

A minimum essential standard of living for a single adult with vision impairment

An NCBI and Vincentian Partnership for Social Justice report



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An NCBI (National Council for the Blind of Ireland) and VPSJ (Vincentian Partnership for Social Justice) research report.

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- Vincentian Congregation
- Daughters of Charity
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Chapter 1 Executive summary

Introduction

The goal of the current study, which is a pilot project, is to provide facts and figures on the additional needs and expenditure which people with vision impairment require in order to have a **Minimum Essential Standard of Living (MESL)**. To date research in Ireland has not provided this data. Reliable information on the additional needs and expenditure associated with disability is essential to ensure the adequacy of social transfers and related payments. The Consensual Budget Standards methodology (CBS) is used in the current study to determine the additional needs and costs associated with vision impairment. This methodology has been used by the Vincentian Partnership for Social Justice (VPSJ) since 1996 to develop budget standards for a range of household types in the general population and its existing data covers 90% of households.

The CBS methodology enables representatives of the household type under consideration to reach a socially negotiated consensus on the goods and services which a household type needs to allow for a **Minimum Essential Standard of Living**. This standard of living is one which at a minimum level meets physical, psychological and social needs. It is a standard which focuses on needs, not wants and enables people to participate in society. It is a standard for the whole of the population and is one below which nobody should be expected to live. In the current study the method is applied to single adults of working age, living alone whose level of vision meets the eligibility criteria for state benefits and have some useable sight.

Vision impairment

Research literature tends to be inconsistent in the use of the terms vision impairment and blind. An estimated 65 different definitions of blindness and low vision have been used in literature on the subject (Jackson et al, 2008). In general, both those that are blind and have low vision can be considered as having a vision impairment (Jackson et al, 2008).

The Government gives direction on the specific level of sight loss an individual must have in order to avail of state entitlements and benefits. The direction is usually linked to definitions and classifications recognised within that state's legal framework (Jackson et al, 2008). In the United States, the direction is for the most part referred to as "legal blindness" whereas throughout Europe definitions differ from country to country. In the UK, for example, there are two official levels of vision impairment "severely sight impaired" (blind) and "sight impaired" (NHS, 2015) and in the Republic of Ireland there is one. To be eligible for state entitlements in Ireland an individual must have "best corrected visual acuity of 6 / 60 or less in the better eye and / or a binocular visual field restricted to 20 degrees or less" (Citizens Information, 2016a). The current study establishes the **Minimum Essential Standard of Living** for a single adult with vision impairment with some useable sight, whose level of vision meets the eligibility criteria for state benefits. While not everyone who fulfils the entitlement criteria has useable sight, 95% of those who access the NCBI services have some level of sight (NCBI, 2016).

While vision impairment does not take a single form or exist at a single level it is possible to specify a level of impairment which is relatively well recognised. There is also a variation in personal living experiences and circumstances. However such variation does not preclude the capacity of people in these conditions to identify and discuss common needs and concerns.

In order to correctly identify the additional needs associated with vision impairment it was necessary to define in clear terms the actual level of the impairment and to construct a case study of an individual with the relevant level of vision impairment and to specify personal circumstances. For the purposes of the current study the term vision impairment is used throughout this report to refer to individuals whose level of vision meets the eligibility criteria for state benefits and have some useable sight.

The person in the case study was also described in terms of working age, living alone in rented accommodation on a bus route, in full time employment and in good health:

“Aoife / Michael is a single, working age adult, and has a level of vision which meets the eligibility criteria for state benefits and has some useable sight. She / he lives alone in a one bedroom rented flat located on a public transport route in an urban area. She / he is in good health and is employed full time.”

It is recognised that the needs of people with different degrees of vision impairment would require a separate study to adequately identify their needs and to take them into consideration when estimating additional costs. The costs associated with living in a rural area with limited public transport would also require specific study.

In the current study the budget standards were developed by people with vision impairment who best understand the needs associated with this particular disability. In groups they identified, discussed and reached a negotiated consensus on the agreed list of items and services needed to maintain a **Minimum Essential Standard of Living**.

This project is a collaborative study between the NCBI and the VPSJ. The social context is one in which the group ‘not at work due to illness or disability’ has a high at-risk-of-poverty rate (34.8%), deprivation rate (53.2%) and consistent poverty rate (22.4%) according to the latest Survey on Income and Living Conditions (SILC) figures for 2015 (CSO, 2017). The context is also one in which there is little recognition that a ‘general disability’ payment cannot allow for the expenditure associated with different types of disability and different levels of severity.

Methodology

The present study builds on the existing body of research undertaken by the VPSJ into the goods and services, expenditure and adequate income required by households and individuals in order to have a **Minimum Essential Standard of Living** (MESL). The Consensual Budgets Standards methodology (CBS) involves facilitating a series of focus group sessions with members of the public who represent the household type under consideration. The facilitation process is detailed, time consuming and transparent (the methodology is described in more detail in Appendix A). The methodology enables the development of a consensus within each group and across the groups about the additional needs which people with vision impairment require in order to have an MESL. It also facilitates the development of consensus about the rationale for the inclusion of additional goods and services. Experts are consulted as required – e.g. nutrition, household energy. Participants reach a socially negotiated consensus on the goods and services required in order to have an MESL.

Three different groups of people with vision impairment discussed in detail whether or not the existing MESL budgets, which had been developed for single adults in the general population who lived alone in rented accommodation, were adequate or needed to be changed in order to allow for different circumstances. In keeping with the previous research the focus was on 'needs and not wants'. Only items which were essential to meet physical, psychological and social needs are included in the lists of goods and services necessary in order to have an MESL. A fourth focus group known as the Check-Back group was established with the goal of rechecking items and costs identified by the three focus groups.

Participants of the focus groups were recruited by NCBI and were drawn from three locations – Dublin North, Dublin South and Cork. The facilitation process was identical with that used with the members of the general public in previous studies with particular attention paid to issues of communication and recording of discussions and decisions.

The cost of an MESL - main areas of household expenditure

The core costs of the MESL are the sum of the following 14 household budget areas: Food, Clothing, Personal care, Health, Household goods, Household services, Communications, Social inclusion and participation, Education, Transport, Household energy, Personal costs, Insurance, Savings and contingencies. In the current study housing costs are not included. For comparison purposes the type of housing in the current study is the same as that for the single adult in the main study – one bedroom rented apartment.

Budget costs

A Minimum Essential Standard of Living for a single adult with vision impairment cost €285.76 per week in 2016, €44.54 more than the cost for a single adult in the main MESL (€241.22).

The majority of budget areas are more expensive for a single adult with vision impairment than for the single adult in the main MESL, excluding Transport which is -€13.18 lower per week (due to the free travel scheme) and Personal costs which did not change in cost. As is the case with the single adult with full sight, the two most expensive budget areas in terms of total budget costs for the single adult with vision impairment are Food and Social inclusion.

The largest additional weekly cost for a single adult with vision impairment is in the Health budget which costs €11.54 extra per week (26% of the total additional cost), followed by Communication at €9.33 extra per week (21% of the total additional cost) and Household services costing €7.69 extra per week (17% of the total additional cost). The smallest additional cost for a single adult with vision impairment is in Household energy of €0.73 per week.

Differences in the items included in the baskets

The Minimum Essential Standard of Living for a single adult with vision impairment includes items that have not previously featured in the MESL budgets such as Household services like domestic cleaning, personal care services (apart from hairdressing which is also included in budgets for the general population) and online entertainment subscriptions.

Services required by a single adult with vision impairment, are the most expensive additional items in the MESL baskets on a weekly basis. The most expensive service is taxis amounting to €19.52 per week, followed by Communication services (landline and broadband package) costing €10 per week and Household services. People with vision impairment rely on the use of services such as these to live independently and to ensure tasks are completed which they cannot carry out themselves. These services help to make possible a **Minimum Essential Standard of Living** for people with vision impairment. There are a number of high cost individual items added to the budgets, the most expensive of which is the magnification software for use with the laptop. The longer lifespan of these items ensures that their weekly costs are put in perspective. In contrast, services need to be purchased more regularly and as a result add in a significant way to the cost of the weekly budget.

A single adult with vision impairment could have a number of eye conditions resulting in a range of physical, psychological and social needs. As a result, it was not always possible for the focus groups to agree upon specific items to suit an individual with vision impairment. For example, in order to deal with differences in need in relation to lighting it was agreed to identify and agree a sum of money which could be spent according to specific requirements.

In order to facilitate comparison with the original budget for the single adult, the housing and transport areas of expenditure are those specified in the original budget for the single adult living alone and are included in the description in the case study.

Household services which are the responsibility of the landlord are not included in the budget.

Conclusions

For obvious reasons the additional costs are the consequences of vision impairment. The findings show that the cost of an MESL is higher for a person with vision impairment than for members of the general population who have full sight. The cost of meeting many of the additional needs is relatively low. However, the accumulated costs add substantially to the weekly budget. While some of the costs cover specialised goods and services which are directly related to vision impairment other additional costs are associated with the need to ensure social inclusion and participation. The additional taxis and tokens of appreciation for the support of friends who make engagement in social activities possible, all contribute to the cost of an MESL. These and other additional expenses are not taken into consideration by decision makers when deciding entitlement rates.

This current study shows that it is possible to establish the estimated cost of an MESL for people with a particular disability in a specific household type. The CBS methodology proved successful in building a socially negotiated consensus among people with vision impairment living in an urban area. Further research could provide additional information on the needs and costs for people with different degrees and forms of vision impairment and for people with vision impairment who live in rural areas.

Chapter 2 Introduction

Background

The current study, which is a pilot study, provides facts and figures on the additional needs which people with vision impairment require in order for them to have a **Minimum Essential Standard of Living (MESL)**. This standard is one which meets an individual / household's physical, psychological and social needs at a minimum but socially acceptable level. Since 2006 the Consensual Budget Standards (CBS) methodology has been used by the VPSJ to establish the cost of an MESL for 90% of households in Ireland. The current study applies the CBS methodology to establish the cost of an MESL for people with vision impairment.

In 1999 a group of women in Cherry Orchard, Dublin asked the questions, “Will no one show the Government what it is like never to have enough to make ends meet? Will no one show them what it is like to live on social welfare or on the minimum wage? Will no one show them what people need just to have a decent life with dignity?”

This plea from people who struggled to make ends meet led to the work of the VPSJ to establish robust facts and figures on the expenditure needed for a **Minimum Essential Standard of Living**. At present the VPSJ data covers 90% of the population and is being used increasingly as a reference by policy and decision-makers, statutory groups and NGOs.

The questions which were voiced by the group in Cherry Orchard could very well be those of many people who have a disability. Watson et al (2016) in an analysis of the CSO Survey on Living and Income Conditions (SILC) data from 2004-2013 found that

during this period, working age people with a disability had the second highest at risk of poverty, basic deprivation and consistent poverty rates after lone parents. The latest SILC (2015) data shows that people not at work due to an illness or disability have deprivation rates of over 50% (53.2%). For this social group, there was also an increase in the at-risk-of-poverty rate (from 25.2% to 34.8% in the year to 2015) and the consistent poverty rate (increasing from 14.4% in 2014 to 22.4% in 2015) (CSO, 2017).

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted by the UN in 2006. The Convention aims to ensure that people with a disability enjoy the same human rights as everyone else and is the first international human rights treaty to clearly recognise the rights of all people with disabilities to live in the community as equal citizens (Parker, 2009). Article 19 of the UNCRPD contains a strong commitment to independent living for all people with a disability as it recognises “the equal rights of all persons with disabilities to live in the community, with choices equal to others” (UNOHCHR, 2006).

At the time of this study going to print, Ireland has not yet ratified the UNCRPD. However in 2015 the Government introduced a ‘Roadmap to Ratification’ which outlines the legislative changes to be undertaken to enable Ireland to ratify the Convention. Steps were taken in 2016 by the Government towards ratification by passing the Disability (Miscellaneous Provision) Bill 2016. However since the Convention was signed by Ireland in 2007 cuts have been made to supports that allow a person with a disability to live independently and to participate in society. These include closing the Mobility Allowance and the Motorised Transport Grant in 2013 to new applicants.

An adequate income is a vital and necessary step to reduce levels of poverty among people with a disability and to enable them to exercise their rights “to live in community, with choices equal to others.” To date in Ireland research has not been undertaken which uses the lived experience of people with a disability to establish the detailed costs of a disability and the subsequent income needed to maintain an MESL.

Current study

Previous research in the area of disability has shown that the additional cost of living with a disability differs according to the nature and severity of the disability (Indecon 2004, Hill et al 2016).

For some years attention had been given to advocating for a cost of disability payment. Disability takes many forms and it is difficult to see how one general payment could meet a range of very different needs. Understanding the cost of a particular disability is key to the provision of supports which meet the needs of people with a disability. The current study seeks to establish the additional needs and expenditure required by a specific group of people – people with vision impairment – in order to have a standard of living which is comparable to that of people in the general population who have full vision.

The decision to work with people who have vision impairment as a pilot project was based on the fact that vision impairment is a distinct and recognised disability. The recognition by the NCBI of the need for such a study and their willingness to collaborate was a second contributing factor to the decision. A third consideration emanated from the 2011 Census in which 12,180 people were recorded as being blind or as having a serious vision impairment in the labour force. Of these 3,598 were unemployed due to

having lost or given up a previous job (CSO, 2011). The findings evoke questions of income adequacy. How adequate is the income of people with vision impairment who for different reasons are unemployed? What is the expenditure they require in order to ensure a minimum acceptable standard of living?

