



Response from the Experts by Experience Panel of the Poverty and Inequality Commission

To

the Adult Disability Payment Consultation on the Mobility Component

1. Background

Experts by Experience Panel

In 2021 the Poverty and Inequality Commission¹ established an Experts by Experience Panel https://povertyinequality.scot/about/experts-by-experience-panel/. The purpose of this Panel is to shape and support the Commission's work in developing and providing advice, scrutiny, and advocacy on poverty and inequality in Scotland. This submission has been prepared by the Experts by Experience Panel.

The Panel is currently made up of 16 people with lived experience of poverty and inequality who are:

- from across Scotland, based in cities, towns and rural areas
- diverse in terms of their identity and experiences of poverty
- from groups most likely to experience poverty in Scotland

The Panel have noted one of its key priorities as being the relationship between disability and poverty and the impact that poverty has on disabled people. Disabled people have lower rates of employment and face higher costs of living and are more likely to be living in poverty ². Due to this link to poverty, the Panel has taken an interest in issues such

¹ The Poverty and Inequality Commission is a statutory body. It was established on 1 July 2019 and is an advisory non-departmental public body which provides independent advice and scrutiny to Scottish Ministers on poverty and inequality. More information about the Commission is at: https://povertyinequality.scot/

² https://data.gov.scot/poverty/#Disability

as eligibility conditions, access to benefits and the amount of disability assistance that is provided to disabled people.

Following a Panel meeting where the Experts by Experience heard from a Scottish Government official involved in the consultation and break out room discussion, a short working group made up of 5 Panel members with direct experience of disability and interest in the subject was formed to submit to this call for evidence on the Panel's behalf. The full Experts by Experience Panel reviewed a draft of this submission at its meeting on 18th April 2023.

2. Responding to the consultation 'Adult Disability Payment Consultation on the Mobility Component'

This response draws on the discussion and input at Panel meetings as well as input from a short working group of Panel members.

2.1 The moving around activity

1. Do you agree or disagree that the moving around activity criteria for Adult Disability Payment are easy to understand?

Disagree

(a) Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

The criteria as it stands is **not written in a way that allows an understanding of a disabled person's daily reality**. The questions within **the eligibility criteria are very prescriptive**, towards a yes or no answer and miss important **context**. If important context is missed at this early point, then there is a risk of people getting either the wrong or nil awards. The criteria also assumes an equivalence for different people, when there are so many factors that can impact a person's ability to move. For example, as noted by a Panel member, for one person it may take 20 minutes to move a certain distance, whilst for another it may be 5 minutes.

Further the **recovery time is not taken into account** and can differ greatly for people. One of the things that the moving around activity criteria does not cover is the **exhaustion**, **tiredness** and **effect on the individual** of moving a distance, including how long it would take to recover. For example, for some the recovery may be relatively short, for

others it could be counted in days, due to the level of the fatigue, pain management and exhaustion.

The criteria under the moving around activity and the 20 metre rule, is similar to the assessment of the Department for Work and Pensions (DWP). A Panel member described much of the criteria and questions as a "cut and paste" from the DWP and Personal Independence Payment (PIP), which was not thought to be reflective of the Scottish Government values around respect and compassion. Panel members had further issues with this as they have had experience of DWP assessors advising individuals "not to overcomplicate" their assessment under this rule. But Panel members felt that this *is* a contextual and complex issue, as the conditions upon which somebody can and cannot meet this criteria is very dependent on context. There needs to be a deeper understanding of the individual's need, as opposed to the current superficial level.

Panel members also favoured having a **50 metre** rather than 20 metre rule in the criteria as it was fairer, and didn't exclude those that need higher support and are penalised if they can move even a little over the 20 metres. Although they also wanted to highlight that physical distance doesn't measure a journey on its own, as a journey can **cause extreme mental and psychological distress**.

There also requires to be more information on **the environment and terrain** which can affect the distance an individual can walk. Whether it is the pedestrian environment, the gradient, and rest spaces that are available. People's understanding of the terrain may be influenced by what is in their own community and what they know as opposed to flat ground, which is used in the application form.

The **criteria** is written using metric measurements, distances should also be provided in alternative measures. As the application guidance talks about metres and doesn't convert to miles and feet, this may also lead to a misunderstanding and confusion for some people.

There was a wider point that there needed to be clarity in how the eligibility criteria was assessed against and influenced by legislation such as the **Equality Act** (2010) ³ to ensure its compatibility with this.

³ www.gov.uk/definition-of-disability-under-equality-act-2010

(b)How could we make the moving around activity criteria easier to understand?

To be made easier to understand, Panel members felt that the **system** and criteria needed to be made more distinct from the existing Department for Work Pensions (DWP) assessment, which does not reflect enough about what real life is like as a disabled person, so the questions in the criteria need to be re-written. For example, the criteria does not consider the consequences of disabled people pushing themselves to meet a particular mobility criteria whereas no consideration is given if the consequence of meeting the criteria is you "can't walk the next three days" as a result of exertion. Linked to this, the questions in the eligibility criteria, which are based on statements such as "Can stand and move more than ..." are also focused on very prescriptive, yes and no answers and not descriptive ones, thus do not seem to be a genuine attempt to gain an understanding of the needs of the individual.

