



**The Health and
Social Care
Alliance
Scotland
(the ALLIANCE)**



**Modernising support for independent living:
the health and disability green paper
ALLIANCE response**

22 July 2024

Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to respond to the consultation on the health and disability green paper, issued by the UK Department for Work and Pensions under the previous government in April 2024¹. The ALLIANCE advocates for a human rights based approach to social security, recognising social security payments as an essential support for millions of people. We believe that as part of this it is important to ensure that there are payments specifically intended to support with the additional costs of disability.

We are therefore concerned by proposals that could see Personal Independence Payment (PIP) move away from this principle. The proposed alternative schemes set out in the green paper would be financially inadequate, stigmatising and fail to respect people's rights and choices. At the same time, the paper appears to be rooted in the medical model of disability, rather than the social and human rights models².

The ALLIANCE recognise that disability payments are devolved to the Scottish Parliament, and we continue to be a key stakeholder for the Scottish Government and Social Security Scotland as that system develops. We therefore understand that the proposals in the green paper would not automatically apply to devolved payments in Scotland.

We are nonetheless highly concerned by the implications of any significant reduction in Barnett consequentials available for social security expenditure in Scotland. These proposals also raise the possibility that changes in UK payments will either lead to a loss of 'passporting' for Scottish payments or force the Scottish Government to make changes against its own policy intentions. We have therefore chosen to respond to this consultation to put our concerns on record.

The ALLIANCE strongly recommends that the new UK Government does not proceed with these proposals.



Question 1: What are your views on an assessment that places more emphasis on condition rather than the functional impact of a condition on the person?

The ALLIANCE do not generally support a purely condition-based approach. We would be cautious about an approach which relies on a specific list of named conditions and matches those to potential levels of support. As the green paper itself notes, there are thousands of different conditions, so administering such a scheme would likely be highly complex, with significant burden placed on general practice. In addition, whilst the general impacts of a given condition may be similar across individuals, there will still be some variance that this approach would fail to account for.

We would also be concerned that this approach is not in line with the social and human rights models of disability and would instead reinforce the medical model. This would be a significant reversal of the direction of travel across society in recent years, which has been moving towards greater recognition of the societal barriers that make disabled people's lives harder and infringe their equality and rights, rather than treating their condition or disability as the root cause.

Question 2: 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?

As per our response to the previous question, we are concerned about the possibility of over-medicalising the PIP process. We do not consider that it would be appropriate or practical to base PIP awards solely on being diagnosed with a condition.

However, there may be certain conditions where it is appropriate to make a PIP award without an assessment or supporting information. These may include certain congenital conditions where the impacts are widely understood (e.g. blindness, epilepsy), or progressive conditions where impacts will only increase over time (e.g. Multiple Sclerosis, Parkinson's).



Question 3: 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?

Notwithstanding our response to the first question, the ALLIANCE does believe that there is a case for some conditions or disabilities to be eligible for an indefinite PIP award rather than undergoing regular review. For many disabled people and people living with long term conditions, that is a lifelong reality.

The current PIP process of frequent re-assessments fails to account for this reality and leads to people having to repeatedly re-explain their circumstances. Offering indefinite awards would significantly reduce both the stress on people receiving PIP and the burden of administering the system.

Rather than conditioning this on evidence from a healthcare professional however, there should be scope to base this on other supporting evidence. This may include an earlier PIP assessment, or evidence from family members, friends or third party representatives such as support workers, as to how someone's disability or condition impacts their life.

The ALLIANCE would also recommend the UK Government consider the recommendations made on award duration to the Scottish Government by both the independent Disability and Carers Benefits Expert Advisory Group and the Ill Health and Disability Benefit Stakeholder Reference Group³, which would also be applicable to PIP.

Question 4: 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.



Question 5: In relation to Question 4, please explain your answer and provide evidence or your opinion to support further development of our approach.

The ALLIANCE strongly oppose making a formal diagnosis a mandatory requirement for PIP eligibility. As per our responses to earlier questions, this would root PIP too much in the medical rather than the social and human rights models of disability. Evidence from medical experts can be useful to identify some of the impacts individuals will experience due to their disability or condition. However, it does not by itself describe the full range of societal barriers and human rights infringements that disabled people and people living with long term conditions face.

In addition, in some cases it may take a significant period to receive a formal diagnosis, particularly for rare or novel conditions. If support was made contingent on a diagnosis, it will result in people facing greater hardship whilst they wait for one. The system must therefore be flexible and based primarily on how a disability or condition impacts a person's life, rather than simply on what it is.

