

# #PeopleBefore Process

**The state of disability  
benefit assessments  
and the urgent need  
for reform**



Z2K's vision is that no-one in the UK should be living in poverty. We believe that adequate income and secure housing are key to creating a more equal society where everyone has the chance to lead a stable and dignified life. We work with people in London to solve their social welfare legal issues, with a focus on social security and housing matters, and we use the evidence from our casework to campaign to change policy and practice that drives injustice. Embedded at the heart of Z2K is our client-centred approach and our work to ensure the voices and views of people with lived experience are heard by decision-makers.

In 2020, we supported 1,085 people with 1,233 cases, securing financial benefits of over £6.5 million for our clients. This included helping over 250 disabled people appeal against decisions by the Department for Work & Pensions (DWP) to refuse their claim for disability benefits – Employment Support Allowance (ESA), Personal Independence Payment (PIP) and Universal Credit (UC) - at the First Tier Tribunal. Before the Covid pandemic and temporary suspension of all re-assessments and most face-to-face assessments, the figure was almost double. Over 90 per cent of the people we help to appeal end up winning their case.

### **Survey summary**

**In April 2021, Z2K surveyed 1,420 people who have been through the assessment process for disability benefits** – 1,220 had been assessed for PIP, 885 for ESA, and 166 for the Limited Capability for Work (LCW) elements of UC.

We asked people to share their insights on the assessment process – including the Mandatory Reconsideration (MR) and appeals process – as well as the changes that they would like to see made to the current assessment regime. We also asked their opinion on whether the Government's upcoming Health & Disability Green Paper will deliver on generating desired reform.

The top findings include:

- **70 per cent of people feel like the assessor DWP contracted to carry out their assessment did not understand their condition**
- **66 per cent of people feel like the assessment report they got after the decision did not reflect what they'd told the assessor in the assessment**
- **49 per cent of those respondents who challenged a decision to refuse their claim at DWP's internal MR stage saw that decision overturned.**
- **By contrast, 87 per cent of the remaining respondents who went on to appeal to the independent First Tier Tribunal had DWP's decision overturned**
- **89 per cent of respondents are either "not at all confident" (69 per cent) or "not so confident" (20 per cent) that the changes they would like to see made to the assessment process will be included in DWP's upcoming Health & Disability Green Paper**
- **Similarly, 88 per cent of people are either "not at all confident" (67 per cent) or "not so confident" (21 per cent) that the Government will use the feedback they receive during this Green Paper consultation to make changes to the assessment process for benefits**
- **74 per cent of respondents think the Government won't even bother to listen to the experiences of those who have been through the assessment process themselves.**

### **Survey responses**

#### **The assessment process**

From the moment people start the process for claiming disability benefits, people are met with barriers, hostility and stigma. Many people find the initial application forms too long and complex, with some unable to complete them without the support of family, friends, advice agencies or support workers. This lack of inaccessibility runs throughout the process – with assessment centres not always being accessible or safe for people to attend. One respondent told us:

**“On one occasion at an assessment a lady was having a seizure on the floor and two assessment workers said “she’s putting it on.” My daughter called an ambulance and they took the lady to hospital! The staff have a very uncaring, hostile attitude to the people they are assessing.”**

At the assessment itself, **70 per cent of respondents felt the assessor did not understand their condition.**

- For many, the process of the assessment and attitude of the assessors debilitates any meaningful understanding of their condition, and instead creates a traumatising and sometimes harmful environment. Respondents shared how assessors work from a script – treating people as numbers as opposed to individuals – and as a result often ask irrelevant questions or make unsuitable demands of people.

**“I was restricted from giving full answers and forced to answer yes or no leading questions which restricted my answers. This opens the door to my answers being misinterpreted and used against me.”**

**“As noted the assessors would ask you not to do anything that would result in injury or pain. They would then ask you to perform a physical action and if you were limited and could not perform that action due to pain, they would say you refused.”**

**“I repeated several times how much pain I was in, which was visible. They still asked me to do physical 'tests' leaving me in tears and in severe pain.”**

**“During my very first assessment, the assessor waved her hand at me when I tried to explain my mental health issues and said "I'm not interested in that, I want to know if you can touch your toes". I received no points during that assessment. However, this was rectified at appeal.”**

- Many people felt like they weren't given time to explain themselves, and that anything they did say wasn't listened to, or was met with judgement and a lack of compassion. People also shared accounts of experiencing discrimination as a result of their ethnicity, as well as their disability, during the process.

