Calling Disabled Artists: Help Us Expose the Impact of PIP Reforms

Many disabled artists, writers, and cultural workers rely on PIP (Personal Independence Payment) to work. It helps cover essential access adjustments—such as mobility aids like wheelchairs and orthotic supports, transport including taxis and adapted vehicles, support workers like British Sign Language (BSL) interpreters and personal assistants, and assistive technology such as screen readers and speech-to-text software.

PIP also funds adapted workspaces, including height-adjustable desks and ergonomic seating, as well as communication support like live captioning and transcription services. Many depend on it for therapy—whether mental health support or physical rehabilitation—both of which are critical for sustaining their ability to work.

Cuts or restrictions to PIP will push even more disabled people out of the arts, where salaries are low, work is precarious, and many opportunities are unpaid or underpaid—deepening inequality in an already inaccessible sector.

Below, disabled artists share how these changes could impact their lives and practice. Please send us your experience via email to be added cripartists@gmail.com

If you don't receive PIP but have faced barriers to applying, have been denied it, or want to highlight how it would change your ability to work, your contribution will help show how many are already excluded from vital support.

(Initials or Anon), (Profession), (Location)

JP, Artist, Writer, Curator. London
I first applied for PIP in 2021. Despite disability dominating much of my life and making me unable to live independently, I was scored 0 across a point system which requires you to get at least 4 points to get any level of support. Every stage of that process was highly demoralising and made

me sicker as a result. Some of the reasons I was rejected the first time around included because I turned up to the interview - which happened over the phone while I was sick in bed - so must be well enough to function day to day. It took me 3 years to find the courage to apply again. Once again I was subjected to relentless, invasive questioning and an assessor who treated me and my mum like criminals.

The disability benefit process - as with other benefits systems in this country - are designed to be punitive and deter people at every stage. Most people who apply for PIP don’t actually qualify the first time around, instead having to wait months for a tribunal - with countless others giving up along the way. This all culminates in the govt wasting vast amounts of money to ensure disabled people don’t receive the support they need.

For many these benefits are the difference between life and death. It enables us to be able to pay for carers, mobility aids, adaptations, treatments we need. Being disabled is expensive and most jobs aren’t set up to be accessible. In my experience many of the disabled people I know are actually facilitated in maintaining jobs by having some of the stress of financial pressure alleviated by the benefit system, allowing us to prioritise flexible jobs, and knowing we have a safety net in the periods where we are physically unable to work.

PIP is already a long outdated system which is focused through a lens of physical disability and isn’t designed to consider fluctuating and invisible disabilities. I can’t even begin to imagine how you would make an already impossible process even harder to qualify for, but the reality will mean even more people failing to receive help that they need to survive.

LM, Producer, Artist London.

PIP (Personal Independence Payment) provides crucial financial support that helps me maintain my independence despite my disability. This benefit makes a significant difference in my day-to-day life by covering additional costs associated with my condition, such as specialized equipment, transportation, medication, or care services that aren't covered by standard healthcare.

Without PIP, I could not manage these expenses on my own, potentially leading to increased isolation, deteriorating health, and loss of autonomy. PIP acknowledges that my condition creates unavoidable additional living costs and helps bridge this financial gap.

The benefit enables me to participate more fully in society and live with dignity. It recognizes that my needs are legitimate and that I deserve support to overcome the practical barriers my condition presents.

ML, curator. London

I have never applied for PIP, despite likely qualifying, because each time I applied for other benefits, I was dismissed for living with a partner the government considers financially responsible for me. He has an average London salary and owns our home, so the state deems me ineligible for support, even though we are not married.

The first time this happened, I was in my early twenties, and our relationship was still new. The idea of being financially dependent on him terrified me. He did not see himself as responsible for me, nor did he provide for me, yet the state insisted I was his dependent. As an immigrant, I had no one else to turn to.

With chronic conditions, I cannot rely on my body for steady income. Unskilled flexible jobs like pubs and shops require physical stamina, while the work my education has granted me in the arts includes many skilled roles that also demand strength and long hours, such as technician roles. The work I can do, clerical, is highly competitive and underpaid. My health fluctuates—sometimes disabling, sometimes manageable—so I need flexibility, yet the system limits my options.

If my partner is seen as my carer or provider and our relationship becomes unsafe, toxic, or coercive, I will be trapped. A lack of financial independence leaves me vulnerable to manipulation and forces me to stay in jobs that harm my health.

PIP, unlike other benefits, is not means-tested, meaning I may qualify. It could allow me to secure stable freelance work, giving me the independence to manage my health, work on my terms, and build healthier relationships—without the risk of coercion or control.

