

# Women's Policy Group NI

WPG NI Response to Modernising  
support for independent living: the  
health and disability green paper

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## 1. Introduction:

The Women's Policy Group (WPG) is a group of policy experts and practitioners who advocate collectively for women and girls by promoting gender equality through an intersectional feminist lens. We challenge systemic injustice and discrimination affecting women and girls by informing society and influencing policy and law. Our work is informed by women and girls' lived experiences and rooted in international human rights law.

The WPG is made up of women from trade unions, grassroots women's organisations, women's networks, feminist campaigning organisations, LGBTQ+ organisations, migrant groups, support service providers, NGOs, human rights and equality organisations and individuals. Over the years this important network has ensured there is good communication between politicians, policy makers and women's organisations on the ground. The WPG is endorsed as a coalition of expert voices that advocates for women in Northern Ireland on a policy level.

If you have any questions or queries about this response, or would like to discuss this evidence further with the WPG, please contact Elaine Crory, Women's Sector Lobbyist at [elaine.crory@wrda.net](mailto:elaine.crory@wrda.net)

This response was prepared by the following WPG members:

- Elaine Crory – Women's Resource and Development Agency
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- Siobhán Harding - Women's Support Network
- Nuala Toman - Disability Action

Please note that this response also includes evidence from other WPG work, compiled by a range of WPG members, and not all member organisations have specific policy positions on all the areas covered in this response.

### 1.1 Endorsements

The WPG would like to endorse the responses submitted to this call for evidence by Disability Action and by the Women's Regional Consortium.

## 2. Past Consultations Responses, Evidence Submissions and Briefings:

The WPG has published a wide range of evidence through various evidence submissions, public consultation responses and specific briefings on issues relating to welfare reform and facilitating independent living. Responses made by the WPG, and some of our members, in relation to these issues include:

- Health Inequalities in Northern Ireland: Chapter Two: The impact of the cost of living crisis on women's health (Feb 2024)<sup>1</sup>
- WPG Response to APPG on Poverty, Call for Evidence into the Inadequacy of Social Security (Jan 2023)<sup>2</sup>
- WPG Briefing: Violence Against Disabled Women & Girls in Northern Ireland (August 2022)<sup>3</sup>
- WRDA: Disabled Women & Discrimination: Facts we need you to know<sup>4</sup>
- WPG Covid 19 Feminist Recovery Plan Briefing: Disabled Women<sup>5</sup>

### 2.1. Content from previous WPG Responses

In a previous WPG consultation response on the Inadequacy of Social Security,<sup>6</sup> we outlined the seriousness of the situation facing many people in receipt of benefits. We argued that the recent cost of living crisis has only worsened the situation and data increasingly shows that it is no longer possible for the vast majority of people on benefits to make ends meet.

Research from the Joseph Rowntree Foundation indicates that, "Almost every low-income household on Universal Credit is going without the basics (90%) – either experiencing food insecurity, or going without basics like a warm home and essential journeys. This rises to 95% where deductions are being made, for example to repay debts to Government."<sup>7</sup> It also shows that, for all low-income households in the bottom 40% of incomes:

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<sup>1</sup> <https://wrda.net/wp-content/uploads/2024/02/WRDA-Research-Chapter-2-Cost-of-Living-Crisis-Womens-Health.pdf>

<sup>2</sup> <https://wrda.net/wp-content/uploads/2023/02/WPG-response-APPG-Poverty-Social-Security-Benefits.docx-1.pdf>

<sup>3</sup> <https://wrda.net/wp-content/uploads/2022/08/Violence-Against-Disabled-Women-Girls-WPG-Research-Briefing.pdf>

<sup>4</sup> <https://wrda.net/2019/11/18/disabled-women-and-discrimination-facts-we-need-you-to-know/>

<sup>5</sup> <https://wrda.net/wp-content/uploads/2021/12/WPG-Briefing-on-Disabled-Women-V2.pdf>

<sup>6</sup> <https://wrda.net/wp-content/uploads/2023/02/WPG-response-APPG-Poverty-Social-Security-Benefits.docx-1.pdf>

<sup>7</sup> <https://www.jrf.org.uk/report/going-under-and-without-jrfs-cost-living-tracker-winter-202223>

- 7.2 million households (62%) are going without essentials. This means that they have reported going hungry, or cutting down the size of meals or skipping meals in the last 30 days, or going without basics like showers or adequate clothing since June.
- 4.7 million households (41%) are in arrears with at least one household bill and the average level of arrears remains above £1,600.
- 4.3 million (37%) are going without essentials AND in arrears with at least one household bill, and
- Over 3 million households (28%) have not been able to keep their home warm since June because they couldn't afford to.

