DBC Submission to Work and Pensions Select Committee Inquiry on Assessments

Introduction

1. The Disability Benefits Consortium (DBC) is a network of over 100 organisations committed to working towards a fair benefits system for all. For our full list of members, see www.disabilitybenefitsconsortium.co/dbc-members/
2. We use our combined knowledge, experience and direct contact with millions of disabled people, those with long-term health conditions, and their families and carers, to ensure that Government policy meets the needs of all disabled people.
3. We welcome the opportunity to make a submission to the Work and Pensions Select Committee inquiry on assessments, which raises issues of great importance to our members.

Summary

4. Every aspect of the assessment process from application to assessment, to decision-making and appeals need to be improved so that disabled people experience compassion, empathy and support, and can live with dignity. The key recommendations in our response are outlined below:

   - Improvements to the application process
   - Better evidence gathering and better use of evidence
   - Assessors who understand and have the knowledge of the condition they are assessing
   - A review of the descriptors for the PIP and ESA/UC assessments
   - The removal of informal observations
   - A choice of assessment method, and an effort made to increase the number of decisions on paper-based assessments

- Assurance that the assessment processes for different benefits will not be combined
- An independent review of the actual costs of disability and the inadequate rate of benefits overall

Q1. How could the DWP improve the quality of assessments for health-related benefits?

The application process

1.1. Claim forms should be easily available, including in Jobcentres, in accessible formats such as audio-described and easy-read, as well as downloadable online. We are pleased that the DWP are introducing an online PIP form, however it must ensure the application process for PIP does not become an online only process and that claimants are still provided with the option to apply and submit their claim through whatever channel is appropriate to them e.g. by post, over the phone, or in person via a home visit if necessary.

1.2. There should be no need to return forms within an arbitrary time limit. We are often told that four weeks is not enough time for people to complete the PIP form, and many are unaware that it is possible to request an extension. This information – that extensions can be requested, and the circumstances under which it could be granted, should be clearly provided with the application form.

1.3. Disabled people and people with long-term health conditions find the form does not allow them to fully explain how their condition affects them, nor does it allow them to fully explain how their condition can fluctuate. In consultation with disabled people and disability charities, the DWP should work to ensure forms allow people, particularly with progressive and fluctuating conditions, to fully explain how their condition affects them.

1.4. The DWP should produce simplified claim forms in consultation with disabled people and disability organisations. All claimants should be provided with information explaining the criteria and how they are scored (not just made available digitally), thus making it easier to fill out the form, and improving the quality and relevance of information given on the form. This would lead to assessors being able to make more paper-based decisions.

Supporting Evidence

1.5. **Better evidence gathering:** The DWP must improve evidence collection processes to ensure that all disabled people and people with long-term health conditions are able to provide relevant, good quality evidence for their claim and that evidence is always collected by assessors.

1.6. It is not clear on the claim form who is responsible for gathering supporting evidence – the individual or the assessment provider. The DWP must make it clear that providing contact details does not guarantee they will be contacted and should be much clearer in encouraging individuals to obtain up-to-date evidence. The Department should reimburse claimants for any costs in doing so.

1.7. The DWP should also provide better guidance on what constitutes good evidence, not just for individual claimants, but also for those providing the evidence e.g. healthcare professionals, family, friends and carers.

1.8. There is the potential for appropriate data sharing of medical evidence to be introduced. This could streamline the process and save claimants time and effort. However, this has to be subject to the required data protection safeguards, and only done with consent and permission from the claimant.

1.9. **Better use of evidence:** The DWP must improve the way it uses and engages with supporting evidence. Supporting evidence must be given equal weighting to the assessor's report. Currently the latter is given more weight.

1.10. Assessors should be obliged to proactively gather and review all the supporting evidence, and where their judgement of a person's capability differs from the individual, and the evidence, give a clear explanation as to why.

1.11. Assessors could make better use of evidence which already exists from the individual’s own healthcare professionals especially where the diagnosis is clear e.g. those who are registered and have certificates confirming significant sight loss, or who have been diagnosed as having a progressive condition.

1.12. Older evidence can still be relevant, many conditions don’t have regular engagement or have constant reviews with a specialist once they have been diagnosed.

