

# Understanding the drivers of food insecurity among disabled people: A rapid evidence review

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Prepared for: **The Trussell Trust**



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# 1. Introduction

The Trussell Trust's vision is for a UK without the need for food banks. Working towards this vision, the Trussell Trust is looking for positive solutions to address the factors which are driving people to use food banks. As part of this work, the Trussell Trust commissioned research to better understand the reasons for the overrepresentation of disabled people accessing food banks in their network. The research aimed to examine the potential impact of the disability benefits system on food insecurity and food bank use among disabled people and the underclaiming of disability benefits among disabled people referred to food banks. The transition from Personal Independence Payment (PIP) to Adult Disability Payment (ADP) in Scotland allowed for further exploration of experiences of applying for PIP compared to ADP and whether the changes made have improved disabled people's ability to access and claim ADP.

To understand what is already known about the relationships between food bank use, disability and the disability benefits system, a rapid review of evidence was conducted, exploring the following questions:

1. What is the prevalence of disability among people using food banks?
2. What are the reasons for the under-claiming of disability benefits among people using food banks?
3. To what extent does the disability benefits systems increase or reduce poverty among disabled people and households?
4. In what ways does the disability benefits system increase or reduce poverty among disabled people/households?
5. Where are their gaps in the evidence and areas requiring further exploration?

This review accompanies a qualitative study involving in-depth interviews with disabled people to explore the drivers of food insecurity.

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# 2. Methodology

## 2.1 Research questions

ScotCen conducted a rapid evidence review (RER) of the existing evidence on disabled people's experiences of the disability benefits system and the drivers of poverty and food insecurity among disabled people and disabled households in the UK. The review focussed on Personal Independence Payment (PIP) and the Adult Disability Payment (ADP). The review identified and synthesised the available evidence to improve our understanding of:

- The prevalence of disability among people using food banks.
- Reasons for the underclaiming of disability benefits among people using food banks.
- The extent to which the disability benefits system increases or reduces poverty among disabled people and households.
- Potential mechanisms by which the disability benefits system increases or reduces poverty, including:
  - The design of the disability benefits system; for example, processes of claiming and reassessment
  - Payment sufficiency
  - Intersectionality between disability status and other characteristics
  - Gaps in the evidence and areas requiring further exploration.

The review was conducted in three stages.

### 2.1.1. Evidence search

In the initial scoping phase of the project, the Trussell Trust and ScotCen agreed on several evidence sources for inclusion in the review:

- The Trussell Trust's call for evidence (reviewing references for relevant papers).
- A systematic search of electronic academic databases (e.g., Scopus, ProQuest, Web of Knowledge and Academic Search Complete).
- Sources of high-quality non-peer reviewed research from independent research agencies, the Department of Work and Pensions, Social Security Scotland and the Trussell Trust.

Inclusion criteria for the search included:



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- Date/language: published in English from 2013 (the year PIP was introduced) to present day.
  - Geography: restricted to the UK as social security systems vary widely between countries.
  - Methodology: findings from both quantitative and qualitative analyses.
  - Disability benefit: Personal Independence Payment, Disability Living Allowance or Adult Disability Payment.

Exclusion criteria for the search included:

- Opinion pieces, editorials, blogs.

The search strategy was piloted and no amendments were made.

### 2.1.2. Evidence selection

The second stage of the review involved selecting the most relevant and robust evidence for the review. Records located in the searches were entered into an Excel spreadsheet and de-duplicated. A two-stage screening process identified evidence for inclusion in the review. Firstly, abstracts, executive summaries or introductions were screened to identify potentially relevant sources for inclusion. Secondly, full texts of identified studies were assessed for eligibility in relation to the inclusion/exclusion criteria.

### 2.1.3. Evidence synthesis

ScotCen reviewed and synthesised the evidence using the 'framework method', which involved summarising the evidence thematically using analytical matrices so that the review systematically captured the information needed to address the core research questions. In addition to synthesising current knowledge in this area, the evidence review informed the qualitative interview sampling strategy and topic guide development.

## 2.2 Overview of included evidence

This review synthesised a large body of evidence. One-third of the sources of primary evidence included here are peer-reviewed articles published in academic journals. Many of these articles report findings from qualitative studies exploring disabled people's experiences of interacting with the social security system. The remaining peer-reviewed articles report findings from quantitative studies measuring associations between disability benefit reforms and processes, or explorations of the adequacy of disability benefit payments. Evidence from a small number of scoping and systematic reviews was also synthesised.

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The review includes evidence from several studies conducted by established disabled people's support and advocacy organisations such as MIND, Scope and the MS Society. Included studies frequently report mixed-methods research; for example, surveys combined with workshops, interviews or focus groups. Evidence was also synthesised from reports of research conducted by respected think-tanks and social change organisations, including the Joseph Rowntree and Resolution Foundations. Research conducted by independent researchers on behalf of The Trussell Trust and the Independent Food Aid Network provided a valuable source of evidence for this review.

The review also includes studies conducted on behalf of the Department of Work and Pensions by professional research organisations, such as The National Centre for Social Research and Ipsos MORI. A range of evidence for this review was provided by the findings of a comprehensive, large-scale Select Committee inquiry examining the assessment process for health-related benefits. The inquiry considered over 100 pieces of evidence submitted by disabled people and advocacy and support organisations. The Committee also conducted a survey of more than 8,500 disabled people and took evidence from panels of academics, assessment provider organisations, government bodies and support organisations.

This review identified several areas where there are gaps in the evidence. Relatively little has been written on disabled people's experiences of food insecurity and the implications for their physical and mental health and wellbeing. The impacts of the recent and on-going cost-of-living-crisis on disabled people's financial and food security are also yet to be explored. Studies have begun to quantify the impacts on disabled people's finances but, as yet there is no qualitative research into the impacts of the cost-of-living-crisis on disabled people and households. Finally, the transfer from Personal Independence Payment to Adult Disability Payment is still on-going and there is currently little evidence on how disabled people view the change, and how it will potentially affect them. The qualitative research conducted as part of this study addresses all of these evidence gaps.

