Merton Centre for Independent Living

Merton Centre for Independent Living's Response to the 'Pathways to Work: Reforming Benefits and Support to Get Britain Working' Green Paper Consultation, June 2025

About Us

Merton Centre for Independent Living (Merton CIL) is a pan-disability, user-led Deaf and Disabled People's Organisation (DDPO) which has been working with Deaf and Disabled adults in the London Borough of Merton since 2008. We work with hundreds of residents every year, and have 13 members of staff, 10 trustees, 12 volunteers, and 431 members.

The definition of a DDPO is that at least 50% of staff and at least 75% of trustees are Deaf and/or Disabled, and the rationale behind the model is three-fold. Firstly, as encapsulated by the slogan 'Nothing about us without us', no policy should be decided without the direct participation of those affected by it. Secondly, lived experience is expertise that can be harnessed in ways that are of service to others. And thirdly, Deaf and Disabled people in positions of leadership bring a wealth of unique perspectives and problem-solving skills to the table.

We operate within the Social Model of Disability, which holds that disability is not an attribute of an individual, but created by societal barriers. Our overarching aim is to decrease marginalisation, isolation and inequality, and to increase inclusion, companionship and equity.

Our main offering is an AQS-accredited Information and Advice Service and a Speaking Up Service. The former provides assistance in a range of areas – welfare benefits, adult social care, housing, concessionary travel, and low income. The latter supports people to navigate healthcare services and address other factors affecting their health.

Further to this, our policy and campaigns work focuses on welfare benefits, adult social care, housing, concessionary travel, and – chiefly through a group of Disabled residents who volunteer as Access Champions – the accessibility of a variety of public services and the built environment.

Additionally, monthly Craftivism and Chat sessions aim to help people to build skills, increase confidence, and feel more connected through art and conversation.

In order to inform our response to this consultation, we have gathered – via in-person meetings, video calls, phone calls, emails, texts and WhatsApp messages – the views of staff, trustees, volunteers, members, service users, and supporters. We feel strongly, though, that it is highly undemocratic of the government to introduce the Universal Credit and Personal Independence Bill before the consultation deadline.

Reforming the Structure of the Health and Disability Benefits System

1. **What further steps could the Department for Work and Pensions take to make sure the benefit system supports people to try work without the worry that it may affect their benefit entitlement?**

Firstly, the government should drop the proposal, in the Universal Credit and Personal Independence Bill, that if a person who currently receives the Health Element stops work after six months, and then successfully reapplies for the Health Element, they will receive only £50.13 a week, not the £97.67 a week that they received before they started work, unless they meet the Service Conditions criteria. We believe that a reduction of money for people who stop work after six months would be deeply unfair. If the government thinks that a reduction will encourage people to stay in work for more than six months, they are failing to appreciate that health needs fluctuate, and that it is likely to be beyond someone's control as to whether their health worsens before or after six months of work. Indeed, the proposal is more likely to incentivise people to stop work within six months, so that they do not face the reduction should their health necessitate stopping work after six months.

Secondly, the DWP should provide every unemployed, working-age recipient of benefits with:

a. a guarantee that trying work will not automatically trigger the loss of an award, or a financial penalty, or a reassessment;
b. accessible information about what will trigger the loss of an award, or a financial penalty, or a reassessment.

Thirdly, PIP should not replace the Work Capability Assessment, as it is not an unemployment benefit and should not be positioned as one. As detailed in the answer to no. 2, it is crucial to enabling some people to buy what they need to stay well enough to work and to meet relevant access needs.

2. What support do you think we could provide for those who will lose their Personal Independence Payment

entitlement as a result of a new additional requirement to score at least 4 points on one daily living activity?

We advise the government to not change the PIP eligibility criteria in the way proposed in the Universal Credit and Personal Independence Payment Bill.

As revealed by the DWP's 15-4-25 response to an 18-3-25 Freedom of Information request, about 9 out of 10 people (87%) with a Standard Rate Daily Living award, and about 1 in 10 people (13%) with an Enhanced Rate Daily Living award do not score at least four points for one of the descriptors, meaning that they stand to lose at their next review, respectively, £73.90 a week (£3842.80 a year) and £110.40 a week (£5740.80 a year). This will have a negative impact in four main ways.