Financial independence isn’t just about money; it’s about the freedom to live on my own terms, care for myself, and escape harmful situations. Systems like PIP are essential in ensuring people like me are not trapped, at home or at work, without a way out.

Anon, Artist, London

Whilst I receive other disability benefits, I have not applied to PIP. I've been encouraged to do so by people I know who have it, and would potentially qualify based on the criteria, but knowing what a difficult process it is from friends, family, and others, I just don't know if I can face it.

Everyone I know who has been through it has felt it was intentionally hard: designed to stop people from claiming it, whether they qualify or not. The process does not seem to be set up to support people who need help, but to block anyone it can from accessing this important resource.

Whilst I began to prepare an application years ago, I had my fears confirmed by a Citizen's Advice Bureau advisor who said that I would have to go to a tribunal, no matter what happened during the application process. That they would say 'no', even though I was entitled to it. I have an 'invisible illness' which took decades of tests and doctors visits to be diagnosed, and the idea of facing a system once again to be met with disbelief is re-traumatising. I couldn't bring myself to go through that.

The fact that under these proposed changes these conditions would actually get **worse** is unimaginable. It will disproportionately affect those who are less able to advocate for themselves, who are often the people who need it the most.

From a personal point of view as an artist, if I'd have had PIP since my diagnosis, I believe I could have done a lot more work as an artist. I could have spent less time not working due to lack of disability access, and said yes to more opportunities. My hope was that these conditions would improve under a Labour government, I'd be able to actually get what I'm entitled to, and expand my ability to work with that support.

This is not what we voted for.

AP, Artist, London

I am 36 and have been on PIP (or its predecessor DLA) for all of my adult life. I was on incapacity benefit from 18-23 years old. At this point there was not a job I could have done. A carer had to lift me out of bed every day.

I now work part time as a freelance artist but every now and then my autoimmune condition causes collapses for 4-6+ months at a time and I'm unable to earn a living. Without PIP I would not be able to eat, let alone get to work reliably. I have no savings and no safety net.

Art is the only job I can do, and that's because I designed an artistic practice in a way that bends to the needs of my body: 'rest' becomes a part of the performance. I have framed entire funding applications around my rehabilitation in a desperate attempt to pay for the support my body needs.

I pay £240+ a month for essential physiotherapy that the NHS cannot provide. This is necessary to recover from the physical strain of the work I do. I pay £2-4000 a year for a specialist mobility aid that works with my body (because the electric wheelchair given by the NHS dislocated my fingers). My doctors have told me to eat a specialist diet and wear expensive compression garments to ease my pain. Because my condition is rare, I often have to pay for private medical treatment that the NHS have explicitly stated they don't have capacity to provide.

Only 9% of homes in the uk meet basic accessibility requirements. Only 92/272 tube stations in London are accessible, and many of these are out of action often. My local tube station's lift was recently out of action for over a year.

What I mean to say is: PIP isn't a lifestyle choice - it's paltry attempt to slightly level the playing field for adults who very literally cannot get into the rooms where decisions get made.

AF, artist, Edinburgh

I get the most minimal PiP, for travel. My life and work are no longer tenable. The system fails to understand many conditions because of the nature of symptoms, such as post-exertional malaise, which are not based on motor function, but delayed impacts that endure for days. I make art to create models and forms of representation, and yet my most elementary experiences are refused representation, or support. As someone with ME and Long Covid those painful and deliberate refusals of representation have endured for 30 years now. No medicine, no medical research, no support. That two million people could have a post-viral disease and be ignored says much for the cruel nature of society and the failure of medical authorities and governments. I hope that one day that struggle would lessen. Instead it is worsening..

SM, Artist, Hull

The demeaning humiliating process of PIP is such an attack on your mental health that I'm too nervous to write about how I feel. I applied with a physical disability but have to note that the process itself is damaging to mental health.

RL, Artist, London

I have a dynamic disability that causes me severe pain and limits my mobility. In order for me to continue working as an artist I spend thousands of pounds a year on pain management treatments. The most expensive of these treatments are not offered through the NHS. I have no financial safety net or intergenerational wealth to rely on. I do this because without them, working would be impossible for me.

Applying for PiP put me through hell and the whole process made me even more unwell. However, without it I would have to give up working as an artist. There is no way I could afford the treatments I need and my health would rapidly decline as it has before.

Last year as I fought to hold onto my career, I tried to fool myself into thinking I could work full time. I made myself so unwell that I could at times barely lift my arms or walk. It’s beyond degrading whilst this is your reality to have to fight so hard to get support. And I know countless other disabled artists who should be getting PiP and don’t because of how inaccessible and traumatising the whole process is.

