modest weekly cost overall. For example, a larger screen laptop making it easier to communicate online using sign language is a one-off purchase adding only seven pence a week on average. Most of the additional cost of technology arises from the recurring cost of a more expensive mobile phone and monthly package to allow using it for sign language communication.

Travel. The budget for travel was slightly higher than for hearing people, due mainly to the need for Deaf people to maintain geographically dispersed social networks, and having to take the train to different towns or cities to meet friends and attend social activities.

Electricity. A small weekly addition to bills to cover the cost of running additional lighting and appliances.

Overall, additional costs for a person who is Deaf add £163.03 to a £198.60 minimum household budget for a single person, excluding rent. Over three quarters of the additions come from interpreters and most of the remainder from social activities.

Discussion and conclusions

This research has shown clearly how living with a disability can bring additional costs in reaching a minimum acceptable standard of living, but that these can vary greatly from one situation to another. A great deal may depend on the amount of personal assistance or personal services that someone requires, since paying regularly for say an interpreter or cleaner can dwarf one-off costs such as purchasing equipment, when that cost is spread over time.

However, the findings of the present study also show that even without such costly additional services, the everyday cost of having a disability can be substantial relative to what a single person would otherwise have to spend in order to meet minimum physical and social needs. This is not just to pay for things directly arising from disability such as specialist equipment. Much of the additional cost arises from how disabled people lead their lives, which may involve for example treating a friend who has helped you out, or paying for additional travel to get to appointments or social activities.

These varied additional expenses can make life much more costly for a disabled person in ways that are not well recognised by the benefits system. Personal Independence Payments (PIPs) are only available for people with a certain threshold of overall need based on a points system. Many people who are eligible to be certified as sight impaired are unlikely to have the characteristics to be awarded sufficient points within this system to create an entitlement, even though they face the additional costs identified in this study. A Deaf person might have

enough points to trigger the standard rate of entitlement, £54.45 a week, but this is well under half the estimated minimum cost of interpreters.

It must be concluded that there is a high risk of needs going unmet or only very partially met under the PIP system. The very precise specification of the limitations that have to be present to score points in PIP assessments makes it almost inevitable that there will be many areas where a disability creates additional costs that are not recognised. Nevertheless, evidence such as has been collected in the present study could help in future to adapt such a list to ensure that it more fairly reflects areas where costs occur.

Scope for future research

This study has demonstrated that it is possible to estimate the additional costs that someone with a given disability in a given household type needs to cover in order to maintain a minimum acceptable standard of living. The research succeeded in building a consensus among disabled people themselves about areas of need and involving them in identifying which additional items are required in a given case. Future research could help build a fuller picture by looking at different levels and type of impairments, the effect of living with other people rather than alone and the costs associated with having a disability as a child and as a pensioner, compared to the present study of costs for someone of working age.

Chapter 1 Introduction

This report gives the results of a research study into the additional amount that it costs people who are sight impaired and people who are Deaf to reach a minimum acceptable standard of living. How much more does it cost for someone to live with a disability? The research was undertaken to trial a new application of an accepted methodology that defines Minimum Income Standards (MIS) for certain population groups. It applied the methodology to single people of working age, living alone, who are eligible to be certified as sight impaired (with some useable sight) or who are Deaf and use British Sign Language. The findings estimated additional costs of living and defined a Minimum Income Standard for each population group.

Background

Understanding the cost of disability is crucial for any social support system that seeks to ensure that people do not have to live in undue hardship. It is especially salient in the United Kingdom today, as the government introduces Personal Independence Payments, which seek to provide fairly for people with different disabilities, while restructuring the basis for eligibility.

Yet the true effect of someone's disability on their everyday living costs and those of the household they live in remains poorly understood. Entitlements in the benefits system are based on a medical assessment linked to payment scales, but this is based neither on a scientific assessment of what additional costs are likely to arise from a particular

condition nor even a clear-cut list of which items the payments are supposed to cover. This makes it is hard to consider what is a fair level of entitlement, which treats people with different conditions reasonably equitably.

Previous research on the cost of disability has in some cases made broad comparisons of the well-being of disabled and non-disabled people on different incomes, to estimate the additional income that disabled people need in order to avoid poverty (Morciano et al, 2012). However, such approximation has been at a very broad and theoretical level, without distinguishing the actual source of additional costs associated with specific conditions. Alternative approaches looked at disabled people's spending, but does not take account of unmet need (Large, 1991; Thompson et al, 1990). Another strand of research has sought to enumerate additional household costs associated with specified forms of disability, but up to now it has been hard to interpret this in relation to the overall living standards of the households concerned (Smith et al, 2004). Background Note 1 at the end of this chapter summarises this previous research on disability costs.

Building on the 'additional household costs' approach and on ongoing research on a Minimum Income Standard (MIS), the Centre for Research in Social Policy (CRSP) at Loughborough University has developed a method for calculating the additional amount that a household needs to spend in order to reach a minimum acceptable standard of living, as a result of someone with a given disability living in the household. Like the baseline Minimum Income Standard, which is the result of detailed consultations with members of the public about household needs, this new research is based on social consensus – in

this case asking groups of people with the disabilities under review about what are additional requirements and why.

The present study is a first application of this method for calculating a Minimum Income Standard for disabled people. The wide range of different conditions that could affect living costs, multiplied by the various configurations of how people live together (or as singles) in households, make the cost of disability not one calculation but many. This study makes a start by considering additional living costs associated with two types of disability - sight impairment and profound deafness - in the case of people of working age living on their own. In both cases, their costs are compared to those of non-disabled single people. While the study thus applies only to these specific cases, it also demonstrates the feasibility of the method and gives an idea of the categories and scale of additional costs that can arise.

The Minimum Income Standard and its value in measuring the cost of disability

In the decade since the disabled people's budgets study was published (Smith et al, 2004), the establishment of the Minimum Income Standard (MIS) method has created a new context in which a consensual budget standard method can be used to identify the additional costs of living for people with a disability. MIS was created in 2006-2008 by a collaboration between CRSP and the Family Budget Unit at the University of York (Bradshaw et al, 2008). In this research, groups of members of the public identify detailed lists of items that are required for households of different types to achieve a minimum acceptable standard

of living. Some expert knowledge is used, for example the checking of food budgets by nutritionists, but the expert role is advisory. In 2008, budgets were compiled covering most household types in the UK, and these are being regularly updated (Davis et al, 2014). Background Note 2 at the end of this chapter summarises the MIS approach.

A method has already been developed to identify additional needs applying to various situations, including rural living and having a foster child in the family. In a similar context, the existence of MIS makes it much more feasible than previously to compile budget standards for disabled households:

- Most importantly, it provides a **baseline** against which disabled people's living costs can be compared. An up-to-date account of the minimum costs of a non-disabled single adult, for example, makes it possible to ask what the additional costs would be if this adult had a particular disability. This baseline is not just a number but a full list of things that the person would require, which gives a qualitative description of what comprises a minimum living standard.
- MIS provides a clear-cut **definition** of what is meant by a minimum, which can be applied across contexts. Members of the public have developed this definition.

'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 a MIS for disabled people to be established in a way that does not start with the premise that they must necessarily 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 in 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.

Investigating the effects of sensory deprivation

This report serves a dual purpose. It identifies a minimum income standard for people with certain sensory impairments and demonstrates the scope for doing similar research with people who have different types of impairment or disability. Sensory loss - i.e. visual or hearing impairment - is a valuable starting point in this respect. While neither of these conditions take a single form it is possible in each case to specify a level of impairment that is reasonably well understood. It is assumed that people with such impairments will require at least some additional resources in their everyday lives, whether through technology, home adaptations or services. Whilst the heterogeneity of people's conditions, their experiences and personal circumstances is recognised, people with these conditions are likely to be able to talk about common needs resulting from their condition.

The choice of these aspects of disability as a starting point was also influenced by the fact that sight and hearing loss are well-defined issues, with various organisations seeking to identify and serve the needs of people with these conditions. One such organisation, Thomas Pocklington Trust, has funded this research. Others, including various organisations supporting people with sight and hearing loss were

involved in a project advisory group which met at the start of the project and fed into the design (see Acknowledgements).

Background Note 1, Previous research on the cost of disability

Research on the cost of disability has taken two main forms, which can be categorised as ‘equivalence-based’ and ‘budget-based’ estimates (Morciano et al, 2012).

The first of these approaches seeks to identify equivalence between the living standard attained on different incomes by households with and without a disabled person. Where the presence of a disabled person is observed to increase the average household income level associated with a given living standard, this difference can be used to deduce the cost of compensating for the disability. This approach of research has used various methods to estimate a household’s living standard. One indicator is the pattern of household spending - based on the tendency of people on lower living standards to spend more on ‘essential’ consumption categories such as food (Jones and O’Donnell, 1995). Another is subjective self-assessment of economic well-being (e.g. Stewart, 2009). A recent study (Morciano et al, 2012) aimed to bring together these two elements with indicators of deprivation (whether households are unable to afford certain essentials). It estimated that, for example, ‘an older disabled person, defined as someone above the median level of disability for all older people, requires a net household income around 62 per cent higher than that of a comparable person with a median level of disability to reach the same standard of living’.

Such research can be particularly useful in making broad estimates of the household living standards experienced by disabled people,

including making adjustments to the income thresholds below which we classify such households as being in poverty. It is less useful for identifying the cost of specific disabilities or relating this to the particular household context. By looking just at outcomes (living standard levels), it gives no account of where additional costs derive from. It does not show, for example, whether people reporting that they find it hard to afford everyday essentials are fully or only partially covering their disability-related costs, and therefore the extent to which these additional costs are being fully measured.

An alternative, budget-based approach seeks more directly to identify additional costs that arise for households with disabled people. One type of study, a number of which were carried out for the Disability Income Group in the 1970s and 1980s, researches actual disability-related expenditure by households (Large, 1991; Thompson et al, 1990). This however does not take account of unmet need: household spending is constrained by household income, and therefore may not always cover fully the additional needs that arise.

In contrast, a study by the Centre for Research in Social Policy (CRSP) built household budgets for disabled people based on **needs**, as identified by groups of disabled people using the consensual method of compiling household budgets, which had been developed by CRSP (Smith et al, 2004). These budgets identified the 'minimum essential needs' for single people with different disabilities living alone, and demonstrated that it is possible for disabled people with particular categories of impairment (including sight and hearing, among others) to come to a consensus about minimum household budgets. A difficulty, however, in translating these household budgets into estimates of the

additional cost of disability was that there was no 'baseline' of costs describing a minimum for non-disabled households. And since disability can have complex effects on people's living patterns, it is not easy to distinguish discrete areas of spending that are 'additional', in isolation from the overall standard at which they live. The highly imperfect solution adopted by that study was to compare an **average** single person's actual expenditure with the minimum calculated as required by disabled people, as an indication of the areas in a household budget where disabled people appear to face additional costs. The weakness of this approach was that it made the comparison relative to the average case, not relative to how someone would live as a minimum.

Background Note 2, 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 alone. 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 groups - for example, those with disabilities or 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? MIS was originally calculated as a minimum for Britain; subsequent research in Northern Ireland carried out in 2009 showed that the required budgets there are all close to those in the rest of the UK, so the main budget standard now applies to the whole of the United Kingdom. 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.

When was it produced and how is it being updated? The original research was carried out in 2007 and the findings presented in 2008, costed using April 2008 prices. 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

Chapter 2 Methodology and specification of cases

The overall structure of the method for researching additional needs of people with a disability under the Minimum Income Standards approach comprises:

- 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 about six to eight 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. The method for doing this is to ask groups to imagine walking through the different rooms of the case study home and talk about whether items are required or not, and if so, whether they need adapting, and whether additional items would be required - as well as then considering needs in relation to activities outside the home. 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 they last) and identifying how much this would add overall to the weekly minimum household budgets.

This project implemented this method for one type of household with sight loss and one type of household with hearing loss, and the following account describes the method in practice. In each of these cases, the project had to ensure that the method was suitably applied to the situation of the disabled people whose needs are under review, in ways set out below.

Specifying the case

A key issue in identifying additional costs associated with a particular disability is to ensure that such a disability is defined in clear terms, and is understandable to participants in groups who themselves have experience of what it is like to live with such a disability. In MIS, an imaginary person is specified as a ‘case study’, described in terms of where they live, with whom and in this case with what impairment.
In the case of people with sight loss, after deliberation including consultation with the project’s advisory group, it was decided to make the case study someone who was certified sight impaired, with some useable sight. This description was thought to be generally meaningful to people, and relates to the needs of people eligible to be covered by the Certificate of Vision Impairment definition as ‘sight impaired’ (partially sighted), but without narrowing it to a specific condition or functionality.

It is recognised that the needs of people who have no useable sight (and included in the certified 'severely sight impaired' category) will differ, and that this would require a separate study to investigate properly. This meant that participants were also recruited to the groups on the basis of being sight impaired but with some useable sight. It is recognised that this description covers a range of different conditions which can vary and fluctuate, some of which have implications for needs such as the degree of additional lighting required. Reflecting this, groups in some cases mentioned more than one possibility and rather than specify specific items suggested an amount of money that could allow someone various options to meet such a need. However, in most cases their common understanding of what it means to be sight impaired allowed a particular item list to be agreed on, even in the context of a relatively general definition of sight loss rather than the specification of a very particular condition.

