

A close-up photograph of a woman and a young child looking out a window. The woman is on the left, looking off to the side with a serious expression. The child is on the right, leaning their head against the woman's shoulder and looking in the same direction. A red star-shaped logo with the text "Action for Children" is in the top right corner.

*Action for  
Children*

# Sick and tired

A look at the hardships and work prospects of sick and disabled parents relying on incapacity benefits

October 2024

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## Executive summary

This is the latest in our series of reports that explores the barriers to work faced by low-income families with children.

There are more than three million people in the UK receiving financial support through the benefits system due to a health condition or disability that affects their ability to work. We estimate around 800,000 of them are parents of dependent children. This report is based on a unique survey of 1,130 parents who rely on these benefits to support their families and a series of in-depth interviews.

## Survey findings

### **Families receiving incapacity benefits face financial, practical and emotional hardships**

- Only 12% of parents on incapacity benefits are keeping up with all bills and credit commitments without any difficulties. Almost three in 10 are falling behind on bills (29%), with one in seven experiencing severe financial problems (15%).
- Among parents who indicated they were facing difficulties, a third said their child had gone without new clothes or shoes when they needed them (32%), three in 10 said their child had not always eaten as nutritiously as they would have liked (30%) and one in seven said their child had not always eaten three meals a day (14%).
- Half of parents receiving incapacity benefits reported feeling down or depressed in the previous month (48%). More than four in 10 worried about the government making changes to their benefits (44%).

### **The NHS, Department for Work and Pensions (DWP) and employers must do more to break down work barriers**

- The most common work barriers among parents receiving incapacity benefits relate to immediate health needs, the capacity of the labour market to accommodate parents' health needs or the design of the benefits system.
- Among parents who did not rule out paid work in the future, the most common barriers were: being too unwell to work or work more right now (35%); a lack of suitable or flexible jobs (23%); not getting the treatment they need from the NHS (23%); a lack of remote jobs (20%) and a fear of losing benefits if they try work (20%).
- When asked about policy solutions, a third of parents agreed that bringing down NHS waiting lists could help them return to work (33%) alongside specific investment in NHS mental health services (36%). Around a quarter felt a stronger role for the public sector to create flexible jobs specifically for disabled people could help (26%) and a similar proportion called for more specialist advisers in jobcentres (23%).

### **Parents report a wide range of physical and mental health challenges**

- The most commonly reported primary health conditions are mental health conditions (29%), other long-term health conditions (23%) and musculoskeletal conditions (16%). Contrary to some recent commentary around a 'sick note culture' of people feeling 'bluesy' in response to everyday pressures, only 8% of parents report that their primary health condition relates to stress or anxiety.<sup>i</sup>

### **Too many parents receiving incapacity benefits feel unsupported by the DWP**

- Parents in our survey frequently expressed dissatisfaction at the quality of the support on offer for those who want to explore a return to work. A third do not feel like DWP staff take their circumstances into account (34%) and three in 10 have felt pressured to enter work before they are ready (30%).
- Around a quarter of parents do not feel listened to by the DWP (26%) and have felt intimidated or harassed by DWP staff (24%).

### **As many as four in 10 out-of-work parents receiving incapacity benefits think they could return to paid work in the future, but this is contingent on their health improving and getting better support from the government and employers**

- Benefit rules permit incapacity benefit claimants to take part in a modest amount of paid work. We found that a quarter of parents on incapacity benefits are engaged in some paid work (25%) and a further 10% are doing some unpaid voluntary work.
- A third of parents who are not in work say that they can't work right now, but might be able to in the future if their health improves (32%). One in 10 out-of-work parents think they could return to work right now *if* they had the right support from the jobcentre and employers (10%).
- Among parents who are not currently in paid work and who do not think their health or disability rules out paid work completely, a quarter think they could be ready for paid work within the next 12 months (25%). Most commonly however, these parents do not know when they will be ready for work (49%).

## Key themes from our interviews with parents

Among the parents we interviewed:

- Most want to work and recognise the value it brings, but need support to do so. Typically, part-time work is seen as more realistic than a return to full-time work.
- Support from the DWP is often lacking and is undermined by the 'compliance culture' that has proliferated within jobcentres and assessment processes.
- Parents are deeply sceptical about the willingness and capacity of employers to accommodate their health needs and the flexibility they require to sustain work.
- Financial insecurity and material deprivation are common features of family life. Relying on incapacity benefits is a frequently precarious existence.



*“When you're worrying about things like, 'Oh, my lad needs a new pair of shoes for school, where the hell am I going to get the money for that?' And then it's like, well, he's having to wear shoes that are too tight for his feet, he's going to end up with ruined feet, and it's like, when you have kids, you want the very best for them, and you feel like you're failing them.”*

(A mum, Wales, one child aged 14)



## Key stats at a glance

### *Among all 800,000 parents on incapacity benefits:*



**29%** are falling behind on bills.



**48%** felt down or depressed in the past month.



**44%** have worried about the government making changes to their benefits.



**30%** have felt pressured to enter work before they are ready.

### *Among the 75% of parents on incapacity benefits and not in any form of paid work:*



**32%** said they can't work right now, but might be able to in the future if their health improves.



**10%** think they could return to work right now if they had better support from the government and employers.

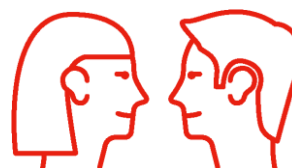
### *All parents on incapacity benefits, when asked what could help them return to work:*



**33%** said bringing down NHS waiting lists.



**26%** called for more flexible public sector jobs for people with disabilities.



**23%** called for more specialist advisors in jobcentres.

## Recommendations for the UK government

A more detailed set of recommendations can be found at the end of this report.

- 1. Invest in specialist advisors in the new Jobs and Careers Service** to lead contact with those who are out of work due to disability or ill-health, including at periodic voluntary meetings with incapacity benefit claimants. These specialists would be deeply embedded in local areas to facilitate close partnership working under a more devolved employment support system.
- 2. The DWP should not proceed with plans to abolish the Work Capability Assessment** which would leave decisions about the level of work requirements that's applied to ill and disabled claimants receiving incapacity support up to work coach discretion.
- 3. Reform the conditionality and sanctions regime** to end the 'compliance culture' in jobcentres and assessment processes.
- 4. Strengthen flexible working arrangements for disabled people.** The Department for Business and Trade and the DWP should ensure the Employment Rights Bill includes specific provisions to strengthen flexible working for employees with health conditions and disabilities.
- 5. Increase the supply of flexible and remote work opportunities.** The Labour Market Advisory Board should work across government to develop proposals for increasing the supply of highly flexible and remote work opportunities, including financial incentives to employers, employer outreach and communications campaigns and considering how the public sector can be mobilised.
- 6. Scrap the two-child limit and benefit cap and increase the child element** of Universal Credit to address high rates of poverty and hardship in families.
- 7. Automatically place claimants waiting for the outcome of a Work Capability Assessment** into a low or no-work requirements conditionality group.
- 8. Confirm and extend the Chance to Work Guarantee** to address concerns that engaging in work activity may also count against a claim for disability benefits.
- 9. Increase the rate of Statutory Sick Pay** so that it at least covers the equivalent hourly rate at the National Living Wage, and allow it to be used more flexibly to support a phased return to work.
- 10. Ensure that those receiving incapacity benefits are able to access skills and training opportunities** on the same basis as any other claimant, and explore how this offer could be expanded.
- 11. Address data limitations to inform policymaking.** The DWP should publish more detailed demographic data on incapacity benefit claimants, including by household type and the number and age of children. Universal Credit health journey data should include a claimant's primary health condition.

# 1. Incapacity benefits in the UK

There are **3.1 million people in the UK** receiving incapacity support through Universal Credit or Employment and Support Allowance because of a disability or health condition that affects their ability to work.<sup>ii</sup> The DWP does not currently publish data on incapacity benefits by household type. It is therefore not possible to know exactly how many incapacity benefit claimants are parents of dependent children. Based on our analysis of the Family Resources Survey, we **estimate this is around 800,000**.<sup>iii</sup>

Rising demand for incapacity benefits, alongside the much-discussed surge in economic inactivity due to long-term sickness and a similar rise in demand for disability benefits, have collectively come to be seen as one of the UK's most pressing policy problems. Significant uncertainty remains about what is driving these trends. A long-term deterioration in the health of the working-age population has been widely identified as a central factor.<sup>iv</sup> A detailed analysis by the Office for Budget Responsibility (OBR) found that only a quarter of the increase in the incapacity benefit caseload since 2019 is explained by more people making an initial claim for these benefits, with fewer people dropping off while undergoing their assessment and a higher approval rate having larger effects.<sup>v</sup>

## What are incapacity benefits?

In this report, we've used the term incapacity benefits (also called 'sickness benefits') to refer to the three main types of benefits provided to support people who have a limited capability for work due to a disability or health condition.

- **Universal Credit (UC)** provides incapacity support to low-income claimants found to have a 'limited capability for work and work-related activity' (LCWRA). They receive an additional payment of £416 a month (2024/25) in their UC award.
- **Income-based Employment and Support Allowance (ESA)** is the main incapacity benefit under the legacy system. It's gradually being replaced by Universal Credit and no new claims can be made. The DWP aims to contact all ESA claimants about moving to Universal Credit by December 2025.
- **Contributory or 'New Style' Employment and Support Allowance** is a contributory benefit for people who have built up sufficient National Insurance contributions. It's not means-tested but can only be claimed for 12 months, unless you have high support needs and are placed into the 'ESA Support Group'.

## What are disability benefits?

Disability benefits are non-means tested benefits provided to support people with the extra costs of having a disability or long-term health condition that affects their mobility or ability to do daily tasks. For working-age adults, this is Personal Independence Payment (PIP) in England and Wales or Adult Disability Benefit in Scotland. For children under 16, it is Disability Living Allowance or Child Disability Payment in Scotland.



## Recent policy developments

The previous Conservative government responded in several ways to these challenges. Positively, this included new funding for NHS talking therapies, an expansion of employment programmes for people with mental health conditions and a series of pilot trials for a new integrated work and health support service, WorkWell, within the NHS. Its centrepiece policy was Universal Support, a DWP-funded programme based on the well-evidenced supported employment model to help people with health conditions and other disadvantages to enter and stay in work through up to 12 months of personalised support.<sup>vi</sup>

More controversially, the previous government planned to tighten eligibility for incapacity benefits through changes to the assessment process – the Work Capability Assessment – from 2025 and, in the longer-term, to scrap that assessment entirely. In its place, generalist work coaches in jobcentres would decide what work-related activities, if any, ill and disabled claimants should take part in. This would, it was said, help more people into paid work by bringing claimants who had little engagement into more regular contact with work coaches, and by increasing claimants' confidence to try work without the fear of being reassessed and losing their incapacity benefits. The proposals left many questions unanswered and carry several significant risks, not least, opening the door for ill and disabled claimants to face sanctions if they don't comply with work requirements set by work coaches.

Following the 2024 general election, the Labour government made some initial announcements on measures to address the challenges posed by rising health-related inactivity, including a reformed Jobs and Careers Service and devolving some responsibility and funding for employment support to metro mayors and local areas. A new Labour Market Advisory Board was established in September 2024 and a white paper is expected in autumn 2024.<sup>vii</sup> The Labour party election manifesto committed to reforming or replacing the Work Capability Assessment, but no further detail had been announced at the time of publication.