Assessors Reports

1.13. Many of our members report frequent problems with the accuracy of the assessors’ report. This can include omitting significant details, the assessors’ account differing to that of the individual being assessed, observations which aren’t backed up by evidence or are inappropriate or irrelevant. Z2K have told us that most respondents to a survey they published said that the assessment report didn’t reflect what they had told the assessor.

1.14. The DBC recommends that everyone should receive a copy of their assessor’s report following an assessment automatically. This would increase scrutiny and accountability, raising standards of the report. If the assessor knew that every person they assessed would see the report it would encourage them to take greater care and improve accuracy.

Audio or video recording of assessments

1.15. To ensure that 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.

Assessors

1.16. One of the most common concerns of our members is the failure of assessors to understand someone’s disability or health condition, and the impact it has on someone’s day to day life. Time and time again, in every survey, in every discussion, this is an issue that never goes away.

1.17. Our members have told us that one of the most common complaints they hear is that assessors don’t understand their condition. A recent survey by Z2K found most people who responded said the assessor didn’t understand their condition. Additionally, Crohn’s and Colitis UK, MNDA, RNIB and the MS Society are just some of our other members who have told us that their research shows people don’t feel the assessors understand the impact of their condition and symptoms, on their day-to-day life.

1.18. Having assessors that better understand someone’s condition and symptoms will lead to an overall improvement of the quality of the assessment, the number of people getting the correct decision first-time, as well as improve the assessment for individuals who often find the process stressful, anxiety-inducing, traumatic, and in some cases worsen symptoms. Mind told us that poor assessors and assessments have led to people contacting them to express suicidal feelings.

1.19. The DBC recognise the logistical difficulty of always matching specialist expertise to particular conditions, but the Department cannot continue to ignore the calls of disabled people and people with long-term health conditions, and the many organisations and charities, calling for assessors to have a more specialist knowledge of the people they are assessing. There are varying degrees of recommendations amongst our members on the actions the Department could take to improve the knowledge and understanding of assessors, from providing funding for specialist assessors, to better training and access to information. We strongly urge the Department to explore ways that the support system for assessors could be improved and designed with disabled people and disability charities to resolve this most important of issues.

Fluctuating and hidden symptoms

1.20. The PIP and WCA descriptors are too rigid and arbitrary for assessing the impact of conditions which fluctuate and have hidden symptoms. Assessing someone's mobility needs by way of the 20m rule is an example of this. We cover the issue of descriptors in Q3 below, but the DBC believes they should be changed to more effectively consider the fluctuating nature of some conditions, as well as hidden symptoms including pain and fatigue.

1.21. Disabled people and people with long-term health conditions cannot be accurately assessed by means of a 'snapshot' or 'typical' day. The PIP assessment guide requires assessors to consider whether the ability of a claimant to carry out activities is impacted by their condition at least 50% of the days. This arbitrary measure should be reviewed by the Department as it cannot accurately reflect the reality of living with a fluctuating condition. Crohn's and Colitis UK suggest a much more holistic approach which includes looking at people's best and worst days, as well as the use of a fatigue rating scale. The DBC suggest that the Department works with disabled people, people with long-term health conditions and disability charities to explore and review better ways to assess people with fluctuating and hidden symptoms.

Informal observations and reliability criteria

1.22. Assessors write observations in their reports which are inappropriate and irrelevant, especially when it comes to assessing people with conditions which fluctuate or have hidden symptoms. Somebody being able to take something out of their handbag does not mean they are able to peel a potato. Somebody who is well dressed or maintains eye contact may still be anxious. Somebody who can walk from the waiting area to the assessment room may still be unable to walk 20m to the bus stop tomorrow.

1.23. Assessments also fail to consider whether the individual being assessed can complete an activity reliably. We know from members that too often there is a failure to apply the reliability criteria during assessments. Through talking to members we know that assessors are not applying the reliability criteria consistently or properly.

1.24. Often these observations will be given more weight than evidence provided by medical professionals, family, friends and carers, as well as the individual being assessed, with little explanation as to why.

1.25. The DBC recommends that the use of informal observations in assessments cease. We also recommend that the reliability criteria, and the definitions must be embedded within the wording of every descriptor and should be applied to all informal observations. Assessors’ reports must set out evidence why they consider that each activity can be carried out safely, to an acceptable standard, repeatedly, and in a reasonable time.

