

National Carer Organisations response to: Adult Disability Payment: Consultation on the Mobility Component

The National Carer Organisations welcome the opportunity to respond to this consultation. We have, over a period of many years, both as a consortium and individually as organisations, provided evidence from unpaid carers themselves of their experiences and views of disability benefits and on the ways in which they believe Adult Disability Payment should develop.

Our response focuses only on some of the questions within this consultation namely those related to criteria and how these could be improved and how to support those with fluctuating conditions more effectively. Our response also builds upon previous consultation responses¹ and discussions with unpaid carers about disability benefits in Scotland, including informal polling of unpaid carers over the past two weeks. We have provided all of the responses to the poll, including unpaid carers' comments in Appendix 1. All comments from unpaid carers in this response are marked in green.

Changes to moving around criteria

The National Carer Organisations believe that there should be fundamental changes to the moving around activity criteria. Since discussions around welfare reform and changes from Disability Living Allowance to Personal Independence Payment, and on the introduction of Adult Disability Payment we have repeatedly reflected unpaid carers' views that the criteria should not have been reduced from 50 metres to just 20 metres and, that Adult Disability Payment is a real opportunity to change this for the better.

*"In the first instance, the 20 metres rule must be immediately scrapped and replaced with the previous 50 metres rule. This should be an interim measure until the Scottish Government moves beyond "safe and secure transition" into changing existing descriptors. The replacement metre rule must recognise pain, fatigue and impact on an individual's health and wellbeing of walking."*²

[National Carer Organisations]

As noted in our previous responses, we believe that the criteria itself should be changed to be replaced with questions on the extent to which a disabled person can undertake everyday activities which require them to move around; and the subsequent impact of moving around upon them.

*"In the longer term, there must be more recognition of what difficulties with mobility actually means for individuals and what assistance with the costs of mobility, be that a Motability car, scooter, taxis etc. can mean to the life of the individual. There is clear evidence of the impact of removing this assistance on independence, wellbeing and employment. The social security system should through disability assistance be aiming to support people live better lives and achieve the outcomes they wish to achieve, not limiting them with arbitrary metre rules"*³

[National Carer Organisations]

¹ For example: National Carer Organisations response to Disability Assistance in Scotland consultation, 2019. <https://carers.org/downloads/scotland-pdfs/aconsultationonimprovingdisabilityassistanceinScotlandresponse.pdf>

² National Carer Organisations response to Disability Assistance in Scotland consultation. 2019 (link as above)

³ National Carer Organisations response to Disability Assistance in Scotland consultation. 2019 (link as above)

This change is supported by the majority of unpaid carers we polled (83%) with respondents believing it would be meaningful and would reflect the real-life impact of many conditions and disabilities, including fluctuations, pain and fatigue, and its role in providing individuals with the ability to be more independent.

“It needs to change. Some people can walk but with immense pain that then floors them and they need hours/days to “recover” while still being in pain and needing support from others in everyday tasks”.

“Mobility isn’t just how far you can walk, it’s about the freedom to do things independently, with support or with walking aids. Mobility aids may assist you to walk a little further so it deems you to not qualify as it means you can walk further than they see fit. A more holistic approach is need remembering not every person is the same. Mobility should be based on the individual person and their overall disability challenges”

“The question should be scrapped and replaced with other questions which are much more meaningful. People with conditions, such as Parkinson’s and MS, experience fluctuations in their condition and mobility which the current questions don’t cover. If someone freezes unpredictably and becomes immobile without warning, this affects every journey, every day, even if they can walk a certain distance on some days. Setting a distance in the question is demeaning and unhelpful.”

In addition, some unpaid carers also recognised that descriptors and assessment of “moving around” can inadvertently negatively impact health of individuals and reduce opportunities to improve health and wellbeing. Given the fact that healthy life expectancy has been decreasing in Scotland⁴ and the considerable cost of managing ill health, consideration should be given to how better descriptors and wider, more inclusive access to support for moving around could instead contribute to improved health and wellbeing outcomes for people with disabilities and long-term conditions and to reducing health inequalities.