## 2. Methodology

The findings in this report are based on a unique survey of parents in receipt of incapacity benefits, carried out in August 2024, and a series of in-depth interviews undertaken with parent claimants. We commissioned Find Out Now to survey parents who are claiming incapacity benefits. To reach a representative sample, they first surveyed 27,850 UK parents of dependent children (aged under 18) weighted to be nationally representative by age, gender and region (quotas derived from census data). From this, they derived a sample of 1,130 of UK parents who were claiming incapacity benefits. Fieldwork took place between 7 and 28 August 2024.

Semi-structured interviews with seven parents were conducted online or over the phone during August and September. Participants were predominantly recruited via the survey. Two participants were recruited via Action for Children communication channels.

### 3. Key characteristics of parents on incapacity benefits

#### Benefits claimed

According to our survey:

- Two-thirds of parents receiving incapacity benefits are claiming Universal Credit with Limited Capability for Work and Work Related Activity (66%).
- A quarter are receiving income-based Employment and Support Allowance (23%).
- The remaining 12% of claimants are receiving contributory or New Style Employment and Support Allowance.

We also asked parents if they were claiming Personal Independence Payment (PIP) – the main adult disability benefit that provides non-means tested financial support to disabled people to help them with the extra costs of their disability.

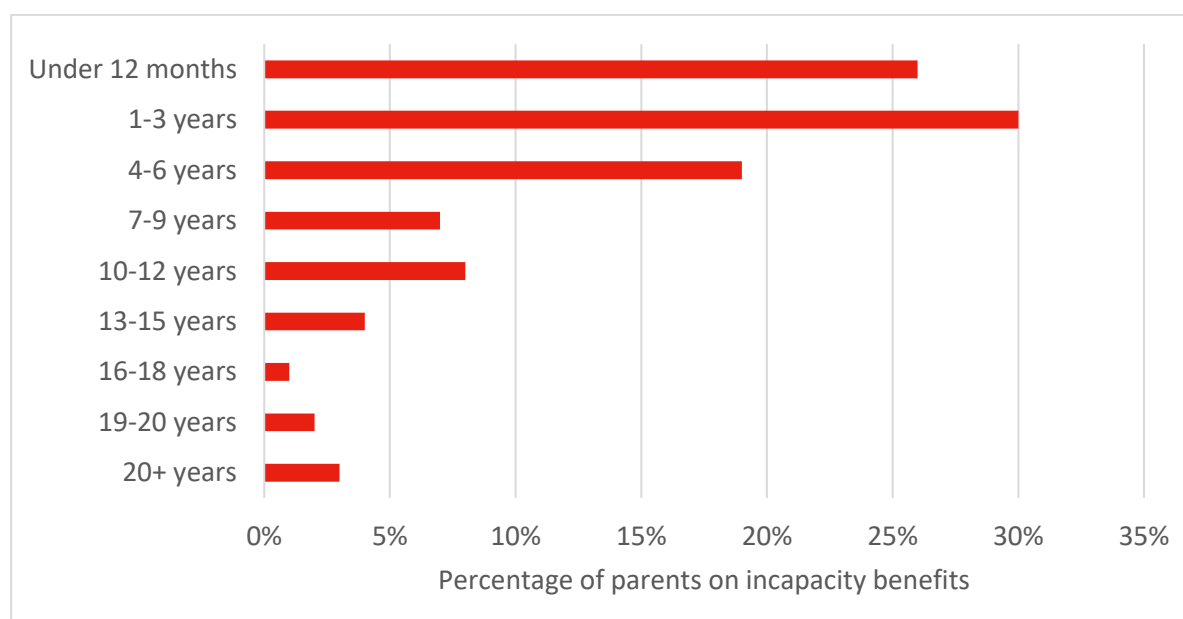
- Half of parents receiving incapacity benefits are also claiming PIP (50%).
- 45% of parents are not claiming PIP, and 5% selected 'don't know'.

#### Duration of claim for incapacity benefits

Over half of the parents on incapacity benefits have been claiming for three years or less (56%), including 26% who have been claiming for less than 12 months.

Almost a fifth of parents on incapacity benefits have claimed for 10 or more years (18%). One in 20 have claimed for close to 20 years or more (5%).

**Figure 1: How long have you been claiming sickness/incapacity benefits (including legacy or predecessor benefits)? (n=1,130)**

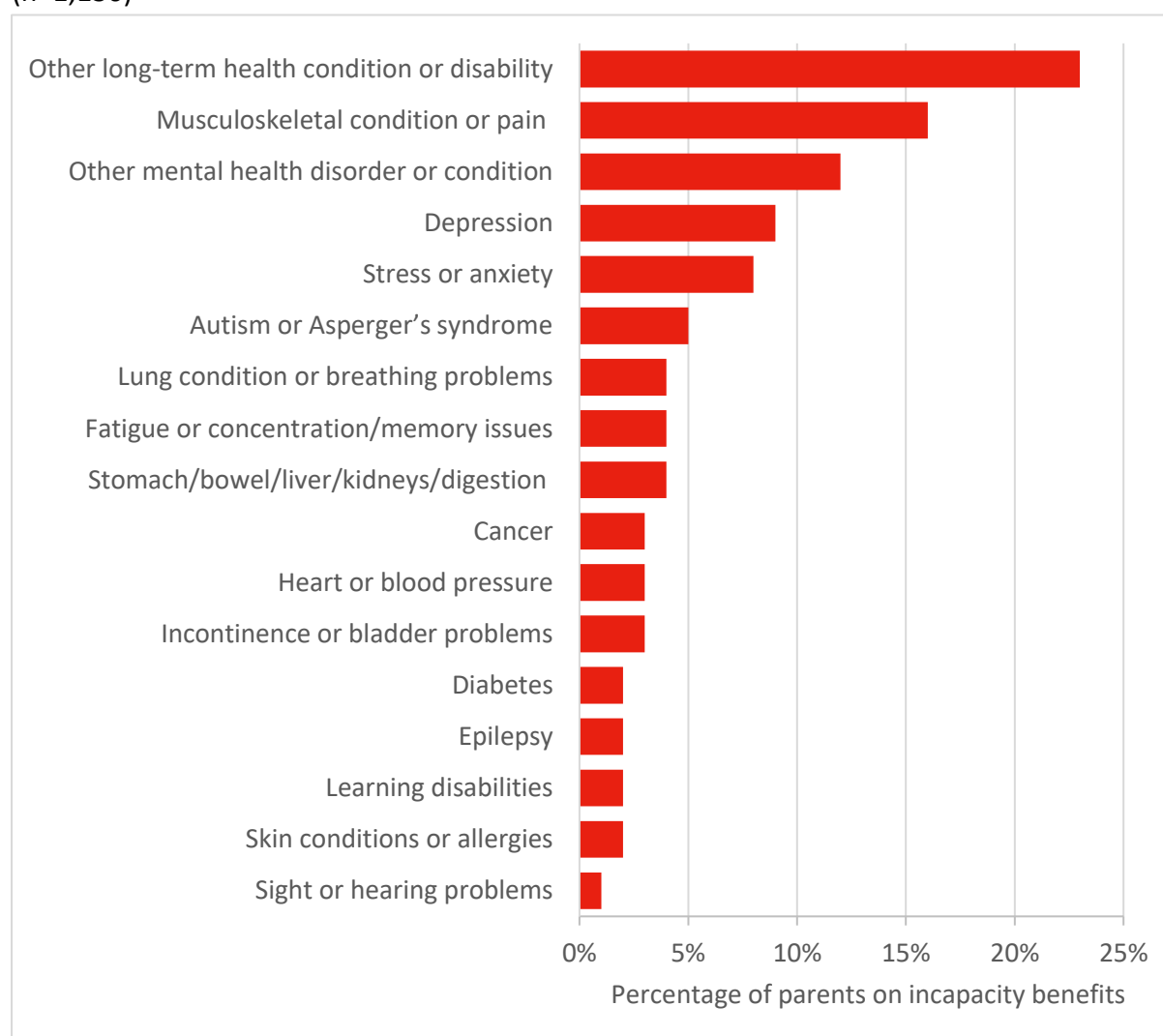


Evidence shows that the longer people are out of work for health reasons, the less likely they are to return to it. Analysis of the data on economic inactivity shows that after two years out of the workforce due to long-term sickness or disability, very few people will re-enter work.<sup>viii</sup> The year prior to a claim for incapacity benefits (for example, while someone is still employed and receiving sick pay) and the first two years after the start of a claim have been identified as the crucial periods for intervention to help people to return to work.<sup>ix</sup>

## Primary health conditions

Parents on incapacity benefits report a wide range of physical and mental health conditions. The most commonly reported single category was the ‘other’ category (23%) followed by musculoskeletal conditions (16%). The next most common conditions all relate to mental health (depression, stress or anxiety, and other mental health disorders). If we group these together, then mental health conditions is the most commonly reported category, though this still represents less than three in 10 parents on incapacity benefits (29%).

**Figure 2: What do you consider to be your primary health condition or disability?**  
(n=1,130)



Some recent commentary has suggested that rising demand for incapacity benefits is being driven by a 'sick note culture' of people feeling 'bluesy' in response to normal everyday pressures.<sup>x</sup> Our findings suggest a far more complicated picture, with only 8% of parent claimants reporting stress or anxiety to be their primary health condition.

#### **Case study: Fiona\***

Fiona is in her early 50s and lives with her husband and two children in rural Scotland. A full-time teacher for 25 years, Fiona had to give up work after she was diagnosed with an aggressive form of breast cancer in 2020. Her daughter, 16, and son, 12, both have additional needs and were diagnosed with autism around the same time. Her husband is a full-time carer at home, and also suffers from a bowel condition and depression.

Following surgery, chemotherapy and ongoing treatments, Fiona suffers with long-lasting side effects, including hand tremors, cognitive issues and memory problems. She initially took sick leave from work, but when that ended the family had to apply for benefits: *"I've had to learn and navigate a whole other world that I hadn't had any experience of, really."*

Fiona is currently receiving incapacity support through New Style Employment and Support Allowance, and the family is also claiming Universal Credit, Carers Allowance and disability benefits for all family members, receiving around £3,000 a month in total. Their financial situation, *"is stressful, it's precarious. We are incredibly careful...We don't drink, don't smoke, we don't eat out. We literally just try to make two ends meet, and I use the community larder"*.

For Fiona, the roughly £1,000 a month they get in disability benefits is vital to the household budget: *"...it would be terrifying without the disability benefits. We would be unable to live on Universal Credit...our mortgage is just over £1,000. Then, the Employment and Support Allowance adds about another £500 on, and those are the two main benefits, so we would have not a hope in hell of trying to keep things together [without the disability benefits]."*

The process for Universal Credit and ESA was reasonably straightforward, and Fiona had a good experience at her Work Capability Assessment. But her experience applying for disability benefits was very different: *"It's such a negative experience...she grilled me for over an hour...and I'd never felt worse about myself in my entire life than I felt at that moment with that woman there. I just was like, 'you've got to be kidding. My case was straightforward. I'm having chemotherapy. Look at me, you can see I'm ill'."*

Fiona hasn't ruled out returning to work in future, but she doesn't think she would be able to do a full-time job again. Alongside her health challenges, her children's additional needs and the family's rural location present further barriers. She thinks there needs to be more support and flexibility from employers: *"I've found when I was working that the general ethos tended to be that, if you were ill, it was viewed almost as a moral flaw in you, and there was very much a get-on-with-things [attitude]"*. She hopes to one day do some work in advocacy to help people facing similar situations.

