

WAVE TWO, AUGUST 2024

DEMOS

“FIGHT LIKE HELL!”

AN ONLINE FORUM LISTENING EXERCISE
REVEALING HOW PEOPLE TALK ABOUT
POVERTY NOW

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with support from
JACK PAY



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ABOUT DEMOS



Demos is a cross-party think tank putting people at the heart of policy-making to create bold ideas and a more collaborative democracy.

This project is part of our work on how to build a *Trusted Political System*, through listening to the voices of those most impacted by policy. In partnership with the Joseph Rowntree Foundation, we have developed an innovative method of social media listening to shed light on the experiences of people living in financial hardship.

We will also use these insights to inform our work on Public Service reform, by understanding the experiences of those who rely on these services. Our goal is to enable more relational public services, that can empower communities and prevent problems.



JOSEPH ROWNTREE
FOUNDATION

Joseph Rowntree Foundation (JRF) is an independent social change organisation, working to support and speed up the transition to a more equitable and just future, free from poverty, where people and planet can flourish.

At JRF we are currently developing an insight infrastructure which, powered by quantitative and qualitative data, will act as a satnav providing a series of possible routes to navigate from problem to solution. Such routes will be paved by data and insights generated through triangulation of data from different sources – established datasets (admin data); new sources (charity data); experimental data products (place-based insight hubs, banking data, consumer data); and lived experience of people (experiential insight, social listening). Data and insights products, which we will generate and disseminate in open collaboration with others, are going to support and sustain a shared movement promoting

innovation, better use of evidence, and data-driven decisions to solve social and economic inequality in the UK.

One of the key aspects of the foundation's insight infrastructure's proposition is to improve our knowledge and understanding of people and communities experiencing hardship, poverty and related issues, in the public and policy debate at a national/regional/local level, on issues they have identified themselves. In this instance, by learning what people share about their experience on social media so to investigate how we can generate and disseminate new and timely insights into the lives of those with direct experience of the issues we care about.

Rosario Piazza, Chief Insight Architect, JRF

Aleks Collingwood, Partnership Insight Manager, JRF

ABOUT THE PROJECT

This report was designed to shed light on the experiences of people living in financial hardship, through analysis of discussions in specific online support spaces. It is the second installment of a series of four waves, which will provide a regular 'dip in' to the online conversation, to pick up salient and emerging insights on poverty and inequality over the course of 2024.

Our analysis consisted of a combination of inductive computational techniques, which allowed us to surface characteristic terms, phrases and discussions occurring across the dataset. We have visualised the outputs of this step into a series of word clouds, which we will be able to compare across the waves to see overarching trends and fluctuations relating to the experiences of and conversations about poverty. The quotes throughout are drawn from our subsequent qualitative analysis, through which we gained a more fine-grained understanding of how individuals are feeling and responding to their experiences.

This method has the advantage of giving us a replicable basis for comparison across each of our waves, while not sacrificing the deeper understanding which is gained from directly engaging with the voices of those with lived experience of hardship.

All quotes throughout this report have been bowdlerised and are indicative of the content of the post rather than verbatim - i.e. the meaning of the post has been preserved but wording or syntax changed. This is so that the author cannot be identified via text matching. Though we cannot know for certain the circumstances of any individual anonymous contributor, we know from both desk research and engagement with the Grassroots Poverty Action Group that these are spaces where individuals experiencing poverty may share their stories or seek help.

Please see the Appendix for full details about our methodology.

ACKNOWLEDGEMENTS

This project was funded by and developed in partnership with Joseph Rowntree Foundation.

We are grateful to CASM Technology for their support with technical infrastructure and to the members of JRF's Grassroots Poverty Action Group (GPAG) for their guidance and input.



JRF's Grassroots Poverty Action Group (GPAG) is made up of 14 people with direct experience of poverty from across the UK. Members of the group include people who are most impacted by the cost-of-living crisis, including people from Black and minority ethnic backgrounds, lone parents, Universal Credit claimants, disabled people and unpaid carers – those most at risk of poverty.

The group works on, and supports, a variety of JRF's research and infrastructure projects. Group members bring their experience of living on a low-income but also the skills, knowledge, and experience they may have from employment, voluntary work, caring responsibilities, and community activism.

CONTENTS

1	EXECUTIVE SUMMARY	<u>PAGE 8</u>
2	BACKGROUND	<u>PAGE 12</u>
3	OUR FINDINGS	<u>PAGE 15</u>
4	METHODOLOGY	<u>PAGE 46</u>



EXECUTIVE SUMMARY

BACKGROUND TO THE PROJECT

In 2023, Demos and the Joseph Rowntree Foundation collaborated on an exploratory pilot project to investigate:

- What can we learn from social media about people's experiences of poverty and hardship in the UK?
- How can these learnings be scaled or tested in the future?

Following [a successful trial](#), we have extended this work into a year long programme consisting of four 'waves'.

Over the course of 2024, we are taking periodic samples of the online conversation to track how people are talking about their experiences, and what insights social media listening can support for better policy development which puts people's needs and lived experience at its heart.

In March 2024, we launched our [findings from Wave 1](#) of this programme: 'The system is rigged', as well as updates to our methodology for gathering social media insights in this area.

In this deck, we present findings from Wave Two of our extended investigation.

Please see slides 12-14 for further background.

KEY FINDINGS - 1/2

In Wave Two (February - March 2024), we made the decision to specifically highlight the experiences of disabled communities. Within this area, we identified two distinct themes.

1 CHALLENGES FACING DISABLED PEOPLE

- We found numerous challenges facing people living at the intersection of disability and poverty. In some cases, we saw difficulty in securing consistent GP care leading to a lack of access to medical expertise needed for PIP applications.
- Many people discussed the gaps in the support available for carers, as well as the additional complexity when family and caring responsibilities are intertwined.

