**Responses to PIP Green Paper.**

This is a combined response from a collection of blind and other military veterans. We are real humans, not AI. While some of us are in receipt of disability living allowance (DLA) and attendance allowance (AA), we appreciate that transfer to PIP remains a possibility for those born after 1948 so any changes to PIP may also apply to us.

**Please note that the themes evident in the following apply to all the proposals and so are not limited to any specific question.**

**We are individuals, not numbers.**

The desire for cost-savings rather than good quality service seems to underpin much of the Paper. Reducing our complex individual circumstances to simple tick-box calculations that can be decided by algorithms is probably over ambitious. However, we welcome improvements in the benefit that recognise our individual circumstances, focus on lost functionality (rather than medical diagnosis), is decided by suitably qualified, experienced people who are subject to the standards of a professional body, is prompt and accurate while also respecting international law, our human rights and dignity. We recognise the time and cost benefits of automated decision-making using Artificial Intelligence but are wary of current problems, bias, prejudice and more being imported into a new system before being fully exposed and resolved by humans.

DWP will be aware of the United nation’s Committee on the Convention on the Rights of Persons with Disabilities which specifically commented on the prospect of use of AI in UK benefit decision-making and their significant concern: “There is a tangible concern that artificial intelligence (AI) tools and algorithms may harbour inherent biases, potentially leading to punitive measures that, fundamentally, could impart a sense of criminalization and psychological distress among individuals” (2024).

Surely no politician or civil servant wants to be associated with activities condemned by the United Nations as violating international law or that are subject to statutory investigation by the Equality and Human Rights Commission. Yet such is the current situation within DWP and this Green Paper risks further exacerbating the Department’s risk of unlawful activity.

Experience of the introduction of Universal Credit should provide a salutary lesson about the failure to address fundamental flaws before rolling out new “solutions”, driven more by policy than the real circumstances of people. Instead, the proposals of this Green Paper seem to by-pass creation of a successful, well-tried and tested human process but leap from one imperfect system to embrace all the risks of automation and Artificial Intelligence. Get it right first and then examine which elements can be automated.

**Let’s rethink the whole purpose of PIP for working age (and other disabled people).**

This paper is too concerned with process rather than the purpose of PIP, namely “Personal” and “independence”. Both these goals seem lost to “system-design” rather than actually improving the lives of people with disabilities.

The Government has announced “only one health and disability functional assessment, the PIP assessment “. While we support a single assessment that covers every form of support from any element of Government, national or local, this should not be the PIP process as it stands or as this Paper proposes. There is little evidence that the Government has the priorities of disabled people at the core of their thinking. Instead, there is significant underlying distrust of Government motivation, underpinned by the data and the United nations’ recent criticisms.

The onset of a major health condition is difficult enough and worse when it threatens work and other aspects of life. No-one wants to be disabled, to need help or to have their future life and work prospects threatened. Most people acquiring such significant health conditions are more likely to deny both the set-back and its consequences than use it simply to avoid work and live in poverty. The psychological impact of having the rug of “normal” life removed can be as devastating as the health condition itself.

PIP could be the start of finding a way back. Expert assessment of the help, adjustments, aids and equipment to regain as much previous functionality as possible would be ideal. Not only helpful but evidence that the Government is keen to support us fulfil our life and work potential. Such assessment should also take into account the psychological consequences of the onset of a disabling, life-changing condition: anger, denial, depression and worse. Interventions and assessments must avoid exacerbating such.

The obvious broader benefit of PIP fulfilling an enabling function is that more people will be able to work, pay taxes, spend money and contribute to the national economy.

**Use professionals to assess functional loss.**

We’re not interested in medical assessment. Those professionals have their own criteria, pressures and focus. For instance, it is apparent that ophthalmologist may be excellent at treating an eye condition and even assessing visual acuity but aren’t experts on the functional consequences.

Instead, we need other professionals such as Occupational Therapists and psychologists who have the skills, qualifications and experience to provide real help. And a professional body that ensures they do a good independent job. Their knowledge and advice (with some condition-specific expertise) could be invaluable as an investment for our futures and long-term freedom from other benefit dependency. Their assessments could set us on the right track, rebuild our confidence, identify what PIP we need and set us up for the rest of life. Using such external professionals would reduce the demand on DWP staff who’d no longer have to juggle information and make decisions beyond their qualifications. We’d feel more confident that independent, objective and expert opinions are supporting us for the future.

And subsequent reviews would be helpful: conditions and situations change so any deteriorations and new needs can be managed.

Having said all of which, experience of OT interventions can be extremely patchy and highly inconsistent. There’s much room for improvement in their training and professionalism. Alongside, their reports need to be unbiased. Functional assessments, like medical diagnoses, must be independent and not subject to external influences. More than one contributor alleged misbehaviour in adjusting the results of such assessments. Example: one commented “I later found out directly, from NHS OT employee and ex-employee of this independent assessment company contracted by DWP that she was TOLD to rewrite her report as it was in the client’s favourable outcome.”

Collaboration and cooperation between patients, medical, psychological and functional experts plus DWP is more likely to succeed for all than reinforcing entrenched attitudes and confrontation.

**Recognise changes in the nation’s health.**

The Paper’s introduction suggests that the original intentions of PIP aren’t being met and that this is due, in part, to “the nature of health and disability has changed and the caseload and costs of the benefit have risen significantly, reflecting increasing self-reported prevalence of disability.” This implies that PIP and its underpinning policies have not kept up with the changing nature of many people’s lives (such as mental ill-health arising from social media/smart phones/algorithms, from ultra-processed food, alcohol, tobacco and fossil fuels (see WHO report 2024) and, possibly, even from microplastics now present in humans.

Alongside, as is well-documented, British people have faced continuing and long delays in obtaining medical appointments/treatment from the NHS over recent years with the inevitable consequence of increased ill-health/self-diagnosis.

The statement also fails to recognise that apparently lower levels of mental ill-health were partly due to the Census before 2021 failing to ask questions about such. Hence the scale of mental ill-health demand may simply have been unknown/ignored in the past. Most seriously, measures to avoid the onset of mental ill-health and adequate early specialist interventions are not addressed.

In talking about the increase in PIP claimants over the last 10 years plus the increase of mental health amongst those claimants, the Paper seems to imply both that more people are “faking” their ill-health and that the current PIP system cannot identify those “fakers”.

