

Disability and financial hardship:

How disability benefits
contribute to the need for
food banks in the UK

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Prepared for: **The Trussell Trust**

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Foreword

By Emma Revie - Chief Executive, The Trussell Trust

For the first time, we look deeper into the reasons why disabled people are more likely to be affected by hunger and hear first-hand their experiences of trying to cope with managing their health against rising costs and the challenges of accessing support.

For a long time, we have heard from our food banks about the numbers of disabled people who are turning to them for support. Earlier this year, our landmark study, Hunger in the UK, found that three quarters of people referred to food banks in the Trussell Trust network say that they or a member of their household is disabled. We knew we needed to look more closely into the reasons why this was happening, and what steps are needed to ensure that people can access the right support.

What is most striking in this report is that food insecurity is an almost universal experience among disabled people in the study. Hearing how much people worry, compromise, and go without until they reach crisis point. Understanding the additional costs of care, transport, and specialist diets, and the devastating impact it can have on your mental and physical health when you are forced to go without the essentials is deeply concerning.

The stories and findings bear witness to what it is like to try and navigate both employment and the social security system with a disability. It highlights the immense difficulties disabled people face when trying to access disability benefits and how numerous barriers often prevent people from receiving vital support, and speaks to the distress experienced by people trying to get help. We also learn more about how factors such as lack of access to suitable work are major drivers of hunger.

The more we understand and share our learnings, the better we can advocate for the change we need to see. We understand clearly that disability benefit payment levels are too low to meet the extra costs related to disability, and that there are solutions and improvements we can make to ensure people can cover the costs of their own essentials and feel protected and supported.

I hope like me, this only strengthens your resolve to create a more just and compassionate society. Together, we can build awareness and understanding around disability, advocate for flexible and supportive employment, and call for solutions that mean our social security system protects people from needing to use a food bank in the future.

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Glossary

Food aid

Food aid refers to the support from a food bank or other emergency provider, including hot or cold meals from an organisation like a soup kitchen, and access to low-cost food from models such as food pantries or social supermarkets.

Food bank

A food bank is an organisation which distributes free food parcels and may also provide additional support by offering or signposting to debt advice and benefits advice. Food banks can be run by individual charities or by other organisations, such as advice centres, faith groups, schools, universities, and hospitals. At food banks in the Trussell Trust network, a person brings their voucher or e-referral from a referral agency and collects emergency food in return. In some cases, the food is delivered direct to their home. The Independent Food Aid Network (IFAN) defines a food bank as a venue that distributes emergency food parcels at least once a week. There are also food banks which are not part of the Trussell Trust network or IFAN.

Food insecurity

For the purposes of this study, we define food insecurity as worrying about affording food, cutting back on the amount, type or quality of food, or going without food due to a lack of money.

Disabled

Someone is disabled under the Equality Act 2010 if they have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to do normal daily activities'. This definition encompasses a wide range of health conditions and impairments.

Disability benefits

A person is receiving disability benefits if they receive one or more of the following benefits: Employment Support Allowance, Personal Independence Payment, Attendance Allowance, Disability Living Allowance, Child Disability Payment, Adult Disability Payment, or additional money from Universal Credit for people who are unable to work due to their disability.

Employment and Support Allowance (ESA)

Employment Support Allowance is a benefit which provides a regular income for people unable to work due to an illness or disability.

Personal Independence Payment (PIP)

Personal Independent Payment (PIP) is a regular benefit for people with a disability or long-term health condition which limits their ability to carry out day-to-day tasks. Someone can apply for PIP whether or not they are working. There are two main components of PIP: daily living and mobility.

- The daily living component provides additional income to help people carry out everyday tasks (including cooking meals, washing or bathing or communicating with others).
- The mobility component provides an additional source of income to help people travel and move around.

A successful applicant will be awarded either a standard or an enhanced level of payment for each component.

Adult Disability Payment (ADP)

The Scottish Government introduced Adult Disability Payment (ADP) as a replacement to the Personal Independent Payment (PIP) and the Disability Living Allowance (DLA). ADP was piloted in several parts of Scotland in March 2022. The full rollout began in August 2022. People on PIP and DLA in Scotland will be automatically transferred over to ADP - this is expected to be completed by Summer 2024.

Disability Living Allowance (DLA)

Disability Living Allowance (DLA) is a legacy benefit which is being replaced by ADP in Scotland and PIP across the rest of the UK. Adults can no longer apply for DLA. The benefit is continuing for people under the age of 16 who have additional care or mobility needs due to a disability or health condition.

Motability scheme

If someone is receiving the enhanced rate for the mobility component of Personal Independent Payment, Disability Living Allowance, Adult Disability Payment, Child Disability Payment, Armed Forces Independence Payment or War Pensioner's Mobility Supplement with at least 12 months left, they are eligible for Motability scheme.

The Motability scheme enables an individual to exchange their enhanced mobility allowance for a new car, Wheelchair accessible vehicle, scooter or powered wheelchair. Under the Motability scheme a claimant will also receive advice from adaptations installer, insurance cover, servicing and MOT, breakdown cover and support with electric car where applicable.

Neurodiversity and neurodivergent

Neurodiversity refers to the different ways the brain can work and processes information. Neurodiversity is the spectrum. Most people are neurotypical which means that their brain works and processes information in the way society expects. Neurodivergent means that the brain works and processes information differently to the way society expects.

The term 'neurodivergent people' can be used to describe Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Dyspraxia, Dyscalculia or Dyslexia. However, Scope prefer to use the term 'learning difficulty' to describe dyslexia, attention deficit-hyperactivity disorder (ADHD), dyspraxia and dyscalculia.

For the purpose of this research, we use the term learning difficulties to describe dyslexia, attention deficit-hyperactivity disorder (ADHD), dyspraxia and dyscalculia and we use the term autism to describe Autism Spectrum Disorder (ASD).

Executive summary

Introduction

The Trussell Trust commissioned the Scottish Centre for Social Research to conduct a study to understand the drivers of food insecurity among disabled people. The research sought to understand the reasons for the overrepresentation of disabled people accessing food banks and the underclaiming of disability benefits among people in disabled households. This research will provide an evidence base for the development of policy solutions related to the social security system to reduce the need for food banks for disabled people across the UK.

In-depth interviews were conducted between March and May 2023 with 57 people with a range of physical and mental health conditions and impairments across the UK. Over half of participants (n=29) had accessed a food bank while others reduced the amount and quality of food they ate, or took out loans, to get by.

Disabled people's experiences of food insecurity

Food insecurity was an almost universal experience among disabled people in this study. Worrying about buying food at the start of the month shifted to compromising on quality and skipping meals by the middle of the month. By the last few days of the month, some had no access to food at all. Others were building up debt on credit cards or relying on the support of family or friends to feed themselves.

Managing impairments and health conditions could require specialist diets that imposed additional financial costs. Participants reported that their physical and mental health conditions and impairments were being compromised by diets which were inadequate in terms of quality and quantity of food, which could lead to unintentional weight loss, weight gain or nutritional deficiency. Food insecurity was also a source of constant stress and anxiety. Participants sought food aid when they reached a crisis point and could no longer afford to feed themselves.

Factors driving food insecurity among disabled people

Economic exclusion

While symptoms such as pain, fatigue and anxiety created barriers to paid work for some disabled people, a lack of accessible employment or inflexible employment structures excluded many participants from employment. Supportive employers enabled disabled people to stay in work. However, this research found that some disabled people had been denied their legal entitlement to reasonable adjustments or equipment to support them in their work.

Participants described a lack of disability awareness and understanding among some employers, including limited awareness of the nature and range of the potential impacts of impairments. Some participants had to reduce their working hours or were forced out of work entirely by employers' failure to provide support. The need to provide care for disabled family members was a further barrier to paid work. Exclusion from employment increased people's financial precarity and was a major driver of food insecurity.

Extra costs associated with impairments and health conditions

Disabled people faced a range of extra costs, above and beyond day-to-day living costs, in the treatment and management of their impairments and health conditions. Participants needed extra money for aids, adaptations, therapies and support that were not provided by the NHS or local authorities. Participants left housebound by inaccessible environments, or whose impairments required them to stay warm, incurred large utility bills. Participants also faced additional transport costs to attend medical appointments, collect medication or attend support sessions.

Overall, participants found it difficult to meet their day-to-day living costs let alone the extra costs associated with their impairment. Even those who were receiving disability benefits were frequently unable to afford a basic standard of living, and struggled to meet everyday costs. Borrowing from family and friends, and through overdrafts, loans or credit cards was needed to afford essentials. Debt, rent and utility bill repayments further reduced already insufficient incomes and caused stress and anxiety. In addition to constant financial worries, the impact on socialising, shopping and leisure activities negatively affected participants' mental health.

Inadequacy of disability benefits

This research found that disability benefit payment levels were often too low to meet the extra costs related to disability. With few exceptions, income from disability benefits was being spent on everyday living costs such as rent and utility bills rather than health and impairment-related costs. The value of disability benefits failed to reflect the impact of multimorbidity for disabled people living with multiple impairments and health conditions.

The cost of living crisis

The cost of living crisis was worsening the financial situation of disabled people. Participants just about getting by in the recent past were now no longer doing so, while those currently meeting their costs feared that this would change as costs continued to rise.

Rapidly rising food prices were a universal source of concern. Participants who had been able to feed themselves adequately a year ago could now no longer afford to do so. Escalating food costs accompanied by equally high fuel costs meant choosing microwaveable meals or food that could be eaten cold. With financial resources severely limited, the requirement to pay essential bills such as rent, utilities and council tax pushed buying food down the list of priorities. Disabled people's experiences of the disability benefits system.

A central aim of this research was to explore disabled people's experiences of applying for disability benefits and identify the ways in which these experiences impacted on their attitudes towards, and engagement with, the benefits system.

Personal Independence Payment (PIP)

It was clear from this research that, while payment rates were low, extra income from disability benefits was vital for many disabled people. However, participants often faced challenges in applying for and being awarded disability benefits.

Applying for PIP could be physically and emotionally exhausting, with participants believing the process was designed to prevent rather than enable a claim. Interviewees described both the PIP application form and assessment as complicated and repetitive, and some felt that they had been designed to catch-out applicants with 'trick' questions. The 'one-size-fits-all' processes prevented participants from fully communicating the impact of their impairments and health conditions.

Participants found the PIP assessment particularly distressing as it required them to focus on their worst days and their limitations. The requirement to share intimate, personal information was a source of humiliation. The regular reviews required of most PIP claimants caused

dread and anxiety that the award would be reduced or removed. This study found that the distress and trauma involved in applying for PIP meant some disabled people did not challenge a refused claim.

Although people in employment are eligible to claim PIP, participants in work felt that having a job was viewed by assessors as evidence that they did not need extra support or that they could afford to meet any extra costs associated with their impairments or health conditions. They described being interrogated about how they were managing to continue to work given the impacts of their conditions.

Adult Disability Payment (ADP)

The devolution of a range of social security benefits to Scotland has seen the recent introduction of a new benefit, ADP, to replace PIP in Scotland. In 2022 the Scottish Government introduced several changes to the ADP application process with the stated aim of improving disabled people's experiences of claiming disability benefits. This research explored disabled people's preliminary experiences of applying for ADP and compared their experiences of claiming ADP with their experiences of claiming PIP.

Participants waiting to be transferred from PIP to ADP reported a lack of information in communications from Social Security Scotland that left them uncertain about what they needed to do or what the new benefit involved.

Experiences of applying for ADP varied. Some spoke of the ADP form in largely similar terms to the PIP form with criticism of the form's length and repetitiveness, noting that they felt its wording was designed to catch out applicants. Others felt the ADP application form was an improvement on the PIP form, with more room to discuss the effects of impairments and more scope to describe the impacts of mental health. While the option to apply online was broadly welcomed, technical problems were a source of frustration. Generally, participants receiving ADP were positive about their experience and reflected that the ADP process appeared to be more compassionate and caring than the PIP process.

As part of this research, disabled people shared their thoughts on the differences between PIP and ADP. The provision of an independent advocacy service, increased numbers of indefinite awards, the removal of routine medical assessments and the reduction in the amount of evidence required in support of a claim were all broadly welcomed. However, some participants expressed concern that over-reliance on medical evidence instead of assessment would penalise claimants without formal diagnoses or with poor relationships with their healthcare providers.

Reasons for the underclaiming of disability benefits and suggestions for improvement

Awareness of disability benefits and eligibility criteria

This research identified a lack of awareness of eligibility criteria as a reason for the underclaiming of disability benefits. To address this, participants wanted to see information about disability benefits promoted more widely.

To guarantee information has a wider reach, a range of ways of promoting information about disability benefits was suggested, including public awareness adverts on television, social media, and other media sources. In addition, more targeted promotion was proposed, such as letters direct to people's homes or pamphlets displayed in public places such as doctor surgeries, post offices and libraries. Disabled people suggested that proactive promotion of disability benefits by people such as healthcare providers is needed to inform people of their entitlements.

Changes to the disability benefits system

Participants thought that the current design of the disability benefits system dissuaded disabled people from applying, as it did not cater for a wide range of health conditions and impairments, particularly fluctuating and less visible conditions.

- Participants would like disabled people to be fully consulted and involved in the design of the disability benefits system to ensure it is person-centred, compassionate and responsive to their needs.
- Suggested improvements to application forms included offering a range of formats, shortening the form, removing unnecessary repetition, simplifying the language, and removing ambiguity by altering the questions to make it clearer what information is being requested. Participants wanted disability benefits forms redesigned in a way that allows them to fully explain the support they need to live full lives.
- This research makes it clear that access to support to complete a disability benefits application is vital for disabled people. Disabled people are often unaware of the support available, and, in some areas, support is lacking or is subject to delay. Participants wanted to see greater funding, promotion and availability of support and improved training for staff supporting disabled people to navigate the often-complex disability benefits system.

-
- The assessment, reassessment, appeals and tribunal elements of the disability benefit system are sources of distress and trauma for many disabled people. Suggested changes to the process included reforming PIP to remove the need for health assessments where clear evidence is provided and reducing the amount of evidence required for a claim, in line with ADP. Where assessments are needed, participants wanted specialist assessors who have specialist knowledge of a claimant's impairments.
 - A key finding of the research was that the current value of disability benefits is insufficient and must be increased to enable disabled people to cover the extra costs associated with their health conditions and impairments. Waiting times for decisions must also be shortened to prevent disabled people experiencing hardship while their application is processed.
 - Greater flexibility for the frequency of the payment would allow disabled people to choose a payment schedule that better meets their needs.

Wider support for disabled people

This research identified changes beyond the disability benefits system that would improve the lives of disabled people in the UK.

- Participants wanted increased public education on impairments and health conditions to help reduce stigma associated with being disabled and claiming disability benefits. More specifically, participants wanted employers to have a better understanding of disability so they can better support disabled people to thrive at work. This included employers implementing their legal requirement to provide reasonable adjustments to disabled people.
- Additional financial support for disabled people was also suggested, including grants for adaptations and costs not covered by the NHS, and increased support with transport, utilities and food costs.
- Finally, participants wanted greater promotion of support and opportunities available, and for public environments to be made more accessible to enable disabled people to take part fully in society.

1. Introduction

1.1 Background to the research

Recent research by the Trussell Trust found that 69% of working-age people referred to food banks in the Trussell Trust network across the UK are disabled, three times the level seen in the general population (23%)^{1,2}. In Scotland, 73% of people referred to the Trussell Trust food banks are disabled³. Being disabled, or in a disabled household, are some of the strongest predictors of poverty in the UK⁴. Compared to the general UK population, disabled people are more likely to live on low incomes; nearly half of all people in poverty live in a household where someone is disabled⁵. Deep poverty (defined as a household income 40% below the national median) is also far more prevalent among working-age disabled people⁶. Single disabled adults are at particular risk of living in deep poverty due to their single incomes and inability to share costs. Compared with non-disabled single people, disabled people in single adult households are twice as likely to live in deep poverty⁶. As a result, disabled people are also significantly more likely to need to access food aid.

The COVID 19 pandemic resulted in increased financial hardship among disabled people⁷. In the two years from July 2021, the cost of living in the UK has risen sharply, with inflation increasing from 2% in July 2021 to nearly 8% in July 2023⁸. In the year to June 2023, gas and electricity prices increased by 36% and 17% respectively and food and drink prices increased by over 17%^{9,10}. 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, thereby rapidly increasing the numbers of people who are struggling to afford the essentials we all need¹¹. As a result of the cost of living crisis, levels of food insecurity in the UK are rapidly increasing¹².

Many people experiencing severe food insecurity are being forced to use charitable food aid. Not only are emergency food providers facing rising need, but many are also seeing significant challenges related to food supplies. As an example of charitable food aid, food banks are seeing a steep increase in the need for their services due to the rise in the cost of living. Some food banks are struggling to keep up with this need 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. The Independent Food Aid Network (IFAN) reported that 89% of its member organisations experienced increased demand for their services between January and March 2023¹³. Similarly, the Trussell Trust food bank network has reported that the cost-of-living crisis is creating a 'tsunami of need', with the provision of food parcels increasing by one-third over the last year and donations not keeping pace with

this need¹. Nearly three-quarters of independent food banks surveyed by IFAN also reported decreases in donations over the same period¹⁴. Disabled people, already at a higher risk of poverty prior to the cost-of-living crisis, are experiencing particularly sharp increases in food insecurity. Rates of food insecurity among disabled people have increased from 8% to 12% since the start of the cost-of-living crisis⁶. Again, food insecurity is highest among single disabled adults, with nearly 20% reporting being ‘very food insecure’⁶.

1.1.1. The role of disability benefits in food insecurity

Disability benefits, such as Disability Living Allowance (DLA) and its replacement Personal Independence Payment (PIP), are intended to help people meet the additional costs associated with having a disability¹⁵. Disability payments play an important role in meeting disabled people’s additional needs. However, difficulties navigating an often-complex social security system and changes to benefits have been identified as playing a central role in disabled people’s increased rates of poverty and associated food insecurity^{1,16}.

Recent research by the Trussell Trust found that difficulties accessing benefits is a key driver of increasing food bank need^{1,16}. Two in three (62%) disabled households referred to food banks in the Trussell Trust network were not receiving any disability benefits to help with the increased costs associated with impairments and health conditions¹.

Research has shown that disability benefit application processes can be difficult to manage and navigate, with many people highlighting the negative impact applying for support has on their mental health¹⁷. Reasons for disengagement also include a lack of confidence in navigating the claims and appeal process and negative expectations of the outcomes¹⁸. Some potentially eligible claimants report that they lacked faith in the Department for Work and Pensions’ (DWP) decision-making process for disability benefit applications¹⁹. Success rates for applications vary according to disability type: for example, claimants with psychiatric disorders tend to have lower assessment award rates compared with claimants with non-psychiatric disabilities²⁰. Additionally, previously unreleased data have recently shown that 49% of PIP appeals were won in tribunals based on the same information shared with DWP during the initial application stage²¹. A need for improved training for DWP assessors and helpline staff in dealing with claimants with mental health problems has also been identified²² (Scottish Government, 2019).