2 ADVOCACY AND MUTUAL AID VIA FORUMS

- Forums served as important spaces for exchanging emotional support as well as practical advice, including links to various charitable organisations.
- The DWP was often framed as an adversary, with users encouraging each other to 'keep fighting' to access the support they need.

KEY FINDINGS - 2/2

There were three themes which were consistent across Wave Two (February - March 2024) and Wave One of the research (Nov 2023 - Jan 2024).

3 NAVIGATING GOVERNMENT SUPPORT SERVICES

- We found that many people turned to the forums for support at the moment they were rejected for an application such as PIP.
- Many were seeking advice on how to appeal a decision, or how to navigate a tribunal.

4 IMPACT OF FINANCIAL HARDSHIP ON RELATIONSHIPS

- Supporting and caring for family members was experienced as complicated and costly for many people.
- Caring responsibilities could become a barrier when seeking paid employment.

5 POLITICAL ENGAGEMENT IN AN ELECTION YEAR

- Despite the fact that the election had not yet been announced when this data was collected, we saw a marked increase in the proportion of discussion which focused on Sir Keir Starmer the policies of the Labour party



FURTHER BACKGROUND

CHANGES BETWEEN WAVES ONE AND TWO

Through the research process, our team has continued to refine our methodology and experiment with new approaches to analysis. Due to the nature of online forums, we have also had to navigate various fluctuations in the content and volume of the forum data.

Between Wave One and Two, guided by reflections from the Grassroots Poverty Action Group, we made the decision to specifically focus on the experiences of disabled people. This meant that we have adapted our thematic analysis related to navigating government support, to split out services specifically for individuals with disabilities and/or health conditions, from other areas such as employment support.

Another notable change between our two waves is the volume of data we have collected. In Wave One, we collected 13,882 posts, whereas in Wave Two, we collected 5,341. There are a couple of factors that we believe contributed to this decline: the difference in the timeframe over which data was collected (3 months vs 2 months) and the transient nature of forums (in which new subforums are created and old ones abandoned). In Wave Three, we will explore methods of supplementing our data sources, such as scoping new forums and subforums.

DATA COLLECTION

Data was collected from all posts and comments between 1st February and 31st March 2024 (total = 5,341). We gathered data from 5 forums, which we narrowed down to relevant subforums. We have referred to these throughout the slides using the following pseudonyms:

- **DisabilityHelp (678 posts)** - A forum dedicated to supporting individuals with disabilities.
- 4 subforums relating to the intersection of disability, government services and financial hardship
- **FamilyHelp (13 posts)** - A forum dedicated to supporting families.
- 3 subforums relating to government services and financial support for families

- **FinancialHelp (1,172 posts)** - A forum focused on providing financial advice and support.
- 6 subforums discussing the intersection of finances with family, disability and employment
- **GovernmentHelp (3,474 posts)** - A group on a large social media site which was related to people interacting with government services.
- **MentalHealthHelp (4 posts)** - A forum providing mental health support.
- 1 subforum related to financial hardship



OUR FINDINGS

KEY THEMES

Across the data set as a whole, we identified a number of key themes across the 5 forums we analysed. The numbers in brackets demonstrate the proportion of our dataset that each theme represents.

1. Challenges facing disabled individuals (1234 posts/ 23% of dataset)

2. Mutual aid and advocacy among disabled communities (a subset of the above)

3. Navigating government support services (1784 posts / 33% of our dataset)

4. Impact of financial hardship on relationships (966 posts/ 18% of dataset)

5. Discussion of politics and elections (320 posts / 6% of our dataset)

As mentioned previously, we made the decision in Wave Two to specifically highlight the intersection of disability and poverty. Our first two themes focus on the challenges facing disabled individuals seeking to access government support, as well as the emotional and practical support that communities share online. The subsequent three themes are a continuation of themes from Wave One.

1. CHALLENGES FACING DISABLED PEOPLE

In Wave 1, we found that the experiences of disabled people cut across multiple themes. In Wave 2, we have chosen to specifically highlight these voices and experiences in greater depth. When clustered together, conversations reflecting the experiences of disabled people represent the second-largest portion of discussion in the forums - 23% of our dataset.

KEY TERMS USED

We found many terms which referenced the **experiences of disabled people**.

- Language that refers to specific benefits for disabled individuals or people with health challenges, such as PIP, LCWRA and DLA came up very frequently.
- In addition, we also found discussion related to the experiences of carers.

