‘Modernising Support for Independent Living: The Health and Disability Green Paper’ Consultation Response by the Centre for Disability Studies at the University of Leeds

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Response compiled by Dr Alex Louise Pearl, School of Law, University of Leeds, email address: A.Pearl@leeds.ac.uk, with particular thanks to Maral Nosratzadeh LLM, Professor Anna Lawson, Dr Miro Griffiths and Professor Roger Slee for their valuable contributions. The opinions attributed to CDS here reflect those of the majority of the CDS members who contributed to this consultation process. There are, however, many CDS members who were not involved. The opinions stated should not therefore be taken to reflect those of all members.

Information about the Centre for Disability Studies (CDS):

The Centre for Disability Studies (CDS) based at the University of Leeds is a cross-disciplinary Faculty Centre supported by the Faculty of Social Sciences. Our members engage in research and teaching excellence across the Social Sciences, Humanities and STEM subjects. Members are united by their commitment to carrying out research and teaching which helps to achieve equality and social justice for disabled people at the domestic and global levels. CDS is recognised as a centre of excellence for research addressing the sociology of disability, disability politics and policy, disability law and human rights, disability studies in education, inclusive design (transport systems and assistive technologies) and deaf studies. The current co-directors of CDS are Professor Roger Slee and Dr Miro Griffiths. Our website can be found here: https://disability-studies.leeds.ac.uk/.

Information about the consultation response:

This consultation response draws upon the collective expertise of academics and researchers from across the University of Leeds. It is informed by our professional and personal experiences as interdisciplinary disability scholars. Many of our members are disabled people and/or have experiences of caring for other people with impairments. The Centre for Disability Studies also works closely with a variety of non-governmental disability rights organisations and this consultation response also draws upon the benefit of their collective knowledge and insights.

We have chosen to respond to the green paper consultation questions in an independent document rather than using the online form. This is to ensure that we can fully explicate and address several consultation questions which raise important and multifaceted issues. We note the concerns expressed by Disability Rights UK that the proposals produced by the former government reflect a ‘clear agenda… to reduce the number of disabled people receiving the crucial support we rely on’.[1] The formation of the new Labour Government provides an important and exciting opportunity for change which can increase the utility and operational efficiency of the Personal Independence Payment (PIP) system for both disabled people and the Government.

CDS members encourage the new Labour Government to reflect on the points raised in this consultation response and to redevelop the proposals set out in the current ‘Modernising Support for Independent Living: The Health and Disability Green Paper’ document. CDS members encourage the new Government to engage directly with disabled people and their organisations in the development of any new proposed reforms to the Personal Independence Payment (PIP) system, or in the design of any regime of support which may replace PIP as the primary benefit entitlement for disabled people in the future. Our responses to this green paper focus upon addressing the key issues raised by the current proposals and suggesting areas for further improvement or consideration. CDS are happy to discuss these responses in more detail with the Government should this be helpful.

Chapter 1 – Consultation Questions

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?

In accordance with the social model of disability, significantly developed through scholarship undertaken within the Centre for Disability Studies at the University of Leeds,[2] CDS members would support any changes to the Personal Independence Payment (PIP) assessment process which could reduce the burden of assessment

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[1] Disability Rights UK, ‘PIP Reform Green Paper’s Clear Agenda Is Reducing Financial Support to Disabled People says DR UK’ (30 April 2024) <https://www.disabilityrightsuk.org/news/pip-reform-green-paper%E2%80%99s-clear-agenda-reducing-financial-support-disabled-people-says-dr-uk> (accessed 29 June 2024).

[2] See: Colin Barnes, ‘Understanding the social model of disability: Past, present and future’ in Nick Watson and Simo Vehmas (eds), *Routledge Handbook of Disability Studies: Second Edition* (Routledge, Oxon 2020) 14-26;
Anna Lawson and Mark Priestley, ‘The social model of disability: Questions for law and legal scholarship?’ in Peter Blanck and Eilionóir Flynn (eds), *Routledge Handbook of Disability Law and Human Rights* (Routledge, Oxon 2017) 6-15;
Colin Barnes and Geof Mercer, *Exploring Disability* (2nd edn, Polity Press, Cambridge 2010) 35-41;
Colin Barnes and Geof Mercer, ‘Theorising and Researching Disability from a Social Model Perspective’ in Colin Barnes and Geof Mercer (eds), *Implementing the Social Model of Disability: Theory and Research* (The Disability Press, Leeds, 2004) 1-13.

(and reassessment) for disabled people, and also improve the operational efficiency of the system as a whole.

The Social Model of Disability is a framework through which to understand and challenge the structural, practical, and social barriers which people with impairments face in their everyday lives.[3] By drawing a distinction between 'impairment' and 'disability', the Social Model recognises that individual impairment, in the form of a long-term physical, medical, psychosocial or behavioural trait, does not itself result in social exclusion, but rather, it is the legal, policy, and social responses to that impairment which determine a person's ability or *dis*ability to participate fully in society.[4] The PIP system is closely aligned with a social model approach to disability by providing direct ongoing cash payments to disabled people in order to assist them in covering the extra costs of living with impairment which result from the practical and social barriers operating in society.

There are compelling practical and economic efficiency arguments in favour of taking condition into account in the PIP eligibility assessment process. Nevertheless, some CDS members raised concerns that an assessment protocol which places too much emphasis on the presence or absence of a particular diagnosed condition, rather than upon the functional impact of a person's impairment on their lives, could reflect an overly medicalised approach to disability and may perpetuate the negative stereotyping and systemic labelling of disabled people. To properly balance these competing considerations and to improve the overall efficiency of the PIP assessment framework, CDS members suggest the development of a new hybrid system for assessing PIP eligibility.

At present, due to the highly individualised nature of the PIP assessment process, unless a person has a terminal illness, they will usually be required to undertake an initial functional eligibility assessment for PIP conducted by the Department for Work and Pensions (DWP).[5] This applies equally to people who experience lifelong health conditions or impairments which do not change over time (such as lifelong visual or physical impairments). Removing the universal requirement to undertake a functional eligibility assessment for particular kinds of impairments, could reduce unnecessary assessment burdens for disabled people. It could also help to tackle the significant delays and the bureaucratic and fiscal challenges facing the DWP under the current PIP assessment system. CDS members therefore suggest that the Government consider developing a 'light-touch' assessment protocol for particular kinds of impairment (where it is evident that there are likely to be significant additional costs in line with PIP's aims), as an optional alternative for individuals concerned, to sit alongside conventional functional eligibility assessments.

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[3] Anna Lawson and Angharad Beckett, 'The social and human rights models of disability: towards a complementarity thesis' (2021) 25(2) *The International Journal of Human Rights* 348, 349.

[4] Colin Barnes and Geof Mercer, *Exploring Disability* (2nd edn, Polity Press, Cambridge 2010) 35-41.

[5] Citizen's Advice, 'Preparing for your PIP assessment' (Citizen's Advice, 2024) <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/help-with-your-claim/your-assessment/#:~:text=Unless%20you%20have%20a%20terminal,Independence%20Payment%20(PIP)%20application.> (accessed 12 July 2024).

A light-touch eligibility assessment for particular types of impairments could operate based upon medical evidence provided by a recognised medical professional (such as a general practitioner). Disabled people could elect to obtain medical evidence which would remain valid for a specified period, and which would provide details about the type of impairment and the functional limitations experienced by the disabled person. This approach would work only if it were developed in partnership with disabled people's organisations. Government would need to work closely with disabled people and their organisations to determine which kinds of impairments or health conditions would be suitable for a light-touch eligibility assessment.

Streamlining the PIP assessment process in this way could yield considerable benefits for public spending. However, CDS members also note the reality that focusing too much on condition may disadvantage groups of disabled people who struggle to obtain formal diagnoses. For this reason, it is important to retain a hybrid system which allows light-touch eligibility assessment for certain types of impairments, but which also allows the disabled person to elect to undertake a functional eligibility assessment conducted by the DWP, if this better meets their needs. For people with fluctuating conditions (such as Multiple Sclerosis, Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome, Parkinson's Disease, and various mental and psychosocial conditions), individuals may encounter a delay of several years before receiving a formal diagnosis of their impairment or may struggle to obtain a formal diagnosis at all. This is notwithstanding the profoundly debilitating impact which these conditions can have upon a person's day-to-day life and wellbeing. This reality has been further worsened by the effects of the Covid-19 Pandemic on hospital waiting times, with 6,377,599 patients in England currently waiting for treatment as of May 2024.[6] This number is set to further increase. Retention of the functional assessment of how a person's impairment affects their day-to-day life is essential, to ensure that some groups of disabled people are not prevented from accessing PIP because they are unable to obtain a formal medical diagnosis of a particular condition or impairment.