Consensual Budgets Standards methodology

Consensual Budgets Standards methodology has been used by the VPSJ since 2006 to establish with members of the public the goods and services required by different household types to achieve an MESL. At present the VPSJ data covers 90% of the population. Groups of people drawn from the general population and from different socio-economic backgrounds in a facilitated process reach a socially negotiated consensus on the goods and services necessary to achieve this standard of living. Experts are consulted as required e.g. nutritionist, household energy consultants. People with the lived experience of the household type under consideration make the decision about what the household needs in order to have an MESL. The budget standards which are developed in the course of the group meetings provide a baseline against which the adequacy of social welfare transfers and minimum wage rates can be evaluated.

In addition to establishing the cost of an MESL for a range of household types in urban areas, the VPSJ established the needs of these household types in rural areas. The work in a number of rural locations, with a range of household types, demonstrated the appropriateness of the CBS methodology for use with groups

which have needs which are additional to those of other sections of the population. In the UK the Hill et al (2017) study which establishes the additional needs of people with vision impairment shows that the CBS methodology is effective in establishing the cost of a minimum standard of living, in allowing comparisons to be made, in identifying additional needs and in providing a benchmark against which to evaluate the adequacy of social transfers and minimum wage rates.

An MESL is one which meets an individual / household's physical, psychological and social needs at a minimum but socially acceptable level. It is one in which the focus is on needs and not on wants and is a standard below which nobody should be expected to live. This understanding of an MESL allows for differences in the ways in which needs are met. While there is an acceptance that people with a disability cannot live a life which is identical in all respects to that of people who do not have a disability, there is recognition that they have a right to equivalent / comparable goods, services, activities and opportunities which are needed in order to have an MESL.

Scope of the current study

The current study provides detailed information on the needs of people with vision impairment – individuals whose level of vision meets the eligibility criteria for state benefits and have some usable sight. These individuals are also described in terms of being working age, living alone in rented accommodation, on a public transport route in an urban area, in good health and working full time. It was decided to work with this household type because their additional needs are more directly derived from their vision impairment and not influenced by factors such as living in a household with family members who have full sight or

living in remote rural area with limited transport. It is recognised that further studies need to be undertaken to deal with other levels of vision impairment and different personal circumstances.

Chapter 3 Summary: methodology

A Minimum Essential Standard of Living

The current study seeks to establish the additional needs and expenses required by people with vision impairment in order to have a **Minimum Essential Standard of Living (MESL)** which is comparable to that of people in the general population. As mentioned in the Executive Summary an MESL is one which meets an individual / household's physical, psychological and social needs at a minimum level. While the focus is on needs not wants, it is a standard for everyone in the population and is one below which nobody should be expected to live. To date the Vincentian Partnership for Social Justice (VPSJ) has used the Consensual Budget Standards (CBS) methodology [1] to calculate the expenditure and income necessary to ensure this standard of living for approximately 90% of households in Ireland. The CBS method draws on the expenditure of people in real life on goods and services which everyone should be able to afford while at the same time drawing on expert knowledge about basic requirements and expenditure. The approach requires the establishment of focus groups for each household type. The following is an outline of the CBS methodology as used with people who have vision impairment in order to identify the additional goods and services associated with the main areas of household expenditure.

[1] The Appendix contains a detailed description of the Consensual Budget Standards methodology as implemented with members of the general public to determine the MESL for different household types.

Main areas of household expenditure

The core costs of the MESL are the sum of the following 14 household budget areas:

Table 1 Core MESL budget areas

| | | |
|----------------------|------------------------------------|------------------|
| Food | Household goods | Education |
| Clothing | Household services | Transport |
| Personal care | Communications | Household energy |
| Health-related costs | Social inclusion and participation | Personal costs |
| Insurance | Savings and contingencies | |

In the current study housing costs are not included. For comparison purposes the type of housing in the current study is the same as that for the single adult in the main study – a one bedroom rented apartment. In the main studies the core MESL costs specify the core minimum costs, and exclude housing costs (e.g. rent), categories of expenditure which may vary by employment pattern such as childcare, and also the effect of secondary benefits such as the medical card.

These additional costs (housing and childcare) and relevant adjustments for secondary benefits are included in the overall cost of an MESL in scenarios assessing a household type's minimum income needs and in the examination of the adequacy of social welfare supports and the national minimum wage.

Case study

In order to correctly identify the additional needs associated with vision impairment it is necessary to define in clear terms the level of the impairment and to construct a case study of an individual with the relevant level of vision impairment and with specified personal circumstances. For the purposes of this study the term vision impairment is used throughout this report to refer to individuals whose level of vision meets the eligibility criteria for state benefits and have some useable sight. The person in the case study was also described in terms of working age, living alone in rented accommodation on a bus route, in full time employment and in good health:

“Aoife / Michael is a single, working age adult, and has a level of vision which meets the eligibility criteria for state benefits and has some useable sight. She / he lives alone in a one bedroom rented flat located on a public transport route in an urban area. She / he is in good health and is employed full time.”

The description was accepted as meaningful and had been developed by the advisory group members, formed of the staff of the NCBI. It is recognised that this description of the level of vision covers a range of differences in sight. It does not offer an inclusive definition of a particular level of vision. Variations in ranges of sight made it difficult in a number of areas of expenditure to identify an item which would be relevant to all conditions of vision within the specification. Household lighting is an example where differences in needs emerge and it was agreed that instead of specifying a particular item e.g. lamp - it was proposed to identify a sum of money which would allow for differences in vision impairment to be taken into account.

The decision to focus on people of working age and who are living alone was seen as particularly suitable for a pilot project to identify the additional needs of people with vision impairment. As is the case in the general population the single adult living alone presents a more straight forward task. The situation of a pensioner couple with vision impairment or the situation of the person with vision impairment living in the family home, while offering possibilities for future studies, presents difficulties to the identification of goods and services, the inclusion of which is justified solely in terms of vision impairment. Age related conditions would impact on the needs of pensioners with vision impairment and the cost of living associated with living in the family home with fully sighted family members could make it difficult to isolate the specific needs and costs which refer only to the person with vision impairment.

Composition of the focus groups

Three focus groups totalling thirty participants were formed by the NCBI and located in three different areas – Dublin North, Dublin South and Cork. Because of the relative smallness of the population of people with vision impairment in comparison with that of people with full sight, the members of the focus groups were recruited by the NCBI and not chosen more randomly as in the case of previous studies with members of the general population. The greater majority of the participants reflected the criteria as specified in the case study. A small number (again due to the small population) did not do so at this point in time.

However until recently they had done so. For example a participant who had, until a short time ago, lived alone no longer did so because of rapid deterioration in vision. The three focus groups, known as the Task Groups, met separately on three different occasions in a series of three hourly facilitated sessions with the task of identifying the additional goods and services required by people with vision impairment. A fourth group – the Check Back Group - which was similar in composition to the Task Groups and was based in Dublin met for one three-hour session. The function of this group was to review the work of the Task Groups which resulted in the final socially negotiated consensus.

Task of focus groups

The focus groups are described in terms of the order in which they met: first, second and third. The task of the first focus group was to study the original budgets for members of the general population (similar in age, accommodation and employment but with full sight) which were established for each expenditure area. The members of the focus group then identified changes which they agreed as necessary in order to meet the needs of people with vision impairment as described in the case study. These changes took the form of additional items or the adaptation of existing items.

The second and third focus groups also became familiar with the content of the original budgets, related to members of the general population, and then concentrated on the changes proposed by members of the preceding group. The changes proposed by members of the first and second groups were then accepted or amended by the third focus groups. Justification of all changes and amendments were provided before decisions were made and a final consensus reached.

Stages of the work of 'Task' focus groups

Orientation stage – A shared understanding is developed of key concepts and principles e.g. MESL, needs versus wants, a socially negotiated consensus.

Study stage – Each of the 14 budget areas as presented in the original research (with members of the general population) is studied and discussed. Changes which are necessary in order to respond to the needs of people with vision impairment are identified and agreed. An initial negotiated consensus is reached regarding additional goods and services.

Review stage – Each focus group reviews the changes proposed by the other two groups and if necessary makes changes to the consensus reached in their specific group. The third focus group in light of the consensus reached by the first two focus groups make any necessary changes to the consensus reached by their group. A 'final' consensus is reached.

Check back group – Consider the 'final' consensus reached by the three Task Groups and identify any points for clarification.

Reaching consensus

When the focus groups had completed their task for each budget area, the researchers identified the consensus among the three groups about the changes to the original budgets which needed to be made in order to meet the requirements of people with vision impairment. In the rare occasion when a consensus was not evident the researchers identified the most frequently held view.

For the most part definite levels of consensus emerged in the course of the work of the focus groups about the additional needs of people with vision impairment. When there were differences in the specification of the additional or different items required to meet these needs the researchers based their decisions on the consensus reached in relation to purpose, functions / features and expectations. For example, participants in the focus groups identified the functions / features they required of a mobile phone and reached a consensus about the functions while differing on the specific model.

Costing of goods and services

In the course of their work the focus groups in the main MESL studies for each household type produced an itemised list of approximately 2000 goods and services which were individually priced in outlets identified by the focus groups. The items included in the main MESL for a single adult formed the basis of the baskets for the single adult with vision impairment. The costs for each item already in the basket in the main MESL were updated to March 2016 in line with the VPSJ MESL 2016 update which is based on a March-to-March cycle. The additional or newly replaced items for the single adult with vision impairment were priced in November 2016 online in the stores nominated by the focus group participants [2]. Household goods and services are included in the household expenditure and the household type is similar to that of the single adult in the main study.

[2] The prices of the new items were not backdated to March 2016 as the average inflation rate between March 2016 and November 2016 was 0% (CSO, 2016).

When the quantity of any items included in the main MESL was increased, the price for the item in the main MESL was used. Where possible, prices for additional goods already present in the baskets for other households were used such as the cost of the chiropodist visits which are included in the pensioner household baskets in the main MESL.

Chapter 4 Summary: literature review

Below is a summary of the literature review which can be found in full in the Appendix B of this study.

Defining vision impairment

Research literature tends to be inconsistent in the use of the terms vision impairment and blind. An estimated 65 different definitions of blindness and low vision have been used in literature on the subject (Jackson et al, 2008). In general, both those that are blind and have low vision can be considered as having a vision impairment (Jackson et al, 2008).

The Government gives direction on the specific level of sight loss an individual must have in order to avail of state entitlements and benefits. The direction is usually linked to definitions and classifications recognised within that state's legal framework (Jackson et al, 2008). In the United States, the direction is for the most part referred to as "legal blindness" whereas throughout Europe definitions differ from country to country. In the UK, for example, there are two official levels of vision impairment "severely sight impaired" (blind) and "sight impaired" (NHS, 2015) and in the Republic of Ireland there is one.

To be eligible for state entitlements in Ireland an individual must have "best corrected visual acuity of 6 / 60 or less in the better eye and / or a binocular visual field restricted to 20 degrees or less" (Citizens Information, 2016a). The current study establishes the **Minimum Essential Standard of Living** for a single adult with vision impairment with some useable sight, whose level of vision meets the eligibility criteria for state benefits. While not everyone who fulfils the entitlement criteria has useable sight, 95% of those who access NCBI services have some level of sight (NCBI, 2016).

The additional cost of vision impairment for an individual

Previous research has shown that the additional cost of a disability differs depending on the nature of the disability, as well as the severity (Indecon, 2004 and Hill et al, 2016). Yet others have emphasised that the burden of a disability felt by an individual cannot be evaluated by simply defining a person's level of disability, as individuals make a personal response to coping with their condition (Owsley et al, 2007, Mac Cobb, 2012).

A range of factors can influence the burden of vision impairment experienced by an individual such as: the life-stage and timing of vision loss; the cause of the vision loss and the extent to which a person with vision loss aspires to be independent. Consequently, the additional cost of vision impairment can be highly individualised and differ from individual to individual regardless of their level of sight (Gravitas, 2006).

The current study establishes a realistic additional cost of vision impairment faced by individuals in Ireland in daily life based on a detailed list of items agreed upon by individuals with lived experience of vision impairment. It identifies the additional cost of a specific disability at a minimum level, using Consensual Budget Standards methodology. Other studies in Ireland have established the cost of a disability using estimates and standard of living approaches. Previous research has focused on establishing the additional cost of a disability using three main approaches: Direct Survey Approaches (DSAs), Expenditure Diary Approaches (EDAs) and Indirect Approaches (IAs) (Cullinan et al, 2008).

The Direct Survey Approach (DSA) involves asking individuals with a disability to compare how much they spend on specific expenditure items to the expenditure of an individual in the same situation without a disability (Cullinan et al, 2008). Any additional costs are aggregated to give an estimate of the total extra costs arising from a disability. However, as cited by Cullinan et al (2008, p.5) Berthoud et al (1993) argue that the DSA method is unlikely to provide accurate estimates of the additional costs of disability, as it may be difficult for respondents to accurately estimate their own expenditures and those of an individual in the same situation without a disability. The use of the Consensual Budget Standards methodology in this study means firstly, the participants are not estimating expenditures but agree upon detailed item lists which are then priced. Secondly, the participants do not have to estimate the living costs of an individual without a disability, as the list of items already agreed upon by members of the population in the main MESL is used as a basis, to which additional items are added.

The Expenditure Diary Approach (EDA) is another method of directly identifying the additional cost of a disability. It involves analysing detailed measurements of expenditure for a sample of people with a disability, compared with expenditures for those without a disability. There are some limitations to this method as the effects of the different nature of disabilities and the level of severity of disabilities on the additional cost of a disability are lost through averaging costs (Cullinan et al, 2008). In addition, the EDA method does not account for every item needed in daily life such as a taxi fare for a person with a

disability to go shopping (Indecon, 2004). Establishing an MESL for a particular household involves examining every single item required in daily life, including taxis to the shop if this is necessary. The items that make up an MESL are based on the accurate, lived experience of the participants of the focus groups. The current study establishes the MESL for a single adult with a specific disability, vision impairment.