KEY INSIGHTS

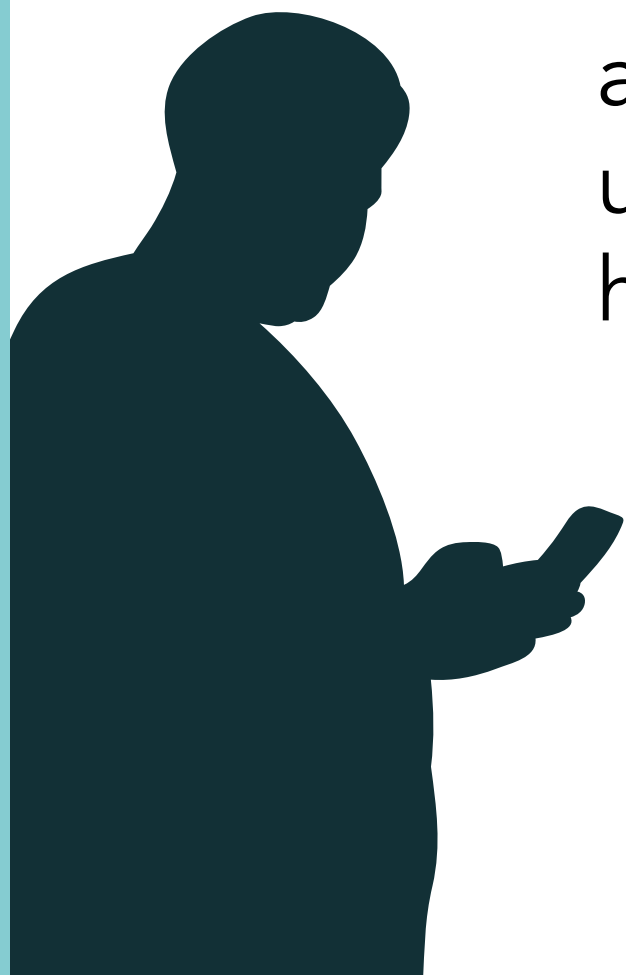
- Intersection of disability and poverty ([P. 18](#))
- Knock-on impact of constraints accessing medical expertise ([P. 19](#))
- Gaps in the support for carers ([P. 20](#))
- Complexities when family and caring responsibilities are intertwined ([P. 21](#))

INTERSECTION OF DISABILITY AND POVERTY

We found discussion of financial hardship and destitution in the context of disability, reflecting the higher than average rates of poverty among disabled individuals and carers.

For many, financial hardship was exacerbated by complexities in navigating the benefits system. In some cases, a household may have little to no financial support while waiting for the outcome of a tribunal.

In addition, the level of financial support available for disabled people often doesn't keep up with the cost of living, with rent and groceries heavily impacted by inflation.



*"Where I live the rent is so high - even just for one room - the rent takes up pretty much all the disability benefits people get. **They basically have to rely on [...] food banks just to survive.** This shit is insane."*

*"I really need some help [...] **Since [the DWP] took my PIP away, being able to pay my bills & survive has been very difficult.** If they take the LCWRA element away too it will become impossible. It is really affecting my mental health.*

I want to go back to work, but [...] full time work will not be viable. I fear my work coach won't care at all [...] even thinking about finances makes me want to kill myself. [...]

Ever since I found out about my review date I've been worrying non-stop."

KNOCK-ON IMPACTS OF DIFFICULTIES ACCESSING MEDICAL EXPERTISE

We saw a knock-on impact of the strain on health services onto difficulties accessing other services, such as benefits claims.

For example, many disabled people found it challenging to access regular support from a GP. There were also concerns about the difficulty seeing the same GP in order to ensure an in-depth understanding of the complexity of their needs.

This in turn created barriers and fears about accessing informed and accurate medical judgments to include as evidence for an application for the Personal Independence Payment (PIP).

"[The PIP application process] is giving me so much anxiety - there is no way my GP would know all of this detail about me. [...] I thought GPs don't have time? At least mine doesn't.

I'm dreading the inevitable reassessment based on the word of a GP who barely knows me, only my medical diagnosis.

Sorry for the rant... I'm panicking."

"In general, if you have a sympathetic medical team and evidence behind you, you will be better off [...] If you don't though... "

"My new GP doesn't know anything about my condition
[...] Has anyone here had a similar experience and can share any advice? Thank you."

GAPS IN THE SUPPORT FOR CARERS

Some reported experiencing delays in receiving Carer's Allowance payments, which intensified existing financial strain.

"After five weeks, my boyfriend has been awarded Carer's Allowance, which has been backdated to when he first applied. Our Housing Benefit was reinstated one day before the rent was due: just in time, but close. I'm still waiting for them to return my ESA and SDP [...] but as the Carer's Allowance has only just been awarded, it may take a while! [...] The waiting is not fun but we are nearly there now."

"I receive Carer's Allowance as my wife has severe MS. I am her full-time carer, but I also suffer with anxiety and depression, which has affected my employment. If I claim ESA, will it cause a problem with the Carer's Allowance payments? [...] I am terrified of the the upcoming interview with the DWP. "

"I feel bad for your daughter if she has no choice but to care for her mum, so cannot access higher education for her future."

Many people felt there was a lack of clarity around how the Carer's Allowance interacts with other benefits, particularly if both individuals in the same family are disabled.

In addition, many carers highlighted their struggle to maintain consistent employment or education alongside caring responsibilities.

COMPLEXITIES WHEN FAMILY AND CARING RESPONSIBILITIES ARE INTERTWINED

We found that the individuals who discussed being responsible for providing care were overwhelmingly family members.

Some felt that the role of family members as caregivers can create complexity in navigating official support services, leading to an unclear division of responsibilities between the family and professionals.

This could take a toll on the health of these individuals, as well as on the relationship. We will address this topic in more detail in our Relationships theme (see [P. 32](#)).

"My wife has been out of work since last year as a full-time carer for our ten year old daughter, who has lots of complex mental health needs. [...] My daughter gets mid-rate DLA, my wife gets Carer's Allowance."

*"Single parent here. Here are some lessons from my own experience: **if your child is struggling and you are struggling, you can apply for child DLA.** If you do, make sure to register yourself as your child's carer."*

*"When the family is willing to step-up and provide some care, **it is easy for Social Services to end up relying on the family to do more than what is agreed, reasonable, or even possible.**"*

2. ADVOCACY AND MUTUAL AID

Within the more general cluster of conversations reflecting the experiences of disabled people, there was a strong theme of advocacy and mutual aid. Many people shared their own experiences in order to motivate others, offering both practical advice and emotional support.

KEY TERMS USED

We found motivational posts which referenced fighting for the rights of the disabled community and encouraged others not to give up.