**\*We've changed names in this case study to protect anonymity**

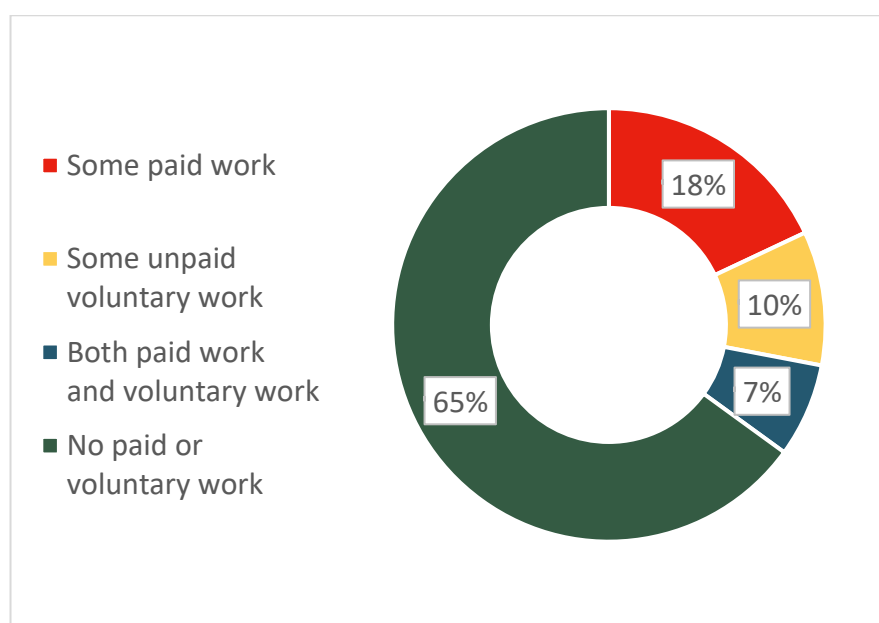
## 4. Work and health

### Current work status

Benefit rules allow for parents claiming incapacity benefits to take part in some paid work. ESA claimants can work for up to 16 hours a week as long as their earnings do not exceed £183.50 a week. UC LCWRA claimants are not restricted by the number of hours, but their UC payment will gradually taper away as earnings increase. LCWRA claimants benefit from a work allowance of £404 a month (£673 a month if they're not receiving housing support) before the taper begins to claw back their UC payment, equivalent to around eight (or 14) hours a week at the national living wage. We asked parents if they were in *any* form of paid or voluntary work.

- One in four parents on incapacity benefits are in some form of paid work (25%), including 7% who combine some paid work with voluntary work.
- The majority of parents are not in paid work (75%), though 10% are doing unpaid voluntary work.

Figure 3: Are you currently in any form of paid or voluntary work? (n = 1,130)



The rules on working while claiming incapacity benefits has attracted significant policy attention in recent years. Evidence presented by the Social Security Advisory Committee in 2022 highlighted how a fear of re-assessments has put some claimants off from attempting work.<sup>xi</sup> The previous Conservative government announced the 'Chance to Work Guarantee' in November 2023, promising that existing UC LCWRA and ESA claimants would not face a reassessment and could try work without fear of losing their incapacity benefit entitlements.<sup>xii</sup> This was a significant policy innovation that attracted surprisingly little attention at the time. The Labour Party similarly committed in its 2024 election manifesto to



giving “disabled people the confidence to start working without the fear of an immediate benefit reassessment if it does not work out”.<sup>xiii</sup> It is unclear if the Labour government will proceed with the Chance to Work Guarantee as planned in 2025 or if changes will be made, but it is right that policymakers are looking to address this well-known issue. Nevertheless, fear of reassessments is only one of many potential barriers faced by parents receiving incapacity benefits.

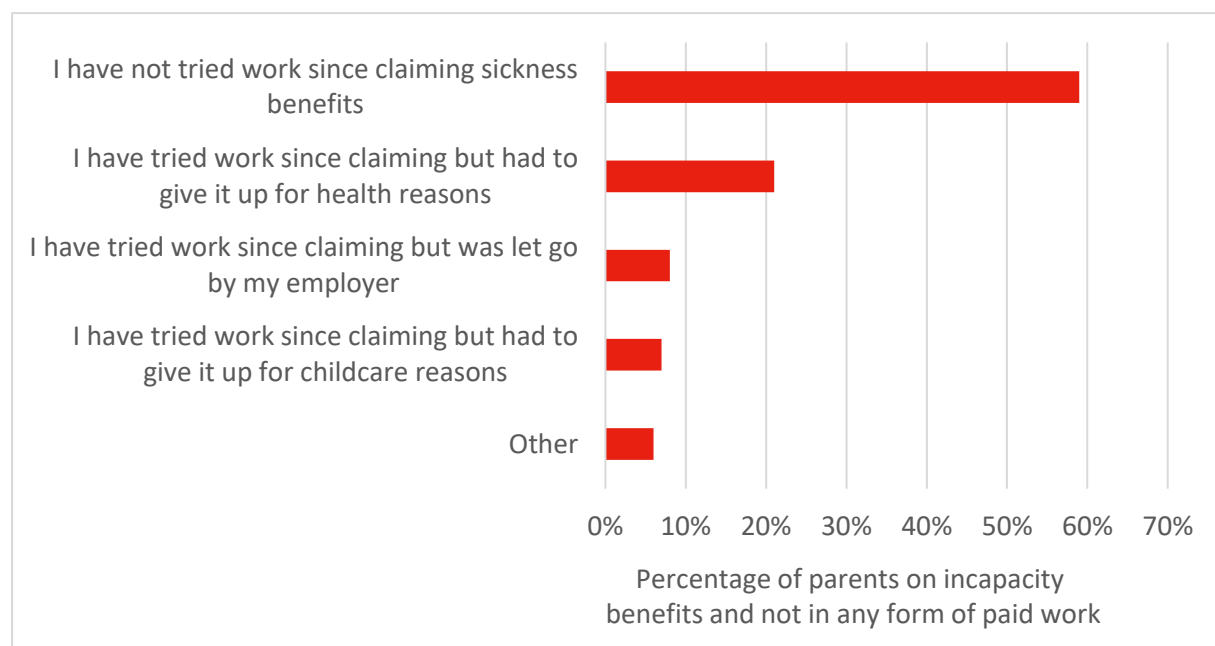
## Balancing paid work, ill-health and parenthood

The difficulty of balancing paid work and ill-health means that for many parents, even if they feel well enough to give work a go, it may not be sustainable for a variety of reasons. Health can fluctuate and worsen, jobs may not work out, employers may prove unwilling or unable to make the necessary adjustments. For parents – especially single parents – balancing the trio of paid work, ill-health and childcare responsibilities can prove impossible to sustain.

In our survey, among the 75% of parents who are **not currently in any form of paid work**:

- One in five have tried to engage in paid work since starting their claim but had to give it up for health reasons (21%).
- One in 12 say they tried work but were let go by their employer (8%).
- A similar proportion of parents engaged in work but had to give it up for childcare reasons (7%).
- Most out-of-work parents have not attempted work since starting their claim (59%).

**Figure 4: Since beginning your claim for sickness/incapacity benefits, have you attempted any form of paid work? (n = 848)**



## Closeness to paid work

Among the 75% of parents in our survey who are **not currently in paid work**:

- Four in 10 believe their health or disability rules out paid work completely (38%).
- A further 12% felt that balancing ill-health with their childcare responsibilities makes work impossible for the moment.
- Nearly a third said they can't work right now, but might be able to in the future if their health improves (32%).
- One in 10 parents say they could return to work right now, *if* they had the right support from the jobcentre and employers (10%).
- The remaining 8% of parents selected 'don't know'.

Among parents who are **not currently in paid work** and who **do not think their health or disability rules out paid work** completely:

- A quarter think they could be ready for paid work within the next 12 months (25%).
- Around one in seven think they could be ready for paid work within the next two years (14%) and a similar proportion said within the next five years (13%).
- The most common response however, from almost half of parents, was 'don't know' (49%). This uncertainty of simply not knowing if and when you will be well enough to return to work was also apparent in our interviews with parents.

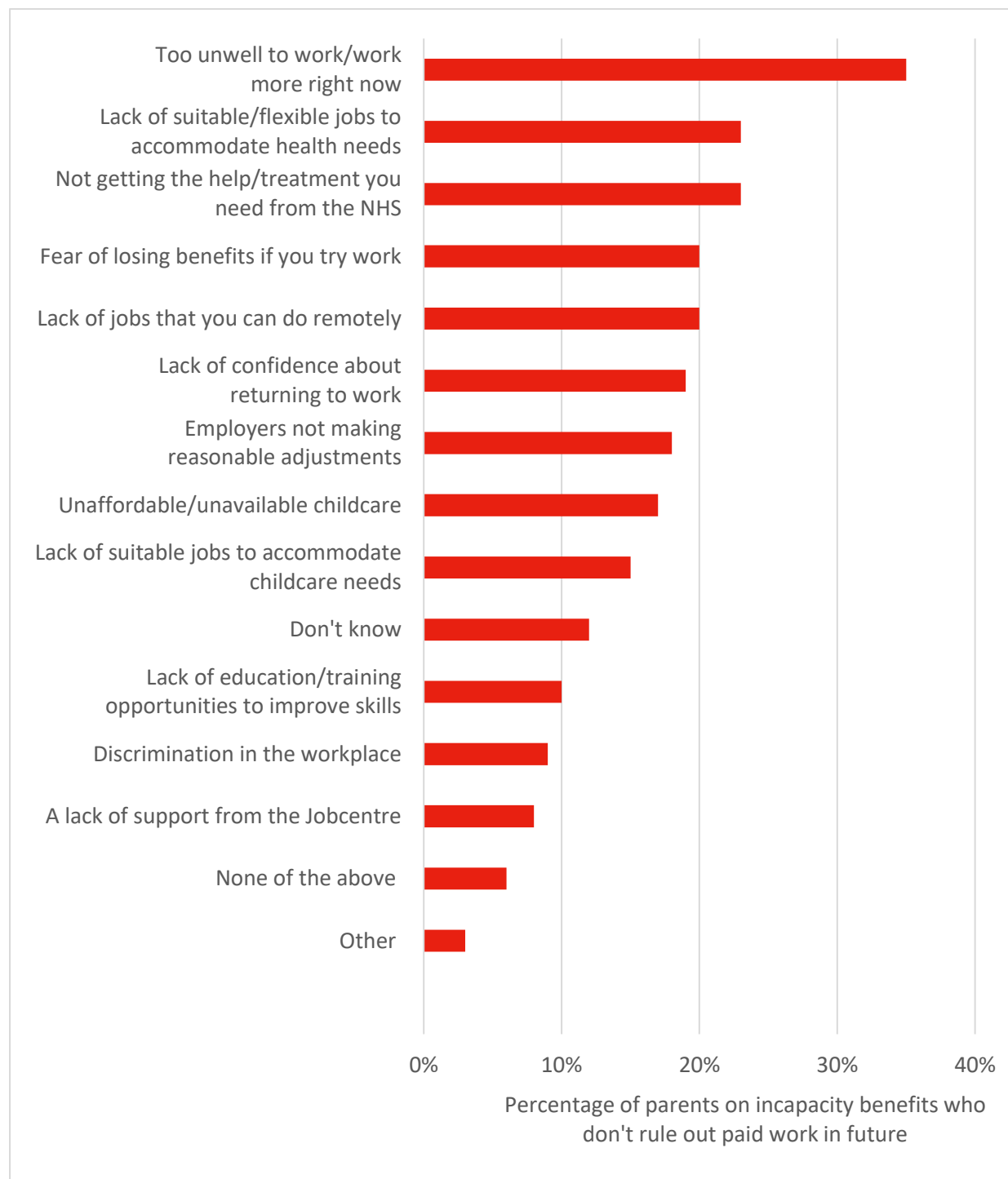
## Barriers to paid work

Parents receiving incapacity benefits face a wide range of barriers to engaging with the labour market, and often several at once. Among all parents we surveyed who did not feel like their health rules out paid work completely, the most prominent barriers were:

- Being too unwell to work or work more right now (35%).
- A lack of suitable or flexible jobs to accommodate their health needs (23%).
- Not getting the help or treatment they need from the NHS (23%).
- Fear of losing benefits if they try work (20%).
- A lack of jobs that they can do remotely (20%).

