**Disability Benefits and Work Impact survey**

A large print and plain text friendly survey version.

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**About the Survey**

This research is being conducted by WheelieQueer - a UK small business supporting disabled people with their disability benefits such as PIP who also provide LGBT+ inclusion training - in collaboration with the Wellcome Collection, a free museum and library that aims to challenge how we all think and feel about health. We will publish a report using the aggregated results from this survey later in the year.

The closing date for this survey is **January 28th 2024.**

The survey explores themes that might impact or affect someone being able to work and be in receipt of disability benefits. We will collect information about your lived experience as a disabled person, its impact on your ability to work and your experience with the UK benefits system. Your responses will help us to shape our internal processes on how to support disabled collaborators in receipt of benefits.

There are 10 sections:

1. About the Survey
2. Eligibility
3. Consent
4. About You/Demographics
5. Disability and Care Responsibility
6. Work
7. Claiming Disability Benefits and Barriers
8. Benefit Gateway Schemes
9. Impact on work
10. Solutions and Beneficial Support Options

The survey should take you around 20-30 minutes of your time.

All your answers will be anonymous, and there is no obligation to provide any personal information.We cannot identify individual responses.

Who can take part?

This survey is designed to be completed by anyone in receipt of disability benefits in the UK and over 16.  Please base you answers on your most recent benefits, even if you have been on benefits for a long time.  You must be currently working, have recently worked or plan to work as a freelancer/in self-employment — but the sector does not matter.

What about privacy and confidentiality?

Responses to the survey will be anonymous and will be stored securely on a password protected computer at WheelieQueer for 5 years. After this time, the data will be destroyed. Only the leads from WheelieQueer and Wellcome Collection on this project will have access to the data. The results of the study may be published but will not include identifiable information.

What if I have any questions?

If you have any questions about the survey, you can contact Jasper Williams by emailing wheeliequeer@gmail.com or Helen Wakely by emailing h.wakely@wellcome.org.

Please share the survey with your disabled friends and encourage them to participate too.

Thank you!

**Eligibility**

This survey is designed to be completed only by people who are aged 16 or older. We kindly ask that you do not complete this survey if you are under 16 years of age. Please delete the appropriate responses when answering the below questions:

Are you aged 16 or older?

Yes

No

Are you either in the process of or currently in receipt of disability benefits?

Yes

No

Are you working, have recently worked or plan to work as a freelancer (including self-employed, small business and any other form of external collaborator)?

Yes

No

Do you live in the UK?

Yes

No

**Consent**

Please delete the appropriate responses when answering the below questions:

I confirm that I have read and understand the information in Section 1.

Yes

No

I have had the opportunity to consider the information, ask questions, and have had these questions answered satisfactorily.

Yes

No

I understand that relevant sections of the data collected during this research will be looked at by the leads from WheelieQueer and Wellcome Collection. I give permission for these individuals to have access to my data.

Yes

No

I understand that the data collected about me during the study will be anonymous and that it may be aggregated into an anonymised report with data from other respondents.

Yes

No

I agree to take part in this survey research

Yes

No

**About You/Demographics**

All these questions are optional, but having demographic information helps us to see how different factors impact the topics and themes we will be looking at, such as support in work. Please delete the appropriate responses when answering the below questions:

What country do you currently reside in?

England

Scotland

Wales

Northern Ireland

Prefer not to say

What is your age range?

16-24

25-34

35-44

45-54

55-64

65-74

75 or older

Prefer not to say

What is your ethnicity?

Arab

Asian or Asian British - Bangladeshi

Asian or Asian British - Chinese

Asian or Asian British - Indian

Asian or Asian British - Pakistani

Asian or Asian British - Any other Asian background

Black or Black British - African

Black or Black British - Caribbean

Black or Black British - Any other Black background

White - English/Welsh/Scottish/Northern Irish/British

White - Irish

White - Gypsy or Irish traveller

White - Roma

White - Any other White background

White and Asian

White and Black African

White and Black Caribbean

Hispanic

Latina/Latino/Latinx

Any other ethnic background

Prefer not to say

Prefer to self-describe ethnicity:

Which of the following describes your gender?

Man
Woman
Non-binary
Prefer not to say

Prefer to self-describe gender:

Do you identify as transgender (including non-binary genders)?