- We found discussion of advocacy groups related to the rights of disabled people, such as Disabled People Against Cuts (DPAC).

KEY INSIGHTS

- The DWP is often framed as an adversary ([P. 23](#))
- Online communities play an important role in providing emotional support ([P. 24](#))
- Users frequently share links to resources, including charities ([P. 25](#))

DWP AS THE ADVERSARY

The DWP was often framed as an opponent, with numerous people sharing their own struggles to access support.

We found extensive motivational posts, with users telling each other to 'keep fighting' rather than accepting the rejection.

This advice corresponds to official statistics showing that 70% of initial PIP rejections which are appealed via a tribunal are subsequently overturned in favour of the claimant.

"The DWP is set up to harm disabled people. [...] Staff are told to invalidate and gaslight disabled people."

"We have rights as human beings - they cannot bully us into taking work."

"Fight like hell!"

"Good luck! If they turn you down, fight! [...] They turn most of us down the 1st time - they want you to give up."

"It took me 2 years to get PIP [...] Don't ever give up - fight the bastards all the way and you'll come out on top."

"After 3 years of fighting for my claim - good news!! Remember: always fight all the way to tribunal!!"

'WELCOME TO THE COMMUNITY'

We saw significant emotional support across the forums.

Established users of the forums would take time to welcome new people to the space, or to offer reassurance.

We saw many users sharing their appreciation of the kindness they had received, thanking others for their support.

"Hello, [query regarding ESA and Carers Allowance]. I'm so confused about this, is there anyone who could give me some advice? Thank you so much!"

"Welcome to the community! I can see that someone is already helping with your questions, but I just wanted to say a quick hello."

"Thanks for welcoming me I am very happy to be here and grateful for all your help. I wish I had found this place sooner."



'DON'T GIVE UP!'

Many people on the forums gave and sought out detailed, practical advice. This often included links to charities and external resources, such as the [Benefits Calculator](#) and [WhatDoTheyKnow](#), a tool from mySociety which helps people to find and make Freedom of Information requests.

The most commonly shared charity was Citizens Advice. Users frequently suggested that those in need should contact their local Citizens Advice Bureau, as well as sharing a range of different resources from their website, including a guide to the [Personal Independence Payment \(PIP\)](#) assessment, a guide to [appealing](#) against a PIP decision and a repository for [general information](#) on PIP.

Other organisations included:

- [Disability Rights UK](#)
- [Age UK](#)
- [Child Poverty Action Group \(CPAG\)](#)
- [Shelter](#)
- [Mind](#)
- [Turn2Us](#)
- [Disabled People Against Cuts](#)
- [Care for Carers](#)
- [Big Brother Watch](#)
- [Joseph Rowntree Foundation](#)
- [Carers UK](#)

*"Do you have representation?
If not, **reach out to your local
Citizens' Advice Bureau** [...] You
do not need to do this alone -
always get expert advice before
you proceed."*

*"I am sorry to hear that, but
please don't give up! **You
need to request a mandatory
reconsideration** - this is the 1st
step in the appeals process.
There is a post here that provides
information on how."*

3. NAVIGATING GOVERNMENT SUPPORT SERVICES

As highlighted in the previous theme, we have separated out government support for disabled individuals or those with health problems from more general services, such as employment support. In this theme, we have excluded the names of specific services related to disability, such as PIP and DLA. However, we recognise that there will still be significant overlap, with terms such as 'DWP' appearing frequently in both themes.

Even though this theme covered a smaller range of topics in Wave Two compared to Wave One, it still reflected the largest portion of conversations in the forums - 33% of our dataset.

KEY TERMS USED

We found many terms which referenced navigating employment support, such as *Restart* and *jobcentre*.

- There was still significant overlap between disability support and general support, with references to the *DWP*, *tribunal* and *mandatory reconsideration* across both themes.

KEY INSIGHTS

- Responding to rejection ([P. 27](#))
- Confusion and contradiction ([P. 28](#))
- Negative interactions with work coaches ([P. 29](#))
- Stress and impacts on mental health ([P. 30](#))

RESPONDING TO REJECTION

Many individuals turned to online spaces after their initial benefits claim was rejected.

Often users were seeking advice on appealing a negative decision, or how to navigate through the tribunal process.

*“Definitely try the Mandatory Reconsideration, but first spend some time reading advice on here. When I first applied, **I did it all on my own and ended up getting things wrong. This forum helped a lot with my appeal.** [...] Once you’ve got that in, you’ll be waiting for a while. Use that time to get advice and support, gather as much evidence as you can, and prepare yourself.”*

***“The DWP ignored my evidence and rejected my appeal.** They are claiming that I owe them 4K. [...] I have buried my head in the sand and just been paying £10 per month, but now they want to increase my payments. [...] Can I take this to the Ombudsman? Looking for advice from anyone in a similar situation!”*

CONFUSION AND CONTRADICTION

The interactions between different types of benefits and support was a particular source of confusion for many.

Often individuals recounted having received conflicting advice from different sources. Even within threads, users disagreed on the correct approach.

*“Could someone please give me some clarity – **Universal Credit have been totally inconsistent in the answers they’ve given me!** They’re taking forever to get back to me even though I’ve been chasing. I am really desperate - I need to know what will happen so I can find somewhere to live.”*

“No, that doesn’t sound right. [...] Are you 100% sure?”

*“Hello everyone, can you please give me some advice? Sorry for asking so many questions [...] **I have no idea how to do all of this benefits stuff.**”*

“They’ve given you terrible advice!”



NEGATIVE INTERACTIONS WITH WORK COACHES AND OTHER SERVICE PROVIDERS

Many people had extremely negative interactions with the service providers of employment support.

