

SUBMISSION OF EVIDENCE: Health assessments for benefits

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Introduction

We are a group of academics, students, parents and carers, practitioners, young people and advocates working together to beat the odds and change the odds in disadvantaged communities. All of us either identify as, or work directly with, children, young people, and families that experience complex life challenges such as additional needs, racism, disability, economic disadvantages, and experiences of government care. Others of us have experienced these things too in the past. Some of us only recently became adults. We have written this submission together and all of us were paid for our time and expertise except for the debt management advocates who are volunteers in a third sector organisation called Grace Advocacy Home (graceadvocacy.org).

This submission addresses questions asked in the call for evidence in the order they were prescribed and under the same headings. We have used our collective experience, knowledge and understanding to provide our evidence. Italicised quotations have been used in places.

Suitability of assessments

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

The quality of assessments could be considerably improved by better attention to two fundamental aspects:

- I. **The location and timing of assessments.** These are sometimes conducted some distance from where the claimant resides. It can incur costly and time-consuming travel arrangements. People are left with little option but to attend if they are to proceed with the claim. The experience is exhausting and can leave the person feeling like they are being set up to fail if they have had to walk down a corridor to the assessment room and the assessor asks how they have got to the venue (mobility activities). The fact that someone has been able to use public transport and walk on the flat with the support of a carer or advocate has, in our experience, been used as a reason for declining a claim.

Similarly, many assessment venues are not wheelchair accessible, and this too is often something that is also used against claimants. For example, if

someone's carer struggles to get their wheelchair down the steps to attend their appointment, (a local one has 2-3 steps leading down to the main door), this is used against the claimant. What the assessor just sees is that the claimant has arrived for the assessment. The assessor does not see in that snapshot of time the devastating effect of making the effort to attend the assessment and the recovery time afterwards.

II. **Better training of the independent assessors** with regards to understanding the mental health needs of claimants and how the stress of the assessment impacts claimants. The focus on physical health and capability can evoke a reaction whereby the claimant makes out that they are better than they are and can do more. *"Of course, I can make a cup of tea"* which does not convey how long it might take them or whether they can do it safely without risk to self, such as scalding from boiling water. Our experience shows that sometimes responses to questions can come across as aggressive and abusive when in fact the claimant is stressed and frustrated. This can be frustrating too for a carer or advocate accompanying the client who is not permitted share any relevant detail if the claimant themselves does not first offer a response to the question.

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

The PIP document requires complex writing skills to assemble evidence following the lead question for each activity. **What are the difficulties, how do you manage and adapt, how often is this an issue during the week, what help do you have and what help do you think you should have.** This is made harder if the claimant has a learning difficulty or cannot read. Help and support is required for completing the document. Advocates often first see the document when the claimant is appealing for a mandatory reconsideration or going to tribunal, assuming they have the energy and support to do so. [Mind (2022) have commented on the lengthy and stressful process of appeal in recent evidence submitted to the DWP.] The evidence is only as good as the way the form has been completed. For many claimants their circumstances and surroundings have normalised their activities in that they do not fully recognise their functional impairment. They have often filed the original paperwork and not sought help with providing evidence in the manner which DWP requires.

If English is not the claimant's first language and the case goes to appeal, interpreting services have not always functioned in the best interests of the claimant. Apart from the disembodied voice at the end of a telephone, especially during Covid times, we have had cases where the dialect of the interpreter's language is not consistent with the claimant's own language (from Sri Lanka), or the interpreter has not fully represented the claimant's case. In one instance this was picked up by the

judge at the tribunal and the panel was asked to refer to the advocate's comments rather than the interpreter's comments and translation. Better interpreting services support is recommended with greater sensitivity to language requirements, for example, various dialects inherent in African and Indian languages.

No attention is paid to sleep as an activity yet its impact on the claimant can be profound in day-to-day functioning. The quality and duration of sleep, where and how the individual sleeps, how sleep is induced and maintained, when it occurs and for how long during a 24-hour period can all impact on how some activities are performed and whether in a safe manner, for example, washing and bathing, managing therapy/monitoring a health condition. The impact of sleep quality is presently integrated within evidence of other activities as is mental health. Sophie Corlett Mind's Director of External Relations, (Mind 2022), recently reinforced this in evidence given to the Work and Pensions Committee on health assessments for ESA and PIP quoting a claimant who said the assessment is not representative of mental health and focuses more on physical health.