“I’m sure the criteria used to be worded like how far can you walk before in severe pain for people who weren’t in chairs etc. For many we are in pain from offset but if you don’t force yourself, you’d get nowhere, become unfit etc. Many of the new criteria in these benefits actually disable you more, than enable and give independence as much as possible as they should. Been through it when they did the sweep, lost my wavy, blue badge etc, got my badge back at least after few years.”

We also reflect that, should the Scottish Government decide initially not to make such fundamental change, a significant minority believe that the distance criteria should be extended to 50 meters (11%) or 100 meters (4%). Given the limitations of this recent polling and given the views expressed by unpaid carers on this question during the development of Adult Disability Payment, the National Carer Organisations believe that as a minimum the distance criteria should be extended to 50 meters with plans to extend to 100 meters and to improve decision-making and assessment criteria to ensure that it recognises fluctuations and impact as effectively as possible.

Changes to planning and following a journey

The National Carer Organisations believe that a new inclusive approach to mobility focused on supporting independence and wellbeing, rather than being restricted to either moving around or planning/following a journey, could more easily recognise and support people with fluctuating conditions and also respond to the variation of impact of mental health, neurological, sensory or learning disabilities – recognising the day-to-day reality of individual lives.

“The criteria need to be changed to be more inclusive of people who can physically walk but for reasons of sensory overload or anxiety etc cannot and stop treating it as it being their choice not to walk. Inability to walk for reasons related to neurological disabilities needs to be properly recognised.”

⁴ Healthy Life Expectancy in Scotland, 2019-2021, National Records of Scotland, December 2022

“Should be scrapped and question about how you get around. My son can walk a distance physically but can’t go anywhere without help as he is blind. Answer to distance walk is yes but actually can’t go on his own.”

Better recognition of fluctuating conditions

The National Carer Organisations believe that the current assessment of mobility also does not appear to fully recognise fluctuating conditions. Our poll of unpaid carers was limited, but our previous discussions with unpaid carers and the comments throughout indicate that they do not believe that it is currently as effective as it could be. Unpaid carers suggested a range of ways to improve both the assessment of fluctuating conditions but also the criteria itself. This included that more than one in 10 (16%) of respondents saying that the criteria should be replaced with a more flexible test instead of rigid points structure, a similar proportion (11%) saying there should be an averaging of hours to reflect good and bad weeks and a small number suggesting different thresholds should be applied for different conditions. Three quarters (72%) said implementing all these changes would improve the system for people with fluctuating conditions.

Unpaid carers went on to comment on some of the changes they believe would improve ADP for people with fluctuating conditions.

“I think the best way of assessing is relying on client's own Consultant and GP reports, and any other health professional. And the person themselves. The points system should be done away with altogether. I don't think any applicant can be judged on a set of points. Years ago, for Incapacity Benefit applications, there was no set of points, no assessments. The applicant applied, sent in confirmation of diagnosis etc, and it was up to DHSS (as DWP was called at the time) to contact applicants health professionals.”

“Get rid of the whole barbaric testing system and allocate as promised on trust and self-reporting. Too radical I'm sure, consequence of which would less stress all round and as there’s massive underclaiming and since none of the sums add up with alleged fraud "trust" could be a path to happiness.”

“It should be humanised instead of points everyone's disability is different.”

Retaining and improving passporting

Unpaid carers felt very strongly that the current passporting arrangements for Adult Disability Payment should be retained with 80% of unpaid carers saying it should be a high priority and 20% a high priority. The National Carer Organisations support this fully and, in addition, believe that the Scottish Government should consider what additional options may be possible for passport, including for those caring for some; whether or not they receive a carer benefit. A more inclusive approach could also explore opportunities around transport, leisure services and more to make communities more accessible for disabled people and their unpaid carers.

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Appendix 1

Results of informal polling of unpaid carers on Adult Disability Payment (Mobility)

The following is a summary of the responses from unpaid carers from Facebook polling carried out week commencing 17 April 2023. We have indicated how many responded to each poll and where comments have been supported other carers

Do you think there should be any changes made to the 'moving around' criteria for Adult Disability Payment?

