

## **Z2K's response to 'Shaping future support: the health and disability green paper'**

### **Introduction**

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, 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 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.

Too many people who apply for health and disability benefits are met with barriers, hostility, and stigma, and are denied the income they're entitled to. The inadequacy of health and disability benefit assessments is demonstrated by the high success rate in challenging their outcomes – the latest figures show that 76% of ESA and PIP Tribunals respectively had the initial decision revised in favour of the claimant.<sup>1</sup> Our own success rate at Tribunal was over 90% in 2020. We have produced extensive research on the failings of health and disability benefits – from our 2018 Access Denied<sup>2</sup> to our more recent Blunt, Bureaucratic and Broken<sup>3</sup> and #PeopleBeforeProcess<sup>4</sup> reports. This consultation response is informed by this research, the experiences of our clients<sup>5</sup> and feedback from disabled people<sup>6</sup> involved in our policy and campaigning work.

There are welcome aspects of the Health and Disability Green Paper that would go some way to improving health and disability benefits. However, this Green Paper doesn't go far enough in addressing the scale of the issue, with the proposals lacking the ambitious, more fundamental change required.

The paper also places too much emphasis and focus on work yet fails to recognise that some people may never be able to work, or the fact that many disabled people are working but living in poverty due to inadequate benefit levels. Income adequacy is one of the key omissions from this Green Paper. 22% of people in the UK are living in poverty,<sup>7</sup> and half of all people in poverty in the UK live

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<sup>1</sup> <https://www.gov.uk/government/statistics/tribunal-statistics-quarterly-april-to-june-2021/tribunal-statistics-quarterly-april-to-june-2021>

<sup>2</sup> [https://www.z2k.org/wp-content/uploads/2018/09/Z2K\\_disability\\_report\\_2018\\_Final\\_singlesheet.pdf](https://www.z2k.org/wp-content/uploads/2018/09/Z2K_disability_report_2018_Final_singlesheet.pdf)

<sup>3</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

<sup>4</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

<sup>5</sup> Pseudonyms have been used throughout to protect our clients' identities

<sup>6</sup> We use the term "disabled people" in this submission to refer both to disabled people and to people with long-term health conditions

<sup>7</sup> [https://trustforlondon.fra1.cdn.digitaloceanspaces.com/media/documents/Londons\\_Poverty\\_Profile\\_2020.pdf](https://trustforlondon.fra1.cdn.digitaloceanspaces.com/media/documents/Londons_Poverty_Profile_2020.pdf)

in a family that includes a disabled person.<sup>8</sup> Over a decade of real-term reductions of working-age benefits has driven down the incomes of low-income households, and while the £20 a week increase to UC went some way to restoring the gap between benefit rates and the cost of living, disabled people on legacy benefits struggled to put food on the table during the pandemic without any increase to their income.<sup>9</sup> And the removal of the UC increase, combined with the soaring cost of living,<sup>10</sup> will see many people pushed further into poverty and destitution.

Ultimately, we need a Social Security system that supports people to live stable and dignified lives. Although the Green Paper takes us only part of the way towards achieving this, and we have reservations regarding some of the proposals, we welcome the Green Paper initiative and look forward to engaging with DWP as this work is taken forward.

## **Z2K's response to questions from 'Shaping Future Support: The Health and Disability Green Paper'**

### **Chapter 1**

#### **15. What more could we do to improve reasonable adjustments to make sure that our services are accessible to disabled people?**

From the moment people start the process for claiming health and disability benefits, they are met with barriers, hostility and stigma. As one respondent to our recent survey<sup>11</sup> 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."*

The attitude and culture of DWP and those they contract requires urgent change, so that the process of applying for and receiving health and disability benefits allows for compassion, empathy and support. We want assessors to receive training to ensure they do not discriminate against individuals and treat everyone they are assessing with dignity and respect.

Alongside this, there are some key changes that DWP must make to ensure health and disability benefits are accessible to everyone.

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 is calling for DWP to 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 the individual to submit their form through whatever channel is appropriate for them, in person (via a home visit if necessary), by post, e-mail, telephone or online. This choice should run throughout

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<sup>8</sup> <https://socialmetricscommission.org.uk/wp-content/uploads/2020/06/Measuring-Poverty-2020-Web.pdf>

<sup>9</sup> <https://disabilitybenefitsconsortium.files.wordpress.com/2021/02/pandemic-poverty-stark-choices-facing-disabled-people-on-legacy-benefits-final.pdf>

<sup>10</sup> In August 2021, the cost of living as measured by the Consumer Price Index hit the highest level yet of 3.2% since records began in 1997 and is set to increase further. And from the 1<sup>st</sup> of October 2021, the energy price cap rose to the highest ever level of £1,277 in response to high wholesale energy prices.