Regulating benefit assessments

1.26. DWP must re-establish direct responsibility for assessment quality and publish regular improvement plans to ensure assessors are conducting assessments consistently and to a high standard.

1.27. The Department should also establish an independent Regulator of Benefit Assessments. This should be independent of the Government, with the power to compel evidence from the DWP, and produce reports which hold them to account. An independent regulator would monitor how well the Department is fulfilling its duties under the law, protecting the rights of people applying for benefits, and living up to the values of dignity and respect.

Q1a. Have you seen any specific improvements in the process since the Committee last reported on PIP and ESA assessments in 2018?

1.28. Reading the recommendations in the Committee's report from 2018, it's clear to see that very little has changed between now and then. Since then, another Green Paper on disability benefits has been published, which follows a very similar one in 2016. There are proposals within the 2021 Green Paper which align with the Committee's 2018 report, the fact the two Green Papers are so similar, and that these proposals are only now being discussed and presented, is indicative of the disappointing lack of progress made during that time.

1.29. There have been some improvements: the introduction of phone and video assessments (which we discuss in Q10); the reintroduction of a 10 year light touch review – although there is still scant information on what this light touch review will look like in practice, as well as staggeringly low numbers of people receiving an ongoing award since its introduction; the Health Transformation Programme and the Health Transformation Area – which we cover in Q9); and improving the appeal lapsing and mandatory consideration process – although there are caveats (discussed in Q7).

1.30. In its response to the WPSC report, the DWP admitted that the current recording process didn't go far enough, and that they intended to make recording the PIP assessment a standard part of the process. We have addressed this in Q1, where we call on the DWP to roll out audio or video recording along with a firm timetable.

1.31. While we welcome changes to the Special Rules for Terminal Illness announced in July 2021 which extend the 'reasonable expectation of death' rule from 6 months to 12 months, this has yet to be implemented. The Government also need to go further, and change the Special Rules award from 3 years to an ongoing award duration. This would improve the experience of people living with a terminal illness who defy expectations and go on to live longer than 3 years.

Q2. Are there any international examples of good practice that the Department could draw on to improve the application and assessment processes for health-related benefits?

2.1. Rather than looking to international examples of good practice, it would be more productive for the DWP to consider the specific recommendations we have outlined in our collective responses to the Green Paper for how these processes can be improved for disabled people and people with long-term health conditions. They could also look closer to home – Scotland for example.

Q3. Do the descriptors for PIP accurately assess functional impairment? If not, how should they be changed?
We have chosen to answer these questions together because of the overlap in some of our main points between PIP and ESA.

Q4. Do the descriptors for ESA accurately assess claimants' ability to work? If not, how should they be changed?
We have chosen to answer these questions together because of the overlap in some of our main points between PIP and ESA.

4.1. A points-based system with a blanket assessment approach is not suitable. It fails to assess or understand how someone's disability or health condition impacts them specifically. The PIP and ESA descriptors are too rigid and arbitrary. They also don't accurately reflect the additional costs people may face, for example, high utility bills for heating or water. The DBC would like to see a thorough independent review of the actual extra costs of living with a disability.

4.2. When it comes to a Work Capability Assessment, the DBC has consistently highlighted a range of structural issues, including the system's inability to account for the barriers that disabled people face when seeking to access employment.

4.3. The descriptors should allow more scope for claimants to describe the way that their disability affects them on a day to day basis. An assessment should follow a less prescriptive format, which provides people with the opportunity to explain themselves the impact of their disability or health condition. This would assist the assessor to understand more fully, the extent to which a claimant’s disability or health condition affects their daily life.

4.4. There should be a more holistic WCA which considers ‘real world’ factors such as mobility issues, including access to transport; skills gaps; the actual availability of relevant employment in the local economy, and employers’ attitudes.

4.5. There should be a thorough review of the various assessment criteria for both PIP and ESA. This should involve meaningful involvement of disability organisations and disabled people in this process, across a range of disabilities and health conditions, physical and mental, to ensure criteria are fair and truly reflect a person’s capacity to work, or the extra costs they face.

4.6. DBC members who represent people living with mental health conditions tell us that the descriptors do not capture mental health problems well enough and that more relevant activities should be added. The problem also lies in the questions the assessor asks to determine which descriptor someone’s experience meets, as well as assessors not applying the reliability criteria correctly to each descriptor (as discussed in Q1). Changes to the assessment must make better use of the reliability criteria.