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# 3. Low income, food bank use and food insecurity among disabled people

Over the past decade, food bank use has been rapidly increasing. In 2012-13, the Trussell Trust alone supplied 300,000 charitable food supply parcels. By 2022-23, this figure had increased 10-fold to nearly three million parcels, an increase of 37% on the previous year<sup>1</sup>. Food banks in the Independent Food Aid Network (IFAN) have seen similar increases in the need for their services<sup>2</sup>. Some food banks are struggling to keep up with demand as donations are not increasing at the same rate, and in some instances food donations have dropped as people who used to donate can no longer afford to do so. For example, nearly three-quarters of IFAN food banks reported decreased donations in the first few months of 2022<sup>2</sup>.

## 3.1 Relationship between disability status and income

While the specific circumstances that lead people to need food aid will be personal and complex, the common factor in food bank use is a lack of money<sup>3</sup>. Data from the Family Resource Survey indicate that, in the past 12 months, 9% of working-age adults and 12% of children living in low-income households<sup>a</sup> had used a food bank<sup>4</sup>. Living with an impairment or health condition, or in a disabled household, are among the strongest predictors of poverty in the UK<sup>5</sup> and disabled people are significantly more likely than non-disabled people to need food aid. Seven in ten (69%) of working-age people referred to food banks in The Trussell Trust's network have at least one impairment or health condition that meets the Equality Act 2010 definition of a disability<sup>b</sup>, a significantly higher level than among the general population (26%)<sup>1</sup>. This trend is also found among people struggling to afford food, with almost half of people facing food insecurity meeting the Equality Act 2010 definition of disability.<sup>3</sup> Compared to non-disabled people, disabled people are more likely to live on low incomes and nearly one-half of people in poverty live in a household where someone is disabled<sup>6</sup>. Deep poverty, defined as a household income 40% below the national median, is nearly twice as prevalent

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<sup>a</sup> Low-income households are those with household incomes 60% below the median.

<sup>b</sup> Defined by the Equality Act 2010 as a physical or mental impairment that has a substantial or long-term negative effect on a person's ability to do normal daily activities.

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among working-age disabled people as among non-disabled working-age people<sup>7</sup>. Single disabled adults are at particular risk of living in deep poverty due to their single incomes and inability to share costs. Over 20% of single disabled adults are in deep poverty compared to 15% of all disabled households<sup>7</sup>. In addition to living on low incomes, disabled people are also significantly more likely than non-disabled people to experience material deprivation, a measure of whether a person can afford basic items such as household contents insurance, to replace worn out or broken furniture or essential electrical items, keep up with bills, and keep their home warm<sup>8</sup>. In 2020/21, 34% of disabled people reported being in material deprivation compared to 13% of non-disabled people. Among the disabled population, people with mental health conditions experience the highest rates of material deprivation, with two in five being materially deprived<sup>9</sup>.

### 3.1.1. Economic exclusion of disabled people

Disabled people face two major sources of economic disadvantage. Firstly, there is a disability employment gap, with disabled people often excluded from paid employment<sup>10</sup>. Over 80% of working age non-disabled people are in paid work compared with 54% of disabled people<sup>10</sup>. Record numbers of working-age people are currently out of the labour force due to long-term ill health and disability<sup>11</sup>. Research by the House of Common's Library identified long-term sickness and disability as the most common reasons for economic inactivity in the UK<sup>12</sup>. The numbers of people unable to work due to their health have increased by around 400,000 since the start of the Covid-19 pandemic in 2020, with 2.55 million people economically inactive due to their health by January 2023<sup>12</sup>. People with mental health conditions or with multiple health conditions face a particularly high risk of unemployment<sup>13</sup>. In addition to an employment gap, disabled people also face a disability pay gap of around 14%, with a disabled person paid, on average, £2 an hour less than their non-disabled colleagues<sup>14</sup>.

### 3.1.2. Extra costs associated with disability

The disability employment and pay gaps, however, only partially explain the income gap between disabled and non-disabled people<sup>9</sup>. In addition to frequently being excluded from full economic participation, disabled people also face significant extra costs required to help mitigate the impacts of their disabilities. Evidence submitted for this review from the MS Society and the Guide Dogs charity report that extra costs can include the costs of buying and running assistive equipment, paying for therapies and treatments, employing paid carers, meeting dietary requirements, and accessible transport<sup>15,16</sup>. A recent study by the disability charity Scope found that on average a disabled household (defined as having at least one disabled member) needed an extra £975 a month to have the same standard of living as a non-disabled household<sup>8</sup>. Adjusting for the current high level of inflation, this figure rose to £1,122 a month<sup>8</sup>. Compounding their economic disadvantage, disabled people are also more

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likely to face a 'poverty premium' that means they pay more for goods and services such as fuel<sup>17</sup>.

### 3.1.3. The cost-of-living crisis

The COVID-19 pandemic increased financial precarity among disabled people<sup>15</sup> and the current cost of living crisis appears to be worsening the situation. People on low incomes, including many disabled people, are particularly affected by rising prices as they spend a larger proportion of their incomes on food and energy<sup>16</sup>. Since late 2021, the cost of living in the UK has continued to rise, with the inflation rate reported to be 9.2% in December 2022<sup>17</sup>. In 2022, average domestic energy bills increased by 74% and food and drink prices increased by nearly 17%<sup>16</sup>. The prices of food and non-alcoholic drinks increased by over 18% in the 12 months to May 2023, the fastest rate in more than 45 years<sup>17</sup>. Prior to the cost-of-living-crisis, disabled people were already more likely to live in cold homes<sup>8</sup>. By the end of November 2022, the proportion of disabled people reporting being unable to keep their homes sufficiently warm had increased from 9% pre-crisis to 41%, compared with an increase from 2% to 23% among non-disabled people<sup>8</sup>. A recent Resolution Foundation survey found that 48% of disabled people had cut back on energy (compared with 32% of non-disabled people) and 31% had cut back on food (compared with 18% of non-disabled people)<sup>8</sup>. The same survey found that disabled people were far more likely than non-disabled people to report that their health had been made worse by the cost-of-living crisis<sup>18</sup>.

To help with the cost-of-living-crisis, the UK government introduced time-limited 'Cost of Living Payments', including £400 for all households to help with energy bills, a £150 council tax rebate for people living in band A-D properties, and £650 for people receiving income-replacement benefits<sup>19</sup>. Disabled people receiving PIP or Disability Living Allowance (DLA) received a payment of £150. While welcome, the cost-of-living support was insufficient to cover people's extra costs. Research by the MS Society estimated that people with multiple sclerosis (assuming they received both income-related and extra-costs benefit and the council tax rebate) would receive around £800 less than the cost increases they faced<sup>18</sup>. Further, the £650 cost of living payment was unavailable to people only claiming the non-means-tested disability benefit PIP due to a government assumption that not all PIP claimants live on low incomes. However, research by the Leonard Cheshire Foundation suggests that people on PIP may avoid claiming UC due to worries over engaging with the Job Centre or because they have a partner in work but also on a low income<sup>20</sup>.