Yes, I am transgender or non-binary

No, I am cisgender

Prefer not to say

Do you identify as LGBTQ+?

Yes, I am LGBTQ+

No, I am not LGBTQ+

Prefer not to say

**Disability and Care Responsibility**

When we say 'disabled', we include Deaf, Autistic, mental health and chronic illness. By health conditions, we are including mental health, physical, sensory or cognitive differences. We are not asking about a formal diagnosis, but what affects you. When we are asking about care or support, this can be either informal or formal care or support, such as from family and friends, support workers, carers and PAs.

Please delete the appropriate responses when answering the below questions:

Do you consider yourself disabled or have a long-term condition?

Yes, I am disabled or have a long-term health condition

No, I am non-disabled

Prefer not to say

Do you experience barriers or limitations in your day-to-day activities related to any health conditions?

Yes, substantial barriers or limitations

Yes, some barriers or limitations

No, I don't face any barriers or limitations

Prefer not to say

What are the types of disability or impairment that affect you? Keep all responses that apply.

Autoimmune condition

Blind or visual impairment

Chronic pain or illness

Cognitive or brain difference

Deafness

Facial difference

Learning difference

Learning disability

Long-term health challenge

Mental Health challenge

Mobility challenge

Neurodivergence

Speech and/or language condition

I am non-disabled

Do you receive any care or support?

Yes, I receive care or support

No, I don't receive care or support

No, but I need care or support

Prefer not to say

What type of care or support do you receive? Keep all responses that apply

Unpaid friends or family

Privately paying friends, family or someone else

Through a care agency

Through social care Direct Payments scheme

Through social care Personal Health Budget scheme

Through Access to Work

Prefer not to say

Do you also have any caring responsibilities (support you provide to someone)? Keep all responses that apply

Yes, I am the caregiver of a child (under 18)

Yes, I am a PA, support worker or carer of a disabled child

Yes, I am a PA, support worker or carer of a disabled adult

Yes, I am a PA, support worker or carer of an older person (over 65)

I have caring responsibilities but prefer not to specify what these are

No, I can't provide caring responsibilities

No, I have no caring responsibilities

Prefer not to say

**Work**

When we ask about location and you work remotely, pick the location where you work from (e.g. if working from home, your home address region). Some answers require a written response. Please delete the appropriate responses when answering the below questions:

What is your employment status? Keep all responses that apply

I previously worked as a freelancer in the UK, but not since January 2023

I am working towards becoming a freelancer in the UK

I am an employee on a freelance contract (PAYE)

I am currently working as a freelancer or otherwise self-employed in the UK

I am a Director of a Limited Company

I am a freelancer on long-term sick leave (e.g. claiming ESA or sick pay)

I am in another freelance or self-employment situation.

Prefer not to say

Which sector do you usually, or plan to, work in?

In which region is your job normally based?

London

South East

South West

West Midlands

East Midlands

Yorkshire and Humber

North West

North East

Scotland

Wales

Northern Ireland

Outside of the UK

Prefer not to say

How do you normally work?

Always remotely

Always in-person

Hybrid, with mostly remote

Hybrid, with mostly in-person

Prefer not to say

In your self-employment, have you had any freelance contracts, partnerships or collaborations?

Yes

No

What type of freelance collaboration work have you had? Keep all responses that apply.

Freelance contract with another freelancer, self-employment or small business

Freelance contract with a corporate business

Freelance contract with charity or non-profit work

Partnership with another freelancer, self-employment or small business

Partnership with a corporate business

Partnership with charity or non-profit work

Collaboration with another freelancer, self-employment or small business

Collaboration with a corporate business

Collaboration with charity or non-profit work

I have not had any form of freelance collaboration or partnerships

Prefer not to say

Have you previously been in contracted, paid employment?

Yes

No

Did you disclose your disability to your workplace?