4.7. Some of our members, including RNIB, Crohn’s and Colitis UK, and the MS Society have conditions with specific needs, such as how the descriptors apply to blind and partially sighted people, and people with bladder and incontinence needs.

4.8. RNIB call for PIP guidance to be improved by having worked examples which relate to how the descriptors apply to blind and partially sighted people. Currently, assessors automatically exclude certain conditions from claims relating to sight loss in other activities such as dressing, budgeting, and engaging with other people. This does not realistically reflect an individual’s needs.

4.9. The descriptors and guidance for PIP and ESA fail to adequately capture the impact bladder and incontinence problems can have on people’s lives, or recognise the difference between types of toilet needs, as well as the psychological impact associated. The assessment and criteria should better understand this.

4.10. Assistive technology should not perversely become a threat to independent living by reducing benefit entitlements and this should be borne in mind in any review of activities and descriptors. It’s illogical to deny support to people who use assistive technology to make their lives easier. It should not mean the level of required support is lower. The aided definition from the criteria for the PIP assessment should be removed.

4.11. The importance of the mobility component in PIP in promoting independent living should be recognised. The 20m rule can have a devastating impact leading to people losing their higher rate of mobility support which can be a lifeline to independent life for so many people. The 20m rule should be scrapped and a review and design exercise undertaken to come up with an appropriate alternative. In the meantime, the 50m threshold should be reinstated.

4.12. There is a particular need to take into account fluctuating conditions and not address them by means of a ‘snapshot’ or ‘typical’ day (as discussed in Q1). The focus on a ‘typical’ day and being able to do something reliably, fails to capture the nature of a fluctuating condition or symptoms. The same applies to hidden symptoms such as pain and fatigue.

Q5. DLA (for children under the age of 16) and Attendance Allowance usually use paper-based rather than face to face assessments. How well is this working?

5.1. The transition from child DLA to PIP is particularly challenging. Supportive, high quality assessment and decision making, and readily available advice and advocacy are crucial. As one of our member organisations powerfully remarked: parents of disabled children are often exhausted by constant medical procedures and appointments and battles to access services and equipment they need at the time they need it, in addition to the day to day worry and huge burden of responsibility of keeping their child healthy, happy, and developing. Child DLA or PIP should assist them – not provide them with another complex battle to fight.

5.2. As the DWP already contacts families to identify if an appointee is needed, this call could be used to explain the differences between DLA and PIP and highlight that independent advice can help. Also, the rule allowing DLA to continue to age 17 to facilitate a claim to be determined could be modified so awards of DLA can continue up to age 17 if PIP is refused, to allow MRs and appeals to be completed. Moreover, the upper age limit for child DLA in any case needs reviewing. In Scotland, it is already the case that young people receiving DLA can now continue to get it until they turn 18, although they can opt to move to PIP earlier if they wish. We recommend that this provision should be extended to the rest of the UK.

6. 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 drawbacks of such an approach?

6.1. Clinicians, people's healthcare professionals and teams often know their patients well, both medically and holistically. It's essential their evidence is given appropriate consideration. There is no advantage to continuing further assessment by someone less qualified than an expert team who have specialist expertise. Members who represent people with progressive conditions have welcomed this approach, saying that people with these conditions can't understand why they are asked to prove what their clinician has already told them.

6.2. This approach, where decision makers rely on clinician input allows the DWP to carry out more paper-based assessments something they've shown they are keen to do in the Green Paper. There is clear evidence from our members which show people who were assessed on paper felt they were more accurately assessed than those assessed by other methods, including on the phone, at an assessment centre, and at home.

6.3. The Department has proposed the introduction of a Severe Disability Group (SDG) which would rely heavily on clinician input. People in this group could bypass detailed assessment and any reassessment. It would build on existing successful measures such as the Severe Conditions Criteria (SCC), and would apply to those who don't qualify for SRTI but may still have severe, lifelong conditions that won't improve, or may well progress. It appears the process would be the same, where a clinician's input will be relied upon. The DBC welcomes this proposed SDG - it sounds constructive and is an opportunity to put right people being reassessed unnecessarily. However, some members will, rightly or wrongly, suspect a Trojan horse for redefining and curtailing access to higher rates of ESA and UC – so we will be hoping for clear assurances here.