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## 3.2 Food insecurity and food bank use among disabled people

While levels of food bank use among disabled people are alarmingly high, rates of food bank use reveal only part of the state of hunger among disabled people on low incomes in the UK. Food bank use is a weak proxy measure for wider food insecurity<sup>21</sup>, with rates of food bank use revealing only the tip of the food insecurity iceberg. Food insecurity is defined in a variety of ways. For example, the DWP's Family Resources Survey (FRS) collects data on food security by measuring whether households have sufficient food to enable an active and health lifestyle<sup>22</sup>. Households are categorised as experiencing very low, low, marginal and high food insecurity<sup>22</sup>. The Food Foundation define food insecurity as experiencing one or more of the following: eating smaller meals or skipping meals; not eating when hungry due to being unable to access or afford food; and not eating for a whole day due to being unable to access or afford food<sup>23</sup>.

Accessing food aid is not an easy option. People needing food banks frequently experience shame, embarrassment and stigma<sup>24–26</sup>, with visits often occurring when someone has reached a crisis point: 95% of people referred to food banks in the Trussell Trust network met the definition of destitute, about 75% were severely food insecure, and 20% were homeless<sup>3</sup>. Lack of accessibility may also limit people's ability to draw upon food aid. There is evidence that some people are prevented from accessing food banks due to barriers such as travel costs<sup>27</sup>. In addition to needing to access charitable food aid, food insecurity takes a variety of forms, including anxiety about affording food, cutting back on the amount and quality of food, and going without food<sup>28,29</sup>. In a survey of households receiving help from a food bank over a three-month period in 2016, many respondents had experienced severe food insecurity for months before accessing a food bank<sup>30</sup>.

Disabled people are among those most likely to experience food insecurity<sup>31</sup>. Research by The Trussell Trust found that one in four (26%) disabled people across the UK are food insecure, compared to one in ten people in the general population<sup>1</sup>. Since the start of the cost-of-living crisis, rates of food insecurity among disabled people have increased by 50%<sup>7</sup>. The Food Foundation food insecurity tracker survey demonstrates large increases in levels of food insecurity among disabled people over the last year. In December 2021, just over 28% of people who reported being limited *a lot* by their impairment or health conditions had experienced food insecurity (compared with 5% of people not limited by an impairment or health condition)<sup>32</sup>. By December 2022, the proportion had increased to 42% (compared with 13% not limited by an impairment or health condition)<sup>32</sup>. A recent survey of Trussell Trust food bank users, conducted by Ipsos MORI on behalf of the Trust, found mental health conditions were particularly common among people referred to food bank in the Trussell Trust

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network (52%)<sup>1</sup>. The same survey also found that 72% of people using a food bank in the Trust's network reported living in a disabled household<sup>1</sup>.

People in receipt of benefits are also especially vulnerable to food insecurity during the cost-of-living crisis, with nearly half of people receiving UC reporting being food insecure in January 2023 (compared with 15% of people not in receipt of UC)<sup>32</sup>. An exploration of how people with Multiple Sclerosis (MS) were coping during the cost-of-living crisis revealed that, particularly for those receiving means-tested benefits, going hungry was the 'horrible reality' for many<sup>18</sup>. Almost one in three (30%) of survey respondents on means-tested benefits reported going hungry, 42% were cutting back on the amount they ate and 20% had lost weight due to insufficient food intake<sup>18</sup>. In addition to low-income as a cause of food insecurity among disabled people, strategies for mitigating food insecurity employed by non-disabled people, for example, shopping around more widely or cooking from scratch, may be more costly or less possible for disabled people, for example, due to difficulties accessing the cheapest supermarkets or symptoms such as fatigue<sup>28,33</sup>.

A qualitative exploration of health care professionals' experiences of food insecurity among patients with long-term health conditions found that being unable to afford sufficient nutritious food was "a very sensitive topic", with patients often ashamed to admit to experiencing food insecurity<sup>34</sup>. Staff were keenly aware they were giving dietary advice that, while vitally important for condition management, was not achievable for patients on low incomes. Food insecurity had a negative impact on condition management, particularly for patients with conditions like type 2 diabetes (who struggled to afford food of sufficient quality to support condition management) and Chronic Obstructive Pulmonary Disease (COPD), who struggled to afford sufficient food to ensure they maintained their weight. Staff also reported negative impacts on medication regimes; for example, patients skipping medication that required to be taken with food, or prioritising buying food over buying medication. Douglas and colleagues conducted a similar qualitative study with people using a food bank and food pantry that supported the disconnect between dietary advice on how to manage health conditions and the realities of life on a low income<sup>35</sup>. In addition to reporting skipping medications that needed to be taken with food and hiding their food insecurity from the GP, study participants reported that their eating was erratic and solitary, with choice and agency over what to eat severely limited. Few ate three meals a day, and many would go without food for several days. Despite understanding the need to eat well to manage their health, participants were seeking out the most calorie-dense foods to stave off hunger<sup>35</sup>.

A 'dose-response' relationship has been identified between disability and food insecurity, with the presence of a physical and mental impairment or health condition strongly increasing the likelihood of someone experiencing food insecurity, with each additional impairment or health condition increasing the severity of food insecurity<sup>25,33</sup>. Further, the relationship between poor

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health and food insecurity is bi-directional as well as linear: poor health increases the risk of food insecurity and food insecurity increases the risk of poor health<sup>35-37</sup>. Food banks cannot (and are not intended to) provide the quantity and quality of food needed to support the management of long-term health conditions<sup>27</sup>. However, in a survey of over 400 people conducted for The Trussell Trust, Loopstra and Lalor found that for many people accessing food banks, severe food insecurity was a recurrent experience, not a one-off event<sup>30</sup>. Food banks had become not just an emergency source of food to tide people over a one-off crisis, but a “regular supplement for some people experiencing severe food insecurity”<sup>30</sup>.



