

Experiences of Living with Visual Impairment: Matching Income with Needs

Research Findings
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This publication summarises findings from research commissioned by Thomas Pocklington Trust to investigate the experiences of visually impaired people who are living on a low income and how they meet their needs. The research was conducted by Katherine Hill, Claire Shepherd and Donald Hirsch from the Centre for Research in Social Policy, Loughborough University.

Summary findings

- Working age visually impaired people can find it hard to access or sustain employment that could help them meet their material, social and disability-related needs. Support in and into work can help, but some feel the odds are stacked against them.
- State benefits are therefore vital, whether contributory or means-tested support or extra cost benefits, but they can be difficult to access, stressful to claim and fall short of meeting the cost of a minimum living standard for visually impaired people.
- Pension age visually impaired people are at most risk of not meeting the income required for a minimum living standard if they have a low pension and are not receiving extra cost benefits such as Attendance Allowance. Registration can trigger benefits assessment and other support but there is uncertainty about the registration process among pension age people.
- Visually impaired people on low incomes prioritise their basic material needs, but also consider it important to be able to afford social participation and avoid the risk of isolation. This involves covering the extra costs of transport and human support, which are more restricted when budgets are limited.
- Visually impaired people can miss out on access to technology and other aids that could support them in performing daily tasks and maintaining independence – due to the cost, limited knowledge about what is available or support in using it.



- Human support can make a vital difference to visually impaired people's lives, but access to it is variable. Self-funded paid support and local authority funded social care tends to cover practical needs and essential trips out. Informal help is more likely to support socialising outside the home but depends on the strength of networks and feelings about asking for help.
- Organisations and services provide important practical, financial and social support for visually impaired people, but the extent of provision and knowledge about what is available is varied, and there are concerns about cuts.
- Living on a low income can involve insecurity for visually impaired people around work, changes to benefits, support and services. This is compounded if they are unable to put money aside for when things go wrong or for future extra needs. Public policy needs to provide greater security and continuity, but in times of austerity it can create uncertainty and anxiety about provision of services and benefit reassessment.
- Ways of helping lower income visually impaired people should include providing good information about what benefits, services and support is available, plus help and training in the use of assistive technologies. Timely information and support when people become visually impaired would be helpful, when the challenges can be the greatest but knowledge of what is available the lowest, particularly for those experiencing sight loss in pension age.

Background

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

“Visually impaired people on low incomes prioritise their basic material needs, but also consider it important to be able to afford social participation and avoid the risk of isolation.”

Research aims and method

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

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

Findings

Factors affecting income

Low disposable income (in relation to the MIS VI level) can be influenced by low gross income from earnings, pensions and benefits, and by high housing costs.

For working age people, the most serious shortfalls occurred for those falling below benefit 'safety net' levels. Having to pay a mortgage or having high rents not fully covered by Housing Benefit could also cause low disposable income.

It was rarer for pension age people to fall very far short of their income needs. Pensioners at most risk are those with a low pension but not receiving means-tested top-ups such as Pension Credit or extra cost benefits such as Attendance Allowance. The latter are particularly important to those receiving Pension Credit, which attracts supplements for those on extra-cost benefits.

Work and earnings

In most but not all cases, any earnings brought participants nearer to the MIS VI level than those without work, an important issue given that only one in four working age visually impaired people are in work. The contribution of earnings to visually impaired people's incomes was impacted by:

- **Negative experiences of looking for work:** Constant rejection was 'disheartening', and eventually seen as a waste of time and effort. Visual impairment was felt by some to stack the odds against them.



- **Experiencing a sudden or drastic change in income:** Having to stop or change work when sight deteriorated can create a major shock to finances.
- **Factors that can help to find or sustain employment:** This includes in-work support from Access to Work; having a supportive employer; help from VI organisations; volunteering; and Permitted Work within out-of-work benefits.

