



DWP response to Modernising support for independent living

NAWRA Response

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The National Association of Welfare Rights Advisers

1. The National Association of Welfare Rights Advisers (NAWRA) was established in 1975 as the Welfare Rights Officers' Group, and then the National Welfare Rights Officers' Group before becoming NAWRA in 1992. It represents advisers from local authorities, the voluntary sector, trade unions, solicitors, and other organisations that provide legal advice on social security and tax credits. NAWRA currently has more than 200 member organisations.
2. We strive to challenge, influence and improve welfare rights policy and legislation, as well as identifying and sharing good practice amongst our members.
3. NAWRA holds four conferences throughout the year across the UK, attended by members from all sectors of the industry. An integral part of these events are workshops that help to develop and lead good practice.
4. Our members have much experience in providing both front line legal advice on benefits and in providing training and information as well as policy support and development. As such NAWRA is able to bring much knowledge and insight to this consultation exercise.
5. NAWRA is happy to be contacted to provide clarification on anything contained within this document. NAWRA is happy for details and contents of this response to be made public.

Executive summary

6. NAWRA's response to this inquiry was informed by an online survey which received more than 110 responses from organisations across England and Wales.
7. While there was some agreement with the idea that using diagnosis as a basis for a PIP award for some conditions (particularly those that are progressive or permanent), it was felt that there needed to be flexibility, particularly in recognition of the fact that some people would be unfairly excluded by over-reliance on 'diagnosis', as many find it difficult to gain access to medical help for a number of reasons, including long waiting lists on the NHS. In addition, while patients are waiting for a diagnosis, they have the symptoms so they need the dignity that allows them to choose how they can best use the money to improve their independence. Diagnoses for mental health problems can be particularly problematic.
8. In addition, it was felt that using evidence other than assessments, including non-medical evidence would be beneficial, for example from people who see the claimant on a regular basis, such as nurses, support workers, carers, and family members, who can comment on the impact of the condition over time.

9. Access to treatment and services will not be a solution for many. People who have lifelong conditions may not have treatment other than repeat prescriptions. This is particularly true for people who may suffer from Long Covid, a condition that includes chronic pain, fatigue or learning difficulties.
10. However, overall NAWRA believes this Green Paper is ill thought-out, and has been put together without talking to disabled people and the organisations that represent them. No recognition is made of the current state of crisis within both the NHS and social care, and this undermines the unwarranted and unexplained assumptions within the Green Paper that an award of a financial benefit can somehow be replaced by better access to treatment and services.
11. NAWRA also believes that the Paper sits alarmingly at odds with the Health and Disability White Paper which sets PIP entitlement as the central measure of disability for means-tested benefits. PIP is also a qualifying benefit for carer's allowance and for further assistance for disabled students, and this has not been addressed. The disparity between the proposed interlinked reforms needs to be addressed, preferably in a reconsidered and reissued Green Paper.
12. In summary, NAWRA considers this Paper unfit for its purported purpose, and recommends any future proposals for reform should be set out following full consultation with disabled people and the organisations that represent them.

Assessment reform

Diagnosis vs assessment vs evidence

13. More than 80% of respondents agreed that people should receive PIP without an assessment, and should not be subject to an award review, if they have a specific health condition or disability as evidenced by a healthcare professional. In particular, the following points were highlighted –
 - Evidence from a healthcare professional, especially someone who knows the claimant's situation well, should be accepted without the need for further assessment by someone who does not know the claimant;
 - Automatic eligibility could easily be applied to conditions which are degenerative, congenital or permanent;
 - When addressing diagnoses for mental health it can be very moveable feast! A patient might present one set of symptoms; fitting one diagnosis at one assessment, then different symptoms meriting a different diagnosis at a second. People make recoveries then relapse into different symptomatology. Labels are of limited utility. At the same time, as differing symptoms are observed the diagnosis might evolve from, say, bipolar to a personality disorder;
 - There should be no need to reassess claimants with lifelong conditions;
 - There should be more use of medical records if they can easily provide the required evidence;

- The current quality of health assessments is poor as documented by the Work and Pensions Committee in April 2023¹ – they can be inaccurate and fail to take account of the full impact of the claimant’s conditions – using evidence from professionals/individuals who know the claimant would be more useful. It is also relevant that the Equality and Human Rights Commission has launched an inquiry² to investigate whether the DWP has breached the Equality Act by failing to make reasonable adjustments for people with learning disabilities or long-term mental health conditions during the assessment process.

Case study 1

A client who has obvious and severe mental health problems is banned from the Jobcentre, from multiple local advice services, from multiple GP surgeries and pharmacies, etc. He does not recognise that he is mentally unwell, and he is unable to engage with these services due to his behaviour. This doesn't mean he doesn't have a mental health condition, but it does mean it's unlikely he'll be formally diagnosed. This is not an uncommon problem with mental health conditions.

