

Written evidence from the Zacchaeus 2000 Trust (Z2K) (HAB0054)

- Z2K's ([Zacchaeus 2000 Trust](#)) 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,¹ 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.
- Based on our extensive experience of helping to represent hundreds of disabled and seriously unwell people in their appeal at the First Tier Tribunal, we have undertaken research on the failings of health and disability benefit assessments.² This evidence is informed by our research, the experiences of our clients³ and feedback from other disabled people involved in our policy and campaigning work.⁴

Suitability of assessments

How could DWP improve the quality of assessments for health-related benefits?

1. Too many people who apply for health and disability benefits are met with barriers, hostility, and stigma, and are denied the income they are entitled to. The inadequacy of health and disability benefit assessments is demonstrated by the high success rate in challenging their outcomes. The latest Government figures show that 76 per cent of Personal Independence Payment (PIP) and 74 per cent of Employment and Support Allowance (ESA) appeals had the initial decision revised in favour of the claimant by the Tribunal.⁵ Our own success rate at Tribunal in 2020 was over 90 per cent.
2. In April 2021, Z2K surveyed 1,420 people who had been through the assessment process for disability benefits.⁶ 70 per cent of respondents felt the assessor did not understand their condition, and 66 per cent felt the assessment report did not reflect what they had told the

¹ In 2020, we supported around 1,000 people with 1,500 cases, securing financial benefits of £3.5 million for our clients. This included helping 270 people appeal against decisions by the Department for Work & Pensions (DWP) to refuse their claim for health and disability benefits – Employment Support Allowance (ESA), Personal Independence Payment (PIP) and Limited Capability for Work (LCW) elements of 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.

² From our 2018 [Access Denied](#) to our more recent [Blunt, Bureaucratic and Broken](#) and [#PeopleBeforeProcess](#) reports

³ Pseudonyms have been used throughout to protect our clients' identities

⁴ We use the term "disabled people" in this submission to refer both to disabled people and to people with long-term health conditions

⁵ <https://www.gov.uk/government/statistics/tribunal-statistics-quarterly-april-to-june-2021/tribunal-statistics-quarterly-april-to-june-2021>

⁶ <https://www.z2k.org/wp-content/uploads/2021/10/PeopleBeforeProcess.pdf>

assessor in the assessment.⁷ This raises serious questions about the fundamental basis of these assessments.

3. To start improving the accuracy of these assessments, there are some changes that DWP must implement immediately. From the start of the process individuals should be encouraged to obtain up-to-date evidence and reimbursed for any costs in doing so, with DWP providing better guidance on what would constitute good evidence. DWP should also ask people at the start of a claim if they wish information from other benefit claims to be considered. It should only do so where permission is given.
4. There is a non-exhaustive list of the types of evidence that could be helpful in demonstrating how a condition impacts on someone – medical evidence, people’s own testimony, evidence from the individuals’ parents, support workers, social workers, mental health workers, advocates etc. Importantly, DWP must change the way it engages with this evidence, with assessors being obliged to review all supporting evidence provided and to give equal weight to this as the assessor’s report. The latter is given much more weight in decision-making currently, which is resulting in too many flawed decisions. DWP must also be proactive in seeking any additional evidence.
5. There also needs to be an understanding that if someone is currently discharged from specialist input or does not have access to a specialist, the assessor does not assume that their condition has improved, or they are too well for the benefits they are applying for.
6. The use of informal observations must also be stopped, and all assessors should have to clearly explain why their judgement of a person’s capability diverges from an individual and their evidence’s account of their capability. DWP should automatically issue all individuals a copy of their assessment report, in their preferred format, to increase transparency and help to raise standards. To ensure that the information provided in an assessment report is not misconstrued, all assessments should be audio-recorded as default (with an ‘opt out’ option), as was recommended by the committee in its February 2018 report:

“The case for improving trust by implementing default audio recording of assessments has been strongly made. We recommend that the Department implement this measure for both benefits without delay.”⁸

7. In its response to that report DWP admitted,

“For PIP assessments, claimants can currently audio record their face to face assessment if they provide appropriate equipment. The equipment must generate two copies at the end of the assessment; one for the claimant, the other for the Assessment provider. Media types that are acceptable are standard CD and audio tapes only. While this arrangement means that claimants can in theory record their assessments, in practice the complexity and potential costs to claimants means that very few take up this option. We agree that this does not go far enough to help build trust in the system and therefore we intend to make recording the PIP assessment a standard part of the process.”⁹

