Chapter 2: 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?

We fully support an individual being able to freely try work without a reassessment being triggered.

It is vital that 'work' opportunities identified in advisor/claimant discussions are realistic and are suited to the needs of the individual. For trust in the system to be rebuilt, individuals need to be trusted themselves by DWP advisors. Within the Access to Work Scheme and beyond, the individual should be shown respect, and it must be acknowledged that in many cases they are likely to be best placed to describe their own support needs.

We understand that within the current system an individual is able to try a role for a fixed period of time with some reassurance that they will be able to return to receiving benefits if the role does not work out. We advocate for a personalised approach which acknowledges that health conditions can fluctuate greatly. A standardised fixed period for all may also have a counter-intuitive effect, by applying pressure to the individual and exacerbating their condition and mental health as a result.

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 four points on one daily living activity?

Our members are gravely concerned that losing PIP entitlement will in many cases have a knock-on effect in terms of eligibility for other benefits claimed. Partly for this reason, we’d like to emphasise the need for the news of losing entitlement to be communicated in a clear and comprehensive manner.

We would like to highlight the need for the message to be delivered with empathy and we advocate for a conversation with a professional to be scheduled, rather than the news being delivered digitally. Counselling services need to be available for those who are no longer eligible, since this likely to have a dramatic effect on the claimant’s life.

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?

It was difficult for our members to comment on this question, since there is a strong opposition to the changes due to be implemented. The consensus is that the changes proposed in the Green Paper couldn't possibly be delivered ahead of significant improvements in the health and social care provision in the UK. Improvements will require both investment and time. Introducing the proposed Welfare changes at this stage will cause excessive disruption and stress and will leave hundreds of thousands exposed to poverty.

Insufficient consideration shown to the role of carers in these decisions is a major concern. Our members question how carers would be funded if PIP entitlement is lost. Reassurance is needed regarding the wider impact for a household, such as loss of funding for carers and access to housing benefit. The alternative is debt and loss of independence for many.

In direct response to the question, there needs to be an effective appeals process for those who initially lose their entitlement. One of our members had appealed a PIP result previously and this process had taken a year, within which time they were forced to borrow additional funds to cover their costs. Cases need to be dealt with promptly to minimise the amount of debt incurred by the individual and limit stress.

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?

We are unconvinced that Unemployment Insurance provides reassurance to those who will lose their PIP entitlement. If it is only available to those who have built up sufficient National Insurance contributions, then there are many scenarios where an individual would not be eligible. For example, we feel that this unfairly penalises the young.

In terms of how long it would last, this should be considered on a case-by-case basis. One of the scenarios in the Green Paper is a person recovering from cancer. There is not a fixed timeframe for this scenario and the mental health of the individual also needs to be taken into account. This is another instance where trust in the individual is essential in order to ensure people are able to trust the benefits system and DWP.

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

We'd like to emphasise the importance of ensuring the best conditions possible for personal conversations with individuals. It should be agreed with the claimant in advance where such conversations will take place and who will be present. Whether family members, carers or anyone else is present can have a significant impact on the effectiveness of the conversation and the emotional impact on the individual.

One way of providing additional safety for an individual would be to offer the option of recording key conversations, so that they could be verified by the claimant afterwards. This may have the additional benefit of ensuring oversight for professionals and disincentivising them from posing leading questions and persuading vulnerable adults. We suggest audio recordings only.

We agree with a transparent approach where individuals are able to access transcripts of conversations and medical evidence shared by health professionals. It should be acknowledged that in some scenarios carers will also need to access these.

Chapter 3: Supporting people to thrive

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

Support conversations need to be personalised. Every individual's experience is different, even if you have the same diagnosis as someone else, how it manifests itself can vary greatly.

Our members emphasised the importance of empathy when designing and delivering support conversations. Supportive conversations need to be genuinely supportive and treat individuals with respect, rather than replicating the tone of the PIP assessment which attendees found degrading, accusatory and patronising.

A mechanism for quality-testing the experience of those taking part in support conversations is needed. To rebuild trust, advisors need to be thoroughly informed about their own policies and procedures.

Our members thrive on their accessible study resources provided by The Open University. The University's free learning materials (OpenLearn) are a valuable resource that advisors can signpost in support conversations to help build confidence. The study pace is tailored to the individual and the wide array of topics include wellbeing, numeracy skills and work readiness. The employability skills modules are also likely to improve retention of employees if they move onto work.

Should an individual go on to study more intensively at the University their benefits should not be compromised as a result. Clear communication about this is essential.

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

We would like to emphasise the importance of understanding why someone has been out of contact without making assumptions. Our members question whether supportive conversations are really supportive if a person with anxiety is compelled to attend them under threat of sanctions. A flexible approach which acknowledges the challenges of an individual is paramount. Agreement needs to be reached on an appropriate frequency for support conversations to adapt to the needs of the individual.

One of our members working in healthcare expressed concern over the drastic cuts to services. This wider environment of NHS staff cuts will have an impact on carers being able to attend and support individuals. This factor needs to be taken into account when designing and delivering conversations with those who have been out of contact who require the support of a carer.

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?

Our members opposed the inappropriate use of AI to make final decisions on Intensive Work Searches and we advocate for a personalised and supportive approach. They suggested the Mental Capacity Act was a useful resource for ensuring that those with particularly high needs were exempt from participating in the stronger requirements.

There was concern about the Intensive Work Search regime. The terminology was overly daunting and threatening sanctions is an aspect that could be detrimental to the mental health of some individuals who are already in difficulty or who have anxiety. In the most severe cases this can result in people taking their own lives.

We urge you to acknowledge the specific needs of young people and the importance of being supportive and encouraging rather than accusatory. Focus group members recall feeling as if they had been put on trial in the past and made to feel guilty. This approach is degrading to anyone but is particularly inhumane when dealing with inexperienced young people.