In the case of hearing loss, the decision was taken to look at the needs of people who are profoundly deaf, and who use British Sign Language (BSL). Many deaf people whose first or preferred language is BSL consider themselves part of the Deaf community. They may describe themselves as Deaf with a capital D to emphasise their Deaf identity. The participants in this study were recruited via Deaf Clubs (see below), and talked about Deaf friends and socialising in the Deaf community. For this reason a capital D is used in this report to describe those who participated and the imaginary person whose needs are being described. Thus the findings of this research must be understood as being specific to the group being studied: people using BSL who are 'culturally Deaf': a minority of all those with hearing loss. It does not seek to represent the heterogeneous experiences of people with various levels of deafness

and different means of communication such as lip-reading. In the longer term there would be value in extending the analysis to include more of these cases.

Note therefore that the sight impairment case is of someone with some usable sight, whereas the Deaf case is for someone without any hearing. The results of each of these cases must therefore each be considered in their own right, and can in no way be used to compare the cost of sight and hearing loss.

For both the sight impaired and Deaf case it was decided to focus on people of working age who are living on their own. While a large proportion of people with sight or hearing loss are of pension age and many of those of working age live with other people, this choice was taken, not as the most 'representative' of cases but, as the context that would most clearly distinguish additional needs associated with the sensory impairment. Starting with a pension age case could have been problematic because of assumptions that might be made about typical interactions between sight and hearing loss and other physical limitations. If the case of someone living with a non-disabled person was used this would require views to be taken about which of the disabled person's needs might be met with assistance from the people that they are living with. Both these issues are highly relevant and could be the subject of future studies, but as a starting point, the person of working age living alone was considered the best context in which to isolate the specific cost of someone living with sight or hearing impairments.

These criteria were used to come up with the following two case studies,

which were used in the groups:

‘Susan or Simon is in her / his thirties and lives on their own in a one bedroom rented flat. She / he is generally in good health and is certified as sight impaired, and has some useable sight’.

‘Susan or Simon is in her / his thirties and lives on their own in a one bedroom rented flat. She / he is generally in good health and is profoundly deaf and uses BSL’.

In each case, groups were asked to contrast this person’s needs with the already specified minimum requirements of an otherwise identically defined person without a sensory impairment.

Recruitment

The Minimum Income Standards research requires people to be recruited from among the general public from a range of backgrounds (gender, age, employment, tenure etc.) and to be in the category of household whose needs are being described. These requirements involved some additional consideration in recruiting people to take part in the groups for this study and the practices used are outlined below.

Purposive recruitment through networks and service centres used by the relevant groups was necessary (see below) in order to find people living in the same general area who were of working age including the disability being described. This was more suitable than sampling the general public in order to find the small numbers of people who met the criteria. While the aim was to target people who live alone (to match the

case study in question), it was difficult to find a sufficient number of people meeting the other criteria who lived in single households. However, by also allowing participation by people who had some experience of living on their own within the past five years, and/or whose partner was also sight impaired or deaf, a sufficient sample was achieved.

The method of recruitment took a pragmatic approach resulting in different forms for each of the strands.

Recruitment of people with sight impairment was organised by Thomas Pocklington Trust, drawing on its networks as a provider of services to visually impaired people and on other networks suggested by members of the project advisory group. This involved circulating information about the project by advertisement and email and inviting eligible people to volunteer to take part in the research. The advantage of this method is that it was able to reach a range of people, other than those who use service centres, many of whom in this case would not have been eligible because they do not live on their own. On the other hand, a self-selection method also risks attracting greater participation by people who are well networked and perhaps more experienced and motivated to speak about sight loss.

In the case of people who were Deaf and use BSL, recruitment was organised by a company, UK4BSL, which provides a range of services for the Deaf community and whose Director was part of the research team. Recruitment involved visiting Deaf groups and clubs and talking to people who might be eligible about the project and what participating might involve. This made it possible to access eligible members of the

Deaf community who would have been hard to reach by other means such as advertising or email lists, although it may also have missed some Deaf people less integrated into the Deaf community.

Drawing on the networks of organisations such as Thomas Pocklington Trust and UK4BSL who work within the communities that were being studied was valuable. They were likely to be a trusted source which perhaps gave people more confidence about putting themselves forward. The person recruiting had (face to face or telephone / email) discussions with participants which enabled them to answer any questions about the project and also check what communication (and other, for example, travel) needs people had.

Participant information leaflets were designed in consultation with both organisations - this involved producing different formats and emailing information for the sight impairment groups, and particular consideration to the language used for the Deaf groups (as they would be users of BSL which has different construction to written text).

Thus, each method represented the best available pragmatic way of recruitment for that particular group. Each proved effective in its most important purpose of bringing together an appropriately-sized group of eligible individuals with a range of characteristics (see below). Moreover, the groups achieved their purpose of having productive discussions that between them developed a consensus about additional household needs, without being dominated by any participants who came with a pre-set ‘agenda’. These are recruitment methods that can be further refined and developed in future research of this kind.

The groups comprised:

- Forty individuals across six groups
- A balance between men (16) and women (24)
- A balance between people aged under 45 (18) and 45 or over (22)
- Participants who all had experience of living alone, and although half were living with someone else at the time the group was held, two of these were lone parents, and nine were with a partner who was also deaf or visually impaired.
- Twelve participants in paid work, 10 did voluntary work, three were in education and 15 were in none of these categories.
- Sixteen owner occupiers, 12 social tenants, eight rented privately, two lived with parents and two had unknown tenure.

Running groups

Communication

Both sight impaired and Deaf groups had specific issues to consider when applying the MIS objective of creating an active conversation in which groups collectively agree items that should go into a minimum household budget.

The sight impaired groups were run in much the same style as groups in previous MIS studies, except that information that would normally be shown on flip charts was talked through by facilitators. This included both a representation of what previous groups had decided where this was under review and the capturing of decisions made by the groups. The latter is especially important in relation to MIS, since the reaching of

consensus is validated partly by facilitators writing down what decisions the group appears to be reaching and giving participants a chance to amend or confirm this. For sight impaired groups facilitators therefore took particular care to check orally that decisions had been accurately understood and recorded.

In the Deaf groups participants used BSL and facilitators used spoken English with qualified interpreters translating between the two. Each group had two interpreters for this purpose supported by an expert in Deaf communication (the Director of UK4BSL) who ensured that not just words but meaning were being correctly understood. UK4BSL also helped the team prepare a topic guide using language and concepts that would make sense to Deaf people and visuals were used alongside lists on flip charts.

In both sight impaired and Deaf groups, more time was allowed than in the standard MIS groups in order to ensure that communication could be effective and help cover all the topics requiring discussion.

Building consensus

In the sequence of the three sight impaired groups and in the sequence of the three Deaf groups the research built up consensus using a review technique that had been used in previous MIS studies looking at differences from the main MIS (for example in remote rural areas). The first group in each sequence started by considering and amending the main MIS budget researched for a single person in 2014. Subsequent groups were also told of the main MIS budget, as well as about revisions proposed by previous groups in the present study. This helped build up a picture, although it did not always result in an iterative move towards

consensus. In practice, the groups between them came to strong levels of consensus about what these needs were, even though specification of the precise items required to meet them (particularly those using technology) could not always be agreed exactly in the groups themselves. The decisions reached within groups were looked at as a whole and budgets produced based on the overall outcome of discussions. They were rooted in reasoning and justification outlined by participants and always based on the criteria set out in the groups in terms of which functional needs should be fulfilled.

Identifying private costs

An important principle of the Minimum Income Standard is that it distinguishes items that households need to have from those that they have to pay for, where direct social provision is an issue. For example, all households need to have prescribed medicines, but for people of pension age and children these are provided without charge. In the case of disabled people, there are a number of goods and services that might be provided free. However, because some of these free items could be available to some households and not others, particularly where provision is at the discretion of a local authority or other provider, the assumptions involved when calculating a household budget are not always straightforward.

For the purposes of this report, the researchers considered carefully, based both on what groups said and where necessary also on further conversations with providers and others, which of the following four categories items should be classified under:

- **Privately purchased**: Items that everyone would expect to have to pay for. This is the great majority of items in all MIS budgets - ranging from food to clothing to furniture - and also includes many additional items that disabled people need to buy. (The items reported in Chapters 3 and 4 below are in this category unless stated otherwise.)
- **Publicly supplied**: Items that are mentioned as being needed, but which it can be generally assumed to be provided free. In the present study, for example, Deaf groups agreed that interpretation should be provided as standard when they interacted with certain public services. The cost of these items are not included in the budgets.
- **Normally publicly provided**: Items that would most commonly be provided free, but which under some circumstances people might have to pay for. Typically, this variation was to do with differences between local authorities in terms of what services and equipment they provide. An example is an alarm system alerting Deaf people to doorbells or smoke alarms. In these cases, the main calculation in this report assumes that the item is provided for free, but we also note the implication in terms of additional cost if it is not.
- **Sometimes publicly provided**: Items that people would normally expect to pay for, but in some cases may be provided for free. An example is peak time travel, which is not included in most travel schemes, but is free for disabled people in some areas. Here, we include their private cost in the main calculation but note the reduction in budget that would occur if someone did not have to pay for the item.

In pricing equipment, VAT has been excluded in cases where goods are zero rated or eligible for VAT relief as being goods and services that are designed solely for use by disabled people.

Chapter 3 The minimum cost of living for a single person who is sight impaired

This chapter looks at the areas of minimum costs that have been identified as differing for a single person of working age living on their own who is eligible to be certified as sight impaired (and has some useable sight), compared to the minimum for an equivalent fully sighted person (covered by the 'main MIS' budget). It starts by reporting what sight impaired groups identified as additional needs, and why, and then goes on to add up their cost.

The following findings describe what were thought to be additional and different requirements for such a person, as well as a few cases where costs incurred by a sighted person would not be required by someone who is sight impaired.

Household fittings and furnishings: safety and maintenance

Sight impairment affects a wide range of needs in the home. These include not just the need for additional or specialised items, but also requirements for the quality or type of items that would be included in anyone's household budget – for example to ensure safety, efficient cleaning or maintenance.

Floor covering

Groups discussed the most appropriate type of floor covering in terms of safety and cleaning. The main MIS budget includes low cost carpets in

the bedroom and living areas, and vinyl in the bathroom and kitchen. There was concern that a cheap vinyl could 'bubble up' or detach from the floor, particularly if it got wet, and become a trip hazard for someone who is sight impaired. A medium quality type specifically designed to accommodate wet areas was considered more suitable. Furthermore, some participants felt that carpets might not be practical in the living and dining areas as it is here that things might get spilt. They explained that carpets are more difficult to clean quickly and more likely to stain than hard flooring such as laminate, and someone also noted that it was more difficult to find things that might be dropped on a carpet.

"…if someone is visually impaired you're going to have those accidents. Whether you've got carpet or plastic they're going to be there, so what you want is ease of operation. Now if I had a wooden floor all of my accidents and what have you I can clear them up in seconds; instead of I've got a carpet and I've dropped a plate and the glass has gone everywhere and I've cleared up what I thought I've cleared up, but then a week later I'm walking around and I've cut my foot." (Group 2)

These points relate, not only to ease of maintenance and safety, but presentation (wanting the home to look nice if someone came to visit) and independence (not relying on someone else to help). On this basis, the budget has been increased to cover a medium quality laminate in the hall, living and dining areas. A doormat (which is not in the main MIS for a single working age person) was also added in the hallway as it was felt that someone who is sight impaired may not be aware if they have something on their shoes when coming into the home.

Sofa and chair

The only change that groups made to the main furniture items was to the sofa and chair coverings. The main MIS includes a low cost fabric two-seater sofa and chair, and this was an area where it was felt that additional costs would be required. The groups discussed the practicalities of a fabric covered sofa and questioned how easy it would be to keep clean. They agreed that if a fabric sofa is included it would be essential that the covers were removable and had a stain protection finish, which would add to cost. This reflects the earlier discussions about carpets and the need to be able to clean it easily as someone who is sight impaired may be more likely to spill drinks or food on the sofa than someone who has full sight. Groups put forward the alternative option of having a leather type sofa (cheap leather or good quality synthetic) which, while they anticipated it being more expensive, was justified as it could be easily wiped clean.

"M: It's the simplicity if I have a leather [sofa] I'll know I'll wipe it and I know it's clean

W: Yes, I hate leather sofas but something that is simple to clean certainly, either throws or a fabric one that you can wash off. You see mine you can't remove the covers so I have to keep going over it with the wet wipes and everything. … It doesn't necessarily need durability, I don't see why a visually impaired person should have a better quality sofa for durability but for cleaning, yes." (Group 3)

The budget was therefore increased to cover a reasonably priced leather sofa and chair. The additional cost could cover adding stain protection to a fabric sofa if this was someone's preference. A throw for each was

also added as groups said that this would save cleaning the sofa so often and be warmer in winter on leather furniture.

Bathroom

Groups made a few changes in the bathroom which related to safety. First, they added a rubber mat to go inside the bath to prevent slipping. Second, they changed the shower curtain which is included in the main MIS - there was not total agreement on this but it was described as a 'trip hazard' by some participants. A solid shower screen was thought to be safer as it was sturdier, and also easier to keep clean. Finally, contrast coloured grab rails were added - these were considered useful for "spatial awareness, so when you are in the shower you know how to get in and how to get out".

Although not everyone in the groups felt that they would necessarily need all of these items themselves, it was recognised that this would vary depending on someone's sight impairment and eye condition. In most cases people felt that, as these are related to safety, it was important to include them in a budget so that someone was able to have them if required.

