

## **Written evidence submitted by MS Society Cymru (BSW0030)**

### **About MS Society Cymru**

MS Society Cymru / MS Society UK is the largest charity for people living with Multiple Sclerosis (MS) in Wales / UK. Our National Lottery funded Pontio Project supports people living with and affected by MS in Wales to access welfare benefits.

Our reason for making a submission to this inquiry is that disability benefits are vital for people living with MS to maintain their independence. However, since Personal Independence Payment (PIP) began to replace Disability Living Allowance (DLA) in 2013, one in three people living with MS moving over to this new benefit have had their support downgraded, including one in ten who have lost support altogether. This is happening even though MS is a progressive condition where people's needs are only likely to increase.

We welcome the Welsh Affairs Committee's inquiry into the benefits system in Wales and submit the following response for your consideration.

### **What are the key challenges for the benefits system in Wales and how do they differ from the other nations and regions of the UK?**

Multiple Sclerosis (MS) is a chronic, neurodegenerative condition for which there is currently no cure. In MS, the body's immune system attacks myelin, the protective cover around nerve fibres. Damage which can occur anywhere in the central nervous system interferes with messages travelling from the brain and spinal cord to other parts of the body.

Symptoms are many and varied, but unique to each person. They can include problems with balance, vision, the bladder, bowel, speech, memory, fatigue and painful muscle spasms, among many other things.

MS affects over 5,600 people in Wales, over 130,000 people in the UK, many of whom experience their first symptoms during the peak of their working lives, in their 20s and 30s.

MS is both a fluctuating and progressive condition. While the progression and symptoms of MS vary from individual to individual, primary progressive MS affects around 10 to 15% of people with MS. This is progressive from the very first symptoms. The remaining 85% of people with MS are initially diagnosed with relapsing forms of MS, where people have distinct attacks of symptoms with the underlying damage building up over time. Many people with MS will go on to develop secondary progressive MS within 15 years of being diagnosed.

When disability benefits provide appropriate and adequate support, which addresses the everyday impact of MS, they can have a substantial positive impact. For many people with the condition, extra cost and out of work benefits provide a vital lifeline, allowing them to afford basic essentials and maintain their independence, as well as participate in family and social activities.

However, too often people living with MS are struggling to access the support they need and have had to reduce spending on essential items as a result. The disability benefits system is not making sense for people living with MS.

The progressive and fluctuating nature of MS presents particular challenges for the assessment of PIP.

Although they have a progressive condition, more and more people living with MS have continued to lose money as the change from DLA to PIP.

UK Government figures showed that between October 2013 and October 2016 – over 2,500 people with MS lost the highest rate of mobility support – almost a third (29%) of those who had the highest rate before they were reassessed. In addition, a quarter of those who had received the highest rate of DLA care support lost access to this during this same period.

It is clear that substantial change is needed to provide the appropriate support to people living with MS and other disabled people. The assessment criteria for PIP has failed to capture the true extent of the difficulties people face. MS Society UK research has found that the resulting loss of support is having significant negative impacts on people living with MS and knock-on effects on communities and local health and care services.

Since the introduction of PIP in 2013, MS Society Cymru has heard countless stories from people living with MS about how difficult it is to get the support they need. 'Humiliating' and 'degrading' are two words that we hear often about the claims process.

There have been a few attempts by the UK Government to improve PIP in recent years. But PIP still continues to fail people living with MS.

People living with MS and their families often have extra costs related to the condition. It costs, on average, an extra £200 a week to live with a neurological condition like MS - that is why disability benefits, like PIP are so vital. These costs include items such as food and fuel, transport and special equipment.

Due to the failure of the benefit assessment process to recognise the invisible and fluctuating nature of MS symptoms, people living with MS often do not get the level of benefits they are entitled to. This has become worse because of the change from DLA to PIP, and reduced awards under Universal Credit (UC).