<sup>11</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

someone's claim, with everyone able to decide how they access and manage their claim (digitally, via letters, face-to-face etc.).

DWP must 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.

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.

*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 29<sup>th</sup> 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.*

It is important that UC50s are issued automatically on the 29<sup>th</sup> day of someone's claim where that person has been providing fit notes, so no-one is gatekept from attending an assessment.

And regarding the assessment itself, in response to our recent survey<sup>12</sup> we received accounts from wheelchair users who had been sent to assessment centres that weren't step-free. Others talked about having to endure significant physical pain, stress and anxiety due to the inappropriateness of the assessment centre. Therefore, individuals must be able to choose where and in what format their assessment takes place, with safe and comfortable waiting areas for face-to-face assessments and the potential need for reasonable adjustments always considered.

### **17. Do you agree with the principles we have set out for advocacy support?**

Given that advocacy is crucial to so many people being able to obtain the support and benefits they need, it is welcome that advocacy and its life-changing role has been recognised by DWP in the Green Paper.

National and local strategies are needed to channel resources to charities and other advice agencies, so they are better able to assist people in navigating the health and disability benefit process. With potential advocacy support funded by DWP, this support would need to remain independent and impartial in order for people to receive effective advocacy and resolution of issues – it would not be appropriate for DWP to represent individuals in any potential dispute with itself. Support should also be easily accessible, and not require a referral from a work coach or stringent eligibility criteria.

Support must be available for not just making an initial claim, but also with ongoing claim maintenance. The importance of this was recently demonstrated by an issue identified in our

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<sup>12</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

casework: instead of PIP prompting people to put in a new claim by posting a PIP2 new claim form 6 months before the end of their award, PIP are now either calling or writing to individuals asking them to call the PIP new claims line and put in a new claim themselves. This onus now being on the individual to re-claim PIP, means that without advocacy support, individuals could unknowingly have their support cut off.

*Cadena was awarded PIP at a Tribunal in November 2020. Her award ended in July 2021, but it wasn't until June 2021 that she was called by PIP to remind her that her award was ending and she needed to put in a new claim. She initially didn't understand what they were talking about and thought they were sending her a new form, but with the support of Z2K she called PIP and requested the form herself. It will take approximately 6 months from this point for her to be assessed, so she currently has a gap in her entitlement. This gap could have been a lot larger had Z2K not supported her in requesting a new form.*

So that advocacy services can provide effective support, with issues dealt with promptly, it is also imperative that DWP stops its explicit consent policy and restores implicit consent. Upholding the importance of advocacy services is futile, unless consent barriers to them acting on an individual's behalf are removed.

DWP also concludes that they would test whether this advocacy support would be 'value for money'. This places the emphasis on how much disabled people are costing the system, rather than what the focus should be – ensuring everyone can access the system safely, and with dignity and respect.

While extra advocacy support to access the system would be welcome if done in the right way, this proposal ultimately fails to tackle the heart of the issue; too many people find the system confusing, inaccessible and fundamentally lacking in compassion and kindness. No one should have to rely on their support network or a charity to access the system because it should not be so complex to begin with, and the primary focus should be implementing the changes outlined in our response to Q.15.

### Chapter 3

#### **31. During the coronavirus pandemic we introduced assessments by telephone and video call as a temporary measure. In your view, in future, what mixture of methods should we use to conduct assessments?**

The individual 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. An issue that we have raised with the Work and Pensions Select Committee, is that of some people not meeting the suitability criteria for undertaking a Work Capability Assessment (WCA) telephone assessment,<sup>13</sup> meaning that if a decision can't be made on paper, they have to wait for a face-to-face assessment. While the Government has stated that these people are being prioritised with the resuming of face-to-face assessments, given the 15,000-back-log of assessments,<sup>14</sup> we are very concerned at the number of people who are struggling to get by without the support they need to help them manage their health condition or disability. Everyone, regardless of their access requirements, should be able to access their preferred type of assessment.

The preferred type of assessment will vary depending on the individual, but we have received feedback from people in receipt of health and disability benefits suggesting that people feel face-to-

<sup>13</sup> <https://committees.parliament.uk/publications/4938/documents/49395/default/>

<sup>14</sup> <https://www.parliamentlive.tv/Event/Index/7eabbf11-8486-484c-a107-1b4ee8945f96>

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.”*

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.”*

Overall, however, the commitment to increase 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 stop undermining medical evidence, there is little trust that an increase in paper-based assessments will lead to significant improvements in the quality of assessments.

If DWP are to deliver on being holistic in their decision making, they must also consider evidence from a variety of professionals, outlined in our response to Q.39, and identify which of these are best placed to assess someone’s condition, because it won’t necessarily be their GP. All of this evidence must form the basis for the decision, as these professionals will be better placed than the assessor to comment on someone’s capability.