Access to benefits

The crucial issue for visually impaired people of being able to claim appropriate benefits successfully was influenced by:

- **Accessibility:** Communications about benefits were commonly sent in inaccessible standard print which could lead to missed appointments and relying on others to read letters and complete forms.
- **Presenting disability on an application:** Claimants disliked having to unpick their daily actions, think about their 'worst possible scenario' and focus on what visual impairment meant that they could not do.
- **The assessment process:** Some working age participants had encountered difficulties with accessing venues and found the assessment and appeal process stressful. The prospect of reassessment caused worry and uncertainty.
- **The importance of registering as sight impaired or severely sight impaired:** This could bring financial, practical and social advantages as it triggered visits from social services, benefits advice and needs assessments leading to benefit receipt, low vision aids and access to VI networks. However, there was uncertainty about the process among pension age participants: not all were registered, and those who were had experienced varied routes to becoming so.

How people meet their needs

Basic material needs

Material necessities including housing costs, utility bills, basic clothing and basic food needs were generally met and prioritised by participants. Compromises were sometimes made, occasionally having to 'stretch' a food shop at the end of the month or sharing accommodation to keep housing costs down. Other costs were also sometimes viewed as important non-negotiable living costs such as extra insurance payments for home emergency services where people did not have anyone on hand to call on, or additional premiums for more expensive household items, mobile phones, or medical costs to limit high unexpected expenses.



Maintaining social participation

Socialising was cited by many of the participants as the next priority after bills and food. Several noted the risk of isolation, especially when living alone – getting out and meeting other people had a positive impact on wellbeing, helped limit seclusion and allowed people to discuss shared experiences and gain useful information.

“If I had to prioritise it I would say that I will always make sure that my bills are paid first, probably it would be socialising would be my next big expenditure and important to me because without that I wouldn’t cope at all so for me to be able to get out you know ... emotional wellbeing is really an important thing.” (WA, SSI).

Participants were involved in a wide range of activities; however, many felt they did not go out as much as they would like to – both for practical and financial reasons. Social participation can incur additional costs related to visual impairment such as paying for transport, treating a friend as reciprocation for practical help, and for some, spending more on maintaining their appearance where they cannot see to do this themselves. Some participants had to restrict spending on socialising in order to prioritise their limited budget on basic needs, and most said that if their finances improved then social activities including holidays would be an area where they would spend more money.

A further aspect of social participation is volunteering. Participants discussed the wide range of volunteering roles they performed. These developed people’s skills, boosted confidence, provided purpose and satisfaction in helping others, but importantly this highlights the contribution visually impaired people make to organisations, local communities and society.

Transport and location – taxis, access to public transport and local facilities

Transport is closely linked to social participation. Taxis can be an important, but costly, means of getting out to socialise, shop or attend appointments – especially for some participants with little or no sight and those unable to access public transport or lifts from family or friends.

Higher costs were associated with living in a rural area or location without major amenities and limited bus services. Where people did not have informal support for lifts or sufficient Personal Assistant (PA) time they either had to pay for a taxi to get to a supermarket or shop locally with higher costs. Trips to towns to access better facilities or attend a group or activity could involve long bus journeys, which can be particularly difficult for older



people with visual impairment and limited mobility. The cost of a taxi for long journeys could inhibit people travelling, which risks social isolation and limits opportunities to attend VI groups, meet other visually impaired people and gain useful information.

In urban locations, taxis were also sometimes necessary, where people felt unsafe walking to a bus stop which involved crossing a road or no pavement and where there were limited evening services to suburbs. In areas where disabled people received subsidised taxi journeys, they were widely used and less cost incurred.

Spending on taxis was an area subject to restriction, deliberation and cutting back if money was short. Participants, especially those of working age, felt that if they had more money in their budget they would use taxis more often, which could enhance their social life and allow more flexible and spontaneous travel.

Accessing and using technology and specialist equipment

Technology and specialist equipment provided participants with important support to maintain independence and help with daily tasks. Software, video magnifiers, CCTV or scanner reader devices enabled people to read their own mail rather than rely on others. The multi-functionality and accessibility features of smart phones were valued and additional apps could lessen the need for separate devices. For some participants they were vital – from getting around alone to dealing with problems in the home – meaning managing without one was hard to imagine.

Some participants had received expensive equipment second hand or free via VI organisations. However, the cost of some specialist items or technology limits accessing, or replacing and updating equipment, such as computer software or a laptop with the specification required to run software. This restricts access to the internet, having to make do with limited functioning equipment, or carry out tasks on a smartphone instead of a computer and can mean extra 'hassle', relying on others, or using credit. The price of devices or software could be off-putting for people wanting to try them out, and act as a barrier to accessing technology or getting online.