The UK government’s austerity measures have also been found to have impacted disabled people hard. Austerity driven reductions in benefit rates and changes in benefit eligibility saw some disabled households lose more than 30% of their net income between 2010 and 2018²³. Furthermore, changes to the disability benefits system can also impact on applicants and recipients. The transition from DLA to PIP frequently resulted in decreases in award levels²⁰. People with mental health problems were particularly negatively impacted in the move from

DLA to PIP, with 44% of claimants with mental health problems having their awards reduced or withdrawn under the new system²⁴. Delays in receiving entitlements have been implicated in food bank use, with over one-third of the Trussell Trust food bank clients (12% of whom were PIP claimants) reporting a requirement to use food aid due to delays in decisions and payments²⁵.

Inadequacy of benefits is a further potential driver of poverty. Payment levels for most working-age benefits were frozen in the UK between April 2016 and April 2020, meaning that their value decreased over this period²⁶. Research by the Trussell Trust and Joseph Rowntree Foundation have found that the standard rate of Universal Credit (which is currently set at just £85 per week) is at least £35 per week too little to enable a single person to afford even the most basic of essential items²⁷. Disabled people also face significant extra costs required to help mitigate the impacts of their disabilities. 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 household²⁸. Adjusting for the current high level of inflation, this figure rose to £1,122 a month²⁸. While disability benefit levels escaped the benefit freeze, there is evidence that disability benefits remain inadequate in meeting the substantial increased costs associated with disability²⁹. Even relatively small amounts of extra money can help to relieve 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 claimants³⁰. Meanwhile, 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 insecurity³¹.

1.1.2. Scotland's approach to disability benefits

In 2016 welfare powers, including a range of social security benefits, were devolved to Scotland by the Scotland Act. As part of these changes, a new disability benefit, Adult Disability Payment (ADP), was introduced to replace PIP in Scotland, with the transition beginning in March 2022 and due to be completed in 2024³². The payment amount is the same and PIP recipients are being automatically transitioned to ADP without the need for review or reassessment.

With ADP, the Scottish Government aims to “fundamentally change the experience disabled people have in accessing the support they are entitled to”³³. There is an intent that the burden of proof of the impact of disability will be lessened for ADP claimants. The Scottish Government has said that only one piece of supporting evidence is required for an ADP claim and equal consideration is given to evidence provided by medical professionals and a person's informal support network (for example, friends, family and unpaid carers). Medical

assessments should only be used where a decision cannot be made based on the written application. If an assessment is required, applicants are invited to a meeting with a practitioner employed by Social Security Scotland, rather than the private sector or third-party providers used for PIP assessments. Further, the intention is that an increased number of indefinite awards of ADP are used, aimed at people whose needs are ‘highly unlikely’ to change and who receive the enhanced rate or both the daily living and mobility components.

Scotland is, however, at a relatively early point in the process of transitioning from PIP to ADP. Concerns have already been raised about delays in payments for new claimants^{34,35}. Further, ADP and PIP have the same eligibility criteria and Citizens Advice Scotland has warned that people with fluctuating conditions such as multiple sclerosis and mental health problems will continue to struggle under the new system³⁶.

1.2 This research

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. With 69% of people referred to food banks in the Trussell Trust network reporting an impairment or health condition¹, it is crucial that we understand the reasons for the disproportionately high rates of food insecurity among disabled people.

To better understand this overrepresentation, the Trussell Trust commissioned the Scottish Centre for Social Research (ScotCen) to explore the reasons for the overrepresentation of disabled people accessing food banks. Food aid in the UK is offered by a range of providers. The Trussell Trust network includes more than 1,400 food bank centres³⁷. Research by the Independent Food Aid Network (IFAN) identified at least 1172 independent food banks in operation across the UK, around 550 of which are IFAN members³⁸. However, the true number of food aid providers is difficult to accurately quantify. Thousands of other organisations, including religious groups, schools and hospitals, also provide food aid in their communities³⁷.

For this research, the term food banks will be used to talk about both the Trussell Trust food banks where a referral is required to access them, and independent food banks, where referrals are not often required. The research also aimed to examine the potential impact of the disability benefits system on food insecurity among disabled people and the underclaiming of disability benefits among disabled people accessing food banks. For the purposes of this study, we define food insecurity as worrying about affording food, cutting back on the amount, type or quality of food, or going without food due to a lack of money. This definition is taken from the Trussell Trust’s recent publication *Hunger in the UK* which draws on metrics used by the DWP¹. People experiencing severe food insecurity may need to rely

on charitable food aid. The transition from PIP to ADP in Scotland also potentially allowed for further exploration of experiences of applying and claiming for PIP compared with ADP.

2. Methodology

2.1 Research aims and objectives

The overall aim of the research was to better understand the drivers of food insecurity amongst disabled people and identify possible solutions. In particular, the research sought to explore disabled people's experiences of engaging with the social security system to assess the extent to which it might be impacting on their financial wellbeing and use of food banks. To address the research aims, the Trussell Trust outlined several research objectives and questions. These are outlined in full in Appendix A. In summary, the objectives of the research were to:

- Understand if and how the design of the disability benefits system impacts on the need for food banks.
- Understand the reasons behind the overrepresentation of disabled people referred to food banks.
- Identify the primary reasons behind the underclaiming of disability benefits.
- Compare people's experiences of applying for PIP and ADP.
- Provide an evidence base for the development of policy solutions related to the social security system to reduce the need for food banks for disabled people across the UK.

2.2 Research design

To address the research aims and objectives, ScotCen conducted a mixed method study. This consisted of a rapid evidence review and in-depth interviews with 57 disabled people across Scotland, England, Wales and Northern Ireland. Interviews took place between 27th March and 11th May 2023. Two workshops, one with disabled people and the other with policy representatives, were also convened in August and September to explore the key findings more widely and to discuss the implications for policy across the UK.

To ensure the research was designed and implemented in an ethical manner, an application was submitted to NatCen Research Ethics Committee (REC). The REC consists of researchers and Senior NatCen Staff who critically review all projects to ensure they meet high ethical standards. The project team attended a meeting with the REC to discuss the ethical considerations of the project and respond to questions. Ethical approval for the research was granted by NatCen REC in mid-March 2023.

This report outlines the findings for the qualitative research only. The literature review has been published separately. Details of how the qualitative study was undertaken are outlined below.

2.2.1. Qualitative research

In the second phase of the study, ScotCen conducted 57 semi-structured interviews with disabled people across the UK to explore in depth their experiences and view of the disability benefits system and the drivers of poverty and food insecurity among disabled people and disabled households in the UK.

Sampling and recruitment

To ensure that a breadth of experiences were represented in the research, ScotCen sought to recruit a diverse range of participants in terms of health condition and impairment type, impact of health conditions and impairments on ability to carry out daily activities, receipt of benefits, employment status and a range of demographics such as age, ethnicity, country of residency and geographic location type. To recruit a diverse range of participants within the project timescales, ScotCen implemented multiple recruitment methods.

NatCen and ScotCen Panels

The NatCen and ScotCen Panels are samples of participants in probability-based surveys who have given their consent to be re-contacted about new research conducted by NatCen and ScotCen. A sample from the Panels was identified in March 2023 and a sub-sample were contacted by email to invite them to participate in the research. Further invitations were sent in April 2023 to target specific sampling criteria such as ethnicity, age and country of residence. Those interested in participating in an interview were asked to contact the project team using a project email address or by phone to express an interest. The research team asked those who had expressed an interest screening questions to assess eligibility for the study. Those selected to take part were then contacted to arrange a time and date for the interview. Those not eligible were informed and thanked for their interest.

Social Security Scotland Client Panel

Social Security Scotland's Client Panel is made up of individuals who have applied for any devolved benefits and have consented to be contacted about further research. This includes those who have been successful and unsuccessful in their applications for ADP, new ADP applicants and those who have previously received PIP or DLA. Social Security Scotland included an advert for the research in the Social Security Scotland Client Panel newsletter in March 2023. The advert included the contact details of the ScotCen research team to enable

those interested in participating in an interview to express an interest in the study. The same screening process and interview set up used for the NatCen and ScotCen Panels were used.

Food banks

Thirty of the Trussell Trust food banks agreed to support the recruitment of disabled people who have accessed their services. ScotCen sent flyers and posters promoting the research to each food bank with a covering letter asking them to distribute or display these within a two-week period at the end of March and the start of April 2023. A small number of both additional Trussell Trust food banks and independent food banks were contacted in April to expand recruitment to meet the sampling criteria. The flyers and posters included a project email address and phone number so those interested in participating in an interview could contact the project team directly to express their interest. The same screening process and interview set up used for the panels were implemented.

Recruitment agency

ScotCen worked with a specialist recruitment agency, to fulfil sampling criteria not achieved by the other recruit methods. After ScotCen specified the sampling requirements for 10 interviews, Criteria conducted screening and gained consent from eligible and interested participants to share their contact details with the project team to set up an interview.

Conducting the research

To make the interviews as accessible as possible, participants were given the choice of an in-person, telephone or video interview. All participants opted for a telephone or video interview. Researchers were available during the day, evenings and weekends to carry out interviews based on the preference of participants and to suit their work, health and family needs.

Participants were sent an information sheet and privacy notice which provided further details about the research. Both the information sheet and privacy notice were screen reader accessible and available in a range of formats including an easy read version. Before the interview, participants were reminded by the ScotCen team that the interviews were confidential and would not affect the benefits or services they receive. All participants were given a £40 Love2Shop voucher as a thank you for giving up their time. The interviews took an average of 60 minutes to complete. At the end of the interview, participants were made aware of relevant support organisations and a list of these organisations were sent to them, by email or letter, after the interview. With the consent of participants, all interviews were audio recorded using an encrypted digital recorder and transcribed for ease of analysis.

Research materials

The interview topic guide was developed in consultation with the Research Advisory Board and agreed by the Trussell Trust. The interview topic guide covered a range of themes, including participants' experiences of living with the health conditions and impairments and experiences of the disability benefits system, including the application, assessment and reassessment processes and the sufficiency of the benefits to meet costs related to disability. The interviews also sought participants' view on the reasons for the underclaiming of disability benefits among disabled people, factors that may result in higher rates of food bank use among disabled people and households, and solutions to reduce the need for food bank use among disabled people and households.

Analysis

The transcribed interview data were managed and analysed using qualitative analysis software NVivo. Analysis involved several stages. First, the key topics and issues which emerged from the research objectives were identified through familiarisation with transcripts by at least two members of the research team. A draft analytical framework was then drawn up by the research team. An internal meeting was held to agree the initial coding framework. The analytical framework was then set up in NVivo and piloted with a few transcripts and any amendments to the framework made. Each transcript was coded, so that all the data on a particular theme could be viewed together. Through reviewing the coded data, the full range of views were systematically mapped, and the accounts of different participants compared and contrasted. Emergent patterns and explanations for individuals and categories of respondent holding particular views were also explored and tested.

2.3 Strengths and limitations of the research

This research has several strengths and limitations.

2.3.1. Strengths

The study's qualitative methodology enabled the collection of rich, in-depth data grounded in the experiences of disabled people themselves. The data provide insights into a wide range of views and experiences that are likely to reflect those of disabled people across the UK. Further, the study findings are strongly supported by previous research into disabled people's experiences of the disability benefits system.

Study recruitment took place through the existing NatCen and ScotCen panels, Social Security Scotland's Client Panel, the Trussell Trust and Independent Food Aid Network food

banks, and a specialist agency experienced in social research recruitment. Using this range of recruitment strategies resulted in a diverse sample of participants, with a variety of relevant characteristics and experiences, drawn from across the UK.

This is the first study to explore the experiences of disabled people in Scotland as they are transferred to, or apply for, ADP. The study also captured new challenges being experienced by disabled people across the UK as they lived through the current cost of living crisis. There is little existing research focusing specifically on disabled people's experiences of food insecurity and accessing charitable food aid. This study adds to our knowledge in these areas.

2.3.2. Limitations

This research study focused solely on qualitative methods with disabled people. A limitation of qualitative methods is that it is not representative of a wider population. Therefore, the prevalence of views and experiences cannot be determined and some perspectives may be missing from this research.

Despite the use of multiple recruitment strategies and undertaking targeted recruitment, disabled people from Black, Asian and Minority Ethnic backgrounds were under-represented in this study's sample. It is also the case that people from Black, Asian and Minority Ethnic groups are under-represented among people accessing charitable food aid despite being more likely to need food aid¹. While it is likely that disabled people from Black, Asian and Minority Ethnic groups share many of the experiences of participants in this study, they may also face different issues which require distinct solutions and are not captured in this research.

ADP was only fully rolled out nationwide in August 2022, although it launched earlier in pilot areas from March 2022. Therefore, to date, only a relatively small number of disabled people in Scotland have direct experience of the new benefit. For this reason, not all participants in Scotland had experience of ADP. However, the study was able to reflect on the experiences of people at different stages of the ADP claims process.

3. Research participants

3.1 Participant descriptions

To ensure a wide range of experiences were represented in the research, ScotCen sought to recruit a diverse range of participants in terms of health condition and impairment type, employment status, receipt of benefits, household composition and a range of demographics including age, ethnicity, country of residency and geographic location type. A description of the participants that participated in the research is outlined below.

3.1.1. Impairments and health conditions

Fifty-seven disabled people participated in the research. Participants reported a wide range of physical and mental health conditions and impairments, learning difficulties (for example, dyslexia and ADHD) and neurodevelopmental disorders (for example, autism spectrum disorder). Table 1 describes the number of participants reporting at least one impairment or health condition across a range of disability categories.

The proportions of participants reporting impairments or health conditions in each category is broadly in line with DWP data on PIP claimants' main disabling condition. DWP data for April 2023 indicates the two most prevalent main disabling conditions were mental health conditions, learning difficulties or neurodevelopmental disorders (37% of claimants) and musculoskeletal disease (32% of claimants).

Table 1: Mental and physical health conditions and impairments of participants

Impairment and health condition category	n
Mental health condition	32
Neurodevelopmental disorder	10
Learning difficulty	10
Musculoskeletal condition	36
Respiratory condition	10
Endocrine/metabolic condition	9
Neurological condition	8
Gastrointestinal condition	6
Cardiovascular condition	4
Sensory impairment	3

Genitourinary condition	3
Skin condition	2
Malignant condition	2
Chronic viral condition	2
Autoimmune condition	1

Multimorbidity was common. The number of impairments or conditions reported by participants ranged from one to seven with, on average, nearly three impairments or conditions per participant. Fifty-six percent of participants (n=32) reported having both one or more physical health condition and one or more mental health condition, learning difficulty or neurological difference. Interacting impairments and conditions were also common. Participants reported that their physical health conditions caused or exacerbated their mental health conditions and vice versa.

3.1.2. Claiming and receiving benefits

Two thirds of participants (n=38) were in receipt of a disability benefit which enabled the research to explore experiences of the disability benefits system. Over half (n=30) of participants were in receipt of Personal Independence Payment (PIP). Four received Disability Living Allowance (DLA) and two received Industrial Injuries Benefit (IIB). Twenty-four reported having previously had a claim for PIP refused, sixteen had appealed the decision and 15 were successful in their appeal. This enabled the research to explore experiences of the appeals process and tribunals.

Of the 28 participants in Scotland, three had made new claims for ADP. Two had been successful and were now in receipt of the benefit. However, one participant's claim had been refused. Four were at various stages in the process of making an application for ADP. Five participants reported being in the process of transferring from PIP to ADP at the time of their interview. A further three were approaching the date of their transfer to ADP. Six participants in Scotland who were receiving PIP had not yet received any information about being transferred to ADP.

As a result, the research was able to explore some comparisons between PIP and ADP. At the time of their interview, one-third (n=19) of participants were not in receipt of any benefit specifically related to their disability. Several had had an application refused and had not appealed or were unaware they could apply. This enabled the research to explore reasons for underclaiming of disability benefits.

Almost two-thirds (n=37) of participants reported receiving at least one out-of-work benefit (Table 2). Approximately half (n=28) received Universal Credit (UC) and over one-quarter

(n=14) received Employment and Support Allowance (ESA). Of the 16 participants who reported having caring responsibilities, 12 received Carer's Allowance.

Table 2: Number of participants claiming and receiving benefits and disability benefits

Out of work benefits	n
Universal Credit	28
Employment and Support Allowance (ESA)	14
Carer's Allowance	12
Disability benefits	n
Personal Independence Payment (PIP)	30
Disability Living Allowance (DLA)	4
Industrial Injuries Benefit	2
Adult Disability Payment (ADP)	
<ul style="list-style-type: none"> • Receiving ADP 	2
<ul style="list-style-type: none"> • Transfer in Progress from PIP to ADP 	5
<ul style="list-style-type: none"> • Making an application for ADP 	4
<ul style="list-style-type: none"> • Applied for ADP, waiting for outcome 	1

3.1.3. Household composition

The research engaged with participants with varied household compositions (Table 3). Nearly one-third (n=17) of participants were single and lived alone. Twelve reported living in families with dependent children under the age of 18. Half of these were single-parent families, and the other half were in two-parent families. One-third (n=19) of participants were living with a partner with no dependents. Four participants lived with their partner and a dependent aged over 18. Four participants were single and lived with a dependent aged over 18.

Table 3: Participants' household composition

Household composition (n=57)	n
Single, living with dependent aged 18 or under	6
Single, living with dependent aged over 18	4
Single, living with non-dependent aged over 18	1
Single, living alone	17
Couple, no dependents	19
Couple, living with dependents aged 18 or under	6

Couple, living with dependent aged over 18	4
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Eleven participants were living in households with disabled family members (either children under or over age 18, a partner or a friend). Among participants living in single or two-parent families, eight reported having a disabled child or children.

Nearly 60% of participants (n=33) reported renting their homes, either privately or through a local council, housing association or the Northern Ireland Housing Executive. The remaining participants owned their home, with three participants owning their homes outright and twenty-one participants living in a mortgaged home (Table 4).

Table 4: Housing tenure of participants

Housing tenure (n=57)	n
Homeowner – own outright	3
Homeowner – mortgage	21
Private rental	10
Council rental	14
Housing Association/Housing Executive rental	4
Rental (no detail provided)	2
Other (temporary shared, bed and breakfast or self-contained rental)	3

3.1.4. General demographics

To enable the exploration of the impact of ADP, most participants were recruited from Scotland. Twenty-eight participants lived in Scotland, eleven in England, eight in Wales and ten in Northern Ireland. Participants lived in urban cities and towns, small towns and rural areas.

Over half of participants (n=29) had accessed food aid, either in the past or at the time of their interview. Some described their food bank use as a one-off event. Others had, or were currently, accessing food aid on a fortnightly or weekly basis over a period of several months. Most participants reported receiving food aid from a food bank. However, some had accessed other forms of food aid, including community larders or pantries that provided cheaper, but not free food, and community fridges that provided free access to surplus food donated by businesses or individuals.

Thirty-three participants self-described as female, twenty-two as male and two self-described in another way (Table 4). Participants were aged between 21 and 67 years. All but two participants described their ethnicity as White Scottish, British, Irish, European or other.