A third approach to calculating the additional cost of a disability for an individual is the Indirect Approach (IA) or the standard of living method. This is an indirect approach which assumes that income determines a household's standard of living and that for a given income there will be a reduction in the standard of living where additional needs arise due to a disability. The cost of a disability in this case is defined as the extra income required by a household of a person with a disability to achieve the same standard of living as an equivalent household without a disability (Cullinan et al, 2008).

Two studies in Ireland that used an Indirect Approach, the standard of living approach, to establish the cost of a disability (Indecon, 2004, Cullinan et al, 2008) found that the cost of a disability can be substantial and varies by the severity of the disability. Cullinan et al (2008) concluded that it is almost impossible for those with a disability to achieve the same living standard as those without disabilities and current policy in Ireland does not address the additional cost of a disability.

Hill et al (2015) also note the merit of the standard of living approach in making broad estimates of living standards experienced by households of people with a disability. However, the method does not establish the full scope of the additional costs faced by the individual, separate from the household (Hill et al, 2015). Instead Hill et al (2015) favour a budget-standard approach to accurately calculate the additional cost of a disability for an individual.

The Centre for Research in Social Policy (CRSP) at the University of Loughborough in the UK has established a Minimum Income Standard (MIS) for an individual with sensory disabilities (vision impairment and hearing loss) (Hill et al, 2015). The CRSP study provides an important resource for the current study and has demonstrated the merits of using Consensual Budget Standards (CBS) methodology when researching the additional cost of a disability. The CBS methodology produced an agreement among people who live with a disability on an extensive range of items they require in their daily lives to cope with their disability. The study underlines the importance of assessing separately the cost of different disabilities. The additional cost of an acceptable minimum standard of living for those with hearing loss and for those with vision impairment differ in line with the difference in the items required to allow for a minimum living standard in each case.

The CRSP has since established the cost of a Minimum Income Standard for a single adult of working age with severe vision impairment and a single pensioner with vision impairment and with severe vision impairment. They found the cost for a single adult with vision impairment increases with both age and the severity of the impairment. Hill et al (2017) explain that the higher costs result from the need for “regular human help” such as help in the home or using taxis rather than the cost of assistive equipment (Hill et al, 2017, p.9). The study also highlighted other factors that influence the cost of vision impairment such as the extent to which family and friends can provide an individual with help and a person’s ability to use assistive technology.

Chapter 5 Results

This section of the report presents the **Minimum Essential Standard of Living** (MESL) in 2016 for a single adult with vision impairment of working age and who lives alone.

The section deals with:

- I. The cost of the **Minimum Essential Standard of Living** in 2016 for a single adult with vision impairment.
- II. A comparison of the difference in cost of the **Minimum Essential Standard of Living** for a single adult in the main MESL budgets and a single adult with vision impairment in 2016.

Minimum Essential Standard of Living for a single adult with vision impairment 2016

Table 2 Comparison of the weekly cost of an MESL for a single adult with vision impairment and a single adult in the main MESL budgets in 2016

| Budget area | Main MESL € | Vision impairment € | Difference € |
|---------------------------|----------------|---------------------------|-----------------|
| Health | 6.25 | 17.79 | 11.54 |
| Communications | 9.39 | 18.72 | 9.33 |
| Household services | 2.88 | 10.57 | 7.69 |
| Social inclusion | 38.01 | 45.45 | 7.44 |
| Personal care | 13.04 | 18.28 | 5.24 |
| Education | 4.96 | 9.66 | 4.70 |
| Household goods | 5.61 | 9.16 | 3.55 |
| Food | 55.23 | 57.95 | 2.72 |
| Clothing | 9.83 | 11.98 | 2.15 |
| Savings and contingencies | 11.50 | 13.25 | 1.75 |
| Insurance | 6.17 | 17.05 | 0.88 |
| Household energy | 27.99 | 28.72 | 0.73 |
| Personal costs | 7.66 | 7.66 | 0.00 |
| Transport | 32.70 | 19.52 | -13.18 |
| Total | 241.22 | 285.76 | 44.54 |

A **Minimum Essential Standard of Living** (MESL) for a single adult with vision impairment in 2016 cost €285.76 per week, excluding housing costs. Overall, the additional costs for an individual with vision impairment add €44.54 more per week to the MESL budget for a single adult in the main MESL excluding housing costs (€241.22) [3]. The word 'main' is used to describe the MESL studies of the general population.

As is the case with the single adult in the main MESL, the two most expensive budget areas for the single adult with vision impairment are Food and Social inclusion. The majority of budget areas cost more for a single adult with vision impairment than for a single adult in the main MESL, excluding Transport which is -€13.18 lower per week and Personal costs which did not change in cost [4].

Table 1 lists the additional weekly costs in the core budget areas of an MESL from the largest to the smallest. The largest additional weekly cost for a single adult with vision impairment is in the Health budget which costs €11.54 extra per week (26% of the total additional cost), followed by Communications which costs €9.33 extra per week (21% of the total additional cost) and Household services which costs €7.69 extra per week (17% of the total additional cost). The smallest additional cost for a single adult with vision impairment is in Household energy (€0.73 per week).

[3] This is the cost of an MESL for a single adult in 2016 minus the cost of water charges which have been suspended.

[4] Personal costs includes charitable donations, trade union membership and passport fees.

Differences in the items included in the baskets

The **Minimum Essential Standard of Living** for a single adult with vision impairment includes items that have not previously featured in the MESL budgets such as household services like domestic cleaning [5], personal care services (apart from hairdressing which is included the main MESL budget for the single adult) and online entertainment subscriptions.

Services required by a single adult with vision impairment, are the most expensive additional items in the MESL baskets on a weekly basis. The most expensive service is taxis amounting to €19.52 per week, followed by communication services (landline and broadband package) costing €10 per week and household services (cleaning and household maintenance) at €7.69 per week. Those with vision impairment rely on the use of services such as these to live independently and ensure tasks are completed which they cannot carry out themselves and which make possible a minimum standard of living. There are a small number of high cost individual items which were added to the budgets, the most expensive of which is the magnification software for use with the laptop. Yet the longer lifespan of these items ensues that their weekly costs are put in perspective. In contrast, services, which are purchased more regularly, result in a higher weekly cost over the year [6].

A single adult with vision impairment could have a variety of eye conditions resulting in a range of physical, psychological

[5] Different household types in the main MESL have a range of household services included in their baskets such as window and chimney cleaning.

[6] The weekly cost of the services in the budgets is the total cost of the services averaged over 52 weeks.

and social needs [7]. As a result, it was not always possible for the focus groups to agree upon specific items to suit an individual with vision impairment. For example, in order to deal with differences in need regarding glasses it was agreed to identify and agree upon a sum of money which could be spent according to specific requirements.

Differences in the cost of individual budget areas

Health

Table 3 Difference in weekly health costs for a single adult with vision impairment in 2016

| Items | Main MESL | Vision impairment | Difference |
|---------------------------|------------------|--------------------------|-------------------|
| | € | € | € |
| Eyewear | 0.00 | 5.74 | 5.74 |
| Over-the-counter products | 0.81 | 4.18 | 3.37 |
| Main care | 5.44 | 7.87 | 2.43 |
| Total | 6.25 | 17.79 | 11.54 |

[7] The adult is assumed to be in good health otherwise.

Health costs for a single adult with vision impairment are €11.54 higher per week than for a single adult in the main MESL budgets and account for the largest portion (26%) of their overall additional weekly living costs. The largest additional cost within the Health budget is €5.74 per week in the eyewear subcategory which includes glasses, sunglasses and prescription swimming goggles.

The focus groups assigned an amount of money to cover the cost of glasses. Due to the specific needs of individuals with different levels of vision it was recognised that it was not acceptable to include the cost of a particular pair of glasses. It also proved difficult to assign an agreed amount of money for lenses and frames due to the variation in eye conditions. The groups identified a possible range in costs for glasses and agreed that €400 would be the minimum cost in the range. groups agreed €400 would cover the cost of glasses for two years [8].

[8] From October 2017, individuals who have earned the required PRSI credits are entitled to a free eye exam once every two years and €42 towards the cost of glasses or an upgrade. Medical card holders are entitled to a free eye test and any necessary standard spectacles once every two years. In the case of the need for specialist lenses, the cost is also covered by the medical card. However, in the MESL core budgets, the full cost of items is included.

The focus groups reached a consensus that €175 should be added to the budget every two years to cover the cost of sunglasses. Once again, it was difficult for the groups to determine the exact pair of sunglasses that should go into the basket as the specification would vary depending on the eye condition. The focus groups stressed that sunglasses were an essential item for an individual with vision impairment as day light can affect a person's eye condition sometimes causing them pain and the cheaper sunglasses already included in the basket were not adequate for a person with vision impairment. Prescription swimming goggles were added into the baskets as it was important that someone with vision impairment could see in the water.

The second highest additional cost (€3.37) is in the over-the-counter products subcategory. The focus groups reached a consensus that €175 per year should be included in the budgets to cover the cost of additional over-the-counter health products required by those with vision impairment. Suggested products ranged from eye drops to first aid kits as the participants agreed those with vision impairment are more prone to falls or burning themselves when cooking. As it was difficult to determine the nature of the items and the exact amount required by individuals with different eye conditions, an agreed amount of money was allocated to cover the cost at a minimum level.

Main care [9] (professional care) is the most expensive subcategory within the Health budget for a single adult with vision impairment and a single adult in the main MESL, costing €2.43 more per week for the single adult with vision impairment. The higher weekly cost resulted from the increase in optician's visits to twice a year and the addition of two chiropodist visits per year.

The focus groups reached a consensus that the number of optician's visits should increase as they emphasised the importance of regular visits to the opticians for those with deteriorating eye conditions. The participants agreed that regular visits to the chiropodist were important for an individual with vision impairment as they were more susceptible to injuring their feet. Many who rely on walking as their main mode of transport, are unable to check on the condition of their feet.

The number of visits to the dentist and the GP did not change as the individual in the case study was in good health, however the focus groups emphasised that vision impairment was connected to health conditions such as diabetes that required individuals to visit the doctor more frequently.

[9] Main care includes the cost of doctors, dentist, chiropodist, optician's visits and prescriptions.

Communications

Table 4 Difference in weekly communications costs for a single adult with vision impairment in 2016

| Items | Main MESL | Vision impairment | Difference |
|---------------------|-------------|-------------------|-------------|
| | € | € | € |
| Internet / landline | 4.35 | 10.00 | 5.65 |
| Mobile phone | 4.64 | 8.32 | 3.68 |
| Post | 0.40 | 0.40 | 0.00 |
| Total | 9.39 | 18.72 | 9.33 |

Communications costs for a single adult with vision impairment are €9.33 higher per week than for a single adult in the main MESL budget and account for the second largest portion (21%) of their overall additional weekly living costs. The highest additional cost within the Communications budget is €5.65 per week for the internet and landline [10]. The participants reached a consensus that having a landline in the house would enable a person with vision impairment to feel more secure. In an emergency, when living alone, it can be easier to locate the landline phone than the mobile phone which can be mislaid. The broadband was added as part of the landline package as the groups agreed it was important to have a good quality internet connection when using the online subscriptions that were added into the Social inclusion budget. In addition the participants explained that the internet was an accessible source of

[10] A recent Comreg (2016) report found that broadband and landlines in Ireland are relatively expensive compared to other European countries. The average monthly broadband bill in Ireland is €35.44 and the average monthly landline bill is €32.47 compared to bills of €28.11 in the UK and €23.62 in Denmark.

information for those with vision impairment when used with magnification software on the laptop and the accessibility features on smartphones.

The cost of the mobile phone subcategory is €3.68 higher per week for a single adult with vision impairment as a smartphone has been included in the budget, replacing the basic mobile in the main MESL budgets. The focus groups reached a consensus that an individual with vision impairment required, at a minimum, a ‘high-end’ smartphone with the following accessibility features: a large screen, ability to enlarge the text, voice assistance and a camera. The iPhone 6, while not the newest Apple model, was added to the budget as the groups agreed it was an acceptable minimum ‘high-end’ smart phone that has the required accessibility features as specified by the focus groups. This model also corresponds with the three-year lifespan agreed by the focus groups.

Household services

Table 5 Difference in weekly household service costs for a single adult with vision impairment in 2016

| Items | Vision | | Difference |
|--------------------------|-------------|--------------|-------------|
| | Main MESL | impairment | |
| | € | € | € |
| Cleaning and maintenance | 0.00 | 7.69 | 7.69 |
| Waste charges | 2.88 | 2.88 | 0.00 |
| Total [11] | 2.88 | 10.57 | 7.69 |

[11] The cost of Household services for the single adult in the main MESL is lower in this study than in the VPSJ MESL 2016 update as water charges have been removed due to their suspension in 2016.

Household services costs for a single adult with vision impairment are €7.69 higher per week than for a single adult in the main MESL budgets and account for the third largest portion (17%) of their weekly additional living costs. The only additional cost within the Household services budget is €7.69 per week for both maintenance and cleaning services. The focus groups reached a consensus that €200 per year was to be included in the budget to cover four deep cleaning sessions and €200 per year for maintenance services such as changing light bulbs etc. The participants agreed that the addition of these two services corresponds with the desire shared by people with full sight of being able to be house proud. The groups also emphasised that it was important for a person with vision impairment not to always feel dependent on family and friends for basic cleaning and maintenance services.

In the case study, the single adult is living in a rented one bedroom apartment which the groups took into consideration when adding items to the budgets. However, it was recognised by the groups that house ownership would result in additional maintenance costs such as painting and chimney cleaning.