150 responded to the poll

- 11% voted that the criteria should be changed so that those who are unable to walk 50 metres would be eligible for enhanced mobility
- 4% voted the criteria should be changed so that those who are unable to walk for 100 metres should be eligible for enhanced mobility
- No one voted that the criteria should be changed so that those who are unable to walk for 200 metres would be eligible for enhanced mobility
- 83% voted that the question about how far someone can walk should be scrapped, and replaced by other questions about whether you can undertake everyday activities which require you to move around.
- 1% voted that there should be no changes made to the current criteria for 'moving around' -

Comments from carers

- My 83-year-old aunt is a wheelchair user and she doesn't qualify for PIP...been a wheelchair user all her life!
- People of pensionable age only qualify for attendance allowance which makes getting Motability cars impossible if they have paraplegia, quadriplegia, or tetraplegia.
- It should also take account of the fact that one day you may push yourself further (due to an appointment or just to try and live some semblance of a life) but it then means that you will be unable to do ANYTHING the next few days due to pain and fatigue. Also, sometimes it's not about the distance you can walk, it's about the after effects of it. You may be able to walk 10 metres one day, but it means you have significantly reduced ability for several days/weeks later. (Supported by 10 people)

- The question should be scrapped and replaced with other questions which are much more meaningful. People with conditions, such as Parkinson's and MS, experience fluctuations in their condition and mobility which the current questions don't cover. If someone freezes unpredictably and becomes immobile without warning, this affects every journey, every day, even if they can walk a certain distance on some days. Setting a distance in the question is demeaning and unhelpful.
- My dad has SCI T11-L4, is paraplegic, with double incontinence and severe TBI with cognitive and executive dysfunction. Requires assistance for everything apart from feeding himself. I know some people with similar brain injuries who are quadriplegic and use assistive technology to speak and are totally dependent on others to help them into their electric wheelchairs. Neither them nor my dad could navigate anywhere without a chaperone, they'd just get lost or take risks unaware they're doing so. I personally think the mobility element should be reserved for people who are only ambulant in wheelchairs, manual or electric. I would include somebody who can only walk up to 20m in this bracket IF they use a wheelchair. My dad effectively can't go out much at all, it's all too much of a struggle for him to get up, showered and into his chair never mind go to an appointment. Shopping and leisure and normal family life stopped the moment the accident happened. I personally think they have it about right with people in my dad's degree of physical and cognitive disability receiving the most support. It isn't anywhere enough though. Because unlike most people with paraplegia who can work and enjoy careers — he also has the incontinence and the severe brain damage. It is not easy for him or my mum and the services we need to buy in are bank breaking. Going to a single appointment affects his energy levels for days afterwards.
- It needs to change. Some people can walk but with immense pain that then floors them and they need hours / days to "recover" while still being in pain and needing support from others in everyday tasks. (Supported by 16 people)
- My friend got enhanced rate they asked how far she could walk she says 100 miles but can't get out the house to do it due to mental health she was awarded enhanced rate on both (pip) not adult disability. I also got a mobility review form from child disability Scotland and it was question on his mobility all about physical and behavioural difficulties
- The criteria need to be changed to be more inclusive of people who can physically walk but for reasons of sensory overload or anxiety etc cannot and stop treating it as it being their choice not to walk. Inability to walk for reasons related to neurological disabilities needs to be properly recognised. (Supported by 11 people)
- I'm sure the criteria used to be worded like how far can you walk before in severe pain for people who weren't in chairs etc. For many we are in pain from offset but if you don't force yourself, you'd get nowhere, become unfit etc. Many of the new criteria in these benefits actually disable you more, than enable and give independence as much as possible as they should. Been through it when they did the sweep, lost my wav, blue badge etc, got my badge back at least after few years. (Supported by 5 people)
- It should take into consideration how walking a distance affects you not how far, for instance yes, they might be able to walk 50/100 yards but they could be floored for next few days (Supported by 2 people)
- Just scrap the question, in my opinion.