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# 4. The role of social security benefits in poverty, food insecurity and food bank use

Disability benefits play an important role in meeting disabled people's additional costs and supporting them when they cannot work. However, insufficient income from the benefits system, either due to benefit levels or barriers to accessing benefits, has been widely identified as the most significant driver of food insecurity and food bank use<sup>3,21,38,39</sup>. Benefits for working age disabled people in the UK fall into two categories: incapacity benefits designed to provide an income to people who are unemployed and disability benefits that are designed to help meet the extra costs of living with an impairment or health conditions. Means-tested income-replacement incapacity benefits, Income-related Employment and Support Allowance (ESA) and a health-related element of Universal Credit (UC), are paid to people whose health limits their ability to work. ESA replaced Incapacity Benefit in 2008 and has itself now been replaced by UC. However, around one million people are still in receipt of income-related ESA<sup>40</sup>. Non-means tested contributory, or 'new style', ESA is available for people who have paid sufficient National Insurance contributions over the last two tax years. New contributory ESA claimants enter an 'assessment phase' (around 13 weeks) after which they must undergo a 'Work Capability Assessment' to ascertain their ability to carry out paid work. Disability benefits, Disability Living Allowance (DLA) and its replacement Personal Independence Payment (PIP), help people meet the extra costs associated with their impairment or health condition. Extra-costs benefits are non-means tested and are not dependent on ability to work. PIP replaced DLA in 2013 but many people are still in receipt of DLA as a 'legacy benefit'. PIP payment rates depend on the extent to which a person requires support carrying out activities of daily living and with mobility. Across the UK, 1.6 million people receive both incapacity (health-related elements) and disability benefits, one million receive only incapacity benefits, and 800,000 people receive only disability benefits<sup>41</sup>.

New research by the Trussell Trust found 62% of disabled households referred to food banks in the Trussell Trust network in 2022 were not receiving any disability benefits<sup>1</sup>. The Trussell Trust's 2023 Hunger in the UK report identified several problematic elements in the design of benefits, including payment delays and inadequate payment levels, made worse by deductions and sanctions, and complex and inhospitable application processes<sup>1</sup>. These design 'flaws' are compounded by adverse life events (for example, ill-health, divorce or eviction) and lack of informal and formal support to tide people over in periods of crisis<sup>3,25</sup>.

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In this section, under the headings of access and adequacy, evidence is reviewed on the ways in which the benefits system contributes to poverty, food insecurity and food bank use among disabled people.

## 4.1 Accessing disability benefits

Difficulties in accessing benefits have been identified as a key factor in increased food bank referrals<sup>3</sup>. Research by the mental health charity MIND found the disability system to be characterised by gatekeeping rather than by support<sup>42</sup>. Studies have shown that some disability benefit applicants report finding the application process overwhelmingly complex, confusing and difficult to manage<sup>26,43</sup>. People living in fear of receiving the ‘brown envelope’ from the DWP and poor experiences of the claims process can negatively impact their mental health<sup>44</sup>. The application system can be experienced as inflexible in ways that fail to reflect the realities of living with a disability. For example, applicants are given four weeks to complete an application form and are only permitted to make one change to their appointment time. Some claimants report being pushed into debt, food and fuel poverty, rent arrears and housing insecurity through system failures, errors and delays in receiving payments<sup>25,45</sup>.

Many studies have identified stigma associated with claiming benefits as a deterrent to people’s willingness to access benefits<sup>26,43,44,46,47</sup>. Stigmatising political and media rhetoric around benefit recipients ramped up after the 2008 recession with “powerful negative identity implications for those who are disabled and claiming benefits”<sup>43</sup>. People on benefits have been characterised as underserving or fraudulent<sup>46,47</sup>, with some claimants feeling scrutinised and judged by society as scroungers and shirkers<sup>43</sup>.

The evidence on various elements of the design of the disability benefits system (the application form, assessment, conditionality and sanctions, eligibility criteria, and payment levels) and the ways in which they may impact on disabled people’s ability to access benefits, is presented below.

### 4.1.1. Application forms

Completing a claim form is the first stage in the disability benefits application processes. The PIP claim form is lengthy and takes time to complete. A survey by Ipsos MORI on behalf of the Department for Work and Pensions indicated that claimants with low literacy levels, English as a second language, or whose disabilities posed challenges with form-filling, found completing the PIP application form particularly difficult<sup>48,49</sup>. In evidence submitted to a recent House of Commons Work and Pensions Select Committee inquiry examining the assessment processes for health-related benefits, some claimants reported that the PIP application form

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did not allow them to fully explain the nuances of their condition(s)<sup>50</sup>. The four-week deadline for submitting the application form has also been criticised by claimants as too short<sup>42</sup>.

The PIP application form has been criticised for being repetitive, with some people with mental health conditions finding that having to explain their condition again retriggered their distress<sup>42</sup>. Claimants have reported being distressed by the requirement to focus in detail on the ways in which they are limited by their disability and their worst days. In evidence provided to the Work and Pensions Select Committee, respondents described the emotional impact of having to ‘admit the extent of your disability’ and the requirement to provide details on deeply personal matters such as toileting and hygiene<sup>50</sup>. People needing support to complete their application form reported feeling degraded by having to disclose highly personal information to another person, whether a friend, family member or a stranger<sup>50</sup>.

Further, with the aim of achieving efficiency savings, the UC claims process is largely digital-by-default, with claims made online rather than by more costly options such as by telephone or in person. UC claimants have reported finding the digital claims process “complicated, disorientating, impersonal, hostile and demeaning”<sup>45</sup>. While online applications work well for many claimants, others, including some disabled people, struggle to apply online. The DWP’s own research showed that over half of disabled claimants needed support to claim online<sup>48</sup>.

Finally, claimants are required to submit evidence of their disability and the ways in which they are impacted. However, what counts as good evidence and what evidence is required is far from clear<sup>51,52</sup>. Some claimants report that collecting evidence in support of their claims was physically and emotionally stressful and financially costly due to administrative fees<sup>52</sup>. Moreover, people awaiting a formal diagnosis of their condition can lack medical evidence<sup>42</sup>.