In reality, there has probably been a real increase in real need over the decade which the Paper prefers to set aside.

**Re-build lives rather than cutting costs.**

“We know that across the claimant caseload, some claimants will have significant extra costs related to their disability; and others will have minimal costs. “Seems to be at the heart of the Paper. Similarly, the ordering of the priorities (para 10) makes it clear that enabling disabled people to reach their full potential comes well behind rationing resources and reducing support to those with “least” need. Likewise, the statement that a “new” PIP should be “better targeted at people who have specific extra costs” lacks evidence of current poor targeting or that such costs are the only causes of life limitation.

The Paper is narrow in avoiding consideration of alternative, wider solutions. For example, higher numbers of disabled people are likely to need “less” support meaning relatively small sums for each could produce the necessary improvements: better lives; more remaining in/returning to work; less demand on NHS/social care provision; potential identification of needs that could be resolved by greater enforcement of the Equality Act and other legislation.

Future operation of PIP is unlikely to be successful if constrained by “silo-thinking” but should be part of investment in wider social change across Government Departments.

**Survival v Independence.**

The goal of PIP to make a “contribution towards the extra costs faced by people with health conditions and disabilities to enable independent living” is strongly supported. However, in times of a cost -of-living crisis, high fuel prices and low unemployment of disabled people, it is not surprising that some will use PIP funds to enable them to simply live, never mind being independent. It is well-recognised that disabled people, particularly those relying on benefits, are amongst the poorest in the country.

Overall, suggesting that current PIP arrangements are unfair to the taxpayer is repugnant.

**Reduce rather than increase suicides.**

One of our major concerns is that any changes to PIP should resolve rather than reinforce the comments made by the United nation’s Committee on the Convention on the Rights of Persons with Disabilities in 2024: “The Committee is appalled by reports of “benefit deaths” referring to fatalities among disabled people in the State party, subsequent to their engagement with the process for determining eligibility for benefits. The evidence received revealed a disturbingly consistent theme: disabled people resorting to suicide following the denial of an adequate standard of living and social protection, starkly contradicting the foundational principles enshrined in the Convention. In addition to numerous personal accounts concerning benefit deaths, a research study shared with the Committee indicated a correlation between the government's initiative to reevaluate incapacity benefits through the Work Capability Assessment (WCA) and an estimated six hundred suicides over a span of three years. Testimonies have also been received regarding the minimal, unsuitable, and/or abusive responses to individuals' mental health emergencies that are frequently precipitated by the benefits assessment.”

While some of this criticism concerns unemployment benefits for disabled people, it covers the wider issues of benefit eligibility that will include PIP.

**National v Local.**

Aligning support with local services sounds workable until one considers the Census results outlining the huge variation of local circumstances. For example, those over-70 living in the most affluent areas have the same prospect of becoming disabled as those in their 40s in the most deprived areas.

Levels of deprivation aren’t limited to finances but also include health and educational opportunities. Hence, local services are far more likely to be limited in such deprived areas. Aligning PIP or similar support with already poor provision will further disadvantage those living in large areas of the country.

Focussing PIP on local support sounds great in principle but isn’t workable until there is a level playing field and it seems that the efforts over several decades have failed.

A single initial assessment for all support (local or national) would be preferable but, as discussed above, should be undertaken by independent qualified, specialists with appropriate experience plus disability-specific skills who are subject to the standards of their professional bodies. Additional assessments may be required due to condition changes/additions etc. Other assessments by similar medical professionals are also desirable but cannot be mandatory until access to such is swifter.

**Room for improvement.**

Regrettably, the DWP has an awful reputation for its treatment of disabled people ranging from its discrimination against disabled employees in recent years through damaging media rhetoric, delays in handling claims and high appeal success rates to the 2024 UN criticisms and the EHRC statutory investigation into discriminatory breaches of the Equality Act. There is little faith or trust in the Department’s role in making our lives easier or helping us to fulfil our potential. Whatever facts might be argued, such is the reputation and it would require a substantial change of ethos, behaviour and attitudes for many of us to have confidence that DWP has our best interests at heart.

**Chapter 1 – PIP – Overview and assessment reform**

**Q1**. What are your views on an assessment that places more emphasis on condition rather than the functional impact of a condition on the person?

**Response:** Unacceptable.

**Reasoning:**

1. **Regressive.** PIP is a benefit aimed at providing support for people with diminished functions due to their health conditions. Medical evidence relates to the existence of a condition, not the extent of its impact on functionality nor the variation of such functional consequences on different individuals according to their various other circumstances/conditions. The concept of “one-size-fits-all” is not appropriate. The proposal risks returning to the de-bunked “medical model” of disability.

**2.** **Unworkable 1.** Many people with disabilities have multiple conditions, each subject to medical assessment. If PIP were to be awarded primarily on the basis of those assessments, there would be risk of totalling all those scores rather than measuring overall functional impact on the claimant.

3. **Unworkable 2.** A medical assessment may be very long-delayed due to current (and foreseeable) pressure on NHS operation. It is wholly unacceptable to rely primarily on medical assessment when delays in obtaining initial GP appointments, referrals, tests/scans, specialist consultation, potential treatment, ultimate assessment can take months or years. Essentially, such delays would deprive the claimant of the medical evidence required to obtain the support to offset the functional limitations already long in evidence.

4. **Unworkable 3.** It is evident from research into the Certification of Visual Impairment (and doubtless other medical assessments) that medical professionals are unwilling, under-resourced/untrained/unable to make appropriate medical assessments that are timely, accurate or consistent with their professional body(s). With CVI, for example, it has been estimated that only some 25%% of those eligible achieve the Certification/Registration milestones that lead to eligibility for various support (including PIP). Reliance on medical professionals is consequently very high risk for both patients and those operating various benefit systems without very substantial reform.

5. **Unworkable 4.** The proposal suggests that the medical assessment becomes the dominant “tick-box” for PIP eligibility. Instead, it should be considered as no more than a desirable clue (taking account of the above) whereupon functional consequences must be the true driving measure. Those functions will vary significantly according to individuals’ other personal, work, health etc circumstances. Attempts to reduce decisions as to PIP entitlement to algorithms based on a medical diagnosis, only valid at that time, are deeply flawed.