More than half (n=35) of participants were either unemployed or unable to work due to their health conditions and impairments. Participants who were unemployed often cited that their difficulty with finding employment was a result of their disability. Approximately a third of participants were working either part-time (n=12) or full-time (n=6) in paid employment. The employment status of three participants was classified as 'other'. Reasons for this included studying at university, not working due to care responsibilities, and recent retirement.

Table 4: Participant demographic information

Participant demographics (n=57)	n
Self-described gender	
Female	33
Male	22
In another way	2
Age	
18-24	2
25-34	11
35-44	15
45-54	15
55-64	13
65+	1
Ethnicity	
White Scottish, British, Irish, European, other	55
Black Caribbean or Black Scottish/British/Irish/European	1
Mixed or multiple ethnic groups	1
Country of residence	
Scotland	28
England	11
Northern Ireland	10
Wales	8
Employment status	
Unemployed/unable to work due to disability	35
Part-time employment	12
Full-time employment	6
Other	3
Volunteering	1

3.2 Participants' experiences of living with impairments and health conditions

Interviewees reported that having health conditions and impairments had a major impact on their daily lives. These impacts are outlined below.

3.2.1. Impacts on everyday living

While interviewees were living with a wide range of physical and mental health conditions and impairments, consistent pain was a common impact of many of these conditions. Living with regular or constant pain affected interviewees basic functions such as their mobility, sleep and self-care. Pain also impacted their ability to socialise, drive, work, shop, undertake household tasks and play with their children. Medication was often taken to try to manage the pain, however, it was reported that it did not always work. Medication had many reported side effects, such as fatigue, nausea and irritability. Therefore, even if the pain was eased, medication did not necessarily assist participants in carrying out everyday activities.

“I'm taking a lot of painkillers each day [...] They do help, they take the initial pain away, but there's obviously side effects with them as well. There's things like you can get a sore head, you can be tired, they can make you feel nauseous sometimes. The tiredness one, you can sometimes sleep round the clock with them. I'm only taking them to help with the pain, because it can be excruciating some days.” (Participant, Scotland)

Pain was not the only aspect of living with mental or physical health conditions and impairments that impacted on everyday living. Overall mobility, energy levels and concentration were affected by a wide range of conditions or their treatments. Participants reported that completing basic daily tasks was either difficult or impossible without support or could leave them feeling exhausted. Consequently, interviewees required aids, treatments and support with daily living. Some of these aids, treatments and supports were provided for free by the NHS, local authorities, voluntary sector organisations, or family and friends. However, others had additional costs which are discussed in section 5.2. Meeting these additional costs could lead to or worsen their financial stability. In some circumstances, family and friends offered financial support however, there were participants who did not have anyone to provide this support.

Many interviewees reported that they were largely housebound. Participants with fluctuating conditions found it difficult to plan activities outside the home due to the unpredictability of their impairments. Participants with autism, learning difficulties, mental health issues, mobility

and sensory impairments described challenges in navigating their everyday environments such as public transport, supermarkets and other public places.

“If I had an appointment in 3 days’ time, I actually do a dummy walk to see how long it’s going to take me, do you know what I mean? Which way to go and all that type of stuff. If not, it goes on and on and on in my head. I worry about it. Like I say if I had an appointment in 3 days, I’d not sleep, I wouldn’t sleep for a couple of nights before it just through panicking and worrying, thinking that I wouldn’t get there you know?”

(Participant, England)

To leave the home and access these spaces, interviewees often had to rely on the support of others. As a result, leaving home caused anxiety for some, while others felt like a burden to family and friends. To manage anxiety, trips outside of the home required careful planning and practice, with any unanticipated events provoking feelings of dread or distress.

3.2.2. Impacts on mental health and relationships

The impacts of living with an impairment or health condition were described by participants as a source of “mental pain”. Being unable to work and socialise was spoken about as a source of frustration and distress. The efforts required to manage symptoms and navigate environments, were experienced as mentally draining.

Participants spoke of their social worlds shrinking to the level of their household. Reduced interaction with people outside their household could lead to feelings of loneliness or isolation, and poor mental health. Participants also said that they felt both distressed and frustrated if their health impairments and their manifestations were misunderstood by others. Participants with autism reported difficulties in engaging socially with people, and how overwhelming it could be to comprehend social situations more widely. Some participants described the impact of their impairment on their sense of identity, being labelled as ‘disabled’ could be a difficult transition. A participant with a recently acquired impairment spoke of a reluctance to present publicly as a disabled person.

“I can’t walk around the supermarket. Not the way you have to, to do a week’s shop, and I’m not going to go in a wheelchair or anything like that. I just refuse. I’m just not doing that. I’m not prepared to, and I say that in reference to me, not to other people. I need to make that point clear. I’m not prepared to give up that much of me yet; I’m just not. I’m not referring to people that do have - because everybody’s got their own personal set of circumstances and troubles, but for me, it’s the bit I’m fighting the most.” (Participant, Northern Ireland)

Relationships with friends and family could be negatively impacted. Participants spoke of difficulties in maintaining friendships with non-disabled people, either because they did not want to share how they were feeling with their friends, or because they felt their friends did not want to be around them.

“I do not have any friends, being this ill has taken away all of my friendships, no one really wants to hang around with a sick person, around my age group anyway.”
(Participant, Scotland)

“Like I don't feel that I have any friends who can understand this at all, [...] It's very emotionally draining to go out and see my friends because a lot of them, they don't know the extent of how low I can feel, and I just feel like I can never explain. I can't put into words what's been going on, and I sometimes feel they've got their own problems too. I don't want to be dragging things up, so what ends up happening is I would put on a mask, just like pretend things are fine, and they would come here to visit, but I don't like going outside of here to meet my friends.” (Participant, Scotland)

There were instances of family dynamics and relationship being impacted. Participants who experienced symptoms such as incontinence or needed help with personal care from family members, reported feelings of embarrassment and shame that could impact on close relationships and wider social interactions.

Participants felt that their impairments or health conditions were reducing their ability to contribute fully to the household, be that financially or through housework and childcare. This was a source of frustration and guilt and impacted on participants' sense of identity. Some participants shared their distress about being unable to parent their children in the way they would like to.

“Yes, so even the simplest tasks can become very daunting. In relation to being a father, how it affects that: I still get out and about with [child] and still get out and doing things and bits and pieces with him but I would love to do more, but I can't plan in advance because I don't know what I'm going to be like that day. Yes, so it's a hard balance to find, extremely hard balance [...] I want to do so much, and I know I'm relatively still young - 44 - but yes, [sighs] it does get me down, like, massively. But that's just one wee tentacle of my mental health, like; not being able to do what a normal father should be able to do.” (Participant, Northern Ireland)

Participants who provided care for disabled family or friends faced additional challenges. Interviewees with parental responsibilities described the emotional and physical toll of providing care for disabled children, behavioural or learning difficulties, on top of managing their own health conditions and impairments.

“Every day varies. Some days are fantastic. When it's a good day, it's a great day, but the bad days, it can be very difficult. You just don't even want to get out of bed, let alone run a house or be mum. You walk downstairs to make yourself a cup of tea, you look at that one bowl in the kitchen, and you just think, ‘Why do I bother?’ But then other days you wake up and you just crack on because it's just the way you are. It's what you do. It's hard to... I don't focus on myself because I spend all my waking time focusing on my son.” (Participant, England)

Experiences of food insecurity

Food insecurity was an almost universal experience among participants, who described a cycle of increasing food insecurity between wage or benefit payments. Worrying about buying food at the start of the month shifted to compromising on quality and skipping meals by the middle of the month. By the last few days of the month, some were left with access to no food at all.

The determination to provide their children with nutritious food worsened food insecurity among parents, many of whom stated that they had gone without to allow their children to eat. Despite their best efforts, however, some parents felt that their children's diets were insufficient, reporting a lack of food in the fridge and scant access to fruit and vegetables.

“At the moment, my fridge is fairly empty, my freezer is just about empty, and my cupboards, there's very little in there, except pasta. I've never been in that position [...] I'm constantly worrying that their health is going to get affected because they're not getting everything that I could provide before, and I can't do it anymore. I can't.”
(Participant, Scotland)

Impairments were also perceived as limiting a person's ability to prepare food. Mental health conditions resulted in reductions in appetite and the motivation to cook meals. For some participants, physical impairments resulted in challenges with food preparation activities such as chopping, lifting, pouring and being around sources of heat. Additional barriers were experienced by people living in shared accommodation such as homelessness hostels and temporary bed and breakfast accommodation, who reported difficulties in accessing the kitchen facilities and reluctance to prepare food in the presence of strangers.

3.3 Impact of food insecurity on health

Food insecurity was perceived as resulting in a range of negative health effects. Affording enough food meant sacrificing nutritional quality. Participants were very aware that the food

available to them was insufficiently nutritious and, potentially, detrimental to their health in the longer term. Healthcare providers recommended food that was unaffordable, with foods of low nutritional value frequently being the cheapest. The necessity of taking medication on an empty stomach was reported as causing symptoms to worsen, sometimes dramatically. Physical and mental health were being compromised by diets inadequate in terms of quality and quantity of food, leading to unintentional weight loss, weight gain and nutritional deficiency. Lack of food and disordered eating were viewed as a particularly “dangerous” combination, as not being able to afford food, and therefore skipping meals, can impact the eating disorder.

“I have gone without food before and I have had issues with eating disorders and eating, so sometimes if I don't eat it feeds into that and it's a really bad cycle when that starts out. So, if I get in a situation where I can't afford to eat I just let it happen because of that disorder with eating. What's really dangerous actually is people are in that situation and they've got these problems. So yes, I have gone without essentials.”
(Participant, Wales)

Food insecurity was reported as a source of constant anxiety, worsening mental health and triggering negative thoughts. Perceptions of failure to provide adequate food for themselves or their families were reported as a further source of mental distress and shame.

“It feels like I'm failing, it has a big impact on my mental health. I feel like a failure, I feel like I'm doing something wrong. I feel like I'm failing at everything.” (Participant, England)

3.4 Emotional, societal and cultural significance of food

Cooking was reported to be no longer an enjoyable activity and the food available was viewed as not constituting a proper meal, lacking key components such as vegetables or a source of protein. In an environment of abundant food choices, participants were aware of the limitations of their options. Participants reminisced about favourite foods and meals they could no longer afford. Social aspects of food, such as meals out of the home or sharing meals with family and friends were also often thought to be no longer a possibility, for participants and for their children.

“I can't remember the last time we had a meal out. I know that sounds very much like a first-world problem, but I can't even remember the last time I had a cup of coffee somewhere that was out. We're doing without so as my son can have. His wee friends

in school bring for lunch stuff that we wouldn't normally get, and lots of his friends go for school dinners, which we can't afford. We try once a month for him to have one school dinner a month so as he can be with his friends at lunchtime, things like that.” (Participant, Northern Ireland)

The ability to show affection through food was also diminished, with parents and grandparents unable to keep treats in for their children or grandchildren. Indeed, the consensus of participants was that there was an inability to afford treats or luxuries of any kind. While recognised as not a dietary necessity, treats were considered important components of life enhancement. Being unable to brighten a day or lift your mood with a treat was experienced as profoundly depressing, particularly when circumstances were difficult. Eating good, and therefore relatively expensive, food for enjoyment or as a form of self-care could also manifest itself as a source of guilt.

“Because you're sitting making dinner and then you're going, 'Well, I could be eating two slices of toast.' Then when you're making the dinner, you're using electric, okay, which is going nowhere at the minute either, whereas if you're having two pieces of toast you just put the toaster on for two minutes and then that's it. I would feel guilty sitting having a baked dinner when I could be having a piece of toast.” (Participant, Northern Ireland)

3.5 Strategies to mitigate food insecurity and protective factors

Participants reported adopting a range of strategies to reduce their food insecurity, including shopping around extensively in search of the cheapest options and reduced items. Stretching the food budget to meet their needs required significant amounts of time and intensive efforts to monitor, calculate and plan.

Going into an overdraft facility, using a credit card to pay for food, or borrowing money from family or friends were helping people get through to the end of the month. However, while providing short-term relief, loans required repaying leaving reduced money for food for the next month.

It was stated that family and friends were a vital source of support, lending or gifting money for food and regularly sharing meals. Participants with family who were also struggling spoke of shopping and cooking together to save money. The ability to cook was widely referenced as vital for “making something out of nothing”.

3.6 Circumstances of accessing food aid

Participants had sought food aid when they reached a crisis point, when a visit to a food bank meant the “difference between eating and not”. Reasons for being unable to afford food included unexpected bills, prioritising rent to avoid homelessness, and waits to receive benefit payments. High fuel bills were a frequent reason for needing food aid. Overall, participants were accessing food banks because their income was insufficient to meet everyday costs.

“That's why I had to go to a food bank. Because we never had enough money to provide us with the food and it was basically pay for gas or electrics or have nothing.”
(Participant, Scotland)

Food banks were the most frequently accessed source of food aid however, community larders, pantries and fridges were also being used. Information about food aid came from a wide range of sources, including friends and family, co-workers, healthcare professionals, voluntary sector organisations, job centres, local authorities and social media.

Food bank staff and volunteers were praised for the welcome they provided. With very few exceptions, participants had found staff to be kind and non-judgemental. Provision of advice and signposting by food bank staff and volunteers was welcomed and had resulted in new benefit applications and support with utility bills.

“I was a bit unsure and a bit unconfident. I felt - I don't want to say that I was degrading myself - but I felt like you sort of, on the way along there, you know, you sort of - obviously your mind, like, what's it going to be like? We shouldn't have to be - we shouldn't end up using a food bank, but once I'd been a few times I got to know the staff and the volunteers, who were really nice and they're welcoming. They made you feel at ease and they talk to you like normal. So, they're not looking down at you or anything like that, yes, it made it a lot easier.” (Participant, Scotland)

While there were participants who had only used food banks once or twice there were others who reported using food banks regularly (weekly, fortnightly or monthly) over periods of up to a year. Participants who used food banks over a longer period of time said they found it challenging to eat a balanced diet because they found that fresh food was rarely provided. As a result, some participants felt food parcels did not contain the ingredients for what they viewed as balanced meals.

“I didn't get any fresh food. You don't get any fresh food; it's all tinned food and it's all pasta and sauces and tea and coffee. I got sugar, which was really lovely; you don't normally get sugar. I think it depends. I can see where it's coming from because the

food bank is relying on donations and I think when people go and put donations into the boxes at the supermarkets, they would choose the cheaper items - which is fair enough. I totally understand that, but just fresh food and that is a struggle.”
(Participant, Northern Ireland)

People with dietary requirements particularly struggled because they could not eat all of the food provided. Participants said they thought it would be demeaning to ask for special foods and wrong to reject the food they were offered. Therefore, to avoid food being wasted participants with dietary requirements tried to avoid using food banks.

“I’m not using it [food bank] because there’s very little we can eat there because whilst I appreciate the fact that they’re trying to give us food if we can’t eat it I would rather it went to somebody that could eat it rather than us just waste it. I don’t want to waste anything. I try not to waste anything so it’s really, really difficult for us to use those kinds of services as well, so our food bill is high.” (Participant, Scotland)

3.7 Barriers to accessing food aid

Food aid enabled some participants to feed themselves however, some experienced barriers to accessing food aid. One of the most significant barriers was stigma. Visiting a food bank was thought to be an admission to others that you were struggling, which could be difficult to overcome, particularly at the first visit. Participants described feelings of failure, embarrassment, shame and the perception that they had hit “rock bottom”.

“You felt ashamed really [accessing a food bank], because you're in that position. My great grandmother was born in a workhouse, because her parents came from Ireland with the potato famine. You think, ‘Oh, back to square one’, you know? It makes you feel really useless, having to go there. I wasn't the only one, by far. Working people, people who were working a full-time job and going to that food bank. [...] it is upsetting though. You feel like an absolute failure.” (Participant, Wales)

Feelings of shame could be too hard to overcome. Media depictions of food bank users as being unable to manage their money, negative reactions from family members, and instances of shaming on social media were all reported as preventing participants from seeking food aid. A reluctance to access charitable food aid because other people were viewed to be in greater need was widespread among participants. Perceptions, and accompanying feelings of guilt, that accepting food aid would be depriving others was a considerable barrier that was reinforced by media reporting of increasing demand and dwindling supply at food banks.

“No, because I'm like this with a lot of stuff, I feel like there's other people that need it more. [...] I just feel like they need it more than me, so yes, I haven't gone to a food bank because there are people with kids for example. I don't have kids. There are kids going hungry. They need food. I don't know. I've never used a food bank. I wouldn't feel right using it.” (Participant, Wales)

“So even if I was a completely healthy person who wasn't terrified of people and who could walk around unaided, I guess it could be like a shame thing. Also people could need it more like yeah, I'm hungry but could there be someone that's even hungrier. Just...it's just awful, you know you've really hit rock bottom when you can't even...when your family is hungry...sorry it's really hard not to get upset.” (Participant, Scotland)

Participants also experienced some practical barriers to accessing food banks. For those without transport, the practicalities of getting to food banks and taking food parcels home was particularly challenging. Also, at busy food banks, the noise and bustle were challenging for people with mental health conditions. There were instances of participants having food parcels delivered which made accessing food aid much easier. It was felt to be a less stressful experience.

While few participants mentioned the referral process, there were participants who described it as complicated and lengthy. Furthermore, there was uncertainty concerning the number of referrals to a food bank that was allowed. This resulted in a participant seeking out other food aid.

4. Drivers of food insecurity among disabled people

One of the aims of this research was to identify and understand the drivers of the over-representation of disabled people and households among those accessing food banks. To achieve this aim, we asked disabled people about their experiences of living with health conditions and impairments, and any associated financial costs. We also asked people about their experiences of the disability benefits system. The drivers of food insecurity are outlined below.

4.1 Economic exclusion

Living with health conditions and impairments impacted on interviewees' experiences of gaining or remaining in employment. There were participants who reported that the symptoms of their conditions such as consistent pain or fatigue, or side-effects of medication, made it difficult for them to work. However, a lack of accessible employment or inflexible employment structures meant that other interviewees no longer worked or had been unable to ever find work. Participants reported that employment structures and environments could present barriers to work, with accounts given of periods of absence or changes of job being necessary. Participants described being forced to stop working, reduce their hours or change jobs, often with a lower salary which resulted in lower household incomes. Being excluded from employment left participants feeling worthless or without a sense of purpose.

Underpinning the challenges of finding and remaining in work, was the role of the employers and whether they sufficiently understood disability and implemented reasonable adjustments effectively. Participants described a range of employment experiences. Some reported that their employers understood their needs and provided the support they needed to carry out their work. However, others had more negative experiences. Some participants had been injured in the course of their work and felt let down by the limited effort made by their employer to support them in their role or redeploy them to another suitable role. Other participants reported that while their employer had support procedures in place, these were sometimes not enacted or failed to adequately address their needs. There were instances of participants being expected by their employer to take on the extra work of sourcing their own workplace support and equipment. Further, some participants had been denied their entitlement to reasonable adjustments or equipment to support them in their work.