Condition vs functionality

14. There were mixed views about whether making provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP with 60% disagreeing or strongly disagreeing and just under 30% agreeing or strongly agreeing. There were also mixed views as to whether eligibility for PIP should be based more on condition (42% disagreeing and 32% agreeing). Around two-thirds of respondents disagreed with the suggestion that the assessment should place more emphasis on condition rather than functionality. The following observations were made –
- Relying entirely on condition would result in unfairness – not all conditions are diagnosed yet can be very disabling – flexibility must be maintained;
 - Making evidence or diagnosis mandatory could exclude very vulnerable people who are unable to access services (see above);
 - However, for those where there is a clear diagnosis of a permanent or progressive condition, it makes sense to give an automatic award and avoid delay in issuing payments ;
 - Delays within the health service make it unrealistic to rely on diagnoses – delays making payment could also lead to deterioration in the claimant’s condition;
 - The same diagnosis can range in severity and impact people differently, and this should be taken into account.

¹ <https://committees.parliament.uk/work/1468/health-assessments-for-benefits/news/194649/benefits-health-assessments-system-continues-to-let-people-down-say-mps/>

² <https://www.equalityhumanrights.com/department-work-and-pensions-under-investigation-treatment-disabled-benefits-claimants>

- Patients may be discharged when there is no further medical treatment that can help them other than, for example, exercises they can do at home – this should not be taken as an indicator that their health issues are resolved.

Fluctuating conditions

15. Many members commented that the current PIP regulations 4 and 7 make provision for fluctuating conditions, but that they frequently are not applied correctly, and are sometimes not applied at all. Rather than proposing changes, improvements can be made through the correct and consistent application of existing regulations. This would also have the benefit of avoiding the time and cost involved in mandatory reconsiderations and appeals against poorly made decisions.

16. Other comments included that –

- A holistic view should be taken over a reasonable period that will give an accurate reflection of the claimant's situation (it could be helpful to provide a simple diary for the claimant to complete) and award lengths should reflect the detriment that premature reassessment might cause;
- Reviews should be light touch – if the overall picture is much the same, then further assessment should not be necessary;
- Account should be taken of severity as well as how long flare-ups might last;
- There needs to be a move away from assessors taking a 'snapshot' picture of the claimant on the day they are seen/spoken to – training should be given to ensure that assessors elicit the necessary information, record it, and properly consider the tests set out in PIP regulations 4 and 7 (see above);
- Side effects of medication should be fully taken into account and it should be acknowledged that a person may not know which issues are due to side effects and which due to their condition(s);
- Interaction of different medical conditions must be taken into account rather than looking at conditions in isolation;
- Reliance on treatments which may not be available to the claimant, or are not available yet, should not be taken into account, and there needs to be understanding that there may be many reasons why a claimant is not able to comply with a particular medical regime

Eligibility reform

17. In response to the questions relating to which needs were a good indicator of extra ongoing costs, the survey responses showed that –

- Aids and appliances – 57% of respondents felt that these were a good indicator with 27% being unsure, and 16% thinking it was a bad indicator;
- Prompting – 69% felt that this was a good indicator with 20% being unsure, and 13% thinking it was a bad indicator.

However, there were comments that this was a very individual thing with a lot of variation between claimants or disabilities.

18. 46% of respondents felt that people who accumulated low points across a number of activities have the same level of extra costs as those who score highly in one or two. 40% were unsure with just 13% disagreeing.
19. There were very mixed views as to whether thresholds and the required periods were set at the right level, but it was highlighted that if changes were to be made it should be examined properly, taking into account the views of disabled people and how they are impacted. It was also pointed out that with some conditions, for example cancer, a person could have very severe impacts that might not last a full year but which create a great deal of need.
20. In relation to the current descriptors and the need for change, there was no real consensus here, although a number of people suggested that there needed to be an improvement in descriptors relating to mental health issues.
21. Generally, it was pointed out that the questions asked in the consultation are very arbitrary, and much more detailed analysis is needed before decisions are taken. The lived experiences and views of disabled people should form a central part of this, and the absence of such views from the Green Paper invalidates it.

Reform of how support is provided

22. It was commented that it was extremely difficult to prioritise which extra costs are more important – many said that the question was unacceptable and arbitrary. What is important to one individual may have minimal impact for another. There needs to be a much more tailored approach to looking at how individuals are affected rather than fitting things into rigid boxes
23. In respect of the four alternative methods of support proposed, responses included that they –
 - Revoke the autonomy of claimants and reduce PIP’s flexibility to meet the varied needs of an individual – one respondent commented ‘PIP claimants are disabled adults, not naughty children that cannot be trusted to spend their own money’;
 - Do not empower disabled people to maintain their independence, thus undermining the policy intention behind PIP;
 - Add an unnecessary administrative burden on both the Department and the claimant;
 - Come across as an attempt to cut costs and remove choice and control for disabled people;
 - Risk being stigmatising and humiliating, taking away people’s dignity.
24. It was highlighted that the proposals in this Green Paper sit at odds with those in the Health and Disability White Paper. If it is proposed to make the universal credit health element contingent on PIP entitlement, then it is disingenuous to be separately reducing

that entitlement. Reform of health and disability benefits needs to be looked at holistically to ensure that people do not slip through the net and to avoid unintended consequences.