CDS commends the recognition in the green paper consultation document that:

> *'Disabled people and people with long-term health conditions should be provided with the right amount of support, given the opportunity to make their own choices, have equal access to services, be supported to access healthcare, treatment and education and be able to participate in society on the same basis as other people.'*[7]

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[6] British Medical Association (BMA), 'NHS Backlog Data Analysis' (BMA, Last updated 11 July 2024), <https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/nhs-backlog-data-analysis> (accessed 15 July 2024).

[7] Department for Work and Pensions, 'Modernising support for independent living: the health and disability green paper' (CP 1061, April 2024, Updated 13 June 2024) [38] <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> (accessed 27th June 2024).

A hybrid approach to PIP eligibility assessment could reduce the assessment and reassessment burden for many disabled people, while at the same time significantly increasing efficiency within the PIP system by reducing overall costs, lowering the number of assessments and reassessments required, and significantly reducing assessment delays and backlog for the DWP.[8]

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?

As mentioned in our response to Q.1 above (which applies with equal force here), there are compelling efficiency-based arguments in favour of adopting a dual or hybrid approach to PIP assessment under which a ‘light-touch’ PIP assessment procedure could be developed for particular health conditions or impairments. Under such a system, a disabled person could elect to provide medical evidence of a specific condition from a recognised medical or healthcare professional, which lasts for a stated period of time and which provides details of the type of impairment and the functional limitations they experience. This light-touch assessment process should sit alongside functional eligibility assessments conducted by the DWP. The Government would need to work closely with disabled people and their organisations in determining which types of impairments and health conditions would be suitable for a light-touch PIP application process, as well as in redesigning the nature of the functional eligibility assessment to better meet the diverse needs of disabled people. Regardless of the types of impairments or conditions which may be appropriate for a light-touch assessment protocol, it is essential that disabled people should retain the choice to elect to undertake a functional assessment for PIP conducted by the DWP, if this better meets their needs.

While there are strong efficiency-based arguments for introducing a dual or hybrid system within the PIP assessment process, CDS members note the importance of the Government ensuring that both potential routes to PIP entitlement are valued equally and can provide the same levels of financial award. Any new hybrid or dual system of assessment must avoid creating novel forms of inequity in the PIP entitlement system. Any new PIP assessment system should be developed in close consultation with disabled people and their organisations, and in light of three key considerations:

1) Firstly, the importance of avoiding the creation of a ‘hierarchy of conditions’ in which particular types of impairment or health condition are prioritised for automatic entitlement while other types of conditions are neglected.
2) Secondly, whichever PIP assessment process is selected by the disabled individual under a new hybrid system (either a functional assessment or an assessment based upon the provision of medical evidence), the financial amount of PIP awarded for any particular impairment should not become ‘fixed’ or entrenched. This would risk both the over-provision and under-provision of

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[8] Citizens Advice, ‘Millions of pounds held up every month due to delays in PIP reviews’ (Citizens Advice, 15 August 2023) <https://www.citizensadvice.org.uk/about-us/media-centre/press-releases/millions-of-pounds-held-up-every-month-due-to-delays-in-pip-reviews1/> (accessed 12 July 2024).

funds, failing to correspond to a person's needs. The same diagnosed condition can affect different people in vastly different ways, and can fluctuate, deteriorate or improve over time. A failure to assess the impact of a person's condition upon their day-to-day life, risks both the over and under-inclusion of individuals in the award of PIP.

3) Thirdly, the development of any light-touch assessment system which requires the provision of medical evidence by a medical or healthcare professional must be adequately funded by the Government to avoid placing further burdens upon the National Health Service (NHS). CDS members suggest that the Government consult directly with the NHS and primary healthcare providers to determine how such a system could best be designed, funded and implemented. This is essential to properly mitigate against the increased burden which such a change would place on frontline healthcare workers such as General Practitioners (GPs). As the green paper consultation recognises:

> *'…an assessment based on condition would require a greater emphasis on the provision of medical evidence of a diagnosis and we would need to consider the requirement this would place on the NHS and health professionals. We have committed across government to reduce administrative burdens on general practice.'*[9]

Given the profoundly over-stretched nature of access to primary healthcare and the substantial challenges already facing general practitioners,[10] an increase in workload for NHS GPs to determine entitlement to disability benefits would need to be properly consulted on, adequately funded, and implemented in a way which minimises complexity and time demands for frontline healthcare workers. At present, the green paper provides no details regarding how this increase in workload for the NHS might be accommodated or costed. In the personal experience of one member of CDS, obtaining a medical evidence letter from their GP for a recent PIP reassessment was deemed to be 'private' medical treatment and cost £75.00. This is a significant additional cost for disabled people who already face increased living costs and may rely heavily on PIP to manage those costs. It is imperative that the costs of obtaining medical evidence under any new hybrid PIP assessment system must be covered by the DWP and must not be passed on to disabled people themselves.

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[9] Department for Work and Pensions, 'Modernising Support…' (n 7) [66].

[10] Claire Sambolino, 'There are not enough GPs to tackle the burden of non-communicable diseases' (PoliticsHome, The House, 3 March 2023) <https://www.politicshome.com/members/article/enough-gps-tackle-burden-noncommunicable-diseases#:~:text=GPs%20are%20already%20stretched%20to%20capacity&text=The%20average%20number%20of%20patients%20each%20GP%20is%20responsible%20for,problem%20with%20access%20to%20healthcare> (accessed 17 July 2024).

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?

In accordance with our responses to Q.1 and Q.2 above, CDS members recognise that multiple benefits could flow from not subjecting certain groups of people to repeat assessments. This is particularly so, in the following circumstances:

- Where a person is experiencing a recognised impairment which is known to remain the same over time, deteriorate or be life limiting and,
- That person is already in receipt of the highest rates of entitlement to PIP or any future disability benefit.

The removal of award reviews and reassessments in these circumstances could have profoundly beneficial impacts both for disabled people themselves and upon the economic and practical efficiency of the PIP framework for Government. It would limit bureaucratic burdens placed on DWP by significantly reducing the number of reassessments required. One CDS member, who has no vision, expressed concern about the actual value-for-money of a reassessment process which, in their case, consisted of a brief conversation (largely about the fact that phones and computers could be made to speak) during a home visit from an official with a physiotherapy background and absolutely no knowledge or understanding of visual impairment or the lives of visually impaired people.

The reduction of the need for assessments in this way would also help to tackle the significant delays currently facing the reassessment system.[11] In a 2023 report for Citizen's Advice, Crunden and Anns found that PIP recipients were waiting over 13 months for a PIP review. Such delays prevent disabled people from accessing other linked benefits such as the Blue Badge and Motability schemes which are vital for their wellbeing. Their report noted that '£24 million a month is being held up and prevented from reaching people's pockets due to delays.'[12]

The green paper consultation document makes clear that the Disability and Health Support Directorate '*are not seeking further feedback on the experience of the assessment process as it is now. Instead, we want to consider new approaches to the basis on which an assessment is undertaken*.'[13]

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[11] See: Oliver Crunden and Victoria Anns for Citizens Advice, 'Playing catch-up: The impact of delayed health assessments for Personal Independence Payment' (Citizens Advice, August 2023), <https://www.citizensadvice.org.uk/Global/CitizensAdvice/welfare%20publications/Playing%20catch-up_%20the%20impact%20of%20delayed%20health%20assessments%20for%20PIP.pdf> (accessed 16 July 2024), and
Carri Swann for Child Poverty Action Group (CPAG), 'Welfare Rights Bulletin 292: PIP reassessment delays' (Child Poverty Action Group, February 2023) <https://askcpag.org.uk/content/208793/pip-reassessment-delays#:~:text=As%20the%20DWP%20grapples%20with,how%20to%20advise%20affected%20claimants.&text=As%20of%20October%202022%2C%20it,for%20new%20claimants%20to%20wait.> (accessed 16 July 2024).

[12] Oliver Crunden and Victoria Anns (n 11) 2.

[13] Department for Work and Pensions, 'Modernising Support…' (n 7) [54].