⁷ <https://www.z2k.org/wp-content/uploads/2021/10/PeopleBeforeProcess.pdf>

⁸ <https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/829.pdf>

8. To have made such little progress on this over a period of nearly four years is extremely worrying. We urge the committee to both restate its previous recommendation, but also call on DWP to provide a firm timetable by which this audio recording will be rolled out nationwide.
9. In the longer-term, we want to see the assessment process fundamentally reformed, with an alternative system that has been co-produced with disabled people and Deaf and Disabled People's Organisations (DDPO) introduced in its place.

Have you seen any specific improvements in the process since the Committee last reported on PIP and ESA assessments, in 2018?

10. We are disappointed there has been so little improvement following the committee's 2018 report, with benefit assessments continuing to all too often deny people the vital income that they are entitled to. For example, in 2020, 58 per cent of the 499,761 new PIP claims were refused. In the first seven months of 2021, 57 per cent of the 300,993 new PIP claims were refused. (It is also worth remembering that even in the 43 per cent of cases when PIP is awarded, it is sometimes at a lower rate than the applicant considers their situation merits.)
11. These continuing high refusal rates help drive appeals. In 2017/18, 68 per cent of ESA and PIP appeals were successful. In 2018/19, this rose to a success rate of 73 per cent for both benefits. By 2020/21, 76 per cent of PIP and 74 per cent of ESA appeals were successful at Tribunal.¹⁰
12. There has, however, been some genuine improvement in the Mandatory Reconsideration (MR) process since 2019. We see less rubber-stamping of the original assessment decision, which we assume to be the result of the new operational approaches that encourage MR decision makers to gather additional oral and written evidence to make their decision. The percentage of PIP MRs that overturned the assessment decision rose from 23 per cent in January 2019 to 40 per cent in December 2019 and 63 per cent in July 2021.¹¹ The proportion of ESA MR decisions resulting in a change in award rose from 54 per cent in February 2020 to 82 per cent in April 2020. Since May 2020, approximately two thirds of MR decisions led to a change in award. And in April 2021, 64 per cent of decisions were revised.¹²
13. For those disabled people applying under Universal Credit, this full case review could be made easier if MR decision-makers were able to request any further evidence via someone's journal, and all applicants and their representatives were automatically able to upload all evidence to their journal without having to request an upload link.
14. In 2018, the committee recommended that DWP look afresh at a sample of MRs which upheld the original decision and were not appealed to assess their appropriateness. DWP rejected this recommendation, but we believe it has helped drive the improvement in performance at MR stage noted above. We would encourage the committee to recommend that DWP examine a

⁹ <https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/986/98602.htm>

¹⁰ <https://www.gov.uk/government/statistics/tribunal-statistics-quarterly-april-to-june-2021>

¹¹ <https://www.gov.uk/government/statistics/personal-independence-payment-statistics-to-july-2021/personal-independence-payment-statistics-to-july-2021>

¹² <https://www.gov.uk/government/statistics/esa-outcomes-of-work-capability-assessments-including-mandatory-reconsiderations-and-appeals-june-2021/esa-work-capability-assessments-mandatory-reconsiderations-and-appeals-june-2021>

sample of negative original decisions that were not then subject to an MR/appeal assess their accuracy and help estimate how many disabled people have been wrongly denied the benefit they are entitled to.

Do the descriptors for PIP accurately assess functional impairment? If not, how should they be changed?

Do the descriptors for ESA accurately assess claimants' ability to work? If not, how should they be changed?