“I had a programme where I could talk into my computer and it would write for me, and it was invaluable. It was really good, and I was going to have the same programme at work because it was on a computer, and I didn't get it. They're supposed to sort out all the reasonable adjustments and equipment. I was working from home so I thought it would be good, but actually they didn't, I had to sort out everything, or try and sort out everything, all of my equipment.” (Participant, England)

“We used to have meetings, like they'd hire [a room] and the cold really affects my pain levels [...] I asked once if I could miss these meetings, one meeting, and this boss said, 'No', I couldn't miss it. I explained why. I said, 'Well, surely it's a reasonable adjustment, especially if I haven't got my equipment?' They said I'd have to take the day off sick [...] It's really put me off trying to work, even though I've got all this knowledge that I could use when my brain does work, but it wasn't a very nice experience, put it that way.” (Participant, England)

Participants described a lack of disability awareness and understanding among some employers, including limited awareness of the nature and range of potential impacts of impairments and how these impacts could fluctuate from day to day. This resulted in participants not receiving the support they were entitled to.

“I try to say, 'No', and I try to only do what I can do and communicate that I've got too much on, and I feel like it's ignored because they consider it not to be too difficult. I try to explain that it may take them five minutes, but it might take me a bit longer for whatever reason and some days it's better than others. So, some days I can feel almost fine, and my work will be of a higher standard, and I won't have as many problems, but it varies basically. There's no adjustment. There's no understanding. They don't want to deal with it.” (Participant, Wales)

Some believed that, while their employer wanted to support them, they felt the wider needs of the business were prioritised over their needs as an employee. Others felt they had been forced out of their jobs by employers who felt they were no longer capable.

“Every time I got to their parameters, they changed them; they added something else in, 'That's fine, but you now need to be able to do this and this.' So, every time I was kind of reaching a goalpost, the goalposts were moved was the whole thing. Actually, they did admit at one point that they just didn't want me to be there because they didn't feel as though I was capable of doing my job anymore.” (Participant, Northern Ireland)

Interviewees were often not the only disabled person in their household. In addition to their own health conditions, interviewees could be caring for other family members with health

conditions or impairments. This also impacted on disabled people's capacity to work, with some having to either reduce their hours or stop work altogether to care for other disabled people in their families. There were circumstances where other members of the household took on this caring role, though this still had a negative impact on the overall household finances. While financial support from the government was available, it rarely compensated for the loss of income.

4.2 Extra costs of living with impairments and health conditions

Disabled people experienced many different additional financial costs related to their health conditions or impairments which could be a driver of financial insecurity. These additional costs are discussed below.

4.2.1. Costs of treatment and support

In addition to a loss of income, disabled people experienced a number of costs in the treatment and management of their health conditions and impairments. Whilst Scotland, Wales and Northern Ireland have free prescriptions, most people living in England still need to pay for prescriptions. It is the case that some impairments grant an exemption from prescription costs, but these exemptions are limited, with many disabled people having to pay for their prescriptions. While an NHS Prescription Prepayment Certificate (PPC) reduces prescription costs for people needing multiple medications, there is still a cost that people on low incomes may struggle to meet. Interviewees in Scotland, Wales and Northern Ireland highlighted that they would struggle to pay for prescriptions if they were not free, adding to the financial pressure they experienced.

“If we didn't have a pre-paid yearly exemption certificate, it would be over £40 a month [...] but we've just had notification that when it expires in May it's going up because the cost of prescriptions is going up and I just think it's so unfair because she's got a lifelong condition.” (Participant, England)

“Quite lucky in Scotland that we get free prescriptions, which is fantastic really, because I don't know how I would cope, taking that much of them.” (Participant, Scotland)

However, it is important to note that some medication and supplements disabled people used to help manage the symptoms of their health conditions and impairments were not covered by the NHS, resulting in extra costs. For some, the cost of a treatment or support was too costly,

resulting in people not being able to access something that could help manage their conditions or improve their quality of life. Being able to manage symptoms of health conditions enabled participants to work, socialise and undertake daily activities independently.

“Even like the supplements I take; I take Corsodex, and Lion's Mane and vitamin D and things like that. I'm not going to be able to get the vast majority of those things on prescription, so they cost £30 a packet as well, which lasts about two months. If I wasn't taking all of those things and doing all of those things and using things like CBD, I very likely wouldn't be able to work.” (Participant, Wales)

“They [doctors] don't give you a prescription to go and get your special soap powder and all that. They'll give you a one-off prescription for it, and then you need to buy it. [...] once every month it's nearly £200.” (Participant, Scotland)

Interviewees also said that they faced costs for aids, adaptations and support to help manage the impact of their health conditions and impairments. While some aids and support were provided through the NHS or local authority, this was not always the case and interviewees had to meet these costs or do without. There were also instances of aids provided by the NHS or local authority not meeting the needs of participants. Examples were given of personal care aids which while functional, did not maintain a participant's dignity and therefore they avoided using it.

“With this house, as I say, I really do need a downstairs toilet because I have problems going upstairs, but the council... It used to be that the council would build one; it's easy enough to do in this house, but they won't anymore. So what I was given by the OT was - what do you call them? A commode to put at the bottom of the stairs, and that is undignified. I've got a son who lives here. So that is why if I'm having a bad day and I know I won't make it to the loo in time, I stay upstairs and watch telly. They're not realistic, really. It's just not enough, really. (Participant, England)

To ensure their needs were better supported, interviewees had to pay for suitable aids and support. Furthermore, even when aids were provided by the NHS or local authority, there could be additional utility costs for running these aids.

“The hearing aid that I have now at the minute, I had to buy. Well, my husband bought it for me because the ones they provide in the health service are just completely not good at all. When I went to the private audiologist and she gave me this six weeks' trial of this amazing hearing aid, it was like a whole new world opened up. I was like, oh my God! This is sensational compared to the hearing aid that I had. [...] it adapts to my surroundings and because it comes with this fantastic app, it just makes my life so much easier.” (Participant, Northern Ireland)

4.2.2. Increased utility costs

Interviewees described the extra utility costs they faced as a direct result of living with physical and mental health conditions. A vast array of conditions that impacted on people's mobility, mental health, immune system and caused them pain, all resulted in them spending most of their time at home and using more gas and electricity as a result.

Disabled people also reported using more gas, electricity and oil to try to manage their health conditions and impairments. For example, several health conditions including arthritis and autoimmune conditions are made worse by cold and damp conditions. Therefore, some participants required a warm home and took hot baths and showers to help ease pain, and others used lighting to help with visual impairments. Several medical aids, such as electric beds and chairs, used additional electricity. Increases to the cost of gas, oil and electricity over the last 18 months were viewed as having further exacerbated the costs of running equipment.

“I have what's called a through floor lift [...] I now have a hospital bed and I have my reclining chair, which is electric. All of that is eating into the electric [...] I have a CPAP machine; because of sleep apnoea, I stop breathing if I don't have my CPAP machine, and it takes the electricity. All these things are draining on the electric. Because of my blood condition I get so cold, so I need more heating, which is a big drain as well. Just last week we had to ask a charity for help with those. They were so good and gave us some oil and emergency electricity, but the emergency electricity was only a one-off. They told us it wasn't going to be ongoing. It's awful that you have to rely on charities for these things. I never thought that I would have to go to food banks, but I have to go to food banks. We have to get food from food banks, because there's only a certain amount of money from my PIP, my ESA, my husband's Carers', and then we're paying off the mortgage. All those things, very, very tight, and that's stress.” (Participant, Northern Ireland)

4.2.3. Transport costs

Interviewees experienced additional transport costs because of their health conditions and impairments. The cost of public transport, taxis or petrol and parking were incurred through attending doctor or hospital appointments, picking up medication or attending support sessions related to their health conditions and impairments. Interviewees also required a car, taxi or public transport to enable them to carry out daily tasks such as going to work and carrying out food shopping. It was common for participants to report that public transport was not accessible to them, therefore, they were forced to use either taxis or a car to get around.

“It’s hard enough when you’re dizzy to walk around never mind get public transport, so I must use my car. If I can’t use my car I can’t go anywhere and because I live out in the countryside where there’s only one shop that doesn’t sell things that I’m able to eat because of my [health condition] like, that’s it. So if I don’t have the...my car then I don’t have a way of getting food.” (Participant, Scotland)

“If I do go to college, it's taxis I get - but I don't get any help with it; they're out of my own money. [...] the bus I would get for college, there's three/four steps you have to take up on to it and it's just a bit much for me, really. Then being round that amount of people for that amount of time in such a small place, it just, no, it would drive my anxiety bad. So, whereas with a taxi it's more comfortable and I'm not having to climb stairs [...] It's a lot more fit for purpose for me.” (Participant, Northern Ireland)

Only those receiving the enhanced level mobility payment for PIP were eligible for the Motability Scheme. Therefore, many disabled people had to meet the additional costs of running a car on their own. It is important to note that there were instances of participants being eligible for but not opting to receive Motability, despite the extra costs they incurred from running their own vehicle. The reason participants did not accept Motability support was because they feared their eligibility for Motability might be removed if they were reassessed which would leave them with no way of getting to work or around more generally. This would in turn have a negative impact on household finances and social isolation.

4.2.4. Food costs

To manage the symptoms of their impairments and health conditions, some participants were restricted in what they could eat. The requirement to buy suitable foods created considerable additional financial expense. Sourcing and preparing suitable food imposed further costs, such as the need to visit multiple shops or cook multiple meals for family members with different dietary requirements. Some participants also incurred additional costs by buying pre-prepared vegetables because they could no longer prepare food unassisted.

“[Health condition] doesn't help because, as I say, often you're having to go and get certain foods, which can cost a bit more [...] for example, I try to avoid milk as well as much as possible, so I'm having to buy, like, the oat milk and the almond milk and all that sort of stuff. It only comes in, like, a wee thing, and it's like £2.40. I have to avoid fatty foods, so all my meat has to be very lean. [...] I have to find things which definitely don't contain these certain things that I can't have, so they tend to be more expensive.” (Participant, Northern Ireland)

“I can't chop the vegetables up. You could buy a pack of prechopped vegetables, but that's more expensive. You buy one pack rather than a big bag of potatoes and a big

bag of carrots, so you buy a prepacked thing, obviously you're not getting as good value for money.” (Participant, Wales)

Being unable to visit shops in person because of health conditions or impairments made online food shopping a necessity for some. Online shopping increased costs through delivery charges or by limiting supermarket choice. For example, the two main budget supermarkets do not offer an online service. Participants living in rural areas or whose impairments limited their ability to travel to supermarkets reported paying a price premium in smaller local shops. The cost of providing food for much-loved, and often therapeutically important, pets was also said to be challenging. Participants said that they invariably prioritised feeding their pets over feeding themselves.

4.3 Inadequacy of disability benefits

Very few participants reported meeting their living costs or the extra costs associated with their impairment or health conditions. Interviewees thought that the design and delivery of the social security system made it difficult for disabled people to apply for and be successfully awarded disability benefits. Without disability benefits, disabled people had to meet these additional costs associated with physical and mental health conditions and impairments on their own. This could lead to financial insecurity, and as a result, food insecurity.

However, there was also an almost universally shared belief among participants that disability benefit payment levels were too low to meet the extra costs related to disability. Moreover, with few exceptions, participants in employment and those receiving out of work benefits reported that income from disability benefits was being spent on everyday living costs such as rent and utility bills rather than impairment-related costs. This was because their level of income was insufficient to cover these costs. Therefore, in some instances, participants were not able to access support that could help them manage their conditions or improve their quality of life.

“If you wanted perspective, it [PIP] doesn't cover our electric bill, and I'm currently sat in a room with no heating on. Our cooker is even turned off at the wall so the clock's not going on it, the wee digital clock. We even turn it off at the wall, so the digital clock's not flashing on the cooker. That doesn't even cover the electric. We live in a two-up two-down end terrace. It doesn't cover very much. My wife works, and without her work, we'd have lost our house by now.” (Participant, Northern Ireland)

It was clear from their accounts that even those who were receiving disability benefits were frequently unable to afford a basic standard of living, and struggled to pay bills. Borrowing from family and friends, and through overdrafts, loans or credit cards was commonly reported.

Participants described the psychological impacts of the embarrassment of having to borrow money from family and friends. Some were falling into debt and into arrears with rent and utility bills, with debt repayments further reducing already insufficient incomes and causing stress and anxiety. Credit card debts and overdrafts were difficult to clear, creating cycles of debt.

“I've used savings and then I am literally at the minute sitting with practically nothing. I think I have 14p in my bank at the moment, and I'm probably going to have to borrow from someone [...] but it's like so embarrassing having to ask and you feel awful, and then you look and go, 'Well, how am I going to pay it back?' That is always something that I'm very aware of, is how do you pay it back afterwards?” (Participant, Northern Ireland)

“I do find myself often getting emails from my bank to say that I'm in unarranged overdrafts and then I'm having to seek money from people and help to avoid things like internet and phone bills being cut off, etc. Constantly chasing up and running to keep up.” (Participant, Scotland)

A widely shared perception among participants was that life was, “not really a life; it's an existence at the moment”. Cutting back, sometimes drastically, on heating was an almost universal experience. Participants listed all the things their lack of money resulted in them having to forego, such as socialising, trips out, watching television and replacing worn out clothes. Parents spoke about being unable to take their children on days out. Being unable to socialise and participate in society was thought to negatively impact on mental health and general wellbeing.

“I suppose the main thing is, I don't really care about myself. I care about people around me rather than myself. So my thing would be because I am basically on the breadline, I can't do the stuff that I would like to do with [child]. His wee nursery friends and stuff, they go away for the day to somewhere and it costs £24 or something and I can't afford it. It'll be £24 a week's groceries for me, you know what I mean?” (Participant, Northern Ireland)

Participants also spoke about the impacts of constantly worrying about money. Some described losing sleep due to worry, with the stress causing their mental health to deteriorate.

“Finances are becoming more and more and more severe, I'm actually losing sleep over it. I know people say, 'I lost sleep over it,' but I'm waking up at the same time, 2:00/3:00 in the morning, no matter what time I go to bed, and it's just like a million things racing round my head and causing me almost to have panic attacks and things. [...]every day, sort of, life and reality is getting very, very difficult. I'm not suicidal or

anything, but you think you've got on top of things, and then something else happens. The electric runs out, you have to go and top that up. You sit and you think, 'Oh, maybe I've got enough to do this', or something, and then something else happens. It's crazy." (Participant, Northern Ireland)

The constant effort needed to attempt to stretch an insufficient income was described as 'exhausting'. Insufficient money meant people frequently had to choose between essentials such as rent, utilities and food. Few were able to build up savings for unexpected events. Unexpected costs such as car or home repairs had sent some into debt and were an added source of worry for others.

"It's going to be those extra, unexpected costs that you don't see coming that are really, those are the ones that I dread and those are the ones that will cripple me for a month or more." (Participant, Scotland)

"It's like a cost benefit analysis, which puts additional data processing on my brain which is hard because my job is quite demanding as it is. Now it's like can I afford this pack of cookies? Can I afford these teabags? Can I afford this pasta? Every little thing is a cost benefit analysis and usually it's, 'No'. Usually the answer is, 'No', now. [...] I'm exhausted. It gives me less memory and processing power to deal with other things that do matter like eating healthily, like calling my friends and family, like performing well at my job and having good relationships with my co-workers. Just being alive, being a human and being alive. It gives me less time to enjoy that and to focus on that because you're dealing with all these calculations all the time to survive." (Participant, Wales)

Participants described fluctuating health conditions or impairments deteriorating over time which could lead to higher costs. However, participants did not always see this reflected in their disability payments when they were reviewed. This was either because they were already receiving the enhanced payment and there was no higher payment they could receive, or were not awarded the enhanced rate. Furthermore, participants could be living with multiple health conditions and impairments, each with different associated costs. Participants did not think the complexity of their health conditions and related costs were reflected in the value of disability benefit payments.

Therefore, participants had to use savings, borrow money and go into debt to meet these costs, worsening their financial situation. This could be challenging for participants who had to stop working or reduce their working hours as a result of their impairments, as out-of-work benefits rarely compensated for the loss of income.

Cost-of-living crisis

Participants reported that the cost-of-living crisis was significantly worsening their financial situation. Those just about getting by in the recent past were now no longer doing so. Others were currently meeting their costs but spoke of their fears that this would change as costs continued to rise. One participant described the difference being awarded PIP had made to their life initially, though the cost-of-living crisis meant this difference was short-lived. The temporary fuel-bill support provided by the government was welcomed but, as the support was withdrawn, participants were growing anxious about how they would pay their fuel bills going forward.

“I genuinely couldn't believe it, but the relief, honestly, like a 1000-pound weight had been lifted off my back. I thought, oh my God, I can be able to not worry. I don't have to stress [...] and then it just got worse, the money situation. Inflation went up and so on. You always think this is as bad as it can be, surely it can't get worse, and then it does. It's like living in the upside down or something” (Participant, Wales)

“Now and again I'm unable to pay my fuel bills. It sometimes takes me a few months just to gather the money for the fuel bills. I was very thankful for the £67 a month that I got throughout winter but this is now the stage where I'm starting to panic. That's another reason why I don't often eat; it's because I'm unable to physically pay the bills to heat my food up.” (Participant, Scotland)

Rapidly rising food prices were reported as a universal source of concern. Increases in food prices were outstripping increases in wages and benefits, and showed no sign of stabilising. The prospect of further price increases was a source of intense anxiety for participants. Those who said that they were currently just about getting by had little room for manoeuvre as they were already buying the cheapest foods from the cheapest supermarkets. Escalating food costs accompanied by equally high fuel costs meant choosing microwavable meals or food that could be eaten cold. As a result, the need for charitable food aid was becoming ever more likely for some. In the face of severely limited resources, the requirement to pay essential bills such as rent, utilities and council tax pushed buying food down the list of priorities.

5. Experiences of the disability benefits system

Previous research by the Trussell Trust has identified widespread underclaiming of disability benefits among disabled people accessing their food banks^{1,16}. In fact, 62% of people from disabled households referred to food banks in the Trussell Trust network do not receive any benefits related to their disability. A central aim of this research was to explore disabled people's experiences of applying for disability benefits and identify the ways in which these experiences impacted on their attitudes towards, and engagement with, the benefits system. The research sought to understand the extent to which the disability benefits system was a driver of food insecurity.

5.1 Importance of benefits

Participants described the ways in which a successful disability benefits claim had impacted on their lives. The income from benefits was perceived as relieving financial worries, enabling individuals to meet some of the costs related to their health conditions and impairments. Disability benefits were used to pay for home adaptations such as accessible bathrooms, grabrails and ramps, and other assistive living technologies. Disability benefits were also used to pay for treatments and support which eased symptoms of their conditions such as massages to ease pain, or social activities to support their mental health.

“I know it sounds really little, but I can't use the tin opener, so I've seen an electric tin opener, so I'm like well, I get my PIP so I can buy the electrical tin opener and that will be able to help me a hell of a lot. [...] It's helping me to be able to adapt in life.”

(Participant, England)

Additional income provided by disability benefits also enabled some participants to increase their financial resilience. For example, through building up savings, paying off debts or helping them switch away from more expensive pre-payment gas and electricity meters. As a result, disability benefits were described as providing participants with a sense of worth and financial independence.