DA artist Manchester

I fail to see how sending a disabled person to court to have their disability needs approved is in any way humanistic. This is what was needed to get my pip. Completely broke me. Cutting off my pip last time left me in shock shaking and in a an e. Coz I thought I was having a seizure, I didn't know what was happening. Now my pip is being reviewed which has been going on for over a year now, which means at any time my support could be lost. MS is making life increasingly more difficult, coupled with autism I am planning a future which will require increasingly more support, how can I plan for this if the there is no safety net which pip provides, I don't know what my artistic life will be i don't know what I'll be able to afford. If I can't pay for support/taxis etc it will be more working in isolation.

SCW, Musician, Poet, Actor, Illustrator, London

I was assessed on how my autism, mental health issues and two IBD conditions affect me by a physiotherapist. He knew nothing about disability.

Before my assessment, I had to fill in a form containing several pages of invasive personal questions about if I could dress myself, wash myself etc but no questions about communicating with people, mental health or IBD. The assessor/physiotherapist asked similarly invasive and private questions.

When I got my letter with the decision of this assessor/physiotherapist, it was clear that he was holding any positive thing about me against me in order to disqualify me from getting the support I was supposed to be entitled to my whole life. He thought that me being intelligent meant I couldn’t really be disabled; as if being clever means you don’t face challenges like being bullied, turned down for job interviews and excluded from social and romantic situations because you seem weird, don’t make eye contact, don’t do well in social situations and so on.

I was given a few points for my social anxiety in the point based system that determines if you are entitled to the support you need to survive, but was given no other points and the support that was necessary for me to survive since I was a child was taken away.

Anon, Illustrator, Hull

I’m a chronically ill artist from Hull who is in the process of applying for PIP. I am currently on LCWRA and have been for years, this includes a payment of £416 a month, this money alone is not enough to support a disabled person. The Green Paper proposes putting this money further out of reach by putting it behind the barrier of a successful PIP application. The process of applying for LCWRA is similar to applying for PIP but is slightly less invasive. The government is aware that PIP has a high rejection rate, they are hiding behind the guise of “making it easier by fusing the two processes together so only one application needs to be done” but instead want to put monetary support further out of reach of disabled people and behind the invasive, degrading and dehumanising process of PIP application, assessment, reassessments and appeals.

I am terrified to apply for PIP and have been putting off the process for 5+ years due to the horror stories from my disabled peers, fear of rejection and the anticipation of the mental toll it’ll take on me. Chronically ill people, like myself, already deal with an immense amount of skepticism from medical professionals and peers, which takes huge amounts of mental strength to deflect and remain a steadfast advocate for our health and well-being. The process of applying to PIP follows the same narrative: that disabled people are liars and can “secretly” work, and it is incredibly traumatic to have to prove to people that you are not a liar and that you in fact suffer every day, and that your suffering is worthy of help.

If I am approved for PIP, the extra money will enable me to access therapy for mental health, massages for my body pain and rejuvenation/healing, a medical device to manage fatigue and pacing, pay for petrol for my partner to drive me places that I feel unable to walk, food for when I cannot cook for myself - all of which will allow me to function better day to day and to create more art. Illustration (and the arts on a whole) is an incredibly unstable sector to work in, especially for disabled people - many jobs are freelance with no real promise of when the next job will be or what the rate will be paid at. A lot of disabled illustrators and artists are self-employed (in order to create an accessible job for themselves), which includes marketing for ourselves, applying to jobs and grants and consistently producing new work - something that is incredibly demanding of anyone but especially of disabled people. With no monetary support I’m unable to produce art at a reliable rate and thus unable to market myself, which essentially means I am getting no income. As it stands, my partner and I are suffering, we are constantly in our overdraft, my disability is completely unmanaged and I am not contributing to the household work, not creating art, I spend most of my days napping or barely moving from fatigue and brain fog and I rarely ever leave the house knowing it will cause me pain. I miss being able to walk around, see friends and socialise. I miss making art. I want to provide for myself and my partner but without support I can’t.

If the government wants disabled people to work, we need PIP to support ourselves with that. PIP is unaffected by whether someone works or not **by design** - enabling people to use the money to help them to work **if they so wish.**

PIP is so integral because it is a form of adaptive accessibility in a world that is so inaccessible. It enables disabled people to carve an accessible route and adapt through life. Unfortunately, PIP is often not only used on disabled people themselves, but in order to bridge inaccessible gaps in the outside world (like work) which drains our money further - really the government should be focussing their energy on creating concrete requirements for workplaces, transport and Britain as a whole to be accessible whilst also providing monetary support for disabled people to look after themselves - then the percentage of us that they keep quoting as “wanting to work” may actually be able to work and those who cannot should be believed and supported as the value of a person is not measured by how much money they generate.

