

Citizen Participation and Public Petitions Committee

3rd Meeting, 2021 (Session 6), Wednesday, 8
September 2021

PE1854: Review the adult disability payment
eligibility criteria for people with mobility needs

Note by the Clerk

Petitioners	Keith Park on behalf of MS Society
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to remove the 20 metre rule from the proposed adult disability payment eligibility criteria or identify an alternative form of support for people with mobility needs.
Webpage	https://petitions.parliament.scot/petitions/PE1854

Introduction

1. This is a new petition that was lodged on 17 March 2021.
2. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe A**.
3. While not a formal requirement, petitioners have the option to collect signatures and comments on their petition. On this occasion, the petitioner elected to collect this information. 3057 signatures and 450 comments have been received.
4. The Session 5 Public Petitions Committee agreed to seek advanced views from the Scottish Government on all new petitions before they are formally considered. A response has been received from the Scottish Government and is included at **Annexe B** of this paper.
5. A submission has been provided by the petitioner (MS Society Scotland) which has been prepared in conjunction with Citizens Advice Scotland and the Health and Social Care Alliance. This is included at **Annexe C**.

6. Adult Disability Payment (ADP) is due to replace Personal Independence Payment (PIP) in Scotland from summer 2022, following a pilot in spring 2022. PIP was introduced across Great Britain in 2013 to replace Disability Living Allowance (DLA), and the implementation of this change is still ongoing.
7. Both PIP and DLA were fully devolved in April 2020 but are being administered by the Department for Work and Pensions (DWP) under an agency agreement. This will continue until all existing cases are transferred from DWP to Social Security Scotland. This transfer process is expected to be complete by 2025.
8. Under the principle of 'safe and secure transition', the 'Scottish versions' of DWP disability and carer benefits will, at least in the short term, have much the same rules as their DWP equivalents.

Scottish Government submission

9. In its submission, the Scottish Government states that it consulted on the draft regulations for Adult Disability Payment between 21 December 2020 and 15 March 2021. The purpose of the consultation was to gather views on the policy and draft regulations and identify any gaps, issues or unintended consequences. The Scottish Government also asked questions on some specific points about the effects of the regulations.
10. The Scottish Government has advised that it will review the responses to the consultation and, if required, adjust the draft regulations in light of the feedback. In accordance with the Social Security (Scotland) Act 2018, the draft regulations will then be scrutinised by the independent Scottish Commission on Social Security. The regulations will be revised as necessary following the Commission's report and then laid in draft for approval by the Scottish Parliament.
11. The Scottish Government's submission highlights that the DWP has been clear that, in order for ADP to be considered a comparable benefit to PIP, ensuring Scottish clients remain entitled to various reserved payments, it must be delivered on a "like for like" basis.
12. As such, it advises that whilst this period of transition from PIP to ADP is ongoing, it has decided not to make any significant changes to eligibility criteria before ADP is launched.
13. The submission advises that the Scottish Government is focusing on the significant changes it can make to how disabled people in Scotland experience accessing disability assistance, such as providing additional application channels and replacing assessments with person-centred consultations.
14. The Scottish Government has proposed a new way of making entitlement decisions for ADP to ensure the criteria is fairly applied to all clients. It states this includes stringently applying the reliability criteria, which require a client to be

able to carry out activities safely, repeatedly, in an acceptable manner and in a reasonable time. It believes these criteria mean that decisions will take full account of how the client experiences moving around.

15. The Scottish Government has committed to facilitating an independent review of ADP in 2023, one year after delivery has begun which it believes will enable all of the eligibility criteria to be considered in the round rather than any changes being made in a piecemeal way.
16. The submission notes the Scottish Government is confident the changes it is proposing will significantly improve how decisions are made. It advises the suggested departure from the current system means formal supporting information to evidence each and every difficulty that the client reports experiencing will no longer be required.
17. Additionally, the Scottish Government will not conduct any functional examinations as part of a consultation which is currently required by DWP. The submission notes it does not believe functional examinations meet its values of fairness, dignity and respect.
18. Instead, an ADP consultation will be a discussion between a client and a practitioner employed by Social Security Scotland that is based on a position of trust. The consultation will seek to provide reliable information to enable a case manager to make an informed decision.
19. If a practitioner makes an informal observation during a consultation, they must inform the client of this observation and any inferences drawn from it. The client, or person accompanying them, must be given the opportunity to respond to the observations. The submission notes this is a significant change to the current system where an assessor can make assumptions about the client without telling them, and can do so before or after the assessment has taken place.
20. The Scottish Government highlight DWP have been unable to provide some of the data required to inform changes to criteria. It notes it is therefore challenging to accurately predict all of the potential ramifications that changes might have on people's eligibility. This risks inadvertently withdrawing eligibility from individuals previously entitled to PIP or extending eligibility to individuals who were never intended to receive disability assistance, due to changes made before delivery.
21. Furthermore, it notes any changes which widen eligibility risk DWP deciding that ADP is not a comparable benefit to PIP and withdrawing automatic entitlement to reserved payments from Scottish clients. DWP may decide therefore that ADP should not provide access to passported benefits and premiums which PIP currently ensures entitlement to such as Housing Benefit and Jobseeker's Allowance.