“I think it [PIP] helps me then be financially a little bit more independent as well. I wouldn't say I'm independent anymore but just gives me a bit of agency, I think, in a world that seems to be increasingly trying to take that away.” (Participant, Wales)

“Today, it gives me the ability to pay part of the mortgage, and I pay the Council Tax and I pay the electricity bill. It makes me feel like I'm worth something. It allows me as well to get things that I wouldn't need to get if I wasn't disabled.” (Participant, Scotland)

Receiving disability benefits also enabled participants to access further forms of support. For example, the extra cost-of-living support for disabled people had helped some participants keep their homes warm. Disability benefits helped participants overcome barriers to taking part in society. Those who had accessed the Motability Scheme described how a Motability car helped them perform day to day activities and enabled greater independence.

“It's [Motability car] been a lifeline. Obviously, it's a big drop in my money each month, but counterbalancing that, I think it gives me... Because of the way my feet and my legs and all that, it still gives me the opportunity to get [child] out, because I don't have to walk and push him in a pram or whatever or a buggy. Yes, so the car has been a lifeline, without a doubt.” (Participant, Northern Ireland)

For other participants, being awarded disability benefits had enabled them to stay in work. The extra money had enabled them to reduce their working hours, which made employment more manageable and benefited their health. For those unable to use public transport, disability benefits helped them afford to use a car or take taxis to work. For others, an award of disability benefits provided welcome confirmation that the impact of their impairment was acknowledged.

“My opinion [of the benefits system] to start with was negative, and then it changed because of the lovely people on the phone. It changed because of the lovely lady at the face-to-face. Obviously, it changed because of them granting me the benefit and saying to me, 'Yes, what is happening to you is valid.' Giving me that idea of being heard and being seen and being validated as a disabled person.” (Participant, Scotland)

5.2 Design of the disability benefit system

In this section we report participants' experiences of applying for PIP and DLA.

It was clear from this research that receiving extra income from disability benefits can have a positive impact on disabled people, both financially and personally. However, many participants faced challenges in applying for and being awarded disability benefits which could lead to missing out on vital income.

5.2.1. Application form

Participants' experiences of applying for disability benefits varied. While some had more positive experiences, overall, the experience was negative, with participants describing various parts of the application and assessment processes that they found difficult, and in some cases, distressing and traumatic. A participant described the disability benefits application process as “gatekeeping”, reflecting a widely shared view that the process was designed to prevent rather than enable people to claim the benefit. The PIP application form was described as “48 pages of hell” and both the application form and assessment process were reported as being long, complicated, repetitive and designed to catch-out applicants with “trick” questions.

“The process was repetitive and repetitive. Everything about it was just repetitive, repetitive, and then you're going, 'Is this being repeated on purpose to try and catch me out?' Because there's nothing to catch me out. My leg doesn't work. I'm in pain, and I'm medicated to the hilt for it, and I'm suffering mentally because of it, and there's never the right words showing all of that. But now I'm having to essentially feel like I have to perform to pass an exam. I think that's where the exhaustion came from, because I'm not a performer and I'm just a person.” (Participant, Northern Ireland)

“So that's the impression I get from them, is that they're constantly trying to catch you out and that they don't believe you, and they tar everybody that claims disability benefits with the same brush. It's almost as if anybody with a disability is a liar.” (Participant, Northern Ireland)

For some participants, the symptoms of their impairments or health conditions created additional barriers to applying. For example, mental health conditions or experiencing chronic pain were reported as reducing concentration levels and the ability to complete the form. Fatigue experienced by many participants, made the application process physically and mentally draining. The application process was reported to increase anxiety levels and worsen the effects of mental health conditions. Participants with autism and learning difficulties described finding it particularly difficult to understand what completing the form entailed.

“With things like autism and ADHD, I can go one way or the other. I'm very all or nothing. I like things to be very black and white. If there's ever any shade of grey, I'm like, 'right, I don't - what?! I need you to tell me exactly'. So, it's either I don't say anything, or I say a lot. It was the same with the form. When I finally started to get going on it, they say at the bottom of the thing, 'Continue on a separate piece of paper

if necessary.' Oh dear, yes. I continued on 22 separate pieces of paper.” (Participant, Scotland)

The one-month time limit for returning the application form was challenging for people who were unwell or who had caring responsibilities. Completing the form, particularly on paper, was felt to require a high level of literacy and participants with autism or those with learning difficulties reported finding it especially problematic.

“The application was - goodness! It was like a big... Because I'm dyslexic and I can't write at all; I can read but I can't write at all. Well, I can't read my ability, like to my age group. I felt like it was a big thick booklet and I think that puts you off and I thought, oh!” (Participant, Scotland)

Participants whose impairments were fluctuating or less visible reported considerable difficulties in communicating the impact of their health on the application form and in their assessment. The form was described as “one-size-fits-all”, and large sections were felt to be irrelevant to many impairments and health conditions. Participants who were awaiting a diagnosis described difficulties in completing the form in the absence of a named condition or impairment. Question wording, on the form and in the assessment, was described as rigid with no scope for nuance or expansion.

“When they were asking you if you could manage such-and-such, there was no flexibility in it. It was kind of like a rigid question, ‘Can you go to the toilet on your own?’ Right, okay, yes, I can go to the toilet on my own. Does that mean I use the rail and stuff? Do I use something to help me? They just asked things like that so there's no kind of flexibility within the question, I felt. It was only rigid, these questions; can you prepare a meal? Well, what do you mean by prepare a meal? Do you mean pour cereal? I can do that, but can I cook a full meal? No, I can't. There don't seem to be very many guidelines on how to put your answer down for it.” (Participant, Scotland)

The requirement to focus on an average day was reported as being unhelpful for claimants with fluctuating conditions that varied daily.

5.2.2. The assessment

Participants reported having their eligibility assessed by staff with seemingly little or no knowledge of their impairment or condition and its potential impacts. They described their frustration at being asked what they judged to be irrelevant or, sometimes, insulting questions about their health and its impacts. Some also described the PIP assessment process as feeling rushed and impersonal, and allowing no time to expand on answers in more detail.

“They were quite degrading, 'Could you touch your toes?' 'Actually no.' 'Why not?' 'Well, I just can't touch my toes because of my back.' Then they would turn round and write on the computer and you're like, 'I'll explain.' 'No, we're moving on.' I felt it was rushed. It was like a rushed assessment; it was like you were on a conveyor belt. That's the way I felt; you were on a conveyor belt, one in, one out.” (Participant, Scotland)

“The way that you answer the questions, they filter the...they filter it in such a way where you just have to say yes or no to their questions. You can't actually talk to them like a person. So it's like...they sort of like take the whole personal aspect out of it completely and I felt like I was treated like a bloody robot really. Yes or no answers instead of saying my opinion [of] how sick I am. If you've got a choice between 'A' and 'B' but you want to say 'C' it's not really a choice.” (Participant, Scotland)

Although people in employment are eligible to claim PIP, participants in work felt that having a job was viewed by assessors as evidence that they did not need extra support or that they could afford to meet any extra costs associated with their impairments or health conditions. They described being interrogated about how they were managing to continue to work given the impacts of their conditions.

It was reported that there could be a hostility towards disabled people among some staff working within both the disability benefits system and the wider benefits system. Many felt that the disability benefits application process was designed around the assumption that claimants were lying until proven otherwise.

“They hate us. Everything disabled ... a fly on the back of society, that's how I feel, definitely. I think it's horrible, and they do make things ... for Uni Credit, you feel like you're not even human, you're disabled. Why are you even here?” (Participant, England)

As part of the application and assessment process, claimants must detail all the ways in which they are “limited” by their impairments and health conditions. Participants found it difficult being required to focus on what living with health conditions and impairments prevented them from doing rather than what would help them live more independently. Thinking about their impairments in terms of limitations was distressing and for some, prevented them from applying for disability benefits at all. Participants outlined the impact of having to answer questions about personal or distressing matters, reporting how the process had made them feel demeaned and humiliated. Several participants spoke of the application process making them feel like they were “begging”, further adding to their feelings of humiliation.

“They just make you feel like shit. They need every detail and there's details that you don't need to give because it's the same answer, but they need to know the nitty-gritty. It really puts you down, it really - I can't really explain [...] it makes you feel labelled, it makes you feel less than human. You're very much dehumanised, you are a number, you are not a person. It can be quite degrading, yes. There has to be a better way, there has to be.” (Participant, Northern Ireland)

“I still really hate the actual full assessment process because you have to talk about your worst experiences of being disabled, and all the things that you can't do. I'm supposed to be positive about myself in real life and try not to get too upset and depressed about it, but you can't help it because all you have to do in your assessment is just, and your form, is talk about the worst parts of yourself. It's just really dehumanising.” (Participant, Scotland)

Interviewees reflected that decisions on applications could take a long time to resolve, with some reporting negative impacts on their financial situations or their mental health. Having a claim refused, in some cases based on assessment reports perceived to be inaccurate, resulted in feelings of distress.

“When the report came it was just pure lies and fabrication. It was like reading a fairy tale [...] They were like, [participant] is breezy, she reads books and watches television shows. She's actively engaged'. I was like, it's all just a pure fabrication, I couldn't believe it. I just felt the whole thing was so traumatic, I just couldn't do it again.” (Participant, Wales)

It is important to note that not all perceptions of the assessment process were negative. There were participants who felt the assessors had been kind and compassionate, listened to them, and given them time and encouragement to fully explain the impacts of their impairment or condition.

“The lady that did my assessment she sat down, she cared what was happening. Like I say I was living on £120 a fortnight, well £60 a fortnight after I'd paid my rent and she understood. She said, 'I don't make the decisions she said but I'll do my best to get you the help that you need because you do need the PIP'. She said, 'you are disabled'. I know I'm disabled but some of the assessors the way they see it they didn't see me as being disabled if you know what I mean?” (Participant, England)

However, these participants were aware of other people's negative experiences, or had previously had negative experiences themselves, which made the process feel more like a lottery.

5.2.3. Award reviews and reporting changes

Over 80% of successful PIP claimants receive an award for less than two years and, therefore, most claimants are subject to regular reviews³⁹. Reviews are triggered by either an award ending or by a claimant reporting a change in circumstances, including any health changes. Reviews were frequently described by participants as a source of dread, with anxiety levels increasing for many as their review date approached.

“I'm dreading the next one [PIP review], because the next one is coming next year. What if I don't get lucky? How is that going to change it? I have spent since I got it worrying about the next one, because you think, ‘Oh God, got to go through that again, but next time it could be worse’, and I've got the bad experience to compare it to in my mind. I got lucky this time. I've heard about brown envelope syndrome, a jokey sort of term that people say about when the brown envelope lands on your mat. Oh God! Yes, I felt myself getting really anxious and almost like meltdown territory the other day because we had a brown envelope from DWP. It's about my bloody change in tax code.” (Participant, Wales)

Participants spoke of their fears of having to complete another lengthy form, potentially attend another assessment, and of having their award reduced or removed. Indeed, despite experiencing no change in their health, some participants stated that their PIP awards had been removed or reduced after a routine review or after reporting a change in circumstances. There were participants who had experienced a decline in their health between reviews but did not report it for fear of their payment being reduced or removed. Participants also expressed bewilderment that reviews were required even when impairments or health conditions were highly unlikely to improve.

“My conditions are incurable, yet I get an award for three years. It's like why do we put people through it when the level of health I have now is probably the best it's going to get? I've come to terms with that. Yes, people who are amputees and stuff being given an award until this time, or people with dwarfism, all of those sorts of things. It's like I think one of my friends - he's an amputee - wanted to write back and say, 'Shit don't grow back!' It's not just going to magically appear.” (Participant, Wales)

As with the application process, participants perceived that reviews were designed to catch them out and demonstrate that they were not being truthful about their health status.

“You get the feeling that they're trying to catch you out, because the girl on the phone said to me something along the lines of - not word for word - but something along the lines of, 'Last time we spoke you said you couldn't get up a flight of stairs without using a banister,' and I said, 'No, I never said that,' and she went, 'Oh, no, you didn't, you're

right, you didn't say that.' I was like, is she trying to catch me out here? [...] It just feels like there's big distrust from them towards everybody that claims for disability benefit, and the majority of people are genuine.” (Participant, Northern Ireland)

5.2.4. Mandatory reconsiderations and appeals

Some participants had successfully challenged unsuccessful claims through the mandatory reconsideration and appeals processes. This could be a lengthy process with some waiting several months and one participant describing a succession of failed applications, mandatory reconsiderations and appeals over a period of six years. Challenging a decision required more form filling and evidence gathering described by a participant as “traumatising and exhausting”.

Others had decided not to challenge the outcome of their application. Participants unsuccessful in their claims offered a range of reasons for not requesting a mandatory reconsideration or deciding not to appeal, including traumatic experiences of the assessment, the potential impact of the process on their mental wellbeing or negative stories on a benefits advice forum.

“A lot of people said to me if you go forward with that [appeal], a lot of people get decisions overturned and stuff. I felt violated, it was really violating, the whole process. The questions they asked, the way they made me feel. It made me feel like I was a scrounger, and I've always worked. Not like big, important jobs, but it's always work, so we supported [child]. It just made me feel like I was worthless, and I just thought, ‘No, I can't do it’. I'm getting upset thinking about it because of the way they made me feel. (Participant, Wales)

For others, caring responsibilities or life events meant they lacked the time and energy to appeal a decision. Again, the fatigue that accompanied many impairments and conditions was also a barrier to appealing a decision.

Some participants were unhappy with the award they received, feeling it did not represent their level of need or cover the costs associated with their health conditions or impairments. Some had successfully challenged the level of their award. Others, however, did not challenge the decision for fear of being reassessed and losing all their benefits. For some, disability benefits were their only source of income and losing their entitlement would plunge them deeper into financial insecurity.

“I'm not going to lie to you, I was scared to appeal it in case it had been a mistake and I shouldn't have got it. I was scared to appeal it in case it was removed because we need it. I can't go to work 9 to 4 anymore. [...] The thought of appealing was there, but

it left very, very quickly at the thought of losing it [...] from the very, very, very beginning of the whole process itself, it was rigged against you, and to have got some award, I just thought, no, that's it, I've got to just take it." (Participant, Northern Ireland)

Participants reported mixed experiences of attending a tribunal. Some spoke of positive experiences that contrasted with their distressing experiences of the initial assessment process, for example, saying that they had been listened to and believed. However, others had experienced a more adversarial and stressful tribunal process. Examples were given of aggressive questioning, scepticism about the impact of less visible conditions, and perceptions of the same type of trick questions used in the initial assessment. One participant had received compensation after a series of distressing events in the months before their tribunal, due to administrative errors. They reflected that the stress they experienced would discourage many people from appealing.

"Even one mistake in this catalogue of errors could be enough to put someone with a disability off continuing with an application, especially if they didn't have a partner/carer like mine who supported me and pushed me to pursue this to the end." (Participant, Scotland)

5.3 Importance of support with making a claim

Participants had received support with making a claim from a range of sources, including voluntary and community sector organisations such as Citizens Advice Bureau, Disability Action Group and the Money Matters financial advice service in Scotland. They also received support from healthcare and support workers, local authority welfare and housing advice teams, Jobcentre staff, local councillors, online support groups, and family, friends and co-workers.

It was clear from participants' accounts that support with assessments was an important determinant of making a successful claim. Several participants recounted their experiences of making multiple unsuccessful applications for disability benefits and shared that they were only successful in their claims when provided with support and advice. Guidance on completing the application form was identified by participants as vital for correctly interpreting questions and ensuring they were answered with sufficient detail.

"I honestly felt like giving up, I was even trying to find out if there was a job out there that I could do because I was like adamant that I was then not ever going to get it [PIP], and obviously, I needed income, so like what can I do? [...] I spoke to Money Matters, and they said that they could help me, and they actually [could] go to the tribunal with you. They said that they will send an email to them, and a letter of their

side of it and everything, so it's all written down. They asked me even more questions, to give better answers and stuff like that. My friend said to try them because she said that they helped her fill out her PIP form. She said, 'Speak to them. You may be like wording something wrong or something like that.' I didn't realise actually how much help they actually give you." (Participant, Scotland)

However, support was viewed as being difficult to find or to access. Not knowing where to go for support was a common experience. Some participants had approached the DWP for support with completing their PIP application but were advised that support was not on offer. Others identified caring responsibilities, work commitments and distance as barriers to getting support. Several participants who had received support in the past found that the support they had accessed was no longer available. Where support was still available, increasingly long waiting times were reported.

"Services are just swamped as well. They've got a five-week waiting list for a meeting. So that's something that worries me, that I might not have somebody's support there to help." (Participant, Scotland)

"It is having that access to support. [...] When I had that specialist support it was brilliant, she put me at ease, she knew what she was looking for, she was great, but I couldn't get that support again because they didn't have - it was a charity, they didn't have enough people to - they wouldn't have anybody available when I was available. All the appointments were booked up. So, it's quite hard really. I live in dread of them contacting me." (Participant, England)

5.4 Claiming Adult Disability Payment

One of the central aims of this research was to explore disabled people's experiences of applying for Adult Disability Payment and compare participants' experiences of applying for PIP with their experiences of applying for ADP.

The 28 participants living in Scotland were at various stages in the ADP process:

- Six were aware that ADP was replacing PIP in Scotland but had not yet received any information about when they would to the new benefit.
- Three participants were approaching the date of their transfer from PIP to ADP.
- Five were in the processing of transferring from PIP to ADP at the time of interview.
- Three, not currently receiving PIP, said that they were making a new application for ADP.

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- One participant was awaiting the outcome of a mandatory redetermination for ADP after having a claim for PIP refused by the DWP.
 - One had made a new application for ADP and had been refused.
 - Two participants had made successful claims and were now receiving ADP.
 - Six were not receiving PIP and reported no knowledge of ADP.

5.4.1. Knowledge of ADP

Levels of knowledge about ADP and what transferring would involve were generally low. Participants had received information about ADP in several ways either directly through letters from Social Security Scotland, or indirectly through third sector and healthcare professionals and services, social media, or the local news. There was some evidence of misunderstanding of the ADP claims process with, for example, the belief that assessments were mandatory. Participants waiting to be transferred reported a lack of information in communications from Social Security Scotland that left them uncertain about what they needed to do or what the new benefit involved.

“I got a letter in and a changeover in April and it just says that you will go from one to the other. That's it, so I'm no really aware what it is. I've tried looking it up. Are there different pay rates and things? [...] when I contacted them, they said my PIP review has been changed to December. Then just after, I got a letter in saying, 'You're moving from PIP to Adult Disability Payment.' So, I don't know how long I'm going to get it for, if there's going to be a review or when there's a review or whatever. Nobody can tell me anything.” (Participant, Scotland)

5.4.2. Expectations of ADP

Participants with experience of claiming PIP expressed a range of views about the introduction of ADP in Scotland. Some were optimistic that the change from PIP would be positive. Among those with negative experiences of claiming PIP, hopes were expressed that ADP would be administered with more compassion, trust and efficiency, and that reform of the ADP eligibility criteria, which are the same for both PIP and ADP, might happen in the future.