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



Being unable to access the internet can exclude people as more services go online and not using online options can mean missing out on cheap deals or offers and incurring extra costs for services.

Knowledge of specialist equipment and technology – what is available and how to access it – was lacking for some participants, particularly those of pension age (the majority of people with sight loss) who could be missing out on beneficial devices. There were also felt to be gaps in accessing IT training and a need for more local face to face provision to help people make the best use of technology.

Money for contingencies and savings

Participants expressed the need to have some leeway in their budget to enable saving to cover unexpected and longer-term costs. Being without savings or flexibility in a budget could cause difficulty where unable to afford to buy or replace necessary high cost items, and also insecurity around the financial implications of future deterioration in sight or general health and changes to disability benefits or social care support.

Access to support that makes a difference

The experience of living with sight loss on a low income is profoundly affected not just by money but also by support from people and organisations.

Human support

Various forms of human support provided help with day to day tasks around the home, getting out and maintaining independence.

- Some participants, particularly those with little or no sight, received local authority funded social care. This provided formal support, at no cost or a contribution, that would have been hard or impossible to afford otherwise. For those without regular informal support this resource was crucial.

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

Social care generally covered daily living tasks. Some participants had to ‘cram’ tasks into their set hours and wait between visits if they could not pay for more support. They would have appreciated more time to support social activities, however were conscious that it was assessed annually and there were fears that it could be cut.



- Informal support from family, friends and neighbours can be instrumental in meeting everyday needs and reduce the necessity to pay for formal support. It provided practical help – more than the basics, social opportunities including holidays, emotional support and the security of having someone to depend on. However, availability of informal support varied. Those without it were more dependent on social care, paying for help or just lacked that ‘extra bit of help’. Reciprocation was important in accepting informal help to show appreciation and redress the balance, as people did not want to feel indebted to others. Informal support is not a given, as family relationships can be complex, subject to instability and changing dynamics.
- The greatest costs for support fell on participants who self-funded paid help. Paid-for services were most often used by pension age participants and working age participants with no useable sight and varied from help with cleaning or gardening to having a PA. Key issues were flexibility in the tasks undertaken and time provided and finding the ‘right’ person. Finding the money to fund paid-for help from stretched budgets was not always possible, and this was an area some participants would have liked to spend more money on if they had it.

For those without access to (sufficient) local authority funded or self-funded support and who do not have regular informal support, needs could be compromised or unmet. In particular, this could limit access to social activities outside the home and allow tasks within the home, such as dealing with paperwork or household repairs, to accumulate or mean having to get by without help.

Support from services and organisations

National and local visual impairment (VI) charities and services, other third sector organisations and statutory services could make a practical, financial and social difference to visually impaired people, through:

- Items and equipment including free basic low vision aids. For older people this was often linked to registration and helpful in the early stages of sight loss when they did not know what is available. A few working age severely sight impaired participants had been supplied with expensive vital equipment that they would not have been able to afford otherwise.
- Training and support ranging from employment skills, IT, braille to cooking skills. Mobility training was important for severely sight impaired participants, though this was an unmet need for some older people who had become sight impaired.

“For those without access to (sufficient) local authority funded or self-funded support and who do not have regular informal support, needs could be compromised or unmet.”

- Information and advocacy, in particular helping with benefit claims and appeals.
- Support getting out through the provision of guide dogs, local guiding services or partner schemes.
- Activities and groups providing opportunities to socialise and share information with others in similar situations. Social groups were particularly valued by pension age participants and an important contact with VI organisations. Working age participants were more likely to be involved in VI activities or sports, but provision varied and some noted a lack of social opportunities for their age group.

Knowledge about what is available is crucial to accessing services and is influenced by: length of time of visual impairment; extent of involvement with VI organisations, social groups or other services; registration; and confidence around asking for help. While being involved in one thing could lead to another, participants noted a need for better information sharing.

Cuts or changes to services such as warden cover and charges, library, chiropody and VI provision had affected some participants and there was concern that reduced funding would impact on services in the future.