354,000 adults have experienced food insecurity in Northern Ireland in 2022/23<sup>8</sup>.

Nearly two thirds of people referred to food banks in the Trussell Trust network in Northern Ireland are disabled<sup>9</sup>.

Families with children are overrepresented in those who turn to food banks<sup>10</sup>.

According to the Trussell Trust the three main factors which lead to people not having enough money for food are:

- The design and delivery of the social security system.
- Work which does not provide sufficient protection from financial hardship.
- Difficulty accessing suitable jobs, especially for disabled people, those with caring responsibilities and parents (especially mothers)<sup>11</sup>.

This stark reality is compounded for those who claim Personal Independence Payments (PIP) as outlined by Disability Action in their 2018 response to the Independent Review of PIP (NI).<sup>12</sup>

There is a much higher prevalence of disability in Northern than in the rest of the UK and we have some of the worst outcomes for disabled people. According to the 2021 Census, 24% of the NI population report being limited in their day-to-day activities, either a little or a lot. This is higher than the 17% and 22% reported in England and Wales, respectively. Although there has been some convergence over time, the gap

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<sup>8</sup><https://www.trusselltrust.org/wp-content/uploads/sites/2/2023/08/2023-Hunger-in-Northern-Ireland-report-web-updated-10Aug2023.pdf>

<sup>9</sup> <https://www.trusselltrust.org/wp-content/uploads/sites/2/2023/08/2023-Hunger-in-Northern-Ireland-report-web-updated-10Aug2023.pdf>

<sup>10</sup> <https://www.trusselltrust.org/wp-content/uploads/sites/2/2023/08/2023-Hunger-in-Northern-Ireland-report-web-updated-10Aug2023.pdf>

<sup>11</sup> <https://www.trusselltrust.org/wp-content/uploads/sites/2/2023/08/2023-Hunger-in-Northern-Ireland-report-web-updated-10Aug2023.pdf>

<sup>12</sup> <https://www.disabilityaction.org/consultation-responses>

remains significant. In the labour market for example, NI has the lowest employment rate for disabled people, the highest economic inactivity rate for disabled people and the highest disability pay gap in the UK.

Research conducted by Disability Action shows that:

- 8 out of 10 disabled people do not have enough money for a decent life
- 7 out of 10 disabled people have reported that their financial position has worsened since last year.
- 7 out of 10 disabled people report that their finances have caused them stress and anxiety over the last 12 months
- 7 out of 10 disabled people report that struggling with bills has had a negative impact upon their health and wellbeing.
- Disabled people have reported increased engagement in borrowing, including borrowing and have been subject to exploitation and abuse by organised crime groups.

Research carried out by the WPG on VAWG and its impact on women has found that:

- Disabled women are more likely than non-disabled women to experience men's violence
- Disabled women are more likely to report men's violence to the police but are also more likely to find reporting to the police not useful

Disabled women were more likely to agree with the following statements:

- Northern Ireland has a problem with men's violence against women and girls
- Northern Ireland should have a strategy to tackle men's violence against women and girls
- Northern Ireland has a problem with attitudes of sexism and misogyny
- Northern Ireland has a problem with rape myths and rape culture
- Northern Ireland has a problem with victim-blaming
- There is stigma surrounding issues of violence against women and girls
- There are barriers to reporting men's violence against women and girls

- Additional action needs to be taken in the violence against women and girls Strategy to address men's violence against marginalised groups of women
- There needs to be a review of how the justice system treats victims and survivors of men's violence against women and girls

This is a particular issue from the WPG's perspective as VAWG, particularly prevalent and particularly deadly in Northern Ireland, is facilitated by any system that requires a person with a disability to be financially dependent on a partner. Financial independence is a safeguard against the escalation of VAWG.