6.4. In considering this approach there are some important things to remember. Not everybody will have access to a clinician or one that knows them well enough to provide sufficient evidence. This shouldn't be interpreted to mean that someone's health condition or disability isn't severe. Also, the type of clinician being relied upon is important, with those with greater specialism likely to have a better understanding of the impact someone's condition or disability might have on their ability to work and on daily life.

6.5. This approach could also put additional demands on a health service which is already facing pressure. The amount of time required by clinicians to give input would needs to be considered. We know from some of our members who have experience of SRTI, that there are issues to resolve around the DWP questioning clinical judgement. This is something which has been experienced by members when it comes to signing off a DS100 form.

6.6. If done well, despite the drawbacks, the DBC would like to see the evidence of clinicians and healthcare professionals given much more weighting than it currently is, and in appropriate cases e.g.

progressive conditions like MS which are unlikely to improve, relied upon without the need for a separate assessment.

Q7. Appeals data shows that, for some health-related benefits, up to 76% of tribunals find in favour of the claimant. Why is that?

7.1. Tribunals engage much better with evidence, which is usually available from the start of a claim. New oral evidence is often cited as a reason for a decision being overturned. This is essentially evidence that should have been available at the outset of someone’s claim if the assessor had carried out a quality assessment in the first place.

7.2. Tribunal hearings give this new oral evidence (and other supporting evidence) equal weighting to the assessment report, listening to the individual. Finally, a tribunal panel consists of a legally qualified judge, and up to two other independent people, including a doctor and sometimes a disability expert. Having an appropriate or specialist level of knowledge and understanding means the panel is in a much better position to understand the impact of someone’s disability or health condition on their day-to-day life, and employment needs.

7.3. People feel they are given more time to explain themselves, their condition, and the impact it has on their lives. What is concerning is the number of people who don’t get as far as an appeal. We know from members that people choose not to appeal unfair decisions because the process is so stressful. This figure shows just a portion of the true number of cases where the DWP has made the wrong decision.

Q7a. What could DWP change earlier in the process to ensure that fewer cases go to appeal?

7.4. You only need to look at our previous answers to this inquiry to see the fundamental problems throughout the whole assessment process for PIP and ESA to see why so many appeals find in favour of the claimant. More needs to be done to make sure the Department get their decisions right first time. Better advice and advocacy services, better evidence gathering process, better use of supporting evidence, changes to the forms and the descriptors, and a better-quality assessment. Improvements to all of these would reduce the need for people to appeal in the first place.

7.5. Decision making needs to be more like the tribunal approach – compassionate and respectful, better-informed, inquisitive, and give proper weight to evidence provided by the individual, family and friends, and carers. To increase impartiality, those looking at a decision again should not be able to see the previous decision-maker's conclusion.

7.6. There has been some improvement in the MR process since 2019 with new operational approaches which encourage MR decision makers to gather additional oral and written evidence to make their decision. The Government themselves have reported that the number of decisions changed at MR stage has nearly doubled since this approach has been implemented. While this is good news – it clearly demonstrates the widespread failure of the previous approach.

7.7. Full audits should be conducted of decisions that are subsequently changed at tribunals. There should be a better feedback loop from a decision being overturned to the person who made the initial decision/assessment. Assessors should be made aware when their decisions are overturned at tribunal and the reasons for this, to help identify where things could be done differently and better. This will help restore confidence in the system and provide ways of improving decision making.

7.8. We cautiously welcome the DWP's intention to improve appeal lapsing. There are risks and the Department must ensure it follows its own guidance consistently to ensure that: applicants have the purpose of an offer to lapse clearly explained to them with any access and communications requirements met to facilitate this understanding (including have someone to support them); individuals are not placed under any time pressure to accept an offer; they are not intimidated into accepting an offer, and they are made aware of their appeal rights regarding a new offer. The lapsing process should also be made clear to people, at the point of a negative MR decision so that people can be aware of what they are, and they know what to expect. We are concerned that some of our members have reported hearing from people who have been called by the DWP and feel pressured into accepting an award lower than what they may be entitled to.

Q8. 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)?