Nevertheless, there is a wealth of literature from disabled people, non-governmental organisations and academic research addressing the damaging and traumatic impact of the PIP application, assessment and reassessment processes. 2023 research conducted by the Personal Finance Research Centre (PFRC) at the University of Bristol reported that 92% of disabled people find interacting with the benefits system 'complicated', with many disabled respondents describing the process of accessing benefits as 'hostile', 'degrading', 'punishing and humiliating'.[14] In their recent questioning of the UK Government, Rapporteurs to the UN Committee on the Rights of Persons with Disabilities described the UK's policy and practice as:

> *'"a pervasive framework and rhetoric that devalues Disabled people's lives", which "tells Disabled people that they're undeserving citizens" and [which] "makes [Disabled] people feel like criminals" – particularly those who are trying to access the social security system.'*[15]

Correspondingly, 71% of disabled respondents in the PFRC research reported that they 'have been made to feel guilty about applying for benefits'.[16] One member of CDS reported that she recently spent 57 minutes on hold while on the phone to the DWP before getting to speak to a person and described the dehumanising impact which repeated experiences like this have. CDS members also raised concerns regarding the frequency of full PIP review assessment processes and the stress and fear which this creates for people who rely on PIP to cover essential disability-related living costs. The Child Poverty Action Group note that as of October 2022, 77% of new awards for PIP were for two years or less.[17] This creates a huge amount of reassessment demand and delay within the system. CDS members felt that the frequency of reassessments should be lessened for PIP recipients. Such measures could significantly reduce costs and assessment backlogs for the DWP as well as significantly reducing the stress and anxiety for disabled people which results from frequent reassessment processes.

The new Labour Government provides an important opportunity to improve the economic and operational efficiency of the PIP system for Government, the DWP, and for disabled people themselves. We encourage the Government to capitalise on this opportunity for positive change and to consult with disabled people and their organisations regarding any proposals to improve the efficiency of the PIP system and to consider how the process of applying for, assessing and reassessing entitlement

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[14] Jamie Evans and others, 'The Financial Wellbeing of Disabled People in the UK' (Personal Finance Research Centre and RiDC, Bristol, 2023), 15, 43-44 <https://www.bristol.ac.uk/media-library/sites/geography/pfrc/documents/The%20financial%20wellbeing%20of%20disabled%20people.pdf> (accessed 13 July 2024).

[15] Inclusion London, '2024 Evidence Session: Watch live as the UK government attempts to defend its record on Disabled people's rights' (Inclusion London, 13 March 2024) <https://www.inclusionlondon.org.uk/campaigns-and-policy/uncrdp/uncrdp-2023-24/crdp24/> (accessed 13 July 2024).

[16] Jamie Evans and others, 'The Financial Wellbeing of Disabled People in the UK' (n 14) 44.

[17] Carri Swann for Child Poverty Action Group (CPAG), 'Welfare Rights Bulletin 292: PIP reassessment delays' (Child Poverty Action Group, February 2023) <https://askcpag.org.uk/content/208793/pip-reassessment-delays#:~:text=As%20the%20DWP%20grapples%20with,how%20to%20advise%20affected%20claimants.&text=As%20of%20October%202022%2C%20it,for%20new%20claimants%20to%20wait.> (accessed 16 July 2024).

for PIP (or any future disability benefit), can be improved to remove the trauma and distress[18] currently experienced by disabled people.

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.

CDS disagrees with the proposal to make the provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for PIP eligibility.

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

As outlined in our responses to consultation Q.1 – Q.3 above, CDS members recognise the potential benefit of a new hybrid approach to PIP assessment which could include a light-touch assessment process based on medical evidence for certain conditions. However, CDS **disagrees** with the proposal to make the provision of evidence or a formal diagnosis by a medical expert a mandatory requirement of eligibility for PIP.

As explained in our consultation responses to Q.1 – Q.3, there is a need to retain a functional assessment of eligibility in addition to the introduction of any light-touch assessment process. This is important for several reasons. These reasons are listed here and elaborated on with evidence contained in our responses to various consultation questions throughout this document. Relevant evidence is cross-referenced as appropriate:

- There are profound resourcing problems already facing primary healthcare services and the wider National Health Service (NHS). The additional strain of a formal requirement to provide evidence of a formal diagnosis in every PIP application would place further demands upon an already over-stretched primary healthcare system. The introduction of any light-touch limb of PIP assessment requiring medical evidence for particular conditions, must be properly funded by the DWP and should be designed and implemented in consultation with the NHS, frontline healthcare professionals, disabled people and disabled people’s organisations.
- Disabled people can face significant delays in obtaining a formal diagnosis of impairment (see the evidence cited in our response to consultation Q.1 above. For the sake of clarity, our comments in responding to Q.1 apply equally here).

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[18] Luke Clements, *Clustered Injustice and the Level Green* (Legal Action Group, London 2020) 42-53, 90-99.

- Disabled people can face barriers in access to healthcare when interacting with primary healthcare channels.

CDS members raised significant concerns over the increased bureaucratic and time burdens which a formal requirement of diagnosis would place on frontline healthcare workers such as general practitioners. The primary healthcare sector is already facing profound challenges resulting from increasing demand for appointments, systemic under-resourcing, staff shortages and staff retention problems.[19] According to the British Medical Association (BMA), ‘the NHS has lost the equivalent of 1,715 full-time, fully qualified GPs since 2015’. At the same time, the number of appointments in the twelve-month period between June 2023 and May 2024 has risen by 68.4 million compared to pre-pandemic levels.[20] Commentators recognise that ‘patients, GPs, and secondary care doctors all agree that there is a problem with access to healthcare. [Which is] not the fault of GPs, but a sign of a system stretched beyond capacity’.[21]

A commentary piece by Elisabeth Mahase, notes that toxic media reporting around the NHS has led to GPs feeling demoralised and blamed for service failures, but medical leaders emphasise that:

> *‘…the real problem is that successive governments have failed to appropriately fund primary care, which handles around 90% of patient contacts for less than 10% of the national health budget.’*[22]

Given the challenges already facing primary care provision, we are concerned about placing further diagnostic responsibilities which govern entitlement to essential disability benefits upon frontline healthcare workers. This should only be considered after a meaningful consultation process addressing how such a system could be adequately resourced and delivered, both in terms of funding and staff recruitment needs. There is no suggestion in the green paper consultation document of how these increased demands could be accommodated by the NHS, nor how the costs of such a system would be covered.

Research by Deborah Fenney and others illustrates that disabled people still face profound challenges in getting adequate access to primary healthcare.[23] Accessibility

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[19] Ian Aikman writing for Which?, ‘Why is it so hard to get a GP appointment?’ (Which? Consumer Association, 27 January 2023) <https://www.which.co.uk/news/article/why-is-it-so-hard-to-get-a-gp-appointment-agsTT2p0SeE3> (accessed 12 July 2024).

[20] British Medical Association (BMA), ‘Pressures in General Practice Data Analysis’ (British Medical Association, Last updated 27 June 2024) <https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/pressures-in-general-practice-data-analysis> (accessed 12 July 2024).

[21] Claire Sambolino, ‘There are not enough GPs…’ (n 10).

[22] Elisabeth Mahase, ‘GPs are being blamed for government failures in primary care, say doctors’ (2021) 374 British Medical Journal 2234, 1 <https://web.archive.org/web/20210915201635id_/https://www.bmj.com/content/bmj/374/bmj.n2234.full.pdf> (accessed 15 July 2024).

[23] Deborah Fenney writing for The King’s Fund, ‘Tackling ableism in health care – the role of primary care’ (The King’s Fund, 12 June 2023) <https://www.kingsfund.org.uk/insight-and-analysis/blogs/tackling-ableism-health-care> (accessed 12 July 2024); also, Deborah Fenney and others, ‘Towards a new partnership between disabled people and health and care services: getting our voices heard’ (Research by the King’s Fund and Disability Rights UK, 27

barriers for people with dementia, communication challenges, visual impairments, learning disabilities, mental health issues and others, remain substantial. Demand for appointments and reduced staffing levels have led many GP practices to adopt online and/or automated appointment booking systems. These systems can be highly inaccessible for disabled people, creating further challenges in securing appointments and indirectly discriminating against people with impairments.[24] These access to healthcare barriers may prevent disabled people from obtaining PIP (or any future disability benefits), should evidence of a formal medical diagnosis become mandatory. CDS opposes such a change.

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.

CDS does not feel there is any way to prevent a requirement for the provision of evidence or a formal medical diagnosis from placing increased bureaucratic and fiscal burdens upon the NHS. Given the precarity in which the NHS system is already operating, if not properly resourced, this kind of change could have significant negative consequences for both frontline healthcare workers and disabled people. The evidence presented in response to consultation Q.5 applies equally here.