## 4.1.2. Assessments

In addition to completing an application form, incapacity (UC and ESA) and disability benefits (PIP) both require most claimants to undergo an assessment, either face-to-face or over the telephone. UC claimants with disabilities or health conditions that affect their ability to work are required to undergo a Work Capability Assessment (WCA) to assess physical and mental functioning and the degree to which they impact on a person’s ability to undertake paid employment. The WCA involves a physical assessment (comprising 17 activities), and a mental, cognitive and intellectual function assessment. Claimants are assessed as having either capability for work, limited capability for work (LCW), or limited capability for work-related activity (LCWRA). People assessed as having capability for work are required to actively look for work for at least 35 hours per week. Those with LCW are placed in the work-related activity group (WRAG) and are required to undertake work preparation activities such as preparing a CV or attending a training course. Those with LCWRA are placed in the

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support group and are exempt from preparing for or seeking work. Personal Independence Payment (PIP) also introduced a functional assessment element (absent from its predecessor DLA) with the requirement for mandatory in-person assessments with a clinical assessor. The PIP assessment focuses on identifying potential extra costs associated with a person's impairment or health condition. PIP has two components: daily living, measured by 10 activities such as self-care (washing, bathing and preparing food), communication and condition management and mobility, measured by two activities (planning and following journeys and moving around). In both UC and PIP assessments, claimants are awarded points against a series of descriptors to reflect how well they can carry out each activity.

UC and PIP assessments are carried out by commercial assessment providers<sup>52</sup>. Like its predecessor, ESA, the UC WCA has been widely criticised for providing inadequate measurement of fitness to work, not considering clinical evidence, rushed assessments and inaccurate recording of claimants' accounts<sup>53</sup>. Similarly, PIP assessments have been subject to criticisms including a lack of compassion, inaccessibility, poor communication of information, and long waiting times<sup>44</sup>. A recent Parliamentary Committee report found that few of the 'significant problems' identified with benefit health assessments in 2018 had been addressed<sup>50</sup>. Errors and inaccuracies are frequently identified in assessment reports<sup>42,43,50,54</sup>. However, assessors are not held accountable for any inaccuracies<sup>42</sup> even though being wrongly denied a benefit can have severe impacts on disabled people<sup>50,55</sup>. An independent review found that the PIP assessment process failed to capture the realities and challenges presented by different types of disabilities and health conditions<sup>51,56</sup> and a lack of knowledge of health conditions and disabilities among assessors has been identified by claimants<sup>50</sup>. A survey conducted by the Royal National Institute of Blind People (RNIB) found that half of blind and partially sighted people felt the assessors were not knowledgeable about sight loss. In several studies, claimants report feeling that the assessor was trying to catch them out or 'trick' them<sup>43,50,56,57</sup>. Questions appeared to be deliberately vague; for example, one claimant recalled being asked, 'can you drive' (to which the answer was 'yes') rather than 'do you drive' (to which they would have answered 'no')<sup>50</sup>. A mixed-methods study conducted by Ipsos MORI on behalf of the DWP found that 40% of PIP claimants felt that measurements and functional tests carried out as part of the assessment were irrelevant and inappropriate<sup>48</sup>. In addition, research by mental health charity Mind found that applicants were largely unaware of their rights around the assessment; for example, the right to record the assessment and the right to receive a copy of their assessment report<sup>42</sup>.

There is a large body of evidence for the negative impacts of disability assessments on claimants. PIP claimants have reported that the assessment process left them feeling judged, misunderstood, disbelieved and disrespected<sup>42-44,54,56,58,59</sup>. PIP assessments can be particularly traumatising for people who have already experienced psychological trauma<sup>58,59</sup>. Indeed, the assessment process has been found to worsen mental health<sup>53,55</sup>. While direct

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causality is difficult to prove, there is evidence that assessments are associated with increased rates of suicide<sup>50,55</sup>. Since 2020, the National Audit Office found that at least 69 suicides could be linked to the DWP's handling of benefit claims<sup>60</sup>. The DWP acknowledged that this number was likely to represent only a proportion of potential benefit-related suicides<sup>60</sup>.

### 4.1.3. Reconsiderations, appeals and reassessments

Unsuccessful applicants for PIP can challenge the refusal of a claim through a Mandatory Reconsideration (MR) of the decision and by an appeal to the Courts and Tribunals Service if the MR is unsuccessful. In the period between its introduction in 2013 and March 2021, 9% of the 4.4 million initial PIP decisions had been appealed and 5% overturned at a tribunal<sup>50</sup>. While this is a relatively small proportion of decision appeals, it represents a “sizable minority” of almost 400,000 people over an eight-year period (around 50,000 a year)<sup>50</sup>. Additionally, previously unreleased data have recently shown that 59% of PIP appeals were won in tribunals based on the same information shared with DWP during the initial application stage<sup>61</sup>.

There is evidence that some potentially eligible people decide not to claim or to appeal an unsuccessful claim<sup>50</sup>. People who fail to appeal an outcome they disagree with are not reflected in the appeal figures, suggesting these could be an underestimate. Reasons for disengagement with the process have been shown to include a lack of confidence in navigating the claims/appeal process, negative expectations of the outcome, anxiety, disillusionment and apathy<sup>44,49,62</sup>. Some potentially eligible claimants report that they lacked faith in the Department for Work and Pensions' decision-making process for disability benefit applications<sup>48</sup>. Others felt that challenging or appealing could jeopardise their other entitlements<sup>43</sup>.

An important difference between DLA and PIP is that most DLA awards were indefinite whereas PIP awards are largely for a fixed period (apart from in cases where a condition is unlikely to improve or a claimant has reached state pension age) and, therefore, can involve repeated re-assessments for eligibility<sup>44</sup>. UC and ESA claimants are also required to undergo regular reassessments. For claimants with poor experiences of the initial assessment process, reassessments can be a source of fear and anxiety<sup>44,50</sup>. Claimants whose conditions would not change or improve over time said that they found the reassessment requirements particularly frustrating<sup>50</sup>.

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## 4.1.4. Eligibility – what counts as a disability?