“I am quietly hopeful about the new ADP benefit. I followed the consultation process with interest and Social Security Scotland really do seem to want to make it better. The fact that they have dropped assessments from the majority of applications and made it clear they will seek out supporting evidence from your doctors and specialists, something which the DWP make it seem like they do for PIP when in fact they rarely actually do, is a very good start. It's a shame they have so far stuck with the same

criteria and points system as PIP, but they have suggested this is mainly for ease of transition and that it may be changed in the future.” (Participant, Scotland)

A participant described how they felt seeing a television advertisement for ADP that reflected their own experiences of being disabled. It made them optimistic that the implementation of ADP would recognise a wide range of health conditions and impairments and would consider the kinds of support required by disabled people, and the costs of these supports.

“There was an advert that I saw [...] and it had different disabilities. It had a chap in a wheelchair getting in a taxi. It had a young lassie who had Down’s syndrome. Then it had somebody in their house, who was using a one-cup hot-water dispenser. I just went, hallelujah. It’s just because they had so many different types of disability expressed in this advert. It’s saying, ‘Do you know anyone, or do you need support? Come to us, this is the support we can offer you’. It was about this new transition. Are you getting the support you need? I thought let’s hope that that’s an image of what they’re actually going to do. Let’s hope that this is genuine. Let’s hope that this because it was all-encompassing, and it’s just that it was like, woah, they picked up that people use these types of things as adapted and as helpful to disabled people. There were people with visible disabilities and people with invisible disabilities. I was like, ‘Oh! This makes me feel a bit more validated and a bit more heard and a bit more seen’.” (Participant, Scotland)

Other participants, also with previous experiences of PIP, were more wary about the change to ADP, with scepticism expressed that anything would improve. Moreover, experience of PIP reviews meant that, for some, the prospect of transferring to ADP was a source of anxiety. Participants expressed apprehension about what the ADP experience would involve, with their trust in the disability benefits system often already low.

“So I now have to reapply for this money to be continued. [...] At the bottom of the letter, it’s got, ‘Dignity, fairness, and respect’. I don’t want to sound bitter, and I’m not bitter, I’m just, I think I’m wary of it, that it’s going to be no different than the system that’s been if you get what I mean. It’s just going to be another system, under another heading... I just wonder is it just another paper exercise that the Scottish Government can say, ‘Well, we’re doing this now’? I sound cynical. I hope I’m wrong and I hope that it will be a better, fairer system.” (Participant, Scotland)

“I felt anxious, even though I knew it was going to happen at some point. Considering the experience, I have had when applying for disability benefit in the last 3 years, I think I will probably feel just as anxious they next time I have a review. I am really hoping that the Scottish system is kinder, more empathetic and realises that the one

tick box fits all approach is unnecessarily cruel and doesn't work for the people it is supposed to be helping." (Participant, Scotland)

5.4.3. Applying for ADP

Participants' experiences of contacting Social Security Scotland for support with an application were mixed. One participant had failed to make contact by phone after many attempts, while another commented on the quick response. Social Security Scotland offer independent advocacy support to help applicants complete the ADP form. No participants said that they had accessed this support, largely because they were unaware of it. Indeed, a participant expressed anger and disappointment that Social Security Scotland had not told them about the advocacy service. When asked to reflect on the provision of advocacy support, they were largely positive. However, a legacy of distrust meant that a participant who was aware of the service questioned its independence.

"I think that would be a massive bridge for people, in order to get what they need, and just knowing that somebody is there to talk to you about it, and guide you, and put you in the right - and make sure that you're getting everything you're entitled to because that's definitely what I'm for. If you're entitled to it and you want it, you should get it." (Participant, Northern Ireland)

"I think that's a fantastic thing. I know from previous people I know who have had to go their maybe welfare rights officer to be able to help with things like that, so I think the fact that it's being offered as help now is a really good thing. Not everybody has got the literacy to fill those forms in. They're quite difficult, believe it or not." (Participant, Scotland)

"They did say about, 'You can phone this number, and someone can help you fill it in.' I think people - not just me. Well, maybe it is just a 'me' thing. You're kind of hesitant to go through the company itself because you feel maybe there's a bias there. I obviously had experience with Money Matters, and I completely trusted their advice in the past [...] I do have that number there. I just feel it is a bias. I feel that you're going through a company, and I don't know how independent it is of Social Security Scotland." (Participant, Scotland)

Opinions on the ADP application form were also divided. Some participants spoke of the ADP form in largely similar terms to the PIP form with criticism of the form's length, repetitiveness and its wording perceived as aiming to catch out applicants. Others, however, thought that the ADP application form was an improvement on the PIP form. For example, participants said

there was more room to discuss the effects of impairments and more scope to describe the impacts of mental health.

"I think the form does seem more like they give you – like they take your mental health a bit more into consideration. I can't pinpoint exactly where it is that I picked that up. I get that sense from the form that even though they're asking about things that have changed and things you've written about before, it just feels like there's a bit more room for writing about how your mental health affects you." (Participant, Scotland)

The two participants receiving ADP described positive experiences of the claims process. One had received at-home support from Social Security Scotland to complete an application. The other had received support with an application from a local voluntary organisation. Initially reluctant to apply due to past negative experiences with the benefits system, they had been reassured by the support organisation that the ADP application process was "a very different animal" to the PIP application process. They were hugely positive about their experience and reflected that the ADP process appeared to be more compassionate than the PIP process.

"I think that's the best way to describe the difference between our experiences with DWP and Social Security Scotland. Social Security Scotland seem to have a general tone that if you're entitled to the benefit, you're entitled to the benefit, whereas DWP, it seems to be, you must show, you must prove that you're entitled to this benefit before we'll agree that you're entitled to this." (Participant, Scotland)

One participant explained how reporting a health change had resulted in their PIP award being reduced by the DWP. Living in Scotland, they were now eligible for ADP. They were being supported by a voluntary organisation in their request for a mandatory redetermination by Social Security Scotland and spoke of their contrasting experiences of the two systems. Compared with PIP processes, the ADP appeals system appeared to be a more compassionate and "caring" process.

"These people [DWP staff] on the other side of a phone think it's all right to just dismiss somebody's pain. No, that's not right. That's why I'm quite happy that it's now no longer the [UK] government that's dealing with it. It's Social Security Scotland. The people that are actually on the end of Social Security Scotland, they actually sit and listen to you, and they are so polite. They're actually caring, and it does make a difference because you can actually talk to somebody on the end of that phone that is willing to listen to everything that you're going through. Listen to all that pain that you're in [...] Within a week, I had a letter to say roughly what the phone call had said, and that they were going through the proper channels to get the mandatory reconsideration done, and it was Social Security Scotland* that sent me it. I was really overjoyed." (Participant, Scotland)

Other participants, however, had more negative experiences of applying for ADP. The move to an online process was broadly welcomed as an improvement on the PIP application process, which required a hand-written form. However, problems, when they occurred, could prove distressing. Participants shared examples of technical errors, such as the online form failing to save an in-progress application or deleting a completed application.

“I began the transfer from PIP to ADP in February of this year. I filled in a detailed change of circumstances form online and when I hit send, the portal deleted it. I had to do the whole thing again. The form went through the second time, and I got a receipt to say it had been received. Then, at the end of April, I got a letter through the post telling me that I would have my benefit stopped if I did not contact them and fill in a change of circumstances form. Luckily, I kept the receipt. My partner/carer called the ADP offices and gave them the receipt reference. It had been received, there had just been a ‘technical error’ on their end. My experience has not been good, and it has caused a great deal of stress and pressure on my already awful mental health.” (Participant, Scotland)

Participants with experience of claiming PIP had described long waits for a decision. Long waits for ADP also appeared to be occurring for some ADP applicants. Supporting anecdotal evidence of decision-making delays due to increasing numbers of applications and transfers, participants were experiencing waits of up to six months for a decision on their claims. One participant’s ADP application had been refused, leaving them angry and distressed.

5.4.4. Wider views on ADP changes

As part of this research, we asked participants to share their thoughts on the changes Social Security Scotland had introduced with ADP. When asked their thoughts about the Scottish Government’s stated aim to increase the number of indefinite awards for ADP, participants were largely positive. The time limits placed on most PIP awards were reported as a source of stress and indefinite awards were viewed as reducing anxiety for claimants and being more efficient to administer. Again, however, distrust in the system due to past experiences of claiming disability benefits was still an issue, with a participant expressing a view that indefinite awards could be changed at any time.

“Well, that would be wonderful. Oh, in that way you don't have to - then you know your date the review is going to end. Like it is at the moment, it says October '24, I wouldn't have to start getting the feeling in the pit of my stomach and that would just take a bit of pressure off you, especially at the moment with prices and you're feeling that perhaps if I get put off, what happens to this? You're not constantly questioning and going over and over in your mind what's going to happen.” (Participant, Scotland)

“I think that's great in the sense that whoever it is receiving it doesn't have to worry continually whether it's a family that's supporting someone going through it. I think it's a lot less pressure on people as well to continually have to go and deal with it. It probably is better as well for the system as well because it means that you probably don't have to do as many man hours on a huge amount of people. So I think for me it's in a sense people don't need to continually have to follow up on both ends of the scale.”
(Participant, Scotland)

“Don't know how I feel about that, to be honest. I just feel like that then they're in charge. They could say to you at any time, 'Well, we think your [ADP] award could be this or that.' I think that might be the case with that.” (Participant, Scotland)

As previously described, medical assessments routinely required for PIP were a source of distress for many participants. Therefore, the decision to significantly reduce the number of medical assessments under ADP was viewed positively. Due to their experiences of the challenge of trying to prove the impact of their conditions during an assessment, those with less visible or fluctuating conditions were particularly positive about the removal of most assessments under ADP. However, participants also identified potential problems with the removal of assessments. A concern raised by participants was that in the absence of an assessment, fraudulent claims may increase.

“It would be for those who are genuine, but I think there's going to be a lot of people will jump on and try and claim which is not great if there's no medical...aye no medical assessments or do they check up on medical records? [...] well if they checked up on medical records that would be okay but I think you would get a lot of people trying to milk the system which would be horrible so ... but...those who genuinely need it I think if you can hand over all your records then those who want to not share their records I would hope they do actually check into them before they just hand out government money on anybody willy-nilly.” (Participant, Scotland)

A further substantial change in the switch from PIP to ADP is the reduction in the amount of evidence a claimant is expected to submit. As with increased indefinite awards and large-scale removal of assessments, views on this change were mixed.

Participants felt that the reduced evidence requirements would take away some of the burden. However, there was also concern that increasing reliance on evidence provided by medical professionals could create problems for claimants without formal diagnoses and those with poor relationships with their healthcare providers. Participants shared experiences of feeling let down by healthcare providers who had been asked to provide evidence for previous disability benefit applications. They felt that because some medical professionals failed to understand or had little experience of their impairments or conditions the evidence

provided did not fully reflect their experience of their impairments and health conditions. They were concerned that some disabled people would be disadvantaged by a greater reliance on medical evidence in the decision-making process.

“They refused it on the grounds of the medical information given by the doctor. Now when we saw what the doctor had filled out, it was an absolute disgrace what he had put. He had basically put nothing; he was asked several questions and he had answered them all with one answer.” (Participant, Scotland)

“I feel like, if you’ve got certain types of illnesses, you’re golden, but I feel like if you’re someone like me who is disabled for a different reason it’s not as easy as cancer, or MS, or things like that. If you have something slightly more complicated where it’s a bit more of a grey area, I still think that people like me are going to suffer.” (Participant, Scotland)

Finally, reflecting evidence reported above on the challenges faced by some in coming to terms with a disabled identity, a participant reflected on the name change from PIP to ADP.

“I think that's gone a step backwards because we're taking disability back in it again. If disabilities are meant to be a protective, part of the protective characteristics, you're actually further impacting on somebody by calling them disabled again. Personal Independent Payment sounded better. Nobody wants to recognise or admit that they're disabled and it is hard to realise that you're becoming ill.” (Participant, Scotland)

6. Suggestions to improve the disability benefits system

With two in three (62%) people from disabled households referred to food banks in the Trussell Trust network not receiving any disability benefits, one of the aims of this research was to identify the reasons for the underclaiming of disability benefits among disabled people facing food insecurity. Identifying these reasons allowed for the development of several policy solutions aimed at reducing the need for disabled people accessing food banks across the UK.

Not only did interviewees identify reasons why disabled people did not apply for or did not receive disability benefits, they also identified how these barriers could be addressed. Improvements to the application and assessment process were suggested, along with wider actions to improve the lives of disabled people across the UK.

6.1 Awareness and eligibility

A lack of awareness of the eligibility criteria was one reason cited for why disabled people are underclaiming disability benefits. It was common for interviewees to have been living with a range of health conditions and impairments for years before becoming aware they could apply for disability benefits. Interviewees reported that it was difficult to find clear information on the eligibility criteria for disability benefits. There were also interviewees who had been informed by staff working in governmental and voluntary sector agencies that they would not be eligible for disability benefits, only to find out years later that they were.

6.1.1. Promoting awareness of disability benefits

To ensure disabled people are aware of the support they are entitled to, interviewees stated that they would like see information about disability benefits promoted more widely. To guarantee this information has a wide reach, a range of ways of promoting information about disability benefits was suggested. These promotional activities included public awareness adverts on television, social media, and other media sources, to more targeted promotion such as letters direct to people's homes or pamphlets displayed in public places such as doctor surgeries, post offices and libraries.

It was also suggested that disabled people should not have to seek out this information. Instead, when a health condition or impairment is diagnosed or identified, the doctor or health

specialist should make a person aware of disability benefits and the application process. In Scotland, some interviewees were unsure whether they should be contacting the DWP or Social Security Scotland for more information now that disability benefits are devolved to Scotland. There were interviewees who would like to see health professionals refer disabled people directly to receive an application.

“A lot of the benefits I didn't know about until friends told me about them. I just never thought, I never realised what existed. [...] There could maybe be a government website which listed all of the benefits available and what you're required to have to qualify for them and things like that. [...] it's difficult for me to search for it on the internet, but if I wasn't on the internet, it would be even worse. Perhaps some kind of pamphlet that you can get from a library or Post Office or something that just lists everything, how you get help and who you phone and things like that. Just a way of getting all the starting information to everybody.” (Participant, Scotland)

“I honestly think if people have health conditions that warrant help, it should be within the remit of the GPs in the NHS to be able to put them forward for that help. That could be as simple as ticking a box on a computer screen. It literally could be as simple as that. I'm on enough codeine to literally wipe out an elephant. That in itself is a good indication there's something wrong, there's a struggle to live with.” (Participant, Northern Ireland)

6.2 Application process

The PIP and ADP application form itself was a barrier to some people applying for disability benefits. As reported above, the application was perceived to be long, confusing and repetitive. Furthermore, interviewees did not think the application form enabled them to explain how their health conditions and impairments affected them. There was a perception that the application form did not cater for a wide variety of health conditions and impairments, including less visible and fluctuating health conditions. Instead, interviewees thought the application had been designed to dissuade people from applying, or make it difficult for their claim to be successful. The repetitive nature of the questions was perceived as a way to trip people up on the assumption that people may be making a false claim. Distrust in the application process came from either personal experience of applying for disability benefits, or hearing about the negative experiences of others.

There was an overall perception that many disabled people would not be able to complete the application form successfully without support. Interviewees who had received such support to complete their application form said that this support was invaluable. However, they thought

there was a lack of support available across the UK, and where support was available, too few disabled people knew about it.

Interviewees shared a range of ways they thought the application process could be improved to both enable them to apply, and to fully express how any health conditions and impairments affected their lives.

6.2.1. Application form

Interviewees called for the application forms for both PIP and ADP to be amended to make them easier for disabled people to complete confidently. Amendments included shortening the form by taking out unnecessary repetition, simplifying the language used and removing ambiguity by altering the questions to make it clearer what information was being requested. Interviewees wanted PIP to follow the ADP application in being available in a range of formats, not just paper, for both online and telephone applications.

“Personal Independence Payment, they insisted that it's done on paper and it's mailed in. I can't help but feel like it's partly because they can't be bothered to modernise it, and partly because it's far easier for them if it dissuades people from applying for it because it takes so long to fill in. It would be much easier for us and for them if it was some kind of internet form that you could fill in. It would be far easier - or have that as an option, either way. [...] Simple, understandable questionnaires, e-questionnaires, online, and of course the option to do it via post if you are unable to do that sort of thing. In order to make it more user-friendly, they need to, like I don't want to say dumb it down, but they need to stop using so much corporate speak because people don't, because normal people don't speak that. [...] that was difficult to decipher.”

(Participant, Scotland)

Disabled people thought that the application form should be designed to enable them to explain the ways in which they are impacted by their health conditions and impairments. Some perceived that this could be achieved by amending the application form to enable people to only answer questions relevant to their circumstances. Others felt that the questions should be changed to make them more relevant to a wider range of health conditions and impairments, such as more open-ended questions asking people to describe the impact of their health conditions and impairments have on their daily lives. This approach was said to ensure that the application was relevant for all disabled people, including those with fluctuating conditions. Interviewees felt strongly that the current application focused on whether people are able to undertake certain tasks, rather than the impact that these tasks might have on an individual.

“I think if they made the paperwork more specialised. [...] Like in my case, I wouldn't need half of that form, so if I just had the part that [was] relevant. That was the word I was looking for. If it was like the section that was just relevant to us.” (Participant, England)

“People have good days and bad days, so asking a question that you can only answer on your worst [day], that's silly. People know that they're going to be kind of, if you tell them that actually today I didn't feel too bad, you know. If you're going to answer in an honest way, because most people are honest and they just answer, 'Well, actually this morning I got up and it wasn't too bad'. They're going to write that then they're going to go, 'There's nothing wrong with you'. Some people don't even know that you have to answer on your worst day, kind of thing. That needs to be improved, because people are too honest. Who thought that would be a thing?” (Participant, Wales)

6.2.2. Application support

In addition to changes to the application form, interviewees stated that improvements to application support were necessary. Interviewees spoke positively about the support they received from third sector support services and reported that without this support they thought they would not have been awarded disability benefits. Greater provision and promotion of support available from statutory and voluntary services was called for to increase disability benefit applications. It was recognised that further funding and staff training might be required to ensure sufficient support is available across the UK. Some interviewees felt strongly that this support should be independent of the government, and could extend to the provision of advocacy throughout the application and assessment process. Others thought both the DWP and Social Security Scotland should be providing support to applicants.

“Everybody that is applying for it should be made aware of the help that they can get to help fill in the forms. I don't know if you've seen the forms but, my God, it's ridiculous the amount of questions that they're asking you there. [...] provide the help or even signpost people to where they can get help from independent voluntary-type charity groups to help you fill in the forms. You see, when people suffer from things like anxiety and stress and things like that, when you have sat down with what looks like a telephone book to fill in with non-stop questions and - that causes anxiety and stress in itself, so a lot of people will just say, 'I can't do this.' People need help to do it, people need advice, and people need to firstly know that the benefits are there to apply for, and how do you apply for them.” (Participant, Northern Ireland)

“More people trained on how to fill it in. As I say, we're very lucky that we've got someone here who can, but I wouldn't imagine that that's a nationwide thing. If there

was people out there specifically trained in like the application process from start to finish, I think more people would actually access that to get the help.” (Participant, England)

6.2.3. Time limit

To enhance the ability of disabled people to apply for disability benefits, interviewees called for the time limit of four weeks from being sent the application to submitting the application to be removed. As previously mentioned, the symptoms of many health conditions such as brain fog, fatigue, pain and lapses in concentration, were said to make the completion of application forms challenging. Therefore, more time may be required for applicants to complete and submit their forms.