Any changes to the PIP scheme to introduce a hybrid system of eligibility taking greater account of medical evidence (for particular conditions), would need to be fully funded and resourced by Government in advance of any such system coming into force. For example, the Government could provide a specific source of funding to the NHS via clinical commissioning groups, which GPs and frontline healthcare workers could access to cover the costs and resources of producing medical evidence for PIP assessments. Primary healthcare providers could issue medical evidence letters which remain valid for set periods of time (e.g. three years, five years, indefinitely). CDS reiterates that any proposed reforms to the PIP entitlement system involving the increased use of medical evidence should be developed, implemented and monitored in consultation with disabled people, disabled people's organisations and the healthcare sector.

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

- Agree
- Disagree
- Don't know

July 2022) <https://www.kingsfund.org.uk/insight-and-analysis/long-reads/new-partnership-disabled-people-health-care#introduction> (accessed 12 July 2024).

[24] The Equality Act 2010 s.19.

This question is impossible to answer based on an oversimplified selection of 'agree' / 'disagree' / 'Don't know'. As outlined in our response to consultation Q.1 – Q.6 above, CDS does not agree that provision of evidence of a formal diagnosis by a medical expert should be a mandatory requirement for PIP entitlement. It is important to focus upon how a person's impairment impacts upon their day-to-day life to determine their eligibility for PIP (or any future disability benefit). This can take into account the impact of fluctuating conditions which may vary or worsen in severity over time.

Any change to introduce a hybrid system in which a disabled person can elect to provide medical evidence (describing the type and extent of functional impairment experienced) for particular types of conditions in order to increase the economic and practical efficiency of the PIP system, should only be considered alongside retention of a functional assessment determining the effect of a person's impairment on their day-to-day life. The disabled person in question can then elect which type of PIP eligibility process they wish to undertake, either the provision of medical evidence for particular conditions, or a functional assessment of eligibility conducted by the DWP.

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.

The starting point for determining eligibility for conditions which fluctuate, vary in severity and which may improve with advances in treatment, is of course to obtain, and give appropriate weight to the evidence provided by disabled individuals themselves or their carers regarding the functional restrictions which they experience in day-to-day life. To accurately measure need, the assessment should consider the impact of the impairment when most severe. There should be no rule cutting off eligibility for people who experience the most severe effects for relatively low percentages of time.

In July 2023, the All-Party Parliamentary Groups representing different fluctuating conditions met to discuss PIP[25] and reported that the current assessment system does not adequately meet the needs of persons with fluctuating impairments or health conditions. MPs heard evidence of the need to scrap 'the 50% rule'.[26] This rule states that if your symptoms effect you for less than half of the time, you are not entitled to support for them. This rule systematically disadvantages people with fluctuating

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[25] MS Society, 'Parliamentary groups representing fluctuating conditions meet to discuss PIP' (MS Society, 14 July 2023) <https://www.mssociety.org.uk/research/news/parliamentary-groups-representing-fluctuating-conditions-meet-discuss-pip> (accessed 129 July 2024).

[26] Parkinson's UK, 'MPs hear how disability benefits are failing people with Parkinson's' (Parkinson's UK, 17 July 2023) <https://www.parkinsons.org.uk/news/mps-hear-how-disability-benefits-are-failing-people-parkinsons> accessed 12 July 2024).

conditions who may experience unpredictable flare ups in their symptoms or relapses which can last for varied periods of time, but which can also be very severe and debilitating. This includes individuals who have conditions such as Parkinson's, Multiple Sclerosis, ME/CFS and various types of psychosocial impairments and mental health conditions.

CDS recommends that any reform to PIP should retain the functional test for eligibility and that any new assessment criteria (such as a hybrid route to assessing eligibility which uses medical evidence for particular conditions) should be developed in consultation with disabled people and their organisations to better meet the needs of those with fluctuating impairments. We strongly advocate the removal of the so-called '50% rule' and feel that eligibility needs should be assessed in ways which better reflect the full impact of impairment upon a person's day-to-day functioning during periods of relapse. This need should be determined by the self-reported evidence of the disabled person in question and, where appropriate, those who care for them. This could be corroborated through the provision of documentary evidence of medical treatment or therapies to provide a bulwark against abuse of the PIP system.

Where advances in treatment options may result in improved living outcomes, CDS advocates retention of the current system under which disabled people must inform the Department for Work and Pensions of any changes in their eligibility criteria. In the opinion of CDS members, the reassessment process should be reformed to be less frequent and less onerous. Data from the Department for Work and Pensions shows that most PIP recipients receive short-term awards of 0-2 years.[27] This places a great deal of stress and anxiety on PIP recipients as well as causing a huge bureaucratic and financial cost for the DWP to keep up with PIP award reviews. A light-touch reassessment process could be designed to ensure any changes to entitlement are detected. Disabled people should be trusted to manage the reporting of any change in their entitlement status. This is particularly so, given the recent evidence published by the DWP in April 2024 demonstrating that the rate of fraud for Personal Independence Payment (PIP) entitlement is effectively 0%.[28]

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[27] Department for Work and Pensions, 'Accredited Official Statistics: Background information: Fraud and error in the benefit system statistics, 2023 to 2024 estimates' (16 May 2024) <https://www.gov.uk/government/statistics/fraud-and-error-in-the-benefit-system-financial-year-2023-to-2024-estimates/background-information-fraud-and-error-in-the-benefit-system-statistics-2023-to-2024-estimates> (accessed 12 July 2024).

[28] Department for Work and Pensions, 'Accredited Official Statistics: Fraud and error in the benefit system, Financial Year Ending (FYE) 2024' (16 May 2024), Chapter 7 <https://www.gov.uk/government/statistics/fraud-and-error-in-the-benefit-system-financial-year-2023-to-2024-estimates/fraud-and-error-in-the-benefit-system-financial-year-ending-fye-2024#personal-independence-payment-overpayments-and-underpayments> (accessed 12 July 2024).

Chapter 2 – Consultation Questions

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

Whether or not the need for an aid or appliance is a good or bad indicator of extra ongoing costs is entirely context dependent. It will vary significantly between people with different impairments as well as between people who have the same impairment but experience different limitations upon their day-to-day lives. For example, a person with cerebral palsy may require an expensive and specially designed motorised wheelchair. In her case, this is a good indicator of ongoing costs because the wheelchair will need to be charged and will cause a corresponding ongoing increase in utility costs. Cerebral palsy can also result in other increased living costs to accommodate the impairment, for example the use of a Motability adapted vehicle, accessible living accommodation, increased transport costs, and costs related to essential medical equipment. In contrast, a person who experiences a developmental or psychosocial impairment may not require an aid or appliance but may still have significant ongoing living costs, such as the need to take taxis instead of public transport in order to avoid sensory overload and the need to pay for expensive therapies on an ongoing basis. The need for aids or appliances may therefore be indicative of the nature or severity of a person’s impairment, and thus indicative of the likely disability-related costs they will incur. However, the absence of such aids or appliances is not indicative of the absence of such costs. In some instances, the presence of an aid might reduce general disability-related costs (e.g. a guide dog might reduce the need for a blind person to use taxis on shorter or familiar routes). Accordingly, there will be instances where the absence of an aid might well be indicative of additional disability-related costs. The relevance of the presence of aids, in this context, is therefore of only limited value and considerable care would be needed in referring to them in eligibility or assessment processes.

CDS members expressed concern that the consultation questions in Chapter 2 which focus upon whether particular elements of the entitlement criteria (such as the need for an aid or prompting) are a good indicator of ongoing costs, may reflect an attempt to draw distinctions between particular types of impairments and to reduce the overall provision of PIP by narrowing the scope of the eligibility criteria. CDS members wholeheartedly support the new Government in attempting to tackle the bureaucratic burdens, delays, and growing costs of the PIP system. We feel that significant cost and efficiency savings could be made through streamlining and simplifying the application process and reducing the frequency of full review and reassessment demands. However, reductions in overall systems costs should not be achieved by narrowing the eligibility criteria and removing essential financial support from disabled people.