### **3. General Comments on the Modernising Support for Independent Living Consultation**

Previous WPG consultation documents<sup>13</sup> and research commissioned by the WRDA,<sup>14</sup> have highlighted the gendered nature of poverty in Northern Ireland, the additional impact of the cost of living crisis and the inadequacy of the current system for those in receipt of benefits. Modernisation of independent living support must be considered against the backdrop of increased poverty and precarity.

The green paper takes a medical-model approach to the experience of disability and to the lives of Disabled people. Focusing on how their disability may be “cured” or “fixed” through different interventions, ignoring the role of social security as social infrastructure, which removes barriers to the participation of disabled people in society. The introduction of any of the policies in this green paper would lead to even higher numbers of attitudinal, institutional, environmental and information barriers.

The green paper frames the need for change around an “unsustainable” rise in PIP claimants. But it fails to address the clear reasons why PIP claims have increased, such as the cost-of-living crisis. A household with at least one Disabled adult or child needs an additional £975 a month to have the same standard of living as non-disabled households, according to Scope<sup>15</sup>.

Yet, even at its highest rate (of £800 a month), PIP is not paid at this level. The aim of the Green Paper is to reduce spending on PIP and not ensure that PIP payments meet the true extra costs of Disabled people. In March 2024, the Work and Pensions Committee of MPs reported in published its report examining the level of benefits in the UK<sup>16</sup>. When considering PIP, it found that “many claimants experienced a significant shortfall between the levels of support provided and the cost of additional health and disability-related costs” and that “the support provided through health and

<sup>13</sup> <https://wrda.net/wp-content/uploads/2023/02/WPG-response-APPG-Poverty-Social-Security-Benefits.docx-1.pdf>

<sup>14</sup> <https://wrda.net/wp-content/uploads/2024/02/WRDA-Research-Chapter-2-Cost-of-Living-Crisis-Womens-Health.pdf>

<sup>15</sup> Disability Price Tag 2023: the extra cost of disability | Disability charity Scope UK

<sup>16</sup> MPs call for ‘uprating guarantee’ for working-age benefits and local housing allowance - Rightsnet

disability benefits were found to have a negative physical and mental health impact on claimants, which in turn could affect their ability to work.” However, in its response to the committee reports, the Government said that “the DWP has ‘no plans’ to commission research to understand the impact of benefit levels on the health and wellbeing of claimants”. The UK Government said that there are “no plans to commission further research to understand the impact of benefit levels on the health and wellbeing of customers and its relationship with economic productivity.”

Worse, it holds that there is “no objective way of deciding what an adequate level of benefit should be” and so has “no plans to commission independent research into the extent to which current benefit levels are meeting its objectives for what benefit levels should achieve in relation to living costs.

Two independent reviews of the PIP assessment process undertaken in Northern Ireland (in 2018<sup>17</sup> and 2020<sup>18</sup>), suggest that d/Deaf and disabled people have lost trust in the PIP process and the work capability assessment associated with entitlement to employment support allowance. The PIP assessment process is a fragmented process that impacts negatively on both claimants and those who seek to support them. The assessment causes fear, anxiety, stress, and frustration. This has a knock-on impact on the health and well-being of claimants, their family and wider support networks, and places even more demands on already stretched services<sup>19</sup>.

Many d/Deaf and disabled people are subject to repeat face-to-face assessments on average every three years for the duration of their claim. This includes people with physical disabilities and neurological disabilities, whose health condition is unlikely to change. For example, cerebral palsy is an impairment acquired at birth, yet people with this impairment are subject to three-year reviews to guarantee continuation of their benefit entitlement. It is of note that in 8 PIP cases known to the Northwest Forum of People with Disabilities, 2 people with cerebral palsy who were unable to work received what are known as 10-year light touch reviews and that in 6 other cases where people with cerebral palsy were in work they received 3-year reviews. There appears to be an inherent bias against d/Deaf and disabled people who are in work and the review period for their claim. It is important to recognise that whatever award is granted to d/Deaf and disabled people in this instance, that cerebral palsy is acquired at birth and its effects are unlikely to change<sup>20</sup>. Only those d/Deaf and disabled people who have received a ten-year review are not subject to ongoing