**“I feel sometimes I have been mistreated because of my race. I had comments such as ‘people like you.’”**

- Respondents explained how the assessment fails to understand how conditions impact someone over periods of time, by reducing how a condition effects someone to a snapshot on a specific day.

**“I feel the system is completely unfit for purpose, in particular with regard to fluctuating conditions like chronic fatigue and pain. The assessment report stated that as my fatigue was owing to cancer a number of years ago that is could not be active now as my treatment was so long ago. I had to send back a statement of challenge, including citing that I would consult a solicitor, and quoting several high profile cancer sites which state clearly that for some people fatigue continues long after treatment. I felt the assessor had no knowledge of basic medical**

**facts. Also, I felt the judgments on what I can and cannot do had no nuance, no real comprehension of what it is like to have a fluctuating condition, and used this against me in fact.”**

- Assessors also routinely fail to understand the individual’s condition because they don’t have the relevant expertise in it, and they ignore or fail to engage with the relevant testimony and medical evidence that could help generate an understanding.

This results in many peoples’ assessment reports omitting or misconstruing vital information - with **66% people feeling like the assessment report did not reflect what they’d told the assessor in the assessment.**

- Many people felt their assessment report was not truthful to their individual’s testimony or medical evidence.

**“Each time I've had an assessment for PIP, I have felt that the report following it has been talking about someone else and not me.”**

**“When I received the assessors report I cried, because it reflected a perfectly healthy person, not someone who cannot clean their house or hold down a full time job, or has to go for a lie down after dusting half a room exhausted and in pain, some days after work I cannot even cross a road safely, I am struggling yet all of this was ignored because I am fine apparently.”**

**“What I said and what they wrote were two different accounts. I feel they judged me based on their interpretation rather than understanding my day to day difficulties.”**

**“She noted in the report that I couldn’t have mental health problems as I wasn’t rocking back and forward.”**

- There are also cases where more deliberate misconstruing of events occurs.

**“[The assessor] asked me if I needed a break, assessment was in my home and I needed the toilet so I needed someone to assist me. My niece was there so helped me out of my chair and then I slowly went up the stairs with her assistance etc. The assessor then said in the report that I got up without assistance and went the toilet so I had no issues with mobility using my crutches and had no issues with the stairs. However from where she was sitting she could not see me go up or down them as I need someone to help me and also ensure I don’t fall.”**

**“I was asked when I last went to the cinema and I was so overjoyed to say I had been a few weeks prior as it was my birthday, and in fact the first and only outing for a number of months. The report stated 'regularly socialises with friends’.”**

### Challenging a decision

In total, 905 respondents had challenged an assessment outcome by requesting an MR. Only 442 of these people had an original decision overturned at MR. 606 people have then gone on to appeal the original decision and MR, and 530 of those have then had the original decision overturned at tribunal. **The overturn rate for an assessment decision amongst respondents to our survey is 87 per cent at the First Tier Tribunal.** This reinforces HM Courts & Tribunals Service statistics, which report the overturn rates for ESA and PIP are both around 75 per cent.

However, challenging a decision at appeal is time-consuming and for many extremely stressful, especially when doing so without the support of advice services that could help them challenge this original decision. Many disabled people have to wait months on a reduced rate of income in the

case of ESA or nothing at all in the case of PIP before their appeal can be heard. Inevitably, this financial and emotional strain can take a terrible toll on people's mental health and well-being.

**"[Going to appeal] caused a massive amount of distress and I seriously considered suicide many times throughout the process."**

**"After the court appeal it sent me in a downward spiral causing depression (which I never claimed for as my depression is reactive to stressful circumstances) I never want to apply again. I felt and still do feel, that if I ever lose my house because I can no longer work and end up homeless there is no hope, no help, no one to rely on, if I found myself in that situation I would probably just end my own life than go through that fight again."**

As a result, many people are not well enough to appeal, especially if they have already been refused again at DWP's internal MR stage. This is particularly concerning given that more than three-quarters of DWP's disability benefit decisions are overturned by the independent Tribunal. Many disabled and seriously unwell people are stuck without the Social Security income they would be entitled to if their assessment have been done right the first time.

**"Didn't have the strength or energy to face appeal. The whole application and assessment is stressful making my symptoms worse and me more unwell. I couldn't put my body through any further stress."**

#### Reassessments

One of the key issues that came up repeatedly was that of reassessments. In particular, the mental and physical toll it takes on the individual to continually reassess people whose conditions are sadly not going to improve. And for people whose condition could improve – the frequency of reassessments often debilitates or slows the recovery process. By the time many disabled people managed to successfully challenge an incorrect assessment decision, they are called back for a reassessment and therein starts the whole process again.