15. A points-based system where a blanket assessment criterion is imposed on everyone is not suitable. It fails to generate an understanding of how someone's condition impacts specifically on them, and regularly results in aspects of their condition being undermined or missed. Instead, an assessment needs to follow a less prescriptive format, and provide the opportunity for people and their supporting evidence to explain for themselves the impact of a condition.
16. First and foremost, there should be a thorough review of the various assessment criteria, in consultation with DDPOs and disabled people. This is so that the assessment criteria can be more clearly communicated to, and understood by, individuals, as well as ensure they are fair and truly reflect a person's capacity to work or the extra costs they face.
17. Many respondents to our recent survey also felt 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.¹³ It is vital that assessors consider how a condition's impact varies over time, not just on a specific day. And assessors must not work only from a set script, but instead be able to respond to the information they are presented with, asking questions that are more personalised and suited to the individual. This is particularly important for ensuring that assessments don't inflict physical or emotional harm.
18. There needs to be much more flexibility concerning an assessors use of criteria. It should be more of a guide to facilitate an understanding on how someone's disability or health condition affects their ability to work, and its impact on their daily lives, as opposed to a rigorous system used to deny support if a set criterion of points are not met.

How practical would it be for DWP's decision makers to rely on clinician input, without a separate assessment, to make decisions on benefit entitlement? What are the benefits and the drawbacks of such an approach?

19. Many respondents to our recent survey said the assessor failed to understand their condition because they ignored or failed to engage with the relevant testimony and medical evidence that could have helped generate an understanding.¹⁴ If an assessor does not have specialist knowledge of the condition they are assessing, it must be a requirement that they consult with experts who do, and obtain up-to-date evidence, when making their decision. They must not undermine the evidence and opinion they are provided with.

¹³ <https://www.z2k.org/wp-content/uploads/2021/10/PeopleBeforeProcess.pdf>

¹⁴ <https://www.z2k.org/wp-content/uploads/2021/10/PeopleBeforeProcess.pdf>

Appeals data shows that, for some health-related benefits, up to 76 per cent of Tribunals find in favour of the claimant. Why is that?

20. In the past, DWP tried to claim that people were winning at the Tribunal because they brought forward new evidence. However, it subsequently transpired that this “new” evidence was almost entirely oral evidence, which would have been available at the outset of someone’s claim if DWP’s assessors had asked the right questions and listened to the answers.¹⁵ All too often it is not until our clients get to Tribunal that the evidence they have been providing from the start of their claim, is adequately engaged with.

Carlo has long term mental health problems linked to a traumatic past and was in receipt of standard rate of PIP for Daily Living (DL) and mobility until 2020. He was prompted to make a new claim when his award came to an end, his health has deteriorated since his last award and he now has a number of physical health problems in addition to poor mental health. His award was reduced to nothing following a reassessment, his mental health needs weren't considered at all, he also lost his Severe Disability Premium (SDP) within ESA. Z2K completed a very detailed MR for him pointing to medical evidence submitted from the mental health professionals supporting him and his GP. His MR came back unchanged, and Z2K lodged an appeal. The appeal was lapsed after just two weeks, using exactly the same evidence as the MR decision maker had, and Carlo was awarded double enhanced for an ongoing period.

21. In the same way the Tribunal does, DWP must start engaging with this evidence from the outset at its own assessment and MR stages, giving it equal weight to the assessment report, and not ignoring, undermining or wilfully misconstruing it.

What could DWP change earlier in the process to ensure that fewer cases go to appeal?

22. First and foremost, DWP must implement the changes to assessments outlined in our response to Question 1, so that assessments are done right first time and the quality of initial decision-making improves. Beyond that, it should build on its new approach at MR stage by conducting full case reviews. Everyone going through an MR should be given the opportunity to provide oral evidence of how their condition affects them, and to increase impartiality, those looking at a decision again should not be able to see the previous decision-maker’s conclusions.

23. There should also be a more appropriate use of “lapsing” appeals, to reduce the number of people who are having to go to Tribunal, which can be very stressful and time-consuming. However, as we outlined in our witness statements supporting Public Law Project’s legal challenge,¹⁶ DWP must consistently follow its own guidance on lapsing appeals¹⁷ to ensure that:

- appellants have the purpose of an offer to lapse clearly explained to them with any access and communication requirements met to facilitate this understanding;
- where an individual is being represented it is their representative that is contacted with this offer; individuals are not placed under time pressure to accept this offer;

¹⁵ <https://questions-statements.parliament.uk/written-questions/detail/2016-05-20/37773>

¹⁶ <https://publiclawproject.org.uk/latest/dwp-to-stop-cold-calling-disabled-people-to-make-low-benefit-offers/>

¹⁷ <https://depositedpapers.parliament.uk/depositedpaper/2283137/files>

- individuals are not intimidated into accepting this offer; and individuals are made aware of their appeal rights regarding this new offer.
24. We would also like to see DWP explain the lapsing process to people, along with their appeal rights regarding this, at the point of a negative initial decision or MR. This would mean offers to lapse weren't unexpected and that more of those whose application is rejected would have confidence in the value of an appeal.