- Some people like my son with Autism need a support worker or other adult to go out with him as he doesn't like going out on his own and has limited sense of danger when it comes to traffic and other issues (comment liked by 20 people)
- Mobility isn't just how far you can walk, it's about the freedom to do things independently, with support or with walking aids. Mobility aids may assist you to walk a little further so it deems you to not qualify as it means you can walk further than they see fit. A more holistic approach is needed remembering not every person is the same. Mobility should be based on the individual person and their overall disability challenges. (Comment liked by 2 people)
- Yes, I think the way the Scottish Government assess mobility should be entirely different to DWP's PIP. It must not be about how many metres you can walk, but rather it should be about understanding the condition itself. For instance, as others say above, it should be about the after effects of any walking or moving around. My ME and Fibromyalgia mean I can be walking (eg. in a shop) and my "battery" very suddenly drains completely. It feels as though my feet are stuck to the floor, and a lead coat is suddenly flung around me. If I don't sit/lie down very quickly, I feel sick and very dizzy. It takes a few days, or longer for my "battery" to re-charge. Add onto that the pain and fatigue of Fibromyalgia, when you can walk along whilst being in pain, despite having taken painkillers. My 33-year-old son who is autistic and has learning difficulties is physically able but has severe anxieties, lack of time management, and this means it's tough for him to travel. The point I'm making is that assessments on mobility must not be about distances, but understanding of the conditions themselves. This is why it's great the Scottish Government will not be employing external companies, whose assessors know nothing about the condition of the person. They will instead concentrate on Consultant's/GP reports and clients own medical records. (Comment liked by 5 people)
- Especially for those who have conditions such as autism who can walk but can't go on a bus unaccompanied or only if on a regular route
- Should be scrapped and question about how you get around. My son can walk a distance physically but can't go anywhere without help as he is blind. Answer to distance walk is yes but actually can't go on his own. (Supported by 5 people)

What, if any changes, would you like to see for the 'planning and following the route of a journey'.

24 voted in the poll

- 96% would like to see some changes made to the criteria for 'planning and following the route of a journey'
- 4% voted that no changes should be made to the criteria for planning and following the route of a journey.

If you or the person you care for have a fluctuating condition, have you been successful in applying for Adult Disability Payment (the new benefit which replaces PIP in Scotland)

6 voted in the poll

- 67% voted that they have successfully applied and receive Adult Disability payment for a fluctuating condition
- 33% voted that they have applied but did not receive Adult Disability payment for a fluctuating condition
- No one voted that they have applied and received Adult Disability payment on appeal for a fluctuating condition

Comments from carers

- I'm currently in the appeal process right now and have an advocate helping me - wish I'd done that from the start as she's shown me how to properly answer the questions. One of the statements given in my refusal letter actually contradicts the Equalities Act. Plus, they never received my supporting evidence (went astray during the postal strike) and didn't ask me to resend or tell me it hadn't arrived. The whole process is flawed throughout.
- Huge waiting times, priority for life limited is a joke too, even with consultant saying 6 months their decision maker said no and chucked in normal waiting time list. Kind of sickens you when you've been in the panels shaping the benefits thinking it'd be a fairer system.

If you or the person you care for have a fluctuating condition which of the following changes to the mobility questions, would you like to see in the Adult Disability Payment application?

57 voted in the poll

- 16% voted that there should be a more flexible test, instead of the rigid points system used in PIP
- 11% voted that there should be an averaging of "points" to reflect good weeks and bad weeks
- 2% voted that different threshold should be applied for different conditions when it comes to assessing mobility
- 72% voted that they would like to see all of these changes in the new Adult Disability Payment

Comments from carers

- Get rid of the points system. I tried to get pip but was rejected basically because I'm a carer for my daughter. Their words were if I can care for her then I can obviously manage my conditions. What other choice do I have? No one else looks after her. The system is a joke.
- I think the best way of assessing is relying on client's own Consultant and GP reports, and any other health professional. And the person themselves. The points system should be done away with

altogether. I don't think any applicant can be judged on a set of points. Years ago, for Incapacity Benefit applications, there was no set of points, no assessments. The applicant applied, sent in confirmation of diagnosis etc, and it was up to DHSS (as DWP was called at the time) to contact applicants health professionals. (Supported by 2 people)

- get rid of the whole barbaric testing system and allocate as promised on trust and self-reporting. Too radical I'm sure, consequence of which would less stress all round and as there's massive underclaiming and since none of the sums add up with alleged fraud "trust" could be a path to happiness. (Supported by 8 people)
- It should be humanised instead of points everyone's disability is different (Supported by 2 people)

How much of a priority should it be to maintain the current "passporting" arrangement for Adult Disability Payment?

59 voted in this poll

- 80% voted that it should be a very high priority
- 20% voted that it should be a high priority