There was no change made to the waste charges subcategory.

Social inclusion

Table 6 Difference in weekly social inclusion costs for a single adult with vision impairment in 2016

| Items | Vision | | Difference |
|-------------------------------------|--------------|--------------|-------------|
| | Main MESL | impairment | |
| | € | € | € |
| Holiday | 9.40 | 14.33 | 4.93 |
| Newspapers / books and magazines | 3.17 | 4.74 | 1.57 |
| Exercise and sports | 6.33 | 7.79 | 1.46 |
| Socialising | 15.58 | 15.58 | 0.00 |
| Household items | 3.53 | 3.01 | -0.52 |
| Total | 38.01 | 45.45 | 7.44 |

Social inclusion costs for a single adult with vision impairment are €7.44 higher per week than for a single adult in the main MESL budgets. The highest additional cost within the Social inclusion budget is €4.93 in the holiday subcategory. The groups reached a consensus that given the unfamiliar environment, it would be necessary for a person with vision impairment to stay in a hotel in the city centre rather than self-catering accommodation included in the main MESL budgets for a single adult. The central location provides easy accessibility and eliminates some of the burden of cooking in an unfamiliar kitchen [12]. The groups increased the holiday spending money by €50 to enable them to acknowledge the assistance of the person who accompanies them by paying for a meal or buying a gift.

[12] Breakfast is included in the cost of the hotel. According to the latest Hotels.com Hotels Price Index (March 2016) the average price of a hotel room in Ireland in 2015 was 15% higher than in 2014, this is the fifth year average Irish hotel prices have increased (Comiskey, 2016).

The second highest additional cost was in the newspapers / books and magazines subcategory of €1.57. The focus groups reached a consensus to replace the novels and DVD rentals included in the main MESL budgets with an annual NCBI online audio book subscription and a basic Netflix package. The participants explained that individuals with vision impairment needed to use a different means of enjoying similar entertainment to that which a person with full sight gains from books and DVDs and the subscription services provided this. It was recognised by the participants that Netflix could be considered a luxury item for the general population. The participants reached a strong consensus that in order for people with vision impairment to enjoy the entertainment shows readily available to people in the general population, it was necessary for them to have access to Netflix, which makes available a wide range of shows and movies featuring audio description [13]. At present, digital terrestrial television in Ireland provides audio description on TV programmes to a very limited degree.

The focus groups agreed that although libraries provide audio books the range of titles available was not equivalent of that for those with full sight and the NCBI offered more titles. The groups emphasised the importance, for social participation and inclusion, of being able to access the media and reading materials which are available to people with full sight.

[13] Audio description is a commentary that gives a viewer with vision impairment a verbal description of what is happening on the television screen, as an aid to the understanding and enjoyment of the programme. The technique uses a second sound track that gives a description of the scene and the on-screen action.

The exercise and sports subcategory is €1.46 higher per week for a single adult with vision impairment. The focus groups reached a consensus that a low-cost gym membership should replace the football included in the main MESL, as those with vision impairment would need to take part in accessible football which can be expensive and not widely available. They also emphasised the need for gyms to be accessible and some individuals with vision impairment may initially require a personal assistant. The removal of items such as football boots reduced to some extent the additional costs of exercise and sports.

Some of the additional costs in the Social inclusion budget for the single adult with vision impairment were offset by the lower cost of the household items subcategory (-€0.52 per week). This can be explained by the agreement of the groups to remove the digital camera and film processing from the budget as the iPhone now included in the Communications budget has a camera.

Personal care

Table 7 Difference in weekly personal care costs for a single adult with vision impairment in 2016

| Items | Main MESL | Vision impairment | Difference |
|--------------|--------------|-------------------|-------------|
| | € | € | € |
| Treatments | 0.00 | 5.22 | 5.22 |
| Cosmetics | 2.87 | 2.89 | 0.02 |
| Hygiene | 10.17 | 10.17 | 0.00 |
| Total | 13.04 | 18.28 | 5.24 |

Personal care costs for a single adult with vision impairment are €5.24 higher per week than for a single adult in the main MESL budgets. The highest additional cost within the Personal care budget is €5.22 per week in the treatments subcategory. The groups reached a consensus that the price of nail cutting on both the hands and feet every six weeks was to be added to the basket in addition to eyebrow shaping every six weeks for the female [14]. Throughout the work in the focus groups, participants emphasised that a person with vision impairment would be unable to safely cut their nails on their hands and feet and would need to visit a beauty salon for someone to do this for them. The participants acknowledged that an important psychological need for an individual with vision impairment is to have confidence in their appearance and in their ability to get the assistance they require.

The cosmetics subcategory is slightly more expensive for a single adult with vision impairment due to the addition of a magnifying pocket mirror for the female. The most expensive subcategory for both a single adult with full sight and vision impairment is hygiene and the focus groups did not make any change to the items in this subcategory.

[14] The treatments were priced in three beauty salons around Dublin and were then averaged.

Education

Table 8 Difference in weekly education costs for a single adult with vision impairment in 2016

| Items | Vision | | Difference |
|--------------------|-------------|-------------|-------------|
| | Main MESL | impairment | |
| | € | € | € |
| Computer equipment | 1.17 | 5.87 | 4.70 |
| Education course | 3.79 | 3.79 | 0.00 |
| Total | 4.96 | 9.66 | 4.70 |

Education costs for a single adult with vision impairment are €4.70 higher per week than for a single adult in the main MESL budgets. The only additional cost within the Education budget is €4.70 per week in the computer equipment subcategory. The additional items included in this subcategory are a larger screen laptop, magnifying software for use on the laptop, a handheld video magnifier and additional ink and paper.

The focus groups reached a consensus that a single adult with vision impairment would need a laptop with a larger screen (17 inches), which was of a high enough standard to operate the magnifying software required to use the laptop by an individual with vision impairment [15]. The groups agreed that magnification software should be added to the budget and emphasised that although the software was expensive and required regular updates, it is essential for those with vision impairment to be able to use a laptop in the same way as people with full sight. The group explained that the inbuilt magnification tools on laptops were not sufficient for those with vision impairment and software such as ZoomText offered a range of functions beyond

[15] The laptop included in the basket matched the ZoomText specifications for ZoomText 10.1, which was verified by the NCBI.

magnification that meets the requirements of different eye conditions such as colour inversion. The price of the ZoomText software includes free phone support and home visits for users.

The groups reached a consensus that a portable electronic magnifier would be required by an individual with vision impairment. This is a device that assists those with vision impairment to read menus or labels and thereby promotes independence. During the group discussions, it was made clear that there is a large variation in the magnification needs of individuals with vision impairment and it was agreed that a portable electronic magnifier would cover the needs of more people with vision impairment than the non-electronic magnifiers. The group explained that an individual would usually go to the NCBI for a consultation and advice on the most suitable magnifiers. Although the product is expensive the cost was put into perspective when seen in the context of a ten-year lifespan.

There is no change in the weekly sum of money allocated for an education course. However, the nature of the training course changed from an ECDL course to an evening course in Irish heritage or languages as the focus groups reached a consensus that the ECDL course in the main MESL budgets would not necessarily be accessible for a person with vision impairment without the correct software or support.

VAT relief can be claimed on certain assistive technology and low vision aids. However, the NCBI explained that taking the VAT off the cost of these products would not accurately reflect the cost of living for those with vision impairment. Individuals with vision impairment must pay the upfront cost of these items and, in the experience of the NCBI, tend not to claim the VAT as the forms are difficult to complete.

Household goods

Table 9 Difference in weekly household goods costs for a single adult with vision impairment in 2016

| Items | Vision | | Difference |
|-------------------------------|-------------|-------------|-------------|
| | Main MESL | impairment | |
| | € | € | € |
| Lighting | 0.05 | 1.54 | 1.49 |
| Kitchen and hardware | 0.41 | 1.29 | 0.87 |
| Home security | 0.00 | 0.52 | 0.52 |
| Appliances | 0.72 | 0.96 | 0.25 |
| Furnishings | 0.03 | 0.27 | 0.24 |
| Other household items | 0.29 | 0.45 | 0.16 |
| Stationery and goods | 0.31 | 0.33 | 0.02 |
| Textiles and soft furnishings | 0.55 | 0.55 | 0.00 |
| Cleaning and maintenance | 3.13 | 3.13 | 0.00 |
| Additional items for a female | 0.13 | 0.13 | 0.00 |
| Total | 5.61 | 9.16 | 3.55 |

Note: The difference in the totals is due to rounding within the subcategories.

Household goods costs for a single adult with vision impairment are €3.55 higher per week than a single adult in the main MESL budgets. The highest additional cost within the Household goods budget was €1.49 to cover the cost of lighting.

The groups explained that lighting was an important feature of a household for those with vision impairment and the lighting needs of an individual can vary greatly depending on their eye condition. The groups agreed to include an amount of money for the lighting in the rooms as follows: €30 for the bathroom, €50 for the hallway, €70 for the bedroom, €100 for the kitchen and €150 for the living room. The amounts of money included cover the special fittings and light bulbs required to last five years, as lighting needs may change depending on the degree and nature of a person's vision impairment.

The kitchen and hardware subcategory is €0.87 higher per week for an individual with vision impairment. There are a wide range of items designed to help an individual with vision impairment in the home to live independently but the groups agreed it was difficult to decide which items were necessary at a minimum as the items required depended on an individual's eye condition. The groups agreed to add a liquid level indicator, bumpons and talking kitchen scales. Bumpons (used to label items) assist those with vision impairment with carrying out daily tasks independently and the talking digital scales allow a person with vision impairment to cook independently. The number of chopping boards was increased by the groups as a person with vision impairment can contaminate foods more easily and a kitchen roll was added into the budget on the basis that those with vision impairment are more likely to spill items.

The home security subcategory is €0.52 higher per week for a single adult with vision impairment. The focus groups reached a consensus that individuals with vision impairment can feel more vulnerable in their homes and needed extra security measures to feel safe which include an intercom system and a house alarm. A wireless intercom and alarm system were added to the budgets,

both of which require minor installation and are portable if the individual moves house, as the individual in the case study is living in rented accommodation. The alarm set includes an outside siren as the groups agreed it was a necessary feature to act as a deterrent. The intercom includes a landline handset which offsets the cost of buying a handset for the landline added to the Communications budget.

The appliances subcategory is €0.25 higher per week for the single adult with vision impairment. The groups reached a consensus that an individual with vision impairment would need a larger screen TV (40 inches) and a large button remote. The additional costs in this subcategory were offset by the removal of the Saorview set-top box and the DVD player. The new television has Saorview built in and the DVDs in the Social inclusion budget were replaced with Netflix.

The furnishings subcategory is €0.24 higher per week for the single adult with vision impairment. The groups reached a consensus that additional items such as a shower rack for toiletries, a grab rail for the shower and a magnification mirror were needed to ensure that an individual with vision impairment could use their bathroom independently and safely. The groups also agreed to add blinds for every room to manage daylight which can affect certain eye conditions.

The other items and stationery subcategories are slightly higher per week (€0.16 and €0.02 respectively) for the single adult with vision impairment as: the torch in the main MESL budgets was replaced with a stronger beam torch for use when walking at night; the alarm clock was replaced with a talking alarm clock and a talking weighing scales was added to the budget. The pens were changed to markers and extra paper was added as

those with vision impairment find it easier to write with markers and require extra paper.

There were no changes made to the textiles, cleaning and the additional items for a female subcategories [16]. The cleaning and maintenance subcategory remains the most expensive weekly cost within the Household goods budget, due to the shorter life spans of the items included.

Food

Table 10 Difference in weekly food costs for a single adult with vision impairment in 2016

| Items | Main MESL | Vision impairment | Difference |
|--------------|--------------|-------------------|-------------|
| | € | € | € |
| Other | 9.75 | 12.47 | 2.72 |
| Food items | 45.48 | 45.48 | 0.00 |
| Total | 55.23 | 57.95 | 2.72 |

Food costs for a single adult with vision impairment are €2.72 higher per week than for a single adult in the main MESL budgets. The only additional cost within the Food budget is €2.72 per week to cover the cost of an extra takeaway each month. The additional takeaway was recognised as offering a further possible respite from the tasks of cooking and shopping which can be more arduous for people with vision impairment.

[16] The additional items for a female include a hair dryer and hair straighteners.

Clothing

Table 11 Difference in weekly clothing costs for a single adult with vision impairment in 2016

| Items | Main MESL | Vision impairment | Difference |
|----------------------|-------------|-------------------|-------------|
| | € | € | € |
| Footwear | 1.96 | 2.53 | 0.58 |
| Personal accessories | 0.27 | 0.79 | 0.51 |
| Jackets | 0.47 | 0.88 | 0.41 |
| Underwear | 1.85 | 2.12 | 0.27 |
| Dry cleaning | 0.19 | 0.37 | 0.19 |
| Clothing | 5.10 | 5.28 | 0.19 |
| Total | 9.83 | 11.98 | 2.15 |

Note: The difference in the totals is due to rounding within the subcategories.

Clothing costs for a single adult with vision impairment are €2.15 higher per week than those for a single adult in the main MESL budgets. The highest additional cost within the Clothing budget is €0.58 in the footwear subcategory.

The groups agreed that additional clothing items needed to be included to accommodate the fact that walking and public transport are the main modes of transport used by individuals with vision impairment. The group added in a waterproof jacket and waterproof shoes as those with vision impairment are more likely to be exposed to adverse weather conditions including rain. A waterproof backpack was added to safely carry essential and expensive technology equipment and leave the hands free for easier mobility.