These barriers all relate to either immediate health needs, the capacity of the labour market to accommodate parents' health needs or the design of the benefits system. Unsurprisingly, it is these three groups – the NHS, employers and the DWP – that have the biggest role to play in addressing the UK's challenge of rising health-related inactivity.

**Figure 5: What, in your opinion, are the main barriers that currently prevent you from working or taking on more hours? Tick all that apply. (n = 796)**



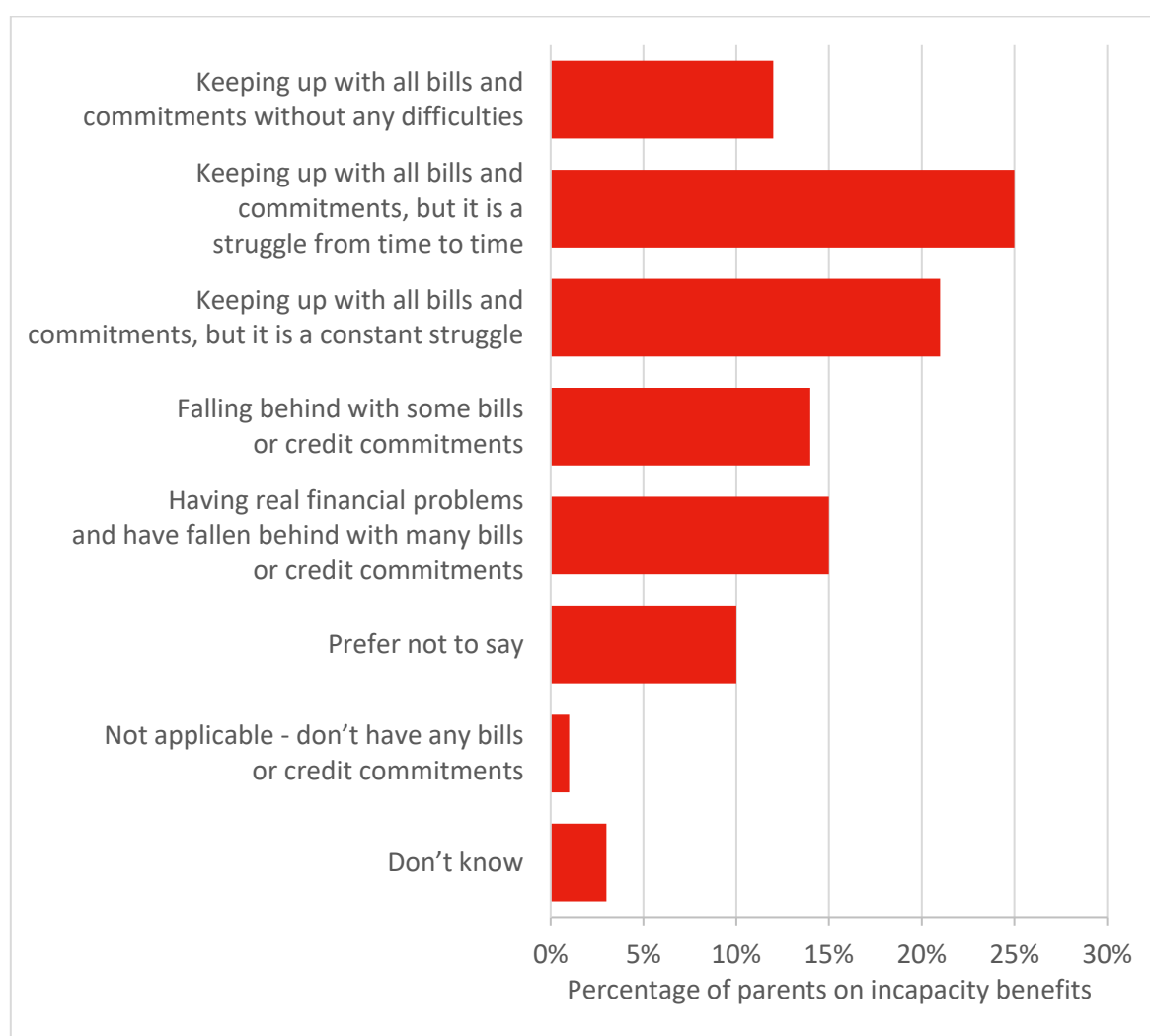
## 5. The impact on children and family life

Families who rely on incapacity benefits to support the household can be impacted in many ways by their situation. In our survey of parents, we asked a series of questions about their finances, impacts on their children and on their own emotional wellbeing.

### Financial situation

- Only 12% of parents receiving incapacity benefits are keeping up with all bills and credit commitments without any difficulties.
- Around half of parents are managing to stay on top of bills but are struggling to some degree (46%). For one-fifth of parents, it is a constant struggle (21%).
- Nearly three in 10 are falling behind on bills or credit commitments (29%). That includes one in seven parents who are experiencing severe financial problems, falling behind on *many* bills or credit commitments (15%).

**Figure 6: How well are you keeping up with bills and credit commitments at the moment?**  
(n = 1,130)



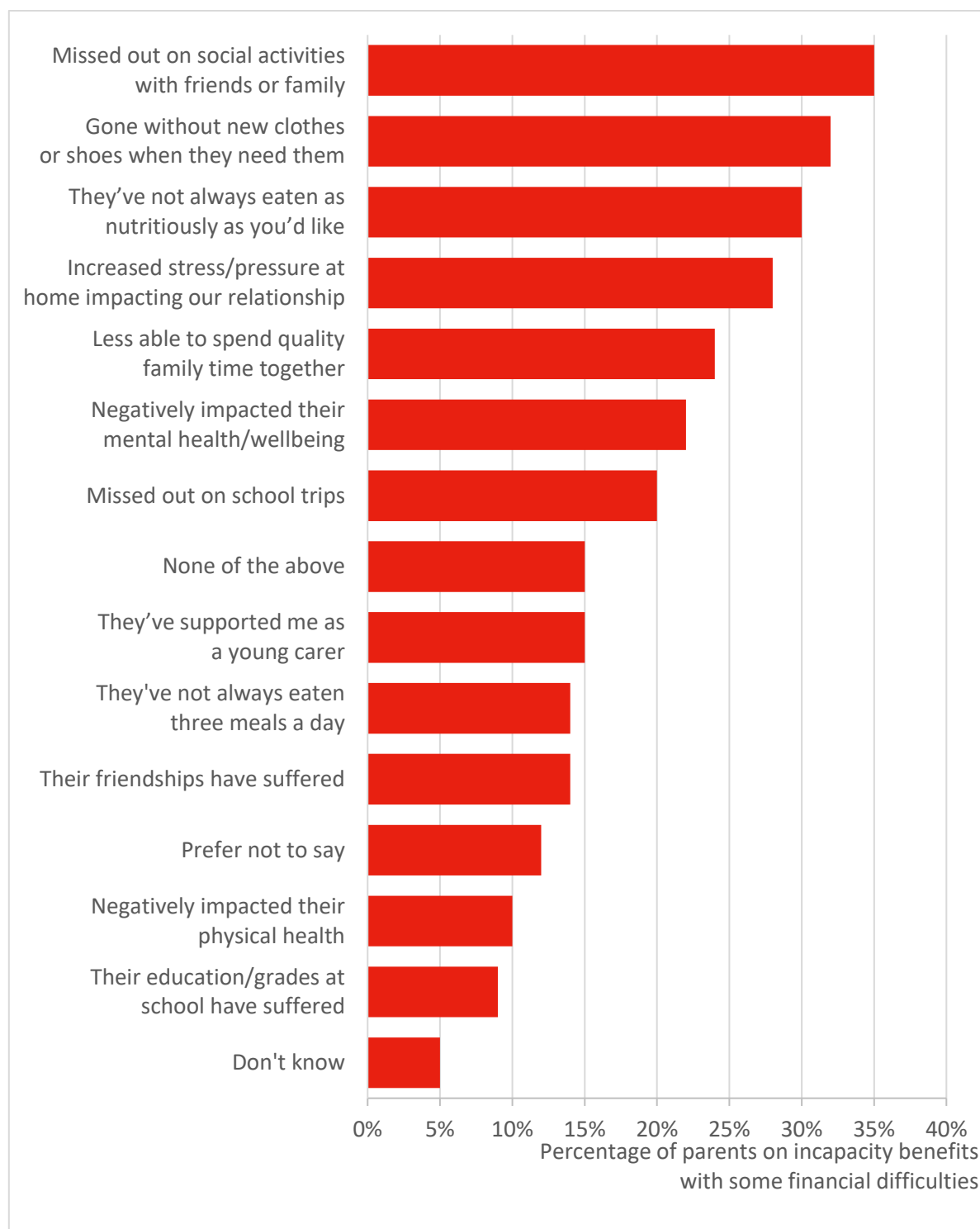
## Impact on children

We then asked parents who indicated they were or might be experiencing some financial difficulties whether their children had experienced any negative impacts as a result.

- Over a third of parents felt their child had missed out on social activities with friends or family (35%) and one in five said they had missed out on school trips (20%).
- A third said their child had gone without new clothes or shoes when they needed them (32%).
- Three in 10 parents said their child had not always eaten as nutritiously as they would like (30%) and one in seven said their child had not always eaten three meals a day (14%).
- 28% felt that increased the stress at home had impacted their relationship with their child, and one in five felt their financial situation had negatively impacted their child's mental health or wellbeing (22%).