6. **Unworkable 5.** Relying on medical assessments assumes that such are nationally consistent. In relation to sight-loss, it is understood that this is not the case as there is no conformity of services or standards within, at least, England due to the lack of a national eye-care strategy, unreliable data, lack of CQC oversight and unclear referral pathways for psychological consequences.

7. **Example**: Patient very short sighted from birth. Acuity is very poor but field of vision normal. Ophthalmologist refuses to consider functionality and to issue CVI. The result is that she has been refused both DLA and now PIP.

**Q2.** What are your views on people receiving PIP without an assessment if they have specific health conditions or a disability as evidenced by a healthcare professional?

**Response:** Acceptable (although this is a poorly worded question).

**Reasoning:**

1. **Discrimination.** PIP claimants should not be denied the support they need simply because the NHS and medical professionals lack the time, resources, skills, competence and incentives to provide medical assessments in reasonable time.

2. **Best evidence.** A claimant’s own description of functional limitations due to a medical condition is the best available for that individual person. Evidence from other suitably qualified, experienced, informed and objective professionals (such as Occupational Therapists or similar, subject to the standards of their professional bodies) would also have merit. However, medical professionals are not necessarily able to provide good evidence of impact on functionality. For example, an ophthalmologist may be able to comment on visual acuity but not on the functional impact on different individuals, taking account of their life/work styles, other conditions and circumstances.

3. **Profit motive**. Departmental “contracting out” has demonstrated many shortfalls such as those related to the Work Capability Assessments. When other organisations involved in any function are driven by profit, eagerness for future contracts and influence, the objectivity and reliability of their contribution is not reliable enough.

**Q3.** What are your views on PIP claimants not being subject to an award review if they have a specific health condition or disability as evidenced by a healthcare professional?

**Response:** Unacceptable.

**Reasoning:**

1. **Conditions change.** This proposal seems to assume that one medical assessment is sufficient to establish a claimant’s lifetime functioning. This is simply not accurate. Firstly, as discussed above, the medical assessment is not a measure of function. Secondly, conditions may improve or deteriorate over time, further undermining the validity of an original medical assessment. This emphasises that functional assessment has more validity and should be regularly reviewed as a matter of due diligence.

2. **Professional evidence.** Only suitably qualified, experienced professionals subject to the standards of their relevant professional body can provide evidence on the functional impact of a health condition on an individual claimant alongside that claimant’s own personal evidence. Medical assessment may be one element of causation but not more. DWP decision-makers can only undertake quasi-judicial roles in evaluating such evidence and based on high success rates of appeals, seem not sufficiently provided with accurate evidence, objectivity, training, supervision or professionalism to discharge their duties effectively.

**Q4.** Do you agree or disagree on making provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP?

**Response:** Disagree and doubt current practicability.

In relation to Question 4, please explain your answer and provide evidence or your opinion to support further development of our approach.

**Reasoning:**

1. **Best Evidence.** The claimant will offer best evidence of the impact of a health condition on his/her functioning. A medical diagnosis of the condition is useful in establishing one of the potential causes for that lack of function, but there may be other causes including other medical conditions. Assessments by other suitably qualified professionals are also valuable evidence and will usually be based on both the application of that professional’s knowledge and experience plus the claimant’s own evidence. Consequently the OT or similar professional’s evidence is likely to provide the definitive assessment of the merits of the claim. As a result, there would be no requirement for a DWP “decision-maker other than to confirm other aspects of technical eligibility.

2. **Example**: a woman has a BD8, the predecessor of the CVI. Her sight is negligible. Her clinic will not issue a replacement CVI and the local DWP refuses to accept the BD8. She is in receipt of no benefits in relation to her almost total sight loss.

**Q6.** How could we prevent the provision of evidence or a formal diagnosis by a medical expert from impacting the NHS? Please explain your answer and provide evidence or your opinion to support further development of our approach.

**Response: Don’t rely on medical evidence.**

**Reasoning:**

1. **Don’t rely on medical diagnosis.** As discussed above, such diagnosis is not always quickly or easily obtained, doesn’t necessarily cover all the claimant’s conditions, is only valid at the time of the diagnosis and doesn’t adequately address functionality which is the underpinning justification for award of PIP. Diagnosis can contribute to PIP assessment but cannot be the sole basis of such. However, GP surgeries providing details of a referral and/or a GP/consultant letter providing a diagnosis provided to the patient claimant can offer medical evidence valid at the time of writing.

2. **Use other professionals.** Other professionals should have first-hand evidence from the individual claimants, possibly their medical reports, and have the skills, qualifications, experience and professional supervision to evaluate such without the influence of other factors.

3. **Trust other intermediaries.** Without adequate evidence of fraud in relation to specific areas of functionality or medical conditions, the Department should recognise that claims are difficult and challenging processes for most individuals who may be confronted, often for the first time, by the scale of their lost functionality. Many will seek the assistance of various intermediary bodies (including charities) to negotiate the psychological and practical difficulties of analysing and describing their lost functionality. Those intermediaries, in turn, have their own charitable and other standards to uphold, balancing their better knowledge of a condition and the information provided by potential claimants. Claims supported by appropriate professionals of accredited intermediaries should offer persuasive cases for PIP, potentially negating the requirement for Departmental “decision-makers”, other professionals and delayed medical diagnosis. DWP might consider the experiences of other Departments where substantial initial work on individual cases is undertaken by trusted intermediaries (e.g. tax agents/accountants providing returns to HMRC) which reduces demand on the Department while ensuring more common standards of input.

4. **Improve anti-fraud measures.** No taxpayer is willing to accept any mismanagement of their hard-earned contributions to the public purse. The Department should be capable of more effective action to reduce fraud and protect vulnerable people. Although not necessarily indicative of the degree of lost functionality, the existence of medical diagnosis may assist in anti-fraud measures. DWP staff, with access to various sources of Government information and (potentially) claimant’s own bank accounts, are likely to remain best placed to detect any fraud using medical, tax, benefit and other histories, ideally verified by an independent professional or intermediary. Better, timely and accurate public reporting of fraud in claimant numbers and financial loss would increase trust in the system and prompt further improvements.