Most respondents said they had been reassessed between 2 – 8 times, with many saying they had been reassessed over ten times, and a lot of people saying 'too many to recall'.

**"It was clear from the evidence I submitted (and on the day also drew her attention to) that my condition (which I have suffered since birth) was untreatable, in decline and with zero prospect of recovery or improvement, yet my award was limited to just three years on her recommendation .... repeating a costly assessment after such a short interval when a condition is clearly degenerative .... is in my opinion entirely frivolous and can simply benefit no one other than the company contracted to complete the assessment on behalf of the DWP .... these assessments are an excruciatingly stressful experience for the individuals unfortunate enough to require assessment, each of whom is already struggling with day to day living and for who a 'bad' result can be truly devastating."**

#### The changes people want to see made

We asked people what changes to the assessment process for disability benefits they would like to see Government make, and some of the recommendations people put forward included:

1. Reinstate indefinite awards for people whose condition will sadly not improve
2. If someone's condition might improve, reassess them less frequently than currently
3. All assessors to receive training to ensure they do not discriminate against individuals, and treat everyone they are assessing with dignity and respect

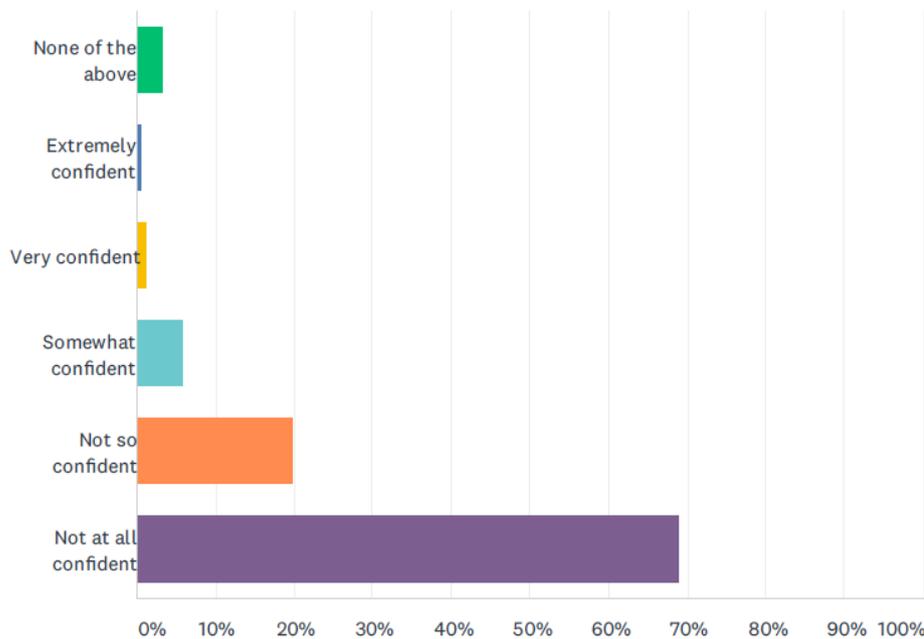
4. Ensure assessors are properly trained in the condition they are assessing
5. If an assessor does not have specialist knowledge of the condition they are assessing, they must consult with experts and use up-to-date evidence when making their assessment
6. Medical evidence, people's own testimony, evidence from parents, support workers, social workers, mental health workers etc. should not be undermined, misconstrued or ignored by assessors
7. Stop assessments entirely and decision to be made solely on medical evidence, people's own testimony, evidence from parents, support workers, social workers, mental health workers etc.
8. Audio record all assessments as default (with an 'opt out' option), and provide a copy to both DWP and individual
9. Remove private assessment companies, and bring assessments back in house or have them conducted by NHS like in Scotland
10. From forms to the assessments – make the process more accessible
11. Make the questions in the form and assessment more personalised and suitable to the individual, so they don't inflict physical or emotional harm
12. Understand conditions are variable and stop taking snapshots of days
13. There should be greater choice and flexibility about how an individual's assessment is conducted (face-to-face, at home, paper, phone, video etc.)
14. Faster decision making on the DWP side, and more notice and flexibility concerning deadlines for the individual
15. Assessors to move away from the medical model of Disability and adopt the social model of Disability
16. Regular input/consultations with disabled led organisations and disabled people on how to improve the assessments in the future

#### The Health & Disability Green Paper

Despite people being clear about what changes need to be made to the assessment process, **89 per cent are either “not at all confident” (69 per cent) or “not so confident” (20 per cent) that the changes they would like to see will be consulted on in the upcoming Health & Disability Green Paper.**

## How confident are you that Government will consult on these changes in the upcoming Health & Disability Green Paper?

Answered: 1,412 Skipped: 8



- A recurring reason people gave for this is the Government's failure over the past decade or so to meaningfully engage with people with personal experience of the system. The evidence gathering process does not lend itself to reform that would be of any real benefit to those people currently required to go through the assessment process.