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<sup>17</sup> Department for Communities (2018): Personal Independence Payment: An Independent Review of the Assessment Process Northern Ireland, p.6 (accessed 5 November 2021)

<sup>18</sup> [DfC \(2021\) Second Independent Review of the PIP Assessment Process in Northern Ireland - report and response](#) (accessed 17 December 2021)

<sup>19</sup> [Rader, W. \(June 2018\): Personal Independent Payment: An Independent Review of the Assessment Process, Executive Summary of Main Findings](#)

<sup>20</sup> **Northwest Forum of People with Disabilities Case Load. Since 2016 the Northwest Forum of People with Disabilities have supported disabled people with their PIP applications including liaison with professional independent advice agencies in 37 cases. They have found that if a disabled person is working, they are more likely to be subject to repeated assessments for PIP on average every 3 years though admittedly the sample size is small and there is no research in this area.**

repeated assessments but instead will have a light touch review at the end of the ten-year period.

Evidence has demonstrated that PIP assessments may not always accurately present information provided by claimants.<sup>21</sup> DPOs have suggested that there is an inherent bias against people with mental health issues within the PIP process<sup>22</sup>, an issue highlighted during a successful legal challenge when the court found that the amendments to the mobility component criteria was discriminatory towards those with mental health issues (psycho-social disabilities)<sup>23</sup>.

In addition, the present system subjects disabled people to a series of often humiliating tests that, in many cases, do not accurately capture the nature of the disability they live with, seemingly without considering that many conditions do not present continually in the same way. They are overturned in approximately 72% of appeals, which indicates that they are recognised as not being an effective way of capturing the ways that a disability may impact the person living with it.

More than £10 million has been spent by the Department for Communities on processing PIP appeals over the last 3 years.<sup>24</sup> From April 2019 to June 2021, there were 9,999 PIP related appeals lodged in Northern Ireland and, of these, 5,969 cases (60%) were won by the d/Deaf or disabled claimant<sup>25</sup>. Furthermore, a PIP award was revised down in only 58 cases<sup>26</sup>. These statistics highlight a significant and ongoing problem with the PIP assessment process. Many d/Deaf and disabled people are being forced to appeal<sup>27</sup> for their rightful entitlement to disability benefits while others are enduring high levels of stress and anxiety due to income uncertainty.

The requirement to be subjected to similar tests across many years when a condition is life-long is not only an unnecessary expense to the public purse but an exercise in

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<sup>21</sup> **Rader, W. (June 2018): [Personal Independent Payment: An Independent Review of the Assessment Process, Executive Summary of Main Findings](#)**

<sup>22</sup> **Mind (2020): [Thousands of people with mental health problems could be missing out on PIP - despite court ruling against DWP \(accessed 5 November 2021\)](#)**

<sup>23</sup> *RF v Secretary of State for Work and Pensions* [2017] EWHC 3375 (Admin) Mostyn J, 21 December 2017 (accessed 17 December 2021).

Disability Rights UK (2021): [Landmark PIP legal challenge success shows effective use of collaborative public law approach \(accessed 5 November 2021\)](#)

<sup>24</sup> The Belfast Telegraph (26 July 2021): [Over ten Million spent on PIP Appeals over the last three Years](#) (accessed 5 November 2021). Please note the intent of the welfare reforms was to make a 20% saving on disability benefits but in Northern Ireland and UK wide social security spending has increased, partly because of appeals.

<sup>25</sup> Department for Communities (2021): [Benefit Statistics Summary Publication \(National Statistics\) – May 2021](#) (accessed 5 November 2021).

<sup>26</sup> BBC (2021): [PIP: Six in 10 disability claimants win case on appeal](#) (accessed 5 November 2021).