MPH, Illustrator, Oxford

I have only been on PIP for a little over a year despite being eligible to claim for it since I was a teenager (I am now in my twenties). I never even considered it could be something I would be eligible for and applying for it took a lot of support from those around me to navigate filling out the forms and attending my consultations. It was a harrowing process that left me broken, crying, and feeling lesser more than once. I have multiple, life long chronic health conditions that have affected me since childhood and I was denied PIP all the way up to tribunal.

The reasons for denying my case were biased and extremely ableist, not to mention ignorant to my conditions. I was scored 0 for managing my treatment because I do not have depression, and therefore should have no struggle handling medication. I was scored 0 on communication because they claimed I do not have a cognitive disorder, when I do and had provided medical evidence of this diagnosis. I was scored 0 for socialising because I went to university and because I am able to talk to clients for my illustrator job. My education and my job was only possible because of accommodations put in place to aid me as a disabled individual. These accommodations do not eradicate my conditions or erase the difficulties I face in everyday life.

It was incredibly clear that the DWP did not sufficiently read my case nor compare it correctly to their own guidelines. Instead they made decisions based on assumptions and biased opinions that somehow both demonise and belittle very common health conditions all at the same time.

I am unable to work full time due to chronic pain and fatigue that leave me confused, exhausted, and prone to fainting. I have worked part time in the past and it was ruthless on my body and my health, leading to further conditions developing and worsening of my health (especially because many work places do not properly accommodate, or straight up discriminate against disabled employees). My art allows me to work at a pace that supports my health, whilst also giving me a semblance of financial independence but without PIP I would be destitute. My PIP has been vital for paying for my private therapies (£100-200 a month on therapy, £200+ a month on private physio) not to mention covering the costs of mobility aids and medication. Without PIP, I would not have been able to purchase a wheelchair that allows me more freedom and the ability to stay out all day without crashing.

Losing my PIP would leave me a financial burden on my retiring parents and likely worse off health wise as I would have to push myself to take on more work and leave less time to rest and recover between projects. Having PIP ***keeps*** me in work, without it, I would likely fall back to being unemployed.

Anon, Artist, Durham

I have been on PIP for roughly 3 years now and claim the minimum allowance due to mental health struggles which I have had for 13 years. I have since suffered from chronic pain, fatigue, brain fog, insomnia resulting in a recent diagnosis of fibromyalgia. I am currently waiting on a review form to update my PIP with the latest diagnosis and new evidence to see if I can get some more help.

Having PIP originally helped me to go back into working (before the chronic pain got bad) as it helped to relieve some of the pressure surrounding how many hours I was working. This meant I was able to work part time which seemed to suit me quite well and the PIP payment helped to cover whatever my wages wouldn't.

I had to give up my job due to the fibromyalgia and all of the symptoms it causes and despite the fact that I would love to be working I haven't yet found something suitable and my condition and symptoms are not yet stable. Without PIP I would probably be in severe debt or possibly worse and I'm scared at the idea of losing it. Being able to get a bit more help could mean that I'm able to pay for things such as private therapy and physiotherapy so that I can learn to manage my symptoms quicker as the NHS waiting lists for these treatments are ridiculously long.

LC, Artist, North Yorkshire

I was diagnosed with Bipolar Disorder in 2012 when I was 20 and was dangerously unwell and unable to hold down a job plus had to have multiple hospital stays over the years. I have since been diagnosed with other things such as PTSD, OCD and BPD. Any job I had exacerbated all my symptoms and I would experience psychosis and have to move back home for months/years at a time. I was just managing to exist. I felt terrified of applying for a PIP and not worthy due to the stigma.

I finally applied 5 years later and I had to wait 10 months for an interview. By the time I was called for my interview I was once again in hospital with psychosis. I was given permission to leave the psychiatric unit with my Mum to go to the interview where the staff working there was so appalled by my appearance he refused to interview me. I begged him to as I was so anxious I would have to wait months again. He asked me how my “illness impacted my life” as I sat slumped on a chair sedated and covered in bandages. I was awarded my PIP a few weeks later but the whole process was traumatic.

My psychiatrist doesn’t want me to work as he thinks it’s destabilises me. But I now have a job, one day a week with an amazing mental health charity who are so accommodating that I manage . Not everyone has that luxury and I wouldn’t cope working anywhere else. The PIP process feels so shaming and difficult anyway and I’m terrified the stigma and difficulty it going to get worse. Trust me if I was able to work full time I’d chose that over living my disabilities any day.