Household fittings and furnishings – the light environment

Lighting

Lighting was identified as a key area that would, without question, require additional spending to meet the needs of someone who is sight impaired. The main MIS budgets include a basic light bulb and ceiling shade in each room plus a low cost table lamp in the living area and bedroom. Groups were unanimous in emphasising that someone who is

sight impaired should have more and brighter lighting throughout their home. This would require decent quality fittings and would need to be targeted to ensure it focussed on particular areas, for example, above the dining table or over the cooker. Lighting would also have to be adjustable and allow flexibility. This reflects other research highlighting the value of good lighting for people with visual impairment (Thomas Pocklington Trust, 2013).

Having different types of lighting to use and being able to adjust it was also important to account for fluctuating eye conditions, as one person explained, her lighting needs varied throughout the day. The types of lighting discussed included central spotlights and multi arm fittings that could light several areas of a room at the same time, fluorescent strip lights, additional wall lamps, under cupboard lighting in the kitchen, around the mirror in the bathroom, and dimmer switches to control lighting levels. Standalone lights were also important such as good quality angle poise or reading light or father / son type lights and portable lights to provide additional lighting in key areas.

Discussions about lighting highlighted the issue that being sight impaired covers a wide range of eye conditions with different and fluctuating needs in terms of lighting requirements, and participants explained that what might suit one person would not necessarily work for another:

“I have to have a lot of light but I’ve got a friend who has to wear sunglasses all the time because if she had a spotlight in her house she wouldn’t be able to see anything, so you’ve got to bear in mind different conditions vary in different ways, and what might be amazing for one person won’t be as effective for somebody else.” (Group 1)

To account for this variation in need the groups came up with a model of a lighting budget per room that could be used flexibly to cover a range of options and someone could use in the way most appropriate to their particular needs. The budget agreed is £90 per room every five years. It was recognised that fittings / items could well last longer than five years but people explained that eye conditions and lighting needs may change over this period and items replaced accordingly. They also talked about an element of trial and error in order to get the best lighting for their needs, and that fittings would not easily be taken if someone moved. The budget also reflects participants' views that in this area the requirements would not be met using low-cost items and retailers, but more likely good quality products and specialist shops. It also includes the cost of bulbs over that period which, given the lighting requirements, would be greater in quantity and cost to allow a better quality / specialist type than the standard light bulbs in the Main MIS. As one participant explained:

"If you're going to source and you're visually impaired one of the key things is that if I was looking for any lamp you probably wouldn't find the perfect one in Wilkinson's because it's going to depend on where the switch is and it's about the light itself, whether it's directed downwards or upwards. You're more likely to go to a higher scale shop and get a halogen lamp or something like that, which is cold, because if you're reaching out and your light is on you want a light that is actually not diffusing a lot of heat." (Group 3)

Curtains, nets and blinds

Groups discussed whether changes were required to the nets and curtains included in the main MIS budgets. This was another area where needs could vary depending on someone's eye condition. Some noted that nets could inhibit the natural light in a room which was important for someone who is sight impaired. There was also concern that nets could be seen through if lights were on in the home - which they more commonly would be for sight impaired people than for others. Venetian blinds were thus suggested as more suitable as they can be adjusted to control and direct the natural light which could be important for some people, but also allowed privacy. The budget was thus calculated to include a ready-made venetian blind (replacing the net and rod), should someone prefer this - but this in fact does not affect total costs, as blinds would not need replacing as often as nets.

Household goods and equipment

Labelling

All groups agreed that a way of labelling household items, foodstuffs, and equipment is valuable for someone living alone who is sight impaired. Participants discussed various methods and added two different types of labelling system. First, they included Bumpons, small self-adhesive dots available in different shapes and colours, or Tactimark, a liquid plastic that sets hard, both of which can be used to mark the controls on kitchen appliances or other equipment so that people can use touch rather than sight to know where the settings are. These were referred to as a 'saviour' by one participant.

Second, a Penfriend labelling device which allows someone to record a

message onto a label was included. Participants explained how this was extremely useful for labelling food, shopping, clothes, recording cooking instructions and even used to label and read back a credit card number when making telephone purchases. While (at £64.99) it was more expensive than the tactile markers, people felt that its value as a multi-use item justified including it in the budget.

One participant did mention that some local authorities were providing visually impaired people with a Penfriend for free. However, this was felt to be rare, and the expectation was that it would be an expense met by the individual.

Kitchen equipment

A range of kitchen equipment was discussed and led to additions and changes to the type of items included in the budgets.

A liquid level indicator, which alerts people when a cup is filled, was seen as a useful yet inexpensive item - there was a view that this could be available for free via a Social Worker or charities, but as this was not always the case the cost has been added to the budget.

Talking scales were also considered ‘essential’ and groups all agreed to include these, rather than the basic scales currently in the main MIS budget. Although talking scales are more expensive, it was thought that they would last over twice as long as basic scales, (five years compared to two years), so do not increase the budget as much when this is taken into account.

A few participants talked about difficulties in seeing clear glasses, for

example, when a visitor had left a glass in the sink a participant not realising this put something on top of it and smashed it. The main MIS budget includes very cheap clear tumblers and wine glasses, and it was suggested that coloured ones could be helpful here and the budget increased to include this option.

The benefits of several other items were discussed including a dishwasher, a talking jug, and a talking microwave. However, the overall view across groups was that these were more 'nice to have' than essential items. In the latter two cases it was felt that people's minimum need could be met through cheaper alternatives, such as using plastic measuring cups, and tactile marking of dials which were included in the budget.

Alarm clock

Groups all thought that a talking alarm clock should be included in the budget since someone who is sight impaired may be unable to clearly see the standard type of bedside alarm clock currently in the main MIS budgets. They explained that this would enable someone to easily reach out and press a button and hear the time. There was also discussion here about whether or not a talking clock was provided free by social services, with mixed experiences even within the same area. However, as this was not generally the case, and there was a view that provision was changing, the cost is included in the budget.

Technology and home entertainment

Groups agreed that the television and CD player in the main MIS budget for single working age people are necessities, but identified changes to the specification and features in order for them to better meet the needs of someone who is sight impaired.

Television

Groups confirmed that, as in main MIS, a 32 inch TV would meet people's needs. However, they made further specifications which restricts the choice of TV available and excludes the use of budget brands. Participants explained that, not only did the TV programmes need to have an audio description, but that this should extend to having speaking TV menus and settings features which can be hard to see for someone who is sight impaired. They stressed how important it was for people to be able to easily operate, set up and control their TV without relying on someone else for help.

"W: The more facilities you have like talking menus and whatever for anybody with a visual impairment what is important is your independence and you want to keep that and maintain it and not be constantly asking friends or family or whoever to come in and help you with what are basically trivial things to a sighted person.
M: But there's a huge difference to the quality of life though, doesn't it?
W: Of course it does absolutely. So the more independence you have with aids or talking facilities or large print or font sizes or whatever the more we feel normal. That is hugely important." (Group 1)

At the time of this research, there was only one manufacturer whose

televisions had a ‘Voice Guidance’ feature on some of their models. The budget was increased to include this more expensive model with a clear message from participants that this was a way of enabling someone who is sight impaired to use their TV in the same way as a fully sighted person. Groups also noted that sometimes using a standard remote control could be a ‘struggle’ and agreed to add a large button remote control to the budget.

Note that, while people who are certified severely sight impaired or blind get a 50 per cent discount on television licenses, this does not apply to someone certified sight impaired but not at the severe level. The person being reviewed in this study falls within the latter category and therefore the full cost of the TV license remains in the budget.

CD player

Similar to the television, the budget portable radio / CD player included in the main MIS was upgraded to include additional features. Participants said that it could be made a lot more accessible to someone who is sight impaired if it had a docking station for an iPhone (see section on mobile phones below). This would enable them to more easily listen to music they had downloaded using the talking menu on the iPhone, rather than having physically to find a CD. This feature was considered a ‘nice to have’ for the main MIS groups but a necessary item for someone who was sight impaired. This was because it allowed them to use the CD player more readily and also enabled them to make best use of accessible iPhone features (included in the budget below).

Technology, communication and adaptive equipment

Mobile phone

Groups all stressed the importance of an accessible mobile phone for someone who is sight impaired. The main MIS budgets include a small basic smart phone on a £10 a month package. The unanimous agreement was that this should be upgraded to an Apple iPhone (4S or above) which was considered 'the best out there' in terms of accessibility. Participants outlined the features that they felt made the iPhone so valuable - including screen magnification, the Voiceover screenreader, dictation and the Siri intelligent assistance tool (a voice activated means of accessing information and carrying out tasks on the phone). People discussed how some of these are available on other brands, but not necessarily as easy to use as the iPhone. One participant described how the magnification feature enabled them to read texts which they were unable to do on other phones, as well as use Facebook and email from the phone rather than computer:

"I think something better than your basic smart phone is a necessity, not just for the communication but because I use it for different things…So what I'm saying is for a visually impaired person the spec of the phone needs to be good enough to maybe do additional things than for someone who doesn't have visual impairment that's already in your mainstream MIS." (Group 3)

Some participants also talked about additional apps such as Prizmo for scanning and reading documents and magnifier apps which broadened the use of the iPhone further for people who are sight impaired, and were particularly useful when out and about (see also below). There

were differences within groups in people's awareness of the various features that were available via the iPhone, and differences in how participants used their phones - this could relate to how familiar people were with technology, what support they might have received and their personal requirements and needs, among other things. However, the message that came out of the groups was that the iPhone can be a multi-use item, as outlined by one participant:

"I'm looking at the bigger picture than if you're looking at cost, you're looking at a multi usage item. So you're spreading that cost out. You're not just spending on one item you'd be looking at that where you've got accessibility to music, accessibility to communication and accessibility maybe to the internet all through one vehicle." (Group 3)

An Apple iPhone is included in the budget and a monthly package with the requirement to include some minutes (as calls could also be made from a landline – see below), and a reasonable amount of data – it was felt that 2-3 GB would be sufficient as a minimum need.

Landline phone and internet connection

The main MIS budget does not include a landline for a single working age person as it was considered that a mobile will meet people's basic needs. However, the groups all outlined reasons why a landline should be included in the budget for someone who is sight impaired. First, it was important for reliability. For example, if a mobile was lost or reception not available it was seen as an important 'back up' to have for 'peace of mind' and could be crucial in an emergency. Second, was to be able to call 08 telephone numbers (commonly used by service providers) which are not generally covered in mobile tariffs. It was felt

that someone who was sight impaired may need to use these numbers more often as it could be less straightforward for them to use the internet for making bookings or payments, planning journeys, or finding out information, as explained by a participant:

“Because say for example, some fully sighted people, they have the luxury of you know going online, websites and things like that. When you’re visually impaired you’d rather speak to someone. If you’re buying, let’s just say concert tickets, you’ve got a timeframe, you’ve got five minutes to put your number in, valid from, expiry date, the whole lot. You’re not able to do that online if you’re visually impaired and you’re using Jaws or magnification, so you’d rather ring somewhere up and that’s an 08 number straight away.” (Group 2)

Thirdly, so that other people could call you at less cost than their phone provider might charge for making calls to a mobile. Finally, a landline can be used for the inclusion of broadband internet connection – the internet being seen as a ‘necessity’. The main MIS budget includes a dongle for internet connection, but with groups already justifying the inclusion of a landline, a broadband connection was included in the budget, and the dongle cost removed. The cost of twin large button handsets was also added to the budget.

Laptop or PC and Software

Groups all agreed the need for a laptop or computer. The main MIS includes an 11 inch netbook, but people said that the screen size would need to be bigger because someone who is sight impaired could be using enlarged fonts. This was changed to cover the cost of either a 17 inch laptop or 20 inch PC, the choice being seen as individual

preference.

Computer software was considered vital to provide screen magnification and reading for someone who is sight impaired. Participants discussed the many different types of such software on the market and noted that there were free versions available. However, they were generally considered not so good or easy to use and were more susceptible to 'glitches' or crashing than software that would have to be paid for, the cost of which ranged up to around £800. People did suggest different ways in which someone might be able to obtain this commercial software for free or at a reduced cost, for example, through local Trusts or a charity grant accessed via the local authority, however, the view was that anyone would be 'lucky' to receive this as they are 'few and far between'. Access to Work and Disabled Student Allowances were also mentioned as sources of software for people in work or study environments. Some of the top end priced versions participants discussed were supplied on a USB stick and are portable. Groups thought that this would not be necessary as a minimum need for personal home use, and if this was required for work purposes should be funded via an employer / Access to Work. The cost of a mid-range priced magnification and screen reader software package that could be installed on the home laptop / computer was therefore included in the budget.

IT / software Training

Groups felt that in order to benefit from the accessibility software discussed above, some sort of IT training would be useful. The need would depend upon several factors, for example, how tech savvy or familiar someone is with a computer. While some participants spoke of

‘struggling’ with software where they had had little or no training, others had taught themselves how to use it without problems. Participants agreed that someone who is sight impaired, as a minimum need, should have the opportunity to receive software training.

“If you’ve got this access technology, you can’t just get it and just use it straight away, just know how to use it, especially if you’ve got to put it onto your computer and you’ve got to learn all the key strokes and things and how to navigate round it and everything. You do need somebody to get you started.” (Group 1)

However, from where, and at what cost was more difficult to specify – it was a ‘murky area’ as one person noted. People had mixed experiences and knowledge about the sort and sources of training available and how to access it. They suggested FE colleges, local ECDL centres, local charities, RNIB who could provide home visits, commercial software suppliers who could provide one-to-one training, or online self-teaching. These options covered basic IT to specific software training and the cost varied from free to hundreds of pounds. The groups concluded that provision is likely to vary greatly depending on someone’s personal circumstances, where they live, as well as individual knowledge and ability regarding how to go about accessing such training.

