

## **Written evidence submitted by Diverse Cymru (BSW0010)**

### **Organisation Background**

Diverse Cymru is a unique Welsh charity promoting and advancing equality for all. We believe that we can work together to challenge discrimination in all its forms and create an equitable future for the people of Wales.

Diverse Cymru aims to make a real difference to people's lives through delivering services that reduce inequality and increase independence; supporting people to speak for themselves and to connect with decision makers; creating opportunities for participation and development; raising awareness of equality issues; and inspiring people to take action against inequality.

Our current services include direct payment, self directed and independent living support for both adults and children, including managed banking and software framework development; a Black, Asian, and minoritised ethnic people's mental health befriending and community support service in Cardiff and the Vale of Glamorgan; and welfare benefit, income maximisation, tribunal, and advocacy for disabled people in the Cardiff and the Vale of Glamorgan.

We produce information resources on a wide-range of equality issues. This includes information for people affected by inequality across all protected characteristic groups, and for organisations and service providers. We provide a conduit for service user voices to decision-makers throughout Wales through our engagement work; run citizen involvement projects for people from protected characteristic groups and carers; deliver equality-related research; and co-ordinate volunteer placements both with Diverse Cymru and supporting external organisations to recruit, involve and support volunteers from under-represented groups.

We provide consultancy services on integrating equality in organisations and equality impact assessments and deliver a range of equality-related training courses. We facilitate forums and groups that work on various issues, from improving access for disabled people to equality impact assessments.

This submission focuses specifically impacts on people from protected characteristic (equality) groups, particularly disabled people. It is based on the experiences of disabled people who have applied for and received PIP and ESA, in particular. We have gathered these views and experiences through engagement events, individual interviews, and surveys with people who have used our welfare benefits advocacy service, supplemented by engagement with wider people with one or more protected characteristics in Wales. We would welcome any opportunity to assist with the development of specific work programmes and actions. We are happy for our submission to this inquiry to be published and would welcome further engagement.

## **Inquiry submission**

### **Key challenges**

The current welfare benefits system is confusing and difficult to navigate for many people. This is exacerbated for disabled people, who are often having to deal with the impacts of health conditions on their lives, whilst also applying for benefits for the first time.

Many of our clients have expressed that the forms and process were so stressful and confusing that they would have given up, despite being entitled to financial support, without an advocate supporting them.

At the same time we are regularly contacted by people who live in a different area of England or Wales who need advocacy support, but cannot find any local services. There is a dearth of specialist welfare benefits advocacy. Where these services do exist, it is because of decisions by local authorities, rather than a UK-wide policy. Funding levels for advocacy support are often also so low that they do not enable advocates to undertake training and development as part of CPD or to ensure continual updates to account for new case law. Many advisors and advocates are also losing their jobs, and the sector is losing their experience and expertise, as a result of insufficient funding and being asked to do more with less in a sector which is person-centred and lean already.

The services provided by CAB in Wales and England are vital. However, these are generalist services. Many disabled people require more in-depth specialist advice and advocacy, rather than information and help filling in the form. Many require an intensive end-to-end service, with an advocate acting on their behalf and enabling clients to express their views and experiences from completing applications, through assessment, mandatory reconsideration, to appeals and tribunals. These specialist services, especially for disabled people, need to be funded and delivered in every area of Wales and the UK.

Advocacy and advice services also have to follow a complex process to be authorised to speak on a client's behalf. This involves a long time on the telephone in a queue with the client present. Linked to this the waiting time on the phone to get advice can often be over an hour, which is both expensive and stressful. Having a designated contact for each advocacy and advice organisation, and being able to email a designated person with advocacy authorisations and enquiries would speed up the process and remove complications for advocacy and advice organisations. HMCTS does have an email contact, which has significantly improved the speed and ease of contact.

The system is not flexible enough to support individuals. Some find speaking on the phone very difficult, so email and face-to-face options are vital, but not provided. People have also often found that DWP does not phone them at the time agreed.

Many clients find Universal Credit confusing and complicated. There is a lot of misinformation and a lack of high-quality advice and advocacy. Many people are also fearful that they will not be fully recognised and will lose money as disabled people if they are currently on ESA and / or PIP. Similarly people who have lost their job and are having to claim welfare benefits for the first time in their life, often in their 50s or 60s, find the process very stressful and difficult to complete. This includes a lack of digital skills or equipment for some people, but those who do have digital skills and access also experience distress and complexity barriers to applying for Universal Credit.

Additional issues with Universal Credit include the fact you cannot sign off if you are working for 3 months on part-time hours. The requirement to continue to look for full-time and better paid work whilst not receiving any Universal Credit payment, regardless of the individual's circumstances, places many people under such stress that they cannot continue to work part-time and / or their health deteriorates. There are also difficulties with people receiving the money they are entitled to if they are on zero-hour contracts. Simplifying and streamlining the system has made it more difficult for many people to get the financial support they need to cover basic costs of living.