The proposals drafted by the previous Government appear to be particularly aimed at reducing provision for people with mental health conditions and psychosocial impairments. We note the comments of The Rt Hon Mel Stride MP in the Foreword to the green paper consultation document that:

> *'…many more people [are] applying for disability benefits with mental health and neurodivergent conditions than when PIP was first introduced. With almost a quarter of the adult population (23%) reporting a disability in 2024, up from 16% in 2013… I am concerned about the sustainability of the current model. Over the coming 5 years, PIP spending is expected to grow by 63% (£21.6bn to £35.3bn, 23/24 to 28/29)… It is not clear at present that the very large scale of government expenditure on PIP translates into support targeted where disabled people and people with health conditions need it most; nor that it is providing value to the public whose taxes make our comprehensive welfare state possible.'*

CDS members advocate that the eligibility criteria for entitlement to PIP should be based upon an individualised functional assessment of how impairment affects a person's day-to-day life or perhaps a new dual-track hybrid system using a reduced number of functional assessments conducted by the DWP, alongside a light-touch eligibility assessment for particular types of conditions based upon medical evidence providing details of the type of impairment and functional limitations experienced. If the eligibility criteria are to be amended or improved, any such changes should be designed and implemented in consultation with disabled people and their organisations along with the healthcare sector. This is essential to ensure that PIP (or any future disability benefit) is fit for purpose and is meeting the different and individualised needs of disabled people. It is crucial that PIP remains 'a non-means tested, tax-free benefit which contributes towards the additional costs that disabled people and people with health conditions can face as a result of their disability or health condition.'[29]

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

Our response to consultation Q.9 applies equally to this question and should be read and adopted here. Whether or not 'prompting' is a good or bad indicator of extra ongoing costs is entirely context dependent and will vary significantly between people with different impairments as well as between people who have the same impairment but experience different limitations upon their day-to-day lives.

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[29] Department for Work and Pensions, 'Modernising support…' (n 7) [17].

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?

The number of points accumulated in the assessment process is context dependent and will vary significantly between people with different types of impairments as well as between people who have the same impairment but experience different limitations in their day-to-day lives. CDS members expressed concern that this question may be aimed at reducing the scope of PIP eligibility entitlement overall and may have a particularly negative impact for people with mental health conditions and psychosocial impairments.

Recent research on the impact of PIP for claimants with mental health problems expressed concerns over the problematic application of assessment frameworks for people with mental health conditions and the anxiety and uncertainty which the system caused.[30] Changes made by the Government in 2017 which sought to exclude people experiencing mental distress when traveling independently from receiving the enhanced rate of PIP, was found by a High Court judge to be 'blatantly discriminatory against those with mental health impairments'. Mr Justice Mostyn went on to say that '[t]he wish to save nearly £1 billion a year at the expense of those with mental health impairments is not a reasonable foundation for passing this measure.'[31]

The extent of a person's ongoing costs is entirely dependent upon how their impairment affects their day-to-day life and will vary considerably between people with different impairments as well as between people who have the same impairment but experience different limitations. A person's eligibility and need for PIP should be determined by an individualised assessment of the ways in which their impairment is affecting their day-to-day lived experiences.

There is currently an extensive backlog of delayed health assessments and reassessments for PIP within the DWP.[32] The House of Commons Work and Pensions Committee also describe an overall 'lack of trust' in the PIP system and note the high rate of decisions which are overturned on appeal against initially unsuccessful applications.[33] As such, there are strong arguments for revising and improving the eligibility criteria and assessment processes for PIP. CDS wholly supports the new Government in their efforts to improve the utility and cost-effectiveness of the entire system for both disabled people and the DWP. Any proposed changes should be developed in direct consultation with disabled people, their organisations and the

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[30] Richard Machin and Fiona McCormack, 'The impact of the transition to Personal Independence Payment on claimants with mental health problems' (2023) 38 *Disability and Society* 1029, 1033-1041.

[31] *RF v Secretary of State for Work and Pensions* [2017] EWHC 3375 (Admin) (21 December 2017), comments of Mostyn J [59].

[32] Oliver Crunden and Victoria Anns (n 11) 1-2.

[33] House of Commons Work and Pensions Committee, 'PIP and ESA Assessments' (Seventh Report of Session 2017-19, HC 829, 14 February 2018) 48-52 <https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/829.pdf> (accessed 12 July 2024).

healthcare sector, to ensure that any future measures are better able to meet the needs of all types of impairments.

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

We do not have a view on this but reiterate that any proposed reforms to the eligibility criteria or assessment measures for PIP (or any future disability benefit) should be formulated in consultation with disabled people, their organisations and the healthcare sector.

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

We do not have a view on this but reiterate that any proposed reforms to the eligibility criteria or assessment measures of PIP (or any future disability benefit) should be formulated in consultation with disabled people, their organisations and the healthcare sector.

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

We do not have a view on this but reiterate that any proposed reforms to the eligibility criteria or assessment measures of PIP (or any future disability benefit) should be formulated in consultation with disabled people, their organisations and the healthcare sector.

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?

CDS members reiterate that any proposed reforms to the current entitlement thresholds of PIP (or any future disability benefit) should be formulated in consultation with disabled people, their organisations, and the healthcare sector. For the reasons espoused throughout this consultation response, any changes to the PIP framework should be concerned with increasing trust and efficiency across the system as a whole.

CDS encourages the Government to work towards ensuring that the amount of disability benefit provision available for disabled people is sufficient to ensure that we are able to function in society as equals.

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 current three-month qualifying period for PIP seems to be working well and, as such, CDS members are not convinced that this requires revision. We are concerned that any amendment to extend the length of the qualifying provision would be based upon considerations of cost and reducing the scope of eligibility for PIP, rather than on meeting the needs of disabled people.

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?

The current nine-month perspective test seems to be working well and, as such, CDS members are not convinced that this requires revision. If any such revision were to be made, we would suggest reducing the prospective test to six months.

Chapter 3 – Consultation Questions

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

We did not feel it was possible or appropriate to ‘rank’ these extra costs in terms of their relative importance.

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

Our members expressed concerns over the structure of Q.18. The requirement to ‘rank’ different kinds of additional living costs in order of ‘importance’ is problematic and potentially prejudicial towards different types of impairments. When completing the online green paper consultation response form, there is no option for respondents to elect not to answer this question. If the preselected options remain in place because respondents feel unable to answer, there is a risk that these submissions could become confounding data in the consultation feedback, erroneously devaluing certain types of impairments and the extra costs associated with them. CDS advises the new Labour Government to analyse responses to this consultation question with this issue in mind.

The extra costs incurred by disabled people are as diverse and varied as the different kinds of impairments themselves. What an individual disabled person requires to protect their health and wellbeing cannot be understood or ranked in such a restrictive or over-simplified way. A person with a long-term health condition who relies on medication to survive would clearly place enormous value on the costs associated with that. However, this medication may be delivered through a machine or nebuliser which increases that person’s energy and utility costs. Similarly, a person with a physical impairment may use a motorised wheelchair and hoist pulley system to navigate their home, profoundly increasing their energy and utility costs. They may require expensive personal care assistance, specialist transport arrangements and may incur specialist food costs. These diverse increased costs are all essential to the person’s day-to-day wellbeing and cannot be ranked. The rare genetic condition Prader-Willi syndrome causes a broad range of physical impairments, learning difficulties and behavioural challenges including excessive appetite, muscle weakness, learning disabilities and challenging behaviours. A person with Prader-Willi syndrome would potentially experience every one of the extra living costs listed in consultation Q.18 and further additional costs not listed. These needs cannot be ranked, as each cost is essential to wellbeing.[34] Commentators have expressed their consternation and alarm that ‘people really are being asked to decide if it is more important that disabled people get their medication, eat properly or heat their homes’.[35]

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

A catalogue/ shop scheme

- **Disadvantages**

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

CDS opposes any move away from a cash-based system of ongoing support. Any such change could increase bureaucratic complexity in the PIP system and would also fail to meet the ongoing, diverse needs of disabled people. Disability Rights UK has noted that:

> *‘Personal Independence Payment is a vital piece of social infrastructure, and the clear agenda of the Government’s latest proposal is to reduce the number of Disabled people receiving the crucial support we rely on. Because of punitive government policies over the last decade, we have already lost average benefit payments of around £1,200 a year.*
>
> *Despite polling suggesting the public supports spending more money on our social security system, the government has… suggested implementing a voucher system… Being offered vouchers is more than an insult; it is dangerous. We all want the right support when needed, and vouchers will not improve our lives. Instead, they will shut us off from our communities, leaving thousands without access to crucial services and support’.*[36]

CDS members entirely support the new Government in considering changes which can improve the operational efficiency of the PIP system and have provided suggestions for doing so throughout this consultation response. However, any system

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[34] Prader-Willi Syndrome Association UK, ‘What is PWS?’ <https://www.pwsa.co.uk/what-is-pws> (accessed 13 July 2024).