Groups therefore agreed that a budget should be included to cover the cost of buying training, but also this would enable anyone receiving training free from a charity to make a donation. They explained that this would enable someone to “feel that they are giving something back and appreciating the help that the other person’s put in”. £80 per year was

added to the budget - this could be ‘banked’ to provide more expensive training, for example, an intense session from a supplier when purchasing or updating new software.

Scanning, reading and printing

Having the technology to enable someone to read documents, letters and books independently was also considered a basic need for a person, living alone who is sight impaired, and groups discussed different ways of achieving this.

“Scanners, well the one I use anyway, if you get post, if you get letters from the Inland Revenue or whoever you can actually put it into your scanner/printer and it will then scan it and then read it back to you via the computer. So again it’s a question of independence. Quality of life and your ability to manage your own life.” (Group 1)

Participants recognised that a standalone scanner reading machine was convenient and easy to use. However, the overall conclusion reached was that, to meet a minimum need, a reasonable quality scanner / printer that could be connected to a computer or laptop would be sufficient. This was felt to be a more cost effective option and would serve the purpose when used with the computer screen magnification and reading software already included in the budget. Furthermore, several participants pointed out that if someone has an iPhone, scanner apps can be added and used in conjunction with the Voiceover feature to provide the capability to scan and read out loud, which was also useful when out and about.

The main MIS does not include a printer at home for a single working

age person, but allows £15 per year for printing at a shop or library. Although groups noted that the need for printing was diminishing with email and smartphones being used more for sending and storing information or confirmation of bookings etc., they felt that someone who is sight impaired should have the facility to print at home should it be necessary. This would make life easier and maintain independence. People said that it would save the 'stress' of having to go out to do printing which could involve planning the journey, asking for help in the shop, and would also maintain confidentiality if dealing with sensitive documents, all of which could be of concern for someone who is sight impaired. A mid-range scanner / printer was added to the budget which it was felt would cover both of the above tasks, and an iPhone scanner app (Prizmo) also included.

Portable magnifier

Groups had various views about what sort of handheld magnifier should be included in the budget, and this is again something they felt would vary depending on an individual's eye condition and level and type of sight. Some participants felt that a conventional magnifier that was generally available free would meet a minimum need, and others noted that the iPhone had magnifying features which could also serve the purpose. However, participants in two groups strongly felt that a handheld electronic video magnifier was a really valuable piece of equipment. It was seen as simple to use, for example, when shopping, or reading a menu, it had adjustable magnification which was useful if people's sight changed, the colour contrast could be altered to suit an individual's need, and the image could be frozen. One participant gave an example of how it could be used:

“With the electronic one, you can increase the magnification, so you can have a small word but you can make it bigger and you can change the colour, you can freeze the image. So if I was looking at an electric meter and I was using my standard magnifier, I need to be this distance to it. With the electronic one I can hold it up, take a snapshot and then hold it down and look at it.” (Group 2)

It was also seen as helpful at home if someone did not have a stand-alone scanner (which is not included in the budget) to read letters and documents quickly without the need to connect to the computer. One participant also spoke of the device being less conspicuous than a conventional magnifier:

“You don’t look so obviously disabled if you’ve just got a little like magnifier thing. Yes I tend to have my hand held one, I’m not that bothered these days, whereas when I first started using magnifiers I didn’t like it and I wanted to seem as inconspicuous as possible.” (Group 1)

A mid-range handheld video magnifier has been added to the budget.

Household bills

Groups felt that energy costs were likely to be higher in households where someone is sight impaired, reflecting other research findings (RNIB, 2012; Donnelly and Winckler, 2012). This was mainly due to having more and brighter lighting which is on longer including during the day, and can also be left on even if someone is not in the room (so that it is better lit when moving between rooms), as explained by one

participant:

“I’ve got double strip fluorescent in the living room, kitchen and bathroom… You know, if I had no vision at all it wouldn’t matter to me whether I turn the light on or off, but it’s an expense because if I’m in I have to keep the light on all the time even in the middle of the day if I want to do something otherwise I can’t see it.” (Group 3)

Participants also pointed out that the computer might be on more frequently and for longer as it is used to read letters or documents or the CD player for talking books which a fully sighted person could do without the need for technology. A calculation for this project by a fuel expert estimates that additional electricity costs based on this extra usage adds up to £72 a year.

Personal and health care

Clothes

Groups did not alter the budget for clothes. There was some discussion about wear and tear on shoes and laundry needs, but when the quantities and replacement rates in the main MIS budgets were outlined, people did not make any changes. A rucksack was added (which is not in the main MIS budget), as people said that this was necessary for carrying things while allowing hands to be free which they thought was important for someone who is sight impaired, especially if they use a cane.

Shaving

The main MIS budgets include shaving items for both men and women - razors / blades and foam for wet shaving. Participants said that using an electric shaver could be safer for someone who is sight impaired and suggested including a mid-range rechargeable type. The cost of an electric shaver is actually cheaper over time, and therefore covered by the existing MIS budget.

Prescriptions

The main MIS budget includes costs to cover four prescriptions per year. All groups agreed that this should increase to account for additional prescriptions that people might need for eye conditions, in particular for eye drops. The budget has been increased to cover 10 prescription charges per year.

Opticians

Optician costs in the main MIS cover an eye test and £50 for glasses every two years. Participants noted that eye tests would be free for someone certified as sight impaired, however, they would still need to pay for glasses[1], and that this is likely to involve more expense than for someone without sight loss. Participants explained that costs would vary depending on someone's eye condition, but that people who are sight impaired may need:

- to pay more for glasses where they require a more complex prescription;

[1] People on certain benefits are entitled to free prescriptions, glasses and contact lenses, however the MIS budgets are based on the assumption that someone would need to pay for these items.

- to replace the glasses more often as eye conditions change;
- coloured sunglasses - sometimes multiple pairs to deal with different light conditions;
- contact lenses plus the related cost of solutions

The cost of the eye test has been removed from the budget. Groups increased the budget for glasses to allow £150 per year as a minimum standard. They felt that the costs incurred would vary, with some years more being required and other years less. It was also noted that costs would depend on the nature of a person's eye condition and that some people will need to spend more.

Services in the home

There were two areas where groups said that the budget should be increased to provide additional services or support in the home.

First, cleaning / home help costs were added. Groups felt that a person of working age, living alone who was sight impaired but with some useable sight would be able to do some daily cleaning, but that every other week they could benefit from two hours of a 'good once over' clean or to deal with particular things such as a stain, ironing or cleaning windows. There was a view that 'everyone's entitled to a clean home' and that someone who is sight impaired should not feel that their home is any different. Participants noted that maintaining the presentation of the home was important for 'self-esteem'. For example, while they themselves might not be worried if a window was a bit dirty, they would not want anyone else to think it wasn't clean or draw attention to it. As

one participant noted:

"You get nasty people, if someone's a bit dirty or a bit messy, people pick on them. So they could say 'Oh you know the blind woman, oh yes she's got all the dirty windows', … and then you're sort of looked at even more." (Group 2)

Second, groups increased the main MIS DIY budget of £100 per year to £150 to allow for occasional extra paid services around the home that could be more difficult for someone who is sight impaired to do themselves, for example, painting[2].

The inclusion of regular help at home or a budget to cover occasional jobs also relates to maintaining independence for someone living alone. While participants highlighted that friends or family are a valuable source of help, for example, to notice something or help adjust a thermostat, a budget for this would reduce reliance on such help, and not everyone has friends or family available.

Transport

The main MIS transport budget for a single working age person includes a bicycle, a monthly bus pass, £7 per week for a single taxi journey, and £100 per year to cover train or coach fares (for social / leisure purposes). Participants felt that the type and frequency of bus travel did not need to be different because someone is sight impaired. The net cost to them of bus travel is lower because of entitlement to a free off-peak bus pass for

[2] Groups noted that ongoing maintenance, major repairs or decorating costs should be covered by a landlord for someone in private rented accommodation.

people with a visual impairment, although five peak time journeys are also costed in the budget. (However, in local authorities that include free peak-time travel with the pass, the travel budget would be £12 a week lower: this is a '**sometimes publicly provided**' item as described in Chapter 2 above.)

Groups also agreed that sight impairment and the increased medical appointments required could affect needs for taxi and longer distance travel. They said that the number of taxi journeys should be doubled to two per week. This would allow for an extra taxi journey in cases where a condition fluctuates meaning it can be harder to see and use the bus some days, and also allow for taxi rather than bus use after hospital appointments where someone's sight is affected by eye drops, the need for which was highlighted by one participant:

"I can't afford a taxi and I was thinking – why are all these people getting taxis and then I remembered the eye drops. When I came out of the hospital, I literally can't see a thing and it is actually dangerous and I walk back from town and I was lucky to be alive. The next time I went I had to save up, I go every six weeks, I had to save up to get a taxi to town rather than wait for hours for the eye drops to wear off. So you do have a lot of extra travel costs because of your medical appointments." (Group 1)

People felt that the travel budget should also increase to allow for trips further afield that related to having sight impairment. This included to hospital appointments some distance away, for example, ophthalmologic consultant appointments in London. Furthermore, there was a need to have someone with them for such appointments, again in relation to

helping to travel after having eye drops. Several participants were involved in voluntary work and active in Visual Impairment networks, and felt that the budget should allow for travel to events or conferences. Another person's experience highlighted the need to allow such travel for social inclusion, as they had felt unable to attend an event some distance away:

"Action for Blind People did a couple of things and I volunteered for whatever they have, you know, to give them feedback, they had a couple of things going on in London and I didn't go because of the expense of going there and coming back and I said no." (Group 3)

Groups added the cost of five long distance rail fares to the budget (one of these was for the cost of a companion to attend a hospital appointment), and also a disabled person's rail card and coach card (which would allow a third off the cost of these journeys). Groups removed the bicycle from the budget.

Social and leisure activities

A budget for social participation was seen as an important need for someone living alone who is sight impaired. People stressed the importance of getting out to avoid isolation and the risk of getting 'depressed' or 'miserable' if someone was to 'sit indoors and dwell on it' (see also Thomas Pocklington Trust, 2010). Groups agreed that the main MIS £20 per week budget for social and leisure (based on two activities per week) was 'not a lot', but for a minimum need, was 'doable'. They noted that most activities would not need to be different for someone who is sight impaired and has some sight or involve additional

cost - going for a walk, having a meal, visiting a museum.

There were some differences (either adding or reducing costs) associated with sight impairment, particularly when visiting the theatre. In some venues they had to purchase expensive tickets to be closer to the stage “to see the production rather than just hear it”, or otherwise access an audio described performance. However, in others they were eligible for reduced rates or free entrance to someone accompanying them. People noted that cinemas also gave free admission for a companion.

Participants talked about the need to sometimes have a friend with them, for example, to help find a seat in the cinema, or help with menus in restaurants which can be dimly lit, or to visit unfamiliar places. They said that having someone else there could give people ‘confidence’ to go to places that they might feel unsure about going to on their own. However, they emphasised that it was important to be able to reciprocate and ‘treat’ friends, by paying for a ticket, buying them a drink or a meal. Being able to do so meant people felt less ‘embarrassed’ as they were conscious of having to ask and feeling reliant on others. As one participant noted:

“I always feel obliged if I ask someone to come with me to give them something in return because I feel like I’m really needy.” (Group 1)

This reflects other research which highlights this ‘hidden’ cost which might be less tangible but still as important as more obvious expenses (Donnelly and Winckler, 2012; Thomas Pocklington Trust, 2010).

The £20 per week budget for social activities remains the same as the main MIS, but with an extra £5 per week added to enable 'treating' a friend, plus a £5.50 yearly cinema concessionary card (to allow free entry for an accompanying person).

Holidays

The main MIS budget for a single working age person includes a one week holiday on the basis of shared self-catering accommodation plus spending money and travel costs. Groups were uncertain about the self-catering model and felt that this would depend on taking a fully sighted friend. They mostly discussed holidaying in hotel accommodation. Specialist holidays or hotels catering specifically for people with visual impairment were mentioned in all the groups, and generated mixed views - from people reporting the benefits of having equipment such as talking alarm clocks or being collected from a station, to others who felt that this type of holiday labelled people who are sight impaired as 'disabled'.

The groups concluded that the budget should accommodate personal choice and therefore need to provide options to cover the cost of holidaying in either a specialist hotel or otherwise in self-catering or standard hotel accommodation, but that these would be on the basis of holidaying with a sighted friend. For the latter they added an extra £50 to enable someone to contribute towards their friend's costs, or buy them meals or drinks during the course of the week in recognition of their help. The accommodation costs were increased to cover the highest cost of these options (the specialist hotel was marginally higher

than the cost of accommodation in a standard hotel plus £50).

Adding up the cost for a single person who is sight impaired

Differences in costs identified are quantified by considering the price of items added or changed from the original MIS budgets, and where relevant, taking out costs that do not apply to people who are sight impaired. In some areas of the budgets these additions and differences have had a significant impact on the overall cost of this minimum basket of goods and services; in others while there may be notable differences in terms of the composition of budgets, the implications for overall costs are small.