In the context of social security benefits, disability is an administrative category that is frequently redesignated when governments and policies change<sup>43,46</sup>. How disability is defined and how disabled people are viewed within a society can have a major impact on financial security among disabled people<sup>28</sup>. People whose impairment or health condition does not fit the social security system's definitions of sickness or disability – or people who are not considered 'disabled enough' to receive support from the benefits system – are particularly at risk of food insecurity as they are ineligible for benefits intended to meet the extra costs of living with a disability<sup>28,46</sup>. The change from DLA to PIP resulted in changes in definitions of what constitutes being disabled. While not all changes introduced in PIP were detrimental to DLA claimants<sup>63</sup>, among the most controversial changes was the replacement of the '50 metre rule' with a '20 metre rule'<sup>c</sup>. DLA claimants were entitled to enhanced mobility support if they could walk less than 50 metres. With the introduction of PIP, this distance was more than halved to 20 metres. In a qualitative study, Machin and McCormack identified the distress caused to claimants judged no longer disabled under new regime, with one participant noting, "I was made to feel like I wasn't disabled anymore"<sup>44</sup>.

Department of Work and Pensions data indicate that one-half of ESA claimants and one-third of PIP claimants have a mental health condition or a behavioural disorder as their primary impairment or health condition, yet the PIP assessment process appears to be inequitable, with a lack of 'parity of esteem' between physical health conditions (that are visible) and mental health conditions (that are less visible)<sup>56</sup>. The transition from DLA to PIP frequently resulted in decreases in award levels<sup>40</sup>. People with mental health conditions were particularly negatively impacted in the move from DLA to PIP, with 55% of claimants with mental health problems having their awards reduced or withdrawn under the new system<sup>56,64</sup>. Success rates for new applicants also vary by impairment or condition type: for example, claimants with psychiatric conditions tend to have lower assessment award rates compared with claimants with non-psychiatric conditions<sup>40</sup>.

It is the formulaic nature of the application and assessment process that appears to be particularly ill-suited to claimants with mental health conditions<sup>44,56</sup> and fluctuating conditions<sup>65,66</sup>. People with mental, rather than physical, health conditions report finding it particularly difficult to fully describe the impact of their condition in an application form "geared towards a person with a physical impairment that can be pinned down and quantified"<sup>50</sup>. A recent qualitative study with people with mental health conditions who had undergone eligibility assessments for disability benefits found that, even for those whose claims were

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<sup>c</sup> The '20 meter rule' refers to the distance used in the PIP assessment as part of the process of determining a claimant's eligibility for the enhanced mobility rate. The 20-metre distance was introduced to identify claimants with significantly limited mobility.

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successful, the assessment process was experienced as intensely stressful<sup>65</sup>. The authors conclude that, “the lived experience of social security was for most [participants] permeated by fear, insecurity and disempowerment; grounded in a perception that financial support could be withdrawn at any time on an arbitrary basis or by a redefining of eligibility that did not include mental health conditions”<sup>65</sup>.

Respondents to a recent MIND survey of more than 1000 people with mental health problems who had been assessed for PIP, ESA or UC felt that the benefits application process was trying to catch them out rather than support them<sup>42</sup>. People felt ‘confused, angry and retraumatised’ trying to navigate their assessment and 66% said the assessment had worsened their mental health<sup>42</sup>. Only 35% of respondents assessed for PIP and 40% assessed for ESA or UC agreed that they trusted the DWP to help them get the financial support they needed. Assessment questions were judged to focus overwhelmingly on physical rather than mental health and the assessment process made participants concerned about the precariousness of the income they received: would they fail the next assessment? Claimants report being assessed by staff who viewed mental health conditions as a belief system that should be challenged and a failure to understand that someone cannot “just get on with things”. People with mental health conditions may struggle to access medical support and may not be taking any medication for their condition and difficulties in evidencing a claim can also act as a barrier for people with mental health conditions<sup>42</sup>.

In a similar way to mental health conditions, ‘proving’ the impact of fluctuating conditions (which may include mental health conditions and conditions such as MS, fibromyalgia and chronic fatigue syndrome) can be challenging. For fluctuating conditions, PIP eligibility is determined by the so-called 50% rule, which states that a claimant must be affected by a symptom for more than 50% of days in a 12-month period to be awarded points under a descriptor that outlines various tasks. A study exploring experiences of the benefits system among people with the autoimmune disease lupus (‘arguably the archetypal fluctuating condition’) found that, for many participants, fluctuation was “an insurmountable hurdle in the battle to be recognised and accommodated” in the benefits system<sup>66</sup>.

## 4.2 Conditionality

Since the 2008 recession, moving disabled people off benefits into work has become the aim of reform of the social security system<sup>67</sup>. ESA, and its replacement UC, introduced levels of conditionality to disability benefits previously only applied to non-disability related out-of-work benefits<sup>53</sup>. A review of social security systems identified four types of disability benefit regimes across OECD countries: ‘demanding systems’ that link high conditionality with strong rehabilitation support (e.g., in Denmark and The Netherlands); ‘passive systems’ that link low conditionality and weak rehabilitation (e.g., Germany and Norway); ‘supportive systems’ that

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link low conditionality and strong rehabilitation (e.g., Sweden); and ‘compliance-based systems’ that combine high conditionality and weak rehabilitation<sup>68</sup>. The United Kingdom system is characterised as ‘compliance based’. In the UK, little support is offered to disabled people to enter or return to employment and, for example, to experiment with work and to ‘fail’ without sanction<sup>68</sup>.

Depending on the outcome of the WCA, disabled people will receive UC or new style ESA on the condition that they fulfil a ‘claimant commitment’. UC claimants found ‘capable for work’ are required to actively look for work for at least 35 hours a week. UC and new style ESA claimants with limited capability for work must commit to undertake work related activities such as preparing a CV or attending a training course, while those found to have limited capability for work are exempt from looking for work. New style ESA claimants in the work-related activity group can only receive ESA for a maximum of one year. Conditionality for disabled people has been criticised for implying that they are unwilling rather than unable to work<sup>68</sup>. Conditionality has also been found to be ineffective in getting disabled people into employment, with “limited but methodologically strong evidence” suggesting that the employment effects of conditionality are much less for disabled people than non-disabled people<sup>68</sup>. Introducing conditionality to disability benefits, particularly for people with mental health conditions, has failed to increase levels of employment. Indeed, conditionality regimes appear to make it less likely that someone will enter work by worsening existing mental ill health<sup>60,69</sup>.