Access to mainstream services can make a difference with getting the best out of the income people have available. It is important that companies communicate in accessible formats and have accessible websites to support financial independence, which wasn't always the case. While internet banking and billing could be helpful, those who do not use technology should not be penalised or charged more for communication.

Health and interaction with visual impairment

Participants in this study had a range of health conditions, including diabetes, and for those of pension age, arthritis, mobility and hearing difficulties. Health conditions alongside visual impairment can make a difference to people's needs and costs.

- Limited mobility can make it harder to use public transport, meaning an increased use of taxis or relying on lifts.
- Where hearing is also impaired it cannot be used to help cope with visual impairment – affecting use of audio, social interactions and confidence if unable to hear or see traffic.
- Other health conditions can involve frequent appointments, specific food and dietary requirements, or spending on private treatments or insurance.



- Mental health can be affected by the emotional impact of the loss of or deterioration in vision, loss of work and income, and dealing with the benefit system.

Conclusions and recommendations

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

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

Potential barriers that can impede meeting needs include: poor health; poor access to local facilities and public transport; and lacking knowledge of how to claim benefits, how to become registered with the local authority as visually impaired, where to find services and support or what technology may help. Some people face greater needs when they become visually impaired, especially in the early stages of sight loss.

Nonetheless, income remains crucial in accessing basic material needs, addressing the extra costs of disability and oiling the wheels of social participation. It enables reciprocation for the help that friends give you or to take taxis where needed. Having enough income helps visually impaired people to maintain independence and agency, and provides security or a buffer to protect them when things go wrong and cover the high cost of equipment or technology.

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

"I just think that the more cuts and the more scrutiny that they do, it could all fall down, it would only take, you know when they do a reassessment of the PIP or the ESA for me to fall through that

"Living under the shadow of potential changes to vital benefits and support can be a cause of anxiety, adding further uncertainty to visually impaired people's lives."

hole and I could be losing everything ... I get zero council tax ... if they said they couldn't cover that you know what I mean? And let's say they put up my care contribution, and my PIP changed to a lower rate, I can just see me falling through this hole and through the cracks. And that is my fear, you sit here worrying. You have got enough problems with your sight problem and how much of a struggle it is and what help you can get and the health and then they are trying to chop your legs off at the same time." (WA, SSI)

Key policy messages emerging from this study:

- Many visually impaired people, particularly those on working age benefits, need more adequate and secure sources of income than offered by the present system to help cope with the uncertainties of deteriorating sight and to build up savings that allow the purchase of expensive equipment when needed. Constant changes in the benefits system bring precarity rather than stability and can be the source of considerable stress.
- Ways of helping lower income visually impaired people should include providing good information about what benefits, services and support is available, advice and advocacy when things go wrong, help and training in the use of assistive technologies and less stressful pathways to claiming the benefits to which they are entitled.
- People need information and support when they first become visually impaired, when the challenges can be the greatest but knowledge of what is available the lowest. Crucial support comes from being well linked in to VI networks, which can be triggered by registration and its follow-up. Access to VI groups before registration can also be valuable. This research suggests that there is a gap in support, especially for pension age people who become visually impaired, and a need to give timely assistance to those trying to cope with the early stages of sight loss. A more joined up system for providing such support would be a good start in improving the sight loss pathway and life in general for people at a critical time.

Authors and terms

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

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How to obtain further information

This paper is a summary of the full report entitled: 'Experiences of living with visual impairment: matching income with needs' which is available at www.crsp.ac.uk/publications or www.pocklington-trust.org.uk.

Free accessible formats of the full report or this Research Findings document are available on request from Thomas Pocklington Trust:

Telephone: **020 8995 0880**

Email: research@pocklington-trust.org.uk

Web: <http://www.pocklington-trust.org.uk/contact/>

About Thomas Pocklington Trust

Thomas Pocklington Trust is a national charity dedicated to delivering positive change for people with sight loss.

Research is central to Pocklington's work. The research we fund supports independent living and identifies barriers and opportunities in areas such as employment, housing and technology.

We work in partnership and share our knowledge widely to enable change. We provide evidence, key information and guidance for policymakers, service planners, professionals and people with sight loss.



for people with sight loss

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