Having an adapted Motability vehicle, or having the money to pay for things like physio or counselling can make a significant difference to someone's independence and quality of life. In the words of one person with MS that our Pontio Project spoke to, PIP can give people the support they need "to live rather than exist". However, unnecessary barriers persist throughout every stage of the PIP claiming process, leading to thousands losing or being denied support.

An MS Society survey of people living with MS about Personal Independent Payments in 2020 highlighted that people who have lost the higher rate of mobility, whether they have lost their Motability car or not, reported feeling isolated.

More than a third of people living with MS who claim disability benefits are finding problematic assessments are harming their health.

43% of respondents reported having had to reduce their spending on social activities because of changes to benefits.

30% of respondents who had a Motability car on DLA lost access to this when moving to PIP.

From tackling the complex and lengthy form, to proving yourself to an assessor, to fighting an incorrect decision – people are facing an exhausting and demoralising battle every step of the way. This is while assessors do not always understand MS and too often ignore invisible and unpredictable symptoms.

This lack of knowledge about MS is particularly worrying when assessors frequently use informal observations in their decision making. These are judgements made by what assessors see rather than what they are told. When these observations are used without being backed up by evidence, they often do not accurately reflect how people are impacted by their MS.

67% of people living with MS who had informal observations included in their assessment report said they did not reflect how their MS affects them. Shockingly, informal observations are even used to make incorrect assumptions about someone's abilities.

Such failures ultimately lead to inaccurate assessments, which means many people living with MS end up with 'wrong decisions'. The majority of

benefit related calls to the MS Society Cymru Pontio Project Information and Support team relate to mandatory PIP reconsiderations and PIP appeals. They have found that more than eight in ten people living with MS who take failed PIP claims to appeal win those appeals.

The fact that so many people living with MS who appeal their PIP decision after moving from the previous benefit DLA win their case at tribunal shows how inappropriate assessments continue to be for people living with MS.

For people living with MS, the biggest change is the introduction of the 20 metre rule to decide who gets the most support with mobility. This has meant that people who are able to reliably walk even the smallest distance over 20 metres can no longer receive the highest rate. This has had the most significant impact on access to support for people living with MS.

Not only does the 20 metre rule use an arbitrary distance measure that seems unable to consistently or reliably indicate the greatest need – in too many cases it is also failing to consider and capture fluctuation and hidden symptoms, particularly pain and fatigue.

The PIP assessment guide requires assessors to consider fluctuation of symptoms in relation to the descriptors they use during the assessment. Healthcare professionals carrying out the assessment should consider whether the ability of a claimant to carry out activities is impacted by their condition at least 50% of the days. However, since PIP was introduced, the MS Society has been highlighting repeated failure by assessors to consider fluctuation.

Changes to disability benefits appear to have exacerbated the difficulties some people living with MS are facing. Nearly half the survey respondents to a MS Society survey from Wales (49%) agreed that changes to disability benefits have had a negative impact on them. In some cases, inadequate disability benefit provision is leading to isolation and financial difficulty.

A large number of survey respondents reported having to reduce expenditure in several areas as a result of disability benefit changes;

- 38% had reduced spending on social interaction with family or friends and 36% had reducing spending on transport.

- 21% reported that they had reduced spending on gas and electricity as a result of changes

- 30% reported reduced expenditure on food.

MS brings with it additional costs while also impacting on individual's ability to work. Up to 80% of people with MS are forced to give up work within 15 years of diagnosis. Previous research by the MS Society found that more people with MS in Wales were out of work than the UK average. In Wales, 81% of those of working age who replied to the survey were unemployed, compared to 75% across the UK. This research suggests there may be a greater need for out of work support among people with MS throughout Wales.

Living in poverty and the financial insecurity that can be associated with it, can have a severe impact on disabled people's quality of life, including a worsening of their physical and mental health. Quality of life outcomes are also significantly poorer among people with MS than in the population as a whole. It is more likely to be impacted if someone's MS symptoms are severe or they experience early MS onset or long duration. The negative impacts of MS on someone's quality of life can in turn result in poorer employment and health outcomes, highlighting the cyclical nature of the effects of drivers and outcomes of poverty.