And people whose decision could be made via paper, must still be allowed to attend an assessment as well if they would like to do so.

Alongside the evaluation of virtual assessments, with Tribunals increasingly moving online, it is important that this process is also monitored, to assess both advantages and disadvantages for disabled people.

### **32. How could we improve telephone and video assessments, making sure they are as accurate as possible?**

Our research shows that 70% of people feel like the assessor DWP contracted to carry out their assessment did not understand their condition.<sup>15</sup> 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.

*“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

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<sup>15</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

accounts of experiencing discrimination as a result of their ethnicity, as well as their disability, during the process.

The result is that many peoples' assessment reports omit or misconstrue vital information - with 66% of people feeling like the assessment report did not reflect what they'd told the assessor in the assessment.<sup>16</sup>

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

With DWP's focus – as referred to throughout the Green Paper – being the reduction of disability benefit spending, the evidence above demonstrates the lack of accuracy or empathy to DWPs overall approach to these assessments. Indeed, assessors routinely fail to recognise the support an individual needs, because they are instead focused on where support can be disallowed.

*At Arif's WCA, the assessor said that there was nothing wrong with him physically and didn't record the fact that Arif requires walking aids because of his hip dysplasia and said that he was fit for work. Arif's doctor was furious and couldn't believe that a professional could have written that about his situation. Z2K supported Arif through the Mandatory Reconsideration (MR) and appeal process, and it took over a year to get this original decision overturned, after which he was put in the LCWRA group. During that time, he had to meet certain commitments to continue receiving his benefit and had to see his work coach at least every three weeks.*

The high levels of inaccurate decision making at assessments is demonstrated by the high success rate of appeals challenging these decisions – the latest figures show that 76% of ESA and PIP Tribunals respectively had the initial decision revised in favour of the claimant.<sup>17</sup>

However, given that challenging a decision at appeal is time-consuming and extremely stressful, it's unsurprising that only 9% of people who receive an initial PIP decision lodge an appeal at a Tribunal.<sup>18</sup> Many of our clients are waiting for over a year 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, and as demonstrated in the responses to our recent survey,<sup>19</sup> many people are not well enough to appeal:

*"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."*

To start improving the accuracy of these assessments, 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 required format, to increase scrutiny and therefore help to raise standards. And to ensure that the information provided in an assessment report is not misconstrued, all assessments

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<sup>16</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

<sup>17</sup> <https://www.gov.uk/government/statistics/tribunal-statistics-quarterly-april-to-june-2021/tribunal-statistics-quarterly-april-to-june-2021>

<sup>18</sup> <https://www.gov.uk/government/statistics/personal-independence-payment-statistics-to-january-2021>

<sup>19</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

should be audio-recorded as default (with an 'opt out' option), and a copy provided to both DWP and the individual.

The use of informal observations must also be stopped. These routinely work against our clients and result in the provision of arbitrary reasons for why an individual isn't entitled to the benefit they are applying for. For example, our clients have been refused support on the grounds that they could travel to the assessment centre. As well as this being a wholly inappropriate measure of someone's overall capability, it also fails to take into consideration that in many cases this results in that individual being bed-bound due to exhaustion or physical repercussions for many days following.

### **33. What more could we do to reduce repeat assessments, where the impact of a person's health condition is unlikely to change significantly?**

It takes a great mental and physical toll on an individual to be continually reassessed when their condition is 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 people manage to successfully challenge an incorrect assessment decision, they are called back for a reassessment and therein starts the whole process again. As one respondent to our recent survey<sup>20</sup> told us:

*“It was clear from the evidence I submitted...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 [the assessors] 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.”*

One of the key issues that we see through our casework, is people being awarded shorter-term awards because their condition is technically curable. However, just because a condition is curable, it does not mean that functional ability is necessarily going to return. For example, our clients severely affected by mental illness are routinely subject to frequent reassessments because technically their condition isn't degenerative or incurable, but unfortunately their health will likely impact them indefinitely and being continually reassessed only worsens it.

We also oppose the discrepancy between awards made by DWP compared to a Tribunal. A Tribunal can only recommend the length of award for ESA and UC, and it's ultimately at the discretion of DWP as to when an individual will be called for a reassessment. DWP does accept that a Tribunal can recommend a minimum period for reassessment, and if so, this should be followed. And if there isn't a recommended minimum period for reassessment, then guidance is that DWP generally wait a minimum of eight months from the Tribunal. But this is only guidance rather than law, and we have a number of examples of DWP not following this minimum period for reassessment guidance.

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<sup>20</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

*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, in October 2019 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.*

While Tribunals can decide the length of a PIP award, DWP can ask people to be reassessed earlier (there are some rules in place to prevent this). 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.