Work coaches were frequently seen to be unhelpful and even hostile, with little understanding of people's mental and physical health challenges.

*"I asked [the case manager] why she was being rude to me and told her that I am calling for help. [...] **I have never felt so belittled before in my life. I was crying after that phone call.** [...] Is it worth me making a complaint? Do you think anyone will even look into it?"*

*"I am on Restart [...] they have made my mental health so much worse. **They blame me for my mental health issues and learning difficulties.** [...] I would not trust them to boil a kettle, let alone to be in charge of finding vulnerable people decent jobs."*

*"I am sorry to hear what you have been going through. I have had very similar experiences with horrible work coaches. **They make you feel like no matter what you do, your best isn't good enough.**"*

STRESS AND IMPACTS ON MENTAL HEALTH

There was widespread consensus that interacting with the benefits system was extremely stressful and often frustrating.

Some talked about their mental health being negatively impacted as a result of negative experiences.

"Please do not feel like you are worthless! **The benefits process is really stressful,** but we are all here to help you."

"You're not alone. [...] Just keep trying, **even when it's frustrating!**"

"**Universal Credit sets off my anxiety and depression.** I wish I could just wash my hands of them."

"I am really sorry. **I know it is easier said than done,** but please try not to think about it."



4. RELATIONSHIPS

This third theme reflected the second-largest portion of conversations in the forum. The proportion is fairly consistent with the last wave: 18% of our dataset in comparison to 17% in the last wave.

KEY TERMS USED

We found many terms which referenced family members, such as *father*, *sister*, in the context of financial hardship.

- We found many terms related to benefits and government support systems, such as *Universal Credit*, in the context of people's relationships.

KEY INSIGHTS

- Supporting and caring for family members can be complicated and costly ([P. 33](#))
- Forums are also used by family members seeking to support their loved ones ([P. 34](#))
- Caring for children can also be costly and prevent people from working ([P. 35](#))
- Relatives and partners are a pivotal source of support for those with such networks ([P. 36](#))
- Relationships can make navigating the benefits system even more confusing ([P. 37](#))

SUPPORTING AND CARING FOR FAMILY CAN BE COMPLICATED AND COSTLY

There were several posts written by people who were caring for a family member with a health problem or disability.

Some were looking for advice about how they would fund care for their sick and elderly relatives while others were looking for clarity around applying for the Carers Allowance.

It was clear that many continue to find the government support systems in place confusing.

"My Dad needs to go into care. He has received a referral to social services but I don't know how long this might take because of backlogs. What if they're unable to find him a care home?...Are the costs of his care means-tested?... Could his wife be forced to pay in the short term? Can I get his care NHS-funded?.. He has no income other than his state pension...could they place a hold on 50% of his house and force its sale when his wife passes away? Is there anything else I should be thinking about or doing? NHS care is a minefield, I don't know how this complex system works! I appreciate any advice you can give me."

FORUMS ARE ALSO USED BY FAMILY MEMBERS SEEKING TO SUPPORT THEIR LOVED ONES

There were many posts from family members helping their relatives to navigate the benefits system.

It was clear that the confusion caused by the complexity of the benefits system was having an emotional impact on some who were concerned for their relatives' financial situation and wellbeing.


*"My mother's pip tribunal is soon but unfortunately she got rushed into hospital last night for surgery. The person I spoke to on the phone said she'd recommend to the judge to postpone but he might not accept. **This is super worrying as we have waited a year for this date and surely they will understand the circumstances are dire?"***

*"I am an appointee for my son who is disabled, he was on old style esa but stupidly took a job which lasted 4 days. I rang old style esa who told me to apply for a mandatory reconsideration, I know now that that advice was wrong... **This is so unfair and his mental health is suffering.**"*

CARING FOR CHILDREN CAN ALSO BE COSTLY AND PREVENT PEOPLE FROM WORKING

Childcare responsibilities were also a barrier to work for some parents which exacerbated their financial difficulties.

This ranged from being unable to return to full-time work due to unaffordable childcare to being unable to find a job flexible enough to accommodate caring responsibilities for a child with a disability.

A silhouette of a man and a child walking together. The man is on the right, holding the child's hand. The child is on the left, wearing a backpack. The man is also carrying a bag in his left hand.

*"I'll be unemployed for several months with no benefits...I used to work full time but after maternity leave I became a stay at home mum because childcare was not affordable...My 2 year old has been attending nursery but they will not to take my child full time or after school. He is being diagnosed with autism or adhd...I also have adhd and receive pip. **This all makes it really difficult to go back to work even though I can and really want to... I don't seem to be entitled to benefits.**"*

RELATIVES AND PARTNERS ARE A PIVOTAL SOURCE OF SUPPORT FOR THOSE WITH SUCH NETWORKS

Some found family members were pivotal in resolving the difficult situations they were in.

This included one person finding somewhere affordable to live through a family connection and another being able to share costs of essentials, such as rent, after moving in with a partner.

*"I was in a really horrendous place renting before, it seems it's the only way for people like me...**luckily my sister's partner was looking to buy somewhere to rent out, so I have a good landlord.**"*

"Regarding rent...my HA needs to be paid in advance but UC only pays them on the 12th of every month so it always looks like i'm behind on rent..."

I'm just glad I qualify for LCFW and will be moving in with my partner soon."

RELATIONSHIPS CAN MAKE NAVIGATING THE BENEFITS SYSTEM MORE CONFUSING

We found many posts from people discussing how the circumstances of a family member or partner had impacted their own benefits entitlement.

Several people found these situations confusing while others were concerned about no longer having enough money to get by.