Petitioner submission

22. The written submission provided by the petitioner was prepared in conjunction with Citizens Advice Scotland and the Health and Social Care Alliance.
23. The petitioner's submission emphasises their view that it is vital that the voices of those accessing social security are listened to and that those with disabilities were hit hardest by the pandemic.
24. In their submission, the petitioner points to the Scottish Government's consultation on proposals for ADP, highlighting that people with disabilities and organisations working on their behalf identified the need to remove the 20-metre rule in their responses.
25. Additionally, a Citizens Advice Scotland Survey in 2021 found that a majority of Bureaux advisers working to help people with disabilities navigate the social security system agree that the 20-metre rule should be extended to 50 metres.
26. In response to the Scottish Government's consideration of impacting on the "like for like" aspect of ADP, the petitioner believes that changing the 20-metre rule to a 50-metre rule would not impact on passported benefits. This is on the basis that those who were receiving the standard rate of mobility would be entitled to the enhanced rate and that an enhanced rate of mobility does not entitle individuals to any additional DWP benefits.
27. The submission notes that there is no evidence that people who can walk over 20 metres have lower levels of need for mobility support. They note that in the Scottish Government's proposals for ADP, it is not argued that the rule is an effective way to measure mobility.
28. Furthermore, the petitioner states that the 20-metre rule does not take into account the fluctuating nature of neurological conditions and that with these conditions someone may be able to walk more than 20 metres one day and struggle to get out of bed the next.

 "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...memory is affected and life as a married couple is difficult. So mental health comes into play." - A person living with MS
29. The submission concludes by noting the impact of PIP when it replaced DLA in 2013, referencing the MS Society Report "[PIP: a step too far](#)" which found that 2% of respondents gave up work altogether because they lost out on the higher rate of mobility support.
30. The report also estimated that 611 people with MS would give up work because of this between 2020 and 2022.

31. Another report by the MS Society, "[The Cost of PIP 20 metre rule](#)", found those who had their mobility support reduced or removed had increased their use of GP services, and reduced spending on food and therapies. The report concluded that the rule increased, rather than reduced, the cost to government due to additional costs for the NHS and a rise in those claiming other income support.
32. The petitioner has asked that the Committee take evidence from stakeholders with respect to this petition.

Action

33. The Committee is invited to consider what action it wishes to take on this petition.

Clerk to the Committee

PE1854: REVIEW THE ADULT DISABILITY PAYMENT ELIGIBILITY CRITERIA FOR PEOPLE WITH MOBILITY NEEDS

Petitioner

Keith Park on behalf of MS Society

Date Lodged

17 March 2021

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to remove the 20 metre rule from the proposed adult disability payment eligibility criteria or identify an alternative form of support for people with mobility needs.

Previous action

We have lobbied numerous MSPs. We have also extensively campaigned for the removal of the 20 metre rule from the assessment framework of PIP since its inception.

Background information

The Adult disability payment (ADP) will replace Personal Independence Payment (PIP) in Scotland and will be delivered by Social Security Scotland.

The Scottish Government is currently consulting on the ADP and the draft Disability Assistance for Working Age People (Scotland) Regulations describe the detailed criteria, rules and processes for delivery of the payments.

We want the Scottish Government to remove the 20 metre rule from the proposed ADP framework for the highest rate of mobility support within the new disability assistance - a position which is supported by Citizens Advice Scotland.

For people living with MS, the biggest change in PIP has been the introduction of the 20 metre rule. This measure of mobility means that people who are able to walk even the smallest distance over 20 metres can no longer get the highest level of financial support under PIP.