**Figure 7: Which of the following impacts, if any, have your financial difficulties had on any of your children? Tick all that apply. (n=993)**

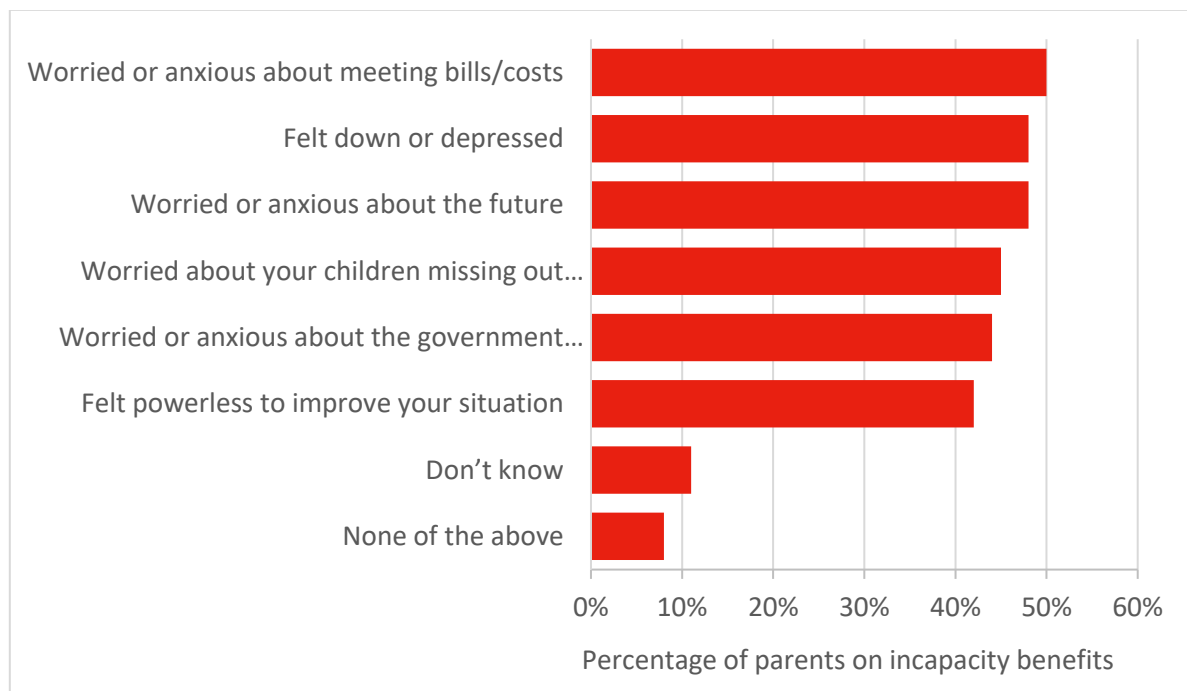


## Emotional impact on parents

Finally, we asked parents how their work and health situation had affected their own emotional wellbeing in the past month. We found that large proportions of parent claimants experience negative emotional impacts due to their situation:

- Half of parents receiving incapacity benefits felt worried or anxious about meeting bills or costs (50%) in the past month.
- Nearly half of parents felt down or depressed in the past month (48%).
- More than four in 10 worried about the government making changes to their benefits (44%) and about their children missing out on things due to their financial situation (45%).

**Figure 8: To what extent, if at all, has your work and health situation impacted you emotionally in the past month? Tick all that apply. (n=1,130)**



#### **Case study: Clare\***

Clare is in her early 40s and lives in the East of England region with her husband and two daughters, 17 and 14, and son, 13. Her husband works full-time as a delivery driver. Clare suffers from a long-term condition caused by degeneration of the discs in her lumbar spine that can cause extreme back and nerve pain. She had an operation in 2008 which helped for a few years, but she suffered a really bad episode just before the pandemic hit, and was unable to get treatment for it at the time.

Alongside her husband's wages, the family receives Universal Credit and Clare is also claiming Personal Independence Payment, which mostly goes into the household budget. Clare budgets carefully and feels like they're managing financially, but she worries about occasions like Christmas and unexpected expenses, like something going wrong with the car: *"I'm constantly sitting down with bits of paper and looking at what we've got left to pay out over the month and what we're likely to have left"*.

Clare was a stay-at-home mum for much of her children's early years, but also felt nervous about working due to her health condition: *"[I was] nervous for a long time of getting a*

*job because of how unpredictable my back can be... I'm not someone who likes calling in sick, and I don't like to let people down. I always felt very unreliable, if that makes sense".*

In 2021 she felt able to try work, and got a job as a sales assistant in retail which she really enjoyed, working 20 hours a week on average. Clare's issues flared up again earlier this year, and she had to turn down a new job that she had been offered closer to home. She is currently on the waiting list to have an operation, but doesn't know when this will be. She hopes to be back at work within the next year if her recovery goes well.

**\*We've changed names in this case study to protect anonymity**

## 6. Interactions with the DWP and Jobcentre Plus

The DWP reports high customer satisfaction ratings annually, with 85% of claimants 'satisfied with DWP services overall' in 2023/24.<sup>xiv</sup> However, independent evidence presents a much more complicated story.

Numerous reports have highlighted issues with how the DWP interacts with and supports claimants, including a survey from the mental health charity Mind, multiple inquiries by the National Audit Office and within an official DWP evaluation of work coach support.<sup>xv</sup> A 2024 survey of DWP staff launched by the Work and Pensions Select Committee found sizeable proportions of staff surveyed felt that they were not adequately trained or prepared to support the safeguarding of vulnerable claimants.<sup>xvi</sup>

### How do incapacity benefit claimants interact with the DWP or jobcentre?

In general, claimants who have undergone a Work Capability Assessment (WCA) and been awarded UC LCWRA or the highest rate of ESA (ESA Support Group) will not have work search conditions that require regular visits to the jobcentre. In practice, it can be a long and difficult journey to reach that point, and claimants may still be subject to conditionality requirements while waiting for their WCA. Many will still have contact with the DWP after their WCA decision has determined they are unable to work in order to resolve administrative issues or notify them of a change of circumstances, during reassessment periods, if they are in paid work or if they are seeking employment support from a work coach or Disability Employment Adviser.

Claimants who have been assessed as having a lower level of support needs – the Limited Capability for Work group (LCW) in UC or the Work Related Activity Group (WRAG) in ESA – are required to undertake periodic 'work-focused interviews' in preparation for returning to work in future.

## Too many parents have negative experiences with the DWP

We asked parents to what extent they agreed with a set of statements about their interactions with the DWP and Jobcentre Plus. The findings paint a distinctly mixed picture.

Sizeable minorities of parents report positive experiences – feeling listened to, feeling like their circumstances are taken into account and not feeling pressured into work before they are ready. Around one in five consistently take a neutral view. But a significant proportion of parents report explicitly negative interactions:

- A quarter of parents do not feel listened to (26%).
- A third do not feel like DWP staff take their circumstances into account (34%) and three in 10 have felt pressured to enter work before they are ready (30%).
- Almost a quarter report feeling intimidated or harassed by DWP staff (24%).

	Net agree	Neither agree/disagree	Net disagree	NA
I feel listened to.	32%	22%	26%	20%
I feel they take my personal circumstances into account.	30%	18%	34%	18%
I've been offered help with moving into work when I'm ready.	24%	19%	25%	33%
I've been given useful information about voluntary employment programmes or schemes that I could take part in.	20%	20%	28%	32%
I feel pressured to enter work before I am ready.	30%	18%	24%	28%
I feel intimidated or harassed.	24%	17%	33%	27%

We also asked the parents we surveyed to describe in their own words how they had interacted with the DWP, the impact it had on them and their chances of moving into paid work in the future. A very similar picture emerged from these qualitative responses. A significant number of parents reported having a positive experience, finding staff helpful, supportive or understanding:



*“DWP have been awesome so far, as I have been unable to work due to having a major operation. I get a phone call from DWP once every few weeks to check progress.”*

*“I've had pleasant experiences, I've been supported really well. I think when I'm ready, I'll be supported even more into paid work.”*

*“Very helpful during a difficult time having treatment for cancer. Had limited follow up since initial claim, but feel this is appropriate as I have a job I will be returning too as soon as I am recovered enough.”*

Overall, however, respondents to our survey were markedly more likely to report a negative experience. Many highlighted the emotional impact their interactions with the DWP had on

them. Words like **stressful**, **degrading**, **intimidating** and **humiliating** came up repeatedly. Others described their experiences as lacking empathy and compassion, or of feeling like they were being judged and, in some cases not believed, by DWP staff. For some, these interactions caused their health to deteriorate further.

“

*“I have found it demoralising and feel like I am being treated like a criminal. Left me feeling suicidal and had a major adverse effect on my mental health.”*

*“I like my work coach but I often feel pressured to go to work when I know in myself I am not ready.”*

*“They are too pushy when chronic health conditions are concerned. If I have a period of improvement in my health, they push too much to get me back into work which causes health relapses because I cannot take the necessary time to get back to normal.”*

## The quality of interactions is highly variable

In the qualitative responses, parents’ reported experiences varied widely across different DWP functions, sites and even between individual staff members within jobcentres.

“

*“Very mixed. Very dependent on the person we see.”*

*“Interactions with DWP are very irregular. Depending on who you manage to speak to you either get helped with abundance or cut off and treated terribly with huge disrespect.”*

*“In [the] jobcentre they were great and helpful, but trying to claim PIP has been stressful.”*

This ‘pot luck’ quality was characteristic of parents’ interactions with the DWP, and suggests the department has struggled to embed a consistently supportive and customer-focused ethos among its workforce. For instance, a significant number of respondents to our survey felt the staff they dealt with were under-trained, lacked experience and had no understanding of their health conditions. This was particularly true of parents with fluctuating, less visible or less widely understood conditions.

“

*“On the whole, the jobcentre has not been very helpful as I am suffering from chronic fatigue and mental health issues. The staff are not qualified to deal with these things, in my experience.”*

*“No understanding of my health condition and how it fluctuates.”*

*“DWP don’t seem to understand the seriousness of my condition or look at my personal situation. Without an understanding of the individual, they are going to cause damage by*



*forcing me back into work before I am ready and then I will become more unwell, won't be able to work and will be a greater burden on the NHS."*

Other issues frequently highlighted by parents included poor, or incorrect, communication of information by DWP staff, accessibility issues at the jobcentre, confusing and complex processes and administrative problems and errors that take a long time to be resolved.

## **Many parents do not feel adequately supported to return to work**

Almost four in 10 out-of-work parents on incapacity benefits believe their health condition or disability rules out paid work completely, and this was reflected in many of the qualitative responses. For others however, there was clear frustration at the inadequacy of the support on offer from the DWP for those who want to explore how they might return to work.

**“***"No interaction, no support or advice on how to move into paid work in the future."*

*"I can't voluntarily speak to them about things without being judged and the fear of repercussions, despite just needing an honest conversation around advice on getting back to work and how this will impact me not only financially but also health wise."*

*"I felt that as soon as they saw my disability, they wrote me off. I've had no contact since being assessed as LCWRA."*

As well as a general lack of engagement on support options, parents highlighted a number of specific issues, including being unable to access specialist advice, a lack of training opportunities and limited support with alternative routes back into paid work, like self-employment.

**“***"I did have the support of a health and work advisor, who did support me better, but that was for a limited time only and funded by the EU, so no longer available anyway."*

*"I claim 'limited capability for work' but I am trying to get back in to work. They haven't put pressure on me and they are helpful where they can be I suppose, but what I really need is retraining to have any chance of working again. Help in this regard seems hard to come by."*

*"Almost non-existent. They have only ever contacted when [they] wanted something. I'm not able to work in a workplace setting but am attempting self-employment from home. I am not gainfully employed so receive no interest, support or encouragement. That is wrong. I could become gainfully self-employed with the right assistance and mentoring."*

Even where specific support programmes may exist, like the Work and Health Programme, our findings suggest that this is not being explored with claimants. Only 16% of parents

responding to the survey agreed that they had been given useful information about voluntary employment programmes that they could take part in.

