

**UK benefit uptake among blind and partially sighted people**

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**Summary:**

* This new research shows a substantial deficit in the take-up of disability benefits among people who are registered blind or partially sighted due to multiple barriers, including poor communication and the challenge of getting to face-to-face appointments. Around one in four blind and partially sighted people (83,000) in the UK are not getting disability benefits they are entitled to.
* People in a low-income household face barriers to claiming disability benefits, while in other households, non-receipt of disability benefits will be the cause of their low income.
* People with sight loss in employment might be particularly susceptible to the barriers caused by welfare stigma and internalised guilt in claiming benefits. Those from ethnic minorities are more likely to face multiple barriers to receiving benefits, including difficulties with language and lack of knowledge and experience regarding the social security system.
* The findings highlight the ongoing need to identify and provide targeted support to specific groups within the blind and partially sighted population who are particularly vulnerable to disengagement with the benefits system, while addressing clear structural barriers to claiming disability benefits in the wider population.

# Executive summary: Blind and partially sighted people face barriers to uptake of benefits they are entitled to

Although they have a higher risk of poverty than in the general population, blind and partially sighted people may be able to improve their financial situation by claiming all the benefits they are entitled to, this research, produced by the University of Loughborough for RNIB, shows.

However, multiple barriers exist that can prevent uptake of benefits, in particular, disability benefits. This can include primary non-take-up – where people who are eligible for social security benefits knowingly, or unknowingly, do not claim them; and secondary non-take-up – where people who have applied for benefits have erroneously had their claim rejected.

Blind and partially sighted people in particular may have concerns around the lack of specialist knowledge of healthcare professionals who are assessing claims for disability benefits. Evidence indicates they can find it difficult to work within the confines and constraints of the application criteria, which can make them feel overlooked in the application process. They may also be deterred by the high rate of rejections and need for appeals when applying for disability benefits. Stigma may also contribute to negative perceptions of the social security system.

All of these factors may contribute to non-uptake of benefits among the blind and partially sighted population. However, until now, the extent of this issue has not been quantified. In this report, we aim to address this gap by modelling benefit uptake among blind or partially sighted people, initially focussing on disability-related benefits: Personal Independence Payment (PIP), Disability Living Allowance (DLA) and Attendance Allowance (AA).

We estimate around 83,000 people in the UK are not getting disability benefits to which they are entitled due to their sight loss. Reflecting the higher prevalence of blindness and partial sight among older people, the numbers are concentrated in the group aged 65 and older, with 29,000 men and 37,000 women in this age group estimated to be entitled non-recipients (ENRs). In all age groups, men are at greater risk of being an entitled non-recipient (ENR), with a rate of 28 per cent, compared with 22 per cent in women. Although they are fewer in number, those aged 16-44 show the highest risk of being an ENR, with a total of 27 per cent not receiving any disability benefits.

**Table A: Estimated number and percentage of those registered blind or partially sighted who are entitled to claim disability benefits, but are not receiving them.**

This table contains four columns and five rows.

|  |  |  |  |
| --- | --- | --- | --- |
| **Age group** | **Number (per cent) of entitled non-recipients:****Male** | **Number (per cent) of entitled non-recipients:****Female** | **Number (per cent) of entitled non-recipients:****Total**  |
| 16-44 | 3,000(30.3 per cent) | 2,000(24.1 per cent) | 6,000(27.4 per cent) |
| 45-64 | 6,000(24.7 per cent) | 5,000(18.1 per cent) | 11,000(21.3 per cent) |
| 65+ | 29,000(29.2 per cent) | 37,000(22.2 per cent) | 66,000(24.8 per cent) |
| Total  | 38,000(28. per cent) | 44,000(21.7 per cent) | 83,000(24.4 per cent) |

Further analysis reveals a higher risk of non-take-up in:

* People in low-income households
* Working-age people in employment
* People in minority ethnic groups

Although we cannot identify the causal factors underlying these differences, we can speculate as to the underlying drivers. In the case of low income, being in a low-income household will likely be a barrier to claiming disability benefits, while in other households, non-receipt of disability benefits will be the cause of their low income. Those in employment might be particularly susceptible to the barriers caused by welfare stigma and internalised guilt in claiming benefits. Those from ethnic minority groups are more likely to face multiple barriers to receiving benefits, including difficulties with language, and lack of knowledge and experience regarding the social security system.

**Conclusion:**

There is a substantial deficit in the take-up of disability benefits among people who are registered blind or partially sighted. Around 83,000 (or 1 in 4) people who are blind or partially sighted in the UK are missing out on benefits they are entitled to. Our findings highlight the ongoing need to identify and provide targeted support to specific groups within the blind and partially sighted population which are particularly vulnerable to disengagement with the benefits system, while addressing clear structural barriers to claiming disability benefits.