Since PIP began to replace Disability Living Allowance in 2013, one in three people with MS moving over to this 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.

The UK Government has never been able to produce any evidence that people who can walk over 20 metres have lower levels of need for mobility support. In June 2018 we produced our report 'PIP: A step too far' which looked at the impact of the

changes on people living with MS. Further research was then carried out and published in our report of April 2019 'The cost of the PIP 20 metre rule.' We found that over the (then) spending review period of 2020-2023 "the total knock-on costs to the UK Government outweigh what it will save by reducing PIP support for people with MS via the 20 metre rule" Additional research was then published in November 2019 focussing on the application, assessment and decision making processes - 'PIP fails: how the PIP process betrays people with MS'.

The basis for the proposed ADP are the principles of dignity, fairness and respect. Throughout the consultation period stakeholders from across Scotland have highlighted concerns about the PIP assessment framework and how it is unfair. In fact the Scottish Government consultation document highlights this and says, "making changes to the mobility or 50% rules in isolation could further embed unfairness in to the framework". This admission that the framework is unfair goes against the principles that underpin the regulations associated with ADP.

Many aspects of our findings are reflected in the Scottish Government's 'Welfare Reform Report' which looked at the impact of welfare reforms on disabled people citing the Lived Experience Panels and comparing the differing approaches between the UK and Scottish Government. So it is disappointing that currently the Scottish Government is looking to retain such a discredited assessment criteria.

The Scottish Government should be thinking creatively as to how it can support people whom would otherwise have been in receipt of the higher level mobility payment if it feels it has to continue with the 20 metre rule. For example, how feasible would it be to introduce a mobility allowance in a manner similar to the Carers Allowance Supplement? 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.

Briefing for the Citizen Participation and Public Petitions Committee

Petition Number: [PE01854](#)

Main Petitioner: Keith Park on behalf of the MS Society

Subject: Adult Disability Payment

Calls on the Parliament to urge the Scottish Government to remove the 20 metre rule from the proposed adult disability payment eligibility criteria or identify an alternative form of support for people with mobility needs.

Background

Social security devolution

Most disability and carer benefits are in the process of being turned into Scottish benefits to be administered by [Social Security Scotland](#).

Adult Disability Payment (ADP) is due to start to replace Personal Independence Payment (PIP) in Scotland from summer 2022, following a pilot in spring 2022. PIP was introduced across Great Britain in 2013 to replace Disability Living Allowance (DLA), and the implementation of this change is still ongoing.¹

Both PIP and DLA were fully devolved in April 2020 but are being administered by the Department for Work and Pensions (DWP) under an agency agreement. This will continue until all existing cases are transferred from DWP to Social Security Scotland. This transfer process is expected to be complete by 2025.²

Under the principle of 'safe and secure transition', the 'Scottish versions' of DWP disability and carer benefits will, at least in the short term, have much the same rules as their DWP equivalents.

The 20 metre rule

As the petitioner notes, the MS Society has campaigned for a number of years to remove the '20 metre rule' from Personal Independence Payment (PIP).

PIP awards are made up of two components: daily living and mobility. Both components are payable at either a standard or enhanced rate, depending on a claimant's circumstances. Claimants are assessed against a list of activities (10 activities for daily living and two for mobility) and are allocated a score which determines their award.

¹ In August 2020 there were still nearly 40,000 working age people in Scotland getting DLA.(StatXplore).

² [Official Report 17 November 2020](#)

To get the enhanced mobility component a claimant must be awarded 12 points in total. The two descriptors for the mobility component are:

- 'Planning and following journeys'
- 'Moving around'.

Under 'moving around' a claimant can get 12 points if they cannot walk more than 20 metres. If a claimant can move more than 20 metres, they would need to score points under 'planning and following journeys' in order to get the enhanced rate.

The Scottish Government proposes that ADP will replicate these rules.

Enhanced mobility awards

In October 2020, 41% of working age PIP claimants in Scotland had an enhanced mobility award (98,779 people), 30% had the standard rate and the remainder did not have a mobility award (Statxplora).

Before PIP was launched in 2013, 47% of working age DLA claimants got the higher mobility rate (Statxplora).

Of those who had higher mobility in DLA who were then reassessed for PIP, just over half (56%) were awarded enhanced mobility in PIP.