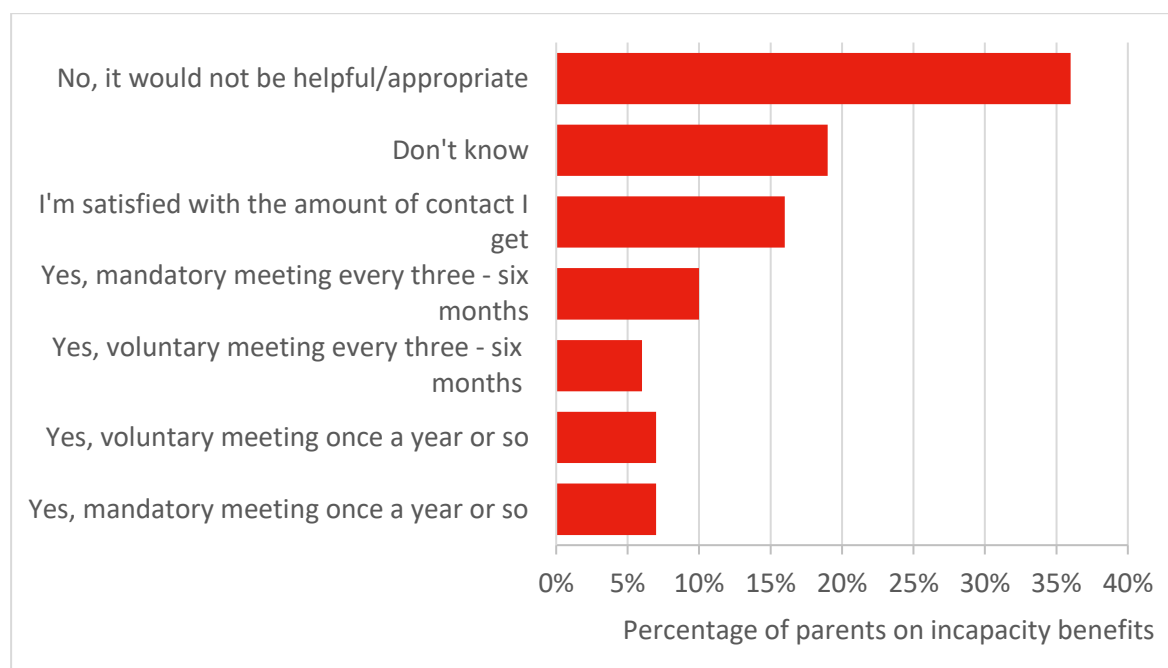
## **Increased contact is no substitute for high quality support**

One option that DWP could explore, and which has featured in recent discussions around reform of the Work Capability Assessment, would be to increase contact between incapacity benefit claimants and work coaches in jobcentres who could discuss their barriers and, where appropriate, support them to re-engage with the labour market.

We asked parents whether they could benefit from more frequent contact from the DWP or jobcentre. We presented this as a choice of either a mandatory or voluntary meeting, one to four times a year, to discuss how they might return to work in future and any support needs.

We did not find strong support for either option. In total, nearly one in three expressed support for some form of meeting (30%). Interestingly, there was little difference in expressed support for a mandatory meeting (17%) versus a voluntary meeting (13%). The most common response was that it would not be helpful or appropriate (36%). A further 19% did not know and 16% were satisfied by the amount of contact they receive.

**Figure 9: Do you think you could benefit from more frequent contact from DWP/the jobcentre to discuss how you might return to work in the future and how they can help with any support needs? (n = 1,130)**



One possible interpretation for this relatively lukewarm support, and supported by our wider findings, is that parents feel there is little to be gained from increasing contact. If parents already feel the support they have received has been inadequate, that they have not been listened to, that staff are under-trained and do not understand their condition, they may feel there is little point in sitting through more meetings. By itself, increasing the intensity of contact is meaningless without also addressing the quality of the experience.

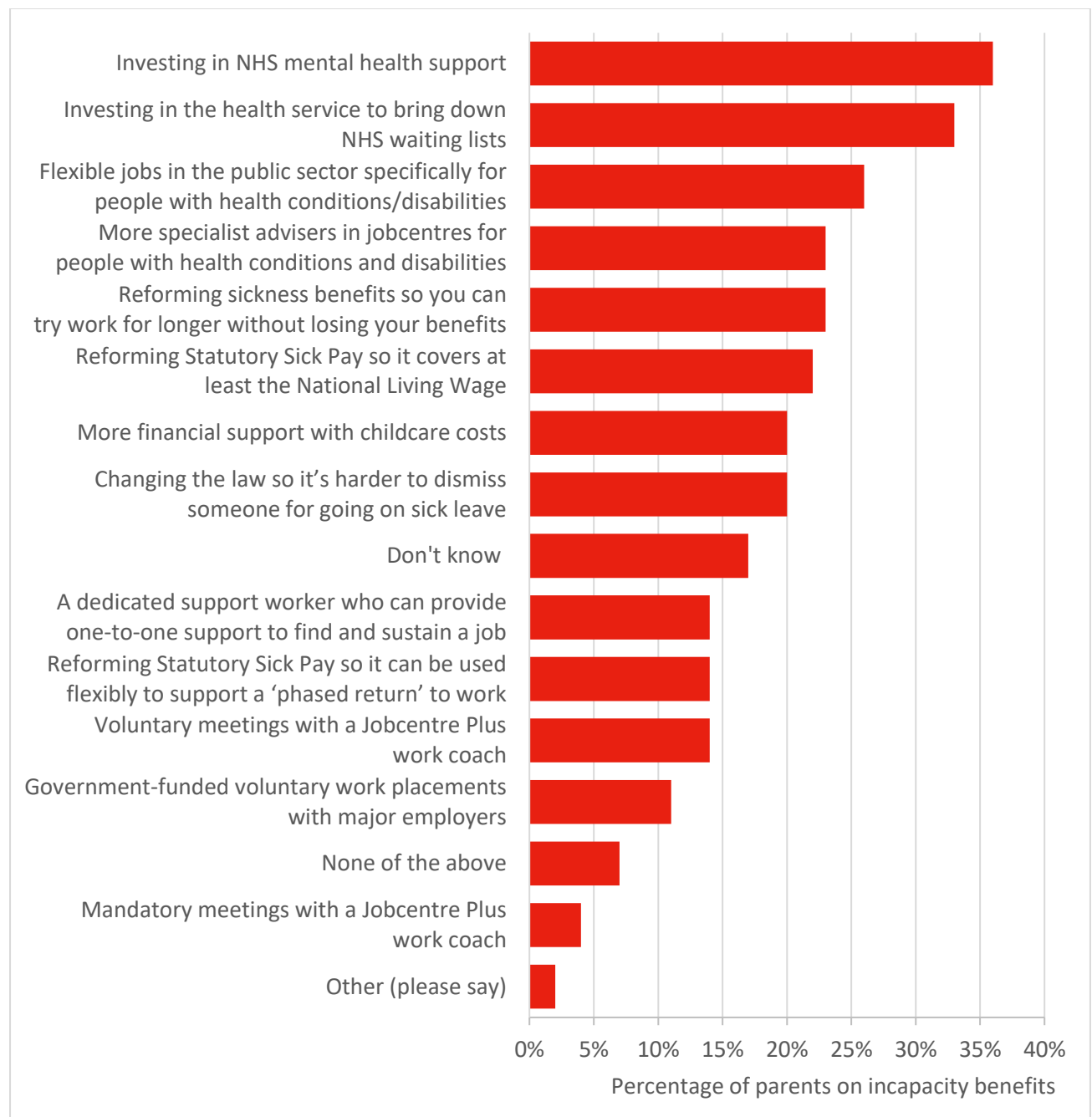
## 7. Parents' views on possible solutions

Our final survey question gathered parents' views on possible policy options the government might look to in its response to the post-pandemic rise in health-related inactivity and increased demand for incapacity benefits.

- A third of parents receiving incapacity benefits think that bringing down NHS waiting lists could help them to return to work (33%). A similar proportion of parents also highlighted the need for specific investment to be targeted at NHS mental health services (36%). This contrasts with analysis from the OBR that previously found a weak link between NHS waiting lists and rising health-related inactivity.<sup>xvii</sup>
- A quarter of parents called for a stronger role for the public sector to create flexible jobs specifically for people with health conditions and disabilities (26%).
- Almost a quarter of parents felt that more specialist advisers in jobcentres would be helpful (23%) in returning them to work.

- Similar to the previous survey question, there was very little support for imposing mandatory meetings with work coaches (4%). Within this question however, we found that respondents were around three times more supportive of voluntary meetings compared to mandatory ones (14%).

**Figure 10: The government has said it wants to introduce changes to help people who are currently 'economically inactive' to return to work, if they are able to do so. Which of the following hypothetical changes do you think could be most effective for your situation? Tick all that apply. (n = 1,130)**



## 8. Sick and tired: life for parents on incapacity benefits

We interviewed seven parents in receipt of incapacity benefits in August and September 2024. Participants were broadly distributed geographically, with four participants from three English regions (south-east, East of England and north-west), two participants from Scotland and one from Wales. Parents ranged in age from their mid-30s to mid-50s. The children in these families ranged in age from three to 18. Women were somewhat overrepresented (five female participants, two male participants). Interviews were conducted online or over the phone, transcribed and analysed thematically.

Five main themes were identified:

- Parents' health is their biggest barrier to working right now, but is often not the only practical challenge they face.
- Most parents want to work, but need support to do so.
- Support from the DWP is often lacking and is undermined by the compliance culture in jobcentres and assessment processes.
- There is scepticism about how supportive employers can be.
- Life on incapacity benefits is often precarious and hard.

### 1. Parents' health is their biggest barrier to working right now, but is often not the only practical challenge they face

The parents we interviewed suffered from a variety of physical and mental health problems, including cancer, spine and nerve conditions, chronic inflammation and clinical depression. Most were dealing with multiple conditions, and more than half had a partner or child with their own significant health challenges. The ongoing nature of their health challenges and the uncertainty that creates was the most immediate and prominent barrier to work among participants. Several described long waits or difficulties they had experienced in accessing timely treatment on the NHS. Some parents explained how their health conditions can fluctuate unpredictably, which makes holding down a job especially difficult.



*"I saw my consultant last month, and we discussed the MRI scan results. He's basically said that he'll put me on the waiting list. I did say to him, how long is the waiting list, but they're quite vague, aren't they?"*

(A mum, East of England, three children aged 13-17)

*"I had a neurology appointment yesterday that took four years to get and, basically, they want to put me on medications that I'm incredibly unhappy about going on"*

(A dad, south-east, two children aged three and 14)

*"I think the NHS just won't do things off the bat, they have to kind of do it at the last moment. So, I think they're just waiting for it to get to that point, but I'm pretty sure it's at*



*that point now. It's pretty bad."*

(A mum, East of England, three children aged 15-18)

Alongside their health, parents discussed other aspects of their lives that make work more difficult. Transport issues were highlighted as a major challenge both in terms of the expense incurred and the lack of reliable public transport, especially for parents living rurally.



*"I'm not going to be able to walk to and from a job every day, or even a couple of days a week...I would have to get taxis, otherwise I'd just be exhausted and in pain by the time I even got to work"*

(A mum, East of England, three children aged 15-18)

*"The last bus is 6:30pm, but if you miss that, you've got to wait until about 10:30pm for the next bus after that...I've looked at some jobs that I could have done that were office-based but didn't finish until 6:30pm, so I would never have got home...I think there should be better transport. There's got to be this joined-up approach to getting somebody into work."*

(A dad, Scotland, one child aged 17)

Some of the parents had caring responsibilities for children with their own physical and mental health issues that they were trying to access treatment for, or additional needs such as autism, that further complicated their prospects of returning to work in the near future.



*"Both our children receive the highest rate of care, which means they require care through the night and the day...I can't imagine actually how we would manage to go back to a situation with me not at home."*

(A mum, Scotland, two children aged 12 and 16)

## **2. Most parents want to work, but need support to do so**

All of the parents interviewed had been in paid work in the past, and most had experience of full-time work. Participants had a diverse range of career experiences, including a teacher of 25 years, an ophthalmologist, an armed forces veteran, a groundworker, a charity fundraiser and a retail worker. One participant was in formal paid work, working around 15 hours a month, while some others were bringing in small bits of additional income on an ad-hoc basis. The majority of participants talked about wanting to return to work in future and recognised the value that being in work can bring, but mostly felt unable to say when they would be in a position to work again or increase their hours. Participants largely felt that part-time work was a more realistic prospect for them.