[35] Benefits and Work, ‘Replace PIP with a catalogue and decide whether food or medication is more important for disabled people – 2024 PIP changes Green Paper’ (Benefits and Work, 30 April 2024) <https://www.benefitsandwork.co.uk/news/replace-pip-with-a-catalogue-and-decide-whether-food-or-medication-is-more-important-for-disabled-people-2024-pip-changes-green-paper> (accessed 13 July 2024).

[36] Disability Rights UK, ‘DR UK Responds To Proposed Changes To Personal Independence Payment (PIP)’ (Disability Rights UK, 29 April 2024) <https://www.disabilityrightsuk.org/news/dr-uk-responds-proposed-changes-personal-independence-payment-pip> (accessed 14 July 2024).

based upon a ‘catalogue’, ‘voucher’, ‘receipt-based’ or ‘one-off grant’ structure would risk failing to meet the diverse and ongoing needs of PIP claimants and may further stigmatise and devalue the lives of disabled people. The design, implementation and monitoring of such a system is likely to place a substantial bureaucratic burden upon the Department for Work and Pensions at significant cost, as well as placing further demands upon the limited time, energy, and resources of disabled people to obtain access to essential resources and services. A system based upon a ‘catalogue’, ‘voucher’, ‘receipt-based’ or ‘one-off grant’ structure would reduce flexibility, responsiveness, and personal choice which is a key strength of the current system of PIP delivery. Direct ongoing cash awards enable disabled people to cover the highly varied and diverse ongoing costs associated with their disability in ways which are most important in their lives. This has a direct economic and social benefit both for disabled people and for the wider economy. Members of CDS reported the transformative power of being able to select and pay directly for needed services, such as employing personal assistance to help with household tasks or gardening, being able to select accessible and disability friendly taxi companies to travel with, and being able to undertake essential alternative therapies such as private hydrotherapy, which are not covered by the NHS.

Any move to a catalogue or voucher-based system would profoundly restrict freedom and choice for disabled people and would inevitably lead to a restriction of the kinds of costs which PIP could be used for. At worst, this may even lead to private market providers having practical control over what ‘vouchers’ or ‘catalogue items’ could be used for. This ‘market capture’ phenomenon has been seen in the Australian welfare system and has been very problematic for disabled people. CDS members suggest that the Government consider undertaking a full economic assessment of the benefits of the current cash-based PIP system for both disabled people and directly for the economy. An independent review of Disability Employment Support, conducted by Liz Sayce in 2011 on behalf of the Government, found that for every £1 spent on Access to Work, the Exchequer recouped £1.48. This significant economic return was further bolstered by the social return on the investment in assisting people’s wellbeing and ability to maintain work.[37] We suggest that it would be very valuable to have a similar review of the economic benefits of PIP – taking into account its benefits for the wider community (for providers of services etc for which disabled people pay using PIP) as well as for claimants themselves.

Research suggests that the UK has one of the least generous social security systems when compared to other wealthy nations.[38] An analysis by the New Economics Foundation in 2021 reported that a decade of cuts under the previous conservative

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[37] Liz Sayce for the Department for Work and Pensions, ‘Getting in, staying in and getting on: Disability employment support fit for the future’ (Department for Work and Pensions, Cm 8081, June 2011) 7, <https://assets.publishing.service.gov.uk/media/5a78e01a40f0b62b22cbd7f0/sayce-report.pdf> (accessed 17 July 2024).

[38] Declan Gaffney, ‘Welfare States: How generous are British benefits compared with other rich nations?’ (Touchstone Extra Publications, Trades Union Congress, London 2015) 5-6, <https://www.tuc.org.uk/research-analysis/reports/welfare-states-how-generous-are-british-benefits-compared-other-rich> (accessed 17 July 2024).

government had ‘hollowed out’ the benefits system.[39] There is a significant body of evidence illustrating that current benefit levels are insufficient to cover even very basic living costs for disabled people.[40] Scope reports that on average, disabled households face additional costs of £975 per month.[41] Low levels of disability benefit provision coupled with higher living costs have resulted in widening disability poverty. Data from the Citizens Advice ‘cost-of-living data trends’ dashboard reveals that 8953 disabled people required crisis support and food bank referrals in June 2024, compared to 5364 people without impairments.[42] Research commissioned by the Department for Work and Pensions in 2023 reported that people who rely solely on disability benefits without other sources of income ‘were often unable to meet essential day to day living costs… such as rent, heating or food and [were] almost always unable to pay for additional health-related costs’, such as therapies and equipment.[43] The cost-of-living crisis has disproportionately affected disabled people and profoundly worsened disability poverty.[44]

2023 research into the Financial Wellbeing of Disabled People in the UK conducted by the Personal Finance Research Centre (PFRC) at the University of Bristol, found that 27% of disabled households are in serious financial difficulty, with 33% of disabled people reporting that they are struggling to pay for food and other essential expenses. Over half (52%) of respondents were unable to keep their home warm and 25% reported that they have stopped or cut down medical services they had been paying for.[45] The report concludes that ‘nothing about the UK benefits system works well for disabled claimants… for many, engaging with that system is a disabling ordeal that… in the documented worst cases leads to distress and self-harm’.[46] The reduction in disability benefit provision and the portrayal of disabled people as ‘welfare scroungers’

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[39] Sarah Arnold, Dominic Caddick and Lukasz Krebel, ‘How our benefits system was hollowed out over 10 years’ (New Economics Foundation, 20 February 2021) <https://neweconomics.org/2021/02/social-security-2010-comparison> (accessed 17 July 2024).

[40] Jamie Evans and others, ‘The Financial Wellbeing of Disabled People in the UK’ (n 14) 3-4.

[41] Scope, ‘Disability Price Tag 2023: the extra cost of disability’ at <https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag-2023/> (accessed 3 July 2024).

[42] Citizens Advice, ‘Cost-of-living data trends’, Record numbers helped with crisis support: ‘Disability or Health Condition’ selection, (Data for England and Wales, June 2024) <https://www.citizensadvice.org.uk/policy/publications/cost-of-living-trends/#h-record-numbers-helped-with-crisis-support> (accessed 17 July 2024).

[43] Department for Work and Pensions, ‘Uses of Health and Disability Benefits’ (National Centre for Social Research on behalf of the Department for Work and Pensions, (DWP research report No.998, March 2023) 24-25 <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1142539/uses-of-health-and-disability-benefits.pdf> (accessed 13 July 2024).

[44] See: Maudie Johnson-Hunter, ‘Our social security system must support households with a disabled person to afford the essentials’ (Joseph Rowntree Foundation, 4 August 2023) <https://www.jrf.org.uk/cost-of-living/our-social-security-system-must-support-households-with-a-disabled-person-to-afford> (accessed 17 July 2024);
Joseph Rowntree Foundation, ‘UK Poverty 2024: The essential guide to understanding poverty in the UK’ (Joseph Rowntree Foundation, York, January 2024) 66-75 <https://www.jrf.org.uk/uk-poverty-2024-the-essential-guide-to-understanding-poverty-in-the-uk> (accessed 17 July 2024);
Scope, ‘Do The Right Thing: Supporting disabled people through the cost of living crisis’ (Scope, November 2022) 6-7 <https://www.scope.org.uk/campaigns/research-policy/cost-of-living-report> (accessed 17 July 2024).

[45] Jamie Evans and others, ‘The Financial Wellbeing of Disabled People in the UK’ (n 14), 6-7.

[46] Jamie Evans and others, *Ibid* 4.

over the last 15 years of austerity imposed by the previous government,[47] has normalised discourses which dehumanise and devalue disabled people. Machin and McCormack argue that '[a]n increasingly negative portrayal of benefits claimants in the media and political sphere has exacerbated this sense of stigma'.[48] It is important to note however, that disabled people who were in receipt of PIP fared slightly better against the measures of extreme poverty than those in receipt of Universal Credit. 35% of disabled people receiving PIP reported struggling to pay for food and other essentials compared to 47% of disabled people who were in receipt of Universal Credit.[49] PIP is an indispensable resource for disabled recipients in covering not just the additional costs of impairment, but also the very basic essentials of life such as sufficient food, housing and heating. An ongoing cash award of PIP is indispensable in the lives of many disabled people and their families. It is not an exaggeration to state that PIP can mean the difference between eating and going hungry. Any reduction in provision or move away from a cash-based award would further worsen disability poverty.