Table 1: Reassessment outcomes for DLA higher mobility, Scotland

Total DLA higher mobility	PIP mobility reassessment outcome			
	enhanced	standard	nil	unknown
71,413	40,210	17,480	10,525	3,190
100%	56%	24%	15%	4%

Source: Statxplora, reassessment data published December 2020

Research by the petitioners

The petitioners have published research on the impact of the '20 metre rule' on people with MS.

- [The Cost of the 20 Metre Rule](#)
- [PIP: A step too far](#)

The 'Cost of the 20 Metre Rule' states that:

“since PIP began replacing DLA in 2013, one in three people with MS have lost support, primarily due to the 20 metre rule that says people who can walk one step over 20m don't need the highest rate of mobility component. Under the previous benefit (DLA) higher rate mobility was generally available to people unable to walk more than 50 metres.”

Social security principles

The petitioners refer to the principles of dignity, fairness and respect. The Social Security (Scotland) Act 2018 sets out eight principles ([section 1](#)) including:

- (d) respect for the dignity of individuals is to be at the heart of the Scottish social security system,
- (f) the Scottish social security system is to be designed with the people of Scotland on the basis of evidence,
- (g) opportunities are to be sought to continuously improve the Scottish social security system

These principles must be reflected in the '[Social Security Charter](#)' which includes a commitment to:

“look for ways to make eligibility rules fairer and consider creating new benefits to meet people's changing needs.”

Expert Group advice

The [Disability and Carer Benefit Expert Advisory Group](#) (DACBEAG) provides advice to the Scottish Government on devolved benefits. They agree with the principle of 'safe and secure transition', recommending in 2019 that:

“In the short term, we agree that no significant changes should be made to eligibility rules to ensure a safe and secure transition from PIP to DAWAP” ([Advice to ministers](#), December 2019)

However, the group also raised issues that could be considered in the longer term (including the 'rigid nature' of the mobility rules) and recommended a legal duty to review (Recommendation 8).

Scottish Government action

A [consultation on disability assistance](#) was held in 2019. In its [analysis of responses, the Scottish Government](#) reported that:

“Significant numbers of respondents commented on the rules and tools used to compile the points assessment system. Most frequently mentioned (including by one in three responding organisations) was agreement that the 20 metre threshold for qualifying for the enhanced rate of the mobility component is problematic.”

A more detailed consultation on [the rules for Adult Disability Payment concludes on 15 March 2021](#). This makes clear that eligibility rules will remain largely the same as PIP but some administrative processes will be different.

The consultation paper discusses the mobility criteria, recognising that there have been calls for it to be changed. However, the paper argues that:

“We have considered carefully whether we should implement changes to these rules when we begin delivery of Adult Disability Payment.

There are a number of challenges associated with this that would risk safe and secure transition and could result in a poor experience for clients”

In summary, these challenges are:

- It is only one amongst many issues raised.
- If ADP was different to PIP, rather than wait to be transferred, people may choose to end their PIP award and make a new claim for ADP, potentially overwhelming the system.
- If ADP was different to PIP, there would need to be more decision-making about eligibility at the point of transfer.
- Delivering ADP with virtually the same rules as PIP will provide baseline data from which to consider future changes.
- The need to be certain DWP would continue to recognise ADP as entitling people to various passported benefits and premiums.³

The paper concludes:

“We do not consider it safe to make any significant changes to the activities, descriptors and supporting eligibility criteria in these regulations.”

However, there will be an independent review starting in summer 2023, and:

“we are committed to implementing reforms as quickly as is achievable once case transfer is complete.”

As noted above, the current expectation is that case transfer will be complete by 2025.

Despite not proposing changes to the descriptors, the consultation paper argues that changes to administrative processes will result in a ‘marked improvement’ in decision making.

Scottish Parliament action

The regulations creating ADP are expected to be laid in the Scottish Parliament before spring 2022. They will be subject to a ‘super-affirmative procedure’ which includes scrutiny by the [Scottish Commission on Social Security](#).

The issue of the 20 metre rule was raised by Mark Griffin MSP, as an amendment to a Government [debate on 29 October 2019](#) (amendmentn S5M-19577.2, calling for the 20 metre rule to be removed).

³ If someone gets PIP, then they are entitled to extra amounts in other benefits such as Employment and Support Allowance. For some of these additions it is necessary to have the enhanced daily living award, for others, the standard rate of PIP suffices. See [DWP- disability premiums](#).