Yes

No, I didn’t have a diagnosis or disability at the time

No, I didn’t feel safe or confident to do so

Prefer not to say

What type of work did you previously do? Keep all responses that apply

Part-time work (less than 35 hours per week)

Full-time work (35 hours or more per week)

Job-share work

Zero hours contract

Temporary employment

Permanent employment

Fixed term employment (less than 6 months)

Fixed term employment (between 6 months and 1 year)

Fixed term employment (more than 12 months)

Prefer not to say

**Claiming Disability Benefits and Barriers**

Some answers require a written response. Please delete the appropriate responses when answering the below questions:

Which benefits have you previously received? Keep all that apply

Adult Disability Payment (Scotland)

Armed Forces Independence Payment

Attendance Allowance

Blind Person's Allowance

Carer's Allowance

Carer's Credit

Disability Living Allowance

Employment and Support Allowance (Support group)

Employment and Support Allowance (Work-related activity group)

Housing Benefit

Incapacity Benefit

Income Support

Jobseeker's Allowance (Contribution-based)

Jobseeker's Allowance (Income-related)

Jobseeker's Allowance (New-style)

Local housing allowance

Pension Credit (Guarantee Credit)

Pension Credit (Savings Credit)

Personal Independent Payment

Universal Credit (Limited Capability for Work)

Universal credit (Limited Capability for Work and Related Activity)

Working Tax Credit

None of the above

Which benefits do you currently receive? Keep all that apply

Adult Disability Payment (Scotland)

Armed Forces Independence Payment

Attendance Allowance

Blind Person's Allowance

Carer's Allowance

Carer's Credit

Disability Living Allowance

Employment and Support Allowance (Support group)

Employment and Support Allowance (Work-related activity group)

Housing Benefit

Incapacity Benefit

Income Support

Jobseeker's Allowance (Contribution-based)

Jobseeker's Allowance (Income-related)

Jobseeker's Allowance (New-style)

Local housing allowance

Pension Credit (Guarantee Credit)

Pension Credit (Savings Credit)

Personal Independent Payment

Universal Credit (Limited Capability for Work)

Universal credit (Limited Capability for Work and Related Activity)

Working Tax Credit

None of the above

Which benefits, if any, have you applied for? Keep all that apply

Adult Disability Payment (Scotland)

Armed Forces Independence Payment

Attendance Allowance

Blind Person's Allowance

Carer's Allowance

Carer's Credit

Disability Living Allowance

Employment and Support Allowance (Support group)

Employment and Support Allowance (Work-related activity group)

Housing Benefit

Incapacity Benefit

Income Support

Jobseeker's Allowance (Contribution-based)

Jobseeker's Allowance (Income-related)

Jobseeker's Allowance (New-style)

Local housing allowance

Pension Credit (Guarantee Credit)

Pension Credit (Savings Credit)

Personal Independent Payment

Universal Credit (Limited Capability for Work)

Universal credit (Limited Capability for Work and Related Activity)

Working Tax Credit

None of the above

*Experience and barriers with the benefits system*

Were you aware of help available to support you with your disability benefits claim?

Yes

No

If any, where did you receive help from with your benefits claim? Keep all responses that apply.

Disability benefits adviser

Facebook group or social media community

Friends, partner or family

PA, support worker or carer

None

Prefer not to say

What help did you get? Keep all responses that apply.

Understanding (‘translating’) what the questions meant

Seeing if I am eligible

Going through the criteria and descriptor points

How to phrase my answers

Filling out the form for/with me

Discussing what evidence to send

Proofreading my application before I sent it off

Templates for supporting information

Helping to write my MR or appeal request

Representation at appeal

Social support, such as talking through feelings/anxiety

None

Prefer not to say

*Stage: New claim and review*

Were you successful with your benefits first time (i.e. you did not need to appeal)?

Yes, and I was completely happy with the rate of my award components

Yes, but I wasn’t happy with the rate of my award components

No, I was not successful in meeting any of the award components

Did you feel confident with the application you sent off?

I felt extremely confident in both my answers and evidence

I felt confident in my answers, but not my evidence

I felt confident in evidence, but not my answers

I felt somewhat confident in both my answers and evidence

I felt somewhat confident in my answers, but not my evidence

I felt somewhat confident in evidence, but not my answers

I felt neither confident in my answers nor my evidence

Roughly, how many months were there between your assessment and getting your entitlement letter?

(Your entitlement letter states whether you are successful, points scored, and the length of your award)

Roughly, how many months were there between you sending off your application form and getting an assessment date?

Rate your experience of barriers with:

Contacting the DWP

0 - not at all

1

2

3

4

5 - significant issues

Filling out the claim form

0 - not at all

1

2

3

4

5 - significant issues

Gathering and finding evidence

0 - not at all

1

2

3

4

5 - significant issues

Taking part in a face-to-face assessment

0 - not at all

1

2

3

4

5 - significant issues

Taking part in a remote assessment

0 - not at all

1

2

3

4

5 - significant issues

Did you appeal the decision?