The issues people had ranged from claims being rejected due to the income or savings held by a family member to becoming ineligible for a particular benefit due to their partner moving in with them.

*“Will legacy ESA also affect the universal credit my mother gets? And housing benefit? **It is a minefield of confusion.**”*

*“**This is turning into a nightmare and is extremely worrying for us all. As if disabled people did not have enough to deal with...** it’s all far too complicated now to go into all the detail on here but any advice you can give is really appreciated. A family members partner moved into our family home to be with them before their baby was born. We did not know we needed to tell DWP about this (a very big mistake we now realise we made).”*

5. POLITICAL ENGAGEMENT IN AN ELECTION YEAR

At the time the data for Wave Two was collected, the election had not yet been called. However, there was widespread awareness that 2024 was almost certain to be an election year.

A notable difference between Wave Two and Wave One was the proportion of discussion about the Labour leader, Sir Keir Starmer. In this wave, we found that Starmer was the single most commonly discussed individual. In the previous wave, he was not even in the top 20.

This final theme reflected the smallest portion of conversations in the forum - 6% of our dataset.

KEY TERMS USED

- The majority of key terms referred to the political parties and machinery of government - including Labour, Tories, parliament and commons.
- Named political figures also featured, such as Sunak and Starmer.

KEY INSIGHTS

- Comparisons of Labour and the Tories ahead of an election ([P. 40](#))
- Harmful rhetoric about 'scroungers' ([P. 42](#))
- Reflections on policy debates ([P. 43](#))

MOST FREQUENTLY MENTIONED INDIVIDUALS



* See Appendix 2 for definitions of acronyms; See Appendix 3 for data used to create word clouds

COMPARISONS OF LABOUR AND THE TORIES AHEAD OF AN ELECTION (1/2)

In addition to increased discussion of Sir Keir Starmer compared to Wave One, we also saw more discussion of the party's wider political platform.

Some criticised the Labour leadership from the left, arguing that a Labour government would not radically alter the current approach to poverty and benefits, which many view as insufficient.

*"Liz Kendall said that 'everyone that can work, should work'. **Labour will bring in more of those rubbish UN-employment courses.**"*

"Starmer isn't a Red Tory. He's a two-faced backstabbing traitor to Corbyn."

"You are correct, apart from Starmer being a centrist. He is firmly on the right of centre-right."



COMPARISONS OF LABOUR AND THE TORIES AHEAD OF AN ELECTION (2/2)

As seen in Wave One, we found further discussion of the Conservative government's proposed welfare reforms.

However, as people were aware that the election was likely to be coming soon in 2024, there was a general consensus that the Conservatives were unlikely to hold power for much longer.

This led to uncertainty as to whether the proposed policy changes would be implemented.

"[The Conservatives] are busy trying to push it through the House of Lords ahead of the election [...] If it goes through before then, we're likely to be stuck with it."

*"The question is: what will come next? It is almost certain the Tories will not win the next election [...] but once they are gone, what will be next? **Whoever it is, it's likely to be just as much of a mess.**"*

*"It's just all smoke and mirrors. **The Conservatives will not be in power long enough to put through any of these welfare changes.**"*

If I vote Labour, will they stop the White Paper reforms?"

HARMFUL RHETORIC ABOUT 'SCROUNGERS'

Consistent with Wave One, we found people expressing frustration regarding how the media and politicians portray people living in poverty.

However, in the context of an election year, some feared that this kind of targeted rhetoric would only get worse.

*"We know this government and the right wing media are going to **ratchet up the 'scrounger' narrative in the run-up to this election.**"*

*"**The mainstream media have so much to answer for, with their disgusting and fake 'scrounger' rhetoric.** The politicians from both of our main political parties are hugely responsible as well."*

*"I watch the Sunday news and so much of it is totally ignorant about people on benefits. [...] **The problem is that the Government makes you feel shame for being on benefits** and the media just sees us as vermin that cannot be bothered to work."*

REFLECTIONS ON POLICY DEBATES (1/2)

Consistent with the previous wave, we saw evidence of political engagement, including debates over current and potential legislation.

In general, individuals were expressing scrutiny of politicians, and seemed to have little faith in their intentions or ability to deliver.

The policy areas covered were wide-ranging, including taxes, out-of-work benefits, transport, education, and health and social care.

"The Tories are trying to push through all these tax cuts by taking money away from the disabled. But the tax bands remain the same - they haven't even provided any real tax cuts."

*"Yeah, it is awful what Sunak was saying about there being too many unemployed, long-term sick doing nothing. **He has no idea whatsoever!**"*

"Mate, have you not seen the state of our trains? How under-resourced education is? [...] Spending on education and infrastructure are the two biggest determinants of a developed or developing country, and we've been in a shocking state for decades."

*"The country is a mess. Any reforms to residential care funding is a low priority. [...] **We need to accept the reality and assume it isn't going to change in the short term.**"*

REFLECTIONS ON POLICY DEBATES (2/2)

As discussed in Wave One, concerns over the Data Protection and Digital Identity Bill also came up in Wave Two.

The bill, which has since fallen, featured a provision which would have given the DWP greater access to the bank accounts of individuals on benefits.



*No, the government proposed legislation which would give the DWP **increased access to banking information, but there's been a lot of pushback.** The bill hasn't made its way through Parliament yet.*

Why are they asking me for so many bank statements?

I thought the government just granted the DWP the power to access the bank accounts of claimants?

Why can't they just go look themselves?

CONCLUSIONS

Wave Two of our extended Social Media Listening partnership between Demos and the Joseph Rowntree Foundation has narrowed in on the specific experiences of disabled people living in poverty. The decision to highlight these voices was a direct result of consultation with the Grassroots Poverty Action Group, and we are grateful for their guidance and generous support.