Question 6: 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.

As stated in our responses to other questions, where existing evidence already exists, this should be used where appropriate to support applications for PIP. It should not be necessary to undergo additional testing, diagnosis or assessment in order to be eligible for PIP. Ensuring that this is the case will help to minimise administrative burden on the NHS, as well as social care services.

Question 7: Do you agree or disagree that eligibility for PIP should be based more on condition?

Disagree.



Question 8: 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.

The ALLIANCE have previously raised concerns that the current approach to fluctuating conditions, typified by the 50% rule, is not necessarily adequate or reflective of the reality of people's lives. We also consider that it may be difficult for individuals to meaningfully estimate how often they are impacted by their condition. Instead, we recommend determining eligibility based on their worst day, as this will be more reflective of the level of support they are likely to need at those time.

Question 9: Do you think the need for an aid or appliance is a good/bad indicator of extra ongoing costs and why?

The need for an aid or appliance is a reasonable indicator of extra ongoing costs. This is particularly the case where such an aid or appliance is powered, such as a powered wheelchair, stairlift, or hoist. These will come with additional energy costs associated with their operation or operation.

Even where aids or appliances are unpowered, they are likely to have ongoing costs associated with wear and tear, requiring repair or replacement multiple times over a period. Such repair or replacement costs are not necessarily predictable, as fault or damage may arise unexpectedly in normal use.

It is important however to recognise that the purpose of social security payments for disabled people is not to pay direct costs of aids and appliances, and we would be concerned about any moves in this direction.



Question 13: Do you think any of the PIP activities should be removed or re-written and why?

Scotland is currently undertaking an Independent Review of Adult Disability Payment (ADP), the devolved equivalent to PIP. In advance of the review the Scottish Government ran a consultation on the mobility criteria, which are currently a near-direct replication of the PIP criteria. In our response to that consultation⁴, the ALLIANCE highlighted several concerns with the mobility criteria.

In particular we called for the 20 metre and 50% rules to be scrapped. We consider these criteria to be arbitrary and do not believe that they adequately capture the impacts that disabled people and people living with long term conditions may experience. There is a significant distinction to be drawn for example between someone who can walk more than 20 metres unaided without serious issue but who may not be able to manage 50, and someone for whom doing so may leave them exhausted or in pain for a period afterwards. We recommended that the activities and descriptors under ADP be amended to take account of pain and exhaustion.

We also highlighted the fact that mobility may be limited by more than physical capability to travel a given distance. We heard directly from our member Crohns & Colitis UK that they were concerned about how the mobility criteria did not currently account for the impacts of bowel conditions that may cause incontinence. The need to plan for access to toilet facilities may represent an additional further difficulty for disabled people and may particularly act as a bar to using public transport or travelling any significant distance away from their home.

The phrasing in some activities of “overwhelming psychological distress” is another aspect of the criteria we noted concerns about. “Overwhelming” is a very high bar for distress, when lower levels of distress may still significantly impact a person’s ability to plan and follow journeys. Reframing the activities to consider anxiety, fear of getting lost, and fear of



encountering hostility may be a useful approach, but this should be approached sensitively and in a non-stigmatising way that does not suggest it is unreasonable for people to be anxious or have such fears.

Although drafted with the devolution of social security powers in Scotland in mind, the principles of the Scottish Campaign on Rights to Social Security (SCoRSS) report 'Beyond a Safe and Secure Transition'⁵ would apply just as well to PIP and other UK-level or reserved payments.

In the report, SCoRSS set out the following six principles for a vision of a social security system for disabled people that:

- Has a clear purpose
- Is human rights based
- Supports equal participation in society and independent living
- Is adequate
- Provides whole-of-life support
- Interacts well with future social security developments and is well connected to other services

As a member organisation of SCoRSS, the ALLIANCE continue to believe these principles form a strong foundation for the social security system. We therefore recommend that the UK Government undertake a whole-system review of disability assistance payments to identify reforms that will realise these principles.

Question 20: What are the benefits and disadvantages of moving to a new system for PIP claimants? A catalogue/shop scheme

The ALLIANCE do not consider a catalogue or shop scheme to have any benefits as a wholesale replacement for PIP. We support a cash-first approach to social security as a matter of principle, and do not consider a catalogue or shop scheme to respect people's rights or choices. This would also fail to account for the additional daily costs of living encountered by disabled people, such as energy and transport costs.