## 4.3 Adequacy

### 4.3.1. Payment levels

Adequacy of benefits is a further potential driver of poverty among disabled people. The UK government’s austerity measures, enacted in response to the 2008 global recession, impacted disabled people particularly hard. Austerity driven reductions in benefit rates and changes in benefit eligibility have seen some disabled households lose more than 30% of their net income since 2010<sup>70</sup>. For a long period, benefit rates have also been frozen (between 2016 and 2020) or have failed to increase with inflation (the year 2023/24 will see an inflation-linked increase in benefits). Between 2010 and 2021/22, disabled households lost on-average £1200 per year from their household incomes, compared with £300 per year on average for non-disabled households<sup>71</sup>.

There is evidence that disability benefits (PIP and DLA) are inadequate in meeting the often-substantial increased costs associated with disability<sup>18,72,73</sup>. Machin and McCormack found that PIP income was often spent on the everyday costs of living rather than health-related spending<sup>44</sup>. In addition, poverty among disabled households is underestimated because extra-



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costs benefits are treated as income<sup>36,74</sup>. That is, disability benefits are included in measures of net income but are not offset to account for the extra costs that absorb the extra income<sup>36,75</sup>. In their ‘Costly Differences’ report, the Resolution Foundation estimated that the 30% gap in median household income between disabled and non-disabled households would increase to 44% if disability benefits were removed from the calculation<sup>9</sup>.

Levels of out-of-work benefits are also low; for example, the standard UC allowance is only one-third of the amount necessary for a minimum socially acceptable standard of living<sup>3</sup>. The introduction of the work-related activity group (WRAG) to ESA in 2008 marked, “a change to the long-standing feature of welfare legislation that placed benefits for disabled people at higher rates than those who were unemployed”<sup>76</sup>. Payments to people in the WRAG were set at the same level as payments to people on Jobseekers Allowance, implying that disabled people did not face any extra costs or any additional barriers to work<sup>76</sup>. Similarly, only UC claimants assessed as having limited capacity for work-related activity receive extra money. Disabled people found capable for work or who are in the WRAG receive only the standard UC rate (people with LCW whose UC or ESA claim was made prior to April 2017 receive an extra payment). Even relatively small amounts of extra money can help to reduce food insecurity. For example, research shows that the temporary £20 per week Universal Credit uplift introduced during the COVID-19 pandemic helped to reduce food insecurity among claimants<sup>77</sup>. People claiming legacy benefits such as Income Support and Job Seeker’s Allowance that were excluded from the uplift saw little change in their levels of food insecurity<sup>78</sup>.

### 4.3.2. Deductions and delays

Claimants can also experience long delays between applying for and receiving benefits. ‘Clearance times’ (time between registering a claim and receiving a decision) vary, with median times in 2022 ranging between 14 and 22 weeks<sup>79</sup>. Delays in receiving entitlements have been implicated in food bank use, with over one-third of clients (12% of whom are PIP claimants) reporting needing to use charitable food aid due to delays in decisions and payments<sup>80</sup>.

In addition, claimants who fail to meet any of the conditions of their claimant commitment may be sanctioned by having their benefits reduced for a period. The latest DWP sanctions data show that 6.51% (around 40,000) of UC claimants were sanctioned in November 2022<sup>81</sup>. Evidence suggests that disabled people claiming incapacity benefits such as UC are more likely to be sanctioned than non-disabled people, most likely due to the increased difficulty of complying with conditions<sup>68</sup>. Sanctions range from ‘higher level’ where the period of reduction lasts 13 weeks (or 26 weeks for a second or subsequent higher-level sanction) that, for example, are imposed for refusing a job offer or failing to apply for a job when told to, through

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to ‘lowest level’ imposed for failure to attend a work-focused interview and lasting until the interview is attended. Sanction deductions are currently £11 per day for those aged over 25 and £8.70 for those under 25. These amounts represent a large proportion of the amount of UC a person receives (standard allowance UC for a person aged over 25 is currently £368.74 per month; just over £12 a day). There is evidence that sanctions may be counterproductive. A study of the experiences of disabled people assigned to the ESA WRAG found sanctions were ineffective at getting disabled people back into work; sanctions could be severely health-damaging and created a “state of constant anxiety” that prevented them engaging in WRA<sup>76</sup>. Sudden drops in income due to sanctions can drive people into debt and further increase their financial insecurity and worsen their mental and physical health<sup>25</sup>. Loopstra and Lalor’s survey of people using Trussell Trust food banks found that many respondents had experienced an income shock due to changes in benefit entitlements or sanctions and 38% were awaiting the result of a benefit application or a payment<sup>30</sup>.

## 4.4 Proposed benefit reforms

Further ‘landmark’ reforms to the disability benefits system were announced in the UK Government’s March 2023 Budget<sup>82</sup>. Reforms that will directly impact disabled people include the introduction of ‘Universal Support’, an employment support scheme for disabled people and the removal of blanket exemptions from work requirements for disabled people. The Universal Support scheme will provide up to £4000 per participant to support people to find and access suitable work. Perhaps the most significant planned reform is the removal of the UC Work Capability Assessment (WCA) to leave only the PIP assessment. The UC LCWRA extra payment will be replaced by a UC health element that will be awarded to people in receipt of PIP. Under the planned reform, PIP will act as a ‘passporting’ benefit for the UC health element. In the absence of the UC WCA, work coaches will determine what, if any, work-related activities people will be expected to carry out.

Creating work incentives and removing barriers to employment are the stated motivations for these latest proposed reforms to disability benefits<sup>82</sup>. People who move into employment generally lose their entitlement to incapacity benefits, creating disincentives to work. Further, making a binary distinction between being able or unable to work fails to acknowledge the complexities of disability (e.g., fluctuating conditions) and the requirements of different jobs<sup>41</sup>. However, in their response to the Budget statement, the Institute for Fiscal Studies (IFS) raised concerns around the proposed reforms<sup>41</sup>. The IFS noted that the changes represent a “radical shift” in how the benefits system treats disability: “the logic of the reform is that those who have conditions that prevent them working but do not mean they incur much in the way of additional living costs would no longer receive any extra support”. Only people in receipt of PIP will be recognised as officially ‘disabled’ and in need of extra financial support. Transitional payments are proposed to avoid sudden and dramatic income losses; however,

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after any transition period, people on incapacity benefit who are ineligible for PIP would lose over £350 a month. The IFS also highlighted the risks of increased sanctions in a system where personalised health conditionality will be overseen by Jobcentre work coaches with no specialist medical or occupational health knowledge<sup>41</sup>. A further concern is the likelihood of a significant increase in PIP applications from the one million people currently in receipt of only incapacity benefits, resulting in hugely increased processing times if resource is not shifted from the WCA to PIP assessments<sup>41</sup>.