“

*“I would love to return to work, I would. I'm so bored. I know I'd only be able to do part-time, I wouldn't be able to manage full-time, but just 16 hours a week would be ideal, get me out of the house a couple of days a week.”*

(A mum, East of England, three children aged 15-18)

*“It's something I desperately want to do. I'd love to go back to work today. I miss it.”*

(A dad, south-east, two children aged three and 14)

*“I'm of the thingy that if you can work, you should work. It kind of gives me a boost to be at work, it helps me actually, that I don't just sit in the house and feel negative.”*

(A dad, Scotland, one child aged 17)

Despite a *desire* to work, parents recognised they need support to do so, which can be difficult to access. One parent was disappointed to discover an employment support scheme for people with mental health problems was no longer operating by the time she heard about it. This parent felt that having access to a scheme that provided one-to-one support, in a compassionate and understanding way, would help to build their confidence for work.

“

*“It's not because I want to sit at home on benefits watching daytime television. I do not want those things. I want a job, but I need support with that. I need maybe to talk to someone who could understand what it feels like to go into a strange place full of strange people, all the dynamics that go on.”*

*“Someone who I could honestly say to, you know, 'Actually, I'm not enjoying this. So and so is not very nice.' And they could, instead of dismiss me and say, 'Oh, just get on with it,' they could be understanding and supportive.”* (A mum, Wales, one child aged 14)

### **3. Support from the DWP is often lacking and is undermined by the compliance culture in jobcentres and assessment processes**

Like the parents in our survey, interview participants had mixed experiences of navigating the benefits system and jobcentre. Several parents felt that they had not been well supported by work coaches, particularly while waiting for their assessment decision. Since being signed off, parents had mostly received minimal contact from the jobcentre. In some cases, this was welcomed, but in others, parents felt they could be doing more.

“

*“I definitely think there's something that they could do. I think I'd be somebody prime for their support, somebody that is willing and eager and qualified to some degree. Yes, I've got some limitations, but that's their job, isn't it, to work around those obstacles.”* (A mum, East of England, three children aged 15-18)

One parent who had previously worked an intensive manual labour job that contributed to his health issues recognised that he would need to do something different in the future. He was frustrated to find that retraining opportunities offered by the jobcentre were not open to UC LCWRA claimants:

*“Now, why can't I do the welding course? Why can't I get the digger tickets from them? Why am I being excluded from this group of people that are able to do it, when you're trying to help people get back to work? I couldn't do the manual labour, but I can do the other bits, but because of the money, I can't afford to do the courses to retrain to do that, to try and make myself more employable to prospective employers.”*

(A dad, south-east, two children aged three and 14)

Some participants recalled feeling like they were not believed by DWP staff and felt they had been badly served by the conditionality and sanctions regime earlier in their journey. One parent had to engage in 30 hours a week of “pointless” job searching while waiting for their Work Capability Assessment decision or face being sanctioned, while being denied any meaningful employment support. His work requirements were only reduced after a charity that supports armed forces veterans put him in touch with an Armed Forces Champion at the jobcentre. Another parent was sanctioned because of issues they had uploading their fit notes from the GP because they couldn't afford the data on their phone and were in too much pain to travel to somewhere with free wi-fi.

“

*“It's like okay, is there anybody I can talk to about the jobcentre supporting me into work? They're going, 'No.' I went, 'All right, okay. What do I do? Do I look for jobs then?' At one point, I had to look for 30 hours of jobs each week until it was heading towards the medical outcome. I was like, well, it's a pointless time, [and they said] 'Well, you have to job search, or you'll get sanctioned for it'.”*

(A dad, Scotland, one child aged 17)

#### **4. There is scepticism about how supportive employers can be**

Participants expressed real scepticism about the willingness and capacity of employers to accommodate their needs and provide enough flexibility for them to return to work. There was a feeling that employers are ultimately driven by business interests that may not be compatible with the needs of potential employees with health conditions and disabilities.

“

*“If I were to return to work and say, 'Well, I have these particular needs, and I won't always be able to remember things,' I'm not sure, realistically, what anybody could do, given the fact that you, essentially, have to be well to work. I suppose at the end of the day, there's only a limited amount of flexibility that employers can give you.”*

(A mum, Scotland, two children aged 12 and 16)

One parent recalled attending an interview at a leading supermarket chain, where the hiring manager told them they were not up to the job because they would not be able to do certain physical tasks, like stacking shelves, even though the role was only advertised as a checkout position. Other parents had avoided paid work in the past because they did not want to “let people down” or had put their energy into voluntary work because “there's no pressure, and there's no expectation”.



*“At the end of the day, they want somebody that's fit and healthy, that can do the job, which can earn them loads of money... Employers don't want somebody that's got issues, because it impacts their profits and the money that they make. Although they have to tick boxes themselves to say that they've given people like me the opportunity, you're never the right candidate for the job.”*

(A dad, south-east, two children aged three and 14)

## 5. Life on incapacity benefits is often precarious and hard

All of the interview participants were facing financial pressures due to their situations. In some cases, this was severe. One parent was living in a homeless hostel after separating from his partner earlier this year. Several were using food banks, struggling with essential bills and dealing with large debts they were unable to pay. Even where parents felt they were managing financially, this required careful budgeting with little room for treats or luxuries and was accompanied by frequent money worries.



*“I use foodbanks. I try to eat just two meals a day rather than three. The local Reverend has an unofficial foodbank, and sometimes he has food vouchers for Aldi, so when we're desperate for stuff we ask the local Reverend. No, we don't have money. Forget new clothes. We don't have money for anything.”*

(A mum, north-west, two children aged 10 and 13)

*“I mean, when you're worrying about things like, 'Oh, my lad needs a new pair of shoes for school, where the hell am I going to get the money for that?' And then it's like, well, he's having to wear shoes that are too tight for his feet, he's going to end up with ruined feet, and it's like, when you have kids, you want the very best for them, and you feel like you're failing them.”*

(A mum, Wales, one child aged 14)

In addition to incapacity benefits, most of the participants were also receiving disability benefits. While disability benefits are ostensibly intended to support with the extra costs of having a disability, in practice, participants largely used this additional income to meet their everyday household costs and to pay essential bills. This additional income was seen as vital to the family.

“

*“We would be absolutely – well, we would be homeless, really, without them”*

(Female participant, Scotland, two children aged 12 and 16)

One parent, who suffers from clinical depression, had previously received PIP but lost their entitlement after a reassessment. They felt that the fact they had done a part-time education course in counselling, which led to some limited and ad-hoc paid work opportunities, was used against them at their PIP reassessment. They explained the impact this had on the family:

“

*“It's impacted us a lot. I mean, it was about £400 a month that we lost. And, of course, it's the impact on your mental health which also has an impact on your physical health because the two are very much intertwined. It affects your family. It doesn't just affect me, it affects my partner, it affects my son, you know... It feels like we're always fighting, fighting for some few pennies, you know?”*

(Female participant, Wales, one child aged 14)

Parents repeatedly emphasised how they would put the needs of their children first, over and above their own needs and wellbeing. Nevertheless, parents were very aware of the ways in which their children inevitably missed out on things that other children have, like not being able to go on school trips or participate in social activities, go for meals together, take family day trips or holidays or afford new clothes.

“

*“Being able to go and do anything with the kids is generally out the window and that now. You have to save for months just to go out for a day.”*

(Male participant, south-east, two children aged three and 14)

*“It sounds awful, but our children, they don't go out... for my son to go trampolining, it's £15, and he would require somebody with him. Even if he went for one hour every week, it's £120. We can't do that...So I would say the first thing to go, really, are the social things.”*

(Female participant, Scotland, two children aged 12 and 16)

## 9. Implications for government policy

The findings in this report suggest that there's a significant group of parents who could be supported to re-engage with the labour market, but **this is highly conditional on them getting the support and the flexibility that they need to find and sustain work**. Many parents will be sceptical about what is possible in practice due to the extent of the barriers they face, their interactions to date with the institutions and systems responsible for benefit

delivery and employment support, and their perceptions of the capacity and willingness of employers and workplaces to accommodate their needs.

The implications of these findings for current and future policy design can be broadly summarised under three headings: parents' interactions with the DWP and Jobcentre Plus, prospects for supporting parents receiving incapacity benefits into work, and our understanding of what life is like for families relying on incapacity benefits.



*“Let's look at a more compassionate system. I think if they're a bit more easier going and helpful, that would shock a lot of people if they turned around and said, 'Is there anything we can do to help you?' and actually mean it. I've never heard that in the jobcentre”*

(Male participant, Scotland, one child aged 17)

## Parents' interactions with the DWP and Jobcentre Plus

The DWP is the second largest government department and employs over 80,000 staff – including 16,000 work coaches working across more than 600 Jobcentre Plus sites. **The DWP frontline is also much smaller today than it was a decade ago while demand for its services has only increased.**<sup>xviii</sup> Despite a big recruitment drive during the pandemic, the number of work coaches has since fallen back and is down by 37% compared to 2014.<sup>xix</sup> Given these pressures, and the scale of such a large and complex organisation, it is perhaps unsurprising that experiences vary so wildly.

Nevertheless, the prevalence of negative experiences among parents receiving incapacity benefits is striking. These are some of the most vulnerable people that will interact with the system and far too many do not feel listened to, understood, treated with respect or adequately supported. Two features of the current system are particularly important for understanding these findings.

**The current Jobcentre Plus model is based on generalist support provided by work coaches with mixed caseloads.** Under this model, all work coaches are expected to have the skills and knowledge to support all claimants regardless of their circumstances. This reflects a conscious decision by the department to move away from specialist roles under earlier programmes towards more generalist provision. While Disability Employment Advisers (DEAs) were retained under the work coach model, their primary role has been upskilling work coaches to better support claimants with disabilities and health conditions, unlike the previous system where they would have their own caseloads.<sup>xx</sup> The DEA role is valued by many disabled people and disability organisations, but there were only 750 of them in October 2023, equivalent to 1.2 per jobcentre and substantially fewer than the 1,115 advisers that were promised in 2021.<sup>xxi</sup> Some organisations have also highlighted concerns about the adequacy of the training DEAs receive: Sense found that 46% of jobseekers with

complex disabilities did not feel supported by their DEA.<sup>xxii</sup> A lack of highly trained specialist support and advice that is readily accessible from the outset and tailored to the individual is a significant shortcoming of the current system.

**The repeated toughening and intensification of the conditionality and sanctions regime and the wider proliferation of a ‘compliance culture’ within jobcentres has also undoubtedly contributed to parents’ negative experiences.** Though incapacity benefit claimants are largely excluded from the conditionality and sanctions regime, many will have been exposed to its hard edges during their early interactions with the system, while waiting for their assessment, during a reassessment or following a change in circumstances. Moreover, the wider cultural effects of these policy choices are ever present. The rules and norms that make up the organisational culture of the DWP frontline will be defined, in large part, by the long-term policy direction set by ministers. In recent years the DWP’s excessive focus on the monitoring of claimants and enforcing compliance has damaged trust with disabled people and absorbed resources that could have been better deployed to provide meaningful employment support.<sup>xxiii</sup>

## Supporting parents on incapacity benefits toward work

The NHS, DWP, employers, local government and private and voluntary sector providers all have central roles to play in developing joined-up plans for supporting parents who could re-engage with the labour market with the right support. **But measures to improve health or employability alone will likely not be enough**, with action needed on other areas – including transport, childcare and social care – to address other practical barriers that limit parents’ availability for work.