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

There is insufficient focus on the reasonable adjustments that employers could make but are not doing. One claimant commented:

"People would have more ability to work if there were more flexible and accessible jobs available. Many disabled people would love the opportunity to work but there aren't enough jobs that understand disabilities and allow for the kind of flexible working many of us need."

Another claimant had her ESA refused because she was undertaking advocacy work and another because she was an academic and delivering online teaching, writing and editing. No account was taken of the fact that the academic worked from home was able to pace herself and had support when needed. There was no recognition of the adjustments made to accommodate working patterns and prevent physical and mental fatigue. Both individuals had invested time and energy in seeking adjustments to function in useful work yet felt they were not allowed to achieve or flourish and access benefits.

5. 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?

In our experience paper-based assessments have worked well with clients seeking help (for example, via third sector advocacy services) to complete what is often viewed as an overwhelming document requiring good literacy skills. When unwell and

distressed by the process, worried that a benefit will be stopped, this can be exhausting for the claimant and require more than one appointment with an advocate to fully understand the impact of disability, and poor physical and mental health. It is a time-consuming process and entails talking and listening to claimants, parents and carers to fully understand the issues (lived experience) affecting their day to day lives and helping them co-produce a coherent written response to the questions. Because their medical condition and side effects of their medication has become part of their daily living, claimants often forget to mention these side effects. This detailed approach has also been useful for finding the right supporting evidence such as medical consultation letters and care summary records which can be obtained from the GP.

During the Covid 19 lockdowns this personalised approach was still possible with the use of video and/or audio-conferencing facilities at no cost to the claimant. A more flexible approach for health assessments in this way could be better utilised by the DWP.

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 the drawbacks of such an approach?

A drawback of not engaging with the claimant either in person or via a video link is the emphasis on physical parameters and measurements of the body to the detriment of wellbeing including the unique physical, psychological and social needs of the individual. The person is more than a set of results and notes from the clinical records. This reductionist approach is recognised and described within the medical sociology literature where 'visualizing bodies and vanishing patients' (Blaxter, 2009) disregards the patient, or claimant in this case, as part of the decision-making process. It is argued that this is equally applicable to the medical assessments required for various state related health benefits, (Blaxter, 2009).

Benefits of not having a separate assessment include that the claimant does not have to experience the distress often caused by explaining confidential, personal and intimate details of their conditions to a complete stranger:

"It can be extremely humiliating and distressing for someone to explain details that their GP or specialist already knows about and has a better medical professional understanding of. Assessors often ask questions that wouldn't have if they had specific medical knowledge of a condition."

One advocate was present at an assessment where the assessor admitted she had no comprehension of the degenerative nature of the claimant's health condition and had asked inappropriate questions.

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

Several of the authors volunteering in the third sector as advocates have first-hand knowledge and experience of supporting claimants through mandatory reconsideration and going to tribunal to appeal a benefit decision. The initial decision has been overturned at mandatory reconsideration in some instances and all appeals at tribunal have been 100% in favour of the claimant. This is because the compilation of evidence for the review has included forensic-like scrutiny of the descriptors to ascertain whether an activity can be reasonably and safely performed on a repeated basis. One claimant noted:

"A culture of systemic dishonesty during assessments is also a large contributor to this statistic."

On reading the above statement from a fellow author, another said:

"I have found that the assessor does not always represent the truth in their narrative. They misrepresent what the claimant has said. I have an example of a client not being awarded PIP. Fortunately, I attended the phone assessment and was able to say that what the assessor wrote was not indicative of the truth. The claimant was awarded enhanced rates on both daily functioning and mobility."

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

"Claimants might be able to address this directly in assessments if we or our carers were allowed to see what the assessor is typing. Often what we say is incorrectly recorded or not recorded at all, but it isn't until much further on in the appeal process that we can access what the assessor has written."

8. 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 (eg. PIP and ESA)?

Yes, but also extending the list of exempt conditions so claimants do not have to reapply where it is known their health is not going to improve due to life-limiting conditions. Our examples include long term conditions such as Huntingdon's Chorea

and recently a client who had pursued a medical negligence claim where nerve damage was irreversible.