The core insights we have identified in Wave Two include not only the **challenges facing people experiencing people living at the intersection of poverty and disability**, but also the **vital role of solidarity and mutual aid** within these communities. We saw understandable **frustration with the providers of public services**, such as the DWP, who were viewed as **failing** to meet the needs of the most vulnerable individuals.

Despite the myriad challenges people were navigating, their frustration was overwhelmingly channelled into a **fierce determination to 'fight like hell'**. This sentiment was shared by people advocating for their own rights, but also for the community as a whole.

Interestingly, despite the fact that at the time of data collection the election had not yet been called, we found an **uptick in the proportion of conversation related to a potential future Labour government**. Some expressed their hopes that a change in government would have a positive impact on the country. However, there was **widespread awareness of the scale of the policy challenges ahead, and little faith in the political class** who will be responsible for addressing those challenges.

We look forward to continuing to share further insights with you over the course of 2024.



APPENDIX 1

METHODOLOGY

OVERVIEW OF METHODOLOGY

We replicated the methodology from the [previous wave of this project](#), collecting data from the same 5 forums. Our theme selection was informed by expert input from JRF and the GPAG, who suggested that we highlight the intersection of disability and poverty. Our analysis was performed using the Method 52 platform, developed by CASM Technology. Our methodology consisted of two broad phases.

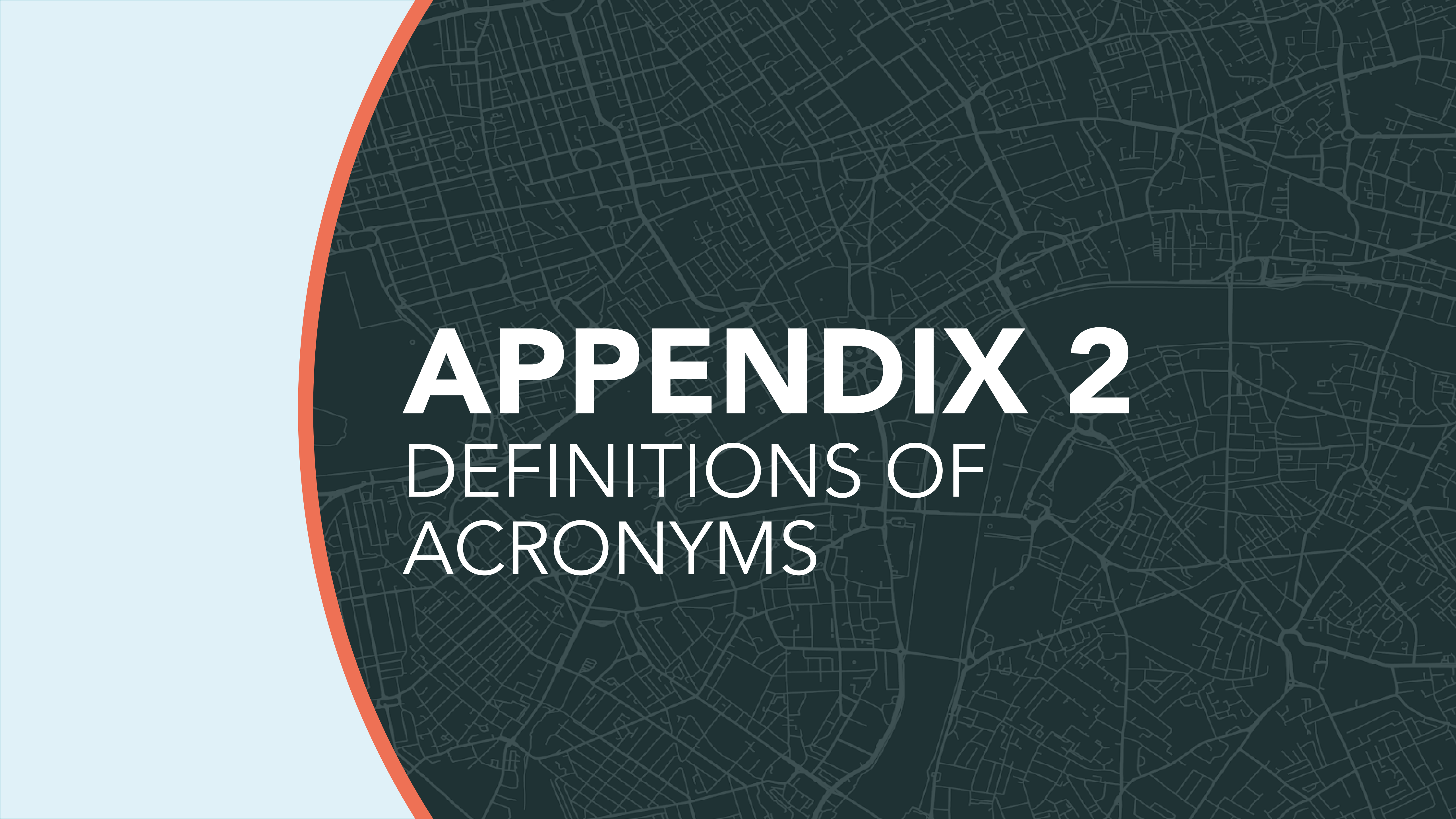
Computational Text Analysis

First, a combination of inductive computational techniques, 'Surprising Phrase Detection' and 'Named Entity Recognition', which allowed us to surface characteristic terms, phrases and discussions occurring across the dataset. In addition, we added a new type of analysis, Link Extraction, which allows us to identify which links and resources individuals are sharing most often. The data tables can be found in Appendix 2.