Mark Griffin MSP also asked whether the Scottish Government had modelled the impact of replacing the 20 metre rule ([S5W-23497, lodged 29 May 2019](#)). In response, Shirley-Anne Somerville MSP, Cabinet Secretary for Social Security and Older People, said: “Any modelling required will be carried out at the appropriate time in order to assist in the policy development process.”

In 2018, a motion by Alison Johnstone MSP welcomed the MS Society Report, PIP: A Step Too Far and hoped that:

“in contrast to the UK’s Government’s approach, the Scottish Government will give full consideration to a fairer system of assessing eligibility for the mobility component of the devolved Disability Assistance.” ([S5M-12864, 19 June 2018](#))

Also in 2018, Alison Johnstone asked about the 20 metre rule and the design of Scottish disability assistance. Shirley-Anne Somerville MSP, Cabinet Secretary for Social Security and Older People, replied that: “We will ensure that the assessment process, including any thresholds used, is built around the needs of clients to deliver dignity and respect.” ([S5W-17334, lodged 19 June 2018](#)).

Key organisations

- [Scottish Campaign on Rights to Social Security](#) (coalition of organisations)
- [Disability and Carer Expert Advisory Group](#)
- [Inclusion Scotland](#)
- [Citizens Advice Scotland](#)

Camilla Kidner

3 March 2021

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Published by the Scottish Parliament Information Centre (SPICe), an office of the Scottish Parliamentary Corporate Body, The Scottish Parliament, Edinburgh, EH99 1SP

Annexe B

PE1854/A

Scottish Government submission of 17 March 2021

Background

1. Throughout the devolution of social security our overriding commitment has been to the safe and secure transition of disability assistance from the Department for Work and Pensions (DWP) to Social Security Scotland ('the Agency'). It is paramount to ensure that clients continue to receive the payments they rely on. DWP have been clear that in order for Adult Disability Payment (ADP) to be considered a comparable benefit to Personal Independence Payment (PIP), ensuring Scottish clients remain entitled to various reserved payments, it must be delivered on a "like for like" basis. Whilst this period of transition from PIP to ADP is ongoing, we have therefore decided not to make any significant changes to eligibility criteria before ADP is launched.
2. Our priority is instead to focus on the significant changes we can make to how disabled people in Scotland experience accessing disability assistance, such as providing additional application channels and replacing assessments with person centred consultations.
3. However, we are acutely aware of the strength of feeling among some stakeholders to see changes made to the existing PIP framework, especially the mobility criteria. We have proposed a new way of making entitlement decisions for ADP to ensure that the criteria are fairly applied to all clients. This includes stringently applying the reliability criteria, which require a client to be able to carry out activities safely, repeatedly, in an acceptable manner and in a reasonable time. These criteria mean that decisions will take full account of how the client experiences moving around.
4. In addition, we have committed to facilitating an independent review of ADP in 2023, one year after delivery has begun. This will enable all of the eligibility criteria to be considered in the round rather than any changes being made in a piecemeal way.

Improvements to the ADP decision making process

5. We are confident that the changes we are proposing will significantly improve how decisions are made. For example, we will aim to collect one piece of supporting information from a formal source, such as from a GP or a support worker. This information only needs to determine, on the balance of probabilities, that the individual's condition is consistent with the needs detailed on their application.
6. This is a departure from the current system which requires formal supporting information to evidence each and every difficulty that the client reports experiencing. We also know that useful insights can be provided by a client's informal support network including family, friends, or unpaid carers. Under the Scottish Government's approach, equal consideration will be given to all sources of information.

7. Additionally, we will not conduct any functional examinations as part of a consultation. Currently DWP carry out examinations as part of an assessment such as a musculoskeletal examinations to test limb strength. We do not believe functional examinations meet our values of fairness, dignity and respect. Instead an ADP consultation will be a discussion between a client and a practitioner employed by Social Security Scotland that is based on a position of trust. The consultation will seek to provide reliable information to enable a case manager to make an informed decision.
8. If a practitioner makes an informal observation during a consultation, they must inform the client of this observation and any inferences drawn from it. The client, or person accompanying them, must be given the opportunity to respond to the observations. This is a significant change to the current system where an assessor can make assumptions about the client without telling them, and can do so before or after the assessment has taken place.