# Introduction – Addressing the low benefit uptake of people with sight loss

Blind or partially sighted people are at greater risk of poverty than the general population, particularly those who are working age. Data showing the eligibility and receipt of benefits among blind and partially sighted people could help others to reduce their risk of financial hardship by claiming all of the benefits they are entitled to. The Department for Work and Pensions (DWP) produces statistics on benefit take-up for a limited number of means-tested benefits. Only pension credit take-up statistics are available for the most recent year. To produce these, the DWP uses a policy simulation model based on the Family Resources Survey (FRS), combined with administrative data, to identify entitled non-recipients (ENRs). However, currently there are no reliable estimates of benefit take-up among blind or partially sighted people.

The analysis outlined here aims to address this gap by modelling benefit take-up among blind or partially sighted people, initially focussing on disability-related benefits: Personal Independence Payment (PIP), Disability Living Allowance (DLA) and Attendance Allowance (AA).

We address three key research questions in this report:

1. What is already known about the barriers to accessing benefits for blind and partially sighted people and their eligibility for these benefits?
2. How many blind and partially sighted people in the UK are not claiming benefits they are entitled to?
3. Are certain subgroups of the blind and partially sighted population at particular risk of not claiming the benefits they are entitled to?

We conducted a review of the literature to identify and evaluate the experiences of claiming benefits among people who are blind or partially sighted. Informed by our findings, we carried out a series of analyses to estimate the number and proportion of blind and partially sighted people who are not receiving the disability benefits they are entitled to (Question 2), and the variation in this risk among subgroups of the population (Question 3). The analysis draws upon administrative data on the number of people registered blind or partially sighted in the UK nations, estimates of the distribution of this population by age and sex, and estimates of the prevalence of entitled non-recipients in the Family Resources Survey.

# Review of the literature and existing evidence

Before presenting our empirical analysis to provide new evidence on the non-take-up of disability benefits among blind and partially sighted people, this section provides context. In reviewing existing evidence, we focus on barriers to accessing benefits for blind and partially sighted people, pointing towards areas of analysis that could be valuable to consider and providing insights into what might be driving the patterns observed in the subsequent findings.

Three studies revisited throughout the literature review conducted research to directly understand benefit take-up and barriers for blind and partially sighted people (Davies et al, 2017; Douglas et al, 2008; Ellis et al, 2015). Ellis et al (2015) and Davies et al (2017) outline qualitative studies conducted around the time that Personal Independence Payments (PIP) replaced Disability Living Allowance (DLA) for adults.

The studies aimed to explore the impact of the transition from DLA to PIP on blind and partially sighted people, and in doing so identified different barriers to claiming benefits. In a study conducted before the introduction of PIP, Douglas et al (2008) carried out surveys to examine experiences of Attendance Allowance (AA) and DLA among blind and partially sighted people.

These studies share clear themes, which inform the headings used in this review, where the overarching barriers to benefit take-up for blind and partially sighted people include: a lack of clear information; feeling overlooked in the application process; perceptions and experiences of inadequate professional understanding and conduct; challenges of attending face-to-face assessments; accessing support; applicant input, appeals and waiting times; and welfare stigma.

These themes are placed with the context of the broader literature. For example, evidence of the everyday experiences of blind and partially sighted people are useful for understanding why particular aspects of claiming social security benefits become challenging.

Similarly, reviews of benefit processes and procedures from a more general perspective add further evidence to the barriers reported by blind and partially sighted people. While this review includes evidence about DLA and AA, it mainly draws on studies about PIP as this is the benefit which is most relevant for blind and partially sighted people currently claiming or making a claim in the future. The studies examining benefit take-up and barriers tend to be based on people who are (or have been) receiving benefits, as opposed to those who the barriers have prevented from claiming benefits in the first place, which highlights the potential issue of access to the latter type of research participant and data.

## A lack of clear information

Existing literature indicates that awareness among claimants and potential claimants of social security benefits and processes is highly variable. Claimants have expressed confusion about:

* How benefit award decisions are made.
* What is required at each stage of a benefit application.
* The timing of each application stage.
* The types of evidence required and from whom.

In other cases, blind and partially sighted people who have been identified as potentially eligible for benefits have also demonstrated little awareness of their benefit options. Confusion regarding benefit claims processes has been identified as a consequence of ineffective communication from the Department for Work and Pensions (DWP).

People can become anxious and uncertain about what is required of them at each stage of the benefit application process (Gray, 2014; Ploetner et al, 2020), and this is made worse by poor communication processes from the DWP. Ellis et al (2015) found that some family members acting as appointees, making applications on behalf of claimants of PIP, had received incorrect information and/or struggled to gain clarification on what was required for the appointee process.

Concerns about the level of customer service for benefit claimants were also expressed by DWP staff and assessment professionals, who reported that even they found it difficult to access information which would allow them to provide claimants with accurate information about the processing timeline of their benefit applications (Gray, 2014). Claimants can feel that the onus is on them to take action to clarify the application process and criteria. Some study participants have described only receiving the information they were looking for when they had used “the ‘correct phrases’ to trigger a certain positive response from DWP” (Ellis et al, 2015, p.20).