Anon: Comedian & Writer, Bath.

According to the DWP’s own figures the rate of overpayment of PIP is only 0.4%, Kendall’s argument that it is being overhauled to expose those fraudulently claiming PIP is clearly a way of covering their true motives which is to attack the most vulnerable in society. According to the trussell trust 2 in 3 disabled people face hunger. This will only go up due to the changes in the benefits system. The thing that is most disturbing about all of this is that it is undeniable that we as disabled people are seen by all political parties as sub-human and something to be ignored and kept away from power. If the Government had any backbone they would introduce the proposed wealth tax, which would bring in 24 Billion which dwarfs the 5 billion they would save with these changes. On a global financial scale 5 billion is nothing, and yet the damage it will do to millions of lifes is catastrophic. This is a choice that this government has taken, for fear of angering the super rich. This shows the opinion and priorities of those in power - to look after their own interests. In the last year UK billionaires added £182,000,000,000 to their wealth, leaving them with a combined wealth of £795,361,000,000. They can afford the wealth tax, those of us that are on PIP cannot.

Throughout our history we have never been consulted on any of the policies that affect us most acutely, if this were to be the case with any other marginalised group there would be public uproar, but we are silenced. There is only one thing that I agree with Reeves about regarding the benefits system; it is not fit for purpose. But it is not fit for purpose because it completely dehumanises everyone that goes through the assessment process. I had my PIP removed while in hospital receiving life saving brain and heart surgery. I was on a Neuro ward for 5 months, and yet it took me 2 and half years to regain my PIP. that is a process I cannot face again, my mental health is hanging by a thread, I have been suicidal at many points in my life due to the nature of the way I and others are treated by the DWP. My renewal is due and I am having daily panic attacks due to the mind numbing fear of what will happen to my life without PIP. I am barely making ends meet as it is, and would be on the street if it weren't for family and friends. The fact that I even need to be reassessed is laughable because I have Cerebral Palsy and Hydrocephalus, both of which are incurable and degenerative. Yet when assessed, the person doing the assessment did not know what Hydrocephalus is. How is that fit for purpose? These people hold complete power over our ability to access the benefits that give us even a slim chance at the life we deserve, yet they don't have the expertise or compassion that make them fit to do their jobs. This system is completely broken, but not in the way that Reeves suggests

Lauren, Aspiring Artist, Wirral

I was diagnosed with Schizoaffective Disorder in 2013 after an initial psychotic break in early 2011 when I was 19. I have had numerous relapses along the way.

I have had countless jobs since I was first diagnosed but for one reason or another nothing stuck and I am currently out of work again. I find work in general to be too stressful to cope with as they expect far too much and aren't empathetic, you're just another number. I even struggle with workplace politics and where I fall within the hierarchy of the team, I feel like the new girl at school who doesn't quite belong and I'm always on the periphery.

I feel like I'm not living my life to the fullest and I'm settled in my comfort zone but it's hard for me because when I do try and venture out I get constant knock backs which affect my confidence and set me back further. I do feel like I don't quite fit in and I believe this is because I have a mental health condition which isolates me. I've lost friends along the way who were ignorant and couldn't comprehend my condition so I am wary of trusting people for fear of getting hurt.

I applied for PIP in 2017 during a particularly bad relapse where I was hospitalised again. Prior to this I had no knowledge that I could even apply for a disability benefit so for the first 6 years I didn’t receive any help. This needs to change as more people should be educated about what they are entitled to receive. I stayed on PIP until around 2023 when they reassessed me and decided I was no longer eligible to receive extra help. I appealed this decision, it was a long winded process which took around a year to be sorted out, I am now receiving PIP again on a lower rate but the entire tribunal process was so humiliating and I was made to feel ashamed of my diagnosis under suspicious questions. I found the whole process very triggering to be asked such invasive questions and not long afterwards I did go through a blip because of it. A girl who had been interviewed before me came out of the court room in tears, I think it was of relief. No one should be made to feel that way.

I very much came out of the tribunal room feeling as though my mental health was in my mind and didn’t really exist, I feel this way when Labour have chosen to reduce PIP payments for disabled people as it makes me feel that it just isn’t very important and that we are more of a hindrance to the budget if anything. It just shows me that society still doesn’t fully comprehend psychiatric illnesses and disorders, there is still taboo and stigma associated with mental health however much people want to label perception as more progressive now. I hope one day that we will be treated with the respect we deserve, because I truly feel that we are more empathic, sensitive and creative and therefore have a lot to contribute to society.