The welfare system should protect people from experiencing poverty and hardship. However, there is consistent evidence that it is not addressing the needs of people living with MS.

### **What reforms are needed to the benefits system and should there be further devolution of powers?**

There are significant yet simple changes that the UK Government can make immediately to improve the process and build trust. Decisions should be backed up by evidence not assumptions, and benefit assessors need to have good knowledge of MS. Having MS is hard enough – it should not be made harder by a welfare system that doesn't make sense.

Reforms:

The UK Government should scrap the PIP 20 metre rule for the highest rate of PIP mobility support. A review and design exercise should be carried out with disabled people, charities and healthcare professionals to design an agreed appropriate alternative. In the meantime the 50 metre threshold should be reinstated.

The Department for Work and Pensions should carry out an evaluation of how the PIP assessment criteria consider hidden symptoms including pain, fatigue and cognitive symptoms.

The Department for Work and Pensions should amend the PIP assessment descriptors to embed the reliably, repeatedly, safely criteria and their definitions within the wording of each descriptor.

The Department for Work and Pensions should review the use of informal observations and their role in PIP assessments. While the review is ongoing, assessors should explain at the beginning of face to face assessments that claimants are subject to informal observations which may be included in the report to decision makers.

The Department for Work and Pensions should develop and implement a fairer process to exempt people with MS in receipt of the highest rate of award and whose condition is unlikely to change from repeated PIP reassessments and ensure award lengths are appropriate.

The Department for Work and Pensions should introduce a requirement that all informal observations included in a PIP assessment should be supported by further evidence from individuals involved in a claimant's care.

The UK Government should remove the 'aided' definition from the criteria for PIP assessment, in recognition that requiring a mobility aid suggests a significant restriction and impairment.

Further powers:

We support further devolution of social security powers for Wales but only if the Welsh Government can ensure that the system of welfare benefits created in Wales is not be a carbon copy of that which currently exists.

A benefits system in Wales should be designed with disabled people, charities and healthcare professionals. It should be fit for purpose and make sense for those who rely on it.

Further devolution of powers are available in Scotland and the Scottish Government have promised that Adult Disability Payment (ADP), Scotland's replacement for Personal Independence Payment (PIP), will be delivered with the values of dignity, fairness and respect.

The draft regulations address many concerns people living with MS have about PIP. Changes include:

- all awards will be made on a rolling basis
- where a person's condition is unlikely to improve there will be at least 5 years between 'light-touch reviews'
- no functional assessments. This means claimants will no longer be asked to carry out physical tasks to support your claim
- ability to apply for ADP on multiple channels (including paper, online and telephone applications) depending on what is best suited to the claimant's needs and preferences.
- more time to appeal the result of an application

- a consultation (a discussion to gather further information) will only take place when it is believed to be the only way to gather the information needed to make a decision. In the majority of cases the supporting information provided with an application will be used to make the decision
- consultations will be carried out by people who are 'suitably qualified'. They can take place by phone, video consultation or face to face, removing the need for people to travel unnecessarily

However, the Scottish Government are planning to use the same eligibility and assessment criteria as PIP. This means they would keep the 20-metre rule as a measure of mobility. Including this rule goes against the values of dignity, fairness and respect.

As we await the decision regarding further devolved powers in Wales, we urge the Welsh Government and the Welsh Affairs Committee to utilise all opportunities to raise concerns about the welfare assessment process for people living with MS to help ensure that it; accurately takes into account the fluctuating and hidden symptoms of MS and their impact and; properly includes evidence provided by experienced professionals who know the person and understand their condition.

We ask the Welsh Government and Welsh Affairs Committee to insist that the UK Government carry out a review of the 20 metre rule along with disabled people, charities and healthcare professionals and design an appropriate alternative to the measure - and whilst this review is ongoing, the UK Government should reinstate the 50 metre threshold as under DLA.

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