Another identified barrier to benefit take-up is that a person may not know about their benefit options and eligibility. Primary non-take-up describes people who are eligible for social security benefits but who knowingly or unknowingly do not claim them (Van Mechelen and Janssens, 2017), highlighting the importance of clear information and guidance around eligibility and application processes. Hill et al (2018) found in a series of 26 interviews that application for AA among pension-age blind and partially sighted people tended to follow registration of their blindness or partial sight and a visit from a professional from social services or a local organisation. However, this was not the same for all interviewees receiving AA, with some learning about the benefit from their optician or consultant, while others came across information by chance. There were four interviewees in the study not receiving AA who were either more recently registered as blind or partially sighted or not registered at all. In these cases, one interviewee said they had been told they were not eligible for the benefit, while the remaining three interviewees said they were either unaware of the benefit or had not considered applying.

The barriers for blind and partially sighted people may also intersect with others relating to a person’s characteristics, experiences or circumstances. For example, immigrants and ethnic minorities may be less likely to know about eligibility criteria for benefits or have experience of making a claim (Moffatt and Mackintosh, 2009; O’Reilly et al, 2021). Ethnicity can also intersect with language, age and gender; Moffatt and Mackintosh (2009) found that ethnic minority older women were more likely to rely on their husbands or other family members for contact outside of the home. The authors cited health problems and sensory loss as adding further barriers. In another example, it has been suggested that evidence of lower benefit take-up in rural areas may indicate a better awareness of eligibility and application criteria in urban areas where there may be greater access to information (O’Reilly et al, 2021). These examples of intersectional barriers make a strong case for clear, readily available and easily accessible information about eligibility criteria and the application processes for claiming benefits.

## Feeling overlooked in the application process

Blind and partially sighted people describe feeling that their needs are overlooked at several points in the application process. For example, they have reported that application forms and correspondence are often received from the DWP in an inaccessible format, such as letters with standard print (Davies et al, 2017). This has led to missed appointments as well as barriers to completing applications (Hill et al, 2018). People have said that inaccessible formats have meant having to rely on family members and friends for support (support is discussed further below). DWP accessibility best practice suggests that people will be offered accessible formats, rather than having to request them, although it appears that this regularly does not happen (Ellis et al, 2015).

Evidence also demonstrates that blind and partially sighted people find it difficult to document their needs within the confines set by application questions and criteria (for example, for PIP). RNIB (2012) identified that PIP criteria emphasise the individual’s basic needs and concentrate on needs in the home. Focusing on needs in this way overlooks the nuanced challenges faced by blind and partially sighted people, that while they may have developed strategies which help them to navigate home and familiar spaces, their needs can change when they are outdoors or in new places (Cairns et al, 2009; McManus and Lord, 2012). In the application for PIP, blind and partially sighted people have little opportunity to demonstrate these needs.

‘Consequently, participants felt that, to sufficiently reflect what it is like living with a sensory impairment, they had to ‘shoehorn’ experiences of living with a visual impairment or dual sensory loss into irrelevant questions.’ (Davies et al, 2017).

In the case of PIP, the success of an application and the level of award a person receives is dependent on a points system. The case for the needs of blind and partially sighted people inevitably appears to fall short of what is required for an award or the highest level of award (Hillet al*,* 2015), because of the restriction in the types of questions used in the PIP application forms.

This may lead to what Van Mechelen and Janssens (2017, p.4) refer to as secondary non-take-up, where eligible claimants make a claim for a benefit but are ‘unrightfully rejected’ due to ‘errors in the evaluation procedure.’ The wider literature demonstrates how unrightful rejection of claims can result from application design, for example if questions more relevant to particular conditions tend to produce lower scores (Machin and McCormack, 2021) or if claimants find application forms inaccessible (Allen et al, 2016; Davies et al, 2017). Secondary non-take up of PIP is also evidenced in the high rate at which initial award decisions are overturned in the claimant’s favour (see discussion of appeals below), indicating that there may be many more eligible claimants who do not appeal an initial negative outcome.

## Lack of confidence in healthcare professional expertise

Literature on claimant experiences draws attention to concerns around the expertise and understanding of healthcare professionals. Healthcare professionals become involved in the application for PIP, for example, during a face-to-face assessment stage which can occur to collect more information about a person’s conditions or treatments, after the claimant has submitted the application forms and supporting documents (Gov.UK, 2023).

Claimants have reported a lack of confidence in the qualifications of healthcare professionals, who sometimes do not possess medical or professional experience relevant to their particular condition (Davies et al*,* 2018; Gray, 2014; Gray 2017). In a study with people with sensory loss, interviewees said that their assessors’ occupations, and therefore expertise, was often in unrelated fields, including mental health, gynaecology and occupational therapy (Davies et al*,* 2018). The most recent independent review of PIP assessment found that claimants were not confident in the ability of healthcare professionals to accurately determine or appreciate the impact of their condition, leading Gray (2017, p. 8) to conclude that:

‘…whether a Health Professional is a specialist in a particular health condition should not have an impact on their ability to conduct a functional assessment, providing adequate training is in place. However, given that this is a very real concern for claimants, the Department and Assessment Providers should do more to reassure claimants about the adequacy of training given to Health Professionals.’