8.1. The Green Paper introduced some potentially very controversial themes: a possible new single benefit to replace both PIP and ESA (and UC equivalent). Members we spoke to all said, in no uncertain terms, that they would be against a single assessment for the following reasons:

- One single assessment, could at a stroke, knock out all financial support, leaving the claimant in serious hardship. There are too many problems with the current assessment process for both PIP and ESA which could lead to inaccurate decisions being made.
- PIP and ESA are different benefits, assessing different things which requires different information. MNDA make the point that some people, particularly those with a progressive condition, may require support from one benefit before they reach a point where they need support from another.
- There is also a concern that starting down this road could lead us to a point where people being able to work is taken as indication that a person has lower extra costs needs, which will undermine the non-means-tested nature of PIP. People face extra costs irrespective of their income and employment status

8.2. Instead of combining the assessment processes the Department should focus on improving the quality of the current assessment process, including how it uses the information it collects and as the question suggests streamlining the process for people. Disabled people often talk about how they have to tell their story repeatedly and provide the same evidence more than once.

8.3. Our members have offered varied suggestions for how the process could be streamlined and reduce the burden that comes with applying for multiple benefits individually. They all have one thing in common – any sharing of information or evidence must be done with the consent of the claimant and data sharing safeguards. Potential ways in which the process could be streamlined include:

- An assessor recommending someone for another benefit if they can gauge from the assessment they could be entitled
- Holding evidence for benefits applications on a central system
- Share the data used for assessments across the two
- Identify where people have applied via the SRTI for one benefit, or similarly the proposed SDG, and passport this to other benefits
- Reduce frequency of reassessments/repeat assessments – exempting people from reassessments or assessing them less frequently will not only increase people's security and stability, it will also streamline the assessment process by reducing the number of unnecessary assessments. Repeat assessments where there is clearly no possibility of change are both frustrating, stressful and a waste of resources. We are pleased to see progress being made in this area in the Government's Green Paper

8.4. There will still be fears by some that their information would be misused due to a deep distrust of the DWP. Work would need to be done to improve this and provide guarantees to improve people's trust in the system.

Q9. What are your views on the Department's Health Transformation Programme? What changes would you like to see under the programme?

9.1. The aims of the programme are positive, and we welcome its development. The Department must engage with disabled people and people with long-term health conditions, charities and disabled people's organisations to ensure that the programme continues to follow a test and learn process.

9.2. Potentially positive developments:

- A combined IT service will be useful (as highlighted in Q8)
- Make the process simpler – assessments only conducted where necessary, and people having to repeat themselves less
- Better use of medical evidence and data
- A focus on getting the right outcome quickly
- Individuals being given more choice about how they interact with the DWP
- Better signposting to other support and benefits that might be able to help the individual

9.3. Potential pitfalls:

- Individuals must give permission and opt in to information sharing
- It should not become a digital only process
- While evidence can be shared, it should not be assumed that the same evidence can always be used for different benefits
- Having a case manager and assessor so closely linked could threaten to undermine the independence and impartiality of challenging decisions

9.4. The DBC is interested to see the early evidence from the first stages of the programme and its roll out, as well as continuing to engage with the DWP on how it is designed and delivered.

Q9b. What would be the benefits and drawbacks of DWP bringing assessments in-house, rather than contracting them to external organisations? In particular, would this help to increase trust in the process?

9.5. The priority is that the DWP improves the quality of the current assessment process to get more decisions right first time and make the experience better and less stressful for people – no matter who delivers it.

9.6. However, the quality of the DWP's contract management of the assessment providers has been sorely lacking, with little evidence of the Department holding them to account where they have been found to be failing on contractual commitments.

9.7. It can also be said that the Health Transformation Programme and the recent improvements at the MR stage suggest the bringing assessments in house enables the DWP to make changes and improvements to happen more quickly when under its own management. It will also make feedback from tribunals to assessors easier and more effective.

9.8. The DWP should watch Scotland’s example carefully to see if their new process improves standard, quality and accuracy of assessments.

Q10. 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?

Q10a. Is there a case for making some of the changes permanent?

10.1. The Department’s commitment in the Green Paper to rely to a greater extent on paper-based assessments is welcome given the stress and anxiety face to face assessments can cause many people. It will also shorten the process and has the potential to improve trust amongst claimants. Getting an outcome through an accurate paper-based assessment only should be the aim.

10.2. However, the Department’s commitment can only be realised if there is change in how the DWP engages with supporting evidence, including giving more time (as was seen during the pandemic) for forms to be submitted, and more weight given to evidence supplied. You can find more details on how we feel the evidence gathering and use of evidence can be improved in our answer to Q1.