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?

The only condition for receiving the health element of Universal Credit should be that you have a health condition or disability that affects your day-to-day life and prevents you from working. Support Conversations should be provided by default, but they should be optional rather than mandatory.

If the support is genuine, then people will receive it and will not need to be forced to attend online or in person. The pressure to take part in mandatory sessions may cause more harm than good to those with certain mental health conditions. Despite this, it is vital that sufficient resource is made available for these conversations to take place, so that there is not a waiting list.

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

A personalised approach is required, and a supportive conversation should be provided by default. It is important to become familiar with the individual but avoid making sweeping judgements from one interaction since conditions can fluctuate greatly.

For example, if someone is able to maintain composed in an interview this doesn't mean their anxiety is gone for good. Fluctuation in a health condition as well as multiple factors such as support, stress, medication and therapy changes can impact whether someone is ready to go back to work. That is why we disagree with an impersonal categorisation approach for determining which people should be exempt from requirements. DWP staff need to be well trained and experienced in order to support the most suitable decision-making regarding requirements.

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

We disagree with someone under 22 being denied the health element of Universal Credit. If children leave the care system at 18, then how can we justify leaving them without this additional support for 4 years?

This approach doesn't take into account the commitment of carers to support the young person in many cases. Even if a young person is supported by family members, their benefits payments could have been enabling family members or other carers to provide support. Retracting these funds is likely to have a knock-on effect on a household. When carers need to return to work to support the loss of income, then additional care support is needed. When carers decide to give up work because private care is now too expensive, the household may then require benefits they hadn't previously needed to support their income to ensure everyone is housed and fed.

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?

We agree that 18 is the right age for young people to start claiming adult disability benefit.

Chapter 4: 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?

We advocate for an advisory email address and helpline for employers which would be particularly valuable for time-poor SME's who have highly restricted resources. It would be highly beneficial if expert guidance could be provided in real time.

Our members highlighted that information on non-visible conditions will need to be incorporated into informative materials for employers including SMEs. This would include information on needs which go beyond equipment and technology and would acknowledge the need for flexibility when accommodating the variability of symptoms of some individuals who experience a fluctuation in concentration, pain and mental health.

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?

To incentivise employers to get involved in the Access to Work (AtW) scheme the sliding scale for employer contributions needs to be safeguarded. We also support a grant scheme for employers who take on staff who will require additional time and support to fulfil their duties.

To maximise the impact of AtW, regular check-in conversations led by the DWP with the employee to gauge their progress and identify any additional adjustments would reinforce effectiveness. We suggest an individual maintains contact with AtW advisors a year into the scheme.

What's more, effective communication between employers and the coordinators of the Access to Work scheme is also critical, as contradictory advice from each party can be distressing for the employee.

Finally, we support more effective promotion of the Health Adjustment Passport to streamline the transition from education to employment for the individual.

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

Access to Work requires a personalised and user-focused design.

Additional staff are required to ensure applications for the scheme are dealt with in a timely manner. Although we are not opposed to efficiencies being made via use of AI, human contact is still essential. There would also need to be flexibility built into the procedures to allow for alterations to claims and ensure issues are resolved quickly to increase retention.

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?

We support the idea of all the organisations named above working together and acting as a source of vital information for employers and employees. This collaboration would be beneficial for spreading awareness of workplace adjustments and ensuring a cultural shift amongst employers.

The Health and Safety Executive (HSE) are already well-known amongst employers, so they would be suitably placed to ensure employers are accountable. Spot checks and visits from the HSE would motivate organisations to fulfil their duties to a high standard. They could also remind employers of the need to carry out fire safety assessments for disabled employees and could scrutinise recruitment practices.

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

We oppose responsibility for Access to Work being devolved to local councils. Some councils are led by political parties who denounce aspects of Equality Diversity and Inclusion. Many local councils also have problematic finances. Both of these factors may result in a postcode lottery for Access to Work Schemes and reinforce inequality.

We also disagree with a private provider being used to coordinate and deliver the Access to Work scheme. This resulted in poor outcomes when it was trialled with PIP assessments. It is important to avoid relying on an organisation that is profit-led and is likely to have a less humane approach.

For Access to Work to be a success a centralised approach is required.

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

- As or 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

Appendix: Introduction from Open SU President, Natalie Baker

The Open University (OU) is the largest provider of access to Higher Education to disabled people in the UK. 38,991 students declaring a disability studied with the OU in 2023/24. As Open SU is the representative body for those students, we feel it is important that we provide a voice to these students who regularly access the benefit system and are concerned about these proposals.

Here at Open SU we support all OU students, and we regularly hear from our disabled students about the difficulties they already face within the benefit system. It is concerning to us also that there is no mention of the role of education in these proposals. Education can be transformative and open new avenues to work for disabled people. We often hear from students who have wrongly had their benefits affected or the incorrect assumption has been made that being able to study automatically means that they can work. The reform that is needed to make the benefit system work requires a multi-agency approach and with public services already stretched to breaking point there is a real concern that we will see our disabled students pushed out of education. This in turn will limit their work choices and opportunities.

One key theme that has come out of our conversations with disabled students is trust. There is currently little to no trust in the system based on the current inefficiencies and contradictions in how decisions are made when awarding benefits. Pushing ahead with these changes will be detrimental to our disabled students and their families/ support systems. The assumptions and ableist language within the green paper is concerning to our members that even with a new system very little will change in how they are treated. We urge the government to reevaluate these proposals and to take a person-centred collaborative approach to reform with disabled people in the room from the start.

We have consulted with our disabled students and officers to compile the answers to the following consultation questions.

Natalie Baker
President – Open SU