It is not clear whether training for health care professionals acting as assessors is adequate, however, and claimant experiences indicate that concerns of professional understanding and conduct go beyond claimant perception. Claimants want to trust the health care professional as their assessor to relay information about their condition correctly on the assessment form ([Ellis et al*,* 2015; Ploetner et al, 2020)](http://pure-oai.bham.ac.uk/ws/portalfiles/portal/26714030/Report_PIP_DLA_14_Case_Studies_30_03_15_final_.pdf). However, a recent conversation analysis study highlighted that assessors can question applicants in ways which minimise their needs and lead them to produce low scores on the assessment (Webb and Albert, 2022). Lacking condition-specific knowledge is also identified as contributing to other aspects of poor practice, with some claimants left upset by the application and assessment process. For example, in one case a healthcare professional asked a claimant to lock their guide dog away in another room before the face-to-face assessment (Davies et al*,* 2017).

## Challenges of attending face-to-face assessments

Face-to-face assessments typically take place in an assessment centre. Applicants can request for the assessment to be carried out in their home, but they are not always made aware of this option. There also seems to be a lack of consistency in what is offered to blind and partially sighted applicants. For example, while some of the participants in the study conducted by Ellis et al (2015) expressed surprise at being offered a home visit for the face-to-face assessment without having requested one, Davies et al (2017) found that only those participants who actively asked for a home-based assessment received one.

‘From participants’ experiences, the extent or severity of a participant’s sight loss or dual sensory loss did not seem to be a key factor; nor did any detail of participants’ sight loss included on their PIP2 form appear to have been considered. Participants who had stated on their PIP2 form that they found leaving the house alone difficult were still asked to attend a face-to-face consultation at an assessment centre.’ (Davies et al, 2017, p. 42).

Getting from place to place outside of the home can be very difficult for blind and partially sighted people (Magnus and Lord, 2012; Slade and Edwards, 2015). Blind and partially sighted claimants expressed concern and difficulties around getting to assessment centres, as they can be far away from their homes, requiring them to navigate unfamiliar transport routes (Davies et al, 2017; Gray, 2014). Issues with assessment venues, such as poor signage and lighting, have also been reported (Hill et al, 2018).

Evidence from Gray (2014) indicates concern among assessment providers about the low attendance at these face-to-face appointments. In the same study, participants were also critical more generally about how face-to-face appointments were booked and managed. There were issues of ‘insufficient notice of appointments, letters received after appointment dates, last minute cancellations and home visit assessors failing to attend’ (Gray, 2014, p. 37). These issues have been described by claimants as inconsiderate of the lives of disabled people and their families (Ellis et al*,* 2017).

## Accessing support

Blind and partially sighted people may need support to make a claim for a number of reasons, exacerbated by the barriers already presented above. Shortcomings in accessibility of DWP correspondence and application forms are key, and can undermine the independence and privacy of blind and partially sighted people (Hill et al, 2018). Support makes a crucial difference to the application process. Douglas et al (2008, p. 8) found that blind and partially sighted people were more likely to receive a positive outcome for DLA when they had received advice:

‘There is clear evidence that receiving advice is associated with successful application for DLA (60 per cent of those who had successfully applied for DLA had received advice, compared to 38 per cent of those who were unsuccessful).’

To overcome the barriers of the application process for social security payments, support is often necessary. However, many blind and partially sighted people lack access to support. According to Slade and Edwards (2015, p. 7), ‘four out of every 10 blind and partially sighted people [feel] moderately or completely cut off from the people and things around them’. People may not have access to support from friends and family, or may find that asking them for support inhibits their privacy (Davies et al, 2017; Hill et al, 2018).

Davies et al (2017) found that blind and partially sighted people living alone were less likely to rely on family for support in making a claim and were more likely to look to organisations and charities instead. While this kind of formal support is considered ‘reliable and trustworthy’ (Davies et al, 2017, p. 34), there is a concern among users that services are restricted due to staffing and funding issues (Ellis et al, 2015).

## Applicant input, appeals and waiting times

Multiple issues relating to time can be off-putting for applicants and have the potential to lead to non-take-up. This includes the waiting and processing times of applications, applicant deadlines, and the further input required of applicants when they need to appeal decisions or because of changes to award periods.

Application delays and waiting times are frustrating and have been linked to deteriorating health among applicants (Gray, 2014). Ellis et al (2015) found that although the DWP had proposed a target wait time between initial PIP application and assessment of six weeks, the wait could be much longer, with several of their participants waiting between seven and 11 months. A comparison of Gray (2014) and Gray (2017) suggests that the wait for an award decision has reduced overall, however waiting times can vary widely from case to case. A recent Parliamentary Question showed the average time to process PIP applications remains high, standing at 15 weeks in July 2023 (Hansard, 2023).

Application timings are more stringent however when it comes to the deadlines placed upon applicants. For example, applicants for PIP must complete the application within one month of receiving it. Given that blind and partially sighted people have often reported receiving DWP correspondence in inappropriate formats, and given that they may often need to arrange for support from family, friends or different organisations, this could make meeting application deadlines a significant challenge (Gray, 2014; RNIB, 2012).