Unintended consequences

9. Another key challenge to substantive change which will lessen once ADP is being delivered, is the lack of detailed and accurate information to inform changes to criteria. Despite best efforts DWP have been unable to provide us with some of the data required, in many instances because they do not collect or do not analyse the specific data we have requested. It is therefore extremely challenging to accurately predict all of the potential ramifications that changes might have on people's eligibility. This risks inadvertently withdrawing eligibility from individuals previously entitled to PIP or extending eligibility to individuals who were never intended to receive disability assistance, due to changes made before delivery.
10. Furthermore, any changes which widen eligibility risk DWP deciding that ADP is not a comparable benefit to PIP and withdrawing automatic entitlement to reserved payments from Scottish clients. DWP may decide therefore that ADP should not provide access to passported benefits and premiums which PIP currently ensures entitlement to such as Housing Benefit and Jobseeker's Allowance.

Annexe C

Petitioner submission of 2 September 2021 PE1854/B Review the adult disability payment eligibility criteria for people with mobility needs

This submission was written by the MS Society Scotland (Petitioners), Citizens Advice Scotland and the Health and Social Care Alliance.

We ask that the Citizen Participation and Public Petitions Committee take evidence from stakeholders with respect to this petition.

Scotland has the opportunity to build a world leading rights based social security service. Free from arbitrary, tick box tests like the 20-metre rule.

It is vital that the voices of those accessing social security are listened to. People with disabilities were hit hardest by the pandemic and are already underrepresented in our parliament. Issues which disproportionately impact them must be afforded the attention of parliamentarians. The petitioners should be offered the opportunity to appear before the committee to discuss the petition.

Background information

The 20-metre rule was introduced as part of the eligibility criteria to access Personal Independence Payment (PIP). Under this rule, if you can walk one step over 20 metres you do not qualify for the higher rate of mobility support. The previous distance under Disability Living Allowance (DLA) was 50 metres.

The Scottish Government are replacing PIP with ADP. As part of this new benefit, the Governments initial proposals largely replicated the eligibility criteria retaining the 20-metre rule as part of the assessment criteria for ADP.

The Government undertook a consultation on their proposals for ADP. During the consultation people with disabilities and organisations working on their behalf identified the need to remove the 20-metre rule in their responses.

In June the Government published their response to the consultation, where they confirmed their intention to keep the rule in the assessment criteria. Their stated reason for this was that they believed any changes to eligibility criteria risk the passported benefits of those in receipt of other support from the DWP.

We believe that changing the 20-metre rule to a 50 metre rule will not impact passported benefits. The eligibility change would mean that those who were getting standard rate of mobility would be entitled to the enhanced rate. Those on the enhanced rate of mobility are not entitled to any additional DWP benefits that those on the standard rate are not.

The 20-metre rule does not measure mobility

The 20-metre rule is not an evidence based policy. There is no evidence that people who can walk over 20 metres have lower levels of need for mobility support. In their proposals for ADP the Government do not argue that the rule is an effective way to measure mobility.

It does not take into account the fluctuating nature of neurological conditions. With these conditions someone may be able to walk more than 20 metres one day and struggle to get out of bed the next.

It does not consider the severity of fatigue many will experience after walking. Nor is it clear what someone who is able to walk this distance is supposed to do if transport or services are further than 20 metres away.

A Citizens Advice Scotland Survey in 2021 found that a majority of Bureaux advisers working to help people with disabilities navigate the social security system agree that the 20-metre rule should be extended to 50 metres.

“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...memory is affected and life as a married couple is difficult. So mental health comes into play.” – A person living with MS.

The 20-metre rule is harming people with disabilities

The MS Society found that since PIP replaced DLA in 2013, one in three people with MS moving over to this benefit had their support downgraded. This is happening even though MS is a progressive condition where an individual's needs will only increase.

The MS Society Report “PIP: a step too far” found that 2% of respondents gave up work altogether because they lost out on the higher rate of mobility support. It estimated that 611 people with MS would give up work because of this between 2020 and 2022.

In “The Cost of the PIP 20 metre rule” report, the MS Society found those who had their mobility support reduced or removed had increased their use of GP services, and reduced spending on food and therapies. The report concluded that the rule increased, rather than reduced, the cost to government due to additional costs for the NHS and a rise in those claiming other income support.

“So many people lost their independence by losing their Motability Scheme car when migrating from DLA to PIP. People became housebound or lost their job as they couldn't afford a vehicle...It would be so much better to give people back the ability to be more independent...and become more integrated members of their communities.” – A Citizens Advice Bureaux Adviser.