The following are the differences between the MIS budgets for a single working age person, living alone who is eligible to be certified as sight impaired (and has some useable) sight compared to a single working age adult who has no visual impairment, in descending order of cost per week:

Additional household goods and services: £17.51 a week

There were a significant number of additional and different household goods included in the budget for someone who is sight impaired. However, as shown in Table 1, no one of these on its own adds much to a weekly household budget largely because household goods last a long time, and so cost relatively little per week of their lifetime. This includes bathroom items (13 pence), kitchen items (37 pence), furniture (76 pence), floor covering (£1.03) and, lighting , (£1.76) with a total of £4.05

per week). In contrast, the addition of a cleaner to the weekly budget greatly increases the weekly cost of household services, adding £12.50 each week, or around six per cent of the entire budget for a single person (excluding rent) in the main MIS calculation. The additional £50 a year for DIY/home maintenance costs adds 96 pence per week. Altogether, all household goods and services account for 17 per cent of the total weekly budget for someone who is sight impaired compared with only nine per cent for single working age adults who are not sight impaired.

Table 1 The additional cost of selected household goods and services

£ per week, April 2014	**Single working age adult**	**Sight impaired single working age adult**	**Cost of additional and/or different items**
Flooring	2.57	3.60	**1.03**
Lighting	0.24	2.00	**1.76**
Sofa, armchair and throw	1.15	1.91	**0.76**
Kitchen, dining items	0.05	0.42	**0.37**
Bathroom safety	0.02	0.15	**0.13**
Cleaner	0.00	12.50	**12.50**
Home maintenance	1.92	2.88	**0.96**
Total	**5.95**	**23.46**	**17.51**

Additional technology needs: £12.39 a week (minus £3.49 if someone was able to access free software and IT training)

Among the considerable number of additional and different needs relating to technology, the most significant involved communication and enabling ease of access to written materials. Table 2 shows that the largest single cost (£4.60 per week) comes from replacing a cheap contract smartphone with an iPhone 5C. The inclusion of a landline also adds a significant amount, but this is partly offset by the cheaper cost of broadband when it is associated with a landline rather than via a dongle adding £1.15 per week in total. Additional IT costs add up to £5.94 each week - from a larger laptop computer (50 pence), scanner/printing (92 pence), specialist software (£1.96), a video magnifier (£1.03) and accessing IT training (£1.53). An upgraded television/remote added 52 pence, a CD player added 13 pence and talking alarm clock added five pence per week to the budget.

Table 2 The additional cost of technology

£ per week, April 2014	Single working age adult	Sight impaired single working age adult	Cost of additional and/or different items
Mobile phone	2.30	6.90	**4.60**
Landline (including cost of phone) and Broadband	3.68	4.83	**1.15**
Scanner / printing costs	0.29	1.21	**0.92**
Laptop	1.00	1.50	**0.50**
Television/remote control	0.32	0.84	**0.52**
CD/radio or iPhone dock	0.08	0.21	**0.13**
Software costs (including iPhone apps)	0.00	1.96	**1.96**
Training for using IT	0.00	1.53	**1.53**
Magnifier	0.00	1.03	**1.03**
Alarm clock (talking)	0.01	0.06	**0.05**
Total	**7.68**	**20.07**	**12.39**

Additional travel costs: £6.50 a week (minus £12 if local authority provides anytime bus travel to disabled people)

Someone who is certified sight impaired saves £16.25 a week by getting a free bus pass, although would still need to spend £12.00 per week on peak-time travel, (except in areas where this is included on the bus pass)

meaning a saving of £4.25 per week on bus fares compared to the single working age adult budget in the main MIS. The cost of a disabled persons railcard and coach card was added to the budget. The effect of adding these is to reduce the cost of coach travel associated with the annual holiday as fares are reduced by one third and a reduction of £33.33 annually in the £100 already included in the main MIS budgets for coach and rail travel. However, this saving is offset by extra costs included for additional and longer distance travel for someone who is sight impaired which added £4.60 per week. The overall additional cost for train and coach travel is £4.28 per week. £7 extra a week was also included for an additional taxi journey, but removing the bicycle and associated costs reduces the budget by 53 pence per week. These costs are outlined below in Table 3.

Table 3 The additional cost of transport and travel

£ per week, April 2014	Single working age adult	Sight impaired single working age adult	Cost of additional and/or different items
Bus pass and travel	16.25	12.00	**-4.25**
Taxi fares	7.00	14.00	**7.00**
Rail and coach travel costs including Disabled persons railcard and coachcard	2.67	6.95	**4.28**
Bicycle and associated costs	0.53	0.00	**-0.53**
Total	**26.45**	**32.95**	**6.50**

Additional cost of regular social activities: £5.19 a week

The budget for social activities for a single working age adult who is sight impaired increased from £20 a week to £25 in recognition of the need to treat a friend accompanying and supporting during social activities. A Cinema Exhibitors Association Card, which verifies that the holder is entitled to one free ticket for the person accompanying them to the cinema also brings a small additional cost.

Additional cost of an annual holiday: £3.79 a week

The cost of a one week, off-peak, self-catering holiday in the UK for single working age adults in 2014 was £194.50 based on the principle that the cost of the holiday would be shared with a friend. Groups

adjusted the holiday specification for someone who is sight impaired to include the cost of hotel accommodation. This nearly doubled the cost to £392 a year.

Additional health care and personal goods: £3.57 a week

There is a small reduction in costs linked to free-eye tests for single working age adults who are sight impaired, removing 19p a week from the main MIS budget. However, a large increase in the annual budget for the cost of glasses from £25 to £150 increases the weekly budget by £2.40. The increase in the number of prescriptions from four to 10 each year adds 92p to the weekly budget. These healthcare costs, shown in Table 4, add up to an additional weekly cost of £3.13. There is also an extra 30 pence per week included in the budget associated with labelling and a 14 pence for a rucksack.

Table 4 The additional cost of health care and personal goods

£ per week, April 2014	Single working age adult	Sight impaired single working age adult	Cost of additional and/or different items
Prescriptions	0.62	1.54	**0.92**
Eye test	0.19	0.00	**-0.19**
Glasses	0.48	2.88	**2.40**
Labelling	0.00	0.30	**0.30**
Additional rucksack	0.00	0.14	**0.14**
Total	**1.29**	**4.86**	**3.57**

Additional energy costs: £1.38 a week

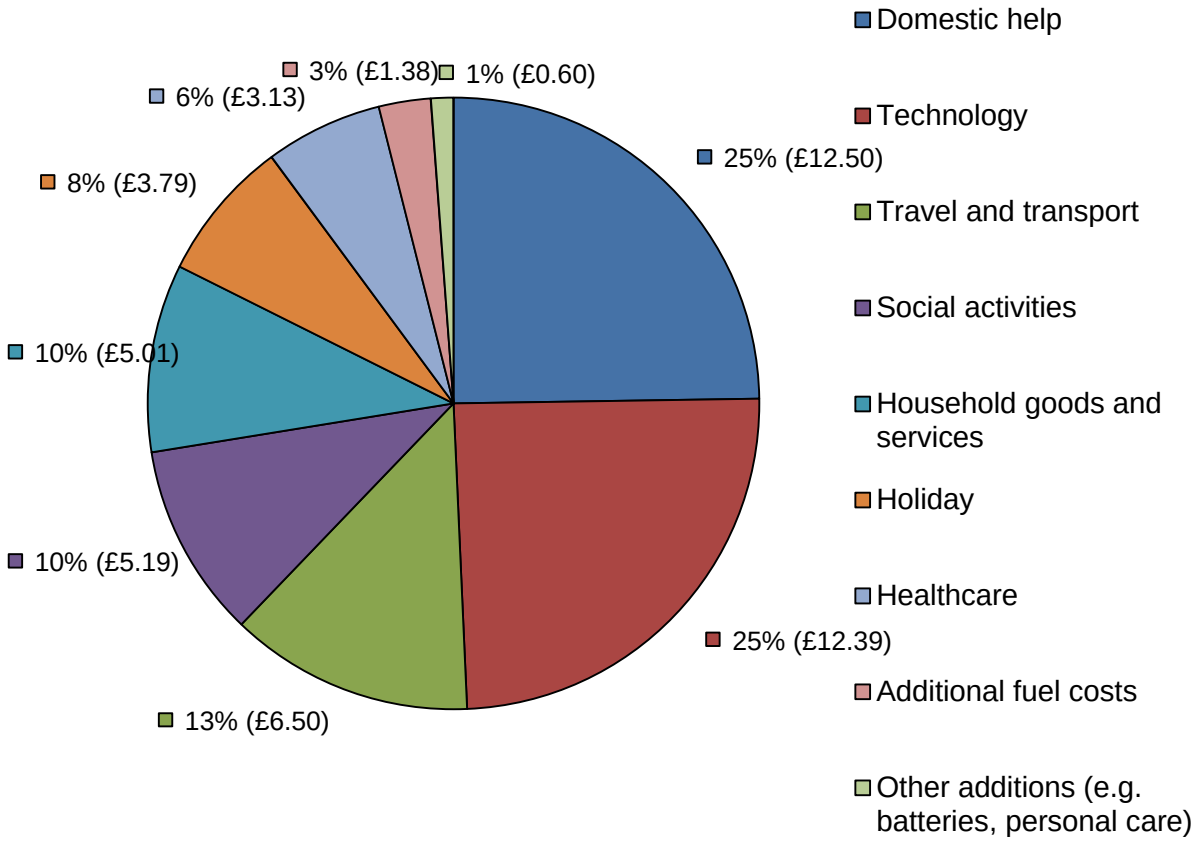
As mentioned above, additional electricity usage is estimated to add £72 a year to electricity bills.

The impact of additional needs on weekly budgets

In total the weekly budget needed to provide a minimum socially acceptable standard of living is £50.49 more for a single working age adult, living alone, who is eligible to be certified as sight impaired than for a single working age adult who has no visual impairment. This adds a quarter (25 per cent) to the standard budget, not including rent, of £198.60 a week, bringing the cost for a person who is sight impaired to £249.09 a week. The total weekly budgets are provided in Annex A.

Figure 1 puts the weekly costs described above into percentages and shows that the additional needs of someone who is sight impaired have cost implications across a range of different areas. The need for a wider range of technology to enable communication and facilitate access to written materials accounts for a quarter (25 per cent) of the additional cost. A further quarter (25 per cent) of the additional costs relate to the addition of a cleaner/domestic help once a fortnight. Extra transport and travel account for 13 per cent of the additional costs. Increases in the amount allocated for social activities accounts for 10 per cent and the additional cost of hotel holiday accommodation account for eight per cent. The need for additional lighting, different flooring and seating, and other household goods and services accounts for a further 10 per cent of the additional costs. Six per cent of the additional budget is for health care costs, and extra fuel cost accounts for three per cent.

Figure 1 Components of additional costs for single working age adults who are sight impaired



Conclusion: the scale and nature of additional requirements for people who are sight impaired

The above analysis shows that while no one item adds dramatically to the minimum cost of living for a single working age person who is eligible to be certified as sight impaired, overall costs add up to around a quarter more than for someone who is fully sighted. The findings have underlined the very wide range of aspects of people's lives that contribute to this – ranging from the use of appropriate mobile phones to employing a cleaner, taking more taxis and buying a drink or meal for a companion from time to time.

One notable feature of this is the way in which advances in technology are changing opportunities and requirements for people who are sight impaired. One aspect of this is that additional products such as audio labelling pens and talking scales can make life easier at a relatively modest cost. The other, however, is that mainstream technologies such as iPhones can increasingly be used to create various forms of aids for visually impaired people (see also Jewell and Atkin, 2013). Furthermore, the use of technology and other items outlined in this research can help people who are sight impaired to use the sight that they do have to best effect (for example, using IT software, a magnifier, or having appropriate lighting). This highlights that, while extra costs can be incurred, the positive impact that this has on people's lives can make a huge difference to living with sight impairment, their levels of functioning and maintaining independence.

A considerable advantage of the method used in the present research to

quantify additional costs is that it consults people not just on what items are needed but on how frequently they would need to be bought. This is significant in showing that various items that may appear to add significant costs are in fact rather cheap when considered in cost per week of their lifetime (although in practice finding the finance to buy a large item can be difficult, even if its long duration makes the eventual cost per week small). On the other hand, items needed regularly – such as a cleaner for two hours every two weeks - can add much larger amounts on a recurring basis.

Chapter 4 The minimum cost of living for a single person who is Deaf

This chapter looks at the areas of minimum costs that have been identified as differing for someone of working age living on their own who is Deaf, compared to the minimum for an equivalent hearing person. It starts by reporting what Deaf groups identified as additional needs, and why, and then goes on to add up their cost. As described in Chapter 2, the Deaf case examined was of someone who is profoundly deaf, using BSL, and represents the needs of a culturally Deaf person.

The following findings describe what were thought to be additional and different requirements for such a person, as well as a few cases where items needed by a hearing person were not needed by someone who is deaf. Throughout this section it should be noted that quotes are drawn from transcriptions of interpreters' verbatim accounts of discussions in BSL.

Visual alarms and security in the home

For people who are profoundly deaf, a starting point to having an acceptable standard of living was being able to feel secure in their homes. Thus, several items seen as vital to safety and security were included as additional to the main MIS household budgets.