### **Effectiveness at tackling poverty and socio-economic inequalities in Wales**

Wales has a lot of rural areas and pockets of poverty, even on the verge of the main urban areas. Combined with the lack of accessibility, frequency, and reliability of public transport this makes the system of having to attend appointments in the main urban centres for PIP or ESA assessments unsuitable for many people.

One client in the Vale of Glamorgan highlighted this issue stating that she had to travel 17 miles from a rural area for her assessment. This seems relatively local, but her condition means it was incredibly painful and difficult to attend an appointment further away.

Another issue exacerbated by rural inequalities is that the descriptors themselves are often set at such a high level that they do not enable anyone to live. One example given was that the higher rate mobility component is now unable to walk over 20 metres. Lower rate is set at 200 metres. Yet for many people the nearest bus stop is 400 to 500 metres away and the nearest shops and services are the same distance away. The criteria should reflect people's circumstances and enable people to access essential services and to live their lives.

Many clients have highlighted that the rates for ESA and PIP are not sufficient to live off. Especially given the increased costs that many disabled people face. Similar concerns have been raised in relation to Carer's Allowance, in terms of the payments not enabling carers to live. Many carers have found themselves having to choose between eating and heating, despite saving public services thousands of pounds per year through the unpaid care and support they provide. There also needs to be a level of Carer's Allowance for people who are caring for a friend or family member for

less than 35 hours a week. The impact on an individual's ability to work full-time and income by providing care should be recognised and compensated for by the welfare benefits system.

### **Impacts of COVID-19**

Many people have found the assessment processes during COVID-19 difficult or impossible. Many disabled people face significant access barriers to completing online tasks and to emails. Online assessments have made the process easier for some people to access and attend. However, for others, online assessments are difficult or impossible, as they need the face-to-face interaction.

Similarly the online process does not allow people to download and complete PIP or ESA forms. For many disabled people this presents barriers in terms of being able to understand, complete and check the forms, and in terms of digital exclusion and inaccessibility. These barriers already exist in the system, but have been exacerbated by a digital only approach during COVID-19. Additionally this has prevented advocates being able to effectively support people to complete application processes, as the forms cannot be downloaded and shared with advocates.

One client had experience of being telephoned with no notice and being told that they had to have their assessment over the telephone at that moment. They had already submitted evidence on why they cannot have a telephone assessment, and needed an online video assessment. The assessor was not accepting their inability to have a telephone assessment, due to anxiety to the extent of not being able to think and answer questions on the telephone. It took an advocate making representations to DWP for the client to be allowed a video assessment. Even then there were technical issues on the DWP side, which resulted in the advocate not being able to join the call, and the call being dropped repeatedly. The assessment was postponed. This happened 3 times before DWP cancelled and reverted to assessing based on the medical evidence submitted, with additional evidence sought from the individual's specialist. This resulted in an appropriate award.

This experience highlights both the need for the system to account for individual barriers to different assessment methods and communication methods and that some assessments are not needed, as the medical evidence could be sufficient.

There are also issues in relation to those that could access online processes not having the confidence or digital skills to be able to do so, whilst many also do not have access to IT or the internet. This indicates a need for providing IT and for digital training to be funded and put in place for individuals as part of the system.

In future having options for video or telephone assessments would be useful, but individuals must also be able to choose face-to-face assessment, including requesting an assessment in their own home.

Another key issue has been the fact that the £20 uplift to Universal Credit has been vital to enabling people to make ends meet. This indicates existing issues with the

levels of benefit payments. Many people who have lost their jobs during COVID-19 are extremely worried about how they will afford to survive after the uplift ends. Simultaneously people in receipt of ESA did not receive this uplift, which has left many struggling to cover their costs.

### **Welsh Government allowances and grants**

People have found Welsh Government allowances and grants essential to being able to afford to live. Many have accessed the Council Tax Reduction Scheme, which has been important, as ESA and PIP are not at sufficient levels to cover their housing costs. Local advice and support is important as part of this process and providing information on other schemes that people may be entitled to when they apply for and when they are awarded UK benefits.

Housing Benefit and Discretionary Housing payments have also been vital to many people in terms of being able to make ends meet. There is significant concern that when people are moved from ESA and PIP onto Universal Credit they may lose money, especially if the UK schemes do not link well with Welsh allowances and payments.

However, clients have raised an issue with Discretionary Housing payments, in that you have to have a support worker or social worker to be able to apply. This is a barrier for many disabled people, as it assumes that all disabled people have a support worker or social worker. This is often not the case for disabled people who have moved to adapted housing and regained a level of independence, due to the adaptations put in place.