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BMV, Artist, Kent

I have been chronically ill with ME/CFS since I was about 13, I am 38 now. I have been in receipt of disability benefits since I was about 16 and have experienced previous, similar ‘reforms’ and benefit rebranding, all contributing to the profound and overwhelming stress I experience surrounding having to claim them.

Initially, I was awarded DLA (the precursor to PIP) with the help of my carer (my mum) and a really dedicated CAB representative who helped us through the absolute quagmire of a form that required endless numerical ratings of how many repetitions of which movements you could do on specific days. I experience periods of weeks and months at a time where I am bedbound, yet I can appear ‘normal’ on a good day, in a good hour, in a good moment. You do not get an understanding of my health in an assessment situation, through judging my outward appearance in the space of one meeting or in the context of the forms. My carer and I could not have adequately filled the form in without help and the assessment process was incredibly traumatic. Thanks to the CAB support I had, I was awarded DLA and Incapacity benefit (precursor to ESA and now UC), until the coalition government rejected my claim in around 2012 under another ‘reform’. I began the appeals process, still bedbound for much of the time, and even with the support of my carer and occupational therapist as a court representative the profound stress exacerbated my condition to the point where I became too ill to go through with the appeal. If this is the effect it had on me with the support of professionals and a carer, I cannot imagine how anyone can do this alone. Being doubted and judged when you are too weak to walk, be around people, to handle light or sound, get dressed or wash is awful but to be expected to undergo a court tribunal in this state is absolutely horrendous.

In the wake of this, my family managed to supplement my financial situation for the interim years, despite the fact that I was too disabled to work and entitled to DLA/PIP. When they could no longer afford to financially support me, I requested the PIP forms several times to re enter the claims process, but even the envelopes arriving in the post made me sick with terror. During this time, without DLA/PIP, on Incapacity Benefit and subsequently ESA, I was treated like a job seeker, and pulled into the job centre every two weeks. I was so unwell, this was the only thing I was able to do- get a taxi to the job centre and taxi back to bed for two weeks until the next one where I was patronised, scrutinised and doubted, and pressured into enterprise schemes that would funnel me off those benefits. It was only in 2022 I was finally awarded PIP with the help of a welfare campaigner, who supported me through everything. I had to pay for this service. I had panic attacks, I wasn’t able to do anything else other than the PIP application for those months as it used all of my energy and I only felt recovered from the assessment two years after I was awarded it. I am due for my PIP claim reappraisal this September.

PIP absolutely needs reforming, its culture is hostile and willfully ignorant of the majority of health conditions and sick people’s needs and, as such, necessitates having to *fight* for your award (and the validity of your ill health), which requires a level of physical and mental endurance that is additionally crippling. PIP needs to account for a much wider range of conditions, particularly long term energy limiting chronic illnesses; the metrics of eligibility criteria are bizarrely specific and tied to a handful of ailments. The generic letters the DWP generate and send as their only form of communication are cryptic and often leave me confused as to why they have been sent and DWP phone waiting times are shocking. The criteria and assessors measure your needs in terms of what you can manage if pushed to extremes rather than what you need in order to help you in order to manage meeting the deficit of access in society. The core stance should be one of inclusion and care, not of ‘guilty until proven innocent’. These are the reforms that should be being discussed, not the government’s current plans which will make the traumatic and hostile aspects of PIP more entrenched.

The idea that these benefits have been ‘too easy’ to get and that anyone would go through the process in all but dire circumstances is ridiculous and promulgating the rhetoric that disabled people are ‘trapped in a lifetime of benefits’ is obscene. Disabled people are more frequently trapped *out* of welfare and our survival is dependent on them.

My experience as a chronically ill person with an energy limiting condition is one of profound loss at not being able to do the work I love. PIP and ESA is the only reason I am able to do small amounts of flexible self employment. The suggestion that these benefits inhibit my will or ability to work is offensive and in absolute violation of the clear facts of my experience and situation.

Anon, Liverpool.
While I would qualify for PIP due to my disability, I have never applied. I don't have the energy to potentially have to fight for what I should be entitled to. I work a full time government based job as well as pursuing art alongside and have worked paying tax for over 20 years. Throughout this time I have relied partly on benefits and some time without.