Additional personal accessories were added to the budget to facilitate individuals with vision impairment to complete daily tasks independently and enhance their mobility. The groups agreed a distance telescope should be added to the budget to enable the identification of an approaching bus. A coin organiser was included as the groups reached a consensus that it would allow someone to have greater independence when shopping. The watch in the main MESL budgets was replaced with a large screen NCBI watch as someone with vision impairment would have difficulty seeing a smaller clock face. A sun cap was also added to the budgets to reduce glare from sunlight when necessary.

The focus groups decided to increase the quantity of specific clothing items to allow for the more frequent dry cleaning and laundering necessitated by the increased risk of stains. Smart tops and tights for women and socks for men were among the clothing items which increased in quantity.

The main clothing subcategory remains the most expensive for a single adult with vision impairment and increased by the smallest amount of money per week, joint with dry cleaning costs (€0.19 per week).

Savings and contingencies

Table 12 Difference in weekly savings and contingencies costs for a single adult with vision impairment in 2016

| Items | Main MESL | Vision impairment | Difference |
|---------------|--------------|-------------------|-------------|
| | € | € | € |
| Contingencies | 5.75 | 7.50 | 1.75 |
| Savings | 5.75 | 5.75 | 0.00 |
| Total | 11.50 | 13.25 | 1.75 |

Savings and contingencies costs for a single adult with vision impairment are €1.75 higher per week than a single adult in the main MESL budgets. The only additional cost within the Savings and contingencies budget is €1.75 to cover increased contingency funds. The focus groups reached a consensus that individuals with vision impairment tended to break objects more easily and the increase in contingencies was to ensure that there was extra money to replace items when necessary. The groups did not accept that vision impairment was an adequate reason to justify an increase in the amount designated for savings.

Insurance

Table 13 Difference in weekly insurance costs for a single adult with vision impairment in 2016

| Items | Main MESL € | Vision impairment € | Difference € |
|------------------|----------------|---------------------------|-----------------|
| Gadget insurance | 0.00 | 1.84 | 1.84 |
| Home contents | 2.23 | 2.23 | 0.00 |
| Health | 13.94 | 12.98 | -0.96 |
| Total | 16.17 | 17.05 | 0.88 |

Insurance costs for a single adult with vision impairment are €0.88 higher per week than a single adult in the main MESL budgets. The highest additional cost within the Insurance budget is €1.84 per week for gadget insurance. The groups reached a consensus that gadget insurance was required to cover the more expensive iPhone added into the Communications budget. The groups agreed that the iPhone was an essential item of communication for those with vision impairment. They explained that people with vision impairment are more likely to lose and damage phones and felt more vulnerable to theft.

The cost of the health insurance package is -€0.96 lower per week for the single adult with vision impairment than for the single adult in the main MESL, as the refunds for the two visits to the chiropodist included as part of the health insurance package have been removed from the overall cost. The chiropodist visits are not included in the Health budget for the single adult in the main MESL.

Household energy

Table 14 Difference in weekly household energy costs for a single adult with vision impairment in 2016

| Items | Main MESL € | Vision impairment € | Difference € |
|--------------|----------------|---------------------------|-----------------|
| Electricity | 16.02 | 16.75 | 0.73 |
| Gas | 11.97 | 11.97 | 0.00 |
| Total | 27.99 | 28.72 | 0.73 |

Household energy costs for a single adult with vision impairment are €0.73 higher per week than for a single adult in the main MESL budgets. The only additional cost is to cover extra electricity usage.

The variety of eye conditions within any level of vision impairment meant that members of the focus groups found it difficult to assign a sum of money to cover the cost of electricity. Because of time constraints and the similarity between the household type in the current study and that of the Hill et al (2017) study it was decided to base the electricity costs for the current study on those of Hill et al (2017). The calculations in the Hill et al (2017) study were made by a fuel expert who estimated that the additional electricity costs would amount to £0.52 extra per week. This additional cost allowed for extra lighting used for longer periods, additional technology usage and greater use of radio and TV. The figure of £0.52 was adjusted to take into consideration the higher cost of electricity in Ireland and the differences in currency. As a result the cost of the additional electricity in the current study was estimated

at €0.73 per week. The Appendix contains a detailed explanation of how the energy costs were calculated for the current study.

Transport

Table 15 Difference in weekly transport costs for a single adult with vision impairment in 2016

| Items | Main MESL € | Vision impairment € | Difference € |
|------------------|----------------|---------------------------|-----------------|
| Public transport | 32.70 | 0.00 | -32.70 |
| Taxis | 0.00 | 19.52 | 19.52 |
| Total | 32.70 | 19.52 | -13.18 |

Transport costs for a single adult with vision impairment living on a public transport route who is entitled to free travel are -€13.18 lower per week than for a single adult in the main MESL. The cost of the weekly Leap card has been removed from the basket as the individual in the case study is assumed to be entitled to free travel on public transport as they meet the required registration criteria.

However, despite the entitlement to free travel, an individual with vision impairment still faces weekly transport costs of €19.52 to cover the cost of essential taxis. The groups reached a consensus that €60 per month should be added to the budget to cover the cost of taxis for social needs, one emergency taxi per month (to the value of €15) and two taxis for travel to eye check-up appointments per year (€20 per taxi).

The groups emphasised that a person with vision impairment should have the same opportunities to socialise as those with full sight. The groups agreed that the taxis included for eye check-up appointments met the physical needs of those with vision impairment. After some check-up appointments an individual will need assistance to get home and the individual might not be able to, or want to, depend on friends or family members for this help. The groups found it difficult to assign particular amounts of money to taxi journeys. They noted that a person's level of social interaction can depend on where they live, which determines the price of taxis.

Chapter 6 Discussion

In the course of the focus group discussions it became obvious that three important human needs are key determinants in establishing the cost of a **Minimum Essential Standard of Living** (MESL) for people with vision impairment: the need to feel independent and not a burden; the need to feel self confident and safe and the need to be prepared as far as possible for emergencies or unplanned events. Levels and cause of vision impairment influence how these needs are met. In this study, the single adult with vision impairment has some useable sight and their level of vision meets the eligibility criteria for state benefits in Ireland.

When considering the results and discussion it is important to keep in mind the definition of vision impairment and the case study which specifies the personal circumstances of the single adult. As previously stated, a case study was constructed of an individual with this level of vision and with specific personal circumstances: working age, living alone in rented accommodation on a good public transport route in an urban area, in full time employment and in good health.

It is recognised that there are variations in the level and type of vision impairment and this variation was taken into consideration when negotiating a consensus on the cost of particular goods and services.

Assistive technology and low vision aids

Table 16 Assistive technology and low vision aids included in the MESL baskets

| | |
|---|-------------------------------|
| Landline and broadband | Magnifying software |
| Talking alarm clock | Talking kitchen scales |
| Distance telescope | Liquid level indicator |
| Sunglasses | Glasses |
| Lighting | Prescription swimming goggles |
| Coin holder | Handheld magnifier |
| Magnification mirror | Grab rail |
| Laptop | Talking weighing scales |
| Large print easy to see watch | Television and remote |
| Subscription to audio book service | Bumpons |
| Subscription to audio description service | |

Throughout the focus group work, participants emphasised the importance of assistive technology and low vision aids in allowing those with vision impairment to have the same opportunities and independence levels as people with full sight. The desire to complete daily tasks independently and have the same level of social interaction as those with full sight results in non-optional costs for a person with vision impairment (Gravitas, 2006).

Non-optional costs can include assistive technology which may be a luxury for fully sighted individuals but a necessity for an individual with vision impairment (BCA, 2016). The participants themselves acknowledged that assistive technology items can be viewed as a luxury but agreed they were essential items at a minimum level for enabling those with vision impairment to meet their physical, psychological and social needs.

The total weekly additional cost of assistive technology and accessibility aids amounts to 61% of the weekly additional minimum living costs for a single adult with vision impairment. However, in reality individuals with vision impairment are faced with large upfront expenses for items of assistive technology. For instance, the ZoomText magnification software added to the budget costs €793.35. It is difficult to comprehend how an individual on a low income or someone who has recently lost their job as a result of acquiring vision loss could afford these high upfront costs.

Often, people with vision impairment are unable to afford the upfront costs of essential assistive technology and have to go without. Some of the members of the focus groups described the levels of deprivation they experienced because of their inability to meet the costs of vision impairment.

“I have to pay a mortgage, living on my own. There are loads of things I have to do without, there are loads of things I would love to buy like a free standing magnifier but I have to make do with a handheld magnifier which is awkward to read with.” (Participant in the Cork focus group)

Acquiring vision loss is an unplanned burden which means individuals have to adapt and learn new ways of doing things. This can lead to isolation, particularly if they are unaware of the relevant services on offer (Hill et al, 2016). It is in this context that people with vision impairment face the expensive costs of essential items such as assistive technology.

The Disability Federation of Ireland (DFI) and Enable Ireland (EI) undertook an analysis of assistive technology services in Ireland in 2016 outlining the benefits of assistive technology and analysing the access system in Ireland. The report explained that assistive technology can support people with a disability to access their human rights; to complete their education and gain or retain employment; to live in their community and to become digitally literate (DFI and EI, 2016). During the work of the focus groups, the participants reached a consensus on a number of accessible technology items specifically designed to help those with vision impairment and listed some of the above benefits as justification for their inclusion in the budgets. The participants across the groups emphasised the significance of accessible smartphones as a multi-use item that allows individuals with vision impairment to not only communicate but access the same level of information and entertainment as those with full sight.

In recent years, mainstream smartphones and tablets have become increasingly accessible and affordable. Many accessible solutions are an integral feature of mainstream devices (DFI and EI, 2016). The groups explained that even at a minimum standard of living a ‘high-end’ smartphone is required to

ensure that necessary features such as magnification and voice assistance are reliable as they are vital to an individual with vision impairment. The groups gave examples of ‘high-end’ smartphones that were most commonly used by people with vision impairment such as the Apple iPhone and the Samsung Galaxy. The participants agreed that the iPhone has the easiest system for a person with vision impairment to use and the developments in technology such as the Siri intelligent assistance tool, built in screen reader (Voice Over) and the screen magnification were indispensable to those with vision impairment.

The ease of use of the iPhone is also recognised by the RNIB (2016) such as the fact the iPhone can be used immediately by someone with vision impairment without installing extra software and some of the newest models have an inbuilt portable magnifier. Furthermore, an iPhone was included in the Hill et al (2015) study which established the cost of a Minimum Income Standard for a person with vision impairment in the UK. A consensus was reached that the iPhone was, “the best out there in terms of accessibility” (Hill et al, 2015, p.34).

Another significant piece of assistive technology added to the budget is the magnification software for use with the laptop. The groups acknowledged that it was necessary for individuals with vision impairment to use magnification software on a laptop to enable them to use it in the same way as an individual with full sight. The groups also emphasised that the ZoomText software added to the budget was a minimum magnification solution dependent on the level of sight, as often individuals would use additional equipment such as standalone magnifiers or screen readers such as JAWS [17].

[17] The individual in the case study relied on magnification of text rather than screen reading software when reading.

Assistive technology that allows those with vision impairment to use the computer in the same way as those with full sight is important in granting them equal access to education and employment. The DFI and Enable Ireland state that “as significant investment is rolled out to support technology based active learning for all school students there is now a new opportunity to ensure that disabled students can participate on a par with their non disabled peers” (DFI and EI, 2016, p.18). Therefore, assistive technology such as magnification software can make mainstream education resources equally accessible to all.

Technology has transformed the lives of most workers but it has been particularly important for people with disabilities because it is often the only way to perform certain jobs that people without disabilities do in other ways. The Workplace Equipment / Adaptation Grant is available for employers, employees and people with disabilities who are self-employed and need to adapt the workplace or purchase specialised equipment for staff with disabilities. Public sector employers are obliged to facilitate the needs of their staff with disabilities (Citizens Information, 2016b).

Despite the clear significance of assistive technology for those with vision impairment and disability in general, Ireland has an underdeveloped national assistive technology system in comparison with other countries such as Norway, Denmark and the Netherlands (DFI and EI, 2016). The DFI and Enable Ireland found the service and delivery of assistive technology in Ireland to be fragmented and uncoordinated across the delivery mechanisms. Assistive technology has the potential to allow Irish society to meet many of its obligations under the UN Convention on the Rights of Persons with Disabilities. Article 4.1 highlights the importance of access to affordable assistive technology as a key component of an inclusive society (UNOHCHR, 2006).

The inclusion of online subscription services Netflix and the NCBI audio book service were also another important point of discussion during the focus groups. The participants explained that those with vision impairment need to access entertainment through a different means than those with full sight.

“Ultimately the online subscription services give us the same choice as everyone else.” (Participant in the Dun Laoghaire focus group)

Participants argued that at present digital terrestrial television in Ireland does not offer audio description features on its television shows at an adequate level. The Broadcasting Authority of Ireland lists a target for RTÉ to provide audio description on only 2.25% of its shows on RTÉ One and RTÉ Two in 2017, increasing to 2.5% in 2018 (BAI, 2016). RTÉ currently lists only seven television shows on its website that can be viewed using audio description (RTÉ, 2016). Furthermore, the participants agreed that a person with vision impairment can access Netflix across a range of devices, assisting their viewing of the shows i.e. on the laptop or large screen television added to the budgets.

The groups explained that the requirement for other low vision aids such as liquid level indicators is often dependent on individual needs. Each person has their own method of coping with vision impairment but the group explained that what may seem like insignificant items can provide independence for a person with vision impairment. For instance the liquid level indicator allows a person to know when to stop pouring and can enable a person with vision impairment to make a cup of tea for a friend independently and retain their dignity.