Firstly, it will exacerbate existing financial difficulties, as analysis by the Joseph Rowntree Association shows that Disabled people are more likely to live in poverty than non-Disabled people, and The Trussell Trust reports that a growing number of Disabled households are facing hunger and hardship. Indeed, it is crucial to note that Scope's research demonstrates that on average, Disabled households need an additional £1095 a month to have the same standard of living as non-Disabled households, as the former is more likely than the latter to have to pay for aids and adaptations in the home, above-average energy bills, mobility aids, taxis, personal assistants, carers, therapies unavailable on the NHS, certain products to maintain personal hygiene, particular items needed because of dietary requirements, specialist clothing, and so on.

Secondly, it has the potential to result in some Disabled people having to give up work, as PIP can be crucial to enabling them to buy what they need to stay well enough to work and to meet relevant access needs. The Office for Budget Responsibility has found that around one-sixth of recipients of PIP are in work, and whilst we do not have access to data showing how many of them are at risk of losing their Daily Living award should the new rule suggested by the government be implemented, we hope that the government would agree that limiting anyone's ability to work runs counter to their aim to increase employment.

Thirdly, it may lead to the loss of: Carer's Allowance, since a PIP Daily Living award is one of the benefits that entitles a person's carer to apply for it; a Council Tax reduction; free or discounted travel on public transport; and free or discounted entrance to attractions and events.

Fourthly, decreasing the chances that Disabled people will be able to afford the essentials will push some into financial crisis, worsen health outcomes, and create a surge in demand for help from an already strained NHS and adult social care system.

We believe that PIP urgently needs reform, but not by changing the eligibility criteria in the way proposed. The government should seek, instead, to review both the assessment process and the review process to make them simpler, less rigid, and more humane – especially for people with hidden disabilities, people with mental health problems, people with fluctuating health needs, and people awaiting a diagnosis from the NHS. The current system creates enormous stress for people by making them detail their difficulties both on paper and either in person or over the phone, with no guarantee that the assessors are specialists in their particular needs or trained in trauma-informed communication. And on top of the fear that they may have to challenge the DWP's decision, this can be too much to bear. Furthermore, the consistently high rate of HMCTS overturning the DWP's decisions and finding in favour of claimants speaks for itself.

We have fed into The Commission on Social Security's work entitled 'Designing an Additional Costs Disability Payment (PIP Replacement)', and urge the government to collaborate with this body.

At the time of writing, there is a rumour that the proposed change to the PIP eligibility criteria may apply to new claimants only. We object to this because it would create an unfair two-tier system which would see people with the same needs receiving different amounts of income.

3. How could we improve the experience of the health and care system for people who are claiming Personal Independence Payment who would lose entitlement?

As stated in our answer to no. 2, we advise the government to not change the PIP eligibility criteria in the way proposed in the Universal Credit and Personal Independence Payment Bill, and we maintain that if they do, they should expect a surge in demand for help from an already strained NHS and adult social care system.

We would also like to point out that losing entitlement to PIP and being pushed into the adult social care system would deny people of the relative autonomy allowed by a PIP award. Income from PIP helps people to have more choice in and control over their lives, including taking proactive measures which prevent deterioration. The adult social care system, in its current form, does not. Our experience is that a person is usually found eligible for a care package only if they are unable to feed, drink, wash, go to toilet, dress/undress, and get in/out of bed by themselves – which is not compliant with the Care Act 2014, but happening because the system is massively under-resourced – and receipt of a care package is subject to strict means-testing. Indeed, adult social care services in our borough frequently find people ineligible for a care package and advise them to use their income from PIP to pay people privately and/or buy items to help them to meet their needs.

4. How could we introduce a new Unemployment Insurance, how long should it last for and what support should be provided during this time to support people to adjust to changes in their life and get back into work?

The proposal to replace New Style Employment and Support Allowance and New Style Job Seeker’s Allowance with one new time-limited Unemployment Insurance benefit which would see

> ‘almost all disabled people and people with long-term health conditions receiving the new contributory benefit … required, as a minimum, to participate in conversations as part of a new offer of tailored employment support with appropriate exemptions’

is too vague for us to comment on. If the government is more specific about the time limit, support, and exemptions that they envisage, we will be able to submit useful feedback.