Machin and McCormack (2021, p. 2) highlight that an important difference ‘between DLA and PIP is that most PIP awards are for a fixed period and subject to review, this is the case even for claimants with permanent conditions.’ The requirement to fill out applications for support at regular intervals and to repeatedly prove one’s needs can become draining and stressful (Disability Rights UK, 2018; Hill et al, 2018; Machin and McCormack, 2021). People with mental health needs eligible for benefits have been observed to withdraw from the application process reporting they have felt unable to continue, even though they were receiving support as part of a benefits outreach project (Frost-Gaskin et al, 2003). Ellis et al (2015, p. 29) described a participant who expressed ‘a sense of world weariness’ at needing to fit PIP applications into her busy schedule. In the same study, it was found that applicants could find this especially frustrating where a lot of documentation already existed about their needs, as demonstrated in the case of ‘Sophie’:

‘Sophie, because she had been in receipt of DLA since she was six months old, expected DWP to have knowledge of her vision loss, including previous letters from doctors and consultants, so did not provide additional documentation (e.g. visual impairment registration status, GP and consultant letters, speech and language reports, physiotherapy reports) when applying for PIP.’ (Ellis et al, 2015, p. 29).

Applicant input can also go beyond the application itself. For example, making follow-up phone calls to chase the progress of an application or to seek clarification can be stressful as well as time-consuming.

‘…claimants and those who supported them frequently expressed frustration at not knowing how long the claims process would take nor being able to find out the status of their claim. This led to numerous repeat telephone calls to the Department and assessment providers because nobody could provide the information the claimant sought; similar telephone calls were noted by the Review during site visits. A claimant at a discussion group described telephoning the Department and the assessment provider at the same time every Monday morning over several months to see if there was any progress.’ (Gray, 2014, p. 33).

Applicants also need to invest time and resources to appeal negative outcomes, for example if they receive a lower payment rate than anticipated, or if their application is rejected. Douglas et al (2008) found that more than a quarter of their blind and partially sighted participants needed to appeal an initial decision to receive their eventual rate of award: 35 per cent for the care component and 25 per cent for the mobility component of DLA; and 23 per cent for AA. Within the PIP appeals process, for example, applicants have one month from the outcome notification date to request a mandatory reconsideration, where they have received a negative outcome. Requesting a mandatory reconsideration first involves completing and sending a seven-page form or making the request over the telephone. Claimants reportedly feel sceptical of the reconsideration stage:

‘…in particular in relation to the provision of Further Evidence. Many felt that their evidence was ignored, with the reconsideration process being deemed to be a ‘rubber stamp’ rather than a thorough audit of the original decision.’ (Gray 2017, p. 45).

Furthermore, ‘not many decisions are overturned at this stage’ (Citizens Advice, 2023) – that is, the initial reconsideration stage – and many applicants need to take their appeal to tribunal. Many decisions (68 per cent of all initial PIP decisions between April 2013 and June 2022, according to DWP (2022)) are overturned in the applicant’s favour on appeal in tribunals, calling into question the reliability of assessments. The appeals process itself can have adverse effects on the applicant, as ‘continued scrutiny of these participants’ sensory impairment caused additional stress’ (Davies et al, 2017, p. 9). Professionals included in Gray’s (2017) PIP review expressed concern that the lengthy and stressful process of appealing award decisions could contribute to the ill health of applicants. With all the potential applicant input burden in mind, people may be deterred from making a claim.

## Welfare stigma

Finally, there may be a higher-level barrier which discourages eligible claimants from accessing social security benefits, namely welfare stigma and internalised feelings of guilt and shame.

‘Welfare stigma…occurs when claimants either perceive claiming benefits as associated with a devalued identity (personal stigma), or perceive that others devalue claimants (stigmatisation).’ (Tarshish, 2022, p. 3).

Ellis et al (2015, p. 8) found that some of their blind and partially sighted participants expressed ‘defensiveness and even guilt about applying for PIP’ as well as feelings of ‘discomfort of being assessed and judged’ (p. 70). This sense of guilt likely stems from stigmatising narratives around benefits and the people who claim them (Machin and McCormack, 2021; Patrick and Simpson, 2019; Ploetner et al, 2020; Van Mechelen and Janssens, 2017).

‘People can experience claiming benefits as leading them to question their “deservingness” and feeling as if they are “seeking charity, rather than availing of a right”.’ (Patrick and Simpson, 2019, p. 479).

Welfare stigma may feed into the welfare application process itself, leading to the negative experiences of claimants, such as where they describe feeling ‘dehumanised’ and being treated as ‘merely a number’ (Ploetner et al, 2020, p. 679). Tarshish (2022, p. 3) argues that welfare stigma informs the very design of the welfare system which creates ‘burden’ for applicants and reduces ‘take-up by deterring (undeserving) claims’. Similarly, welfare stigma may explain why ‘people's own expertise about their conditions is disregarded’ in favour of top-down assessment procedures (Patrick and Simpson 2019, p. 479).

Issues of stigma and the applicant input burden overlap, and each can feed into problems of both primary (unclaimed eligibility) and secondary (erroneous rejections) non-take-up, in Van Mechelen and Janssens’ (2017) terms.