<sup>27</sup> Northern Ireland Public Services Ombudsman (2021): [PIP and the Value of Further Evidence: An investigation by the Northern Ireland Public Services Ombudsman into Personal Independence Payment](#) (accessed 5 November 2021)



illustrating the lack of trust that DWP seems to have in people with disabilities, and the tendency to declare very severely disabled people, including those nearing the end of life, as “fit for work” seems a Kafkaesque approach to human lives and wellbeing. It is also not an effective or responsible use of public money to continue to use a system that costs more money than it saves, on top of its impact on human life, wellbeing and dignity. Our position is that the entire process needs to be reconsidered.

There are also concerns that the current practice by which so many disabled people lose access to their disability benefits if they marry or cohabit with a partner. This is a concern for a number of reasons; from a WPG perspective; it is particularly concerning because of the way that it impacts the work towards Gender Equality that forms the bedrock of our work, but it also contributes in a meaningful way towards the inequalities that disabled women face, including disproportionate rates of VAWG, which is borne out in WPG’s 2022 research<sup>28</sup> on the topic, and in many other pieces of research.

The fact that those in receipt of disability benefits risk losing all or part of their benefits is a significant intrusion on their right to a private and family life. Should they choose to cohabit or marry anyway, they become entirely financially dependent on their partner, which we know increases a person’s vulnerability to abuse and limits their access to escape routes should they choose to leave. A lack of available and adapted social housing is also an issue that contributes to trapping disabled women in abusive homes, but as a first priority we must guarantee the financial independence of disabled adults - something the current system explicitly does not do.

## **4. Response to Consultation Questions**

### **Chapter One: PIP Overview and Assessment**

**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?

This proposal is difficult to balance, as there often is no obvious “average” impact of any given condition; its impact on one patient will be different to the impact on another. In addition, some conditions will impact an individual more profoundly at some times than at others, with impacts fluctuating over time.

Firstly, the same condition can have a very different impact on different people. Equally, the same condition can affect the same person very differently at different times, especially if it is a condition that is known to deteriorate.

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<sup>28</sup> <https://wrda.net/wp-content/uploads/2022/08/Violence-Against-Disabled-Women-Girls-WPG-Research-Briefing.pdf> p.3

The proposal could only result in a league table of qualifying conditions with fixed entitlements and not reflect the disability-related costs of individual PIP claimants.

Therefore functional impact would seem to be a more appropriate way to assess the level of support needed, but there should be a more humane and effective way of assessing that impact than is in place at present; for example allowing for a patient to self-report and to have any significant changes signed off by a health professional. This requirement would need to be resourced specifically so as not to place additional burdens on either the NHS nor the individual claimant.

With that said, there could be provision made for certain conditions of disabilities to receive PIP without an assessment, with a pro forma that could be signed off by a professional upon diagnosis.

**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?

This would be a positive move for many with certain conditions and disabilities. It would be vital not to overload the NHS or to place a cost burden on the individual claimant. As such this should be resourced specifically and should take the form of a pro forma that doctors or other medical personnel can complete without additional cost such as postage, eg an online form.

Fundamentally, this approach represents a switch towards trusting the evidence of medical personnel and as such is to be welcomed.

**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?

Again, our view is that it is best to trust medical personnel; when they have determined that certain conditions or disabilities will not improve over time, the individual claimant should not have their award be subject to review; it is an unnecessary stress and an unnecessary cost to the public purse.

**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?

- Disagree

**Q5.** In relation to Question 4, please explain your answer and provide evidence or your opinion to support further development of our approach.

The proposal that people cannot receive PIP without an assessment if they have specific health conditions or a disability as evidenced by a healthcare professional would remove access to PIP for a large number of people waiting for a diagnosis. This

will bar support for those who have a disabling condition that has yet to be medically identified.

Mind<sup>29</sup> reports that around two million people are sitting on waiting lists for mental health support. Many of these people will be awaiting a formal diagnosis. ADHD UK reports that waiting times for a diagnosis can be 18 months<sup>30</sup>.

Therefore, requiring a formal diagnosis by a medical practitioner would inevitably impact on the NHS. This would be disastrous for both the NHS and for claimants.

Either medical experts would be diverted from caring for patients because they had benefit claims to deal with, or they simply wouldn't prioritise benefits applications, and claimants would wait many months for the necessary evidence.