5. **Reduce official error.** Likewise, better, timely public reporting of official error and successful appeals in claimant numbers and financial loss to them/the public purse would increase trust in the system and prompt further improvements.

**Q7.** Do you agree or disagree that eligibility for PIP should be based more on condition?

**Response:** Disagree.

**Reasoning:** See above.

**Q8.** How could we determine eligibility for the following conditions?

Conditions that fluctuate.

Conditions that vary in severity

Conditions that might be cured or have access to better / new/ novel treatments over time.

Please explain your answer and provide evidence or your opinion to support further development of our approach.

**Response:** This question is flawed in continuing to focus on conditions rather than the consequent functionalities that are the basis of PIP awards.

**Reasoning:**

1. **Fluctuating and varying conditions.** Many conditions do have fluctuations and variations meaning that PIP claims should be based on the “Worse”, rather than “best “, days as describing the most loss of functionality and, hence, need. For example, those with severe sight impairment, as opposed to total blindness, can experience variations due to factors such as barometric pressure, hunger, emotional state and physical comfort may have a profound effect on sight, consequent functionality plus psychological well-being. Those who are blind usually have no variation although their functionality can also be affected by such factors.

2. **Consistent support.** While conditions may fluctuate or vary, it is often not possible for claimants to similarly vary their support arrangements. For example, help at home for various functions is often subject to long-term contracts or other arrangements. “On/Off” arrangements are more likely to increase costs and hence further undermine the effectiveness of PIP.

3. **Better or worse?** Periodical 5-year reviews by appropriate professionals/intermediaries capable of assessing functionality, supported where appropriate by current medical diagnoses would appear the answer. However, it would seem sensible, beforehand and regularly, to obtain medical research evidence concerning those underlying conditions which are likely to fluctuate, vary in severity, might be cured, or have access to better / new/ novel treatments before undertaking the costs of blanket regular reviews. Additionally, availability of “better / new/ novel treatments” is unlikely to be universal meaning reviews would need to be targeted to be worthwhile/cost-effective. Finally, many alterations/variations in functionality are likely to be subjective rather than objectively evidenced. There are likely to be cost implications in securing adequate further medical evidence plus professional re-assessment of function in order to re-assess entitlement.

4. **Time passes.** As with all people, functionality of PIP claimants is likely to deteriorate with age. Again, current medical research evidence should enable periodic re-assessment to be best targeted.

5. **Status Quo.** However, it is likely that for many PIP claimants, the adjustments they use to optimise their remaining functionality will often be sufficient for their future years. Having made such adjustments as are possible, they may be able to manage other life-deteriorations without further recourse to the benefit.

6. **Keeping in touch.** Decades ago, it became evident that people consigned to Incapacity Benefit were largely subsequently ignored meaning that any prospect of return to work was unlikely. Many claimants with disabilities want to regain their functional and employment independence. Currently, the PIP process requires claimants to report “changes in circumstance” although few may read often inaccessible letters from the Department or succeed in eliciting any timely response to such notifications. This suggests that routine contact/enquiries with claimants is beyond the capacity of the Department. Perhaps focussing the Department on procedural activity, rather than decision-making, would release sufficient capacity for routine contacts that could trigger alterations/ending of claims.

**Conclusion:**

medical professionals are not trained, qualified, experienced or employed to assess the functional consequences of the conditions they diagnose: over-reliance on their evidence is wholly misplaced.

The Department may lack the objective professionally qualified and professionally supervised personnel to make sound decisions based on such medical evidence. However, there are other organisations/professionals who could do so leaving the Department to focus on effective delivery and potential review of the benefit.

Essentially, PIP eligibility should be based on best evidence obtained from the claimant, other professionals and medical sources and decided objectively by appropriately qualified, supervised and experienced professionals from a range of disciplines.

Additionally, the Department might avoid “silo-thinking “and look to other parts of Government regarding most effective delivery of the benefit. For example, impact on the NHS could be reduced by unnecessary over-reliance on medical evidence. There are also opportunities to learn from other Departments and assess the wider consequences of the benefit on, say, social care, any further demand on the NHS, collateral impact on families, employment etc. Review of the benefit should take account of wider societal and economic circumstances.

Finally, the United Nations Committee on the Convention on the Rights of Persons with Disabilities stated in 2024 its concerns that “the UK was in violation of international law in relation to its duty to provide a level of social protection which ensured an adequate standard of living, including for disabled people. “We strongly advise policymakers to avoid any changes to PIP that would breach international law.

**Chapter 2 – PIP – Eligibility reform**

**Q9.** Do you think the need for an aid or appliance is a good/bad indicator of extra ongoing costs and why?

**Response:** Helpful but not definitive.

**Reasoning:**

1. **Too early.** Many PIP claimants are at the start of their journey to manage what life remains possible/functional. Many will not know or have obtained the aids and appliances that can help them and some needs/solutions will only emerge with time.

2. **Too narrow.** Aids and appliances are not appropriate to all conditions that reduce individuals’ functionality hence too much reliance on such as “evidence” will discriminate against some e.g. those with mental or other psychological conditions. Additionally, while aids or appliances may be appropriate for one of a claimant’s conditions, other conditions may prevent them using such. For example, an electric wheelchair may be useful for someone with significant mobility limitations but not if that individual is also blind.

3. **One size doesn’t fit all.** There is a potential risk that obtaining a certain aid or appliance could become a “passport” or not to PIP. Such fails to take account of the enormous variety of circumstances in which people, even those with the same/similar disabilities, live. For example, would possession of talking scales, microwave, thermometer have more evidential value than reliance on ready meals?

5. **Example:** One contributor described using PIP and its shortfalls: “: All appliances except one we have paid for out of savings, so no holidays which we could do with. Taxis to even the doctor's & hospital transport for visits to hospital. but without carer as not covered by insurance.”

**Q10.** Do you think the need for prompting is a good/bad indicator of extra ongoing costs and why?

**Response:** Good indicator

**Reasoning:**

1. **Risk.** All the functions contribute to survival: inability to carry them out risks further health deterioration and, ultimately, death. Inability due to loss of physical or mental function has equal consequences. Prompting for some is therefore essential.