Recently, however, I applied for PIP for my disabled child and hoped by providing them with the lifelong hospitalisations and treatment would prove a fairly simple process and outcome despite horror stories. I thought with a well-written application and reams of evidence, we should be able to prove that she is both entitled to and in desperate need of financial support to live independently. However after a horrendous experience at assessment when the assessor asked if her lifelong well documented neurological condition ‘would get better as she got older’, traumatising a vulnerable young person by repeatedly asked her what would happen if she became lost and being told we had provided no evidence to receive any points at all I am now in the process of beginning a fight. I have had to fight for services her entire life and i’m exhausted. Why does it have to be like this? This may further disable me having to go through this process. I had little trust in the system and now I have nothing but distrust and fear. The fear that after applying for something we would both be able to achieve by design then having the bar moved higher is completely devastating. If we get through the tribunal process to be awarded will it then be stripped from us due to changes we had no idea of when applying.

Alongside this, my elderly parent was recently awarded and has made changes to her life which make her entirely reliant on the tiny income she receives from PIP. If this is stripped from her, who takes on that financial burden. Is it me as her only child? I'm drowning already.

GG, artist/writer/poet, London

For many years I was made to believe that PIP was only for physical disabilities.
I have long term serious mental illness since a teenager (I am now in my late 40's)

Finally with more information I made an application alone and with no support, my form was half filled and I was called for an interview.
I was out in a room with 2 men they closed the door and proceeded to ask me to twirl a hula hoop around my body, on my form it stayed I have complex severe trauma from both childhood and adult abuse, I became very disturbed and shouted and asked "why are you doing this?" and run out the building.

It took me a further 8 years, in which my health deteriorated I had further physical health conditions as well,causing me to struggle with daily tasks like washing,cooking and independent travel.

A charity supported me with my application and I was granted PIP which enabled me to take on part time work and spend more time with my children and friends gratefully added to my quality of life.
Last year my PIP was increased as my health has deteriorated and I now can access specialist therapy which is not available on the NHS and without a doubt this support has saved my life.

I am an artist, writer and poet and work part time from home for the NHS, helping to advocate for my fellow service users, as we are now called.

I write for a homeless magazine for free and sometimes my artwork is shown in libraries.
I speak about my experiences of homelessness, domestic violence and my health.
Art heals and soothes in a fractious world and I am proud to say people have told me my work has given them hope as they have felt seen in my work.
I need PIPS support on days I am too unwell to get out of bed so that on my better days I can create art and share with the world

I am currently under a mental health team and as well have numerous physical medical appointments and am able to use my PIP for taxis for myself and my carer and coffees and sandwiches for long exhausting days involving body being prodded and poked and multiple questions about my disturbed mind.

Because the NHS is so fractured, I get no support other than prescriptions. My financial support from PIP is my lifeline to access transport needs, food when I am unable to cook and the therapy I've been recommended for over 30 years.
I am terrified all of this will be removed and there is nothing else.

Anonymous, 30, Midlands. Musician and Producer

Since leaving school at 14 after being diagnosed with M.E., participating in the 'normal' world has been a struggle for me. After exiting an environment ill-equipped to care for students with special care needs and access requirements, I was given the lifeline of attending a local outpatient classroom at the hospital twice a week. Though not perfect itself - teachers were not qualified to teach me some subjects, and I largely taught myself the skills required for my Maths and English GCSEs straight from textbooks, the periodic manila envelopes from the school rarely enough.

The GCSEs were sat in my teacher's office, as a baby was screaming in the courtyard below and kids in the classroom (which catered to students of primary and secondary ages) shouted to one another. It was purely down to my determination that I got A and A* for these exams. Not the support of people who should have been caring for and championing someone who clearly had the potential to succeed. It was the first of many times I was let down by a system which - apart from exceptions I will never forget and remain grateful for - never told me that it was OK to be ill and that I was doing well for my circumstances.

The attitude from the very beginning, when it wasn't assumed I was lying about my condition, was that I should be trying harder and pushing forward. Moulding myself to fit into places which weren't designed for me. Pushing my body beyond its limits in hospital gym sessions, my pleas that I was tired were not accepted. When I took an A-level via distance learning, the comments from my occupational therapists were not "well done" but rather "why couldn't you take it at college?" Never once was I given permission to be hurting or upset or struggling. It was about pushing me into studying and working as soon as possible, something I forced myself to do and had to fight for. After years of rejected applications, enquiries and a lack of knowledge as to whether part time apprenticeships were even possible or allowed, I finally managed to land one with my local council. I worked 10-3pm, and on my first day, I cried when I got home because I was so overwhelmed. I couldn't face the fact I might have to do this 5 days a week, indefinitely.