Another discrepancy is that an individual who has won their PIP at Tribunal has to make a new claim when their award ends, instead of being sent a review form to complete. Being assessed for the new claim often takes so long, that someone's existing PIP ends while awaiting an outcome on their new PIP claim. This does not happen when an individual's award was decided by DWP - they are instead sent a PIP review form which asks whether anything has changed since their last award. Their PIP remains in payment until they are assessed so there is no gap in entitlement. In addition to this, we're concerned about the recent advancement outlined in our response to Q.17, that people aren't even being sent PIP2 forms now, but instead required to request a new PIP form themselves. For anyone who would like to continue receiving their benefits at the end of their award, they should be able to specify this by completing a review form, instead of having to submit a new claim, regardless of whether their award was made by DWP or a Tribunal.

Aspects of the Severe Disability Group (SDG) group are welcome, in particular the streamlined application process. However, many people whose conditions will sadly not improve are currently not assessed as meeting the Severe Conditions Criteria which exempts them from reassessments. DWP must therefore commit to ensuring more people are correctly assessed as meeting the Severe Conditions Criteria, and that those who are eligible are not refused access to a future SDG or equivalent. DWP must also commit to a genuine consultation process before any changes are implemented, as currently there is too little information on this to be able to support the proposal – in particular, further details are required on the frequency at which a member of this group's entitlement will be reviewed, and the eligibility criteria.

The feedback we received from Z2K clients and disabled people regarding this SDG proposal, was concern that DWP would continue to undermine professional evidence and opinion to incorrectly refuse someone access to this group. And there would need to be an understanding, as discussed in our response to Q.31, that someone's GP might not always be best placed to provide an opinion on someone's capability, with DWP decision makers considering evidence from other professionals where appropriate. People also wanted clarity on what constituted as 'severe', with some disabled people rejecting this use of terminology:

*"Not everyone likes to be categorised as severely disabled...not everyone should be put into boxes."*

There would need to be assurance that the SDG would not replace any of the current groups such as the LCWRA group. And DWP would have to be very clear when communicating with individuals who

were placed in a SDG group – as many would already be in receipt of Support Group or LCWRA with a Severe Disability Premium (SDP) – leading to the potential for confusion.

There would also need to be the assurance that people placed in this group, or any similar, were in receipt of the maximum rate before they were exempt from assessments, because conditions can always deteriorate and the individual's requirement for additional support could increase.

Ultimately, it is important that for anyone whose condition will sadly not improve, they are not subject to reassessments. And for people whose conditions might improve in the future, the frequency at which they are assessed must be reduced so that their focus can be on recovery rather than the stress and anxiety of continually being assessed.

#### **34. Decisions can be changed after an appeal has been lodged but before a tribunal hearing takes place. How can we improve the way we communicate a new decision in this situation?**

It is not unusual for our clients to be offered an increased benefits award by DWP after lodging their appeal, which if accepted, would lead to their appeal being lapsed. We have become increasingly concerned, however, by the way in which some of these calls were being made.

We have clients who didn't understand the purpose of the call and were contacted in place of their representative. Some were placed under time pressure when given this offer, in some instances being told they had a day to make a decision. Many were also unaware of their appeal rights regarding the new offer and did not have these explained to them, or subject to intimidation tactics, with one client being told by DWP that they could appeal this new offer but that they wouldn't recommend it because the Tribunal would likely take their higher entitlement offer away.

We therefore supported Public Law Project with their legal challenge on this matter, first providing a witness statement in October 2020, and a supporting witness statement in June 2021.<sup>21</sup> Our main concern was that some of the appeals we were directly involved in had been lapsed in a manner that was not in accordance with the guidance DWP had issued to its staff,<sup>22</sup> in particular the Best Practice Memorandum. This clearly left disabled at risk of not availing themselves of their rights of appeal and potentially obtaining a lower rate of benefit than they were actually entitled to.

The DWP conceded on this challenge before it was heard in court, a huge testament to the strength of evidence provided by ourselves and the other organisations involved, and updated guidance was issued straight away by DWP.<sup>23</sup>

DWP must now start following their own guidance on lapsing appeals to ensure that: individuals have the purpose of this communication clearly explained to them with any access and communication requirements – for example, an interpreter – 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; individuals are not intimidated into accepting this offer; and individuals are made aware of their appeal rights regarding this new offer. We would also like to see DWP explain the lapsing process to people, and an individual's appeal rights regarding this, at the point of a negative assessment decision or MR. This would mean offers to lapse weren't unexpected by the individual, and what's more, if people knew there was at

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<sup>21</sup> <https://publiclawproject.org.uk/latest/dwp-to-stop-cold-calling-disabled-people-to-make-low-benefit-offers/>

<sup>22</sup> <https://depositedpapers.parliament.uk/depositedpaper/2283137/files>

<sup>23</sup> <https://publiclawproject.org.uk/content/uploads/2021/07/CO042632020-consent-order.pdf>

least some possibility of a lapse, more people might be motivated to go ahead with an appeal. As it stands, the time and stress involved in going to a Tribunal deters many people from doing so.