Is there a case for combining the assessment processes for different benefits? If not, how else could the Department streamline the application processes for people claiming more than one benefit (e.g. PIP and ESA)?

25. Pursuing a single assessment in future, would not be supported by people accessing the system. Fundamentally, it doesn't make sense given that they're two very different assessments which require different information and relate to different benefits, and as one of our clients explains:

"People on different benefits have different requirements. They might have different reasons for wanting each of those. I can see from DWP fiscal perspective why they might want to merge benefits, but from a claimant perspective I think it's terrible."

26. Merging two very different assessments could also result in an increase in inappropriate decision-making where participation in employment is taken as an indication that a person has lower extra costs needs which would undermine the non-means-tested nature of PIP, or means-testing could just be completely applied into extra costs benefits and contributory benefits displaced.
27. It is also worth remembering, PIP is currently protected from the Benefit Cap. It is essential that support to help individuals manage extra costs related to their disability is not impacted by artificial caps and limits on benefits.
28. Bearing in mind the high rate of flawed decision-making by DWP, a single assessment could also leave people without any form of income if an incorrect assessment decision was made. As it stands, if someone in receipt of both PIP and ESA / a LCW element of UC is incorrectly refused one of these benefits following an assessment, they at least continue to receive some income until the other is restored. This would not necessarily be the case with a single assessment, as all income would stop.
29. We have received feedback that suggests having a system whereby evidence provided for a benefits application was held on a central system so it could be used for additional applications for other benefits, could help streamline the application process:
- "They could do with sharing information if the claimant agrees so you're not repeating too much. The amount of times I'm repeating the same things about my disabilities for two assessments. They shouldn't be the same assessment and benefit, but could the data that is used across the two assessments not be shared if the individual agrees to it?"*
30. However, there is a real concern that this data could be shared with other parties to the detriment of the individual, and we have clients who said they would be unwilling to have their

evidence held on such a system for fear of this being misconstrued and resulting in a worse or incorrect decision regarding their case.

What are your views on the Department’s “Health Transformation Programme”? What changes would you like to see under the programme?

31. The aims of the programme are positive, and we welcome the following changes: individuals being given more choice about they interact with DWP; better use medical evidence and data; focus on getting the right outcome quickly; assessments only conducted where absolutely necessary or desired by the applicant; the system being made more user friendly; decision-making improved first time round; and engagement with stakeholders improved.
32. However, we do have some concerns about this programme. The first is that having a case manager that is responsible for undertaking a challenge of the assessment they conducted could threaten the independence and impartiality of challenging decisions. The second relates to the data concerns outlined above with any potential system where DWP holds an individual’s evidence on one system that spans across all Social Security benefits. We are interested to see the early evidence from the pilot.

What would be the benefits and drawbacks of DWP bringing assessments “in house”, rather than contracting them to external organisations (Capita, Atos and Maximus)? In particular, would this help to increase trust in the process?

33. Until the Government starts to focus on where support must be provided as opposed to disallowed, we don’t believe there will be any real improvement in these assessments whether it is DWP itself conducting them, or a company contracted to do so. That said, the quality of DWP’s contract management of the assessor companies has been sorely lacking over nearly a decade now, with little evidence of decisive actions being taken by the Department to ensure improvement. This raises serious doubts about DWP’s capability to manage such outsourced contracts going forward. It is also fair to say that that many disabled people are distrustful of a system in which both the companies and the individual assessors appear to be profiting from a process which they find demeaning and even hostile, as well as failing in its own terms as evidenced by the number of successful MRs and appeals.
34. The HTP and the recent improvements at the MR stage both suggest DWP can improve the quality of decision-making more quickly when management lies in its own hands. Whatever approach is taken, however, there must also be an adequate feedback loop to those conducting assessments (be that contracted assessors or DWP itself) for incorrect decisions made at the assessment and MR stage that are overturned at the appeal stage. Perhaps surprisingly, at a presentation to the Disability Benefits Consortium in 2019, the assessor companies gave more persuasive explanation how this is done currently when DWP’s decision-makers disagree with an assessor’s conclusion, than DWP offered in relation to initial decisions overturned by MR or appeal. DWP must ensure it learns lessons from cases it gets wrong.

