

## **Modernising support for independent living: the health and disability green paper Consultation response from Equity Trade Union**

16 July 2024

### **Introduction**

1. This is a response from Equity Trade Union<sup>1</sup> to the consultation announced on 29 April 2024 by Mel Stride MP, then Secretary of State for Work and Pensions, entitled, "Modernising support for independent living: the health and disability green paper" (the "Green Paper").
2. Equity is the UK's largest trade union for performers and creative professionals (around 50,000). Most of our members are self-employed. The work is usually short-term and project-based. The creative industries currently make up nearly 6% of the UK economy.<sup>2</sup> 3% of members identify as deaf or disabled and we have a dedicated Deaf and Disabled Members Committee.
3. Equity is the only UK trade union to offer an in-house social security advice service. We have been operating for several decades. We run a twice weekly helpline and a casework service. We have considerable frontline experience on issues in practice for members experiencing ill health and/or long term disability, including recurrent periods of ill health preventing work.
4. We are of the opinion that this consultation is not justified and is in breach of pre-election purdah rules and we wrote to the Cabinet Secretary on 7 May 2024 complaining of this. We have not received a reply.

### **Our assessment: over-arching points**

5. Equity fundamentally disagrees with the approach to PIP reform proposed in the Green Paper. Reform should be led by disabled people with the social model of disability at its heart and should include a full and proper consultation. We believe the underlying motivation behind the Green Paper is to cut the welfare bill regardless of the needs of disabled people. The appropriate governmental response to an increasing number of people with long-term health conditions is to treat and support the people with those conditions, not to remove the support. Some of the proposals in the Green Paper are disrespectful; for example, paying disabled people in vouchers is infantilising.
6. Therefore, we are not answering the specific questions in the consultation.

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<sup>1</sup> <https://www.equity.org.uk/>

<sup>2</sup> Centre for Economics and Business Research (2020), <https://www.artscouncil.org.uk/research-and-data/contribution-art-and-culture-sector-uk-economy>

## Scapegoating

7. Equity recently provided detailed evidence alongside other Deaf and Disabled People's organisations and trade unions, to the United Nations Committee on the Rights of Disabled People.<sup>3</sup> The UK has been signed up to the United Nations Convention on the Rights of Disabled People (UNCRDP) since 2009. By following the UNCRDP, the UK has agreed to protect and promote the human rights of disabled people, including the right to independent living (article 19), employment (art. 27) and social security (art. 28).
8. In 2016 the UNCRDP found that 'grave and systematic violations' of disabled persons' rights had taken place since 2010 and that welfare reform had 'disproportionally and adversely' affected the rights of disabled people.
9. This year, it again found that the UK had 'failed to take all appropriate measures to address grave and systematic violations of the human rights of persons with disabilities and has failed to eliminate the root causes of inequality and discrimination.'<sup>4</sup>
10. The [report](#) was published on 22/05/24 a few days after the Prime Minister's declaration of his 'moral mission' to 'reform welfare' including a perceived 'sick note culture.' In stark and significant contrast, the UNCRDP report refers to complaints upheld against the UK Government for 'stirring up hostility' against benefit claimants, as well as 'misleading and inaccurate' articles in the press that give 'a false impression about eligibility and generosity' of the UK social security system:

*'There is a pervasive framework and rhetoric that devalues disabled people and undermines their human dignity. Reforms within social welfare benefits are premised on a notion that disabled people are undeserving and wilfully avoiding employment ("skiving off") and defrauding the system.'*

11. It also reported on the serious consequences that have come out of the UK government's failure to address the UNCRDP findings and recommendations:

*'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*

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<sup>3</sup> We refer to the convention as the Convention on the Rights of Disabled People (CRDP) rather than the given name - Convention on the Rights of People with Disabilities (CRPD) - as we follow the social model of disability. The convention allows us to do this.

<sup>4</sup>[tinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FGBR%2FFUIR%2F1&Lang=en](https://internet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FGBR%2FFUIR%2F1&Lang=en)

*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.'*

## **The voice of disabled people**

12. If reform is to happen, make it led by disabled people. For example, current PIP assessment decision-making often largely ignores the voice of the disabled claimant. A freedom of information request (FOI 2024/22801 dated 3/4/24)<sup>5</sup> said that only 3% of PIP new claim decision-makers made a decision inconsistent with the advice of the healthcare professional and this figure is only 0.8% where it relates to Activity 9 descriptors (engaging with other people face to face). This is the case even when the disabled claimant themselves provided evidence in their PIP2 form which contradicts the healthcare professional's report. This indicates the healthcare professional's voice, not the voice of the disabled claimant, is the more significant in the decision-making process.
13. See paragraph 19 below to hear the voice of disabled workers at the Trades Union Congress Disabled Workers Conference 2024.

## **Social security is a trade union issue**

14. PIP is for people in and out of work. This section considers issues relating to PIP for workers.
15. In our advice work, we see that workers regularly secure PIP entitlement. This fact is rarely mentioned and is at odds with the "tough on welfare" rhetoric which paints social security claimants as skivers.
16. Disabled workers face a higher level of insecurity than non-disabled workers<sup>6</sup>. Disabled workers tend to be in more precarious work with irregular earnings, such as insecure contracts or self-employment. Regular non-means-tested PIP payments help provide security by levelling-off irregular work income for these workers.
17. Social security is a trade union issue and this is especially true for disabled workers. If the social safety net is not adequate, employers are at liberty to impose weaker terms because the out-of-work alternative is unacceptable.
18. We see the adverse treatment of the self-employed on Universal Credit via the minimum income floor causing disabled self-employed workers to rely even more on PIP to help level-off irregular income, or be driven to the Work Capability Assessment to become assessed as not fit for work. This is regressive.

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<sup>5</sup> [https://www.whatdotheyknow.com/request/details\\_of\\_decisions\\_where\\_health\\_incoming-2608463](https://www.whatdotheyknow.com/request/details_of_decisions_where_health_incoming-2608463)

<sup>6</sup> Navani, A., Florisson, R. and Wilkes, M. (2023). The disability gap: Insecure work in the UK. The Work Foundation at Lancaster University

## **Trades Union Congress Disabled Workers Conference 2024 – winning motion asks for PIP reform**

19. Disabled workers want PIP to be reformed. The motion carried as the winning motion at the TUC Disabled Workers Conference 2024 says as follows:

*The social model of disability should be at the heart of PIP claims to ensure disabled people's independence and dignity.*

*It is extremely difficult to navigate through the protracted PIP claim especially when the assessment procedure creates an openly hostile environment and, in many cases culminates in an inconsistent and uncaring conclusion.*

*The PIP assessment is based on one size fits all, coupled with the lack of quality trained assessors with understanding of all impairments. This process discriminates particularly, against those with non-apparent impairments as they have no signpost that shows obvious indications regarding their condition.*

*Additionally, the DWP insists on evidence to support each claim. This becomes another hurdle for claimants having to identify proof that could be supplied showing their ability to carry out normal daily activities.*

*To stop this humiliating and dehumanising process, Conference calls upon Disabled Workers Committee/General Council to demand that the Government and the DWP establish a new fairer system by:*

- i. Introducing quality assessments replacing the current tick box exercise and include a discussion with a medical professional who will make an informed decision.*
- ii. Rethinking work and the individual's impairment*
- iii. Providing genuine support for neurodiverse people and those with other non-apparent impairments*
- iv. Ending privatisation*

### **Summary**

20. We conclude that the Green Paper should be abandoned because it does not form an acceptable basis for reform. Any PIP reform should be led by disabled people and should have the social model of disability at its heart.

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