Alarm / alerting system

All groups agreed that a warning alarm system alerting them to the fire / smoke alarm and to the doorbell was essential for the safety of someone

who cannot hear the noise of a standard alarm. This would include a portable vibrating pager or flashing light unit, and a vibrating pillow pad for use at night. Many of the participants had had such alarms installed in their homes for some time. Older versions, connecting to the mains lights, have been discontinued, so it was agreed that the budget should include a currently available model with individual preference as to whether this is a pager or flashing unit. Having identified this as a need, there was then an issue about whether it would be provided for free by social services. While this is commonly the case and reflected participants' experiences, it is not a statutory obligation. There was some uncertainty (in one group) whether this was still the case or whether in some cases it would need to be bought privately if being replaced, or in the future. On the other hand, subsequent enquiries of social services departments carried out by the researchers showed that in general such an alarm would be provided. This item was therefore not included in the Deaf budget, but is classified as **normally publicly provided,** with the extra cost of private purchase specified separately.

Burglar alarm

A burglar alarm, which is not included in the main MIS budgets, was seen as essential for security and to provide a person who is Deaf and living alone 'peace of mind' in their home. Participants explained that deafness can make a person feel vulnerable through fear that they would not be able to hear an intruder should one break in, but also that being Deaf might make them potential targets.

"Deaf people are worried about burglars, maybe people have watched the house and recognised that there are Deaf people living there. A lot of Deaf people have been suffering because actually they've had things

burgled from their homes. Two times in six months our house has been burgled. If we're outside signing then people can see that we're Deaf, they know that we're Deaf, they watch our homes and we're vulnerable, we're easy to break into because we might be out or we might not hear anything." (Group 3)

Some main alerting systems have a device that can be used with a standard burglar alarm and therefore connected to the pager / flashing unit making them useable for people with hearing loss. This was seen as a cost that would need to be met by an individual, rather than any social services provision and therefore added to the budget.

Window blinds

Linked to the issue of privacy within the home, groups discussed and agreed that a vertical blind at the window could better guard against being seen from outside than the net curtains provided in main MIS. This also related to the fact that lights might be on when Deaf people are in and using sign language or lip reading. A budget to allow the choice of a ready-made vertical blind, that can be angled to let in light but afford privacy, was therefore included in the living area and bedroom.

Alarm clock

There was also agreement that a vibrating / flashing alarm clock specifically designed to alert people with hearing impairment was required, replacing the standard alarm clock in the main MIS. There was discussion about using a mobile phone instead but this was reconsidered after concerns were raised about sleeping with it under the pillow (in order to feel the vibration) regularly. Although there was an awareness that Social Services might provide this equipment, and had in

the past, there was concern that this was something subject to Government cut backs and, that while it might be available in some areas, people were more likely to have to fund this themselves. This is therefore included in the budget as a **sometimes publicly provided** item.

Communications technology and computing

Participants specified a number of ways in which they need to access different kinds of technology to hearing people, primarily related to communication.

Mobile phone

The main MIS includes a basic smart phone and £10 a month contract. The clear message across the groups was that a better specification smart phone, specifically an Apple iPhone, should be included in the budget. While for a hearing person this might be seen as a 'nice to have', the groups outlined how, for someone who is Deaf, a good quality smart phone is actually a necessity. It is required in order to 'participate in society', as specified in the MIS definition of minimum. The iPhone was generally considered the most suitable in terms of quality and reliability – having a clear picture that did not freeze; reliability was seen as important, as people could not afford to be 'let down'. But of particular value are features that provide accessibility and ease of communication for someone who is Deaf, such as a front and rear camera to enable signed conversations with Skype, and in particular Facetime. People described how useful this was as an 'instantaneous' means of communication with others, and also helpful where someone may not be so confident using written text. The 4S model or above was

considered appropriate as it allowed Facetime to be used when out and about and not connected to WiFi.

“It’s important to have an iPhone because they’ve got Facetime…You can use Facetime to go, ‘right we’re going to meet at the pub’, for example, and actually have that conversation and get there. If you were texting it would be even slower and waiting for replies and it could be like an hour before you get your text back saying, ‘meet in town’.” (Group 3)

The groups also made changes to the contents of the monthly mobile phone package. They did not require the minutes allowed for voice calls, but on the other hand needed a large (unlimited) data download allowance in particular to use Facetime. This meant a package costing an additional £17.99 a month (which also includes the more expensive phone). However, groups were clear that such an extra cost is ‘not a luxury’ because it made instant communication so accessible to Deaf people.

Landline phone

The main MIS for a single working age person no longer includes a landline phone as people have agreed that just a mobile is now sufficient for a minimum need (this exclusion dates only from 2014). There was some discussion among groups about whether to include a Minicom / text phone in the home. A few people felt that it could be useful, for example, in an emergency or to make appointments. However, there was a general feeling that it was a slow means of communication, calls could be expensive and it was seldom used, especially by those who are familiar and confident with using a smart phone. The overall decision (bearing in mind the budget is for a person of working age) was not to

add a Minicom to the budget.

“People don’t really use the Minicom anymore. It’s kind of gone out of fashion, so we use the mobile and it’s much better, it’s instantaneous and you can get your text message so I really like that.” (Group 3)

Note, however, that the budget does still include the rental of a landline in order to get broadband access – see below.

Laptop and internet connection

Groups agreed that, as had been decided in the main MIS, a laptop computer was an essential item and particularly valuable for keeping in touch with friends who could be spread across the country. They felt that the screen size would need to increase (from 11 inch in main MIS) to 15 inch in order to more easily communicate by sign language on line, for example, using Skype or ooVoo.

“I’d prefer 15 inches because I think that’s more comfortable otherwise it’s quite small and it’s watching somebody that’s signing very tiny. You know I prefer it because I think it’s more comfortable on the eye. Hearing people obviously they only look and they just talk at the screen so that might be fine for them, but obviously for signing you need a bit more space. It can be a bit more of a problem as well if it freezes or something and the speed of the laptop as well. Sometimes it freezes and that’s something to be considered as well.” (Group 1)

The main MIS included a dongle for internet connection. However, all groups felt that this should be changed to a broadband line. They stressed that having a fast and reliable connection was really important

given the laptop/internet's role in helping people who are Deaf to keep in touch with each other.

Printing

The main MIS budgets acknowledge the fact that someone would need to print documents from time to time, and (for a working age person) includes £15 per year to go to a print shop / library etc. to do so as this works out cheaper than having a home printer. There were differing views among the groups as to whether a printer should be included at home, and it was pointed out that it is becoming more common to use downloads to phones to show as evidence. When the cost efficiency of using a print shop was explained to people, some felt that this would be sufficient. However, it was also felt that having home printing would be useful for someone who is Deaf. This was because they could more easily print off documents, for example travel bookings, to show and not have to think about how they explain something or are understood by a third person to do so. For this reason a print at home option is included in the budget.

Household bills

There was a feeling across the groups that household electricity costs were likely to be higher for someone who is Deaf compared to a hearing person for a number of reasons. First was the need to have lights on more often in order to see clearly when signing or lip reading at home. Second, groups felt that Deaf people were likely to have more electrical equipment, and items in use and / or on charge. This includes running equipment such as the alarm system, pager and the alarm clock, but also people felt they made greater use of laptops and mobile phones, as

this was their main means of keeping in touch with friends, finding information and entertainment. Hence it was important to keep these items fully charged, which for example, could involve charging a phone twice a day. As explained by one participant:

"Obviously they're using laptops more, you know it all adds up so it's more expensive for a Deaf person because of what they use .... Because you can't hear the radio or can't find out information. Obviously if you're by yourself you're lonely and you need something to do, so that's why you would use your laptop more. And also to talk to friends as well so that's why we use the laptop." (Group 2)

A calculation for this project by a fuel expert estimates that additional electricity costs based on this extra usage adds up to £50 a year.

Interpreter and personal assistance support

By far the most expensive additional item required by Deaf people, in terms of week to week costs, is the use of an interpreter. Groups discussed how the cost of some interpreter time would be covered by service providers but some would need to be funded by the individual.

Service providers have a requirement under the Equality Act 2010 to make reasonable adjustments to ensure that their service is accessible to disabled people, for example by providing an interpreter. Groups noted that some services, in particular hospitals, doctors or dentists often provided an interpreter for appointments and agreed that, in theory, and in accordance with legislation, such interpreter provision should not incur a cost to individuals. However, people did talk about difficulties

with this ‘free’ provision and related their experiences of where it had not worked in practice, such as if it was a short notice appointment, if an interpreter was not available, or if the service was running late and the interpreter had another appointment (reflecting other research, see Lacey-Davidson, 2012).

Furthermore, many services fail to meet their legal duty to pay for an interpreter and in some cases it may not be considered a reasonable adjustment for the service to make this provision. Reflecting this, groups felt that in some circumstances interpreter costs were unlikely to be covered by a service provider and would end up being funded by the individual so a cost for this is included in the budget. For example, people talked about paying for an interpreter when seeing a solicitor, visiting a passport office or doing training. It also related to if someone wanted an interpreter for what they described as more personal or ‘private use’, such as visiting a travel agent to discuss booking a holiday, going on a trip, or attending a workshop where, given their experiences, they thought that an individual would need to arrange and pay for an interpreter themselves.

“I know if I have to go to a solicitor they won’t pay for an interpreter. Like say if a Deaf person wants to sort out their will they have to go to the solicitor’s to make a will and the Deaf person might have to pay for an interpreter to go…. a hearing person goes they just have to pay for the solicitor and that’s it.” (Group 2)

It was quite hard for the groups to decide on the amount of time or hours that someone might require as much would depend on an individual’s circumstances and what they might need an interpreter for. They

explained how it would vary, depending on the type of appointment or event, it could be drawn on in an ‘emergency’ if a service provider did not supply an interpreter, or could be split between others if used in a group situation such as booking an interpreter for a trip. Groups agreed to include 10 hours a month interpreter time in the budget based on the understanding that this might be drawn on less in some months and ‘banked’ and used more in others (this does not include any interpreter costs associated with employment which should be covered by Access to Work provision).

People’s views about the cost of interpreters ranged from £30-£60 per hour and they noted that there could be a minimum booking time with examples of charges up to £100 or £150 even if an appointment only lasted one hour. Furthermore, they stressed the importance of having a fully qualified interpreter which they felt was likely to be reflected in the rates. The budget used to calculate the minimum reflects the common practice of agencies - £50 an hour, plus travel expenses.

A further issue raised in all groups was that some Deaf people may have difficulties with reading and written text, and it was suggested that a personal assistant or support worker could be valuable. This was linked to communication, but the need here was for more general literacy and advocacy support. Groups explained that this would very much depend on the individual, their written or reading ability, and may also depend on if they have speech. They felt that the person carrying out this role would need to be able to sign in order to communicate with a Deaf person, and could also be someone who was deaf themselves. This could provide help, often in the home, with reading and explaining things, for example, understanding letters or bills, making phone calls for an

appointment or to query something / sort out a problem with a company that might otherwise be difficult. They could also help with communication if someone needed a service at home, such as a plumber, or electrician.

“It’s difficult if there was anything wrong with the bills, it’s difficult to phone to actually complain or discuss. Also, the English on all of the bills, you know, is just very complicated. Also, if there’s a mistake, you know, maybe I’ve made the mistake, it’s very difficult.” (Group 1)

The groups felt that the budget for 10 hours per month allocated to interpreter time could cover this type of role if someone required it. The cost could be less per hour than for an agency-arranged interpreter, but this would give people the option to draw on more personal assistance per month and therefore use the budget how it most suited them.

Hearing aid batteries

The only personal care items raised by groups as being something that could have additional cost implications for someone who is profoundly deaf was hearing aid batteries. There were differing views across the groups as to whether an amount should be included to cover this or not, given that they should be supplied free. However, concerns were raised as to whether this will continue in the future in the context of government cutbacks. While some people had no problem obtaining plenty of batteries from the hospital or GP surgery, including through the post, others talked about difficulties in getting enough or making long trips to the hospital. The decision was to allow a small amount to cover an ‘emergency’ supply a couple of times a year which could allow for the

cost of buying some if someone ran out or lost batteries or were unable to get to more supplies when they needed them. Groups made no other changes to budgets for personal and health care items (toiletries, medicines) and services other than interpreting/assistance (see above).

Social participation

Having a social life, getting out to meet friends and take part in activities was seen as very important across the groups, and increases were made to main MIS budget for social participation, (based on £20 a week for a single working age person to cover two activities), to £40 a week to cover four activities. Participants repeatedly noted the potential isolation felt by Deaf people and the need to get out of the house frequently, particularly for someone living on their own, to avoid the danger of becoming lonely and depressed. Groups stressed the value of social activities as being not just important for participation, but also for wellbeing.

“Don’t forget, if he’s Deaf it’s very easy to get very stressed at home. He’s very isolated, so you do want to go out.” (Group 3)

“[You need 3-4 activities a week…] just to get more energy and more activities and you know stop being bored, we don’t want them bored, we want to keep that person motivated.” (Group 3)

“Hearing people can go out and they’ve got so much, they’re open to so much information, so just generally walking and listening to people you’re learning things and you ‘ve got information all the time, you’re consuming that information. Whereas Deaf people sit in silence and

they learn things at a slower rate compared to hearing people…hence the reason why they need double the activity." (Group 3)

As well as commenting on the frequency of activities, participants discussed how similar leisure activities could involve different requirements for Deaf people – namely travel and planning.

Participants discussed activities such as swimming, playing or watching sport, going to the gym or the pub, and meeting friends, which would not necessarily incur extra costs because someone is Deaf. They also described other activities which were more specialist to Deaf people - for example, attending Deaf clubs and groups which were seen as extremely valuable for meeting others and sharing information. These can be wide ranging in a large city where people talked about a variety of groups and activities (pub, bingo, Muslim Deaf groups), but more limited provision in other locations where people had to travel in order to take part (see below). People explained how this would also involve going further afield to visit different clubs in the surrounding area or special events held nationally (with implications for the travel budget - see section below).