What lessons should the Department learn from the way that it handled claims for health-related benefit claims during the pandemic: for example, relying to a greater extent on paper-based assessments, or using remote/telephone assessments?

35. We received mixed feedback from clients regarding virtual assessments, with some feeling face-to-face assessments can better explain their physical disability, whereas paper-based assessments are preferable for explaining their mental health:

“For the mental health side of my disability the paper would be better because that side you can’t see...I can explain it better with more time to articulate it on paper rather than on the spot...but for the physical side I can write on the paper what I can or can’t do but...there’s not always as much evidence for that...they need to see me for that.”

36. They also raised concerns that virtual assessments are less personal and facilitate an easier refusal of support. One person said virtual assessments make it *“less personal and easier for an assessor to say yes this person isn’t entitled,”* with another saying: *“I think moving away from face-to-face is a cost saving exercise.”*

37. Overall, the commitment to relying to a greater extent on paper-based assessments is welcome given the stress and anxiety face-to-face assessments cause for many people, but this must be accompanied by a shift in DWP’s attitude to evidence. Until DWP stops undermining medical evidence, there is little trust that an increase in paper-based assessments will lead to significant improvements in the quality of decision-making.

Is there a case for making some of the changes permanent?

38. Going forwards, people being assessed should be able to decide which method of assessment would work best for them – be that face-to-face at an assessment centre or via a home visit, telephone, video or paper-based. And everyone, regardless of their access requirements, should be able to access their preferred type of assessment.¹⁸

39. We are also concerned that virtual assessments are sometimes being arranged without reference to the applicant. Two of our clients were recently sent a link for a video WCA – despite not requesting one – and both were stuck in the virtual waiting room for over an hour because DWP didn’t admit them. This cannot become the default approach, as many people who are digitally excluded will be unable to attend their assessment and at risk of being marked as having missed it.

DWP believes that applications for some benefits dropped sharply at the start of the pandemic because claimants weren’t able to access support (for example, from third sector organisations) to complete their applications. What are the implications of this for how the Department ensures people are able to access health-related benefits consistently?

40. 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. Z2K believes that everyone who would like to, should be able to complete an application form by themselves, and so DWP must now produce simplified forms in consultation with DDPOs and disabled people. All forms should be readily available from a variety of locations – including jobcentres, online, via post – and in a variety of formats – including audio-described and easy-read. It should also be possible for people to submit their form through whatever channel is

¹⁸ <https://committees.parliament.uk/publications/4938/documents/49395/default/>

appropriate for them, in person (via a home visit if necessary), by post, e-mail, telephone or online. This choice should run throughout someone's claim, with everyone able to decide how they access and manage their claim (digitally, via letters, face-to-face etc.).

41. DWP should also establish a "tell us once" service, across all DWP-administered benefits, for reasonable adjustment requests, and from the outset all communications with individuals must be clear, specific and in their requested format.

How can the Department best help the third sector to support claimants in their applications?

42. The end of Legal Aid for most Social Security benefits cases has had devastating consequences for hundreds of thousands of disabled and seriously unwell people at a time when they needed it most. As a result, most applications and almost all MRs and appeals are being taken forward without any state assistance even at a local level. For example, in 2019, Z2K helped 450 Londoners appeal against one of DWP's ESA or PIP decisions. This was only possible because of the financial support of trusts and foundations, individual donors and *pro bono* support from our partner law firms. Some of those people may have succeeded at appeal without us. But some wouldn't have. And many more wouldn't have even tried.
43. Z2K believes it is inappropriate for the State to force its citizens to have to seek the support of charities to negotiate its assessment obstacle course for Social Security benefits Parliament has deemed they should be entitled to. If the Government is not minded to restore Legal Aid for Social Security, then it must look again at the appropriateness of disabled people suffering a postcode lottery of voluntary sector organisations who might be able to help. DWP and the Government in general need to move beyond procuring contracts with a few big national charities to a system whereby it properly funds advice at a local level and leaves local authorities to determine who is best placed to provide it.
44. In a practical sense, so that advocacy services like our own can provide effective support, it is also essential that DWP stops its "explicit consent" policy and restores "implicit consent". Time and again Z2K's advisors are delayed or even obstructed by DWP's insistence upon explicit consent in cases where implicit consent would have been acceptable previously. Upholding the importance of advocacy services is just lip-service, unless obstructive consent barriers to them acting on a service user's behalf are removed. In April 2019, the Information Commissioner made clear the scope for DWP to change its current practice.¹⁹ Z2K is bemused that DWP has still not done so.²⁰

