The Adult
Cerebral Palsy
Movement

EVIDENCE SUBMISSION TO THE TIMMS REVIEW OF PIP

28 May 2026

ABOUT UP

UP – The Adult Cerebral Palsy Movement is the UK's only charity focused exclusively on improving the lives of adults with cerebral palsy. We represent a community of approximately 130,000 people: the largest group in the UK living with a child onset physical condition, yet one that is consistently underserved by health and social care services and underrepresented in policy.

Cerebral palsy is caused by damage to the developing brain, most commonly before or during birth. It affects movement, posture and coordination and, unlike many conditions, does not improve over time. For many adults, its impacts become more significant with age, with 20–50% experiencing a deterioration in walking function between the ages of 20 and 40. Adults with CP also face higher rates of chronic conditions including pain, fatigue, anxiety, depression, arthritis and osteoporosis.

Children with CP receive coordinated, multidisciplinary support through paediatric services – physiotherapy, occupational therapy, specialist medical oversight, and structured care planning. At 18, that support ends. There is no equivalent NHS pathway for adults. The investment made in childhood is abandoned at the very point it could be built upon, and many adults with CP find themselves without clinical support, navigating a system that does not recognise their needs. For this community, PIP is frequently the only structured form of support available – and the only means of funding care that the NHS no longer provides.

UP was co-founded in 2018 by Emma Livingstone, who lives with cerebral palsy, and Miriam Creeger, a specialist neurophysiotherapist. Our work spans direct community support, health education, clinical partnerships, and systemic advocacy. We campaign for the NHS and government to recognise cerebral palsy as a lifelong condition requiring dedicated adult services, and for the people who live with it to be treated with the dignity, understanding and support they deserve.

We are responding to this call for evidence as an organisation that supports and represents disabled people and people with health conditions.

ABOUT THIS SUBMISSION

This submission draws on a structured consultation with adults with cerebral palsy conducted specifically to inform our response to the Timms Review. The consultation comprised two elements: an initial survey, designed to surface themes and gather written testimony; and a facilitated focus group, in which a smaller group of community members explored those themes in depth across the four areas of the review.

Adults with CP are not easy to reach. There is no dedicated NHS care pathway for this community, no centralised register, and no natural institutional gathering point. The people who contributed to this submission did so through UP's community networks, built over years of sustained engagement. Their willingness to share detailed, often deeply personal accounts of their experiences with PIP reflects both the trust UP has earned within its community and the strength of feeling about the issues this review is examining.

The value of this evidence lies in its depth, not its scale. The Timms Review has asked for insight and lived experience to sit alongside quantitative data; that is what we are providing. The testimonies in this submission are representative of themes we hear consistently across our community – themes that have been validated through the focus group discussion and through UP's ongoing direct engagement with adults with CP across the UK.

Unless otherwise indicated, quotes are from survey or focus group participants. In line with our data protection commitments, and given the sensitive nature of some of the experiences shared, we have used first names only throughout.

THEME 1: THE ROLE AND PURPOSE OF PIP

PIP is described by government as support for the 'extra costs' of living with a disability. For the adults with cerebral palsy who contributed to this submission, this framing does not reflect their reality. PIP does not cover extra costs – it covers essential, unavoidable costs that arise directly from living with a lifelong condition affecting both daily functioning and mobility.

When asked what PIP allows them to do, respondents painted a picture of a benefit that is woven into the fabric of daily life:

- Transport and mobility support – cited by the large majority of participants
- Disability-related costs including equipment, adaptations and care
- Support for mental health and wellbeing
- Support for the ability to work, study or volunteer
- Covering essential daily living costs including food and bills

"PIP allows me to have weekly physical therapy alongside tailored personal training sessions as well as regular therapy to support my mental health. It also supports the transport to get to these things as well as social activities, as I am not allowed to drive. These things allow me to live fully and have a healthier life." – Anonymous

"PIP makes a huge difference to my life as there are so many disability-related costs I need to cover. PIP doesn't cover all of them but if I didn't receive it, I just wouldn't manage. It is essential to me. The thought of PIP being under threat is having a hugely negative impact on my mental health. It is essential to so many of us and enables us to be valued members of our communities." – Janene

A critical and recurring theme was the relationship between PIP and employment. The government's Get Britain Working white paper emphasises the importance of enabling disabled people to enter and remain in work. Our evidence strongly supports this ambition – but shows that PIP is, for many adults with CP, the very mechanism that makes work possible. It funds the physiotherapy, transport, personal assistance and equipment that allow people to sustain employment.