### **35. What other changes could we make to improve decision making?**

Regarding holistic decision making, while it is important that DWP staff have the time to engage with all the relevant evidence when making a decision, if it isn't accompanied by a shift in DWP's attitude towards that evidence, so it's less frequently undermined in favour of the assessor's own assessment, then this exercise is futile.

What's more, the concern with holistic decision making is that it will further delay the already unacceptable wait times people have to endure before receiving support. And parity concerning this extension of time and flexibility with deadlines must be provided to both the individuals receiving support, as well as DWP. It is also important that the deadline for requesting an MR of a decision is more clearly communicated as being thirteen months not one month, and that everyone is exempt from claimant commitments when challenging a WCA or PIP assessment decision.

The avenues for individuals and their advocates to provide correspondence and evidence concerning a decision must be improved. Our caseworkers routinely encounter issues with UC where items sent to the free post address do not arrive. And without an email address to send correspondence via, and due to issues with explicit consent and the requirement to request upload links (often multiple times) on the UC journal, submitting correspondence can be a challenge. All individuals and advocates must be able to email correspondence to UC – this is especially important when a claim has closed and the only avenues for providing correspondence are the inadequate free post address, or telephone which is subject to extensive wait times.

What's more, DWP decision makers don't have the ability to put upload links on peoples' journals, only UC case managers do, and our caseworkers often have to chase UC case managers to do this, with some not always understanding the process. Decision makers must be able to request any further evidence they might require to support them in making their decision via someone's journal, and all individuals and their representatives should be automatically able to upload all evidence to their journal without having to request an upload link.

MR decision-makers must then use this evidence to conduct a full case review, as opposed to just rubber stamping the original assessment, as we see all too often in our casework.

*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 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.*

MR decision-makers must consider all the evidence, and if necessary, contact the individual for further information. All individuals going through an MR should also be given the opportunity to provide oral evidence of how their condition affects them. To increase impartiality, those looking at

a decision again should not be able to see the previous decision-maker's conclusions. There are too many cases of MR reports being copied from the original decision.

The fact that DWP's assessments are outsourced means there's a lot less accountability regarding decision making. There must also 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. This is important for greater accountability, and more crucially, for recognition that the process needs to change. DWP must commit to learning from why decisions are overturned.

## Chapter 4

### **37. Is there anything about the current PIP activities and descriptors that should be changed?**

**AND**

### **38. Is there anything about the current WCA activities and descriptors that should be changed?**

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. As one of our clients, and a respondent to our recent survey<sup>24</sup> explained:

*"The more they expand and explain the activities and descriptors the better, because then we understand them...at the moment, there appears to be an ambiguity. If they can tighten up that ambiguity so it doesn't exist anymore, it's clearer for everybody. If they leave it as ambiguous as it is, DWP can interpret the answer one way when we meant something completely different. I think what they're doing at the moment is basically allowing the people making the assessments to interpret an answer the way that suits them."*

*"It's so hard for anyone with a mental health condition or learning disability to fill in the form without the help of a charity to explain what these questions actually mean for them."*

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. As our client explains:

*"The questions are artificial, repetitive, and the details given do not help anyone make up their minds as to whether we are ill, or what help we need."*

Instead, an assessment needs 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.

Many respondents to our recent survey<sup>25</sup> 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.

*"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*

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<sup>24</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

<sup>25</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

*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."*

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 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.

And finally, in line with DWP's aim for greater holistic decision making, there needs to be 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 aren't met.

### **39. Should we seek evidence from other people, such as other health professionals or support organisations?**

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. However, once again, seeking this evidence is futile if it is not accompanied by a shift in DWP's attitude towards the evidence itself, so that it is less frequently undermined in favour of the assessor's own assessment.

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. As our client explains:

*"There is never a honing in on what evidence is useful or required. So doctors aren't always aware of what they need to write for DWP."*

DWP should also ask individuals at the start of a claim if they wish information from other claims to be considered, but should only do so where permission is given.

Assessors should be obliged to review all supporting evidence provided by an individual. The assessor report is currently given more weight in decision-making, which is resulting in too many ill-advised decisions. DWP should ensure that other types of evidence are given equal weight to assessment reports. DWP must also be proactive in seeking any additional evidence and opinion that can support them in making their decision.

There also needs to be an understanding that if an individual 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. This is especially the case within the psychiatric system, where due to caseloads, patients rarely have access to a psychiatrist except in an acute crisis where a review of medication is deemed appropriate. This doesn't mean

that the individual is recovered – just that the psychiatrist thinks the medication they are in receipt of is appropriate. Assessors frequently take the approach that no current psychiatric input means someone is well enough to not require the applied for benefit, even when supporting evidence from a GP says the contrary.