Question 21: What are the benefits and disadvantages of moving to a new system for PIP claimants? A voucher scheme

The ALLIANCE do not consider a voucher scheme to have any benefits as a wholesale replacement for PIP. We support a cash-first approach to social security as a matter of principle, and do not consider a voucher scheme to respect people's rights or choices. We would also be concerned that vouchers would be more stigmatising than cash payments, further discouraging people from applying for PIP and from using the vouchers even if awarded them.

Question 22: What are the benefits and disadvantages of moving to a new system for PIP claimants? A receipt-based system

The ALLIANCE do not consider a receipt-based scheme to have any benefits as a wholesale replacement for PIP. We support a cash-first approach to social security as a matter of principle, and do not consider a receipt-based scheme to respect people's rights or choices.

The need to provide receipts for purchases may contribute to stigmatisation and may also discourage people from making essential purchases for fear that they will not be reimbursed, be unfairly challenged on their spending, or the perception that receipt monitoring is demeaning and an invasion of their privacy.

As set out in other answers, it is important however to recognise that the purpose of social security payments for disabled people is not to pay direct costs of aids and appliances, and we would be concerned about any moves in this direction.

Question 23: What are the benefits and disadvantages of moving to a new system for PIP claimants? One-off grants

The ALLIANCE do not consider a one-off grants scheme to have any benefits as a wholesale replacement for PIP. This would be a complete



abandonment of the principle behind PIP, which is to make some contribution to the additional costs of disability, estimated at £975 per month on average by Scope⁶.

These costs are consistent, lifelong, and cannot be addressed via one-off grants. For example, whilst a one-off grant could be used to purchase a powered wheelchair or install a stairlift, it would not cover the ongoing energy costs of charging or operation. One-off grants could not adequately cover additional transport costs, or the costs of additional heating for people whose condition impacts their ability to thermoregulate, or food for people whose condition results in specialised dietary restrictions.

Question 24: 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?

The ALLIANCE strongly opposes the proposal that PIP may no longer be used to passport access to other payments and services. In Scotland, the risk to passporting has been consistently highlighted by the Scottish Government as a justification for not pursuing significant changes to devolved payments relative to existing payments.

This demonstrates the degree of importance put upon passporting. It would be highly disruptive for many people if passporting arrangements were ended, with potentially significant impacts on their health and financial wellbeing if they suddenly lost access to other payments and support.

In addition, as noted in the paper itself, it is not only the person receiving PIP who the payment acts as a passport for. It also determines eligibility for unpaid carers to access Carer's Allowance. We are concerned at the possibility that some unpaid carers may lose their entitlement to Carer's Allowance entirely in some cases, whilst alternative means of establishing entitlement may prove administratively burdensome both for the individual and the DWP.



It is not clear what other practical arrangements could establish eligibility for other disability related supports and services. As per our responses to other questions, we would not consider providing medical evidence to be appropriate as this would follow the medical rather than the social and human rights models of disability. Some services already struggle to keep pace with developments in the social security system and expecting them to follow a potentially expansive and frequently amended list of eligible medical conditions would also be inefficient and complex. In addition, we would be concerned about the privacy implications of people having to disclose personal medical information to a wide range of services and organisations in order to demonstrate eligibility.

Question 25: 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?

As per our answer to the previous question, we are concerned that if PIP could no longer be used as part of the eligibility criteria for Universal Credit, this would add significant complexity to the system and may lead to people losing out on support that they require and have a right to. We would similarly be concerned about the possibility of people being either formally required or feeling forced to disclose personal medical information where that should not be necessary.

Question 26: 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)?

As currently formulated, PIP is not responsive to changes in the additional costs facing disabled people. This has been particularly apparent in recent years as a result of the cost of living crisis, when energy bills especially more than doubled at their peak. Whilst the UK Government instituted a price cap, this was only in relation to the average bill, and a direct



additional payment of £150 to people receiving disability payments was not sufficient to make up the difference.

Those who were already paying more than average for their energy bills therefore experienced commensurately greater increases in their new bills. Disabled people and people living with long term conditions are more likely to have higher energy bills, for example due to powering assistive technologies, less ability to thermoregulate and thus more need for heating, or to keep medicines at the correct safe temperature for use.