**“From my experience so far the [Health & Disability Green Paper] process has been extremely opaque with as little attention being drawn to the review process as possible, so that as few people as possible are aware it is happening. It has also been delayed repeatedly.”**

**“The mechanisms for consultation are not good and reach only the tiniest fraction of those who have experienced issues and of those that respond.”**

**“Feels like the government is notoriously bad at consulting and making sure consultations are accessible.”**

- There is also the belief that Government have already made up their mind of what changes they want to see. Therefore, this consultation will merely act as lip-service, and they will not consult on any meaningful changes to the assessment process, because fundamentally Government have no commitment to real reform – only cosmetic changes.

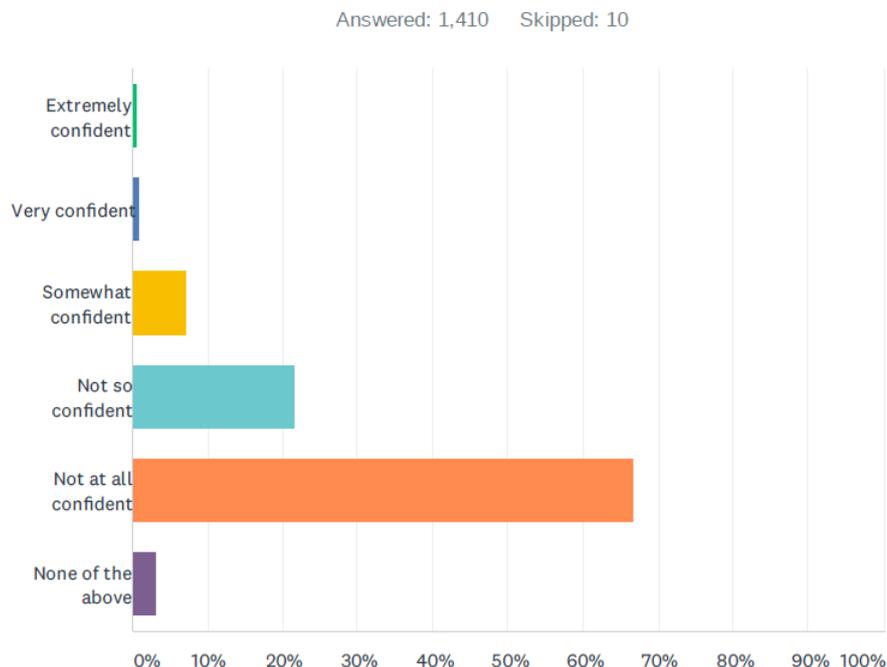
**“This Green Paper has been delayed multiple times and the current administration seems determined to funnel everyone into Universal Credit or push them off benefits where possible to reduced the benefits costs, as opposed to considering any meaningful reform of a broken system.”**

**“There may be a consultation, a paper work exercise which shows evidence of contacting some relevant groups, ticked the boxes, but ticking a box is not the same as listening and acting on evidence.”**

**“The Government, I have found, have their minds made up already and rarely listen...to the people who are ill and having to apply for help. They listen to experts who have not been ill themselves but who think they know how we feel day to day.”**

Even if Government does adequately consult on meaningful reform to the assessment process in the upcoming Green Paper, there is little hope that Government will act on this consultation, with **88 per cent of people either “not at all confident” (67 per cent) or “not so confident” (21 per cent) that Government will use the feedback they receive during this Green Paper consultation to make changes to the assessment process for benefits.**

**Q11 How confident are you that Government will use the feedback they receive during this Health & Disability Green Paper consultation to make changes to the assessment process for benefits?**



- There is a concern that much like in the individual assessment reports themselves, any evidence will be skewed to benefit the DWP over the individual.