**40. What type of evidence would be most useful for making WCA and PIP decisions, and should there be a standard way to collect it?**

AND

**41. How could we make sure the evidence we collect before a WCA or PIP assessment directly relates to a person's ability to do certain things?**

Unfortunately, all too often it's not until our clients get to Tribunal that the evidence they have been providing from the start of their claim, is adequately engaged with. The result, more often than not, is that they are awarded the benefits that they were incorrectly denied at their assessment and MR - Z2K's success rate at Tribunal in 2020 was 93%.

Therefore, it's clear that new types of evidence are not what's needed, but instead DWP must change the way it engages with existing evidence. DWP must start adequately engaging with the non-exhaustive list of evidence provided in our response to Q.39 that is already in circulation, and not undermine or misconstrue this.

**42. How could we improve assessments or the specialist support available to assessors and decision-makers to better understand the impact of a person's condition on their ability to work or live independently?**

Many respondents to our recent survey<sup>26</sup> said the assessor failed to understand their condition because they didn't have the relevant expertise in it, and they ignored or failed to engage with the relevant testimony and medical evidence that could have helped generate an understanding.

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. And they must not undermine the evidence and opinion they are provided with. Notably, though, it must be recognised that because the points-based system that currently exists is competency based, rather than based on diagnosis – even if the assessor has full expertise of the person's condition and / or disability – the structure of the system would not allow the assessor to stray from the set questions. This brings us back to the urgent need for reform of the process because even with these changes, ultimately the structure of system does not allow for flexibility.

**43. How can we make it easier for people to inform us if their condition or circumstances have changed so that a review of entitlement can be carried out at the right time?**

Further details of the Health Impact Record (HIR) are required, in particular: who, alongside the person whose claim it is, could provide evidence; who at DWP would review this evidence and decide whether a review should take place; would certain evidence take precedence over other evidence, who would undertake this review, and what advocacy will be available to support people to navigate this new requirement? An HIR and any other similar system that is introduced must also be done so in consultation with DDPOs and disabled people.

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<sup>26</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

One concern would be that the focus of this HIR would be to justify the removal rather than increase of support. A check would need to be in place to ensure a new assessment (or similar) took place before support was reduced following the uploading of new evidence. However, given the inadequacies of the current assessment process, there is little faith that an assessment would act as an adequate safeguard against the removal of support. Furthermore, it would be important that a review of entitlement didn't take place unless evidence in support of one was provided – all too often our clients write 'no change' on their benefit review forms and their award completely changes.

Also, it must be understood that someone's health might have improved to a degree because of their benefits, and as people in receipt of health and disability benefits told us this should be reason for the maintenance, not removal, of support.

*"My mental health has improved because of the money I get from PIP providing me with things I need...then they see this as a reason to take it away!!"*

The HIR would also place further onus on the individual - making and managing a health and disability benefit claim is already a lot of work. And this proposal fails to understand that many people in vulnerable situations are incredibly isolated and without the capability or support to enable them to upload evidence. The system would need to be underpinned by the assumption that someone's condition hasn't changed unless they tell DWP otherwise, with no requirement for individuals to report continually to prove their conditions haven't improved, and no-one was penalised for not providing evidence. As one of our clients explained:

*"The immediate thing with HIR is that it's not going to work for people who don't have a support network, people who don't have much contact with healthcare professionals...what someone thinks about their illness, and someone else, is often subjective, and some people might not be able to articulate as well as others. Some people might have better access to other healthcare professionals than others."*

We are also concerned that for certain individuals, for example those who have post-traumatic stress disorder (PTSD), continually producing evidence and testimony about their condition could be detrimental to their mental health and wellbeing.

There is a real worry, too, that comes with any potential data sharing agreement between government bodies and the NHS that results in patients being deterred from accessing medical help for fear of their records being shared with, for example, the Home Office or the DWP.

Apprehensions regarding data also apply to DWP's Health Transformation Programme, and any other potential system where DWP would hold evidence relating to an individual on one system that spans across all benefits. The concern is 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.

There are some, however, in receipt of health and disability benefits who could see the value in such a system if it was operated in a way that was in the interest and with the consent of the individual:

*"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?"*

Fundamentally, the priority first should be a shift in DWP's attitude towards evidence itself, so that it is less frequently undermined. Otherwise, regardless of where and how evidence is kept, the issue of the right decision not being made first time because it is not properly engaged with, will persist.

## **Chapter 5**

### **46. How could we simplify the system for people applying for multiple health and disability benefits?**

There is a heavy indication in this Green Paper that DWP will pursue a single assessment in future, this 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."*

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. Someone in receipt of health and disability benefits was:

*"Concerned that people would be penalised for working as a disabled person...I would be worried that some of my support would be taken away."*

What's more, PIP is currently protected from the Benefit Cap, and it'd be important that any support to help individuals manage extra costs related to their disability continued is not impacted by artificial caps and limits on benefits.