CDS members wholly support the Government in their commitment to national renewal, a politics of public service and the belief in a better future.[50] We also commend the Government's plan to bring forward a Draft Equality (Race and Disability) Bill to tackle the pay gap for disabled people and ethnic minorities.[51] This legislative change should help to tackle the current issues around disability poverty. CDS members encourage the Government to scrap the proposals in Chapter 3 of the green paper consultation document, and instead to consider increasing the operational efficiency of the PIP system while retaining a direct ongoing cash award. This can ensure that disabled people are better protected from poverty and enabled to live as equal and valued members of society. The proposed reforms contained in Chapter 3 of the green paper consultation document are opposed in the strongest possible terms by members of the Centre for Disability Studies at the University of Leeds.

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

A voucher scheme

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[47] See: Margaret Ledwith and Jane Springett, *Participatory Practice: Community-Based Action for Transformative Change'* (2nd edn, Policy Press, Bristol, 2022), 53, 63; and
Frances Ryan, *Crippled: Austerity and the Demonization of Disabled People* (Verso, London, 2020) 4-5.

[48] Richard Machin and Fiona McCormack, 'The impact of the transition to Personal Independence Payment…' (n 30) 1032.

[49] Jamie Evans and others, 'The Financial Wellbeing of Disabled People in the UK' (n 14), 63.

[50] Prime Minister's Office, 10 Downing Street and The Rt Hon Sir Keir Starmer, 'Kier Starmer's first speech as Prime Minister: 5 July 2025' <https://www.gov.uk/government/speeches/keir-starmers-first-speech-as-prime-minister-5-july-2024> (accessed 21 July 2024).

[51] Prime Minister's Office, 10 Downing Street and His Majesty King Charles III, 'The King's Speech 2024' (London, 17 July 2024) <https://www.gov.uk/government/speeches/the-kings-speech-2024> (accessed 21 July 2024).

- **Disadvantages**

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

Any system based upon a ‘catalogue’, ‘voucher’, ‘receipt-based’ or ‘one-off grant’ structure would risk failing to meet the diverse and ongoing needs of PIP claimants and may further stigmatise and devalue the lives of disabled people. The design, implementation and monitoring of such a system is likely to place a substantial bureaucratic burden upon the Department for Work and Pensions at significant cost, as well as placing further demands upon the limited time, energy, and resources of disabled people to obtain access to essential resources and services. A system based upon a ‘catalogue’, ‘voucher’, ‘receipt-based’ or ‘one-off grant’ structure would reduce flexibility, responsiveness, and personal choice which is a key strength of the current system of PIP delivery. Direct ongoing cash awards enable disabled people to cover the highly varied and diverse ongoing costs associated with their disability in ways which are most important in their lives. This has a direct economic and social benefit both for disabled people and for the wider economy. Members of CDS reported the transformative power of being able to select and pay directly for needed services, such as employing personal assistance to help with household tasks or gardening, being able to select accessible and disability friendly taxi companies to travel with and being able to undertake essential alternative therapies such as private hydrotherapy, which are not covered by the NHS.

Any move to a catalogue, or voucher-based system would profoundly restrict freedom, and choice for disabled people and would inevitably lead to a restriction of the kinds of costs which PIP could be used for.

CDS members encourage the Government to scrap the proposals in Chapter 3 of the green paper consultation document, and instead to consider increasing the operational efficiency of the PIP system while retaining a direct ongoing cash award. This can ensure that disabled people are better protected from poverty and enabled to live as equal and valued members of society. The proposed reforms contained in Chapter 3 of the green paper consultation document are opposed in the strongest possible terms by members of the Centre for Disability Studies at the University of Leeds. See further evidence cited in our response to consultation Q.20 which applies with equal force to this question.

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

A receipt-based system

- **Disadvantages**

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

Any system based upon a ‘catalogue’, ‘voucher’, ‘receipt-based’ or ‘one-off grant’ structure would risk failing to meet the diverse and ongoing needs of PIP claimants and may further stigmatise and devalue the lives of disabled people. The design, implementation and monitoring of such a system is likely to place a substantial bureaucratic burden upon the Department for Work and Pensions at significant cost, as well as placing further demands upon the limited time, energy, and resources of disabled people to obtain access to essential resources and services. A system based upon a ‘catalogue’, ‘voucher’, ‘receipt-based’ or ‘one-off grant’ structure would reduce flexibility, responsiveness, and personal choice which is a key strength of the current system of PIP delivery.

Direct ongoing cash awards enable disabled people to cover the highly varied and diverse ongoing costs associated with their disability in ways which are most important in their lives. This has a direct economic and social benefit both for disabled people and for the wider economy. Members of CDS reported the transformative power of being able to select and pay directly for needed services, such as employing personal assistance to help with household tasks or gardening, being able to select accessible and disability friendly taxi companies to travel with and being able to undertake essential alternative therapies such as private hydrotherapy, which are not covered by the NHS. Disabled people experience far higher levels of poverty and do not have the financial resources to purchase potentially very expensive equipment, medication, care services and other goods before claiming the costs of these items back from the DWP through a receipts-based system. Such a system would inevitably lead to disabled people going without essential provision and would create an unwieldy and intractable system of light-touch bureaucracy and delay for the DWP. Not to mention the increased anxiety, stress, and cognitive load which interacting with such a system would place on disabled people.

CDS members encourage the Government to scrap the proposals in Chapter 3 of the green paper consultation document, and instead to consider increasing the operational efficiency of the PIP system while retaining a direct ongoing cash award. This can ensure that disabled people are better protected from poverty and enabled to live as equal and valued members of society. The proposed reforms contained in Chapter 3 of the green paper consultation document are opposed in the strongest possible terms by members of the Centre for Disability Studies at the University of Leeds. See further evidence cited in our response to consultation Q.20 which applies with equal force to this question.

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

One-off grants

- **Disadvantages**

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

Any system based upon a ‘catalogue’, ‘voucher’, ‘receipt-based’ or ‘one-off grant’ structure would risk failing to meet the diverse and ongoing needs of PIP claimants and may further stigmatise and devalue the lives of disabled people. The design, implementation and monitoring of such a system is likely to place a substantial bureaucratic burden upon the Department for Work and Pensions at significant cost, as well as placing further demands upon the limited time, energy, and resources of disabled people to obtain access to essential resources and services. A system based upon a ‘catalogue’, ‘voucher’, ‘receipt-based’ or ‘one-off grant’ structure would reduce flexibility, responsiveness, and personal choice which is a key strength of the current system of PIP delivery.

Direct ongoing cash awards enable disabled people to cover the highly varied and diverse ongoing costs associated with their disability in ways which are most important in their lives. This has a direct economic and social benefit both for disabled people and for the wider economy. Members of CDS reported the transformative power of being able to select and pay directly for needed services, such as employing personal assistance to help with household tasks or gardening, being able to select accessible and disability friendly taxi companies to travel with and being able to undertake essential alternative therapies such as private hydrotherapy, which are not covered by the NHS.

A system of ‘one-off grants’ would be incredibly difficult to implement in practical reality. It would place significant burdens on DWP staff and assessors who would be expected to accurately quantify the cost of ongoing impairment through a one-off assessment. As well as being incredibly difficult to implement in practice, this system would also fail to accommodate the needs of people with impairments or conditions which fluctuate, worsen over time or which can progress in unpredictable ways, such as dementia.

CDS members encourage the Government to scrap the proposals in Chapter 3 of the green paper consultation document, and instead to consider increasing the operational efficiency of the PIP system while retaining a direct ongoing cash award. This can ensure that disabled people are better protected from poverty and enabled to live as equal and valued members of society. The proposed reforms contained in Chapter 3 of the green paper consultation document are opposed in the strongest possible terms by members of the Centre for Disability Studies at the University of Leeds. See further evidence cited in our response to consultation Q.20 which applies with equal force to this question.

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?

The award of PIP is a useful and sensible determiner of eligibility to passport to other benefits and services such as Carer’s Allowance, the Benefit Cap exemption, council tax reduction or exemption, access to the Blue Badge Scheme, and the Motability

Scheme. CDS members see no reason to change or amend the current system in this regard and do not feel it is appropriate to offer alternative suggestions.

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?

The award of PIP is an appropriate determiner of eligibility to additional financial support in Universal Credit. CDS members see no reason to change or amend the current system in this regard and do not feel it is appropriate to offer alternative suggestions. The need for reform across the social security system as a whole, is a far larger issue which cannot be fully addressed in this consultation response.