25. Many respondents highlighted the importance of PIP being a cash-based, non-means-tested benefit, and that additional financial support should not be limited to means-tested benefits
26. In respect of people who are not having their needs met sufficiently, NAWRA members highlighted mental health, neurodiversity, cancer and fluctuating conditions. Many pointed out the difficulty getting support through health services which was then having a negative impact on the person's condition
27. While it was agreed that improved access to other support was vital, NAWRA members felt this should not be in place of a cash payment.
28. It was also pointed out that long waiting lists and the severe underfunding of both the NHS and social care are key contributors to the recent rise in PIP applications, and that resolving these overarching problems would have a beneficial effect on PIP: if people could gain access to good health support more rapidly, then there would be less need for PIP applications.

Aligning support

29. Both local authority support and NHS services are stretched to the limit, with people not receiving the level of help they need and/or having to wait a very long time for it. Indeed, only 26% of respondents thought claimants were in receipt of such support. While it is vital that these services are improved, they are not a replacement for the cash benefit which is there to meet everyday additional costs.
30. In respect of the NHS or local authorities helping with any of the named services, again respondents highlighted the severe constraints that the services were under, severely limiting available resources. Where services are provided, they are usually means-tested and many local authorities take PIP into account when means-testing - the knock-on effect of this is that a reduction in PIP could lead to an increase in social care spending. Examples were provided of help with taxis being refused due to a claimant being in receipt of PIP mobility component. Furthermore, support is not always long-term, there can be long waiting lists, and provision can be unreliable and variable according to post-code.
31. There were very mixed views about whether aligning support would improve things for disabled people and people with health conditions, and whether doing so would reduce the number of assessments needed.
32. Other comments in relation to aligning support included –

- This should not be considered until there is adequate funding across the board – it was remarked that it is difficult to align support with a health and social care system on the brink of collapse;
- While this could be beneficial in some circumstances, there has to be need for flexibility dependent on the person’s condition and where they live, for example there could be differences between rural services and those in the city;
- Again it was commented that if the NHS and social care were adequately funded, there would be substantially fewer PIP claimants;
- Some commented that while this could be worthwhile, it would need heavy investment and good management to make it work – there was much scepticism that this would happen

Conclusion

33. NAWRA believes that this paper is ill thought-out – it has its basis in cutting costs without consideration of what would work best for disabled people. There is no acknowledgment of the current strain that both the NHS and social care are under. Until these services are back on their feet, it is completely unrealistic to propose that PIP could in any way be replaced by them. It is worth noting that previous attempts to cut the budget without taking into account the original policy intent have been deemed unlawful.³
34. NAWRA completely opposes the proposal to change PIP from being a cash-based, non-means-tested benefit. Disabled people need to have choice and control over their lives, and PIP goes a little way to helping provide that. To consider removing that is completely unacceptable.
35. While it is acknowledged that there may be some improvements that could be made to the PIP assessment and eligibility criteria, any proposals should start by talking to disabled people, and disabled people’s organisations, and presented in a considered document looking at options and alternatives based in reality. For the then Prime Minister to present the Green Paper saying it needs to be ‘harder to exploit by those who are trying to game the system’⁴ perpetuates the negative myths that are so often put out in the media about disabled people that can lead to hate crime. Recent statistics⁵ show that the overpayment rate for PIP is currently at its lowest recorded level of 0.4% - NAWRA considers that this issue has been hugely overstated for political gain and to the detriment of disabled people.
36. In addition, NAWRA believes that this Green Paper sits at odds with the Health and Disability White Paper which puts PIP as the central measure of disability for means-tested benefits. PIP is also a qualifying benefit for carer’s allowance and further support

³ <https://www.bailii.org/ew/cases/EWHC/Admin/2017/3375.html>

⁴ <https://www.gov.uk/government/news/disability-benefits-system-to-be-overhauled-as-consultation-launched-on-personal-independence-payment--2>

⁵ <https://www.gov.uk/government/statistics/fraud-and-error-in-the-benefit-system-financial-year-2023-to-2024-estimates>

for disabled students and this has not been addressed. Any reform of health and disability support must be done holistically to ensure that people do not slip through the gaps.

37. In summary, NAWRA considers this Paper unfit for its purported purpose and recommends any future proposals for reform should be done in full consultation with disabled people and the organisations that represent them. It is hoped that the new government will take this on board and approach any reform in an inclusive and holistic manner.