This review has identified a number of distinct but related barriers to benefit claims and take-up among blind and partially sighted people. These barriers do not only exist for blind and partially sighted people. For example, having access to clear information is important for anyone eligible for benefits, and people in particular circumstances may be far more likely to lack the awareness of their own eligibility. Likewise, attending face-to-face appointments or completing the application process for benefits in the face of long waiting times may be problematic for people for many different reasons. And yet, the evidence demonstrates the nuanced ways that these barriers can be experienced by someone who is blind or partially sighted, highlighting why each barrier described above can be so challenging.

It remains unclear, however, the extent to which these barriers – as well as potentially unknown factors – mean that blind and partially sighted people are not receiving the benefits to which they are entitled. Quantifying the magnitude of this problem, and identifying subgroups who might be particularly at risk of missing out on benefits for which they are eligible, is the primary aim of the analysis presented in the subsequent sections of the report.

# Analysis: data and methods

Below we provide a brief overview of the methods used to produce the findings in the remainder of this report.

## Estimating the population at risk

Around 340,000 people are registered blind or partially sighted in the UK (RNIB, 2021). To produce a distribution by country, age and sex we refer to estimates produced by Deloitte Access Economics for RNIB (Deloitte Access Economics, 2014; 2019). By focusing on the registered population, rather than all adults affected by sight loss, we can be confident that we have a clear and precise definition of the population at risk, the vast majority of whom will be eligible for disability benefits of some kind. However, this also means that the results outlined here are the most conservative estimates of non-take-up of benefits for blind and partially sighted people, and it is likely that the extent of the problem is much greater across the wider population of people with sight loss.

## Estimating the entitled non-recipient rate

To model the risk of being an entitled non-recipient, we used the FRS, pooling the data from financial years 2018/19 to 2021/22 to produce a sufficient sample size of eligible blind or partially sighted people. The FRS includes detailed data on benefit receipt, and also asks respondents broad questions about their health. While we cannot obtain any direct information on the type or severity of sight loss that respondents report, we are able to make some assumptions about severity using the Equality Act definition of disability, and additional questions on the impact of health conditions on day-to-day living.

The definition of blindness or partial sight with entitlement for disability benefits in the FRS states:

1. Respondent reports visual difficulties.
2. Respondent recorded as having a disability according to Equality Act 2010 definition.
3. Respondent reports that health condition severely limits their day-to-day activities.

To estimate the proportion of ENRs, we carried out regression analysis to predict whether those defined as eligible for disability benefits using the above criteria were receiving them. The model included covariates for year of the survey, sex, age band, country, and whether the respondent was registered as blind or partially sighted. We then produced predicted probabilities of disability benefit receipt, broken down by these key characteristics.

We applied these probabilities to the overall population at risk for each UK nation, broken down by age and sex (as defined in section 3.1) to produce an estimate of the total number of people defined as ENRs in each subgroup. We then aggregated and calibrated these estimates to the total population at risk in the UK.

## Subgroup analysis

To estimate the risk of benefit non-take-up in subgroups of the blind and partially sighted population, we carried out additional regression analyses, this time including estimates of risk based on three key sociodemographic characteristics: household income, economic activity status and ethnicity.

### Household income

To investigate the role of household income, we used the DWP definition of relative poverty after housing costs, with a low-income household defined as having an equivalised income below 60 per cent of the contemporary median.

### Economic activity

Economic activity was defined in four broad categories:

1. Employed
2. Unemployed/inactive
3. Retired
4. Long-term sick

### Ethnicity

Unfortunately, relatively small sample sizes for minority ethnic groups in the FRS meant that we were unable to use a fine-grained definition of ethnicity, and were limited to using a binary categorisation of white and minority ethnic. While we recognise that this masks much heterogeneity within the minority ethnic population, we have included the results here to provide an indication of the important role that ethnicity can play in determining people’s risk of missing out on the benefits to which they are entitled.

# Results

## How many blind and partially sighted people in the UK are not claiming benefits they are entitled to?

Table B shows estimates of the number of men and women who are registered blind or partially sighted in the UK, broken down into broad age groups. As expected, the number of people registered increases with age, especially after the age of 65 years. Women aged 65 and above represent the largest proportion of this population, driven both by higher life expectancy among women compared to men, and a higher risk of certain types of vision loss, such as age-related macular degeneration, among women. Among working-age people, there is little difference in the number of men and women registered blind or partially sighted.

**Table B: Estimates of the population who are registered blind or partially sighted, by age group and sex (RNIB, 2021)**

This table contains four columns and five rows.

|  |  |  |  |
| --- | --- | --- | --- |
| **Age group** | **Male** | **Female** | **Total**  |
| 16-44 | 11,000 | 10,000 | 21,000 |
| 45-64 | 26,000 | 27,000 | 53,000 |
| 65+ | 98,000 | 168,000 | 266,000 |
| Total  | 135,000 | 205,000 | 340,000 |

Table C shows the results from regression analysis in the FRS, modelling the probability that people registered blind or partially sighted are not receiving any disability benefits. Overall, nearly a quarter of this group are estimated to be missing out on benefits to which they are entitled. In all age groups, men are at greater risk of being an ENR, with a rate of 28 per cent, compared with 22 per cent in women. In both men and women, those aged 16-44 show the highest risk of being an ENR, with a total of 27 per cent not receiving any disability benefits. However, the rate is almost as high for those aged 65 and older, at 25 per cent, with those aged 45-64 showing the lowest rate of 21 per cent.