No, I was happy with my result

No, I didn’t know how to appeal

No, I missed the deadline

No, I was worried my given award would be taken away

No, I was aware that I could but didn’t have the energy or support

Yes, I appealed by myself

Yes, I appealed with support

*Stage: Mandatory Reconsideration*

Roughly, how many months were there between your mandatory reconsideration request and getting the DWP's decision letter?

(The DWP decision letter states whether they changed their decision, if you were successful, points scored, and/or the length of your award)

Rate your experience of barriers with:

Understanding the DWP’s decision letter

0 - not at all

1

2

3

4

5 - significant issues

Reading through the DWP assessor’s report

0 - not at all

1

2

3

4

5 - significant issues

Making a mandatory reconsideration request

0 - not at all

1

2

3

4

5 - significant issues

Finding and submitting additional evidence

0 - not at all

1

2

3

4

5 - significant issues

*Stage: Appeal*

How many months were there between your appeal request and getting a court date?

(The court date is usually from HM Courts & Tribunals Service and will be a letter or email)

How many months were there between your tribunal hearing and receiving your back payment?

(Your back payment is the money you received after a successful appeal hearing)

Rate your experience of barriers with:

Making an appeal request - grounds for appeal

0 - not at all

1

2

3

4

5 - significant issues

Going through appeal bundle sent from DWP

0 - not at all

1

2

3

4

5 - significant issues

Preparing for appeal tribunal

0 - not at all

1

2

3

4

5 - significant issues

Going to tribunal court

0 - not at all

1

2

3

4

5 - significant issues

Please rank the following barriers from 1 - 7

(1 being the least and 7 the most substantial barrier)

Difficulty understanding and processing DWP correspondence

Inaccessible DWP contact methods, such as audio phone calls

Inaccessible application form, such as complex jargon or no BSL submission

Impossible timescales for submitting forms, additional information or appeal requests

Financial impact in order to get evidence from consultants

Emotional impact in enduring assessment/invasive questions

Physical health and flare-ups from engaging with the benefits system

If comfortable, please share any other experiences/challenges when navigating the system.

**Benefit Gateway Schemes**

Benefits gateway schemes are the things you are entitled to once you are in receipt of benefits, such as a blue badge or bus passes. Please delete the appropriate responses when answering the below questions:

Are you aware of other gateway schemes you can access?

Yes, and I claim everything I’m eligible for

Yes, but I don’t receive everything I’m eligible for

Yes, I’ve heard of some but not sure what I’m eligible for

No, I’ve never heard of any of them

What schemes do you receive or have you applied for? Keep all responses that apply

Travel assistance:

Blue badge

Disabled person’s bus pass

Disabled person’s bus pass with companion pass

Disabled person's railcard

Disabled freedom pass (London only)

Motability scheme

Taxicards

Vehicle Tax Exemption

Top-ups and discounts:

Cost of living £150 payment

Council tax discount

Disability, enhanced or severe disability premium

Crisis or other financial aid:

Budgeting Advances Crisis Grant (Scotland only)

Budgeting Loans

Community Care Grant (Scotland only)

Disabled Person's Allowance (Northern Ireland only)

Discretionary Assistance Fund (Wales only)

Discretionary Housing Payment

Household Support Fund

Individual Assistance Payment (Wales only)

Self-Isolation Support Grant (Scotland only)

Universal Credit Contingency Fund (Northern Ireland only)

Energy payments, discounts and schemes:

Cold Weather Payment (Scotland only)

First Time Central Heating grants

Lower cost broadband and phones

Priority services for energy and power companies

Scottish Welfare Fund (Scotland only)

Warm home discount

Water Bill Scheme

Water Charges Reduction Scheme (Scotland only)

Winter Fuel Support Scheme (Wales only)

Winter Heating Payment (Scotland only)

Social and leisure assistance:

CEA card

Free TV licence

Leisure access cards, e.g. National Trust and museums

Leisure access scheme such as companions for gyms and swimming

Theatre and cinema access schemes

Healthcare assistance:

Disabled Facilities Grants

Healthcare Travel Costs Scheme/HTCS

Medical exemption certificate

NHS low income scheme

Do you feel you would benefit from support in knowing what is available to you and how to (or helping you) apply for the above?