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)?

Our response to consultation Q.8 above, outlines our collective concerns regarding the appropriateness of PIP entitlement assessments for people who experience fluctuating conditions. There will undoubtedly be other groups of people whose needs are not being adequately met by the current system of provision. This is an argument for improved access to PIP and increased levels of direct cash payment provision, rather than for the reduction, abolition or replacement of PIP with new or existing services. There remains a profound need to provide direct access to adequate ongoing cash-awards which enable disabled people to meet their day-to-day living needs and additional costs. This is in addition to, and quite apart from, the provision of better access to healthcare services and social care assistance which should be available to disabled people through the National Health Service and the care system[52] in addition to the receipt of PIP.

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)?

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[52] Under the Care Act 2014.

CDS members reiterate the need for improved access to PIP and increased levels of direct cash payment provision, rather than for the reduction, abolition or replacement of PIP with new or existing services. There remains an urgent need to provide direct access to ongoing cash-awards which enable disabled people to meet their day-to-day living needs and additional costs. This is in addition to, and quite apart from, the provision of better access to support and/or treatment which should already be available to disabled people through the National Health Service and the care system[53] in addition to the receipt of PIP.

Chapter 4 – Consultation Questions

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?

- Yes
- No
- Don't know

This question is impossible to answer based upon a simplistic selection of 'yes' / 'no' / 'don't know'.

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

Services such as care respite, personal assistance, health services, day-to-day living support, therapies, and medications etc., provided through the NHS and the Care Act 2014 frameworks are all needed in addition to the provision of direct ongoing cash payments through PIP. Any reduction in the provision of PIP based upon the justification of alternative resources provided through local authorities or the NHS, risks leaving disabled people without access to essential day-to-day living resources. We are concerned that placing further burdens upon the already overstretched local authority and NHS systems, could leave disabled people at the mercy of postcode lotteries in which their access to essential resources and services are determined by the financial viability of local authorities and clinical commissioning groups which are already facing significant resourcing challenges.

A 2024 Policy Paper published by the Department for Levelling Up, Housing & Communities reported that local authorities are issuing formal notices of severe financial distress 'at an alarming rate' and raising stark concerns over their abilities to maintain delivery of essential services. The Committee report notes that in the social

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[53] Under the Care Act 2014.

care sector 'a consistent and sustainable increase in funding is required in the long term' in addition to crisis funding to ensure the ongoing provision of essential services.[54] The current funding gap for local authorities in England is estimated to be £4 billion. Local authorities have seen 'significant reductions' in their spending power coincide with increasing demand for their services.[55] Placing even greater responsibilities for provision on local authorities which are already in a state of crisis, seems at best to be an ill-considered notion and, at worst, may be interpreted as an attempt to directly reduce state provision of support for disabled people.

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

Local authorities and/or the NHS may help with one, several, or differing services from the ones listed in Q.30, depending upon the geographic location and needs of a particular disabled person. Disabled people require the provision of these resources in addition to the direct award of ongoing cash payments through the PIP system, in order to manage the increased costs of life with impairment. The factors listed in Q.30 should represent differing elements of state provision across a joined-up health and social care sector which aims to better meet the needs of disabled people.

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

Local authorities and the NHS may provide assistance with one or all of the health and social care needs listed in Q.30, along with many other forms of support. However, the availability and quality of these services can vary significantly between different geographic locations and depending upon the individual needs of the disabled person in question. Of further concern are the profound financial challenges already facing

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[54] House of Commons Levelling Up, Housing and Communities Committee, 'Financial distress in local authorities' (Third Report of Session 2023-24, HC 56, 1 February 2024), 3-4. <https://committees.parliament.uk/publications/43165/documents/214689/default/> (accessed 17 July 2024).

[55] *Ibid* 3.

local authorities[56] and clinical commissioning groups[57] across the country. The services mentioned in Q.30 should be provided to disabled people through the NHS and social care systems, in addition to the direct ongoing cash payments awarded through PIP to cover the increased costs of living with impairment in day-to-day life.

The consideration of a complete overhaul of the health and social care sector is not within the scope of this consultation green paper. However, there are emphatic calls for such a change.[58] The House of Commons Levelling Up, Housing and Communities Committee recently outlined the need for immediate action and investment by government in order 'to save the sector from the brink of collapse'.[59]

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

CDS Members elect not to answer this question in light of the concerns already expressed in our consultation responses to Q.29 and Q.31 which apply equally here.

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[56] *Ibid*.

[57] NHS Clinical Commissioners, 'Written evidence submitted by NHS Clinical Commissioners' to the House of Commons Committee of Public Accounts, 'NHS Financial Sustainability: progress review' (Ninety-First Report of Session 2017-19, HC 1743, 3 April 2019), Published Written Evidence NHS0005, <https://committees.parliament.uk/writtenevidence/99765/pdf/> accessed 17 July 2024).

[58] See: National Audit Office, 'Reforming adult social care in England' (Department of Health and Social Care, Session 2023-24, 10 November 2023, HC 184), 5-13 <https://www.nao.org.uk/wp-content/uploads/2023/11/Report-reforming-adult-social-care-in-England.pdf> accessed 17 July 2024); and;
Lucy Series, *Deprivation of Liberty in the Shadows of the Institution* (Bristol University Press, Bristol 2022) 211-212.

[59] House of Commons Levelling Up, Housing and Communities Committee, 'Long-term funding of adult social care' (House of Commons, Second Report of Session 2022-23, HC 19, London, 4 August 2022) 3-5 and at 15, <https://committees.parliament.uk/work/1080/longterm-funding-of-adult-social-care/publications/> (accessed 17 July 2024).

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

CDS Members elect not to answer this question in light of the concerns already expressed in our consultation responses to Q.29 and Q.31 which apply equally here.

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?

CDS Members elect not to answer this question in light of the concerns already expressed in our consultation responses to Q.29 and Q.31 which apply equally here.

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, CDS does not agree that aligning PIP with local authority and NHS services could reduce the number of assessments or reduce duplication. Such a change risks placing the National Health Service and local authorities under further bureaucratic and financial strain at a time when both systems are already over-stretched and under-resourced. It also risks placing disabled people at the mercy of postcode lotteries which determine the availability of support based upon local resources. This could result in a fragmented and inequitable system of provision with disabled people bearing the negative consequences. There is no suggestion in the green paper consultation document of how such increased demands on the NHS or local authorities could be met. PIP should be retained in its current form of ongoing direct cash benefit awards in addition to adequate health and social care support through the NHS and by local authorities under the Care Act 2014 system.

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

This question is impossible to answer and risks creating a hierarchy of need for services or the prioritisation of certain kinds of impairments over others. All community support services are essential to the health and wellbeing of disabled people as a collective. The relative importance of particular services or supports will vary significantly based upon individual need.

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

CDS members feel strongly that a centralised, Government-led approach to the provision of support for disabled people must be maintained. This is the only way to ensure that disabled people are not subject to profound variations in the availability of resources based upon the financial status of local areas and local authorities. Notably, Bristol City Council recently faced a significant backlash after proposing 'inhumane' care policies forcing disabled people into residential homes against their will, based upon the justification that the cost of their care could be significantly reduced for the local authority.[60]

The formation of the new Labour Government provides an important and exciting opportunity for change, to improve the operational efficiency of the PIP system for both disabled people and the DWP. The Government now has the ideal opportunity to lead a centralised and comprehensive review of the proposed reforms to PIP developed by the previous government, and to develop a new set of proposals through consultation with disabled people, their organisations, and the healthcare sector. CDS feels strongly that the new Labour Government can reduce delay and anxiety for disabled people in the current PIP system, while at the same time reducing unnecessary cost and bureaucracy which will yield substantial benefits for public spending. Such positive change could increase both trust and efficiency in the Personal Independence Payment system.

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

CDS Members elect not to answer this question in light of our concerns expressed in consultation responses addressing Q.29, Q.31, Q.35, Q.36 and Q.37 which apply with equal force here.

Compulsory question

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

No. Members of the Centre for Disability Studies at the University of Leeds have responded to this green paper consultation document in their personal and

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[60] John Pring, 'Letter from DPOs accuses care cuts council of 'inhumane' policies' (Disability News Service, 18 April 2024) <https://www.disabilitynewsservice.com/letter-from-dpos-accuses-care-cuts-council-of-inhumane-policies/> (accessed 17 July 2024).

professional capacities as interdisciplinary disability scholars, many of whom are disabled people who have experience of interacting with the PIP system.