Services and assistance

The participants emphasised throughout the discussions, the significance of assistance with daily activities. As outlined earlier in the study, there were services included in the baskets such as taxis and cleaning where the individual would formally pay for the assistance. However, the groups highlighted the significance of unpaid assistance which is also essential to their daily living such as that of helpful shop assistants. The participants explained that shopping can be difficult for those with vision impairment as they often cannot see the prices on the shelves and can find it hard to navigate around large stores at busy times. As a consequence, the person with vision impairment may decide to use a local convenience store and pay more.

The groups also highlighted the 'social contract' that develops between a person with vision impairment and their friends and family. The participants explained that individuals with vision impairment can feel that they are a burden to their loved ones if they are constantly seeking their assistance. It was made clear during the focus groups that independence is a very important value and need for the majority of people with vision impairment. An example of the 'social contract' in the budgets is the additional spending money for the holiday to buy the person accompanying the individual a meal or gift to thank them for their assistance during the trip.

Contingencies and vulnerability

The importance of having a plan to deal with emergencies or unplanned events for those with vision impairment was apparent in the items added to the budgets across all areas to deal with contingencies. These additions to the baskets reflect the fact that those with vision impairment have different living costs as they have to be prepared to deal with the worst case scenarios in order to remain independent.

For instance, additional clothing and dry cleaning were added to the budget based on the group's agreement that those with vision impairment tend to spill more items. In general, the contingencies budget was increased as the groups agreed that those with vision impairment tended to break items more easily. Although it is not feasible at a minimum level to allow for every possible mishap, the group agreed that a specific sum of money should be allocated for dealing with accidents.

The need to plan for contingencies stems from the feelings of vulnerability associated with vision impairment. The inclusion of the landline in the home, the alarm and intercom system, the emergency taxi once a month and the gadget insurance for the mobile phone are examples of such planning. The landline was added to the budget as an extra assurance as the groups agreed those with vision impairment are more likely to misplace their mobile phone. In a similar way, the emergency taxi was added to the budget in case an individual was stranded in an unfamiliar place or had to get to their destination at short notice. The groups added the alarm and intercom system as they stressed that it is important that those with vision impairment feel safe in their homes and protected against burglary. The insurance for the mobile phone was added to take into consideration the possibility of loss or theft.

“It is not nice opening the door and having no idea who is there.”
(Participant in Dun Laoghire focus group)

Transport and mobility

Mobility and transport was another key discussion area during the focus group work. Even though the individual in the case study is entitled to free travel, their travel expenses are still approximately €20 per week. It is important to emphasise that the transport scenario outlined in the case study (living on a public transport route in an urban area), on which the budget is based, can be considered an ideal living scenario. For those living in rural areas or urban areas with poor transport links, the cost of transport for people with vision impairment would be much higher as they would be more reliant on taxis for transport.

One of the most significant impacts of vision loss is on mobility, an individual’s ability to move independently, safely and purposefully. A collaborative report issued by the NCBI and Irish Guide Dogs in 2012 found that mobility was a critical issue for those with vision impairment living in Ireland (Mac Cobb, 2012). The study highlighted that reduced mobility resulting from vision impairment can lead to social exclusion and affect an individual’s quality of life. As a result of restricted mobility, those with vision impairment rely on taxis, face difficulties with public transport and depend on others for lifts (Gravitas, 2006). In the course of discussions participants in the focus groups frequently mentioned the importance of taxis for mobility in emergencies and for social inclusion. It was also noted that the personal circumstances of some people meant they had to rely on taxis on a daily basis.

The groups explained how those with full sight often take for granted the ability to get from one place to another in the dark, in an unknown area or at short notice. Without the service of taxis, travel in these circumstances, would be impossible for people with vision impairment. Vision impairment creates psychological restrictions on an individual's mobility. Mac Cobb (2012, p.67) cites Goodman (1989) who suggests that fear of travelling with vision loss is a significant barrier to mobility for those with all levels of vision impairment. This highlights the psychological need for individuals with vision impairment to feel secure and confident in their ability to travel independently to their destinations. Taxis play an important role in reducing the risk of social isolation for people with vision impairment and increase the likelihood of participation and inclusion by removing the obstacles and stress associated with travel.

The need for other important items for transport and mobility are less obvious and represent the hidden costs of vision impairment. These include the torch for walking at night time, the reflective clothing and the waterproof shoes and coat added to the budgets.

Cost of work

The groups were asked if there were additional costs for individuals with vision impairment to take up employment. The participants explained that apart from the necessity to use a taxi if one's employment is not directly on a public transport route; there were not any additional specific work-related costs as a grant is available to adapt a person's workplace. However, they emphasised that some of the items already added to the budgets for general use were essential in enabling an individual to work. For example, the hi-vis vest, the waterproof shoes and jacket and the torch added

to the budget by the focus groups. These items are essential for allowing an individual with vision impairment to have greater independent mobility.

The psychological and social needs for an individual with vision impairment at work are also met by items included in the baskets. The inclusion of extra dry cleaning and clothing items ensure the individual would feel clean and presentable at work. The online subscription services like Netflix ensure that participants feel socially included and could converse with colleagues. They acknowledged that the items needed for work depend on the nature of the work in which they were employed and agreed that most of such work was office based.

The groups agreed the main obstacles to taking up employment for people with vision impairment were not primarily financial but were the negative attitudes they faced. They explained that many of the general public assumed that people with vision impairment were not capable of working efficiently and successfully. They also noted it is more difficult for people with vision impairment to get a promotion or to get a job. The acknowledgement of individuals with a disability not being viewed as equally capable is widely recognised in literature on attitudes towards disabilities (Hannon, 2007). In the UK, the Department of Work and Pensions, conducted a survey 'Disabled for life 2002' that found 1 in 5 people believe that in general, people with a disability cannot be as effective at work as their colleagues who do not have a disability (Grewal et al, 2002).

Reaching the consensus

The participants lived experience of vision impairment allowed them to successfully agree upon particular items to fulfil functional needs of those with vision impairment. The items added to the budgets were based on the reasoning and justification of participants in the context of a general definition of vision impairment rather than specific eye conditions. However, at times the focus groups were unable to reach a consensus on some specific items in the budgets and instead agreed on amounts of money needed to meet a particular need rather than identify the specific item. This was not due to conflicts within the groups on the needs of individuals at a minimum level but rather an acknowledgement that within the category of vision loss specified in this study, there were a range of possibilities of individual need and this was reflected in a range of possible costs.

The burden of a disability felt by an individual cannot be evaluated by simply defining the nature or level of a person's disability, as individuals make a personal response to coping with their condition (Owsley et al, 2007, Mac Cobb, 2012). A range of factors can influence the burden of vision impairment experienced by an individual such as: the life stage and timing of vision loss; the cause of the vision loss and the extent to which a person with vision loss aspires to be independent. Consequently, the additional cost of vision impairment can be highly individualised and differ from individual to individual regardless of their level of sight (Gravitas, 2006) [18].

The sums of money included in the budgets in this study are based on a strong consensus amongst the focus groups and on

[18] See the Literature review in Appendix B for further detail.

the clear identification of need and the function of items added to the baskets. For instance, in the case of lighting it was agreed that those with vision impairment would need additional lighting compared with a person with full sight but the group agreed that the type of lighting required would vary depending on their eye condition.

The variation in individual requirements within one category of vision loss raises an important point for consideration when forming policy concerning vision impairment services. As identified by the participants in this study, there is a large range of need and price in items such as glasses. This may be better resolved with tailored services based on an assessment of individual need rather than broad payments to cater to all those with vision impairment.

Chapter 7 Key conclusions

1. The cost of a **Minimum Essential Standard of Living** (MESL) for a single adult with vision impairment is higher than that for a single adult with full sight.
2. In 2016, a **Minimum Essential Standard of Living** for a single adult with vision impairment cost €44.54 (18%) more on a weekly basis than for a single adult in the main MESL budgets. An MESL for a single adult with vision impairment with some useable sight cost €285.76 per week in 2016, excluding housing costs, compared with €241.22 for a single adult with full sight.
3. The additional cost of vision impairment arises from the need for items and services that enable an individual to realise their right to independent living in the community as outlined in the United Nations Convention on the Rights of Persons with Disabilities. Currently, of the additional items of expenditure, taxis are the most expensive on a weekly basis. Taxis play an important role in daily life of people with vision impairment. For example, taxis as a form of transport reduce the risk of social isolation and can ensure the keeping of important hospital appointments as well as a safe journey home after particular treatments.
4. This study establishes a socially acceptable minimum standard of living for individuals with vision impairment, grounded in the lived experience of those with vision impairment. It provides an important indicator of the costs faced by single adults with vision impairment in order to meet their physical, social and economic needs.

5. A similar study using the Consensual Budget Standards methodology would be useful to determine the additional cost of vision impairment for people whose circumstances differ from those in the current study based on the degree of vision impairment, age, location and household type.

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Appendix A Methodology

Background and development of the research in Ireland

In 1999, the VPSJ studied 118 low income households dependent on social welfare payments or low wages to highlight their experience of deprivation. This work was in a response to a plea from a group of women who asked, “Will no one ever show the Government what it is like to never have enough to make ends meet? Will no one show them what people need to have a decent life with dignity?” The findings showed that none of the households could meet the weekly cost of rent, energy, clothing, education, over-the-counter medication and food.

The cost of a Minimum Essential Standard of Living with the primary focus on experts

In 2004, the focus of the VPSJ changed from measuring deprivation to determining the minimum level of expenditure needed for a **Minimum Essential Standard of Living** using Low Cost but Acceptable (LCA) budget standards, as developed by the Family Budget Unit (FBU) at the University of York. This methodology uses empirical data from national surveys of poverty and exclusion to determine prevailing patterns of consumption in society and to arrive at a consensus on what the essential necessities of modern living are. Input from focus groups was also used to:

- Gain information on the shopping patterns of low income households.
- Draw up a framework for the food menus and shopping lists.

- Assist in the validation process of the budgets.
- Learn about the realities of life on a low income.

This methodology was used by the VPSJ in 2004, in a study of a Low cost but acceptable standard living for three household types.

The cost of a Minimum Essential Standard of Living with the primary focus on people

Budget standards, based on the actual expenditure choices and judgments of people in real life as they manage their money to contribute to a final consensus, were developed as a methodology by the Centre for Research in Social Policy (CRSP) at the University of Loughborough. It avoided expert judgments and reaching consensus by coincidence. This approach is known as Consensual Budgets Standards (CBS) methodology.

Determining the cost of a Minimum Essential Standard of Living according to the people with input from the experts

Consensual Budgets Standards (CBS) based on the expenditure of people in real life on goods and services that everyone should be able to afford, while at the same time drawing on expert knowledge about basic living requirements and expenditure patterns, were developed as a methodology in 2004 by the Family Budget Unit at University of York in partnership with the Centre for Research in Social Policy at the University of Loughborough. In 2006, the VPSJ applied the CBS methodology, but used Irish sources to establish the individual items for each of the 16 areas of expenditure.

The following are the 16 areas of expenditure in the MESL data:

Table 17 Budget areas included in the MESL data

| | | |
|---------------------------|------------------------------------|------------------|
| Food | Household goods | Education |
| Clothing | Household services | Transport |
| Personal care | Communications | Household energy |
| Health-related costs | Social inclusion and participation | Personal costs |
| Insurance | Housing | Childcare |
| Savings and contingencies | | |

Because of the variation in types of housing (owner occupied, private rented, social housing etc) the cost of housing is not included in household expenditure.

The CBS approach is being increasingly adopted internationally and variations of the methodology have been used in New Zealand, Australia and the US. Budget standards using the CBS approach are currently being developed in France, Austria and Portugal, as well as in Japan.

Since 2006, the VPSJ has extended the use of the CBS approach and has undertaken studies to develop budget standards for additional household types, as well as households in rural areas. The MESL data is updated every year, and the website, www.budgeting.ie presents a wide range of information on the expenditure and income necessary for a **Minimum Essential Standard of Living**. The Minimum Income Standard Calculator, www.misc.ie allows individuals and households to calculate the expenditure and income needs for their particular situation. The Reasonable Living Expenses as used by the Insolvency Service of Ireland in its work are based on the MESL work of the VPSJ, as are the calculations used to determine the annual rate for the Living Wage.

How is a Minimum Essential Standard of Living determined?

An MESL is determined using the Consensual Budget Standards methodology. This methodology, which is grounded in the experience of people, involves detailed research, with members of the public specifying the items that need to be included in a minimum household budget. Focus groups are formed for each household type. Each group consists of between 8 and 12 people from a mixture of social and economic backgrounds, and represents the household type under consideration. For example, the focus groups of parents with children determine the minimum requirements of such households. In order to ensure the reliability and validity of the research, three different focus groups are established for each household type. While the process is detailed and time consuming, it is thorough and robust. In a series of sessions, the groups arrive at a negotiated consensus about the goods and services a household requires to have an MESL. Where necessary, experts are consulted in order to ensure that the negotiated consensus meets basic criteria, such as nutritional standards and home heating standards. However, ultimately the people themselves are the experts.

What does it include?

While an MESL is concerned with more than survival, its focus is on needs, not wants. It identifies the minimum goods and services that everyone should be able to afford. There are approximately 2,000 items in the budget, and these goods and services are subsequently categorised into 16 areas of expenditure. The goods and services are then priced in shops or outlets identified by the focus groups. The totals of each of the 16 categories of household budgets show the expenditure required to allow for a **Minimum Essential Standard of Living**.

While some items are bought every week, others may only be bought every couple of months or even years. For example, furniture is expected to last a number of years, while a large proportion of food items are bought on a weekly basis, e.g. fruit and vegetables. However, there are food items which are bought every couple of weeks or even months, e.g. salt and oil. To calculate the weekly cost of each item, the price of the item is divided by the number of weeks it is expected to last. For example, salt, which costs €1 and has a lifespan of 26 weeks, costs €0.04 per week.