While a significant proportion of parents with health conditions and disabilities report positive experiences with the DWP and Jobcentre Plus, it is clear that too often, this relationship is not functioning well. Some parents who would benefit from help are not being offered it, while others feel pressurised and misunderstood. Simply increasing the frequency of contact between work coaches and incapacity claimants does not by itself constitute meaningful support. **The current jobcentre model is not working for these claimants and a different approach is required.**

A different approach would see **all engagement with people who present at the jobcentre with health conditions or disabilities that affect their capacity for work led by highly trained specialist advisors**, not generalist work coaches. These trained specialists would maintain their own caseloads and provide a consistent point of contact with their clients. Incapacity claimants would be invited to attend periodic voluntary meetings to discuss any support needs. This would include making voluntary referrals to well-evidenced personalised employment support programmes, a skills and training offer, support with transitioning to self-employment, childcare and Access to Work support. Specialists would be deeply embedded in local areas, working in close partnership with local government, Integrated



Care Systems and service providers to maintain a detailed understanding of the local employment support landscape. This will be particularly important under the more devolved system that the government intends to move towards.

**Above all, policymakers should proceed carefully.** There is evidence that previous attempts at reform unintentionally contributed to rising demand for incapacity and disability benefits. In particular, that the ratcheting up of conditionality alongside the increasingly threadbare and inadequate nature of the wider social security system has increased the incentive for claimants to seek out the more generous incapacity and disability parts of the system, in order to top up inadequate benefit levels and escape the reach of policies like the benefit cap and strict work-search requirements.<sup>xxiv</sup>

## **The reality of life on incapacity benefits**

Across the survey and interviews, the picture that emerges of family life is one **characterised by struggle and insecurity, of parents juggling bills and debts and children going without items and experiences that most would regard as necessities.** At best, families are just about managing financially. At worst, they are in severe difficulties and relying on charities and the support of family and friends to survive.

Parents must deal with the stresses and strains of ill-health while also navigating a complex, inadequate and frequently hard-edged benefits system. At the same time, they have to fulfil their role as parents, supporting their children through the financial and emotional impacts of growing up when money is tight and the family is facing multiple challenges.

Families are not in this situation by choice, and few would not wish for things to be different. As the new government develops its policy response, policymakers must seek to understand the realities and complexities of these families' lives and avoid retreating into tough rhetoric that will not deliver the reset that is needed or help to build the case for wide-ranging reform. The stakes for those concerned are very high. An approach based on positive engagement and recognition of the challenges families face and the support they need to overcome them will help deliver the best outcomes.

## Recommendations for the UK government:

- 1. Invest in specialist advisors in the new Jobs and Careers Service.** The DWP should invest in specialist advisors and expand their role to include managing their own caseloads. Specialists would lead all contact with those who are out of work due to disability or ill-health, including at periodic voluntary meetings with incapacity benefit claimants. They would be deeply embedded in local areas and work closely with local government and providers to offer voluntary referrals to personalised employment support programmes, a skills and training offer, support with transitioning to self-employment, childcare and Access to Work support. Single parent and carer champions should also be recruited to support parents with other barriers.
- 2. Rethink proposals to abolish the Work Capability Assessment.** The DWP should not proceed with plans outlined in the Health and Disability white paper to abolish the WCA that would leave generalist work coaches to decide how conditionality will be applied to claimants receiving incapacity support through Universal Credit. Instead, the department should consider and consult on how the WCA should be reformed.
- 3. Reform the conditionality and sanctions regime to end the ‘compliance culture’ in jobcentres and assessment processes.** This would mean scrapping prescriptive work search requirements like the 35 hours rule and reversing the ramping up of in-work conditionality. Sanctions policy must also be reviewed to reduce the sanction rate, ensuring they are only used as an absolute last resort in exceptional circumstances.
- 4. Strengthen flexible working arrangements for disabled people.** The Department for Business and Trade and the DWP should ensure that proposals to strengthen flexible working in the Employment Rights Bill includes specific provisions on the expectations on employers to meet the needs of employees with health conditions and disabilities.
- 5. Increase the supply of flexible and remote work opportunities.** The Labour Market Advisory Board should be tasked to work across government departments to develop proposals for increasing the supply of flexible and remote work opportunities that could be of particular benefit to people with work-limiting health conditions and disabilities. This could include financial incentives through publicly funded placement schemes or wage subsidies, outreach and communications campaigns with employers, industry bodies and trade associations, and a central role for the public sector to create new opportunities.
- 6. Fix the basic adequacy of social security to address high rates of poverty and hardship in low-income families with children.** Scrap the two-child limit and benefit cap policies that are the main drivers of rising and deepening levels of child poverty, and restore the social security system to an adequate baseline through targeted investment in the child element of Universal Credit.

- 7. Do not impose work search requirements on claimants waiting on the outcome of a Work Capability Assessment.** Claimants who are waiting for a WCA and have a valid fit note should be automatically placed into a low or no-work requirements conditionality group until an assessment decision has been reached.
- 8. Confirm and extend the Chance to Work Guarantee.** Ministers should confirm plans to proceed with the Chance to Work Guarantee, and develop proposals for how it can be extended to address concerns that engaging in work activity may count against a claimant's separate claim for disability benefits. This could involve changes to guidance around work activity, appeal processes and other steps to improve the quality of decision-making within PIP assessments.
- 9. Go further in reforming Statutory Sick Pay.** The government's proposals for reforming Statutory Sick Pay (SSP) will not address the low rates of pay or its lack of flexibility. These should go further by increasing the SSP rate so that it at least covers the equivalent hourly rate at the National Living Wage, and allowing SSP to be used more flexibly to support a phased return to work. For example, workers who are initially working reduced hours could be paid at their usual wage level for hours worked, which would then be topped up by SSP for the hours they are not working. This could help to make the return to work more financially sustainable.
- 10. Support parents with training and skills.** Ensure that those receiving incapacity benefits are able to access training and skills opportunities on the same basis as any other claimant, and explore how this offer could be expanded.
- 11. Address data limitations to inform policymaking.** The DWP should commit to publishing more detailed demographic data on incapacity benefit claimants (and other benefit types and UC elements) including by household type and the number and age of children. UC health journey data should also include a claimant's primary health condition. This will help to inform policymaking and support the government's forthcoming Child Poverty Strategy.

# Endnotes

<sup>i</sup> The Telegraph (March 2024) '[Mental health culture has gone too far, says Mel Stride](#)' and Financial Times (April 2024) '[Is Britain suffering from a "sick note culture"?](#)'.

<sup>ii</sup> In this report we have focused on the two main forms of incapacity-related financial support, Universal Credit LCWRA and Employment and Support Allowance. Data obtained from [Stat-Xplore](#) shows that there are 1.52 million people claiming Universal Credit LCWRA (June 2024) and 1.54 million people claiming Employment and Support Allowance (February 2024). A further 360,000 people are on the Universal Credit 'limited capability for work' (LCW) caseload. However, as these claimants do not receive an additional incapacity-related payment in their Universal Credit award, they have not been included in the definition of incapacity benefits used for this report.

<sup>iii</sup> We used the Family Resources Survey 2022/23 to produce an estimate of the number of parents in receipt of incapacity-related benefits, by grossing up the number of adults with dependent children in the survey in receipt of Employment and Support Allowance and Universal Credit LCWRA. Universal Credit LCWRA claimants were estimated based on receipt of Universal Credit where the adult is disabled and is not in work or unemployed and actively seeking work. The FRS is known to under-report receipt of benefits. The [DWP has reported](#) that the FRS estimate of the number of claims for Universal Credit is 30% lower than the total in DWP administrative data, while the FRS estimate of the number of claims for ESA is 34% lower than the administrative total. Our FRS estimates have therefore been scaled up to adjust for this under-counting. This gives a figure of 170,000 parents of dependent children in receipt of Employment and Support Allowance and 634,000 parents receiving Universal Credit LCWRA, or 804,000 in total.

<sup>iv</sup> See Resolution Foundation (June 2024) '[Under Strain](#)', Health Foundation (November 2023) '[What we know about the UK's working-age health challenge](#)', IFS (April 2024) '[Recent trends in and the outlook for health-related benefits](#)', IPPR (September 2024) '[Our greatest asset: the final report of the IPPR Commission on Health and Prosperity](#)'.

<sup>v</sup> OBR (October 2024) '[Welfare trends report – October 2024](#)'.

<sup>vi</sup> DWP (November 2023) '[Employment support launched for over a million people](#)'.

<sup>vii</sup> DWP (September 2024) '[Government action to tackle the "greatest employment challenge for a generation"](#)'.

<sup>viii</sup> Resolution Foundation (February 2023) '[Post-pandemic participation: exploring labour force participation in the UK, from the Covid-19 pandemic to the decade ahead](#)'.

<sup>ix</sup> Gregg, P. (September 2024) '[Employment, economic inactivity and incapacity: past lessons and implications for future policy](#)', Health Foundation.

<sup>x</sup> The Telegraph (March 2024) '[Mental health culture has gone too far, says Mel Stride](#)' and Financial Times (April 2024) '[Is Britain suffering from a "sick note culture"?](#)'.

<sup>xi</sup> Social Security Advisory Committee (August 2022) '[Out of work disability benefit reform](#)'.

<sup>xii</sup> DWP (November 2023) '[New "Chance to Work Guarantee" will remove barriers to work for millions](#)'.

<sup>xiii</sup> Labour Party (June 2024) '[Change: Labour Party Manifesto 2024](#)'.

<sup>xiv</sup> DWP (August 2024) '[DWP Customer Experience Survey: Benefit Customers 2023 to 2024](#)'.

<sup>xv</sup> Mind (March 2023) '[Reassessing assessments](#)', NAO (July 2024) '[DWP customer service](#)', NAO (February 2020) '[Information held by the Department for Work and Pensions on death by suicide of benefit claimants](#)'.

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NAO (March 2019) '[Supporting disabled people into work](#)' and DWP (May 2023) '[Work coach provision of employment support](#)'.

<sup>xvi</sup> Work and Pensions Committee (May 2024) '[Survey results – safeguarding vulnerable claimants](#)'.

<sup>xvii</sup> OBR (July 2023) '[Fiscal risks and sustainability – July 2023](#)'.

<sup>xviii</sup> Institute for Government (January 2023) '[Whitehall Monitor 2023 \(Part 1\): the size, cost and make-up of the civil service](#)'.

<sup>xix</sup> Most recent figures from March 2024. See House of Commons (April 2024) '[DWP response to parliamentary question UIN22700](#)'. According to the DWP's annual report, there were 26,300 work coaches employed in March 2014. DWP (June 2014) '[DWP annual report and accounts 2013-14](#)'.

<sup>xx</sup> Work and Pensions Committee (November 2016) '[The future of Jobcentre Plus](#)'.

<sup>xxi</sup> House of Commons (November 2023) '[DWP response to parliamentary question UIN210](#)' and DWP (April 2021) '[Government unveils new support for disabled jobseekers](#)'.

<sup>xxii</sup> Sense (2024) '[Research on the employment support available to people with complex disabilities](#)'.

<sup>xxiii</sup> Institute for Employment Studies (September 2024) '[Working for the future: final report of the commission on the future of employment support](#)'.

<sup>xxiv</sup> See discussion in OBR (July 2023) '[Fiscal risks and sustainability – July 2023](#)', Resolution Foundation (June 2024) '[Under Strain](#)', IFS (April 2024) '[Recent trends in and the outlook for health-related benefits](#)', and IFS (February 2023) '[Do work search requirements work? Evidence from a UK reform targeting single parents](#)'.



## Safe and happy childhood

Action for Children protects and supports children and young people, providing practical and emotional care and support, ensuring their voices are heard, and campaigning to bring lasting improvements to their lives.

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