The impact of assessment/application on claimants

DWP recently published research on the impact of applying for PIP or ESA on claimants' mental and physical health. What would be the best way of addressing this?

45. To address the impact applying for health and disability benefits takes on an individual's mental health, we are calling for all assessors to receive training to ensure they do not discriminate against individuals and treat everyone they are assessing with dignity and respect. Our research

¹⁹ <https://questions-statements.parliament.uk/written-questions/detail/2020-09-22/93509>

²⁰ <https://z2k.org/dwp-routinely-refusing-to-implement-their-own-guidance-on-working-with-representatives/>

shows that the way the assessments themselves are conducted cause physical harm on individuals, with assessors often asking irrelevant questions or making unsuitable demands of people.

“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.”

46. This is why we are calling for changes to the descriptors as outlined in our response to Questions 3 and 4 to be implemented, so the assessments themselves aren’t responsible for worsening anyone’s mental or physical health.

47. The long waits people must endure to be assessed, and then challenge an incorrect assessment decision, take a huge physical and mental toll on people. In many cases, it deters people from fighting to get the income they’re entitled to – with only 9 per cent of people who receive an initial PIP decision lodge an appeal at a Tribunal.²¹ And as one respondent to our survey told us:

“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.”

48. DWP must work to reduce wait times for assessments and appeals, and more fundamentally focus on getting these assessments right first time, so people’s conditions aren’t worsened while waiting and fighting to get the support they are entitled to.

49. The continual reassessment people are currently subject to takes a huge toll on both their mental and physical health, as well as recovery. Most respondents to our survey 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’.²²

“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...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.”

Waits for assessments

What could the Department do to shorten waits for health-related benefit assessments—especially for ESA/UC?

50. Because the provision of UC50 forms is not automatic (it is the responsibility of a work coach to issue these), we have clients receiving UC who have been supplying fit notes and wrongly denied access to an assessment, and therefore additional support.

²¹ <https://www.gov.uk/government/statistics/personal-independence-payment-statistics-to-january-2021>

²² <https://www.z2k.org/wp-content/uploads/2021/10/PeopleBeforeProcess.pdf>

Our client Sara first applied for UC in May 2018 and had been providing fit notes from her doctor since June 2018. She should have been provided with a UC50 on the 29th day of her claim, but still hadn't received one over two years later when she came to Z2K for support. During this time, she had been subject to work search requirements. With our support, we contacted UC requesting that a UC50 was issued, and Sara completed this in February 2020. However, it took until April 2021 and Z2K repeatedly chasing DWP and Health Assessment Advisory Service for Sara to be offered a telephone assessment. Following this, it was decided that she had Limited Capability for Work and Work Related Activity (LCWRA), and she was also awarded a back-payment of £10,435 to cover the period from June 2018. While this is a fantastic result, Sara had to manage without this much needed income for an inexcusable 2 years, and because of the capital gains limit, Sara will need to ensure that this back payment is spent within 12 months.

51. It is important that UC50s are issued automatically on the 29th day of someone's claim where that person has been providing fit notes, so no-one is gatekept from attending an assessment. DWP should also continue to conduct more assessments via paper, if that is the preference of the individual, and only assess people when necessary, which would reduce the number of people requiring a face-to-face assessment, in turn reducing the wait time.
52. There should also be more inclination to maintain awards unless there is clear evidence of an improvement in someone's health. DWP's approach of continually reassessing people, means more people are being assessed than necessary, increasing the wait times for an assessment. To address this, DWP must reinstate indefinite awards for people whose condition will sadly not improve, and for people whose condition might improve, reassess them less frequently than it does currently.
53. There must also be a mechanism in place for Tribunals to be able to set, not just recommend, the length of award for all DWP administered benefits, and DWP should certainly not be able to reassess someone earlier than their award end date.