**Table C: Estimated proportions of blind or partially sighted people who are entitled to claim disability benefits, but are not receiving them**

This table contains four columns and five rows.

|  |  |  |  |
| --- | --- | --- | --- |
| **Age group** | **Per cent who are entitled non-recipients:****Male** | **Per cent who are entitled non-recipients:****Female** | **Per cent who are entitled non-recipients:****Total** |
| 16-44 | 30.3 per cent | 24.1 per cent | 27.4 per cent |
| 45-64 | 24.7 per cent  | 18.1 per cent | 21.3 per cent |
| 65+ | 29.2 per cent | 22.2 per cent | 24.8 per cent |
| Total  | 28.4 per cent | 21.7 per cent | 24.4 per cent |

Table D sets out the number of people who are registered blind or partially sighted who are ENRs. We estimate that around 83,000 people in the UK are not receiving disability benefits to which they are entitled due to their sight loss. Reflecting the higher prevalence of blindness and partial sight among older people, the numbers are concentrated in the group aged 65 and older, with 29,000 men and 37,000 women in this age group estimated to be ENRs. However, as Table D shows, the risk of missing out on disability benefits is highest for those aged 16-44, and there are still 6,000 people in this age group who are not receiving any disability benefits.

**Table D:** **Estimated number of those registered blind or partially sighted who are entitled to claim disability benefits, but are not receiving them**

This table contains four columns and five rows.

|  |  |  |  |
| --- | --- | --- | --- |
| **Age group** | **Number of entitled non-recipients:****Male** | **Number of entitled non-recipients:****Female** | **Number of entitled non-recipients:****Total**  |
| 16-44 | 3,000 | 2,000 | 6,000 |
| 45-64 | 6,000 | 5,000 | 11,000 |
| 65+ | 29,000 | 37,000 | 66,000 |
| Total  | 38,000 | 44,000 | 83,000 |

## Are certain subgroups of the blind and partially sighted population at particular risk of not claiming benefits they are entitled to?

We now investigate the extent to which certain subgroups within the blind and partially sighted population may be especially likely to be missing out on the benefits to which they are entitled.

### Household income

Figure 1 shows the ENR rate by age group and household income. A low-income household is one that has a net household income below 60 per cent median income, after housing costs. Across the age bands, being in a low-income household is associated with a markedly increased risk of being an ENR. In the total population, 41 per cent of those in a low-income household are estimated to be missing out on disability benefits to which they are entitled, compared with just 16 per cent of those who are not in a low-income household. This pattern is mirrored across the age groups.

The causal relationship between being in a low-income household and receipt of disability benefits is complex however – in some cases, being in a low-income household will likely be a barrier to claiming disability benefits, while in other households, non-receipt of disability benefits will be the cause of their low income. Additional analysis indicates that while we would estimate 24 per cent of those registered blind and partially sighted to be living in a low-income household overall, if we disregarded disability benefits from their income, this would increase to around 31 per cent. Therefore, in some cases disability benefits are acting to lift households above the poverty line.

**Figure 1: Estimated proportion of those registered blind or partially sighted who are not receiving disability benefits, by household income status and age group**

### Economic activity

Figure 2 shows the estimated proportion of people registered blind or partially sighted who are not receiving any disability benefits, by economic activity status. This indicates that for both men and women, the risk of being an ENR is highest for those who are in employment, at 69 per cent for men and 44 per cent for women. Although the survey data cannot tell us anything about why people are not receiving benefits, it seems reasonable to assume that those in employment might be more likely to be susceptible to the barriers caused by welfare stigma and internalised guilt in claiming benefits, as identified in the literature review.

The risk is also high for those who are unemployed or inactive, at 57 per cent for men and 38 per cent for women. However, those with the lowest risk are the group who report being long-term sick or disabled, at 13 per cent for men and 10 per cent for women. This is not unsurprising, given that being economically inactive for this reason is likely to be indicative of more severe disability, which may in some cases mean that their needs are more apparent in the process of applying for disability benefits, or that they have been more effectively signposted to their eligibility for benefits by other support services.

**Figure 2: Estimated proportion of those registered blind or partially sighted who are not receiving disability benefits, by economic activity and sex**

### Ethnicity

The final subgroup that we focus on is people from minority ethnic groups (Figure 3). As noted in section 3.3, due to small sample sizes, we cannot disaggregate ethnicity beyond looking broadly at white and minority ethnic groups. The results nevertheless provide a clear picture of the excess risk experienced by those from minority ethnic backgrounds. The risk is particularly pronounced at younger ages. At age 16-44, 44 per cent of people who are from minority ethnic groups are estimated to be ENRs, compared with just 23 per cent of those in the white population. This reflects the issues touched upon in the literature review around intersectional risk factors – those from ethnic minorities are more likely to face multiple barriers to receiving benefits, including difficulties with language, and lack of knowledge and experience regarding the social security system.