Another key concern raised by people is in relation to the spare bedroom reduction. For many people, especially those people who become disabled people later in life, they have a property they could afford when working and was appropriate for their family size before children left home. During COVID-19 the property size requirements have led to people who are clinically vulnerable to COVID-19 not being able to self-isolate or shield effectively, as they do not have a spare room. There is also insufficient housing available for people to be able to move to smaller properties. This lack of appropriate sized housing is exacerbated for disabled people, who may often need to stay in a particular area to be able to access their healthcare services, and often need adapted or accessible housing. There is a dearth of accessible housing and lifetime homes across the UK.

### **Reforms needed**

Several reforms needed have been indicated in the previous sections of this submission. Additional reforms needed are indicated in this section.

DWP had started opening pop-up benefits advice and information services in local job centres, hubs, community centres and other community venues before COVID-19. These have been very useful for people who need information or support, but find telephone or online contact difficult or impossible. Continuing and extending this

outreach service, in conjunction with local authorities and local health boards would help people understand and navigate the system.

Advocacy and advice services are vital to many disabled people being able to understand and navigate the system. Many clients have indicated they would have given up without support. This indicates a need to fund and support high-quality, specialist, independent advocacy services in every area of Wales and the UK.

Forms and applications need to be simplified and written in Plain English.

People have experience of being treated with a lack of respect by DWP staff on the telephone and in assessments. Many have been made to feel that they are being accused of making up the impact of their health conditions. There needs to be comprehensive training for all staff in disability equality and all protected characteristic, focusing on individuals and treating everyone with respect and as the expert in their own lives.

Many clients have experiences of the assessors having little or no knowledge of their particular health conditions. This has often led to reports being produced where they, in the words of a couple of clients 'do not recognise themselves' and in some cases interpretations are the opposite of what the individual said and experiences. The system needs to change to support the evidence submitted by medical experts and to recognise individuals as the experts in their own experiences and what they can and cannot do.

Some clients had their appeals heard in the County Court. This experience was extremely distressing for them, as they felt they were on trial. These clients felt they would not have been able to express themselves as all without an advocate present. This indicates venues need to be appropriate for individuals who are extremely distressed by the benefits and assessment process.

Another key issue raised by many clients is the cost of obtaining GP letters and medical evidence needed for ESA and PIP applications. For many who are already experiencing financial difficulties whilst applying, this additional cost has forced them to not eat properly, which exacerbates their health conditions. Similarly there is not sufficient time to submit evidence and respond to requests for further information. Many clients reported receiving letters with requests 2 weeks after the date on the letter, resulting in them having to compile complex evidence in 2 weeks. This is extremely difficult for most and impossible for some, given their health condition. Letters need to be in Plain English, allow people sufficient time to respond, and the costs of obtaining medical evidence need to be addressed.

Reassessment periods often seem to be arbitrary, where individuals who have medical evidence that their condition will never improve are having to reapply and experience the stress of that process every 2 to 3 years. Longer awards 5 year should be standard, to remove the continual stress and anxiety, which exacerbates most disabled people's health conditions. There should also be clear processes to support longer awards for people whose conditions will never improve.

## **UK and Welsh Government working together**

Increased localisation of services would be helpful. The links between Welsh Government support and schemes and UK Government schemes would be better supported and information more appropriate for individuals if they were delivered locally. The infrastructure is in place to support this on a Welsh and local level.

## **Welsh UBI pilot**

We welcome the Welsh UBI pilot, and would like to see a geographic pilot introduced. Many people feel that Universal Basic Income is an important way in which the stress and anxiety of applying for and being on benefits could be reduced. UBI would There are many circumstances where someone could need to be on benefits for a short time. These include carers, people in insecure or seasonal employment, people with variable health conditions, people fleeing domestic abuse, and self-employed and freelance workers.

One example where UBI would have made a significant difference was provided by one of our advocates. An individual was working in 2017 when their aunt was diagnosed with terminal cancer. The aunt needed 24/7 care, but that was not covered by social services. The individual had to give up work to be able to care for their aunt. It took over 20 weeks to receive any payment, during which time the individual had no income. Even once received the rates for Carers Allowance are so low that it was insufficient to make ends meet. During the 20 weeks their aunt died. Then the individual was left in a situation where they did not know and were not provided with information on how to move to a different benefit after the person they were caring for died. They did have a full Council Tax reduction, but were left having to pay housing and all bills and expenses from £200 to £400 a month. Until Carers Allowance came through they were also expected to look for work, while providing 24 hour care, which is impossible. The criteria are inappropriate for many and hard to prove. In this case having a safety net of Universal Basic Income would have removed not only some of the financial difficulties, but also the stress of having to look for work and provide 24 hour care.

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