2. **Costs.** Prompting isn’t like just setting an alarm or reminder. For some people, often with complex needs, the intervention of other people will be required. Again, this won’t necessarily be the nag from a remote family member but require a carer or other professional to make regular, persuasive, consistent interventions in person and often at the claimant’s own home where they can fully appreciate the scale of need. Hence, time, frequency of support is likely to represent on-going cost.

**Q11**. Do you think people who accumulate low points across activities have the same level of extra costs as those who score highly in one or more activities.

**Response:** Yes, often.

**Reasoning:**

1. **Too simplistic**. Help is help and the cost isn’t necessarily predicated on “Low” or “High” points but on time needed, frequency of need, personal or equipment solutions and much more.

**Q12**. Do you think any of the PIP activities measure similar functions and could be merged?

**Response:** The form and questions are a poor proxy for professional assessment.

**Reasoning:**

1. **Over complicated.** The PIP form is over long, too complex and seems designed to “trap” potential claimants into contradictory statements. Its very length is daunting to many especially when it is well recognised that people with disabilities have no/less formal qualifications than others. It appears that the process itself is designed to discriminate against and exclude people with disabilities. There is also the risk that the Department believes that staff can balance the responses to very many complex questions to make sound decisions as to eligibility. This is not evidenced by the outcomes of appeals.

2. **Possible discrimination.** Reassurance is required that the form and its language meet the average literacy levels of the population (namely that of an 11-year-old). The NHS already estimate that 61% of the adult population are not able to understand health directions. (Such is not indicative of intelligence levels but of poor, often inaccessible documents that, in turn, impact on health outcomes or claims)

3. **Process 1.** The complexity and length of the PIP form, the variety of functions and the absence of professional input all place the process at risk. It appears that the form and process seek to reduce humans, often with complex and multiple health conditions plus equally varied functional needs to a series of numeric scores applied by trained but not professionally qualified decision-makers. More holistic assessments by suitably trained, experienced independent professionals would be more desirable and bring confidence in the process.

4. **Process 2.** “Managers” may simply count process outputs to measure success rather than human outcomes. Even a poor team-member can tick the boxes to score benefit eligibility but the process may not reveal whether the claimant can recover sufficient functionality to achieve life and work potential. Over-reliance on processes can create automatons who literally don’t “Think outside the box” meaning the skills and insights of others are less valued and the overall purpose of the benefit fails.

5. **Simplification.** Additionally or alternatively, some simple “high street” assessments might determine some/all eligibility. For example, although visual acuity as certified by ophthalmologist can be considered “shorthand” for eligibility, it is recognised that some 75% of those eligible are not so certified/registered. Perhaps simple opticians could fill the gap at far lower cost and less demand on the NHS? Other similar tests might be feasible for other conditions.

**6. Disability-friendly.** The Department lacks a positive reputation for its dealing with disabled people (viz the high level of discrimination cases concerning its own disabled staff - 2020). Better reputation would provide more confidence for claimants that their situations are being fairly considered.

**7. Example:** man in process of complete mental meltdown. Declared a “vulnerable person” by GP. The PIP form was so complex that he required another’s help and that of CAB to complete it. It then took 28 weeks from initial application to the award of PIP.

**Q13.** Do you think any of the PIP activities should be removed or re-written and why?

**Response:** Yes, see Q14.

**Q14.** Should we consider adding any new activities? If so, which activities should be added and why?

**Response:** Yes

**Reasoning:**

1. **Digital by default.** This seems to be the credo of the public, private and voluntary sectors but excludes many disabled people due to poor accessibility, comprehension, age and cost. While enforcement of the Equality Act remains weak across all these sectors, formal recognition of this vital area of functionality needs to be embedded in the PIP criteria.

**2.** **Assessments.** Noting the United Nations’ comments in 2024: “the minimal, unsuitable, and/or abusive responses to individuals' mental health emergencies that are frequently precipitated by the benefits assessment “. While these related to DWP and, primarily, unemployment benefits for disabled people, it should be recognised that when there remains a range of assessments for various forms of support both locally and nationally, disabled people will often require support to undertake and, where necessary, challenge such.

3. “**Languishing”.** Many people with disabilities are likely to be in the vulnerable psychological situation between good mental health and depression: languishing according to Professor Corey Keyes (Emory University). The social isolation, sense of uselessness and lack of meaningful and worthwhile life have doubtless contributed to poorer mental health (diagnosed or not) resulting in disability being the primary factor of the high rate of suicides amongst middle-aged men. Likewise, interactions with the benefit systems have been connected with such levels of suicide that the EHRC has launched a statutory investigation. It is vital that the Department recognises the risk it can raise for all disabled people, whether or not they have a clinically diagnosed mental health condition, and that they accommodate such vulnerability in their processes and assessments.

**Q15.** Do you think the current entitlement thresholds levels are at the right levels to define the need for Government financial support and why?

**Response:** No

**Reasoning:**

1. **Inflation-proofing/minimum wage**. Many PIP claimants use the benefit to fund care provision hence the benefit must be increased in line with both inflation and changes to the minimum wage at the very least. The same logic applies to the costs of aids and adaptations. Disabled people relying on benefits are well recognised as being amongst the poorest in the community.

2. **Not work-related.** It should be better recognised by all policymakers that work or not is wholly irrelevant to PIP. The Green Paper risks confusing the two whereas faster, more realistic PIP assessments and payments could better enable claimants to remain in/return to work.

**Q16.** What are your views on changing the length of the current three-month qualifying period for PIP which is used to establish that the functional effects of a health condition or impairment have been present for a certain time period before entitlement can start?

**Response:** Irrelevant unless PIP claims are processed without delay.

**Reasoning:**

1. **Arbitrary.** Requiring a three-month delay to confirm continuing reduced functionality appears to ignore the reality of many claimants’ lives. The majority will have been faced with progressive loss of functionality for months/years before reaching the point/diagnosis when they consider applying for PIP. Additionally, that application alone may take more time to complete and submit and, it is understood, can then take some 7 months for processing by the Department. This is already far too long for claimants to struggle without the support they need. If a further confirmatory check is required, it should be made at the time of the initial decision by no more than a letter (in whatever accessible format required by the claimant). Actioning of responses and initial claims should be subject to stringent time limits and, if such are exceeded, decisions made in favour of the claimant.

**Q17**. What are your views on retaining, removing, or changing the length of the current nine-month prospective test which is used to determine if the functional effects of a health condition or impairment are likely to continue long-term?