And having a single assessment in light of the high rate of incorrect DWP decision making, would 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 be the case with a single assessment, as all income would stop, and as someone in receipt of health and disability benefits told us:

*"Going to my PIP tribunal, I only had ESA to live off which wasn't enough...so I'm concerned about that."*

### **Additional changes to our Social Security system**

One key issue on which the Green Paper is silent, is the adequacy of benefit rates.

The rates of working age benefits were already insufficient when the then Chancellor decided to freeze them in 2015. The year-on-year erosion in their value that followed has resulted in a Social

Security system that fails to provide people with a minimum standard of income and has pushed 400,00 people into poverty.<sup>27</sup>

Z2K therefore welcomed the Government's decision to increase UC and Tax Credits by £20 a week in April 2020. While this increase wasn't enough to reverse the cuts to the Social Security system that preceded it, it went some way to restoring the support that had been progressively cut from peoples' incomes.

*Kelly is a single parent to a two-year-old child. In March 2020 she received £407.91 from UC (£251.77 standard allowance, £231.67 child element with £75.53 deducted for arrears and advance payments), as well as £89.70 in Child Benefit, giving her a total monthly income of £497.61. After paying bills, she was left with approximately £75 a week to spend on food and other essentials for herself and her infant child. She had to turn to food banks on many occasions but preferred not to do this as she likes to provide fresh food for her child instead of tins. Since April 2020, she received the Covid-19 increase to her UC standard allowance, and since May 2020 when Kelly turned 25, she has also been entitled to the over 25 increased UC rate. These increases, combined with Child Benefit, meant Kelly was left with approximately £115 a week for food and essentials after paying her bills. But with the removal of the £20 uplift, she will no longer be able to provide for her child without needing to rely on foodbanks.*

Taking it away leaves people like Kelly once again struggling to pay for essentials, having to rely on foodbanks and support from charities, and at risk of falling into rent arrears. This £20 a week increase should have been maintained and extended to the over 1.8 million people<sup>28</sup> in receipt of legacy benefits – many of whom are disabled and struggled to meet the extra costs associated with the pandemic and pay for essentials like food and bills without any increase. Research conducted by DBC in February 2021<sup>29</sup> showed that two thirds (67%) of disabled claimants have had to go without essential items at some point during the pandemic.

*Chris has a rare health condition, has survived five heart operations and has been told he has a life expectancy of 35 years. Because of his condition, Chris receives ESA and lives with his parents. The pressure on his parents became immense because of the pandemic. They worried about income and whether they would have enough to eat and to pay their bills. His mother is his full time Carer yet only gets £67 a week in Carer's Allowance. Chris struggled to manage with the money he receives from ESA during the Covid-19 lockdown. Chris says: 'It feels like they are only looking after people on UC [...] 'Just because you are on a legacy claim, doesn't mean you should be left behind'.*

From the start of the pandemic, Z2K opposed this creation of a discriminatory two-tier Social Security system and called for the £20 increase to be extended to legacy benefits.

The inadequacy of Social Security income is especially stark for people in the LCW group on UC and Work Related Activity Group (WRAG) on ESA, who are not required to search for work in the short term because of their disability or health condition. However, as a result of the 2016 Welfare Reform

<sup>27</sup> JRF 2019, End the benefit freeze to stop people being swept into poverty

<sup>28</sup> <https://www.gov.uk/government/statistics/dwp-benefits-statistics-august-2021/dwp-benefits-statistics-august-2021>

<sup>29</sup> <https://disabilitybenefitsconsortium.files.wordpress.com/2021/02/pandemic-poverty-stark-choices-facing-disabled-people-on-legacy-benefits-final.pdf>

Act, anyone placed in these groups after April 2017 have been without any additional financial support to help them manage their condition. As a result, many people in this group struggle to cover the additional costs incurred as a result of their health condition or disability. Government must therefore restore the UC LCW rate and the equivalent ESA WRAG rate.

The fundamental issue regarding benefit rates is that although (except for years in which they have been frozen) benefits are normally uprated annually according to an index of inflation, the initial amounts to which that uprating is applied have not been assessed for adequacy. The 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.

And in addition to this, artificial caps and limits on peoples' benefits such as the Benefit Cap and Two Child Limit, which have a seriously detrimental impact on people's already limited Social Security allowance, must be removed.

### **Next steps**

When we surveyed over 1,200 people with experience of the health and disability benefits system in April 2021,<sup>30</sup> they were clear about what changes are needed. This Green Paper has therefore provided a welcome opportunity to feed these views into the work of the Department.