“Combining these assessments could prevent trauma and distress caused by the process and could also prevent potential confusion. I was once given an appointment for ESA which I knew I wouldn’t be able to get due to my partner’s income but I turned up to the assessment which was very far from where I live with my carer thinking it was for DLA.”

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

Digital exclusion and digital poverty are frequent barriers for claimants and one of the reasons they seek third sector support. They may not have a suitable digital device that facilitates a clear interface or lack digital literacy skills, an internet contract with sufficient data services or printing facilities that would incur a cost. For example, the 29-page interactive document for an Attendance Allowance claim.

a. (For people claiming) Would you like to be able to manage your benefit claim online?

“Being able to submit evidence digitally would be preferable for me as the printing costs for 50+ pages that I needed to submit for evidence was not something I, or many others can easily afford.”

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

As described in response to question one, better preparation and training of the independent assessors is recommended for whoever conducts the assessment. In-house assessors that are trained to ensure they are mental health informed with knowledge and understanding of how someone’s mental health can fluctuate and impact their lives as recommended by Mind (2022) would increase trust.

“A lack of any assessor’s medical knowledge, specifically around mental illness, is often directly damaging to the health, safety and wellbeing of claimants attending assessments. There needs to be more awareness of stigma and the harm this can cause. For example, a claimant has been told during an assessment that they can’t actually have an eating disorder due to the size of their body. If the assessor was educated about mental illness and eating disorders, they would know that this is actually incorrect and is a very harmful thing to assume/say.”

12. 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?

“There could be a fund that claimants could access if they need support with filling out the application or help covering costs of things like printing. If someone needed to submit evidence but didn't have access to a printer at home they would have had to wait for libraries or internet cafes to open to be able to print off their evidence. They would also need to have enough money in their budget to cover the cost of this which can be considerable.”

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

Additional funding to third sector organisations that support individuals making benefit claims is helpful but with that comes criteria and targets embedded in policy, plus loss of independence. DWP would be better focusing on enabling clients to offer additional forms of evidence that third sector organisations can help provide.

The impact of assessment/application on claimants

13. 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?

“Making sure assessors have good medical knowledge and understanding of stigma surrounding physical and mental illnesses. Providing some kind of support for claimants following assessments as they can be very triggering and cause extreme distress. This often leaves claimants vulnerable and unsafe following assessments.”

Waits for assessments

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

It would be helpful to permit other forms of evidence to be submitted in a digital format and to speed up the process. It is only when the claimant's case enters the court service that the process eases and files can be attached and uploaded. Up until this point the DWP systems appear opaque and designed to trip the claimant up. A recent example is video evidence of a severely autistic child submitted for a DLA appeal and accepted yet the parents had to endure the distress of the process to this point. Delays and cancellations can have far-reaching consequences. See CPAG (2021) for examples during the pandemic and the narrative below:

“When my last assessment was cancelled in the morning just before I was about to attend, I experienced a mental health crisis and climbed onto the roof of my building because I couldn’t cope with my suicidal feelings and wanted to end my life. I felt completely unable to cope with the stress and anxiety leading up to the assessment all over again. The police and ambulance service attended my flat that day as a result of this and I needed lots of support from mental health services to keep myself safe in the time leading up to my rearranged assessment. Suicidal feelings and attempts during all parts of the process, including the appeal and tribunal stages are common for people experiencing mental illness.”

a. 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?

“Yes, most people need financial support while they wait for assessments, financial hardship during these times can and does directly contribute to worsening illness and symptoms for many.”

Policy development

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

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

Mind (2022) has already recommended the DWP should establish an independent commission led by disabled people to design new benefits assessments. We agree and in addition think people with lived experience should be paid to co-produce more ethical policies and practices.

Mind (2022) has also suggested the UK Government should create an independent regulator of the benefits system to monitor how well the DWP is fulfilling its duties under the law and protecting the rights of people applying for benefits.

References

Blaxter M (2009) in Nettleton S (2013) *The Sociology of Health and Illness*. 3rd Edition. Cambridge: Polity.

Child Poverty and Action Group (2021) [Assessment delays for ill health and disability | CPAG](#)

Mind (2022) Evidence to the Work and Pensions Committee on health assessments for disability benefits Employment and Support Allowance (ESA) and Personal Independence Payment (PIP) See

[Benefits assessments continue to fail people with mental health problems, according to expert evidence - Mind](#)