It would harm patients, further demoralise NHS staff and impact on waiting times and disadvantage PIP claimants.

Waiting lists are a concern here; a change to this approach would create an immediate backlog and before agreeing to this change, it would be essential to know how it would impact those facing long waiting lists. Waiting lists are a concern across the UK but of particular concern to those in Northern Ireland where waiting lists are the longest in the UK by a considerable distance. There would need to be a guarantee that a claimant would not be excluded because of a wait to receive this evidence.

**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.

It is very difficult to see how this will not impact on the NHS, unless there are system-level changes that would facilitate this. An obvious course of action for new claimants would be to standardise a letter or an online form that could be completed upon receipt of a diagnosis at no cost to the patient, and with minimal administrative cost to the NHS. It is more difficult to see how this would work for existing PIP recipients, but an option would be for PIP assessors to accept letters or statements of diagnosis that do not meet the standard format. A questionnaire by the Women's Regional Consortium, quoted at length in their submission to this inquiry, outlines how patients had to approach numerous medical personnel with whom they worked (GP, physiotherapist, surgeon, OT, etc) to gather evidence - this is unhelpful to the NHS as well as very burdensome for the recipient; ideally, one letter or online form from their GP stating their diagnosis should suffice.

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

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<sup>29</sup> [NHS fails on mental health targets as waiting list rises 1.2 million | The Independent](#)

<sup>30</sup> [ADHD assessment system 'broken' with five-year waiting times - BBC NewsADHD UK](#)

- Disagree

Firstly, the same condition can have a very different impact on different people. Equally, the same condition can affect the same person very differently at different times, especially if it is a condition that is known to deteriorate.

The proposal It could only result in a league table of qualifying conditions with fixed entitlements and not reflect the disability-related costs of individual PIP claimants.

It is very difficult to answer this question definitively. For some conditions that will not improve or be cured, condition would suffice. For others where there are a wide variety of patient experiences and where impact can vary widely, or where periods of remission are possible. For this reason there may need to be differential approaches.

However it would be best, regardless, if DWP was willing to accept medical evidence over and above the current approach that necessitates regular reassessment from people who do not know the patient or their condition and who necessarily rely on a narrow range of experience with their condition.

**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 in our approach.

PIP should be awarded on the basis of disability. Variations in condition are unlikely to impact on the costs of disability.

## **Chapter Two: 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?

Yes. The cost of any aid or appliance needed by a person with a disability may or may not be a “one off” cost, but even where it is, it represents something that needs maintenance and/or has an expected shelf life. As such, and particularly because many aids and equipment will need to be replaced regularly, it is an evident need of extra ongoing costs and as such should be addressed through PIP.

However, it is important that so-called one off costs are not deducted from PIP removing independence and autonomy for Disabled people to decide what to spend their cash PIP benefit payments on.

With a receipt system, Disabled people would need to already have the money to buy the item they require, or they simply would not be able to get it, essentially reducing the support they get. In addition, respondents to the Women's Regional Consortium survey on this issue indicated that many conditions preclude tracking and keeping receipts in the manner likely to be required by such a scheme.

The DWP would also likely impose a spending limit for specified items, likely to be the cheapest available regardless of its actual suitability to the claimant. This undermines dignity, choice and control.

It would likely lead to lengthy waits for reimbursement and the need for an appeal system. Any future changes to the support provided via PIP should focus on increasing the already meagre financial support given to claimants.

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

Prompting is a very good indicator and was successfully used for Disability Living Allowance and then for PIP itself. It is a good indicator because it is one which has been used successfully for PIP since the benefit was introduced.

The law relating to PIP, states that "prompting" means reminding, encouraging or explaining by another person.

**The term "prompt" is relevant to the following PIP activities:**

- Preparing food.
- Taking nutrition.
- Managing therapy or monitoring a health condition.
- Washing and bathing.
- Managing toilet needs or incontinence.
- Dressing and undressing.
- Reading and understanding signs, symbols and words
- Engaging with other people face to face.

- Making budgeting decisions.
- Planning and following journeys.