2. Are there any other issues with the moving around activity that we have not captured above?

Yes

(a). If you said 'yes' what other issues with the moving around activity do you think need to be considered?

The criteria also doesn't take into consideration, the **affordability** aspect. Some people with mobility issues, **can't afford mobility aids**. Panel members discussed people being assessed for wheelchairs, where there is a long wait to be assessed. Some people need the motorised vehicle as they don't have the ability to self-propel. Panel members were concerned about stories of people having to crowdfund for these items. They felt that there is an inequality element that has to be considered to enable people to move around.

Also people can be **penalised in attempts to reduce their social isolation,** (for example having a pet and walking your dog) being counted against them, when this can be a huge support for those living alone. **The current system focuses in on the weaknesses of disabled people** and the criteria does not take into account the wider aspects that are central to an individuals' life.

Also some Panel members noted the need to understand the importance of considering past (and ongoing) **legal cases** that have challenged the interpretation of the 20 metre rule when determining the present standard and evaluating whether someone fulfils the necessary criteria.⁴

(b) In your view, what are the positive aspects of the moving around activity that we have not captured above?

Some Panel members thought that by having a points based system combined with the support options available to assist those applying, may mean that more people that need disability support will be eligible. Particularly in comparison to the Personal Independence Payment.

3. How effective do you think the moving around section of the application form is at helping us understand a person's mobility needs?

Not very effective

Although adding in pictures and more explanation was recognised by some as a positive. The content in the application form needs reviewed. This includes issues such as:

• Length of application (the combined application is 100 pages long) and the section on Moving around is from page 90 near the end). There is the risk that people will be too tired, lack awareness or not have the support needed to either complete the application form or provide the necessary additional information, beyond the space in the application form. There is also the risk that people won't complete an application, due to the level of anxiety that is caused by going through this process and the risk to their mental health being too high. The application was regarded as not easy to complete for those with a learning disability or difficulty and would result in excessive pain and impact for someone with a chronic pain syndrome.

A suggestion was made to simplify the form as a whole and ask those applying to write in their own words where possible, with opportunities to summarise the barriers and difficulties they faced. Also to make the process easier and less stressful, there should

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⁴ <u>www.disabilitynewsservice.com/court-hears-appeal-on-unfair-pip-20-metre-rule-consultation/</u>

be support during the application stage for those applying to send in any relevant photographs/voice/other method as suited to them to assist in explaining their conditions in a more simplified (and person centred) form.

• Although support from **third party organisations** was recognised, there were some concerns raised around the support available.

For example:

- (i) Panel members talked about having to take the initiative and bring numerous A4 pages of information when meeting with a welfare rights advisor to complete an application form. Due to the staff member time constraints, staff were unable to do the preparation work to understand the individuals needs and condition and relied on the client to do this.
- (ii) There was appreciation that Social Security Scotland have an agreement with an advocacy agency, Voice ability ⁵, to assist individuals to apply for Social Security Scotland benefits. However, there was a need to ensure the arrangements and funding of this support was transparent and upfront so that individuals could be assured of the independence in arrangements.
- There was also an issue with the way that the application form is worded, it does not account for what people have to give up to be able to do a task.
- The application form asked about mobility aids to assist individuals. The wording around aids should be more neutral so people don't assume that these have to be used for assistance. Some people have had experience of being advised not to use crutches or mobility aids when moving around, due to the adverse impact these can have, for example in inflammation of wrists.
- Although there are visuals of distances such as pictures of car parks to work out the distance, there needs to better explanation of distance for those that do not use car parks or don't drive and also for those with a visual impairment.

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⁵ www.voiceability.org/

- The question on have you been staying in a hospital, residential accommodation or legal definition was confusing. Someone might have stayed recently in one of these places but were not staying currently and it was difficult to understand this question.
- 4. What impact do you think the changes to how we make decisions on the moving around activity have on understanding a person's mobility needs?

A negative impact

There was the recognition of measures such as removing the need for physical examinations and starting from a position of trust. However, other points that the Scottish Government regarded as positive, such as only requiring one piece of supporting information and minimising the need for consultation (and thus relying on the application form) due to the reasons outlined above was an issue as it **would not give a whole picture of an individual's needs**. Panel members noted the values of dignity, fairness and respect in the ethos of Social Security Scotland, the Panel members highlighted the need for this to be evidenced by action.

Overall Panel members felt that whilst there have been enhancements to the process for applicants with disabilities, the approach was **still too tied to a medical model of disability** as opposed to a social model of disability. This was not just because of the criteria that is used, that was described by a Panel member as 'dehumanising' to fit people into categories, but also because it did not account for the **societal and attitudinal barriers** that impact upon disabled people.