**Response:** Neither the three month nor 9-month timescales are reasonable until the Department is able to process all claims within, say, 28 days.

**Reasoning:**

1. Capability. It is not clear as to what qualifications or professional basis DWP decision-makers have in making any assessment as to functional capacity and its likely duration. Where medical diagnosis is available (within reasonable timescale), this may offer indication as to likelihood of recovery and timescale. Otherwise, the claimant’s own assessment cannot be contradicted. The legal definition of disability should also be applied in so far as a condition becomes such when functional limitations have or will last for 12 months or until death if earlier.

2. **On-going assessment**. Periodic confirmation of functional limitations are sensible if the Department has sufficient capacity and the causal condition(s) are likely to change/improve. However, the Department should equally recognise that the original condition may deteriorate and/or be exacerbated by other additional conditions and so be prepared to make increased awards.

3. **Delays.** The Department needs to be incentivised to handle all dealings with claimants in accordance with strict time limits. These claims are made by people who are often struggling to achieve very basic and essential day-to-day functioning, coping with the psychological distress of their health conditions and facing the prospect of job-loss/benefit dependency. They are highly vulnerable but prompt action by the Department may be an important step in their return towards previous life and work.

**Chapter 3 – PIP– What do we provide support for?**

**Q18.** PIP provides a contribution towards extra costs. Which extra costs incurred by disabled people are the most important for a new scheme to address? Please rank the following options in your order of importance:

Equipment and aids

Medications and medical products

Personal assistance (costs arising from hired physical and/or emotional support within and outside the home, e.g. help with household tasks or assistance with transportation)

Health and personal care (including physical therapies, talking therapies, massages, etc. Also includes greater spending on personal hygiene or appearance)

Extra transport costs (from reliance on taxis or accessible taxis, hospital parking fees, vehicle adaptations, etc.)

Additional energy and utility costs arising from disability or health condition (including digital access)

Additional food costs arising from disability or health condition.

Additional spending on clothing, footwear, and bedding items arising from disability or health condition.

Higher costs of insurance

Additional housing costs arising from disability or health condition, including home adaptation costs.

**Response:** Fatuous.

**Reasoning:**

1. **Impossible.** This is an impossible question. This is an attempt to make one size fit all which is definitely contrary to the spirit of the Care Act. Any attempt to rank such a list is denying the concept of individual needs as every single person would regard different items as a priority.

2. **Indicative.** That the Department can even consider that there could be a ranking in terms of extra costs reflects a total misunderstanding of the needs of disabled people. No results of any such process that attempts to ascribe higher priority to one need over another is valid. It is hugely disturbing that part of Government responsible for contributing to the livelihoods of millions of people could be so naïve, so foolish, so misinformed. The whole credibility of the Paper is undermined.

3. **Maslow’s Hierarchy of needs**. These well-recognised elements of human needs for well-being would be a preferable basis for allocating priority: survival; emotional and belonging needs; intellectual and cognitive needs; artistic and cultural needs; self-actualisation needs. Any prioritisation must take account of such needs in relation to each individual and, as health conditions and their consequences vary so extensively, complicated by multiple conditions and other circumstances, attempting to give higher priority to, say, a contribution towards an aid over, say, personal assistance seems to suggest that some conditions are more “worthy” than others. The concept of ranking different health conditions is wholly out-of-step with 21st century thinking and legislation concerning disability. Focus on responding to needs that will improve people’s lives but realise that those interventions will be as variable as the needs.

**Q19.** In relation to Question 18, please explain your answer below and tell us about any other important kinds of costs not listed above.

**Response:** see above plus:

**Reasoning:**

1. **Mental health, neurodiversity and other psychological support**. It is already evident that there is inadequate provision for children and young adults with mental health and neurodiversity conditions both in terms of medical interventions where feasible and additional support during education and transition to employment. Additionally many people with other life-changing conditions suffer considerable mental distress and need help to regain as much of their former life as possible, often incurring cost to offset shortfalls in “State provision”.

**Q20.** What are the benefits and disadvantages of moving to a new system for PIP claimants?

A catalogue/ shop scheme

Benefits

**Response:** None.

Disadvantages

**Response:** Multiple

**Reasoning:**

1. **No confidence.** Lack of trust in the Department to provide the range of choice and quality needed by the breadth of disabled people. Again, one size doesn’t fit all.

2. **Anti-competitive.** Free-market competition is the best method of keeping prices as low as possible and responding to the significant range of disability needs.

3. **Unworkable.** It is not clear what sort of “catalogue” could be provided in a format accessible to every person with a disabling condition. On-line would exclude many with visual impairments, hard copy might not suit many with various forms of dyslexia, others would not manage the reams of information and “categorising” would not be appropriate for those with multiple conditions. There is little/no evidence that Government Departments currently communicate effectively with all disabled people.

Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

**Response:** The best the Department could offer is a directory signposting claimants to sources of support (as suggested in 1999) covering functional support sources, advocacy, back-to-work and other help available from across the public, private and voluntary sectors. A local version was developed for part of Derbyshire during the Help to Work project.

**Q21.** What are the benefits and disadvantages of moving to a new system for PIP claimants?

A voucher scheme

Benefits

**Response:** none

**Reasoning:**

1. **Deeply discriminatory.** This will have the consequence of making people who are already marginalised to feel more so because the “State” is imposing further controls, limiting their freedom of action and choice. Such action seems likely to reinforce hostile attitudes towards claimants rather than manifest State empathy and support for those who are, unwillingly, already disadvantaged.

3. **Unworkable.** It is not clear how the Department will be able to provide vouchers in accessible formats or how those unable to see will manage the use of such.

Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

**Q22.** What are the benefits and disadvantages of moving to a new system for PIP claimants?

A receipt-based system

Benefits

**Response:** None

Disadvantages

**Response:** Multiple

**Reasoning:**

1. **DWP track record of delay.** It is already well recognised that disabled people are amongst the poorest in the country. Repayment of receipts will take time being processed by DWP. The Department already demonstrates inability to handle claims and other correspondence in a timely manner. The assumption that claimants can bear cost while waiting for the Department to process repayment is untenable and deeply unfair exploitation of many poor people to sustain the Department’s “cash-flow”. The experience of problems created by the “5-week” wait time for Universal Credit payments reveals the inability of many deprived people, such as disabled people. To survive financially during the DWP processing timescales.