Without prompting and encouragement some Disabled people would be in danger of self-neglect and harm. The need for such support has never been questioned previously by Disabled People or their organisations. It is worrying that it is being so now as a consideration of how to reduce PIP eligibility.

**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?

This is an unanswerable question. Someone who scores low points across a range of activities may struggle with virtually every aspect of daily living and therefore have considerable costs spread over numerous activities. Someone who scores highly for just one activity may have considerable costs just for that single activity.

We fear this question is designed to provide justification for removing low scoring descriptors and so reducing the cost of PIP.

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

No

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

No. We believe the impetus for this consultation is aimed at reducing the cost of PIP. Any meaningful or valid reforms cannot be considered in the absence of the active engagement by Disabled people. Any future changes to the PIP system must be co-produced with Disabled people.

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

No. The only way to add new activities would be by co-producing the entire application system with Disabled people, alongside a thorough evidenced review. This questionnaire cannot achieve those necessary goals.

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

This question is difficult to answer. Linking levels to points means that disabled people who should be receipt of the high rate are often offered the lower rate.

There has to be a better approach, but this should be well researched and evidence based.

**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?

The qualifying period works effectively as it is and does not need changing.

**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?

There should be no requirement for the nine month prospective test. Disability is unlikely to change within this period. This is just an extra layer of bureaucracy.

### **Chapter Three: 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, eg. 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

It is offensive for the DWP to produce a questionnaire which asks disabled people to decide between food, medication, heating and other vital costs that Disabled people have to pay. Being Disabled is not a homogenous experience –It is impossible and grotesque to choose or rank which costs are more important than others in the way outlined in question 18.

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

It is offensive for the DWP to produce a questionnaire which asks disabled people to decide between food, medication, heating and other vital costs that Disabled people have to pay. Being Disabled is not a homogenous experience – there are at least 16 million Disabled people, and all have different impairments, backgrounds, hopes and aspirations and lead different lives. It is impossible and grotesque to choose or rank which costs are more important than others in the way outlined in question 18.

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

A catalogue/ shop scheme

- Benefits
- Disadvantages
- Other

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

We do not see any reason to change to an alternative method. A catalogue is not a viable option and will remove the capacity for disabled people to make independent decisions.



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

A voucher scheme

- Benefits
- Disadvantages
- Other

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

We do not see any reason to change to an alternative method. There are no viable suggestions given so it is impossible to understand the goal of this question. Any future changes to the PIP system must be co-produced with Disabled people.

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

A receipt-based system

- Benefits
- Disadvantages
- Other

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

Forcing disabled people to claim back the cost of equipment by providing receipts to DWP will leave people out of pocket. Given the high rates of disabled people's poverty, disabled people are unlikely to have money to purchase equipment upfront.

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

One-off grants

- Benefits
- Disadvantages
- Other

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

One off grants remove the independence and autonomy of disabled people. Adaptations and large scale purchases should be addressed through a system outside of PIP.

**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?

PIP should continue to be used to passport to other benefits and services. There is no viable alternative.

**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?

PIP should continue to be used as eligibility for additional financial support to UC. There is no viable alternative.

**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? What form should this support take (eg. 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)?

PIP does not address the additional costs of disability. This means the requirements of the majority of disabled people are not being met.

The assessment process poorly serves people experiencing mental distress and who are neurodivergent. People experiencing mental distress face considerable barriers in accessing the high rate of PIP and the mobility element, despite the fact that many cannot use public transport and require assistance for independent living.

**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)?

Absolutely not. Access to support or treatment should already be available from the NHS or local authority, regardless of whether you are a PIP claimant or not. In no circumstances should such support be seen as a replacement for a cash benefit.

Investment is required in mental health services and respite provision. Access should not be deducted from PIP.

#### **Chapter Four: 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?

- No

No- there are a small number of energy rebates which assist with running life saving equipment at home. Councils in NI do not assist disabled people with the costs of disability.

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

There are a small number of energy rebates which assist with running life saving equipment at home. Councils in NI do not assist disabled people with the costs of disability.T

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

- Equipment and aids
- Medical products
- Personal assistance (eg. help with household tasks)
- Health services
- Social care
- Respite
- Transport
- Utility costs
- Other

Support levels and quality vary greatly between different Health trusts. It is therefore not possible to accurately answer this question.