10.3. During the pandemic, the move to remote assessments was welcome, and one the DBC want to see continue. There are mixed views amongst members, about which method is preferable when it comes to face to face and remote assessments. Members report hearing varied experiences from their communities.

10.4. Some people have found having a phone assessment much better. For example, they may not have to travel, they can be assessed in a place they are familiar with and informal observations play a reduced role. Other people prefer face to face assessments - talking on the phone may cause anxiety for example, or people feel they are better able to explain their physical disability in person. It’s also important to remember that online and virtual assessment processes are not always accessible to everyone, this could be because of their condition and their symptoms. We know that many people don’t have access to digital technology or lack the digital skills required.

10.5. What is clear through discussions with our members is the need for choice. Where an assessment beyond a paper-based one is deemed necessary, the Department must offer a variety of assessments, and one that best meets the needs and circumstances of the individual claimant. The DWP must give people more information and details on assessment methods, so they are able to make an informed choice. The assessment method must be chosen by the person being assessed.

10.6. Another common theme amongst members is that problems with the assessment process as a whole remain – no matter the assessment method, including an assessor’s knowledge and understanding of the condition they are assessing, claimants not having support, and problems with the claim forms. Until these are addressed inaccurate decisions will continue to be made.

Q11. Not answered.

Q12. 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?

Q12a. How can the Department best help the third sector to support claimants in their applications?

12.1. Firstly, there has been an issue with take up prior to the pandemic. This failure to claim entitlements should be addressed via regular and well-funded take up campaigns. There is also a need to update our understanding of non-take up. It has long been known that lack of the existence of a benefit, or of the eligibility criteria; difficulty in navigating complex claims processes; and the effects of stigma; are all factors discouraging take up. The DWP should commission research to update our understanding of under-claiming.

12.2. Regarding access to support, we know that someone is more likely to get an accurate decision first time if they have received support with the process. The Government should fund an independent advice and advocacy network made up of Local Authorities, peer networks, VSCEs, and community-based organisations. This would support parity of access and consistency of high-quality advice across the country. Recent discussions with Ministers and officials have suggested a growing awareness of the importance of advice and advocacy, but it is important that they understand any services, must be independent.

12.3. Another way in which advocacy services can provide effective support is through the DWP restoring implicit consent and remove the need for explicit consent. This is an unsustainable policy. The respiration of an orderly system of implicit consent is essential if problems with claims are to be promptly and effectively resolved.

12.4. Ultimately, if the claims and assessment process was simpler and less onerous, the high level of demand for third sector support wouldn’t be as necessary.

Q13. 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?

13.1. The research findings are largely consistent with what our members tell us. People are mentally and emotionally impacted by the whole assessment process, and in some cases people’s symptoms can worsen.

13.2. In particular, having to go through unnecessary repeat assessments can cause real anxiety and stress for many claimants, and on occasion physical harm. We speak to people who cannot understand why they are being reassessed for a condition that will not change or will progress and has been confirmed by their clinician. For example, the MS Society shared the view of an individual with MS who said

13.3. “DLA was – you say you have this condition, how can we help you? PIP is predicated on – you say you have this condition, now you need to prove it, and then you need to prove it again and again to prove you are worth of assistance. My clinician has told them I have an MS, and that I won’t get better. That’s fact. Surely that’s enough.”

13.4. The research shows that there is a need for a person-centred, flexible system that considers people’s individual needs and circumstances. The assessment process needs to be fairer and less stressful. The best way of addressing the findings of the research is to improve the whole process, details of this can be found in our answers to the questions in this submission.

Q14. What could the Department do to shorten waits for health-related benefit assessments, especially for ESA/UC?

14.1. One of our members suggests that UCA50 forms should be issued automatically on the 29th day of someone’s claim where that person has been providing fit notes (currently it is the responsibility of a Work Coach), so that nobody is faced with ‘gatekeeping’, which stops them from attending an assessment.

14.2. More effort should be made to conduct paper-based assessments which would reduce the number of people waiting for a face to face assessment.

14.3. Award lengths should be longer, reducing repeat assessments, in particular, for people whose condition will not change, or is likely to get worse. This would reduce the number of people waiting for a face to face assessment.

14.4. The DWP could also employ more staff to cope with excessive waiting times.

Q14a. 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?