Cutting PIP would therefore have the opposite effect to that intended: it would push more adults with CP out of work, not into it. Several participants described exactly this dynamic.

"Tops up my income as I can only manage part-time work. Mobility component pays for my Motability car so if I didn't get PIP I would lose my car and freedom to get around independently. I also wouldn't be able to afford my wheelchair." – Claire

"When I had PIP it enabled me to stay working as a Band 5 nurse. I do not have the physical or mental energy to take on more work, but now, without PIP, I am having to think about just that to survive." – Jo

There is a further systemic dimension to this. Because there is no dedicated, specialised care pathway for adults with CP in the NHS, many people are forced to fund essential clinical support privately – specialist physiotherapy, speech and language therapy, pain management and mental health support. PIP is frequently used to fill this gap. This means it is doing two jobs at once: covering the extra costs of disability and substituting for NHS services that should be available but are not. This is a significant policy failure that the Timms Review should note.

"It doesn't cover physiotherapy which would make a huge difference to me. As a child I received ongoing physiotherapy but when I left school at 16, this completely stopped and I've had significant deterioration because of this." – Diane

Although PIP was introduced in 2013 there are still people who are on the DLA scheme who have not been converted across to the PIP scheme.

"Remove the permanent cloud hanging over the head of those still on DLA waiting for a transfer to PIP. Please tell us that if we have an indefinite time limit on our DLA then we will remain on it until we have a change in condition that means we request re-assessment on to PIP."
– Anonymous

THEME 2: ELIGIBILITY, FAIRNESS AND EQUITY

The assessment experience

The PIP assessment process is, for the majority of adults with cerebral palsy who have experienced it, deeply distressing. The most common experiences described were negative or very negative – only a small minority described the process as positive. The most consistent theme across both the survey and focus group was a sense that assessors approach claimants with suspicion rather than understanding – that the process is designed to catch people out rather than to understand the reality of their lives.

"I found my home assessment very traumatic. My assessor was a non-specialist physio who worked in the NHS as their day job. Her approach really increased my wariness around NHS health professionals. So many questions were very personal as a way to test my answers on my form. Do I have friends? Do I see friends? Do old school friends visit? I felt like I was being watched and observed." – Bethany

"My face-to-face assessment was cut short due to a lack of time. The assessor was dismissive of my difficulties, particularly my pain when walking. I was actually told there wasn't time to discuss it. The assessor showed a huge lack of empathy and respect and said they just wanted to get the standard questions answered as soon as possible." – Alison

Assessor knowledge of cerebral palsy

A serious and repeated concern is that assessors lack the knowledge needed to understand cerebral palsy: its lifelong nature, its fluctuating symptoms, its comorbidities, and the way it interacts with daily life and employment.

Participants described assessors who focused on what a person could do on a good day, or at the moment of assessment, rather than on the full picture of their condition. Mobility descriptors were widely felt to be inadequate – failing to capture the role of fatigue, pain, spasticity, or the safety risks of independent mobility.

"The lack of understanding of CP and its comorbidities – even the unmedicalised comorbidities of pain and fatigue – are not taken into account in terms of criteria. Is the distance you are able to walk a criterion by which one should decide whether someone needs mobility support? It seems to me it's not fit for our community." – Emma

"The concept of fluctuating mobility and the factors that influence it with child-onset, long-term conditions is still poorly appreciated by healthcare workers." – Miriam

Comorbidities – including epilepsy, pain and fatigue – were frequently overlooked. One participant described how her epilepsy and catheter were dismissed by an assessor focused solely on the fact that she could walk:

"The assessor said, 'I'm not interested in that. It's not important.' All she wanted to focus on was the fact that I can walk. Because I make the effort, because I don't want to be stuck in the house staring at the same four walls, they almost say, well, you're capable of doing it yourself. The more you try to do things for yourself, you're told you're not disabled enough." – Alison

A structural solution to the assessor knowledge problem exists, and it does not require the creation of new infrastructure. GPs know their patients. An annual health review – already provided for adults with learning disabilities under NHS contract – would give adults with CP a documented, clinician-verified record of their condition, its fluctuations, and its real-world impact. This record could then be submitted as part of a PIP application, providing assessors with the informed clinical picture they currently lack and placing the burden of understanding where it should be: on the system, not the individual.