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# 5. Scotland's approach to disability benefits

In 2019, welfare powers, including a range of social security benefits, were devolved from the UK Government to the Scottish Government. As part of this transfer of powers, a new benefit, Adult Disability Payment (ADP), was introduced to replace PIP in Scotland<sup>83</sup>. ADP was launched in March 2022, initially for new claimants living in Dundee City, Perth and Kinross and the Western Isles. Additional areas were added in June and July 2022 and from August 2022 onwards, all applications for extra costs disability benefits in Scotland were for ADP rather than PIP. The transition from PIP to ADP is due to be completed in 2025.

ADP payment levels are set at the same rates as PIP, and PIP recipients will automatically transition to ADP without the need for review or reassessment. However, with ADP, the Scottish Government claims that it is aiming to “fundamentally change the experience disabled people have in accessing the support they are entitled to”<sup>84</sup>, with ‘dignity, fairness and respect’ at the heart of delivering the benefit<sup>83</sup>. With input from people with direct experience of the benefits system, the Scottish Government has introduced several changes to ADP<sup>84</sup>. The burden of proof of the impact of disability is lessened for ADP claimants and medical assessments will be used as a last resort. Only one piece of supporting evidence will be required for an ADP claim and equal consideration will be given to evidence provided by medical professionals and a person’s informal support network (e.g., friends, family and unpaid carers)<sup>83</sup>. The removal of the requirement for a medical assessment has long been called for<sup>44</sup> and this is likely to represent an important development for ADP. Where a decision cannot be made based on the written application, applicants will be invited to a consultation – a “person-centred conversation” with a practitioner employed by Social Security Scotland, rather than the private sector or third-party providers used by the DWP<sup>83</sup>.

An increased number of indefinite awards of ADP are planned, aimed at people whose needs are “highly unlikely” to change and who receive the enhanced rate or both the daily living and mobility components<sup>83</sup>. Figures are not currently available for the proportion of ADP awards that are indefinite. However, data on award rate by level give an indication of the likely rate of indefinite awards: 37% of applicants were awarded the enhanced rate for both ADP components between March 2022 and January 2023 (the rate of enhanced rate daily living and mobility awards fell over time. By January 2023, 31% of applicants received this level of award), suggesting a maximum indefinite award rate of around one-third. In practice, the rate is likely to be lower as not all of those awarded the enhanced rate for both components will have conditions that are ‘highly unlikely’ to change. The remaining two-thirds of ADP

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claimants will remain subject to award reviews. Changes have also been made to the review process for ADP. Where an award is reduced and the change is challenged by the recipient, Short Term Assistance payments will be provided to maintain the original award level until a re-determination or appeal is decided.

The Scottish Government is seeking to actively promote the uptake of benefits, including ADP, and is funding an independent advocacy service to support ADP applicants<sup>83</sup>. The Scottish Government expects the changes made to ADP will result in more people being eligible leading to the requirement for higher public spending on the benefit. However, the Scottish Government is clear that spending on ADP must be affordable and sustainable<sup>85</sup>, and it is too early to say whether ADP claims will represent an increase on PIP claims. Data on ADP awards suggest that ADP is becoming harder to claim.

Scotland is at a relatively early point in the process of transitioning from PIP to ADP, and there will be lessons to be learned. Reports have already been published about delays in payments for new claimants<sup>86,87</sup>. Further, ADP and PIP have the same eligibility criteria and Citizens Advice Scotland has warned that people with fluctuating conditions such as MS and mental health problems will continue to struggle under the new system<sup>88</sup>. An independent review of ADP will take place in 2023, the first stage of which will focus on the mobility component of ADP, which currently retains the PIP '20 metre rule'<sup>83</sup>. However, the Scottish Government is clear that changing the eligibility criteria for ADP would result in increased spending and could have unintended consequences for entitlement to other benefits<sup>85</sup>, a particular risk considering the proposed reforms to UC that will result in PIP (and ADP) becoming passport benefits to the health element of UC.

Machin and McCormack identify other lessons for the implementation of ADP from the switch from DLA to PIP, including the need for 'meaningful and timely' equality impact assessments undertaken with input from disabled people<sup>44</sup>. Further, the process of claiming or transferring between benefits can be complex, bewildering and anxiety provoking. For these reasons, communications must be clear, timely and compassionate<sup>44</sup>. Anecdotal evidence is emerging that some claimants are experiencing problems contacting Social Security Scotland about their applications<sup>87</sup>. Processing times for ADP applications are increasing as the number of applications increase. Claims were processed in an average of 58 days in November 2022, 67 days in December 2022 and 79 days in January 2023 (around 4 months)<sup>89</sup>. Social Security Scotland had initially expected disability benefit applications would take around 8 to 10 weeks to process<sup>89</sup>.

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## 6. Conclusion

This review aimed to explore what is currently known about associations between food bank use, disability and the disability benefits system. It is clear from the evidence that disabled people's high rates of food bank use can be explained by inadequate income due to exclusion from employment, the extra costs associated with disability and, most recently, due to rapidly rising costs of everyday living.

Disability benefits are intended to provide support with the additional financial demands experienced by many disabled people. Incapacity benefits are intended to support disabled people who are prevented from accessing employment. However, this review found abundant evidence that the design of the benefits system acts as a significant barrier to disabled people accessing their entitlements. Disabled people frequently experience the benefits system as a demanding and hostile system of gatekeeping rather than enabling. Lengthy and complex application forms; adversarial and dehumanising assessment and review processes; and inadequate payments can worsen health and increase financial precarity by discouraging claims. There is also increasing evidence of the additional barriers to accessing benefits experienced by people whose impairments or health conditions are less visible or are fluctuating. Further research is needed into the ways in which the benefit system recognises and responds to more 'subjective' impairments and health conditions.

The recent introduction of ADP to replace PIP in Scotland provides a valuable opportunity to study the impacts of a system that the Scottish Government claims will treat disabled people with dignity, fairness and respect. Both quantitative and qualitative research will be important to understand the impact of ADP on disabled people's financial security, mental and physical health, and their trust in the disability benefits system. As this review makes clear, it is vital that disabled people with direct experience of the benefits system are enabled to contribute to evidence on what works and what must be improved.

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