Councils in Northern Ireland do not provide assistance with the extra costs of disability.

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

Support levels and quality vary greatly between different Health trusts. It is therefore not possible to accurately answer this question.

Councils NI do not provide assistance with the extra costs of disability.

**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 (eg. help with household tasks)
- Health services
- Social care
- Respite
- Transport
- Utility costs
- Other

Councils in NI have different functions than other parts of the UK.

The bureaucracy and diversity of approaches which councils apply to funding streams would result in schemes becoming ineffective and disabled people would experience significant barriers in accessing schemes offered by councils.

Local authorities and trusts are already overwhelmed by costs and do not have the resources to take on additional provision.

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

Councils in NI have different functions than other parts of the UK.

The bureaucracy and diversity of approaches which councils apply to funding streams would result in schemes becoming ineffective and disabled people would experience significant barriers in accessing schemes offered by councils.

Local authorities and NHS trusts are already overwhelmed by costs and do not have the resources to take on additional provision.

**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?

We categorically oppose this proposal – it would be a dangerous and total failure. There is no recent precedent that suggests that a combining of two vastly different systems of support would work. There would be significant barriers for disabled people which would undermine access to any such system.

**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?

NO- this would increase complexity. Councils in Northern Ireland have different functions to local authorities in England.

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

This again is another question that is impossible for us to answer. Disabled persons are diverse and have their own specific needs. There is no way to rank which services are most important, and this is a reductive framing from the DWP.

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

This is irrelevant in the context of a consultation on PIP.

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

We don't believe that there should be any attempt to align PIP with local authority and NHS services as they are so variable around the country. It would, in any case, simply be an attempt to introduce cuts through the back door.

## Compulsory question

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

**Yes** - Disability Action, who contributed a great deal to this response are an organisation that supports claimants who are applying for PIP, but the wider WPG is not an organisation as such, it is a collective of women policy workers from different kinds of organisations.

## 5. Additional Comments

To conclude, the Women's Policy Group has relied on the expertise of Disability Action, a Disabled Persons' organisation, and on the research carried out by the Women's Regional Consortium, of which we are part, with women who are in receipt of or have applied for PIP in order to write this response. We have done this because, in all our work, we are guided by best practice, by expertise, and by the lived experience of the people who have been through the process.

We are also operating in Northern Ireland, a place subject to the same rules around benefits, including PIP, as in Great Britain, but with very disparate impacts because things are different on a devolved level, which can cause unforeseen impacts. Several questions in this consultation refer to the role of Councils in the provision of services to Disabled people - this is evidence of the need to properly consider the impact of these decisions on devolved regions of the UK.

Below we have provided some quotes from the experts by experience of PIP:

*"Financial support is difficult to access. For example, PIP requires a long, handwritten form to be completed. You cannot complete it online or type, which meant I had to ask someone to write the form out for me, sharing details I would rather have kept private. The assessment process was conducted by someone who told me that I would not be helping myself if I extended my family and that the Government would penalise me in the assessment if they knew I wanted more children. This is discrimination! Many complaints about the assessment process focuses on what you can't do rather than what you are able to do. The whole process was quite humiliating and dehumanising"*

- Disabled Woman with long-term health condition aged 45-49

*“The current benefits system is designed to be as restrictive as possible. The assessment process is demeaning and not at all person-centred. Perhaps if disabled people were involved in co-designing and co-delivering the benefits system it would be much more effective and supportive than it currently is. The current system can create a disincentive to people trying to move towards employment, as the rules around part-time and permitted work are such that people can often be worse off in work than on benefits. There is also a lot of fear that if someone tries taking up employment, but finds they can't cope with the demands, they will be penalised for leaving work and becoming 'wilfully unemployed', resulting in a loss of benefits”*

- Non-disabled carer, female aged 60-64.

Again, we urge the Department of Work and Pensions to listen carefully to the concerns of those with lived experience of the system, and to co-design any changes with Disabled people and their organisations.

ENDS

*For any questions or queries relating to this submission, please contact:*

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