Integrated Care Boards are already mandated to address the health needs of their populations, including those with long-term neurological conditions. Were they to fulfil this mandate in respect of adults with CP – commissioning annual reviews and ensuring CP is explicitly included in population health strategies – the quality of evidence available to PIP assessors would be transformed. A fair system of allocation cannot function if the method of assessment is not robust. Fixing the assessment requires fixing the clinical infrastructure that feeds it.

Being active is penalised

One of the most troubling findings of our consultation is that being active – working, volunteering, maintaining social connections – is frequently used by assessors as evidence that a person's needs have reduced, when the opposite is true. PIP is what makes that activity possible. Removing it does not reflect improved capability; it removes the support that enables participation.

"I wasn't less disabled because I was working. I was working because I'd managed to get some physiotherapy input and some strategies to be able to try working. I use PIP towards my physiotherapy, and when I'm working I need more physiotherapy to be able to continue, not less." – Bethany

"PIP is there to promote independence, and they promote your independence, and then because they've done that they take it away because you're more independent. So it doesn't make sense." – Kayla

The points system

The current points-based assessment system was widely described as reductive, inaccurate and poorly suited to the reality of living with CP. It relies heavily on observations made during a single interaction, which may occur on a good day and which cannot capture the fluctuating, cumulative nature of the condition.

Participants highlighted specific problems including: assessors making observations about physical capability based on brief interactions; the difficulty of accurately self-reporting needs when you are accustomed to chronic pain; and the system's failure to account for the cumulative impact of managing a complex, multi-system condition.

"The cumulative impact of managing multiple medical appointments, treatments and administrative processes is substantial and often underestimated within the PIP system." – Marianna

"We all know that if you're used to pain for a long time, you don't realise how much pain you're in. To actually report it in a way that's reliable is so difficult, because we all just want to get on with it." – Kayla

THEME 3: THE EXPERIENCE OF CLAIMING PIP

Reassessment of a lifelong condition

Mandatory periodic reassessment is experienced by the adults with CP in our community as one of the most distressing aspects of the PIP system. Cerebral palsy does not improve. Its effects are, if anything, more pronounced with age. Subjecting people to repeated reassessment of a condition that will never be cured causes significant anxiety, without clinical justification.

Participants described a culture of fear around reassessment – fear not of scrutiny itself, but of losing support they depend on to function. Several described deferring requests for reassessment even when their needs had increased, because they were afraid of losing what they already had.

"That would be up to me to go, but I shouldn't be afraid to go to the DWP and say my needs have increased and risk losing the whole award." – Sarah

"I didn't dare to appeal for years out of fear of losing all PIP." – Charlotte

"Reassessment and reapplying is extremely stressful and an unnecessary cost for the government, as my disability is lifelong. Life as a disabled person is difficult enough as it is, without the added stress caused by the uncertainty of PIP." – Janene

"Ridiculous waste of time, money and stress. It makes life even harder as you age. Without a brain and nerve transplant, no treatment will improve it." – John

The appeals process

Of those who had received a decision they could have challenged, a significant proportion went through mandatory reconsideration or appeal, and others considered it but decided not to. The decision not to challenge was, in most cases, driven not by acceptance of the outcome but by the anticipated burden of the process.

Those who did appeal described the process as emotionally draining and frequently unfair. Several described reaching tribunal stage for conditions that assessors with appropriate clinical knowledge should have understood from the outset.

"I had to call back in tears for a mandatory reconsideration, to be told to call back if I was too upset. To then still get 0 points and now be at tribunal stage is mentally exhausting and I think cruel, frankly. It has made me suicidal at times." – Jo

"The panel apologised at the end for me having to attend, as they could see when I entered the room that I needed it." – Anna

Accessibility of the process

The process itself presents particular challenges for people with CP. The telephone systems used by DWP are poorly adapted for people with speech difficulties, slow motor reflexes, fatigue, cognitive overload or dexterity problems. Automated identity verification, rapid response requirements and long waiting times create barriers that are not incidental but structural.

The form itself was described by one respondent as taking ten hours to complete. Several said they required external support from a charity or professional simply to secure an award they were clearly entitled to.