Farouk was placed in the Support Group of ESA at a Tribunal in May 2019, with the Tribunal providing a 24-month award length recommendation. However, less than six months later, Farouk was issued with a new ESA50. After completing and submitting this form with the support of Z2K, he was awarded Support Group again without needing to attend an assessment. But receiving this form and having to start the process again so soon after his Tribunal made him lose sleep and was very distressing for him.

How effectively does the "assessment rate" for ESA cover disabled peoples' living costs while they wait for an assessment? Is there a case for introducing an assessment rate for other health-related benefits?

54. DWP's primary focus must be on reducing the wait time for assessments and making sure these assessments are done right first time, so people aren't left struggling without the income they need to help them manage their disability for months on end. This would also mean fewer appeals and so a shorter waiting time for those to be heard at the Tribunal.

55. It is vital that no-one waiting to be assessed, or challenging an assessment decision, is subject to the Benefit Cap, claimant commitments, or at risk of sanction.
56. So that the ESA assessment and appeal-pending rate – as well as the standard allowance for income-replacement benefits such as UC and JSA against which they're benchmarked – provides more adequate support to people, Government should regularly commission research on minimum income standards and use this research to inform benefit rates, so Social Security income matches the cost of living.
57. The Government should also explore the potential for providing an assessment and appeal-pending rate equivalent for disabled and seriously unwell people going through a reassessment on PIP, where they've been entitled up until the end of their previous award and there has been no change to their condition or disability.

Health assessments in the devolved administrations

The Scottish Government intends to introduce its own assessment process for the Adult Disability Payment, which will replace PIP in Scotland from 2022. What could DWP learn from the approach of the Scottish Government?

58. The Scottish Government's development of Adult Disability Payment co-produced with disabled people, is a model DWP should follow when reforming our Social Security system. It would also benefit from adopting some of the other principles the Scottish Government have developed, in particular its regard for Social Security as a human right, and commitment to ensuring that those who are entitled to Disability Assistance are able to access it whilst being treated with dignity, fairness and respect.
59. To address some of the issues disabled people face when claiming and receiving PIP, DWP should also follow the Scottish Government in making decisions about entitlement using the applicants account of their circumstances and existing supporting information, and significantly reducing the number of face-to-face assessments and only asking someone to undertake a face-to-face assessment when it is the only practicable way to make a decision.

Policy development

How effectively does DWP work with stakeholders—including disabled people—to develop policy and monitor operational concerns about health-related benefits?

60. DWP's focus is very much in engaging with the larger national health and disability charities, as opposed to smaller organisations, DDPOs, or disabled people themselves. DWP therefore fails to consult or act on the changes that would have a meaningful and positive impact on disabled people, as demonstrated through the responses to our recent survey:²³
 - 89 per cent were either “not at all confident” (69 per cent) or “not so confident” (20 per cent) that the changes they would like to see made would be consulted on in the upcoming Health & Disability Green Paper.

²³ <https://www.z2k.org/wp-content/uploads/2021/10/PeopleBeforeProcess.pdf>

- 88 per cent of people were 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.
- 74 per cent of people thought Government wouldn’t listen to the changes people who have been through the assessment process themselves want to see made.

What steps could the Department take to improve its engagement with stakeholders?

61. As a first step, it is vital that DWP start engaging more with smaller organisations, DDPOs, and disabled people themselves. This engagement must be meaningful, with a clear process for how this feedback will inform and drive DWP’s work. The Social Security Advisory Committee’s report earlier this year, *How DWP engages disabled people when developing or evaluating programmes that affect them*,²⁴ provides a good basis for much more open and trustworthy engagement. Ultimately however, DWP Ministers and their Cabinet colleagues must be willing to act on this feedback on its entirety, not just that which is in the interest of or will benefit the Department. The Government as a whole must be open to fundamentally reforming this system, if that’s what this feedback suggests.