Yes

No

**Impact on Work**

Some answers require a written response. In written responses, please do not include any identifying information. Please delete the appropriate responses when answering the below questions:

Did the impact of work on your disability affect your decision to become self-employed?

Yes

No

Prefer not to say

Have you faced disabling barriers in applying for work, or in your career?

Yes

No

Prefer not to say

What disabling barriers have you faced in any previous contracted work?

(If none, type N/A)

What disabling barriers have you faced in current freelance work?

(If none, type N/A)

Do you consider your previous or most recent contracted workplace to be accessible and inclusive? Rate the inclusivity and accessibility from 0 - 5

0 - not at all

1

2

3

4

5 - significant issues

What made your previous or most recent contracted workplace inclusive, or not?

What could make your previous or most recent contracted workplace more accessible and disability inclusive?

Do you consider your most recent freelance collaborative work to be accessible and inclusive? Rate the inclusivity and accessibility from 0 - 5

0 - not at all

1

2

3

4

5 - significant issues

What made your current or most recent collaborative work to be accessible and inclusive, or not?

What could make your recent or other collaborative work more accessible and disability inclusive?

How often have you been supported by your freelance collaborations?

Always supported

Sometimes supported

Neither supported or unsupported

Hardly ever supported

Never supported

I don't tell anyone about my access requirements

Prefer not to say

Have you ever applied for Access to Work?

Yes, I currently have an Access to Work grant

Yes, I have had an Access to Work grant in the past

Yes, but I didn't get a grant

No, I've never applied for Access to Work

Has anyone in your freelance work supported or directed you to support for your Access to Work claim?

Yes

No

N/A

What was the role (i.e. the job title such as manager) of the person who supported or directed you to support for your disability benefits claim?

**Solutions and Beneficial Support Options**

Looking ahead, we want to see how freelance partnerships, collaborators and associates can be more inclusive of disabled freelancers on benefits. Some questions require a written response. Please delete the appropriate responses when answering the below questions:

Would you find having a designated disability benefits co-ordinator or liaison to help guide you though benefits claims, entitlement and Access to Work helpful?

Yes

No

Would you find being directed to external support for your Access to Work and Disability Benefits claims helpful?

Yes

No

Would you find being offered accessible in-person or remote therapeutic support to help with emotional/mental wellbeing of engaging with the benefits system helpful?

Yes

No

Please state any other support that would be useful

For you, what are important things to consider around payment for those on disability benefits - especially with work conditions, for example Universal Credit and ESA?

Please rank these possible solutions for equitable payment from 1 (least helpful) to 5 (most helpful)

Receiving vouchers

Paid in structured instalments

Provided with an exchanged, equitable service

Endorsements and references for services

Accommodation and travel costs covered

If you are unable to receive income for work because of your benefits, what would be your ideal method of payment for your services, so that it is still seen as equitable?

Which of the following would you consider best practices for freelance collaborations? Keep all responses you like.

(For instance, practical ways that freelance collaborators can reflect on their practice to be more inclusive)

Having specific disability benefits updates training as CPD/in CPD days

Access to disability benefits drop-ins for questions or queries for specific situations

Creating and providing signpost resources for disabled collaborators on benefits

Mentioning alternative payment options in all paperwork and resources

Reading up and campaigning for a better disability benefits system

Engaging in disability benefits consultations

Platforming and sharing fundraisers and crowdfunding

How else can freelance collaborations reflect on how to best support people on disability benefits?

Which would you like companies or businesses do to support people on disability benefits? Keep all responses that apply.

(For instance, ways that freelance collaborators can improve support to disabled collaborators)

Give access to disability benefits co-ordinator/liaison from job application

Mention disability benefits coordinator/liaison contact in every document or resource provided

Provide accessible resources on signposting to support and useful organisations

Covering costs of access that would otherwise be from ATW if they received payment

Explaining about alternative payment options being available in every conversation and resource

Platforming and sharing fundraisers and crowdfunding

Are there any other practical ways that companies and businesses could support people on disability benefits?

Can you share any examples of good practice where an institution has helped you to feel comfortable making an application for freelance work?’

Is there anything else you would like to add?