Qualitative Content Analysis

Our second phase consisted of building up keyword lists of related terms from the first step into broad thematic areas. We honed in on the four key themes from the pilot project (Family, Politics, Services and Health), plus an additional examination of housing as a particularly prominent area. We used these keyword lists to filter our dataset into smaller samples, which we could analyse qualitatively through in-depth close-reading by analysts. This allowed us to build up a detailed picture of how individuals were responding to particular challenges and circumstances.





APPENDIX 2

DEFINITIONS OF ACRONYMS

DEFINITIONS

DWP	The Department of Work and Pensions
HMRC	HM Revenue & Customs
NHS	National Health Service
A&E	Accident and Emergency
ADP	Adult Disability Payment
CMS	Child Maintenance Service
SSP	Statutory Sick Pay
WCA	Work Capability Assessment
UC	Universal Credit
DLA	Disability Living Allowance
LPA	Lasting Power of Attorney



DEFINITIONS

ESA	Employment Support Allowance
DSA	Disabled Students' Allowance
JSA	Jobseeker's Allowance
SDP	Severe Disability Premium
LWC	Limited Capability for Work
PIP	Personal Independence Payment
CHC	NHS Continuing Healthcare
SMP	Statutory Maternity Pay





APPENDIX 3

UNDERLYING DATA

ABOUT OUR UNDERLYING DATA

The following tables show a section of the outputs of our main computational methods of analysis - Named Entity Recognition (NER) and Surprising Phrase Extraction (SPD) - which we used to produce our wordclouds.

NER is a process by which we train an algorithm to identify particular phrases within our dataset which are likely to be the names of individuals, places or organisations. This method struggled to distinguish between the acronyms commonly used to discuss types of benefits, such as UC for Universal Credit, and the acronyms used to refer to organisations, such as the DWP for the Department of Work and Pensions. As a result, our analysts manually sorted the dataset into these two categories.

SPD process which compares the entire text of our dataset with an 'average' selection of text (in this case, a large collection of Wikipedia articles), in order to identify which words and phrases are much more likely to occur in our dataset than the 'average' dataset. This allows us to draw out the topics which are distinctive, enabling us to understand the overall contents of our dataset.

In subsequent waves of this project, the following datasets will be used as a benchmark for comparison, allowing us to understand how the topics of discussion vary over time.

TABLE OF EXTRACTED ENTITIES - ORGANISATIONS

ORGANISATIONS	COUNT
DWP	587
NHS	108
Google	24
A&E	16
Social Security	14
ADP	13
CMS	11
SSP	9
UN	9
HSBC	8
EU	7
Tesco	7
Cornwall Council	6
Kia	6

ORGANISATIONS	COUNT
Social Security Scotland	6
Tribunal Service	6
Asda	5

Note: The entity extraction has picked up many acronyms which are types of benefits, which we manually separated

TABLE OF EXTRACTED ENTITIES - PEOPLE

ORGANISATIONS	COUNT
Starmer	12
Mims Davies	8
Rishi Sunak	6
Jo Churchill	6
Liz Kendall	6
Stephen Timms	6
Sunak	4
Neil Couling	2
Peter Schofield	2
Helga Swidenbank	2
Paul Maynard	2
Dorinnia Carville	2
Blair	2
Lee Anderson	2
Linda Burnip	2

ORGANISATIONS	COUNT
Kamran Mallick	2
Rebecca Hilsenrath	2
Lucy Letby	2
Clare Moriarty	2
Iain Duncan Smith	2

TABLE OF EXTRACTED ENTITIES - BENEFITS

BENEFITS	COUNT
WCA	62
UC	60
DLA	46
LPA	23
ESA	21
CMS	6
DSA	5
SDP	4
JSA	4
LCWRA	4
LWC	4
PIP	4
CHC	2
SMP	2

TABLES OF SURPRISING PHRASES (BY FORUM)

DisabilityHelp		
PHRASES	SPD SCORE	COUNT
dwp	6.049025907	145
lcwra element	5.184114613	20
carers allowance	5.043779675	36
freepost dwp	4.571136029	33
esa		
uc50 form	4.167180355	17
esa	4.095701331	716
for the wca	4.021291082	4
esa50 form	4.021291082	12
smp is	4.021291082	6
the descriptors	3.850422019	8

FinancialHelp		
PHRASES	SPD SCORE	COUNT
the dwp	4.816044181	78
taxable income	4.326590698	46
motability	4.019634493	50
the lpa	3.914495731	19
descriptor e	3.605146767	12
to hmrc contributing 2k for instance	3.245446102	8
dla	3.201191093	22
descriptors	3.154886525	21
doesn	3.154886525	0
the carers	3.1063333	8

TABLES OF SURPRISING PHRASES (BY FORUM)

FamilyHelp		
PHRASES	SPD SCORE	COUNT
carers allowance	8.1780353	5
carers allowance	4.603581849	5
child maintenance	4.195400513	12
child maintenance	4.024782499	12
payments	3.817119386	4
paying	3.456403216	4
income	2.908851376	7
other parent	2.743347839	4
his daughter	2.54399317	4
full time education	2.536355942	6

Note: Due to the reduced data volume, we were unable to use SPD on MentalHealthHelp. In addition, some of the phrases for FamilyHelp are repeated, again due to low data volume.

GovernmentHelp		
PHRASES	SPD SCORE	COUNT
the dwp	5.925926968	337
lcwra	4.219364072	105
adhd	3.922441851	78
for a mandatory reconsideration	3.842505838	11
doesn	3.643682718	0
wca	3.55528598	54
carer	3.478472802	41
the jobcentre	3.458310829	27
mandatory reconsiderations or tribunals to help	3.437733971	41
pip	3.383510365	847

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