Stigma

A striking and largely hidden dimension of the PIP experience for adults with CP is the stigma attached to receiving disability benefits. The majority of participants said they felt judged or uncomfortable because they receive or have applied for PIP. Most said they do not discuss it openly – typically only their closest family members know.

"I don't talk about my PIP with anyone for fear of judgement and negative comments. Only my mum and partner know I have it." – Anonymous

"I've been very careful about who I tell. There is stigma and misunderstanding around disability benefits, and I worry about being judged by people who do not understand the reality of living with a lifelong condition. Many people do not see the daily challenges, pain, fatigue, or extra costs that come with cerebral palsy." – Raven

"I think they can't see why I need it as my CP is a bit hidden, because I hide it as best I can. Which in itself is a mental health issue about low self-esteem and shame." – Jo

THEME 4: CHANGING CONTEXT AND THE IMPACT ON PIP

PIP as the gateway to other benefits

The proposed change to make PIP the single gateway to a range of health-related and disability benefits was discussed at length in our focus group. While some participants acknowledged that a single assessment could, in principle, reduce bureaucracy, the overwhelming concern was that this change, implemented in the current form of the PIP assessment, would significantly restrict access to support.

Participants already described experiences where PIP, used as a gateway to other support such as Blue Badges and bus passes, had blocked access rather than enabling it.

"Even though I've got high-rate mobility, I can't actually get my disabled badge on my PIP these days, whereas I used to be able to get it on my DLA." – Molly

The concern is that a system widely experienced as inadequate, unfair and poorly informed about CP would, if given wider powers, replicate those failures across a broader range of support. The risk is not theoretical – it is a direct extrapolation of what participants are already experiencing.

"The risk is that a single point of access becomes a single point of failure. The PIP assessment is very simplistic and not fit for purpose for adult CP. It would need to understand all the layers of CP and take a holistic, informed, person-centred approach, rather than using criteria as punitive hurdles." – Bethany

"As it's difficult for people who need PIP to be able to get it at the right level to begin with, making it a gateway to other benefits will cause far more problems than it is perhaps designed to solve. Costs for mandatory reconsiderations and tribunals will increase. This will cause unnecessary stress and anxiety to millions of disabled people who are likely already struggling." – Alison

PIP and employment in a changing world

Since PIP was introduced in 2013, the world of work has changed significantly. Remote and hybrid working has opened up employment possibilities for many adults with CP who previously found commuting, office environments and fixed hours prohibitive. But accessing these opportunities still requires support – for home adaptations, equipment, personal assistance, and the additional physiotherapy needed to sustain employment.

Several participants felt that PIP's current framework does not reflect these evolving costs. The Access to Work scheme, which should complement PIP in enabling employment, was widely described as inadequate and failing.

"It would be helpful for PIP to reflect the cost of staying fit enough to keep working. My care and mobility needs pre-date and exist regardless of work. If PIP could reflect this, it would free me to work and participate in a way that works with my body, not against it." – Bethany

OUR RECOMMENDATIONS

Our recommendations are grounded in the evidence above and reflect the consistent themes across our survey and focus group. They also connect to the government's stated ambitions in the Get Britain Working white paper and the NHS 10 Year Plan – demonstrating that reforming PIP in line with these recommendations is not in tension with wider policy goals, but essential to achieving them.

Recommendation 1: Continued access to PIP for people with CP, at appropriate levels

CP is a lifelong condition. PIP must remain accessible throughout a person's life. The current system, in which awards can be reduced or removed at reassessment despite no clinical change, is causing harm and must be reformed.

Recommendation 2: PIP must remain non-means-tested and employment-neutral

PIP must be accessible regardless of employment status. Our evidence shows that assessors regularly use employment as grounds to reduce awards, when the reverse is true: PIP frequently makes employment possible. Being in paid work does not reduce the extra costs of CP. For many people, it increases them. Losing PIP can force people to reduce hours or leave work entirely, creating a double penalty.

Recommendation 3: Automatic standard-rate award at age 16 for people diagnosed with CP

CP is permanent and lifelong. Automatic entitlement at 16 would reduce unnecessary administrative burden and anxiety during the transition to adulthood – a period that is already challenging for young people with CP and their families.