2. **Unworkable.** No-one is likely to trust DWP sufficiently to send an original receipt to them. Hence, we would need to send a copy. How does a blind person: know which side of a document to copy/scan? Address an envelope? Get the letter to a Post Office for registered or other recorded post? Even electronic submission presents multiple problems. Knowing when payment has been made is equally difficult for those of us without access to on-line banking or accessible statements. This process risks actually increasing the level of support and costs required simply to fulfil it.

3. **Invasion of privacy/breach of GDPR**. It is noted that the DWP has/is seeking powers to scrutinise the bank statements of claimants in relation to a benefit that is no more than a “contribution” to their additional disability-related costs. It is not clear on what basis the Department can judge the use of a claimant’s income when this is not a benefit related to employment status.

Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

**Q23.** What are the benefits and disadvantages of moving to a new system for PIP claimants?

One-off grants

Benefits

**Response:** Sounds good in theory but unlikely to be practicable.

Disadvantage

**Response:** Multiple

**Reasoning:**

1. **Unworkable.** See all disadvantages to Question 22 above.

2. **Unlikely.** Fails to meet ongoing needs which may deny access to other services.

Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

**Q24.** If PIP could no longer be used to determine eligibility to passport to other benefits and services, what alternative ways could service providers use to determine disability status?

**Response: Naïve.**

**Reasoning:**

1. **Use the law.** The concept of “disability Status” seems troublesome to DWP. Ideally, the legal definition as set out in the Equality Act 2010 plus subsequent case law would seem the clear standard. This does require the existence of a health condition (physical or mental) but does not require such to be medically “certified” although such can be useful, if obtainable. The 2021 Census likewise doesn’t rely on medical evidence. Hence medical assessment has value but cannot be mandatory. Without professional assessment as to the extent of consequent limitations on the ability of the individual to carry out normal day-to-day activities, that individual’s own account of such limitations, their duration and substantial effect remain the best evidence. The difficulty for the DWP (and others) seems to be how to distil such evidence into a simple tick-box process which risks ignoring the variable ability of claimants to express their evidence best. This ignores use of other professionals such as Occupational Therapists with skills, knowledge and independence equivalent to their medical peers.

2. **“Passporting”.** This proposal suggests that the DWP (and other agencies) seek some cheap, simple, reliable “one size fits all” solution to deciding an individual’s disability and its consequences without relying on the individual’s own account. Such a generic approach seems unlikely to succeed without significantly disadvantaging those who are less perceptive, less articulate and/or have multiple health conditions. Yet many disabled people are likely to fall within those parameters suggesting high risk of disadvantage/discrimination. The high levels of successful appeals against PIP decisions highlights the failures of the existing process.

3. **Sight-loss**. Reliance on a CVI is wholly unacceptable when research has estimated that some 75% of those eligible don’t succeed to progress through the Certification/Registration route. Such problems extend further as one contributor said: “I have come across people who have been refused benefits because they were in possession of a BD8, the predecessor to the CVI. “

4. **Increasing impact on mental health.** Filling in a long, complex form with details of one’s new functional limitations can be hugely distressing in itself. Help by others, ideally experienced and knowledgeable about disability and PIP, is often essential. If the DWP wishes to retain a process/form similar to that currently in use, it should actively encourage the voluntary sector and other professionals to provide the support required. This would be likely to produce good information on which the Department can confidently rely. For example, HMRC works closely with some voluntary sector organisations supporting those on low-income etc to help achieve better returns. Alternatively, and preferably, use of independent professionals to assess the impact of a health condition upon an individual’s functionality should be pursued.

5. **Example**: woman with cancer. Confidence blown and is unable to go out on her own and cannot be left on her own because of extreme anxiety. It took 14 weeks for a PIP application form to arrive and that only after frequent phone calls. Her self-esteem and confidence are now so low that her supporter is currently unable to get her down to CAB to go through the form. A clear case of “terminal giving up”.

**Q25.** If PIP could no longer be used as the eligibility criteria to additional financial support in Universal Credit, what alternative ways of determining eligibility should we use?

**Response:** see response to previous question.

**Q26**. Are there specific groups of people whose needs are not being met by the current PIP provision and have a need for a greater level of support?

**Response:** Yes.

**Reasoning:**

1. **Discrimination.** There is a poor level of take up of services by people from ethnic minority backgrounds and those living in conditions of social and economic deprivation. The additional needs of some people with complex requirements risk being ignored. For example, people with learning disabilities are three times more likely to have sight impairment than the general population and yet very few have a CVI. Similar problems are likely amongst those with dementia, MS, Parkinson’s and diabetes. The current PIP process seems to reinforce discrimination against the most vulnerable.

What form should this support take (e.g. help with specific extra costs, access to improved healthcare such as mental health provision or enhanced local authority support such as care packages and respite)?

**Response: All the above but, essentially, better access to PIP or whatever eligibility assessment is available.**

**Reasoning:**

1. **Muddle.** The suggestions seem to confuse the need for better/any medical interventions with other support for functional limitations. Currently, the UK seems to lack a comprehensive system for combining both elements of action to enable disabled people to regain the best life and work prospects possible.

2. **Realistic?** The under-funding and consequent substantial decline of local services over recent years makes such support doubtful if not impossible. For example, one contributor commented, “I am totally blind, living on my own. I was offered £7 a week as a care budget which I had to pay for. As a former social work manager I find that pretty appalling.”

3. **Sight-loss.** Various studies reveal that sight loss professionals have almost literally no one to whom they can sign post people for mental health support. Even the government accepts it is a post code lottery. It is estimated that only 17% of people with sight loss get any emotional support despite this being probably one of the most psychologically devastating forms of disability.

**Q27**. Instead of cash payment, are there some people who would benefit more from improved access to support or treatment (for example, respite care, mental health provision or physiotherapy)?