**Figure 3: Estimated proportion of those registered blind or partially sighted who are not receiving disability benefits, by ethnicity and age group.**

# Conclusion

People with sight loss in the UK face many barriers to gaining access to the disability benefits they are entitled to. Some of these are related more generally to failings within the benefits system, while some are specific to those with sight loss. Our review of the literature has identified key areas of concern, linked to multiple factors including difficulties in accessing clear and accurate information, a lack of tailored support in applying for disability benefits, practical obstacles to engaging with the process of applying for benefits, and negative perceptions of the social security system.

The results of our analysis suggest that these factors are contributing to a substantial deficit in the take-up of disability benefits among people who are registered blind or partially sighted. Around one in four of those who are assumed to be eligible for these benefits are not receiving them, whether because they have never applied for them, or because their application has been refused. This means around 83,000 blind and partially sighted people in the UK are missing out on benefits to which they are entitled.

It is also clear that this shortfall in take-up is not equally distributed across the blind and partially sighted population, albeit for different underlying reasons. Of particular concern is the interaction between benefit receipt and poverty; our findings suggest a strong association between living in a low-income household and being an ENR, and further suggests that some households would be pushed below the poverty line if they did not have access to these benefits. It is also notable that individuals who are in employment are particularly unlikely to be receiving disability benefits, indicating that issues around perceptions of the welfare state and ‘deservingness’ could in some cases be a key part of increasing take-up of these benefits. Finally, the strong association between ethnicity and benefit take-up is unsurprising, but highlights the ongoing need to identify these subgroups within the population who are particularly vulnerable to disengagement with the benefits system, and find ways to improve this.

The findings also point to some areas that require additional research. First, having identified the magnitude of the issue of non-take-up of disability benefits among people who are blind and partially sighted, it will be important to continue to track how this might change in the future, particularly in the context of policy reforms such as the planned changes to the work capability assessment. In terms of specific groups at risk of non-take-up, it is clear throughout the findings that men are at greater risk of being ENRs than women, additional exploration of this, perhaps through qualitative research, could help identify the underlying explanations for this, whether related to welfare stigma, lack of awareness of eligibility, or for other as yet unidentified reasons. Further analysis of the interaction between poverty, sight loss and take-up of disability benefits could also increase understanding of why people in low-income households are particularly at risk of being ENRs.

Overall, improving take-up of benefits within the blind and partially sighted population is not a straightforward task, and requires a multi-faceted approach. Nevertheless, attempting to address some of the clear structural barriers to claiming disability benefits, including those specific to the blind and partially sighted population, is an essential part of this process.

## 6.1 Notes on our analysis

The analysis focuses on the 340,000 individuals registered blind, or partially sighted, in the UK in 2021– as such, the estimates produced here are likely to be conservative, as they do not include the wider, unregistered population of people with sight loss. The 340,000 figure was the most recent figure available at the time of analysis, which was undertaken in 2023. February 2024 brought the latest data release from NHS Digital whereby RNIB now estimates the blind and partially sighted population to be around 320,000. To estimate the number of entitled non-recipients (ENRs), we use data from the Family Resources Survey for the years 2018/19 to 2021/22, and model the probability that blind and partially sighted adults defined as eligible for disability benefits were receiving them. We also carried out analysis to identify the risk of non-take-up varied according to key sociodemographic characteristics.

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# Glossary

**AA – Attendance allowance**

Benefit that helps pay for personal care for those who have reached State Pension age and are disabled.

**DLA - Disability living allowance**

Benefit to help with care and mobility needs for those living with a disability. For adults, DLA has now been replaced with PIP (see below) for all new claimants.

**ENR - Entitled non-recipient.**

An individual who is eligible to receive a particular type of benefit but is not receiving it.

**FRS – Family Resource Survey**

Annual survey of UK households containing detailed information on income, including benefit receipt, as well as information on health status.

**PIP - Personal independence payment**

Benefit for people who have extra care needs or mobility needs as a result of a disability, which has replaced DLA for people aged 16 up to State Pension age.

# About the authors

Dr Juliet Stone is Research Fellow at the Centre for Research in Social Policy (CRSP), an independent research centre based in the School of Social Sciences at Loughborough University. Over the past 40 years, it has built a national and international reputation for high quality applied policy research. The Centre’s biggest role at present is the researching and analysis of A Minimum Income Standard for the United Kingdom. Funded by the Joseph Rowntree Foundation, this is the leading standard of its kind in the UK, where it is being used to set the living wage; other countries are replicating this as they seek to establish benchmarks for acceptable household income levels rooted in social consensus.

Juliet focuses on quantitative analysis relating to low income and living standards. This includes research for the end-of-life charity Marie Curie to produce the first ever estimates of the number of people who die in poverty and working with the End Child Poverty Coalition to produce annual estimates of child poverty rates at a local level. Juliet plays a key role in the longstanding and influential Minimum Income Standard (MIS) programme of research that was pioneered at CRSP, and takes the lead on producing and analysing MIS data for a wide range of outputs, including the annual *Households Below MIS* report.

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