5. What practical steps could we take to improve our current approach to safeguarding people who use our services?

We are pleased that the government wants to ‘conduct a thorough review of … current processes and work with stakeholders to identify areas for improvement’, ‘then develop and implement a new departmental wide approach to safeguarding’, and ‘publish this new approach to provide clarity on what the department does.’ Likewise, we applaud the government’s aim to ‘build trust through being more transparent.’ Several bodies and individuals outside of the DWP have conducted research into the ways in which services, in their current form, harm Disabled people. However, there has, hitherto, been no indication that the DWP has looked at the findings and recommendations, or plans to do so.

We ask that people on the receiving end of the services, and DDPOs, DPOs (Disabled People’s Organisations), and other bodies who help people to navigate the services, are included as stakeholders. And we request that co-production with these stakeholders is embedded in the initial evaluation, subsequent revision, and ongoing evaluation of safeguarding policies and procedures.

Supporting People to Thrive: Our New Support Offer

6. How should the support conversation be designed and delivered so that it is welcomed by individuals and is effective?

We welcome the government's: intention to personalise support; recognition that what is appropriate in terms of timing, location, and format will vary from person to person; and appreciation that 'the support needs of disabled people … are varied and complex.'

We think that in order for Disabled people to feel safe to engage in the support conversation, it should:

a. not be one of the conditions of receiving a benefit, as positioning it as part of the eligibility criteria is likely to generate fear about the loss of income and thereby inhibit a frank discussion;
b. be with someone possessing specialist knowledge of disability and trained in trauma-informed communication;
c. allow the Disabled person to bring a trusted person into the process to support them, if that would be helpful;
d. involve meaningful follow-up, not signposting that simply passes responsibility to other bodies.

We urge the government to co-design the support conversation with Disabled people, DDPOs and DPOs.

7. **How should we design and deliver conversations to people who currently receive no or little contact, so that they are most effective?**

Please see our answer to no. 6.

Supporting People to Thrive: a New Baseline Expectation of Engagement

8. **How we should determine who is subject to a requirement only to participate in conversations, or work preparation activity rather than the stronger requirements placed on people in the Intensive Work Search regime.**

The criteria used to separate Disabled people into the different groups should be flexible enough to:

a. take into account individual circumstances, as broad categories will inevitably lead to incorrect assumptions about capability;
b. allow for movement between the different groups to happen without penalty, in order to account for fluctuating health needs.

The system should err on the side of caution and trust that Disabled people are being honest about self-reported limitations not captured in standardised assessments.

A Disabled person should never be put into the Intensive Work Search group without a detailed exploration of how this would affect their health, safety, and family life.

Robust safeguarding must be embedded to ensure that an independent review is triggered if a Disabled person is at risk of harm because of expectations placed upon them by the DWP.

9. **Should we require most people to participate in a support conversation as a condition of receipt of their full benefit award or of the health element in Universal Credit?**

   No. Please see our answer to no. 6.

10. **How should we determine which individuals or groups of individuals should be exempt from requirements?**

    The government should automatically exempt people who are: terminally ill; undergoing intensive treatment; in hospital; have recently been hospitalised; are in a period of recovery.

Supporting People to Thrive: Delaying Payment of the Health Element of Universal Credit

11. **Should we delay access to the health element of Universal Credit within the reformed system until someone is aged 22?**

    No. To introduce an arbitrary age threshold would be discriminatory and counterproductive.

    Whilst we understand that the proposal is underpinned by the government's aim to establish a 'Youth Guarantee' that will see all 18-21 year olds 'learning or earning', we suspect that the government is inaccurately assuming that a Disabled person under the age of 22:

    a. will be able to engage with a scheme which has not yet even been designed;
    b. can never have the same health needs as a Disabled person aged 22 or above;

c. is receiving enough financial support from their family and/or other sources to not need the income provided by the Health Element.

Cutting or delaying access to financial support when Disabled people are transitioning into adulthood will undermine movement from dependence to independence.

Supporting People to Thrive: Raising the Age at Which Young People Start Claiming Adult Disability Benefits

12. Do you think 18 is the right age for young people to start claiming the adult disability benefit, Personal Independence Payment? If not, what age do you think it should be?