While there are some positive proposals in the Green Paper that align with these desired changes, overall, this consultation is too unambitious and limited in scope to address the scale of change that people want to see made and that is required. We are therefore calling on DWP to listen to disabled people and develop more fundamental reforms.

This is especially important given that three quarters of disabled people told us that they think Government won't listen to the changes they want to see made. It is therefore vital that DWP uses this opportunity to meaningfully engage with, and act on, the evidence it receives to this Green Paper from respondents with experience of the system, and those who support them and act on their behalf, to implement the more fundamental changes they propose.

### **Conclusion**

While there are proposals outlined by DWP that would go some way to improving health and disability benefits in this Green Paper, there is a general lack of detail to fully demonstrate how DWP will deliver on their aims, with a strong focus on what DWP *want* to do, but not enough on *how* they will do it.

And ultimately, the proposals in this Green Paper don't address the scale of the issue. We need a system that supports everyone to live stable and dignified lives, results in decisions being made right the first time so people receive the vital income they are entitled to without being subjected to a lengthy and stressful appeals process, and that recognises work is not suitable for everyone and stops pushing people into work when that is not an appropriate option for someone. As our client told us:

*"What was their agenda behind this paper? It seems to me...it's just oriented towards getting disabled people to work. There isn't very much around supporting people for example that won't be able to work. There's a little sidenote that people will be looked after if they can't, but they don't explain how."*

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<sup>30</sup> <https://www.z2k.org/wp-content/uploads/2021/05/FINAL.pdf>

Government must now fulfil its 2019 manifesto pledge to empower and support disabled people and be an ally by co-producing a new health and disability assessment process with DDPO's and those with experience of the system, and start putting people before process.

### **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 - some of which are consulted on in the Green Paper and some of which go beyond the proposals in this consultation:

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. DWP's explicit consent policy must be stopped, and implicit consent restored.
6. All individuals and advocates must be able to email correspondence to UC.
7. UC50s must be issued automatically on the 29<sup>th</sup> 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. People whose decision could be made via paper, must still be allowed to attend an assessment as well if they would like to do so.
14. There should be a thorough review of the various assessment criteria, in consultation with DDPOs and disabled people.
15. 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.
16. Assessors must consider how a condition's impact varies over time, not just on a specific day.
17. 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.

18. 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.
19. The use of informal observations must be stopped.
20. All individuals should be automatically issued with a copy of their assessment report, in their required format.
21. All assessments should be audio-recorded as default (with an 'opt out' option), and a copy provided to both DWP and the individual.
22. 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.
23. Assessors should be obliged to review all supporting evidence provided by an individual.
24. Other types of evidence must be given equal weight to assessment reports.
25. 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.
26. 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.
27. 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.
28. MR decision-makers must conduct a full case review.
29. Parity concerning deadlines must be provided to both the individuals receiving support, as well as DWP.
30. The deadline for requesting an MR of a decision must be more clearly communicated as being thirteen months not one month.
31. All individuals going through an MR should also be given the opportunity to provide oral evidence of how their condition affects them.
32. The MR decision-maker should not be able to see the previous decision-maker's conclusions.
33. Everyone must be exempt from claimant commitments when challenging a WCA or PIP assessment decision.
34. 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.
35. DWP must start following their own guidance on lapsing appeals.
36. 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.
37. 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.
38. For anyone who would like to continue receiving their benefits at the end of their award, they should be able to specify this by completing a review form, instead of having to submit a new claim, regardless of how their benefits were awarded.
39. For anyone whose condition will sadly not improve, they must not be subject to reassessments.

40. For people whose conditions might improve in the future, the frequency at which they are assessed must be reduced.
41. The £20 a week increase to UC must be reinstated and extended to those on legacy benefits.
42. The UC LCW rate and the equivalent ESA WRAG rate must be restored.
43. Artificial caps and limits on peoples' benefits such as the Benefit Cap and Two Child Limit, must be removed.

And in the long-term, Z2K wants to see the introduction of an alternative Social Security system, that is guided by the following overarching principles:

- **Our Social Security system must be co-produced with the people who access it, so that it works for those with direct experience of the system.** There are countless suggestions from people who both access our Social Security system and those who advocate on their behalf 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, reform, and delivery.
- **Our Social Security system must provide people with an adequate and stable income.** 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 and allows people to live dignified lives.
- **Our Social Security system must create equality and offer people more independence, choice and control.** As a starting point, DWP should adopt the Social Model of Disability, which is a model developed by disabled people that states people are disabled by barriers in society not by their impairment or difference, and work to provide a Social Security system that actively removes these barriers.
- **Our Social Security system must treat the people accessing it with dignity, fairness, and respect.** For years people have been subjected to a benefits system they have described as 'degrading', 'hostile' and 'discriminatory'. Our Social Security system must provide people with the vital income they need to survive, and the respect they deserve.