The following are the four phases in the focus group stage of the CBS process [19].

1. Orientation phase: The initial phase explores the language, concepts and priorities that people use in thinking about spending and consumption. During this phase the group develops a working definition of an MESL and identified the difference between needs and wants.

[19] For a more detailed description of Consensual Budget Standards see Middleton, S.(2000) and Bradshaw et al.,(2008).

2. Task groups: In this phase, each budget component is considered in turn (i.e. food, clothing, personal care, household goods, household services, social inclusion, fuel, transport etc). Each item is then categorised as a need or want. Together, the participants produce an agreed list of items. The lists are reconsidered. Are they too limited or too generous?

3. Costing phase: The items agreed by the focus group are priced by the researchers to compile a minimum essential budget. In general up to two thousand individual items are priced in outlets which are identified by the focus groups.

4. Check back phase: The final phase is particularly important and it involves the rechecking of items and costs in order to reach a final consensus. Before this can be done, the consensus must be tested. Firstly, participants are asked whether they think the amount allocated to provide the agreed list of items, is too high or too low. Secondly, the group is asked how much they would be prepared to reduce the budget at the request of the “Minister for Finance” (Middleton, 2000, p. 64).

References

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Appendix B Literature review

Introduction

The first section of the literature review examines the definition and level of vision impairment considered in this study, while the second section outlines some of the broad impacts of vision impairment on the physical, psychological and social needs of an individual. The third section considers the different types and levels of costs that result from vision impairment such as direct and indirect and the cost to society and to an individual. The next section examines previous studies on the cost of a disability and vision impairment followed by a consideration of the influences on the individual cost of vision impairment for example the desire to live independently. Lastly, the equality and living standards of individuals with a disability in Ireland are briefly outlined. The purpose of this literature review is to provide a framework for the study and to contextualise the question at the heart of this study - what is the additional cost of vision impairment for a single adult?

Defining vision impairment

Research literature tends to be inconsistent in the use of the terms vision impairment and blind. An estimated 65 different definitions of blindness and low vision have been used in literature on the subject (Jackson et al, 2008). In general, both those that are blind and have low vision can be considered as having a vision impairment (Jackson et al, 2008).

The Government gives direction on the specific level of sight loss an individual must have in order to avail of state entitlements and benefits. The direction is usually linked to definitions and classifications recognised within that state's

legal framework (Jackson et al, 2008). In the United States, the direction is for the most part referred to as “legal blindness” whereas throughout Europe definitions differ from country to country. In the UK, for example, there are two official levels of vision impairment “severely sight impaired” (blind) and “sight impaired” (NHS, 2015) and in the Republic of Ireland there is one.

To be eligible for state entitlements in Ireland an individual must have “best corrected visual acuity of 6 / 60 or less in the better eye and / or a binocular visual field restricted to 20 degrees or less” (Citizens Information, 2016a). The current study establishes the **Minimum Essential Standard of Living** for a single adult with vision impairment with some useable sight, whose level of vision meets the eligibility criteria for state benefits. While not everyone who fulfils the entitlement criteria has useable sight, 95% of those who access the NCBI services have some level of sight (NCBI, 2016).

Identifying the physical, psychological and social needs

Previous research has highlighted that individuals with vision impairment have different physical, social and psychological needs from those of people with full sight. Individuals with vision impairment experience, greater difficulty with daily living and social interaction and face higher risk of depression, anxiety, an early death, risk of falls and premature admission to nursing homes (Deloitte, 2011). Consequently, different items are required by those with vision impairment to fulfil these needs and may result in a different cost of a **Minimum Essential Standard of Living** compared with those who have full sight. Below are some of the main ways in which vision impairment impacts upon the physical, psychological and social needs of an individual.

Mobility and transport

One of the most significant impacts of vision loss is on mobility, an individual's ability to move independently, safely and purposefully. Throughout the research literature there is a consensus that reduced mobility greatly affects an individual's quality of life. A collaborative report issued by the NCBI and Irish Guide Dogs in 2012 found that mobility was a critical issue for those with vision impairment living in Ireland. A quarter of adults in the study did not travel without a sighted guide even in their local area (Mac Cobb, 2012). Previous research has found that as a result of restricted mobility those with vision impairment rely on taxis, face difficulties with public transport and depend on others for lifts (Gravitas, 2006).

Mobility restrictions also impact on the social needs of an individual with vision impairment. Mac Cobb (2012) explained that the restrictions on mobility due to vision impairment can result in social exclusion. It is not disputed that an individual with vision impairment has the same need for social interaction but engaging in social interaction for those with vision impairment can be more difficult due to not being able to drive or having access to public transport, resulting in different costs of living such as taxi fares.

Vision impairment also creates psychological restrictions on an individual's mobility. Mac Cobb (2012, p.67) cites Goodman (1989) who suggests that fear of travelling with vision loss is a significant barrier to mobility for those with all levels of vision impairment. This highlights the psychological need for individuals with vision impairment to feel secure and confident in their ability to travel independently to their destinations.

Daily living

Vision impairment makes engaging in daily tasks more difficult for an individual, even something as routine as making a cup of tea and more strenuous daily activities can become impossible to complete independently. Hill et al (2015) have found that an individual with vision impairment acquires additional financial costs for assistance with daily living tasks such as paying for specialised household equipment and the need for paid assistance to undertake household activities such as cleaning. Frame (2004) highlights that those with vision impairment can feel a burden if they are asking for help continually from family members and friends with tasks they cannot complete themselves. This results in a psychological need to feel independent and complete tasks without feeling a burden.

Communication and societal participation

Communication and participation in society is another area greatly impacted by vision loss as information is received and processed by an individual with vision impairment in a different manner from those with full sight. Individuals with vision impairment rely on assistive technology in order to communicate and engage with society.

The term assistive technology refers to the practical tools that enhance independence for people with disabilities, “any item, piece of equipment or product system whether acquired commercially, modified or customised that is used to increase, maintain or improve functional capabilities of individuals with disabilities” (WHO, 2011, p.101). For most people technology can expand opportunities yet for those with a disability,

assistive technology can assist with daily activities and enable individuals with a disability to participate in Irish society to a degree not previously possible (DFI and EI, 2016). It is clear that assistive technology is a need for those with vision impairment; yet it imposes additional living costs on these individuals.

Identifying the cost of vision impairment

The cost of vision impairment has been established on both a societal and individual level. It can be further classified into direct, indirect and intangible costs (Köberlein et al, 2013). The direct costs of vision impairment include both medical and non-medical costs, which on an individual level encompasses the cost of medical treatments and assistive technology. On a societal level, the direct cost of vision impairment includes public funding and subsidies for medical equipment and employment supports etc. The indirect costs of vision impairment can be understood as the loss of output due to the disability, such as income loss and absenteeism. Intangible costs of vision impairment refer to the burden of illness upon the individual and the loss of quality of life (Köberlein et al, 2013).

The decision to assess which type of cost or all costs when establishing the additional cost of vision impairment is dependent on the purpose of the study. For instance, the analysis of the direct costs can be used to set priorities for medical funding by ranking costs or using cost-utility analysis (Chou et al, 2003). Direct costs are formal and easily identified using sources such as patient records and data bases from vision services (or vision rehabilitation) organisations. However, Chou et al (2003) point out that data obtained only from direct costs, excluding indirect costs, does not represent

the true total costs of vision impairment to individuals and society, as it excludes the socio-economic impacts of vision impairment and the hidden costs. Yet, indirect costs are rarely included in estimations as they are complex and often difficult to obtain (Chou et al, 2003).

The current study identifies the indirect and direct costs as well as the hidden costs that an individual with vision impairment faces each day based on the lived experience of people with vision impairment. Establishing the cost of vision impairment on an individual level is significant in assessing the adequacy of direct government supports for those with vision impairment.

The cost of vision impairment to society in Ireland

The Deloitte Access Economics study the Cost of Sight Loss (2011) estimated that the total economic cost of vision impairment and blindness in the Republic of Ireland in 2010 was €2.1 billion projected to rise to €2.7 billion by 2020. This total economic cost is comprised of direct costs and indirect costs (the actual financial costs) and the economic value of the disease burden (DALYs)[20]. The economic value of the disease burden (DALYs) comprised 82% of the total cost.

The Cost of Sight Loss study provides invaluable information on the burden of vision loss on the state and society. However, the estimates of the cost of sight loss include the costs of all degrees of vision impairment. The findings do not elaborate on the contribution of each degree of vision impairment to these costs.

[20] The burden of disease from vision impairment and blindness is a measure of the loss of wellbeing from disability and premature death due to these conditions. The burden of disease is measured using the non-financial metric of disability-adjusted life years DALYs converted to financial equivalent using the monetary value of a statistical life year.

Green et al (2016) produced a similar study which focused only on the cost of blindness to society. The study concluded that the total economic cost of blindness (including the burden of impairment) was to rise from €809 million in 2010 to €1.1 billion in 2020. The study used a similar method to Deloitte Access to calculate the cost of blindness. The study found that the cost of vision impairment rises when its severity increases and that intervention from the state to prevent moderate impairments from getting worse would reduce the cost of vision loss to society.

The study also highlights the significant role of informal care in the lives of those with vision impairment and the financial cost of care that is reduced for the state through the work of informal carers. Green et al (2016) acknowledge the significance of the indirect costs of vision impairment which can be hidden. They argue that unless the indirect costs and effects of disabilities are integrated into decision making, the correct resources will not be allocated to relieve the negative impacts of vision impairment on an individual's quality of life. However, the study does not establish what the indirect daily costs of vision impairment consist of, or the specific items required by an individual to cope with their vision impairment and enhance their quality of life.

The additional cost of vision impairment for an individual

The purpose of the current study is to identify the additional cost of a **Minimum Essential Standard of Living** for a single adult with vision impairment. The definition of 'additional cost' can determine the method used to calculate these costs as found in a study conducted by Indecon (2004) into the cost of a disability in Ireland. The additional cost of a disability implies that the cost is captured by a comparison between the circumstances of an individual with and without a disability (Indecon, 2004).

The additional cost of vision impairment in the current study refers to the additional cost of a **Minimum Essential Standard of Living** for a single adult with vision impairment compared with a single adult in the main MESL.

In Ireland, there are studies that have established the additional cost of a disability. Previous research has focused on establishing the additional cost of a disability faced by individuals using three main approaches: Direct Survey Approaches (DSAs), Expenditure Diary Approaches (EDAs) and Indirect Approaches (IAs) (Cullinan et al, 2008).

The Direct Survey Approach (DSA) involves asking individuals with a disability to compare how much they spend on specific expenditure items to the expenditure of an individual in the same situation without a disability (Cullinan et al, 2008). Any additional costs are aggregated to give an estimate of the total extra costs arising from a disability. However, as cited by Cullinan et al (2008, p.5) Berthoud et al (1993) argue that the DSA method is unlikely to provide accurate estimates of the additional costs of disability, as it may be difficult for respondents to accurately estimate their own expenditures and those of an individual in the same situation without a disability. The Consensual Budget Standards (CBS) methodology is used in the current study to establish the additional cost of an MESL for people with vision impairment. Firstly, this means the participants are not estimating expenditures but agree upon detailed item lists which are then priced. Secondly, the participants do not have to estimate the living costs of an individual without a disability, as the list of items already agreed upon by members of the population in the main MESL is used as a basis, to which additional items are added.

The Expenditure Diary Approach (EDA) is another method of directly identifying the additional cost of a disability. It involves analysing detailed measurements of expenditure for a sample of people with a disability, compared with expenditures for those without a disability. There are some limitations to this method as the effects of the different nature of disabilities and the level of severity of disabilities on the additional cost of a disability are lost through averaging costs (Cullinan et al, 2008). In addition, the EDA method does not account for every item needed in daily life such as a taxi fare for a person with a disability to go to the shop (Indecon, 2004). Establishing an MESL for a particular household involves examining every single item required in daily life, including taxis to the shop if this is necessary. The items that make up an MESL are based on the accurate, lived experience of the participants of the focus groups. The current study establishes the MESL for a single adult with a specific disability, vision impairment.

A third approach to calculating the additional cost of a disability for an individual is the Indirect Approach (IA) or the standard of living method. This is an indirect approach which assumes that income determines a household's standard of living and that for a given income there will be a reduction in the standard of living where additional needs arise due to a disability. The cost of a disability in this case is defined as the extra income required by a household of a person with a disability to achieve the same standard of living as an equivalent household without a disability (Cullinan et al, 2008).

Indecon (2004) undertook a study that examined all three approaches to establish the cost of a disability in Ireland. The study found that there are very different cost estimates depending on the methodology employed and the sample

group analysed. Indecon (2004) found the standard of living approach was most consistent with their definition of additional costs, “the amount of money required to bring the standard of living of an individual with a specified condition or disability up to that of a comparable individual without such a condition or disability, controlling for as many personal characteristics as possible” (Indecon, 2004, p.38). The study explains that although the survey approach used produced statistically unreliable data it proved useful in signalling which areas extra costs are incurred. Those with vision impairment were one of the groups surveyed and it was found that they faced additional expenses on equipment and aids which they received state assistance with but also daily living costs which they did not receive assistance with. The study also describes the budget standard approach as useful in presenting specific costs faced by people with a disability but the method is built largely on assumptions. However, the Consensual Budget Standards methodology used in the current study ensures that specific items are agreed upon by several groups of individuals with vision impairment during a rigorous and thorough focus group process.

Using the standard of living approach they estimated the cost of a disability to be €143 per week for working age households at the median income level. The results of the study suggest that costs of a disability can be significant and vary with severity. However, Cullinan et al (2008) point out the determinant of a household’s disability in the study was based on whether the household was in receipt of the disability related payment and as a result may be subject to measurement error bias.