Furthermore, even where some leisure activities did make provision for people who were Deaf, such as interpreters at a theatre or subtitles at a cinema, this was often at limited times and involved travelling some distance. This meant that leisure activities of this type had to wait and be planned – people could not just go spontaneously.

Thus overall, social and leisure activities themselves could sometimes have similar costs for Deaf people as hearing people, but there needed

to be more of them, they might need to be carefully planned and chosen, and, as set out below, could add to travel costs. In relation to the view that social circles for Deaf people can be widespread, an additional £10 per year was also included to cover extra stamps at Christmas to post cards that could not be hand delivered.

Travel

The Main MIS single working age transport budget allows a bicycle, a monthly bus pass, £7 per week for a single taxi journey (for shopping or an evening out), and £100 per year to cover train or coach fares. Groups all agreed that the transport budget should increase for a Deaf person to allow for more frequent and greater distance travel than the Main MIS budget currently covers, and this was primarily linked to travelling for social purposes.

As outlined above, the budget for social participation and leisure was increased to allow for more activities per week. However, the key issue that impacts on the travel budget explained by the groups is that social circles and activities are more often geographically spread for someone who is Deaf than for a hearing person. Therefore, travelling to another town or city becomes necessary to enable participation and choice, for example, in order to visit a Deaf club, or to find a cinema showing a film with subtitles, as one participant explained.

“It’s very easy for hearing people to have access to all these different things very locally but it’s difficult for Deaf people, they have to travel to be in these different groups where they’ve got that full communication… He wants to be able to travel everywhere. You know it’s Deaf culture,

this is what we do as Deaf people, we travel all over the place." (Group 2)

The same applied to visiting friends, as someone noted, she knew of only four Deaf people in her area. Groups suggested budgeting for one train journey per week to another town / city, and a Disabled Persons Rail Card (to allow a third off ticket prices) - these costs could go towards coach or additional taxi travel if rail travel was not available to meet particular travel needs. Participants also felt that occasional longer journeys, for example, to an event in London should also be included, although thought that coach travel could be used as a cheaper option here.

The groups felt that, as in the budget for a hearing person, daily travel needs could be met by bus. Overall, this created a lower budget for bus travel, since a Deaf person can get a free bus pass for off-peak travel. The bus budget needs therefore only to include peak journeys, estimated at five per week for travel to work, college, appointments etc. Bus passes provided by some local authorities allow free travel at all times of day. In these areas the peak-time fare cost can be subtracted from travel budgets – a case of a **sometimes publicly provided** item. The groups did not feel that there was any need to change the number or type of taxi journeys that a Deaf person would need compared to the working age person in main MIS, however, they did add a small extra cost of £1 per trip. This related to additional time that they felt it may take to communicate with a taxi driver, who could potentially have the meter already running.

Holidays

The main MIS budget for a single working age person includes a one week holiday a year, based on half the costs of self-catering accommodation shared with a friend, plus spending money and transport costs. Groups saw no need to change the spending money or travel costs because someone was Deaf. However, they did think that the accommodation budget would need to allow for a different type of holiday. They explained that self-catering accommodation would need to include a vibrate-alert / flashing fire / doorbell alarm system, otherwise someone would need to rely on holidaying with a hearing friend. The feeling was that such self-catering accommodation would be hard to find and book and, in reality, meeting these needs would limit choice and add to the cost. Groups most often discussed holidays in terms of using hotel accommodation. They felt that hotels, in particular chain hotels, were more likely to be deaf aware and provide essential safety equipment such as an alarm / vibrating pillow pad. Groups talked about the benefits of going on holiday with a friend or in a group, but this was for company rather than for communication support, with the expectation that each person would have their own room and pay for their own accommodation. The budget is therefore based, as in main MIS, on a one week off peak holiday, but rather than self-catering it covers the price of hotel (single room) accommodation in a chain hotel.

Adding up the cost for a single person who is Deaf

Differences in costs identified are quantified by considering the price of items added or changed from the original MIS budgets, and where relevant taking out costs that do not apply to someone who is Deaf. In some areas of the budgets these additions and differences have had a

significant impact on the overall cost of this minimum basket of goods and services; in others while there may be notable differences in terms of the composition of budgets, the implications for overall costs are small.

The following are the differences between the MIS budgets for a Deaf single working age person, living alone, compared to a single hearing person, in descending order of cost per week:

Interpreter costs: £126.58 a week

This is by far the most significant additional weekly cost. It is based on 120 hours of interpreter time a year or 10 hours a month at £50 an hour. The calculation assumes that this will involve 40 occasions a year of three hours of interpreter time and includes £15 travel costs for each occasion, making an annual total of £6,600.

Regular social activities: £20 extra a week

The weekly budget for social activities for single working age adults in 2014 was £20 a week to cover the cost of two activities. The groups doubled this for someone who is Deaf to £40 each week to cover the cost of four activities in recognition of the importance of preventing social isolation.

Additional technology costs: £6.10 a week

The additional and different needs relating to technology are centred principally around enabling and easing communication. Table 5 shows how the costs associated with technology differ between single working age adults who are Deaf and those who are not. The most significant addition in terms of cost arises from replacing the cheap contract smartphone needed by working age adults with an iPhone 5C which

adds £4.14 per week. The inclusion of the landline rather than a dongle to receive internet makes a smaller weekly addition of £1.04, and the other computer costs include an extra 85 pence for printing at home and 7 pence for a larger screen laptop per week.

Table 5 The additional cost of technology

	Single working age adult	Deaf single working age adult	Cost of additional and/or different items
Mobile phone	2.30	6.44	**4.14**
Landline rental/broadband costs	3.68	4.72	**1.04**
Printing costs	0.29	1.14	**0.85**
Laptop	1.00	1.07	**0.07**
Total	**7.27**	**13.37**	**6.10**

Additional travel costs: £5.43 a week (minus £12 if local authority provides anytime bus travel to disabled people)

Although the differing transport needs of Deaf working age adults do bring with them additional costs, they are able to travel off-peak by bus for free. This saves them the £16.25 weekly bus pass that non-disabled adults need to buy. However, this is partly offset by the cost of peak-time bus travel, estimated at £12.50 a week. The cost of a disabled persons railcard and coach card was added to the budget. The effect of adding these is to reduce the cost of coach travel associated with the annual holiday as fares are reduced by one third and a reduction of

£33.33 annually in the £100 already included in the main MIS budgets for coach and rail travel. However, this saving is offset by extra costs included for the additional travel required for social activities for someone who is Deaf which added £9 per week. The overall additional cost for train and coach travel is £8.68 per week. An extra £1 per week was also added to taxi fares.

Table 6 The additional cost of transport and travel

£ per week, April 2014	Single working age adult	Deaf single working age adult	Cost of additional and/or different items
Bus pass and travel	16.25	12.00	**-4.25**
Taxi fares	7.00	8.00	**1.00**
Rail and coach travel costs including Disabled persons railcard and coachcard	2.67	11.35	**8.68**
Total	**25.92**	**31.35**	**5.43**

Annual holiday: £2.79 a week

The cost of a one week, off-peak, self-catering holiday in the UK for single working age adults in the 2014 Main MIS was £194.50 based on the principle that the cost of the holiday would be shared with a friend. As set out above, the groups changed the holiday specification for a Deaf single working age person to include one week accommodation in a chain hotel which was seen as more accommodating of specific needs.

This increased the cost of the holiday accommodation to £340 a year, £145.50 more than for single working age adults who are not Deaf.

Other goods: £1.17 a week (plus 49p if smoke/doorbell alarm not provided)

Because household goods have a long duration, their average weekly cost is small. The largest single household goods item is the burglar alarm (41p a week). Hearing aid batteries add 23p a week, and other items such as the vibrating alarm clock, additional batteries, extra stamps and replacing nets with blinds add less than 20 pence each per week. Note also however that it is assumed that the alarm system that includes the doorbell and smoke alarm alert is covered by local social services; were this cost to be shouldered by individuals this would add another 49p a week to the budget.

Additional energy costs: 96p a week

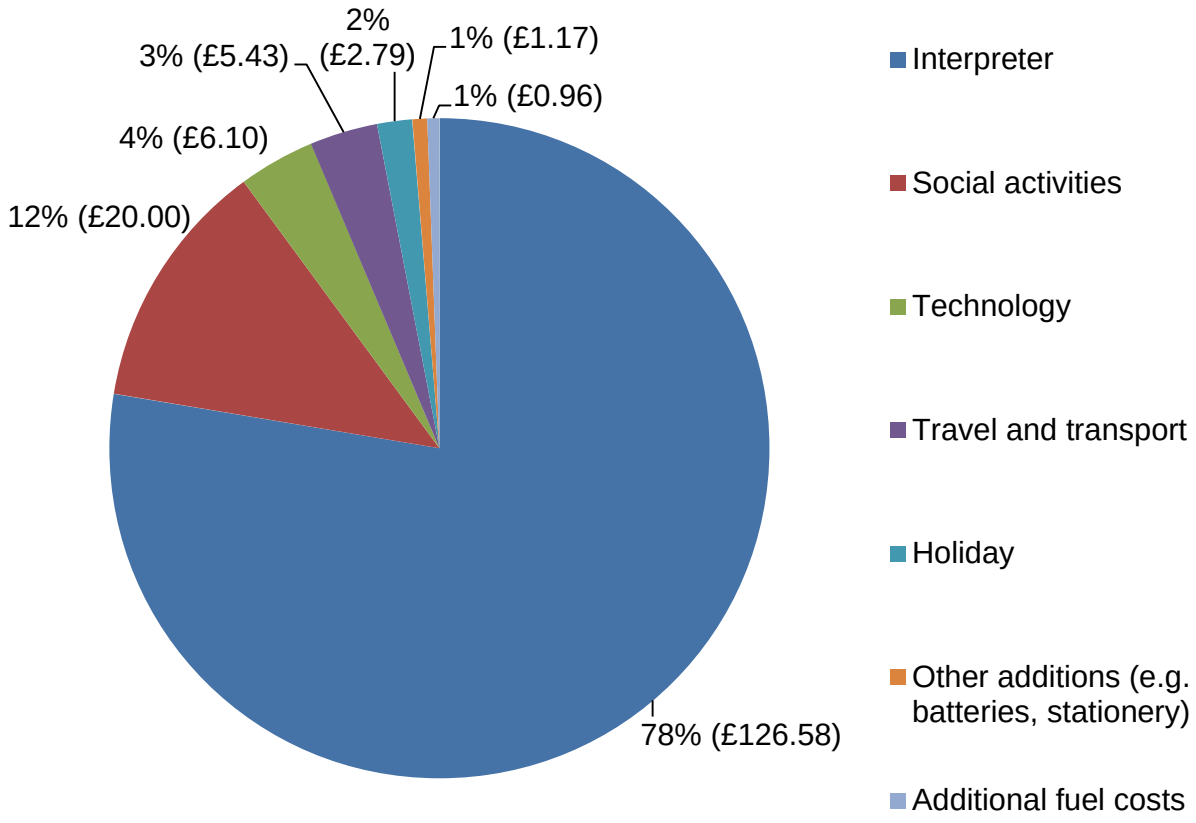
As mentioned above, additional electricity usage is estimated to add £50 a year to electricity bills.

The impact of additional needs on weekly budgets

In total the weekly budget needed to provide a minimum socially acceptable standard of living is £163.03 more for single working age adults who are Deaf than for single working age adults who are not hearing impaired. This compares to a hearing person's budget (excluding housing costs) of £198.60, and thus adds 82 per cent to the minimum cost of living as a result of being Deaf. The total weekly budgets for a Deaf person is thus £361.63, see Annex A. As shown in Figure 2, the overwhelming majority of the difference in cost is

accounted for through the addition of interpreter costs - these account for more than three quarters of the additional costs (78 per cent). Changes to the budget provided for social activities account for 12 per cent of the additional costs for Deaf single working age adults. Differences in other areas of the budget all result in smaller additional costs: four per cent on technology, three per cent on travel, two per cent on a holiday, and one per cent each for fuel costs and other household items.

Figure 2 Components of additional costs for Deaf single working age adults



Conclusion: the scale and nature of additional requirements for someone who is Deaf

The above analysis shows that it costs over 80 per cent more to cover minimum household costs as a single Deaf person than as a hearing person, of working age.

Despite the identification of various areas of a household budget identified as different for people who are Deaf, it is important to note that most areas of household spending requirements are no different than for hearing people. Basics of life such as food, clothing, furniture and most other household goods cost exactly the same regardless of one's hearing, and none of these categories were changed by Deaf groups in this research.

Some physical requirements such as alarms and technological equipment bring additional costs, although these are relatively small, especially when the lifetime of items is included. The bulk of the additional cost comes rather from spending on services and activities outside the home. By far the most important of these is interpreter costs, followed by additional costs of regular social participation. Together with extra travel and holiday costs, these items comprise 95 per cent of additional costs for people who are Deaf. Thus it must be concluded that while Deaf people need to spend similar amounts as hearing people on the physical necessities of life, being able to function in society brings a very large extra cost.