So long as Disabled people are allowed to claim Disabled Living Allowance until they reach their 18th birthday, we support the proposal to ‘better align the age at which young people first claim adult disability benefits with other key milestones in the transition to adulthood and support available.’

Supporting Employers and Making Work Accessible

13. How can we support and ensure employers, including Small and Medium Sized Enterprises, to know what workplace adjustments they can make to help employees with a disability or health condition?

The government should:

a. ensure that all employers are aware of their duties under the Equality Act 2010;
b. set up a hub that enables employers to share and learn from real-world examples of good practice;

c. fund DDPOs and DPOs to deploy their specialist knowledge to support other employers;
d. improve Access to Work (please see our answer to no. 15);
e. increase awareness of Access to Work amongst employers;
f. provide relevant HR advice to employers as and when it is required.

14. What should DWP directly fund for both employers and individuals to maximise the impact of a future Access to Work and reach as many people as possible?

Please see our answer to no. 13 and our answer to no. 15.

15. What do you think the future role and design of Access to Work should be?

In its current form, Access to Work is not fit for purpose in numerous ways. This needs to be addressed urgently and before any changes to the benefits system are considered:

a. The option of pre-employment support should be introduced, as some Disabled people would benefit from support to submit job applications and attend interviews.
b. The option of a trial period should be introduced, as it is not always possible for an applicant to know before they start a job exactly what support they will need.
c. Measures should be taken to ensure that the system supports adequately jobs that fall outside of the traditional 9-5 model, hybrid working, and freelancing.
d. The requirements and different stages of the application process should be made clearer.
e. Applications, reviews and requests for reconsideration should be handled in a timely manner. Disability News Service discovered that at the end of February, 62,000 applications

were still waiting to be processed, the average processing time for new applications was 84.6 days, and the average waiting time for a request to be reconsidered was 96.9 days. This is an unacceptable state of affairs, as it leads to Disabled people being unable to do their job to the best of their ability, perhaps facing demotion or job loss as a result, and makes it harder for employers to consider or commit to employing Disabled people. Such uncertainty for not only employees and their employers, but also job applicants and their potential employers, is deleterious.

f. It should not be the case that an application is likely to be more successful and dealt with more quickly if a Disabled employee's manager is involved in the process.
g. Every applicant/recipient should have one case manager, as the involvement of multiple case managers makes processes slow and disjointed.
h. Every case manager should have specialist knowledge of disability and be trained in trauma-informed communication.
i. Training on the needs of neurodivergent people should be improved, as a lack of understanding on the part of case managers makes it hard to get support in place.
j. The tailoring of support to meet individual needs should be enhanced. Unfortunately, a one-size-fits-all approach from case managers is all too common.
k. Case managers should never state or intimate that a Disabled person's support worker is doing the job for the Disabled person. To suggest that a Disabled person who requires a support worker is surplus to requirements is discriminatory.
l. Payments for equipment, transport, support workers, BSL interpreters, and so on should be made on time. Late payments make it difficult or, indeed, impossible for Disabled people to pay for what they need to be able to do their job to the best of their ability, which can, in turn, lead to debt,

demotion, and job loss, as well as create massive precarity for support workers and BSL interpreters.

m. The phone line should be more efficient and other methods of communication, introduced. It is not unusual to wait for about 45 minutes to speak to someone. Perhaps an online journal, like that for Universal Credit, would help.
n. All administrative processes should be streamlined, as they are burdensome and thereby use up time and energy that employees and employers should be spending on core responsibilities.
o. DDPOs and DPOs should be funded to deploy their specialist knowledge to help to revamp Access to Work and to support other employers.

16. How can we better define and utilise the various roles of Access to Work, the Health and Safety Executive, Advisory, Conciliation and Arbitration Service and the Equalities and Human Rights Commission to achieve a cultural shift in employer awareness and action on workplace adjustments?

The four bodies could work together on joint campaigns.

17. What should be the future delivery model for the future of Access to Work?

Please see our answer to no. 15.

Other

18. Which of the following best describes how you are responding to this consultation?

On behalf of an interested charity or other representative organisation

19. Do you consider yourself to have a health condition or a disability?

Prefer not to say

20. Do you live in England, Northern Ireland, Scotland or Wales?

England