Cullinan et al (2008) using the standard of living approach have established the cost of a disability at between 35-55% of average household income. The study found that the cost of a disability varies by the severity of the disability and the household type under consideration. The modelling approach taken by the study allowed for the estimation of additional costs for households with individuals with a disability after disability-related payments and supports are taken into consideration. These findings are important for considering the effectiveness of policies that aim to address economic problems associated with disability. The study concluded that it is almost impossible for people with a disability to achieve the same living standard as those without disabilities and current policy in Ireland does not go far enough in addressing the impact of these extra costs.

Hill et al (2015) also noted the merit of the standard of living approach in making broad estimates of the household living standards experienced by people with a disability. The method is useful in justifying the adjustment to the income thresholds below which those with a disability are classified as being in poverty (Hill et al, 2015).

However, they explain that the standard of living approach does not establish the full scope of the additional costs faced by the individual, separate from the household (Hill et al, 2015). Also, the method does not account for the source of the additional costs of a disability.

Hill et al (2015) argue that a budget-based approach is more effective in directly identifying additional costs that arise for people with a disability. A study conducted by the Centre for Research in Social Policy (CRSP) in the University of Loughborough established household budgets for people with a disability based on needs as identified by groups of people with disabilities, using the Consensual Budget Standards methodology (Smith et al, 2004).

This study demonstrated that it was possible for people with a disability to reach agreement about minimum household budgets. However, there were no comparable costs of a minimum living standard for individuals without a disability. Instead the study compared an average single person's expenditure with the minimum living standard for people with a disability. Hill et al (2015) describe this as a weakness in the method as the average case is not relative to how someone would actually live at a minimum level. Furthermore, it is not easy to distinguish hidden additional costs in isolation from the overall standard of living when using an average living standard.

More recently, the CRSP has established the additional weekly cost of a Minimum Income Standard (MIS) for an individual with sensory disabilities (vision impairment and hearing loss) (Hill et al, 2015). This study provides an important resource for the current study and has demonstrated the merits of using the Consensual Budget Standards method in researching the additional cost of a disability. The additional costs attributed to vision impairment were widely agreed on by people who know what it is like to live with vision impairment and who are familiar with the costs of necessary goods and services.

The CRSP research was conducted in three waves and they have since established the cost of an MIS for an individual with severe vision impairment and for a single pensioner who with sight loss (Hill et al, 2016). The most recent report, brings together the previous work and adds to the data the cost of an MIS of a single pensioner who is severely sight impaired (Hill et al, 2017). The cost of an MIS for a single adult with vision impairment increases with both age and the severity of the impairment. Hill et al (2017) explain that the higher costs result from the need for "regular human help" such as in the home or the use of taxis (Hill et al, 2017, p.9). Other factors found to influence the cost of vision impairment in the study are the extent to which family and friends can provide help and a person's ability to use assistive technology.

The CRSP use the legal definitions of sight loss in the UK as the basis of the sight levels investigated in their studies.

However, the categorisation of vision impairment in Ireland differs from that of the UK which may impact on the items added to the budgets. There is only one legal definition of vision loss in Ireland compared with two in the UK.

The influences on the additional cost of vision impairment for the individual

Indecon (2004) and Hill et al (2016) have shown that the additional cost of a disability differs depending on the nature of the disability, as well as the severity. Other research demonstrates that the burden of a disability felt by an individual cannot be evaluated by simply defining a person's level of disability, as individuals make a personal response to coping with their condition (Owsley et al, 2007, Mac Cobb, 2012). A range of factors can influence the burden of vision impairment experienced by an individual such as: the life stage and timing of vision loss; the cause of the vision loss and the extent to which a person with vision loss aspires to be independent. Consequently, the additional cost of vision impairment can be highly individualised and differ from individual to individual regardless of their level of sight (Gravitas, 2006).

The life stage at which a person experiences vision impairment is a critical factor in determining the additional cost of vision impairment they incur. For instance, developing vision impairment as a working age adult is likely to impose significant financial and opportunity costs such as a loss of earnings, employment opportunities and the cost of accessible technology. However, if a person develops vision impairment when they are older, this may compound other existing physical impairments or health conditions and result in higher living costs. Hill et al (2016) found that the costs of vision

impairment are greater for someone of pension age compared with an individual of working age with the same level of sight. The higher costs are partially offset by the lower cost of technology as those of pension age do not rely on accessible technology as much as those of working age (Hill et al, 2016).

Within the VPSJ work, in the general population, the cost of the **Minimum Essential Standard of Living** differs between the age groups. In the VPSJ MESL data, the weekly cost of an MESL for a lone pensioner in an urban area in 2016 (€255.65) is €13.28 higher than for a single adult of working age (€242.37) (VPSJ, 2016). The difference in costs is a result of including items in the budgets based on the different needs of the individuals due to their age, such as a pendant alarm for the pensioner. In order to isolate the additional costs of vision impairment, the age of the individuals should be considered as well as their level of sight (Gravitas, 2006). The current study focuses on the additional costs of vision impairment faced by one age group by establishing the MESL for a single adult of working age with vision impairment.

Secondly, the cause of vision loss is an important factor in determining the additional cost of vision impairment as individuals may need different specifications of similar items in order to live with their impairment. Age-related Macular Degeneration (AMD) is the primary cause of vision loss in Ireland, followed by glaucoma and diabetic retinopathy (Deloitte, 2011).

These conditions affect a person's eyesight in different ways, for instance AMD affects the macula, the part of your eye that allows a person to see detail (AMD et al, 2007) whilst glaucoma is an eye disease that affects your 'wide-angle vision' as black patches appear in your peripheral vision (MSD, 2013). The varying effects on eyesight result in a range of requirements in low vision aids such as magnification aids, which do not all cost the same. The variation in the impact of eye conditions is significant for the Consensual Budget Standards methodology used in the current study, as a consensus is usually reached on specific items to be included in the budgets.

The level of independence an individual with vision impairment aspires to have also influences the additional cost of vision impairment. As outlined earlier, vision impairment increases the difficulty of daily living activities and social interaction. The desire to complete daily tasks independently and have the same level of social interaction as those with full sight results in non-optional costs for a person with vision impairment (Gravitas, 2006).

Non-optional costs can include the cost of transport and assistive technology such as the cost of a taxi fare to a hospital appointment which may be a luxury for fully sighted individuals who can drive their own car but a necessity for an individual with vision impairment (BCA, 2016). It can be difficult to distinguish the needs from the wants of a person with vision impairment but comparing the living costs of a person with full sight to those with vision impairment may be useful in discovering which costs are non-optional (Gravitas, 2006). The current study aims to discover the additional needs of a working age single adult with vision impairment compared with a single adult with full sight, establishing their non-optional costs and in turn their **Minimum Essential Standard of Living.**

Equality and living standards

The right to independent living

There are a number of international measures that enshrine the equal human rights of those with a disability such as the EU Charter of Fundamental Rights (2000) and the UN Convention on the Rights of Persons with Disabilities (2006).

Particularly relevant to this study is the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) adopted by the UN General Assembly in 2006. The Convention aims to ensure that those with a disability enjoy the same human rights as everyone else and is the first international human rights treaty to clearly recognise the right of all people with a disability to live independently in the community as equal citizens (Parker, 2009). Article 19 of the UNCRPD contains a strong commitment to independent living for all people with disabilities as it recognises “the equal rights of all persons with disabilities to live in the community, with choices equal to others” (UNOHCHR, 2006). This includes ensuring that they have the opportunity to choose where they live and have access to support services, “to prevent isolation or segregation from the community” (UNOHCHR, 2006). Importantly, Article 19 states these services and supports should be equally available and responsive to the needs of those with a disability.

However, at the time this study was going to print, Ireland was the only EU country yet to ratify the UNCRPD despite signing it ten years ago (March 2007). In 2015, the government introduced the ‘Roadmap to Ratification’ which outlined all the legislative changes to be undertaken to enable Ireland to ratify the Convention, along with the estimated timeframe involved. In

recent months the government has taken steps towards its ratification by approving the Disability (Miscellaneous Provisions) Bill 2016, which will address remaining legislative barriers to Ireland's ratification of the UNCRPD. Inclusion Ireland argue that Ireland's failure to ratify the convention shows that "Ireland is out of step with international norms on the rights of persons with disabilities" (Inclusion Ireland, 2016).

Since the government signed the Convention in 2007 there have been cuts to the very supports that allow a person with a disability to live independently and to participate in society. These include the stopping of the Mobility Allowance and the Motorised Transport Grant for new applicants in 2013 and the funding cut made in August 2012 to PA services which was subsequently withdrawn following protests. The DFI argue that this cut was "symptomatic of the absence of a shared understanding, within the HSE and beyond, about the purpose and value of the PA service" (DFI, 2014, p.11). Personal Assistant services in Ireland were originally established in the early 1990s to enable those with a disability to live independently. However, the DFI (2014) argue that the PA service has since shifted to providing for basic personal care needs with less attention to supports for independent living.

The DFI have made several recommendations for improving the Personal Assistance scheme in the context of Article 19 of the UNCRPD. Firstly, they argue that the Department of Health should further develop the definition of the PA service so that it encompasses equality based independent living, as reflected in the UNCRPD. Secondly, they recommend that the Department of Justice should consider establishing the PA service on a statutory basis as one of the supports which enable people with a disability to participate fully in society (DFI, 2014).

Employment and poverty

Watson et al (2016) in an analysis of the CSO Survey on Living and Income Conditions (SILC) data from 2004 to 2013, found that during this period, working age people with a disability had the second highest at-risk-of-poverty, basic deprivation and consistent poverty rates, after lone parents. In addition, working age adults with a disability had the highest level of Quality of Life deficits (QOL). Health problems accounted for a higher proportion of their QOL deficits compared to other social risk groups and mental distress was also more significant for this group than any other social risk group in the study (Watson et al, 2016).

Previous research has also found that people with a disability have a lower rate of participation in the labour market, a lower employment rate, a higher rate of part-time working and a higher unemployment rate (Watson et al, 2013, p.24). However, the 2006 National Disability Survey found that over a third of people with a disability (37%) would be interested in work if it was accessible to them (Watson et al, 2013).

Individuals not at work due to an illness or disability have deprivation rates of over 50% (53.2%) according to the latest SILC data (2015). This is the second highest rate of deprivation after lone parents and has increased slightly since 2014. For this social group, the at-risk of poverty rate has increased (from 25.2% to 34.8% in the year to 2015) and the consistent poverty rate has increased (14.4% in 2014 to 22.4% in 2015) (CSO, 2017).

The 2011 census recorded 12,180 people that were blind or had a serious vision impairment were available and looking for work (in the labour force). Of those, 3,868 were unemployed, mostly due to having lost or given up a previous job (CSO, 2011).

Conclusion

Previous research has found that the nature and severity of a disability impacts on the additional cost of a disability which makes it difficult to accurately establish the cost of disability in general terms.

The current study takes this into consideration by establishing the additional cost of one specific disability, vision impairment, for a specified level of vision impairment. There have been studies in Ireland which have established the cost of a disability on an individual level but based on estimates and standard of living comparisons. Research in Ireland has also estimated the cost of vision impairment on a societal level.

This study identifies the cost of vision impairment on an individual level and the cost is based on a detailed list of items agreed by individuals that live with vision impairment.

The cost of vision impairment for individuals can be influenced by their life stage, the cause of their vision loss and the level of independence sought by the individual. The current study establishes the cost of vision impairment for an individual at a specific life stage (working age, single). The study determines the level of independence sought as that which allows an individual with vision impairment to have a **Minimum Essential Standard of Living** equivalent to that of an individual without vision impairment.

This study is based on specific personal circumstances as outlined in the case study such as the individual living in an urban area so is a starting point in researching the additional cost of vision impairment. Further research is required to identify the additional cost of vision impairment for an individual at a different life stage and in a different living situation such as a rural area with poor transport links.

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Appendix C Calculating additional electricity costs

Table 18 Calculating additional electricity costs

Eurostat data cost of electricity domestic customers (euro) Semester 1 2016

| | 2016 S1 | % difference |
|---------|----------|--------------|
| UK | € 0.1951 | 18% |
| Ireland | €0.2306 | |

Weekly additional electricity costs for a single adult who is sight impaired used in the Hill et al (2017) study (sterling)

| | |
|------------------------|-------|
| UK | £0.52 |
| Ireland (18% increase) | £0.61 |

Central Bank currency rate forecast euro / pound Q1 2017

| | € | £ |
|----------------------|------|------|
| Euro / pound Q1 2017 | 0.84 | 1.00 |
| | € | £ |
| | ? | 0.61 |

Weekly cost of additional electricity €0.73

Sources: Eurostat Electricity prices for domestic consumers - bi-annual data (from 2007 onwards); Hill et al (2017) energy calculations; (Central Bank, 2017)

Eurostat (2017) electricity prices for the first semester of 2016 (most recent data) were used to compare the cost of electricity in the UK and Ireland. Ireland's electricity was 18% more expensive than that of the UK during the first semester of 2016.

The Hill et al (2017) study added £0.52 extra a week to their energy budget to cover the cost of additional electricity usage for an individual with sight loss. In order to find out the equivalent cost of additional electricity for a single adult with vision impairment in Ireland, the UK cost was increased by 18% in line with the Eurostat data, amounting to £0.61 per week.

The Central Bank (2017) forecasts for conversion rates Euro/Pound for the first quarter of 2017 were used to convert this cost into Euro (£0.84/€1.00). This resulted in an additional weekly cost of electricity for an individual with vision impairment of €0.73.

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