²⁴ <https://www.gov.uk/government/publications/ssac-occasional-paper-25-how-dwp-involves-disabled-people-when-developing-or-evaluating-programmes-that-affect-them/how-dwp-involves-disabled-people-when-developing-or-evaluating-programmes-that-affect-them-occasional-paper-25>

ANNEX A - Summary of recommendations

The fundamental reform that is required of health and disability benefits will clearly take time, yet change is needed urgently. That is why we are calling on DWP to make the following more immediate changes that would go some way to improving our Social Security system:

1. All assessors must receive training to ensure they do not discriminate against individuals and treat everyone they are assessing with dignity and respect.
2. Simplified benefit application forms must be produced in consultation with DDPOs and disabled people.
3. Everyone should be able to choose in what format and via what channel they make and manage their claim.
4. A “tell us once” service must be established across all DWP-administered benefits for reasonable adjustment requests, and all communications with individuals must be made in their requested format.
5. National and local strategies are needed to channel resources to charities and other advice agencies.
6. DWP’s explicit consent policy must be stopped, and implicit consent restored.
7. UC50s must be issued automatically on the 29th day of someone’s UC claim where they’ve been providing fit notes.
8. Individuals should be encouraged to obtain up-to-date evidence to support their claim and reimbursed for any costs in doing so.
9. All individuals and their representatives should be automatically able to upload all evidence to their journal without having to request an upload link.
10. Better guidance should be provided on what would constitute as good evidence to support a claim.
11. Individuals should be asked at the start of a claim if they wish for information from other claims to be considered, and this should only be done where permission is given.
12. The individual being assessed should be able to decide which method of assessment would work best for them. And everyone, regardless of their access requirements, should be able to access their preferred type of assessment, with safe and comfortable waiting areas for face-to-face assessments and the potential need for reasonable adjustments always considered.
13. There should be a thorough review of the various assessment criteria, in consultation with DDPOs and disabled people.
14. Assessments need to follow a less prescriptive format and provide the opportunity for individuals and their supporting evidence to explain for themselves the impact of a condition.
15. Assessors must consider how a condition’s impact varies over time, not just on a specific day.
16. Assessors must not work from a set script, but instead be able to respond to the information they are presented with, asking questions that are more personalised and suited to the individual.
17. There needs to be flexibility concerning an assessors use of criteria, where it’s used more as a guide to facilitate an understanding on how someone’s disability or health condition affects their ability to work, and its impact on their daily lives.
18. The use of informal observations must be stopped.

19. All individuals should be automatically issued with a copy of their assessment report, in their required format.
20. All assessments should be audio-recorded as default (with an 'opt out' option), and a copy provided to both DWP and the individual.
21. Evidence must be considered from a non-exhaustive list of sources – medical evidence, people's own testimony, evidence from the individuals' parents, support workers, social workers, mental health workers, advocates etc. - and decision makers must identify which of these are best placed to assess someone's condition.
22. Assessors should be obliged to review all supporting evidence provided by an individual.
23. Other types of evidence must be given equal weight to assessment reports.
24. If an assessor does not have specialist knowledge of the condition they are assessing, it must be a requirement that they consult with experts who do, and up-to-date evidence, when making their decision.
25. All assessors should have to clearly explain why their judgement of a person's capability diverges from an individual and their evidence's account of their capability.
26. Decision makers must be proactive in seeking any additional evidence and opinion that can support them in making their decision, and be able to request any further evidence they might require to support them in making their decision via someone's UC journal.
27. MR decision-makers must conduct a full case review.
28. All individuals going through an MR should also be given the opportunity to provide oral evidence of how their condition affects them.
29. The MR decision-maker should not be able to see the previous decision-maker's conclusions.
30. It is vital that no-one waiting to be assessed, or challenging an assessment decision, is subject to the Benefit Cap, claimant commitments, or at risk of sanction.
31. There must be an adequate feedback loop both within DWP and to their contracted assessors for incorrect decisions made at the assessment and MR stage that are overturned at the appeal stage.
32. DWP must start following their own guidance on lapsing appeals.
33. DWP must explain the lapsing process to people, and an individual's appeal rights regarding this, at the point of a negative assessment decision or MR.
34. There must be a mechanism in place for Tribunals to be able to set the length of award for all DWP administered benefits, and DWP must not be able to reassess someone earlier than their award end date.
35. For anyone whose condition will sadly not improve, they must not be subject to reassessments.
36. For people whose conditions might improve in the future, the frequency at which they are assessed must be reduced.

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