**Response:** Emphatically Yes as a first step but it’s not “either/or” as some will still need PIP subsequently.

**Reasoning:**

1. **Empowering.** All types of effective and good quality medical care and functional rehabilitation should be widely available to everyone with relevant needs. Progression through such should enable disabled people to regain as much of their lives and work as possible, reduce their lost functioning or identify means of offsetting such. Completion would provide the basis of assessing further support needs and the PIP contribution. Periodic reassessment by those delivering the medical/functional support would permit adjustment of PIP needs in the future. However, such interventions will not necessarily avoid all PIP claims but would provide a more realistic basis for assessment. The risk remains that Government-funded provision of such support would be leveraged by the goal of reducing PIP. Use of qualified, experienced medical or occupational professionals, subject to the standards of their professional bodies, would help to reduce this risk.

2. **Staggering**. It is depressing that this Green Paper should be the vehicle for suggesting that some/many disabled people aren’t yet receiving the care and support they need to return to their maximum life and work potential. This reinforces the core problem of drafting Government proposals in a silo without pan-Department consideration.

**Chapter 4 – PIP– Aligning support.**

**Q28.** Do people already receive support from local authorities or the NHS?

with the need/costs that come with having a disability or health condition?

**Response:** Yes – Some but tends to be means tested.

**Q29.** In relation to Question 28, please explain your answer and provide evidence or your opinion to support further development of our approach.

**Reasoning:**

1. **Under-funding**. The local services are too diminished to provide much in the way of support to anyone.

2. **Sight-loss.** 86% of local authorities have failed to meet the social care needs of people with sight loss within the specified time. In addition, this is not covered by CQC and in effect, in spite of regulations and statutory requirements, the social care of people with sight loss seems to be safely ignored. As far as the NHS is concerned the majority of eye clinics have no conception or interest in the implications of sight loss. If you are lucky, you may receive guidance from an ECLO but very few of these are supplied by the NHS. In effect the NHS have such a huge disconnect with sight impaired patients that the help and assistance they provide is non-existent. In addition, there is some evidence to indicate that they are failing to either reach or properly certify at least three out of four of their patients. it is on record that far too many people of an ethnic minority heritage and those living in deprivation are also grossly underrepresented.

**Q30.** Which of the following do local authorities or the NHS help with?

Equipment and aids

Medical products

Personal assistance (e.g. help with household tasks)

Health services

Social care

Respite

Transport

Utility costs

Other

**Response:** Various.

**Reasoning:**

1. **Ignorance.** It is not clear why this information isn’t already available to DWP through various official sources covering range and eligibility criteria for support. This Green Paper is no alternative to gathering actual facts.

2. **Variability.** Local provision even in one area is hugely different. For example, two women were waiting to leave the same ward, both requiring similar home support but such would be provided by different local authorities with different criteria/offer/timescales. Unless the Government creates a universal system, regardless of the body delivering such, with consistent criteria and funding, standardisation of local provision is highly unlikely to occur. Consequently, tailoring PIP to such will also fail unless it is able to backfill shortfalls in local support. Expecting even a national benefit to resolve entrenched disparity of services is highly over-optimistic.

**Q31.** In relation to Question 30, please explain your answer and provide evidence or your opinion to support further development of our approach.

**Response:** see above.

**Q32.** Which needs/costs that come with having a disability or health condition could local areas help with further?

Equipment and aids

Medical products

Personal assistance (e.g. help with household tasks)

Health services

Social care

Respite

Transport

Utility costs

Other

**Response:** Academic when there is insufficient funding, patchy provision and inadequate assessments.

**Q33.** In relation to Question 32, please explain your answer and provide evidence or your opinion to support further development of our approach.

**Reasoning:**

1. **Under-funding.** Shortfalls in funding for local authorities is already well recognised as, for example. Support for SEND children. There is no logic in expecting these authorities to provide more services without the necessary funding.

2. **Local v national provision**. Just moving the deckchairs on a sinking ship won’t resolve the problems. There needs to be national recognition that disabled people require professional reliable assessments concerning their functional needs, often supported by a medical diagnosis. The range of solutions for those needs will be as variable as the people, their conditions, their lives and work: one size, one catalogue will not fit all. Enabling people, often with the support/advice of those professionals, is most likely to meet their deeply individual needs and best equip them to return to their previous lives and work. Ideally, any decision-making as to support/funding should be comprehensive and holistic, not relying on the vagaries of complex form-filling or local provision. Such assessment should ideally be as close to the disabled person as possible rather than via remote administration that has little or no exposure to the realities of life for disabled people.

3. **Example:** Comment from one contributor: “To many hoops to jump through to get any help, even something simple like a bus pass.”

**Q34.** If we align the support offered by PIP into existing local authority and NHS services, how could this improve things for disabled people and people with health conditions?

**Response:** Unlikely to produce any improvement without complete re-engineering of both national and local systems and their funding.

**Q35.** Do you think aligning PIP with local authority and NHS services could reduce the number of assessments a person with a disability or health condition would have to undergo? Would this help to reduce duplication?

**Response:** Yes, but not without all the caveats outlined above.

**Q36.** What disability support services in your community are the most important services or support to deliver?

**Response:** Impossible question.

**Reasoning:**

1. **Unlawful.** Prioritising some support/disabilities over others is discriminatory. DWP seems to have some concept that some loss of functional ability is more important than others. This is a false premise and would condemn many to further second-class citizenship.

**Q37.** How much flexibility should local areas have to decide their priorities in supporting people with disabilities and health conditions?

**Response:** None.

**Reasoning:**

1. **All should be equal**. Support provision should be set at a national standard to enable disabled people to fulfil their life and work potential. Those living in one area shouldn’t be less favoured simply due to their location.

**Q38.** What capacity and capability would be required to better align PIP with local authority and NHS services?

**Response:** Total overhaul of support provision for disabled people.

**Reasoning**:

1. **Requirements**. This would mean abandoning PIP as a national benefit and establishing: good local professional assessment of functional needs (often supported by medical diagnosis); allocation of any medical services to reduce those needs (e.g. physiotherapy and other interventions); expert disability-specific advice on functional aids, equipment, support and much more; a funding mechanism to deliver such; a regular review to ensure that return/retention of previous functions is progressing/succeeding; interactions, advice and legal interventions with employers to retain employment (with or without use of Access To Work support).

**Compulsory question**

**Q39.** Are you an individual or an organisation supporting claimants applying for PIP?

We are a collection of blind and other military veterans drawing on our personal and professional experiences of disability.