6.3 Assessment process

It was common for interviewees to report that a fear of how they would be treated during the application and assessment process could prevent disabled people from ever applying or reapplying for disability benefits. As previously described, assessments, reassessments, appeals and tribunal elements of the disability benefit system caused distress and trauma to participants, and the process itself was perceived to be flawed.

Participants identified several ways in which the assessment process could be amended to improve the experience for disabled people and encourage more disability benefit applications.

6.3.1. Improved understanding of health conditions and impairments amongst assessors

Overall, there was a sense that assessors did not have a good understanding of a wide range of health conditions and impairments to make a fair, well-balanced assessment. A physiotherapist undertaking an assessment for someone with mental health issues was given as an example of this.

Interviewees said that assessments should be undertaken by assessors with specialist knowledge of a claimant’s particular health condition. Alternatively, assessors should be trained to understand a wide range of different health conditions and impairments. Some went further to suggest that the assessment should be undertaken by a health professional that knows the claimant.

“It just seems like common sense to do something really basic like have people with a specialist knowledge of the applicant’s particular disability/needs to do the initial assessment. Having to explain over and over again to multiple, unqualified people why you think you are disabled and should qualify for financial help is degrading and exhausting. A physiotherapist putting the questions to someone with complex mental health issues means that subtle nuances will be missed or even misconstrued. Someone with autism can come across as being rude, a mental health specialist would understand why. At the very least, improve the training of the assessors so that they have even a basic knowledge of the condition they are trying to assess. This would also cut down on administration and probably shorten response times. If the right person is assessing, there may not be the need for the process of mandatory reconsideration or tribunal. The people needed to deal with those alone probably costs millions every year. That’s money that could be spent on training.” (Participant, Scotland)

6.3.2. Provision and use of evidence

Disabled people frequently talked about the burden of providing multiple sources of evidence and the difficulty of contacting health professionals to provide such evidence, which was time-consuming. To reduce the burden on disabled people, participants called for a greater sharing of information between health professionals and the DWP.

Participants suggested that greater clarity on the types of professionals that could provide evidence on the impact of their health conditions and impairments on their life would be useful. There was a view that employers or support workers could provide a better account than a GP in some circumstances. For example, some participants had limited contact with their GP in the management of their impairments, while others did not think that their GP understood their condition fully, while other specialists did.

“I think it should be done in conjunction with the specialists that that person's already seeing. If somebody's applying for something like PIP, whether it be for a physical disability or a mental disability, or whether it be special needs or anything like that, all those people are in the system somewhere. Whether it's for their medication, treatment, whether it's for courses of treatment, surgery, whether it's for mental health outreach work, or counselling, or whatever, we're all in the system. All that stuff's there on the government's computers. It really should be a case of a simple phone call to my GP. [...] but you have to be put through on display to show how disabled you are to qualify for these things. That in itself is not only unnecessary, given the records that they have for the vast majority of people who'd be applying for that who are already in

the system, and multiple facets of the system, I think it's incredibly unnecessary.
(Participant, Northern Ireland)

“The GP wouldn't know you from, they wouldn't know anything about your condition. It may be on your records, but they may never have seen you. Consultant may only have seen you 12, 14 years ago, and yet, they have that expectation of them actually having to provide this evidence when you may have a sensory worker who knows your condition, who is also a medical professional, not being able to get that support, the evidence from them. I think it's all about the additional evidence.” (Participant, England)

Some interviewees also suggested removing assessments altogether. They questioned the need for assessments if clear evidence had already been provided. They thought that the evidence provided by specialists should be trusted and sufficient to claim benefits.

Interviewees perceived that the requirement for a health assessment in addition to providing evidence illustrated that the system was based on the concept that people were not being truthful about their conditions and impairments.

“I think the main problem I've seen is they don't believe you. You seem to have to jump through lots of hoops to prove you're - they should take the word of the doctors. If the doctor feels that you're not well, then they should believe that. They just seem to have this underlying opinion that even though you're ill you can still work, and they try to push you to not get benefits. I presume they're just trying to save money and get as few people as possible on benefits.” (Participant, Scotland)

Finally, interviewees also called for an end of the requirement to resubmit evidence at reassessment if a health condition and impairment had not changed or symptoms had not improved. Again, interviewees referenced the time and effort required to access evidence from health professionals. They also thought the need to repeatedly resubmit evidence for conditions that have not improved illustrated a lack of understanding of the range of health conditions and impairments that disabled people may be living with.

“It just needs to be a bit more person centred, I think, and with that review phase if you've, like I said, if you've got an incurable condition or if you were born with dwarfism or you've had an amputation, just recognise that and give lifelong awards.” (Participant, Wales)

6.3.3. Being treated with dignity and respect

While some participants had kind and compassionate assessors, it was common for interviewees to report that they felt they were being “interrogated” and made to feel as if they were lying, leading to feelings of humiliation and distress. Interviewees were unanimous that

all assessors treating disabled people with dignity and respect would vastly improve the assessment process. It was thought that staff and assessors having a greater understanding of health conditions and impairments would go some way to achieving this, but interviewees also wanted staff in these roles to be properly trained and steps taken to ensure they acted with empathy.

“It's dehumanising and it's degrading, if I'm honest. That's the word, it just feels that they're very sceptical of you when they're dealing with you, these assessors. It's almost like they're sceptical about how honest you're being about your condition, and that sort of attitude and coldness from them can cause anxiety as well. [...] They treat everybody like they're just the same. You know that they don't understand the condition. They haven't got a clue. They're just reading questions to you, and they're ticking boxes, or marking scores, whichever, and there's no understanding that by talking to somebody like this and by treating somebody like this and by their obvious scepticism, that they are actually causing somebody to be unwell. So, I think that, maybe going back to what you were saying about the assessors, I really do think they need to be trained properly, and maybe do some mental health awareness courses and things like that.” (Participant, Northern Ireland)

“For us, it's trying to find a place that we can feel that we can communicate our thoughts and our feelings to someone in a safe manner. I think for me it's about going to a place that I know that's designed and that people are correctly trained on how to communicate with us and have the patience to be able to give us more of a little bit longer to answer questions, a little bit more time to understand if we don't quite understand the question they'll be able to express it a little bit better and knowing where that place is.” (Participant, Scotland)

6.3.4. Person centred design

Interviewees wanted the disability benefits system to become more person centred. This would require the system to be more adaptable to a range of needs. For example, enabling individuals to choose the format of their application and their assessment to best meet their needs. Some interviewees felt that an in-person assessment would help them to illustrate how their health conditions or impairments impacted on their lives. However, others perceived that a video or telephone assessment would be less stressful, particularly if they found leaving the house challenging.

“We shouldn't all be looked at as a group. We should be looked at individually because everybody's disability affects them differently. [...] They don't do that. They don't look at people as an individual. They just look at it as a group, and that's not fair. We should

be looked at as individuals and treated as individuals. I worked in care for a lot of years, and we had something called person centred care. I think we should be dealt with in that way. We should be looked at as the main person in this, and then look at everything else that surrounds us and what we have to do on a daily basis. Not everybody that's got the same condition as I do have kids. Some are older, some are younger, but how it affects them is different to how it affects me, so it should be person centred. It isn't at the moment, and that's not fair.” (Participant, Scotland)

“Definitely more accessibility, so more remote meetings, less in person, because they make you go all the way down to the centre and for a lot of people with disabilities that's really difficult. So, surprisingly more accessibility for disabled people would be great. It's not rocket science, but there we go.” (Participant, Wales)

Involving more disabled people in the design and delivery of disability benefits was suggested as a way of helping the system become more person centred. It was perceived that involving disabled people could help implement a better understanding of the impacts of disability. It could also make the system more accessible and empathetic, improving the experience for disabled people. There were participants who worked in disability support roles who viewed their lived experience of the disability benefit system as an asset in supporting their clients.

“Having more people in the industry with a lived experience would help as well. A lot of the people deciding for disabled people aren't disabled, and have a very ableist outlook on life. That is not often done in a malicious manner. Sometimes it can be, but sometimes it's just due to plain harmless ignorance, and I call it harmless ignorance because it's people just haven't been educated enough. But I do feel there needs to be more representation for disabled people within the decision-making pool for these benefits and for these applications' systems. That would help massively. If someone has a lived experience similar to yours, they're going to have a little bit more empathy towards your situation than someone who believes that taking a walk in the sunshine and going for a jog is going to take away all your life issues.” (Participant, Scotland)

“I think involving disabled people in the actual process, to say how can we make this more accessible? It should be all about accessibility because it's about disability. We need to look more at the able side of disabled because we're still able, but you need to help us to harness that part of us that is still able.” (Participant, Scotland)

6.4 Payment value and frequency

Overall, the amount participants received from disability benefits was said to be insufficient to cover the extra costs related to their health conditions and impairments. This was viewed as being more difficult since the cost of living crisis. Participants wanted the value of disability payments to increase, at the very least in line with inflation. One view was that a greater understanding of the extra financial costs of living with a range of health conditions and impairments was needed to tailor the benefit to the individual. As highlighted in section 4.3, participants did not think the complexity of their health conditions and related costs were reflected in the value of disability benefit payments.

“I don't think the benefits reflect the extra cost, to be honest with you. [...] I do think the levels of the disability - the money that you're paid should be increased. I'm not expecting thousands, but they should at least go up in line with inflation, if not a bit more at the moment.” (Participant, England)

“The payments should also be increased so that disabled people don't have to struggle to get by. The current rates of all benefits are far too low, and if you are to survive you would usually need to be in receipt of a number of different benefits, each with their own application and award criteria.” (Participant, Scotland)

There were also interviewees who reported that they would like disability payments paid more frequently. It was thought that receiving payments every week or every fortnight, instead of every four weeks, would help with the management of their finances.

“I think it's quite hard to manage your money when sometimes if you just have a massive chunk of money in the bank it can look like you've got a lot of money and it's really hard then remembering that you haven't because it's got to pay all your bills and stuff so yeah I guess for me weekly makes a lot more sense for people that struggle to kind of manage things long term like me. I find that really, really helpful getting it weekly because I know exactly what's going in every week and what exactly is coming out every week so that makes it easier for me.” (Participant, Scotland)

6.5 Reduce time from application to award

Finally, some interviewees perceived that the time from submitting an application to receiving a decision should be reduced, as this would help alleviate the stress of waiting for a decision. Some suggestions to reduce this time period included increasing staffing and ending the need for assessments where sufficient evidence has been provided.

“The timeframe really because that's extremely stressful. As I said, the six or eight weeks that it took for me to get the result felt like forever and it was so stressful but it's as if they knew straightaway if I didn't get accepted I wouldn't appeal it because it was just too stressful. It was such a long time from the time you fill in the form to the time you get your assessment and then get your result.” (Participant, Wales)

“I think the timeframes need taking up a bit because I think the time it takes for everything to fall into place and all the rest of it, can actually be quite - because what they don't think about is the stress that it is to wait the length of time that they're talking about. So, it's not about turning round and saying, 'Oh, we'll give you an answer in 12 weeks' or whatever. If you've had to go through this whole process and at the end of it you're then getting told, 'It could be another 12 weeks' or whatever before you hear anything, then that in itself is the stress of that 12 weeks that you're having to wait. So, quicker timeframes would maybe make it easier.” (Participant, Scotland)

7. Wider support for disabled people

Interviewees identified a number of changes outside the disability benefits system that would improve the lives of disabled people in the UK. Some of these suggestions were also thought to address financial insecurity faced by disabled people.

7.1 Reducing stigma

Throughout the interviews it was common for disabled people to talk about the stigma of claiming benefits, in particular disability benefits. Participants felt that if they claimed disability benefits, or other sorts of benefits, they were perceived to be “scrounging”. They believed that both the public and the government perceived them to be lying about their health conditions or impairments in order to claim benefits, particularly if their impairments were not obvious or visible. This feeling was perpetuated by how disabled people felt they were treated while applying for disability benefits and how disabled people are portrayed in the media.

Consciously or unconsciously, stigma was also internalised by some participants. When explaining why they had not applied, or delayed applying, for disability benefits participants talked about not wanting to admit to themselves that they had a disability. Others said they did not feel worthy of the support or that they thought that others were impacted more by their health conditions or impairments. One participant described it as “internalised ableism” which they thought prevented disabled people from accessing the support they were entitled to.

“I suppose people might not do it because - yes, I think maybe they may feel ashamed that they have to admit that they can't cope. It might be a shame thing. I think sometimes, too, a lot of programmes don't help on TV. You know like Benefits Street? Things like that, people think, oh, I don't want to be like them, even though that's just how TV's portraying people. [...] I think maybe the media and government would rather portray people in that position as people like the worst-possible... They portray the worst-possible side of them, so then people think, I don't want to be like them, and they look down on people. It creates a shame over applying for benefits, and it creates a shame using food banks as well, but I don't think it's right. I think, yes, the media has a lot to answer for in terms of creating that shame around it, so, yes, shame.”

(Participant, Scotland)

To reduce the stigma of living with a disability and claiming disability benefits, interviewees called for more public education on health conditions and impairments. This was perceived to be particularly important for hidden and fluctuating conditions. It has hoped that if people had a better understanding of disability they would be more empathetic and more likely to enact change. To achieve this, interviewees suggested a range of approaches, from education in schools to public awareness campaigns.

“More education about disabilities would be great. If we were just all taught from a young age about disability that would be great. [...] I was speaking to my partner about this and he basically said that he's learnt so much since being with me because of my mum and stuff and his family never ever thought about it. It's not like they were mean to disabled people or anything. It didn't even cross their minds because they didn't know anyone who was disabled. I was saying that's really interesting. Maybe most people don't think about disability, not because they're being nasty, but because it doesn't enter into their minds. I don't know. Maybe more education would be good.”
(Participant, Wales)

7.2 Improving access to work

As reported above, a number of interviewees also said that a greater awareness and understanding of disability was needed in workplaces to help disabled people find and sustain meaningful employment. Interviews described experiences of being denied reasonable adjustments at work, having to educate employers on their legal requirements or being made to feel that they were not capable of doing their job because of their impairments. Some interviewees feared telling their employer or colleagues about their health conditions or impairments for fear of how they would react.

Fluctuating and less visible health conditions, as well as neurodiversity were highlighted as being particularly poorly understood and therefore inadequately supported in workplaces. It is important to note however, that there were also examples of workplaces which did have a good understanding of disability and were supportive both on an emotional and practical basis.

Interviewees spoke about how important being able to work was to their wellbeing and sense of purpose and their desire to be supported to work in a job that meets their skills and expertise. Therefore, interviewees wanted workplaces to have a better understanding of the wider range of health conditions and impairments people may have to enable employers to take action to better support disabled people to thrive at work. Participants would like to see employers treat disabled people as individuals in the workplace, with adjustments reflecting individual needs and preferences. These are legal requirements which should be

implemented. Not only would this have a positive impact on people's wellbeing, but it could reduce the financial insecurity of disabled people.

"I think employers have got to understand about disabilities. [...] Understand that not everybody is the same. Everybody has good days, bad days. [...] if we want to start getting more people into the workforce, which is what we want to do, we want to start getting more, making it more accessible for the people who have got disabilities to be able to get out in the workforce, and actually be happy in the workforce, and contribute towards that sort of situation. I think we've got to have that knowledge and that understanding of disability, and understand that. I think that will then take a bit of pressure off the Government, in the sense of providing benefits and all those sorts of things." (Participant, England)

"I think workplaces need to have a better understanding, across the board, of the law, and also, outside of the law, things that can - adjustments and stuff like that. I think some employers need to have a better understanding of how a small change can have a big impact on somebody's life, and it doesn't need to cost them the world to do it. They also shouldn't have to be looking at the law all the time, in order to make those adjustments. So it's about education, I think, of employers, as much as possible to - and doing more research into the benefits of being able to support people who are working but have conditions which don't necessarily - you don't have to go by the letter of the law, in order to make adjustments and stuff like that. So I think that would be a real benefit if there was some sort of - being able to encourage employers to be as flexible as possible." (Participant, Northern Ireland)

"Obviously everyone is different. So, there are some disabled people that don't want to be treated any different. There are some people that would not like this, but in my case, I would really like some sort of reduced responsibilities to my appropriate level. I'm really happy to be pushed and not take things easy. The trouble is you get branded as lazy if you start asking for slightly less work, but I really am okay with a high workload. I've been doing this for years. It's just I need it to be lowered." (Participant, Wales)

7.3 Additional financial support for disabled people

As described in Chapter 4, both interviewees in employment and those who received out of work benefits reported that income from disability benefits was not enough to meet all the costs related to their health conditions and impairments. Furthermore, it was common for participants to be using disability benefits to pay for everyday living costs such as rent, utility bills and food because their level of income from either work or benefits was insufficient to cover these costs. Therefore, being able to access the financial support available to disabled people was not thought to be the only driver of food insecurity.

Participants highlighted that when they did not have enough money to meet all of their needs, they often chose to pay bills over food. For some, if food banks were not available, they would not be able to eat. To reduce food insecurity, interviewees would like to see more financial support available for disabled people. Examples included implementing grants to help pay for adaptations and costs associated with health conditions and impairments that are currently not covered by the NHS or local authorities. Other suggestions were to provide discounts for disabled people for costs such as utility bills and food to address the higher costs related to health conditions and impairments.

Finally, participants would like to see additional support specifically to buy food, to ensure that people are able to prioritise eating well. There was an acknowledgement that similar support was provided by both the UK and Scottish governments to families with young children in the form of Healthy Start vouchers and Best Start Foods.

Transport was identified as a major extra cost linked to living with health conditions and impairments, yet only those who were awarded enhanced mobility payments on PIP could apply to the mobility scheme. For many, transport was viewed as being vital in being able to work and access treatment and support. Interviewees called for support for transport to be expanded to more disabled people. This included greater access to financial support to pay for transport, either through the Motability Scheme or other means, and greater investment in making public transport more accessible to a wide range of disabled people. The provision of a small number of wheelchair spaces on buses and trains was not sufficient to make public transport accessible to disabled people.

“What I think would be really helpful is for example, when my car does eventually die, there is no way I can finance a new one because I’m disabled and I’m no longer working. I know there’s a Motability Scheme, but it seems like you have to be really connected to be able to get that but that’s it that’s the only help. So, I think for disabled

people to have help with that would be incredible. Yeah, finance in general yeah.”
(Participant, Scotland)

Interviewees would like to see greater promotion of all support available to disabled people. It was common for interviewees to say they did not know what financial and practical support they were entitled to, or that in the search for support they were often passed from organisation to organisation. Interviewees would like finding and accessing all types of support to be made easier for disabled people. One suggestion was for a government website with all the different types of support listed in one place. Again, there was recognition that to ensure all disabled people had access to this information, a variety of approaches, in a range of accessible formats, would be needed to promote the support available to disabled people.