In an engagement event to inform the ALLIANCE report 'Disabled People, Unpaid Carers and the Cost of Living Crisis'⁷, we heard directly from disabled people about the cutbacks they were already making. These included food, lighting, and showers, whilst one participant stated that they were struggling to afford the cost of charging their powered wheelchair. They explicitly identified this as a breach of their human rights, as they were now more frequently confined to their home and less able to participate equally in society.

Although energy bills are now lower than at the peak of the crisis, they remain significantly higher than before. PIP and other forms of financial support for disabled people and people living with long term conditions must be responsive to both these kinds of sharp, sudden changes, and to the possibility they may create a new normal. As detailed elsewhere in this response, the ALLIANCE recommends the SCoRSS principles, one of which is adequacy, and adequacy should be evaluated in part against increases in specific costs.

Question 27: 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)?

In line with our responses to other questions, we consider the framing of this question to be rooted in the medical model of disability rather than the social or human rights models. Whilst we would welcome a whole-person



approach to support that recognises the links between health and financial wellbeing, delivered via appropriate signposting of services and training of service providers, we would strongly caution against conflating financial support and treatment for health conditions.

The purpose of PIP is to offer disabled people support with the additional costs of disability. This purpose is best delivered through the social security system. Where individuals require greater support to manage their disability or condition, this is best delivered through the health or social care systems. We do not believe it would be appropriate or possible for medical treatment to substitute for financial support.

Question 34: 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?

In line with our responses to other questions, we consider the framing of this question, and those following, to be clearly rooted in the medical model of disability rather than the social and human rights models. We would strongly caution against conflating financial support and treatment for health conditions.

Question 35: 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?

Notwithstanding our concerns about entrenching the medical model and conflating financial support and treatment for health conditions, where a person has been medically assessed for a disability or condition, it would make sense to use that evidence where necessary rather than duplicate the assessment. This is partly the approach that Social Security Scotland take to determining eligibility for disability payments.

With Social Security Scotland, rather than a mandatory assessment for the payment, eligibility can be demonstrated in most cases by providing



supporting information, which may include from medical professionals. Only in cases where there is no acceptable supporting information are people invited to a consultation where the impacts of their disability or condition will be discussed. Applying this approach to PIP would help to reduce duplication, as well as the stress that can be caused by requiring people to repeatedly explain their circumstances because services are not appropriately joined up.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice and service delivery. Together our voice is stronger and we use it to make meaningful change at the local and national level.

The ALLIANCE has a strong and diverse membership of over 3,500 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by



informing national policy and campaigns, and putting people at the centre of designing support and services.

We aim to:

- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner, and foster cross-sector understanding and partnership.

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¹ UK Government, 'Modernising support for independent living: the health and disability green paper' (April 2024), available at:

<https://www.gov.uk/government/consultations/modernising-support-for-independent-living-the-health-and-disability-green-paper/modernising-support-for-independent-living-the-health-and-disability-green-paper>

² Inclusion Scotland, 'The Social Model of Disability', available at:

<https://inclusionScotland.org/get-informed/social-model>



³ Disability and Carers Benefits Expert Advisory Group advice to Scottish Government Cabinet Secretary for Social Security and Older People (3 December 2018). Available at <https://www.gov.scot/binaries/content/documents/govscot/publications/correspondence/2019/03/disability-and-carers-benefits-expert-advisory-group-award-duration/documents/dacbeag-advice-to-ministers-award-duration/dacbeag-advice-to-ministers-award-duration/govscot%3Adocument/DACBEAG%2Badvice%2Bto%2Bministers%2B-%2Baward%2Bduration.pdf>

⁴ The ALLIANCE, 'ALLIANCE respond to the ADP Mobility Criteria consultation' (April 2023), available at: <https://www.alliance-scotland.org.uk/blog/news/alliance-respond-to-the-adp-mobility-criteria-consultation/>

⁵ Scottish Campaign on Rights to Social Security, 'Beyond a Safe and Secure Transition' (August 2020), available at: https://www.cas.org.uk/system/files/publications/scorss_report_beyond_a_safe_and_secure_transition.pdf

⁶ Scope, 'Disability Price Tag 2023', available at: <https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag-2023>

⁷ The ALLIANCE, 'Disabled People, Unpaid Carers and the Cost of Living Crisis: Impacts, Responses and Long Term Solutions' (October 2022), available at: <https://www.alliance-scotland.org.uk/wp-content/uploads/2022/10/ALLIANCE-Cost-of-Living-Report.pdf>