Recommendation 4: Remove mandatory reassessments for CP

Routine reassessment of a lifelong condition is clinically unjustified and causes significant harm. The current system should be replaced with one in which individuals can request reassessment if their needs increase, but are not subject to periodic review that could result in a reduction of their award. In no circumstances should reassessment result in a lower award for a condition that is known to be stable or degenerative.

Recommendation 5: A fair, holistic, person-centred assessment process

The assessment must be reformed. Specifically:

- Assessors should have appropriate, verified knowledge of the conditions they are assessing. For neurological and lifelong conditions, this should mean neurological expertise.

- Greater weight must be given to evidence from consultants and specialist clinical teams who know the person.

- The points-based system should be reviewed to ensure it captures fatigue, fluctuating symptoms, pain, spasticity and the cumulative impact of co-morbidities.

- Mobility descriptors should be updated to reflect the full range of factors – not just distance walked, but safety, reliability, frequency of falls, fatigue and the conditions under which mobility is possible.

- The process should be accessible: telephone systems, forms and assessment environments must be adapted for people with speech difficulties, motor impairments and fatigue.

- Assessment reports should be subject to quality control. Inaccurate or misleading records, of the kind described by several of our participants, should be challengeable through a clear, accessible process.

Recommendation 6: PIP should not become the single gateway to benefits and support until the assessment is fit for purpose

We support the principle of reducing assessment fatigue for disabled people. However, our evidence demonstrates clearly that the PIP assessment, in its current form, is not fit for this role. Widening its gatekeeping function before reforming it would entrench and extend the existing failures. The gateway change should only proceed once the recommendations above have been implemented and independently evaluated.

Recommendation 7: Address stigma through public communication

The government and DWP should take active steps to address the stigma around disability benefits. Our evidence shows that a significant proportion of adults with CP feel unable to discuss their PIP openly, and that shame and fear are a regular part of the experience. This is not acceptable. PIP is not a perk or a luxury. It is an essential contribution to the costs of living with a lifelong disability.

Recommendation 8: Annual health reviews for adults with CP, delivered through primary care

As we set out in Theme 2, the inadequacy of the PIP assessment for adults with CP is partly a consequence of a wider failure: there is no NHS care pathway for this community, and no systematic mechanism for GPs to monitor and document the condition over time. Annual health reviews – already provided for adults with learning disabilities under NHS contract – would address this directly. They would give adults with CP a clinician-verified record of their condition and its real-world impact, which could be submitted as part of a PIP application. They would also provide the kind of proactive clinical oversight that can delay deterioration and reduce the long-term costs of unmanaged CP to the NHS.

ICBs are already mandated to address the health needs of their populations, including those with long-term neurological conditions. We call on them to fulfil that mandate in respect of adults with CP. This is not a new ask; it is an existing obligation that is not being met. Meeting it would benefit individuals, reduce pressure on PIP, and support the government's ambition to shift healthcare towards prevention.

Recommendation 9: Develop a dedicated NHS care pathway for adults with CP

The evidence in this submission points repeatedly to a fundamental gap: adults with CP have no dedicated care pathway in the NHS, and are forced to use their PIP to fund essential clinical support that other patient groups access as a matter of course. Until this is addressed, PIP will continue to substitute for healthcare rather than supplementing it. We urge the DWP to raise this finding with NHS England and the relevant government departments.

As part of this, we recommend:

- Cerebral palsy to be explicitly named in NHS service specifications for adult neurological conditions
- ICBs to include adults with CP in their population health strategies, as they are mandated to do
- A clear commissioning framework for adult CP services, comparable to those that exist for other lifelong neurological conditions

CONCLUDING REMARKS

The adults with cerebral palsy who contributed to this submission are not asking for more than they are entitled to. They are asking for a system that recognises the reality of their lives – that understands what it means to live with a lifelong condition in a body that does not work the way most people's does, and that provides support accordingly.

PIP, at its best, does exactly this. It enables people to work, to stay healthy, to participate in their communities, and to live with dignity. The evidence in this submission shows that it is frequently failing to do so, and that the consequences of that failure are serious: deteriorating health, financial hardship, loss of employment and profound damage to mental health and self-worth.

We are grateful to the Timms Review for the opportunity to contribute this evidence, and we stand ready to discuss it further, or to provide additional evidence from our community, at any stage of the review process.

Emma Livingstone and Miriam Creeger
Co-founders, UP – The Adult Cerebral Palsy Movement

upmovement.org.uk