



## **MS Society Scotland Briefing: Social Justice and Social Security Committee Adult Disability Payment evidence session Committee Adult Disability Payment evidence session**

*The MS Society Scotland is Scotland's largest charity for people living with multiple sclerosis (MS). As part of our work to represent the interests of the MS community we seek to engage with government and parliament on relevant issues.*

*We are grateful to the Committee for inviting us to contribute.*

### **Overview**

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We support many of the changes outlined in the Adult Disability Regulations. Changing the nature of the assessment process to one that is “person centred” as outlined in the regulations is encouraging. However, we believe the inclusion of the 20-metre rule undermines ADP from the beginning. The rule is incompatible with a system based in dignity, fairness and respect. It cannot be mitigated and must be removed.

If it remains in ADP regulations and there is no prospect of its removal until 2025, after the Government's review in 2023 and the time required to implement any changes, many people with MS will continue to be unable to access the support they require.

We encourage the Government to replace the 20-metre rule with the former Disability Living Allowance 50-metre rule, until policy experts, medical specialists and people living with disabilities can find a holistic and fair way to measure mobility. The 50-metre rule was far from perfect, but it is preferable in the interim.

### **Our work so far**

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Throughout the legislative process the MS Society has worked to ensure that the views of people living with, and affected by MS have been heard. Working in partnership with the MS community to gather their experiences of the existing Social Security system and their hopes for the new Scottish system.

With this starting point we have engaged throughout the process with the Scottish Government and MSPs to ensure the voices of people with MS contributed to policy and legislative development. As part of this process we have taken part in roundtable events, held focus groups, given evidence to the parliamentary committees, completed consultation responses, met with Government ministers and policy teams, reviewed the draft ADP decision making guidance and recruited people living with MS to participate in research programmes testing and designing the proposed application processes.

### **The 20-metre rule does not measure mobility**

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No evidence exists that people who can walk over 20 metres have lower levels of need for mobility support or that the 20-metre rule is an effective way to measure mobility.

The rule does not take into account the fluctuating nature of neurological conditions like MS where someone may be able to walk more than 20 metres one day and struggle to get out of their bed the next.

Fatigue is one of the most debilitating symptoms of MS. Yet, the rule does not consider the severity of fatigue people with MS experience after walking 20 metres. Many would have to rest for days in advance of walking such a distance and be unable to take part in physical activity for days afterwards. Nor is it clear what someone who is able to walk this distance is supposed to do if public transport and local services are further than 20 metres away.

A Citizens Advice Scotland (CAS) Survey in 2021 found that a majority of Bureau advisers working to help people with disabilities navigate the social security system agree that the 20 metre should be extended to 50 metres.<sup>1</sup>

***“Today I can stand and walk. That is not the case tomorrow. Every day is different. My body can go into spasms anytime and I can lose my ability to have the strength to stand never mind walk...Fatigue is overwhelming...” - A person living with MS.***

### **The 20-metre rule is harming people with disabilities.**

Since the introduction of PIP in 2013, one in three people with MS had their support downgraded, including one in ten who were denied access to support altogether.<sup>2</sup> MS is a progressive condition where people experience worsening disability, a rule that leads to them deemed as being in less need over time is not fit for purpose.

The MS Society 2018 Report “PIP: a step too far” found that 2% of respondents gave up work altogether because they could no longer access Motability and the enhanced rate of mobility support.<sup>3</sup>

People have lost their independence and their employment because losing that mobility support has meant that they are unable to physically get to their workplace. We estimate that 611 people with MS have or will give up work because of this between 2020 and 2022.<sup>4</sup>

On average, a neurological condition such as MS leads to extra costs of £200 per week.<sup>5</sup> In “The Cost of the PIP 20 metre rule” report, we found those who had their mobility support reduced or removed altogether had been forced to increase their use of GP services, and reduce spending on food and therapies. The report concluded

<sup>1</sup> CAS – ADP Consultation response, March 2021

<sup>2</sup> MS Society – PIP: A step too far, June 2018

<sup>3</sup> MS Society – PIP: A step too far, June 2018

<sup>4</sup> MS Society – PIP: A step too far, June 2018

<sup>5</sup> MS Society – Cost of the 20m rule, April 2019

that the rule increased, rather than reduced, the cost to government due to additional costs to the NHS and a rise in those claiming other income support.<sup>6</sup>

**“...I lost the higher rate mobility payment and I was without a car for five or six months in the end. I couldn’t go to work at that point as I had no way of getting to the bus stop. It ruled out anything I might have done. I was essentially housebound for those months.” - A person living with MS.**

### **Will changing the 20 metre rule impact passported benefits?**

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Contrary to the Government’s position, it is our belief that changing the 20 metre rule to a 50 metre rule will not impact passported benefits. This eligibility change would only mean that those who were getting standard rate of mobility would be entitled to the enhanced rate. We do not believe those on the enhanced rate of mobility are entitled to any additional DWP benefits that those on the standard rate are not. Thus we have no reason to believe there will be any issues with passported benefits.

Even if passported benefits were to be impacted by the rule, it should not be out with the gift of two governments to come together and resolve any issues.

### **2023 Review**

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The review must establish what difference the changes to the application system have made. It is not enough for people to stop having their rate of support downgraded. We need to see a trajectory of more people having their support increased over time. The experience of applicants must be at the heart of the review, we have to see a drastic change in the experience of those accessing it.

If the government have not removed the 20 metre by this point, they must commit to doing so as part of the review. We have established that these rules are arbitrary, unfair and inadequate ways of measuring mobility.

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<sup>6</sup> MS Society – Cost of the 20m rule, April 2019