Chapter 5 Discussion and conclusions

This research has shown clearly how living with a disability can bring additional costs in reaching a minimum acceptable standard of living. It has examined these costs for two types of household: someone who is eligible to be certified as sight impaired (with some useable sight) and someone who is Deaf, both of working age and living alone. While these are only two examples among many, the research illustrates how additional costs can arise from a wide variety of sources, ranging from specialist equipment to adaptations in the specifications of everyday items like televisions and mobile phones to extra costs associated with maintaining social relationships. These costs can be seen not just in terms of meeting needs associated directly with a sensory impairment but also as providing opportunities: many are associated with supporting people to participate in society and maintain independence.

The scale of additional costs

The results show that the additional cost of disability can vary greatly from one situation to another. The sight impaired case considered gave rise to additional costs that add 25 per cent to a single person's weekly budget person, while the in the case of someone who is Deaf it adds 82 per cent. The most important source of this difference in this case is that the latter involves a one-to-one personal service – interpretation – which is extremely costly, so that even a modest quantity of this service is expensive relative to a minimum household budget. This reflects the findings of an earlier study of disabled people's minimum needs (Smith et al, 2004) in which the overall scale of additional costs was found to

depend to a great extent on the amount of personal assistance considered to be necessary as a minimum. It is essential in interpreting the results of this study to bear in mind that they do not directly compare the overall cost of sight and hearing loss, and they look at different levels of severity of impairment within each category – with the hearing loss case but not the sight impairment case at the more severe end of the spectrum. The assistance needs of someone with no usable sight or less severe hearing loss (not considered here) are likely to be different.

The findings of the present study also show that even without such costly personal assistance, the everyday cost of disability can be substantial relative to what a single person would normally have to spend to reach a minimum living standard. The case of someone who is sight impaired but has some useable sight demonstrates this well. Their additional costs are divided between: a) the cost of having a cleaner for two hours a fortnight, b) the cost of making life easier through various types of technology, c) additional costs incurred in social activities including going on holiday, d) additional travel, and e) a range of other extra household and personal expenses. Each of these on its own adds only between £6.50 and £12.50 a week to living costs, but between them they add over £50 to a nearly £200 weekly budget. In other words, being sight impaired does not produce any one very large weekly expense, but affects such a wide range of aspects of one's life that the overall extra cost is substantial.

Moreover, many of the additional costs identified by sight impaired and Deaf groups were not to pay for things directly arising from disability such as physical aids. Rather, they resulted more broadly from the lives that people with these conditions would lead - whether treating a friend

who has helped you out, paying for additional travel to get to appointments or social activities or paying a higher electricity bill because of the different usage of lighting or appliances. These costs were widely agreed on by people who knew what it was like to live day to day with particular sensory impairments.

Relationship to PIP assessments

The fact that a wide variety of additional expenses, other than interpreter services / personal support, none very large in itself, can make life much more costly for a disabled person is not well recognised by the benefits system. Personal Independence Payments (PIPs) are only available for people with a certain threshold of overall need based on a points system. The minimum threshold that must be reached to be entitled to the daily living component of the payment is a score of at least eight points across 10 different areas. Seven of these were not highlighted by groups as areas that would give rise to the kinds of additional costs encountered by someone who is certified as sight impaired: taking nutrition, washing/bathing, managing toilet needs, dressing, communicating verbally, engaging with other people and making budget decisions. Of the remaining categories:

- **Food preparation** can cause a sight impaired person to require some aids, as detailed in Chapter 3 above, likely to score 2 on the PIP scale, but a higher score would only occur for someone who needed supervision or assistance to prepare a meal.
- **Managing therapy or monitoring a health condition** can score 1 point if an aid or appliance is needed for medication, but would not score higher unless supervision were needed.

- **Reading and understanding signs, symbols and words** is likely to attract some score, such as 2 for requiring an aid or appliance (other than glasses) to permit reading, but a higher score is available only for those unable to read things at all or unable to do so without prompting.

This suggests that on the basis of the needs identified for the sight impaired 'case study' whose needs are considered in Chapter 3, a score above 5 in the PIP assessment is unlikely for Daily Living Activities: this is below the 8 needed for a benefit entitlement. On a separate assessment of Mobility Activities used to judge eligibility for the mobility component, the main qualifying criterion for this case would be being unable to plan the route of a journey or to follow the route of an unfamiliar journey without another person, assistance dog or orientation aid. For someone with some useable sight and no particular additional needs, like the case study considered in the research, it may be hard to show this to be the case.

This does not mean that nobody who is eligible to be certified as sight impaired (and has some useable sight) could be eligible for PIPs, since each person's needs are distinctive. However, the key point here is that some of the most substantial needs found to trigger substantial extra weekly costs for such a person - most notably the need for a cleaner and the spending on reciprocal costs for others (accompanying on holiday, social activities or to appointments) on interactions outside the home - are not recognised at all in the PIP assessment (see also RNIB, 2012). The consequence is that living can be substantially more expensive as a result of a disability, without money being available to help with these costs.

In the case of a person who is Deaf, the research also identifies additional costs unrelated to needs acknowledged by the PIP assessment. The most important is the additional cost of social participation, arising from needing to go out more often to avoid isolation and additional aspects of socialising such as having to travel further to access far-flung networks. On the other hand, a person who is Deaf is likely at least to be assessed at the 8 points given for needing 'communication support to be able to express or understand basic verbal information'. This however would trigger entitlement only to the standard rate of entitlement, £54.45 a week, which is well under half the estimated minimum cost of interpreters calculated in Chapter 4 above.

It must be concluded that there is a high risk of needs going unmet or only very partially met under the PIP system. The very precise specification of the limitations that have to be present to score points in PIP assessments makes it almost inevitable that there will be many areas where a disability creates additional costs that are not recognised. Nevertheless, evidence such as has been collected in the present study could help in future to adapt such a list to ensure that it more fairly reflects areas where costs occur, taking into account the scale of such costs. Some of the most significant costs that recur week to week are for items such as personal services or travel. Others, such as buying expensive equipment, can have a much smaller weekly cost but people on low incomes may find it hard to come up with the initial outlay, suggesting a different form of support than a weekly allowance may be more helpful. A better understanding of relative costs, across a range of disabilities and living situations could over the long term provide evidence that would allow an assessment system to become more

sensitive to what truly makes disabled people's lives more expensive.

Public provision

It is well beyond the scope of this research to comment on the extent to which public service provision, by local authorities and others, adequately meets the needs of disabled people. However, in order to assess the extent to which households incur additional costs as a result of disability, it has been necessary to make assumptions about what people need to buy privately that might otherwise be paid for or provided directly by a public body.

Most of the expenses identified in the present report involve items that disabled people would expect always to have to buy themselves. However, there were a number of cases where participants thought that in some areas public provision could cover this expense - although since this was not the norm, the items were still included in the budgets. These included some technological items whose cost worked out on a weekly basis tended to be low, of which the most significant were computer training and software which cost £3.49 a week between them. A much bigger weekly cost that could be saved as a result of local support was peak-time bus travel, which some local authorities include for free with a disabled person's bus pass. This could save £12 a week on the basis of the travel patterns assumed for both the sight impaired and Deaf case studies considered in the research.

In terms of the type of items that are normally paid for by local authorities but could not be taken for granted everywhere, only one was identified in this study: an alarm system giving people who are deaf a

visual alert of the doorbell and fire alarm. The cost of this was minor - 49p a week.

Thus while the 'localism' agenda could potentially cause minimum household costs for disabled people to vary greatly according to what different local authorities provide, most of the costs identified by the present study are not so far being affected by this. Having said that, the importance of the bus concession described above in itself demonstrates how even one public decision about free provision can have a substantial effect on the overall spending requirements of a disabled person.

Moreover, there is considerable potential for any cuts in current provision to have huge impacts on people's lives. Based on the present study, the most obvious way that this could be true concerns interpreter costs. People in the Deaf groups said that in general when they interact with public services, interpretation should be provided for free. Research has already shown, however, a decline in services for people with hearing loss: a 2012 survey found that 20 per cent of local authorities had already cut such services and 70 per cent were uncertain about whether they would do so in the following two years (Calton, 2012). Most local authorities in this survey used under-qualified interpreters in their services. Although all services, public and private, are required under the Equality Act to provide BSL/English interpreters for Deaf people as necessary, participants in our research described this provision as sometimes unreliable, unavailable or hard to access. This suggests that there is presently some unmet need, although not to the extent that Deaf people often have to pay for interpreter services themselves. Yet if service provision does continue to decline it is not

unforeseeable that they may need to do so in order to access a range of everyday goods, services and facilities.

One other related issue is of access to public and/or other provision, for example, through charities that can be a valuable source of equipment and services. The discussions in groups highlighted the variation in peoples' experiences, not only of what they had received, but of their awareness of potential resources available to them. The reasons are likely to be varied and depend upon personal circumstances, but having the knowledge about what could be provided was seen as key. For some participants a valuable asset was being involved in or having access to networks, for example, forums or events for visually impaired people. This is something that requires people not only to have the confidence to become involved, but also to have access to computers, and to be able to travel, bringing additional costs. As shown in this study, if people cannot afford to cover such costs, they can be less well placed to access the very resources that can provide support.

The scope for future research

This study has demonstrated that it is possible to estimate the additional costs that someone with a given disability in a given household type needs to cover in order to maintain a minimum acceptable standard of living. The research succeeded in building consensus among disabled people themselves about which additional items are needed in a given case. This only creates some initial points on a map of disability costs, but shows that it is feasible to fill in more details of this map using a robust and consistent method.

Among further issues that could be explored are:

- Differences along the range of impairment within the same general category. For example, what are the commonalities and differences in additional needs for people who have no compared to some useable sight?
- The difference that it makes to live with others compared to living alone. For example, which of the needs identified for a person who is sight impaired/Deaf would be the same or different if they were living with a partner and/or living with a child, and whether this other person also had a visual/hearing impairment or not?
- The difference in additional costs at various stages of life, for example how much would be spent on the additional needs of a child or someone of pension age who is sight impaired compared to a working age adult?
- The nature of additional needs associated with categories of disability other than sight and hearing loss, such as physical impairments or mental impairments that impact daily independent living skills.

While it would potentially take many years to cover each of these aspects in detail, the more dimensions of additional disability costs that can be studied, the more understanding of the true costs of disability can grow. For example, while the precise results of the present study only apply to two particular cases (which in themselves each represent a range of individual experiences), some general findings about the cost of sensory impairment, including the great importance of the cost of meeting social and not just physical needs, have wider relevance.

Such insights can potentially inform the way in which the cost of disability is conceptualised, and ultimately the shape of support through financial transfers and service provision that help people manage

additional costs. Disabled people themselves have always known that living day to day with a disability can be expensive. Quantifying the extent to which it adds to minimum costs and describing the range of items that produce these extra expenses is an important step in designing systems that help meet disabled people's needs.

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Annex A Tables comparing overall budgets

Table A1 Table comparing the overall budgets for the main MIS single working age adult and the budget for someone who is sight impaired

£ per week, April 2014	Single working age adult	Sight impaired single working age adult
Food	43.95	43.95
Alcohol	4.82	4.82
Tobacco	0.00	0.00
Clothing	6.76	6.76
Water rates	5.63	5.63
Council tax	15.34	15.34
Household insurances	1.16	1.16
Fuel	17.32	18.70
Other housing costs	1.92	2.88
Household goods	14.48	18.68
Household services	2.79	23.34
Childcare	0.00	0.00
Personal goods and services	13.56	18.73
Motoring	0.00	0.00
Other travel costs	26.45	32.95
Social and cultural participation	44.43	56.17
Total	**198.60**	**249.09**

This table using the Main MIS categories shows that there were no changes in the weekly budgets for food (£43.95), alcohol (£4.82), tobacco (£0.00), clothing (£6.76), water rates (£5.63), council tax (£15.34), household insurances (£1.16), childcare (£0.00) and motoring (£0.00). Categories that differed were fuel (+£1.38), other housing costs (+£0.96), household goods (+£4.20), household services (+£20.55), personal goods and services (+£5.17), other travel costs (+£6.50) and social and cultural participation (+£11.74). The total weekly budgets are £198.60 for the Main MIS single working age adult and £249.09 for a single working age adult who is sight impaired.

Table A2 Table comparing the overall budgets for the main MIS single working age adult and the budget for someone who is Deaf

£ per week, April 2014	Single working age adult	Deaf single working age adult
Food	43.95	43.95
Alcohol	4.82	4.82
Tobacco	0.00	0.00
Clothing	6.76	6.76
Water rates	5.63	5.63
Council tax	15.34	15.34
Household insurances	1.16	1.16
Fuel	17.32	18.28
Other housing costs	1.92	1.92
Household goods	14.48	15.13
Household services	2.79	10.46
Childcare	0.00	0.00
Personal goods and services	13.56	140.49
Motoring	0.00	0.00
Other travel costs	26.45	31.88
Social and cultural participation	44.43	65.83
Total	**198.60**	**361.63**

This table using the Main MIS categories shows that there were no changes in the weekly budgets for food (£43.95), alcohol (£4.82), tobacco (£0.00), clothing (£6.76), water rates (£5.63), council tax (£15.34), household insurances (£1.16), other housing costs (£1.92), childcare (£0.00) and motoring (£0.00). Categories that differed were fuel (+£0.96), household goods (+£0.65), household services (+£7.67), personal goods and services (+£126.93), other travel costs (+£5.43) and social and cultural participation (+£21.40). The total weekly budgets are £198.60 for the Main MIS single working age adult and £361.63 for a single working age adult who is Deaf.

In this publication, the terms ‘visually impaired people’, ‘blind and partially sighted people’ and ‘people with sight loss’ all refer to people who are either eligible to be certified as sight impaired (partially sighted) or severely sight impaired (blind).