“A campaign of some sort. Have it in the newspapers, have it in your local newspaper, have it on the radio, have it on the TV. I've not seen anything about it at all, nothing about it at all. [...] Are you struggling with disability at the moment? Are you having problems with your mobility? You be could incurring extra costs because of that disability. You could be having to work less hours, not work at all, that type of thing. Promote it, rather than being a negative thing.” (Participant, Scotland)

7.4 Greater community support for disabled people

In addition to greater financial support, disabled people reported that more community support for disabled people would be beneficial. Transport and public spaces such as shops, eateries and arts venues were all highlighted as not being accessible to disabled people with a range of health conditions and impairments. This often left disabled people feeling isolated from engaging in their communities. Interviewees wanted to see more action taken to make communities accessible and accepting of disabled people. Examples included Bluetooth being utilised in arts venues so that those with hearing impairments could better engage in performances or shows, and improving accessibility on transport further so that more disabled people could use it. To ensure that accessible technology can be utilised, participants suggested that staff in public spaces should be properly trained in its use.

Finally, some interviewees also called for more opportunities to meet other disabled people, particularly those with similar health conditions or impairments. Interviewees who had met with others with similar impairments found that the experience was invaluable in understanding what support and services were available to them.

“I feel like when you're disabled you can get forgotten about and I do feel like there isn't much help and especially with people like me who have got a hidden disability. You do get judged quite a lot and I do feel like there should be more help out there for that type of thing, you know and I don't feel like there is. [...] I don't speak to anyone who has got my disability. You know you go out and you're searching for things because you want answers and you don't know where them answers are [...] There is groups out there, but it's finding them, you know. They're not very publicised or you know, there's not very much.” (Participant, England)

8. Conclusions and policy recommendations

The overall aim of this research was to understand the drivers of food insecurity among disabled people to enable the development of policy solutions. Specifically, this research sought to understand the reasons for the underclaiming of disability benefits and the extent to which the design of the disability benefits system is driving food insecurity. To explore these issues, the Scottish Centre for Social Research conducted 57 in-depth interviews with disabled people across the four countries of the UK.

This research identified a range of drivers of food insecurity among disabled people, brought about by financial insecurity.

8.1 The disability benefits system

8.1.1. Accessibility

It is clear from this research that the inaccessibility of the disability benefits system was a major driver of food insecurity. Disabled people who took part in this study had almost universally struggled to access disability benefits, either because they did not know they were eligible, they found the application difficult to complete or because their application was refused. Furthermore, this study also found evidence that being in work can create barriers to accessing disability benefits. Although people in employment are eligible to claim disability benefits, participants felt assessors perceived being in employment as evidence that they did not need extra support.

Due to negative experiences of the disability benefits system, some of the disabled people interviewed did not challenge a refused claim, potentially resulting in the loss of valuable extra financial support. Current figures show that 68% of DWP refused claims were overturned and revised in favour of the claimant⁴⁰.

The DWP's Health Transformation Programme aims to "vastly improve customer experience" and "build trust" in the PIP service. This research demonstrates the necessity for these aims to be addressed quickly in order to tackle disabled people's food insecurity⁴¹.

8.1.2. Adequacy

While improving the accessibility of the disability benefits system is crucial, increasing up-take alone will not be sufficient to relieve food insecurity for disabled people.

This research adds to a wealth of previous evidence that the value of both disability and incapacity benefits is inadequate. Even disabled people in this study who were receiving their full benefits entitlements were not always protected from food insecurity. This research also supports previous findings that disabled people have to use their disability benefits income to cover everyday living expenses, rather than to meet the extra costs associated with their impairments.

8.1.3. Introduction of Adult Disability Payment

With the introduction of ADP to replace PIP for disabled people in Scotland, the Scottish Government has implemented several changes with the stated aim of improving disabled people's experiences of claiming disability benefits. This research was conducted when the roll-out of ADP was ongoing and is the first study to gather insights into disabled people's expectations and experiences of the new benefit. Recognising that experiences are limited and in their early stages, the evidence is clear that experiences of applying for ADP varied.

- As evidenced in this study, the disability benefits system is a source of fear for many disabled people. To help reduce anxiety and worry, communications about benefits must be timely and clear. However, participants waiting to be transferred from PIP to ADP reported a lack of information in communications from Social Security Scotland, often leaving them worried and uncertain about what they needed to do or what the new benefit involved.
- Some participants spoke of the ADP form in largely similar terms to the PIP form, with criticism of the form's length, repetitiveness and its wording. As was the case with people who had completed the PIP application, the ADP form was perceived as an attempt to trick applicants. However, there were participants that felt the ADP application form was an improvement on the PIP form, with more room to discuss the effects of impairments and more scope to describe the impacts of mental health.
- While the option to apply online for ADP was broadly welcomed, technical problems were a source of frustration. Participants who had received ADP were positive about their experience and reflected that the ADP process appeared to be more compassionate and caring than the PIP process.

As part of this research, disabled people shared their preliminary thoughts on the differences between PIP and ADP. The provision of an independent advocacy service, increased numbers of indefinite awards, the removal of routine medical assessments and the reduction in the amount of evidence required in support of a claim were all broadly welcomed. However,

some participants expressed concern that over-reliance on medical evidence instead of assessment would penalise claimants who did not have a formal diagnosis or those who have poor relationships with their healthcare providers. It could also be challenging for those who experienced difficulties accessing medical evidence.

8.1.4. Complexity of circumstances

While other research, including a recent study from Scope, has highlighted the additional costs associated with disability, there has been little discussion of the complexity of these additional costs as a driver of food insecurity²⁸.

In this research, it was common for participants to have multiple health conditions and impairments, the treatment and management of which often increased the costs faced by disabled people. It was also common for participants to be living with family members who also had health conditions and impairments. This too increased the additional costs related to disability-facing households. Moreover, reduced working hours, or giving up work to support the care of disabled people in the household, often resulted in a loss of income, augmenting the financial problems faced by those with these conditions.

This research found clear evidence that disability benefits, and the wider social security system, are not designed to take into account the full complexity of disabled people's lives and the ways in which this complexity can increase costs associated with disability. Therefore, financial and food insecurity were perceived to be driven by a lack of understanding of the complexity of disability and the living circumstances of those with often multiple, and fluctuating, conditions.

8.2 Wider drivers of food insecurity

This research found that many of the drivers of food insecurity among disabled people and households are linked directly or indirectly to issues of accessibility caused by a widespread lack of understanding of disability or, in some cases, stigma and prejudice directed at disabled people.

8.2.1. Accessing financial support

A poor or limited understanding of the wide range of health conditions and impairments can lead to stigma, particularly for people with less visible and fluctuating impairments or conditions. Stigma around, and prejudice related to, the claiming of disability and other benefits, can prevent disabled people from applying for both financial and practical support which could help their financial stability. The public stigma of people accessing benefits being

labelled as ‘scroungers’ or being perceived as making false claims was so strong that participants readily wanted to distance themselves from this image. However, in doing so, participants inadvertently reinforced the perception that people may be making false disability benefit claims.

It is clear from this research that the current social security system supports a narrow definition of disability that does not fully accommodate the wide range of health conditions and impairments with which people are living. This is illustrated by the volume of disability benefit applications being initially rejected and then overturned on appeal or at a tribunal. However, this research has highlighted that some disabled people may not appeal the decision due to the deep distress inflicted by the initial application and assessment processes. Therefore, disabled people can be excluded from receiving financial or other support that reflects their needs.

8.2.2. Access to employment

Economic exclusion has been widely identified in previous research as a central driver of financial insecurity among disabled people. This study found that a lack of understanding of disability, and negative assumptions and stereotypes around disabled people and their capabilities can exclude people from the workforce. There is evidence that employment structures can prevent disabled people from accessing and maintaining stable and rewarding employment. Despite legal requirements, disabled people in this study had encountered employers who were not implementing reasonable adjustments or lacked the understanding of how they can support disabled people to thrive at work. However, this research also heard examples of supportive employers and where reasonable adjustments were enabling people to stay in employment.

8.2.3. Accessing wider support

A lack of understanding of disability can also prevent disabled people from receiving wider support. Participants described challenges accessing public spaces and services because they were often inaccessible for disabled people, leading to exclusion and isolation. Furthermore, participants were not aware of support available to them because it was not promoted as being available and accessible to disabled people.

8.2.4. Cost of living crisis

Previous research exploring food insecurity among disabled people pre-dates the cost-of-living crisis. This current research has highlighted the ways in which the cost of living crisis has exacerbated the financial insecurity of disabled people and resulted in disabled people accessing food banks for the first time or more frequently than they did previously.

Food bank use is only one manifestation of wider food insecurity faced by disabled people. Rather than accessing food banks, participants were accumulating debt on credit cards or other loans, relying on support from family or friends, and making changes to food shopping and eating habits to ensure they could pay their bills. While the rate of inflation is now falling, prices of everyday essentials such as food remain high. It is important to note that a falling inflation rate means only that prices will rise less quickly. Therefore, while the cost-of-living crisis will eventually ease, disabled people's food insecurity is likely to remain at alarmingly high levels unless their incomes are increased to reflect higher prices.

8.3 Policy recommendations

While there are several drivers of both financial and food insecurity among disabled people, there are also several policy solutions that the governments across the UK, local authorities, the Trussell Trust and other relevant stakeholders should consider. These solutions are embedded in the social model of disability and focus on changing social structures and attitudes and challenging prejudices and assumptions about disabled people. Given that disabled people interviewed for this research were facing hardship, exacerbated by the cost of living crisis, it would seem imperative that action is taken to redress this immediately.

This research identified a number of drivers of food insecurity for disabled people, including barriers to applying for disability benefits, accessing employment and accessing other financial support. To address these barriers, a number of policy recommendations can be made.

8.3.1. The disability benefits system

Promotion of disability benefits eligibility criteria

A lack of awareness of the eligibility criteria has led to the underclaiming of disability benefits. To ensure disabled people are aware of the financial support they are entitled to, greater promotion of eligibility criteria is needed. Both government and other sectors could take action on promoting eligibility criteria more actively.

- A variety of promotion methods are required to ensure that the information is accessible to all disabled people. Methods of promotion should include both public awareness adverts via a range of media, and more targeted promotion such as letters direct to people's homes or pamphlets displayed in public places such as doctor surgeries, post offices and libraries.
- More proactive promotion of disability benefits is required so disabled people are aware of their entitlements. Action is needed from those working directly with disabled people to

make them aware of their eligibility. For example, when a health condition or impairment is diagnosed or identified, the doctor or health specialist should make a person aware of disability benefits and the application process.

Changes to disability benefits application form

The design of the PIP and ADP application forms acts as a barrier to disabled people applying for disability benefits. The current application forms are long, confusing and repetitive and do not enable disabled people to fully explain how their health conditions and impairments affect them. The application form does not cater for a wide variety of health conditions and impairments, including less visible and fluctuating health conditions.

Amendments to both the PIP and ADP application forms are needed to make it easier for disabled people to apply for disability benefits and to fully express how any health conditions and impairments impact on their lives. Amendments suggested by disabled people include:

- Shortening the form by taking out unnecessary repetition.
- Simplifying the language used.
- Remove ambiguity by altering the questions to make it clearer what information is being requested and why.
- Changing the design of the application form to enable disabled people to explain the ways in which they are impacted by their health conditions and impairments, and to outline the extra costs that relate to their impairments and health conditions. This could include allowing people to only answer questions relevant to their circumstances, or changing them to increase their relevance to a wider range of health conditions and impairments, such as more open-ended questions asking people to describe the impact of their health conditions and impairments on their daily lives.
- Follow the example of ADP and make the PIP application form available in a range of formats, including via online and telephone applications.
- Remove the time limit of four weeks from being sent the application to submitting the application.

Overall, participants would like applying for disability benefits to be accessible to all disabled people. While not expressed explicitly by participants, this could include ensuring that the application form is available in a range of languages and formats that accommodate the needs of different impairments. For example, large text and easy read.

Improvements to disability benefits application support

It is clear from the research that having access to support to complete both the PIP and ADP application forms is vital for many disabled people. However, disabled people are unaware of what support is available in the public and voluntary sectors and how to access it. Current levels of support in some areas may be insufficient with waiting lists in place.

To ensure disabled people are aware of and can access support with disability benefit applications, a greater provision and promotion of support from both statutory and voluntary services is needed. Whilst acknowledging that both the DWP and Social Security Scotland have a role to play in promoting and providing support with applications, this should also involve health sector staff, local authority staff and voluntary sector support organisations. Suggested improvements included:

- Increased public promotion of and direct signposting to public and voluntary sector support services across the UK that can help with disability benefit applications. Directly informing disabled people that they are eligible for disability benefits and signposting them to support was particularly important to minimise burden on disabled people.
- Increased long-term funding of existing and new independent support services to avoid the loss of more services and to ensure sufficient support is available across the UK. This could extend to the provision of advocacy throughout the application and assessment process.
- Upskilling of a wide range of staff in public and voluntary sector support services across the UK. This could include health, public and voluntary sector staff. Doctors, other health specialists and job centre staff were among those mentioned who may lack a thorough understanding of disability.

Changes to the disability benefits assessment process

Assessments, reassessments, appeals and tribunal elements of the disability benefit system caused distress and trauma to participants due to the sorts of questions they were asked and how they were treated during the process. Disabled people frequently talked about the burden of providing multiple sources of evidence and the difficulty of contacting health professionals to provide such evidence, which was time-consuming.

To improve the experience for disabled people, and encourage more disability benefit applications, changes to the disability benefit assessment process are needed. Changes suggested by disabled people include:

- Adapt PIP to be more like ADP in terms of:

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- Responsibility of government to gather evidence from professionals identified by the claimant.
 - Remove the need for a health assessment where clear evidence is provided.
- Where assessments are needed, provide assessors who have specialist knowledge of a claimant's health conditions and impairments.
 - Train all PIP and ADP assessors to have a greater understanding of a wide range of different health conditions and impairments and to act with empathy.
 - Provide greater clarity on the types of professionals that can provide evidence for PIP and ADP applications.
 - Remove the requirement to resubmit evidence at reassessment if a health condition and impairment had not changed or symptoms had not improved.
 - Involve more disabled people in the design and delivery of disability benefits to make the system more person centred. Involving disabled people could help ensure that a better understanding of the impacts of disability is embedded in the system. It could also make the system more accessible and empathetic, improving the experience for disabled people.

Changes to the receipt of disability benefits

The current value of disability benefits is not sufficient to cover the extra costs related to their health conditions and impairments. The implementation of disability benefits do not sufficiently meet the needs of disabled people.

To improve the implementation of disability benefits the following actions were suggested by disabled people:

- Increase the value of disability benefits to better meet the extra financial costs of living with a range of health conditions and impairments. This should reflect the individual's circumstances and the costs required to manage their conditions and enable them to participate equally in society.
- Provide the option for all people to be able to choose whether to receive disability payments weekly, fortnightly or monthly.
- Reduce the time from submitting an application to receiving a decision. Some suggestions to reduce this time period included increasing staffing and ending the need for assessments where sufficient evidence has been provided.

8.3.2. Wider support for disabled people

The research identified a number of changes outside the disability benefits system that would improve the lives of disabled people in the UK. Some of these suggestions were also thought to address financial insecurity faced by disabled people.

Reducing stigma

- More public education on health conditions and impairments to reduce the stigma of living with a disability and claiming disability benefits. This could include:
 - education in schools.
 - public awareness campaigns.
 - poverty and disability awareness training for all staff in public facing roles.

Participants did not suggest who should be responsible for paying for and implementing these actions. A combination of government, private and voluntary sector action may be required.

Additional financial support for disabled people

There is evidence from this research that for some disabled people the income they receive from either employment, benefits or a combination of both, is not enough to cover daily living expenses. Therefore, participants are using disability benefits or getting into debt to meet or alleviate these costs. To improve disabled people's financial stability, greater financial support is required, both in relation to their disability and more widely.

- Provide more financial support to disabled people to meet the extra costs related to their health conditions and impairments. For example:
 - Grants to help pay for adaptations and costs associated with health conditions and impairments that are currently not covered by the NHS or local authorities.
 - Provide discounts for disabled people for costs such as utility bills and food.
 - Provide government support to disabled people to meet the cost of food.
 - Expand support to meet the cost of transport to more disabled people.
- Greater promotion of all types of support available to disabled people to make it easier to find and access support.
 - A variety of approaches, in a range of accessible formats, would be needed to ensure all disabled people had access to this information.
 - More opportunities to meet other disabled people, particularly those with similar health conditions or impairments, to help disabled people understand what support and services are available to them. While participants did not suggest who should be

providing these opportunities, local authorities have a role to play in ensuring these opportunities are available in their local authority.

While it was not explicitly mentioned by participants, increasing other benefit levels could help disabled people to better meet their daily living costs.

Changes to public environments

- Make environments, particularly public and community spaces, more accessible to disabled people. For example, utilising Bluetooth in arts venues so that those with hearing impairments could better engage in performances or shows. This would need to be accompanied by staff training to implement these changes.
- Disability education and training in workplaces, to enable employers to implement their legal requirements and take better action to support disabled people to thrive at work.

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10. Appendix A

Research objectives

1. To understand if and how the design of the disability benefit system impacts the need for food banks.
2. To identify the primary reasons behind the significant underclaiming of disability benefits among people referred to food banks.
3. To understand how different experiences of claiming, or attempting to claim ADP and PIP can drive different outcomes.
 - a. An examination of disabled people's experiences of the application and reassessment processes, including their experiences of challenging decisions.
 - b. A comparative analysis of the experiences of applying for ADP and PIP, underlying which elements of these benefits work well and, equally, which elements are failing to protect people from needing to use a food bank.
 - c. Gathering qualitative evidence which can act as a springboard for the development of policy solutions.
4. Equip colleagues across the Trussell Trust with the robust evidence that they need to campaign on issues relating to disability, drive change, and work with partners in the disability advocacy space.

Research questions

1. What factors drive the significant need for food banks from disabled people in the UK?
 - a. What do disabled people consider to be the most significant drivers of this trend?
2. What do disabled people consider to be the primary reasons for the widespread underclaiming of disability benefits among people referred to food banks?
 - a. What impact does a person's experience of applying for ADP or PIP have on their attitudes towards, or ability to engage with, the benefit system?
 - b. What impact does the underclaiming of disability benefits have on access/passporting to other forms of support?

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3. What are disabled people's experiences of applying, and being assessed for PIP in England, Wales and Northern Ireland and ADP in Scotland?
 - a. How do the experiences of ADP and PIP compare? Is one system more accessible, less restrictive or easier to navigate than the other?
 - b. For people who have previously claimed PIP in Scotland and are now in receipt of ADP, how do the experiences of each benefit compare?
 - c. In the absence of differences between award amounts, what are the practical and emotional differences between the two and what impact do they have on food insecurity, destitution and food bank use?
 - d. Which elements of current disability benefits do participants think are having a positive impact? What is currently working well?
 4. Do disabled people consider the amount of income provided via ADP and PIP sufficient to meet the additional costs of their disability? How are their additional costs – is this above or below the amount provided by PIP and ADP?
 5. What do disabled people consider to be the best solutions? How should disability benefits be delivered to reduce the need for disabled people to use food banks?