14.5. The assessment rate for ESA is currently not high enough to cover disabled people’s living costs, in fact we would argue that current rates of all disability benefits are inadequate. Although benefit rates are normally uprated annually according to an index of inflation (except for years in which they have been frozen), the initial amounts to which that uprating is applied have not been assessed for adequacy. It is our understanding that there has been no official assessment of adequacy since an unpublished internal study in the early 1960s (and not acted upon).

14.6. We would like to see policy in relation to benefit rates informed by research on minimum income standards, along the lines of that conducted annually by the Centre for Research in Social Policy at Loughborough University for the Joseph Rowntree Foundation.

The Government should regularly commission such research, not least in relation to the benefit rates that particularly pertain to disabled people. As one of our member organisations put it: nobody should rely on charity to meet basic needs and it is fundamental that benefit rates meet an acceptable cost of living. This is not merely a matter of subsistence. Independent living requires that disabled people should be able to afford to take part in the range of social and cultural activities that most of society takes for granted.

14.7. Regarding the assessment rate particularly, it is vital that nobody waiting to be assessed or challenging an assessment decision, is subject to the Benefit Cap, claimant commitments, or at risk of sanction.

Q15. 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?

15.1. The experience of some of our members who have been engaging with the Scottish Government in designing the Adult Disability Payment has in the whole been a positive one, and the belief that the DWP should adopt some of their principles and learn from them. One member told us: the development process has shown an understanding that the costs of living with a disability or a long-term health condition are not only financial, but also include the cumulative adverse effects.

15.2. Members who have been engaging with the Scottish Government in the development of the ADP have told us that engagement has been wide and positive, with service user experience at the heart of any changes.

15.3. There was some surprise that in the Green Paper, the Government offered cases studies of other countries, including: Australia, New Zealand, France and Switzerland, yet failed to consider reforms being made by the Scottish Government. This is surprising given its close proximity and the similarities between the two systems.

Q15a. Not answered.

Q16. How effectively does DWP work with stakeholders – including disabled people – to develop policy and monitor operational concerns about health-related benefits?

Q16a. What steps could the Department take to improve its engagement with stakeholders?

16.1. We do recognise that there has been an effort to improve engagement between the DWP and disabled people, and disability charities recently, but this could always be improved. More notice could be given of upcoming consultations rather than vague timescales, and more time should be given to respond. It’s not always clear whether the contributions we make, and the feedback and insight provided is used and acted upon. Greater transparency of process and decision making will facilitate better trust in the consultative process.

16.2. DBC membership consists of large and small organisations, some have more capacity and resource than others. This means that the experiences of the levels of engagement between the DWP and our members varies greatly.

16.3. From the perspective of DDPO members, they are clear that the DWP does little to engage with them, and disabled people directly. There is ongoing concern within DDPOs that they are not given nearly the priority they should be for engagement across Government. This is a missed opportunity to engage with the views of organisations run by and for disabled people. One of our members told us: this is unfortunate because we cannot think of another equalities group where government would feel it appropriate to engage with stakeholders that do not themselves form part of the affected group. The DWP should prioritise engagement with DDPOs and show a clear commitment to hearing those voices.

16.4. Our smaller sized members have a similar experience to DDPOs, one told us: DWP's focus is very much on engaging with larger, national health and disability charities, as opposed to smaller organisations. We would argue this leads to a failure on their part to consult or act on the changes that would have a meaningful and positive impact on disabled people and this is backed up by our own research.

16.5. Larger organisations tend to have a better experience but recognise the privileged position they are in. One of our larger organisations told us: We find that the more we engage with DWP, the more we are invited to participate. For example we will receive more invitations to smaller meetings with DWP officials. Increased invites to participate have come from building a reputation on an issue and from the opportunity to build relationships with civil servants. As a result, we are able to provide insights on our community's experiences and the changes they want to see. Without us having the resources and capacity to engage we wouldn't be able to do this.

16.6. It is vital that DWP start engaging more with those it often overlooks and we aim to use our position to represent all our members, small, large, national and local to urge them to do so. The SSAC report earlier this year 'How DWP engages with disabled people when developing or evaluating programmes that affect them' provides a good basis for much more open and trustworthy engagement.

For more information please email Anastasia Berry at anastasia.berry@mssociety.org.uk