But I internalised that upset as simply myself not being strong enough or needing to adapt further. I pushed myself into the apprenticeship, and for a short while, it went ok. Until it wasn't. After a few months, I suddenly began to get extremely anxious about the thought of making phone calls. Rather than support me through this, I was forced into situations I would find difficult and made to transfer to a call centre, which it was hoped would desensitise me. I soon became so stressed with the whole thing that I started forgetting to eat. Visiting my M.E. specialist, I asked if I could be helped by a dietician to create a meal plan as I needed to have something to stick to. She weighed me and said I was under a threshold, which meant I had to be referred to an eating disorder clinic. I became terrified that such a referral might mean I would have to go to an inpatient facility and lose my job, and thus, I ended up developing a fear of eating in case I were sick and lost more weight. This created a vicious cycle which left me at 5 1/2 stone and having to wear size 4 trousers for work. Eventually, I went to the doctors and got prescribed Sertraline and was given a referral to the eating disorder clinic. I tried to explain that I didn't have an eating disorder; I was just extremely anxious and stressed about everything. They didn't listen, insisting once again I must be lying. So I received years of treatment as an eating disorder outpatient, before eventually a letter was sent to me upon my discharge acknowledging that I hadn't had one after all. During the acute phase of my low weight and mental health breakdown, I only recall receiving a couple of weeks off work.

One positive to the situation is that during the therapy, I happened to be diagnosed with OCD - something which went on to make sense of much of my life previously, but added further struggles. I completed the apprenticeship, regained a healthy weight and left for a new job at a marketing agency. This time, it was full-time. Here, it was much less stressful, and the good times were good. But not every day was good - some days, I was struggling with my OCD so badly that I could barely concentrate on my work. Some days, I was so tired that my eyes were physically closing at my desk, and I had to take naps on the toilet floor for however long I felt I might be able to get away with. My boss wasn't sensitive to people like me. He wanted his employees to work every second of the day and thought I needed extra supervision for taking rests. Eventually, he sat me in a position where he could see my computer screen and asked me regularly what I was working on. He had no respect for my abilities and wouldn't allow me to progress beyond minimum wage or into new areas of work. At the beginning of this job, I was receiving EMDR therapy, which required me to see my therapist weekly. I also saw other medical professionals. I was allowed this time off, until later on when I was told I couldn't have it off and had to take annual leave for my appointments instead.

One time, I had a sickness bug which left me so drained physically that I feared I might have to go to the hospital. As I was lying on my back, my boss texted me asking if I would be in the next day. I found it stifling there and simply had to leave for my own well-being. I decided to take my savings and pursue the dream I had been chasing in the background of becoming a musician. I had sung since I could remember, and music was my ultimate goal. I have now been a full-time musician for 7 years, but the industry is incredibly expensive, and I have now spent all of my savings. For the first 6 years, I made a loss, and I have had to cut down every area of my life from dying my hair to going out. I live with my parents, and my life has shrunk. I am happy with the decision I made to pursue my dream, but I now feel utterly stuck financially, as the next stage of my music career requires investment. I work around 30 hours a week on my business but earn far less than minimum wage. Some months I don't even go over £100.

I have been encouraged by friends to apply for universal credit or PIP, but I am so affected by every experience mentioned previously that I simply could not face going for an assessment. My friend whom I grew up within the hospital system, recently had to go to court. The same friend also wasn't entitled to a COVID-19 vaccine as part of a priority group during the pandemic, but her registered carer parent was. I am telling this story to highlight the myriad of ways that this country, from top to bottom, is not designed for disabled and chronically ill people. And this is BEFORE the proposed welfare cuts. As you can see, I have made every single effort I could to partake in the able-bodied world. I work incredibly hard to this day, even busking to raise extra funds, which is hard on my body.

There are millions like me. But we are suffering. Outside of music, I have little social life, and it's very hard not to be depressed and despondent about the future. I no longer receive any specialist care from the health service, and they don't even have my conditions listed in an easily visible way on my notes. We are oppressed and discriminated against on a daily basis, so to have a government we thought we might be able to trust make such a cruel move which they are comparing to cutting pocket money for teenagers and telling them to get a saturday job is disgusting. That language alone is completely patronising and out of touch. We are already traumatised. To bring in an assisted dying bill at the same time as cutting benefits is like another message to us that we are not worthy of being valued as people and citizens of this country. It is telling us that we either damage and traumatise ourselves in a system which, for the most part, doesn't understand us, or we die. That's how serious it is. I am lucky to be fairly high-functioning, but my friends are not. This is for them. Shame on the UK government for being so needlessly cruel. Supporting the war in Ukraine is vitally important, but what values are you fighting for if in your own country, you have decided to treat your most vulnerable as cruelly as an oppressor would?