**“I was shocked to hear of the recent report which did not find evidence of institutional racism in England. This suggests that any report can be written to support one particular point of view, without necessarily reflecting the evidence and general lived experience of the population.”**

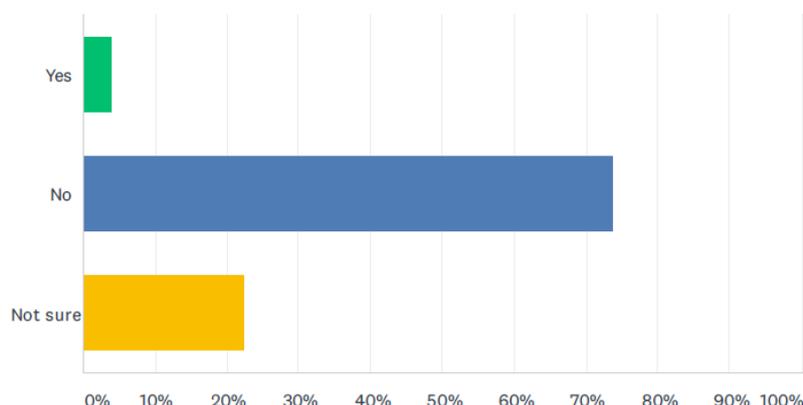
**“It seems the Government consultations can be narrowly focused to ensure the intended result is obtained.”**

- And people feel that any feedback that is acted on, will be that which ultimately benefits the DWP over the individual.

This is symptomatic of the general lack of faith people have in the Government’s desire to listen to or act on behalf of people receiving disability benefits, with **74 per cent of people thinking Government won’t listen to the changes people who have been through the assessment process themselves want to see made.**

## Q12 Do you think the Government will listen to the changes people who have been through the assessment process themselves want to see made to the assessment process for benefits?

Answered: 1,411 Skipped: 9



- One of the key reasons for people’s lack of faith, was that they felt the Government doesn’t care about or listen to disabled people – many cited that even the number of lives lost as a result of the current assessment system hasn’t resulted in any action.

**“I do not believe that they care enough about us. It’s why they try so hard to deny us the money we are entitled to under their system.”**

**“I don’t believe the Government care in the slightest about sick and disabled people. This has been demonstrated by their determination not to raise the level of legacy benefits in line with Universal Credit, leaving many long-term sick and disabled people disadvantaged during the pandemic.”**

**“I do not trust the government at all. Too many claimants have died yet they continue to allow this system to exist. They know it’s unfair and cruel. It’s had enough coping with health issues without this system affecting your mental health. It does make me feel suicidal at times.”**

These responses chime with a speech the former Work & Pensions Secretary, Amber Rudd, gave at Scope in March 2019, when she acknowledged the breakdown of trust between her department and many disabled people and accepted the need to do better in future.

More recently, the Government’s own independent Social Security Advisory Committee (SSAC) has confirmed that lack of trust remains. It made a series of recommendations for DWP to engage more meaningfully with disabled people, some of which would be especially useful in the context of the Green Paper. Ministers have yet to confirm which, if any, of these recommendations they will implement.

### **Conclusion**

As the results from this survey show, the assessment processes for disability benefits are failing even on their own terms of deciding whether someone gets the benefit Parliament has decided someone in their circumstances is entitled to. Success rates of claimants who appeal prove that even though some of the very worst decisions are being reversed by DWP at its internal MR stage, far too many are still not. We believe the numbers of disabled people appealing to the Tribunal and the numbers winning would be even higher if people had easy access to advice and support.

Even worse than being inaccurate however, these assessments are demeaning and degrading for many of those who undergo them. Many of the respondents to our survey felt the assessment processes were deliberately designed this way. As one said:

**“The whole experience has left a psychological scar along with the many others, which will no doubt stay with me for the rest of my life, I feel the anger and betrayal of it whenever I have to deal with it, or whenever something brings it to mind, or hearing about others having to go through the same process. There is no forgiveness for what I and others are being put through, no accountability for it, which is the greatest fear and sadness, and that they can continue to experiment with people’s lives in this way.”**

Like most respondents to our survey, Z2K believes that the assessment processes for disability benefits must be fundamentally reformed if it is to be fit for purpose and able to correctly assess people’s ability to access work or receive support for their disability.

This will clearly take time. And yet change is needed urgently. That is why we support many of the more immediate changes to the assessment process recommended by survey respondents.

And in the long-term, an alternative system should be co-produced with disabled people themselves, so that it works for those with direct experience of this regime and those that went before it. There are countless suggestions from people with experience of the system – both personally and through advocating for people going through it - that must be acted on. It is vital that going forwards, disabled people aren’t just seen as ‘users’ or ‘customers’ of the system, but play an intrinsic role in its creation and delivery.

**“Assessment process should be coproduced with disabled people and based on a Social Model examination of the socio-economic barriers facing each individual.”**

For further information about the survey and its results, please contact [rebeccastacey@z2k.org](mailto:rebeccastacey@z2k.org)