5. If there was an opportunity to change the moving around activity criteria, what changes would you make (if any)?

Panel members felt that the eligibility criteria as a whole required to be changed and rewritten, taking the above comments into account. Although there was an attempt through Adult Disability Payment to make enhancements, these do not go far enough. The criteria as it stands is based on a model that focuses on the limitations and weaknesses of disabled people, is not attuned to those with lived experience and is exclusionary rather than inclusive.

2.2 The Planning and following journeys activity

6. Do you agree or disagree that the planning and following journeys activity eligibility criteria is easy to understand?

Disagree

(a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

The criteria does not cover contextual factors that can impact upon a journey. For example it focuses on if someone can plan and follow a journey, not if they would. It was stated that if you are disabled, planning a journey can be a nightmare. It can only take one part of that journey to not go right for the journey to be impossible. Issues impacting a journey can be dependent on the type of day, weather and if services are interrupted unexpectedly. For example a sudden change to bus routes, which means a person is dropped off far away from an accessible structure or toilet. Even for those that access things such as passenger assistance at a train station, the anxiety levels are high as on the day the service can be cancelled or delayed, which means that people can be "let down at the first hurdle." Whilst familiar journeys could also be impacted, such as by a road closure which can have a heightened impact for an individual, for example, those with sensory conditions.

Many rely on volunteer drivers to attend appointments, whilst patient transport and community transport options can also be unreliable and face last minute cancellations. **Having support with you**, someone with you, is **not a nice to have**, but is **required**. As noted by a Panel member, the "'holy grail' of an accessible taxi to rescue your journey is not feasible or too expensive for many". All these aspects can also seriously affect your confidence and willingness to go again on a journey, if you have had a bad experience. **Stigma and discrimination** in community settings was an additional factor as well. Again the criteria doesn't take these things into consideration.

In terms of planning and following journey, many people, won't do this independently, because not everything is likely to go to plan. The **public environment is not accessible** enough to make that journey or have the confidence to make that journey feasible. Panel members also felt that the criteria also does not take into considerations the importance of factors like self-confidence in being able to get to a destination and back. It was more complex to understand than just one journey, regardless of whether it was a familiar or unfamiliar journey. And the wording of the

criteria, "planning and following" a journey were felt as two different things and needed to be separated.

Criteria also doesn't take into account the **risk of something happening**, for example, if someone fell and could not get back up. Also for those self-shielding from **Covid**, the descriptor does not take into account the risk for those individuals. **The descriptor has not been updated for a post-pandemic reality.**

(b). How could we make the planning and following journeys activity eligibility criteria easier to understand?

It was suggested that the criteria for eligibility be **rewritten**. It **has to involve those with lived experience** and relate to the reality that people live with.

Those with a deeper understanding of the individual's needs, have to be at the centre of decision making. A case manager is unable to have a deeper understanding and can only understand the person's needs at a surface level.

7. Are there any other issues with the planning and following journeys activity that we have not captured above?

Yes

(a). If you said "yes", what other issues with the planning and following journeys activity do you think need to be considered?

Panel members also felt that the criteria also doesn't take into consideration the needs of those with learning difficulties and needs to be **more specific**. It should be person centred and tailored to the person's specific needs.

It also doesn't account for **access to toilet facilities** for individuals when they wish to leave their house and have to use these facilities regularly due to anxiety or a health condition.

There also needs to be better linkages between policies, for example sustainable travel and the use of public transport options to reduce social isolation. Particularly due to the difference in transport between **urban and rural routes.**

(b). In your view, what are the positive aspects of the planning and following journeys activity that we have not captured above?

Some Panel members thought that by having a points based system combined with the support options available to assist those applying, may mean that more people that need disability support will be eligible. Particularly in comparison to the Personal Independence Payment.

8. How effective do you think the planning and following journeys section of the application form is at helping us understand a person's ability to plan and follow journeys?

Not effective at all

Beyond similar issues raised with the application form in the 'moving around' section (2.1 (3)) above. Other key issues raised are noted below:

People that need help, don't get it. The application form assumes that people get the help they need to plan and follow a journey. By not having had the experience or the assistance to go on journeys, this can impact upon areas such as providing evidence or 'fresh' evidence.

The application form is not formatted in a way that is suitable for those with a range of different disabilities and accessibility needs.

9. What impact do you think the changes to how we make decisions on the planning and following journeys activity has on understanding a person's ability to plan and follow journeys?

A negative impact

There was appreciation around measures such as removing the mental examination and starting from a position of trust. Some Panel members thought that consultations can be more positive, **if** the staff members are brought into the culture of dignity, fairness and respect. However, there were **concerns that staff have been recruited from other social security agencies that have operated under a more punitive culture**, which can immerse itself in their ways of working and thus impact upon disabled applicants.

Panel members also felt, as earlier with the moving around section, that whilst there have been enhancements to the process for applicants with disabilities, overall, the approach was still too tied to a **medical model** of disability as opposed to a social model of disability.

10. If there was an opportunity to change any specific aspects of the planning and following journeys activity, what changes would you make (if any)?

Panel members felt that the eligibility criteria as a whole required to be changed. Although there was an attempt through Adult Disability Payment to make enhancements, these do not go far enough. The criteria as it stands is unrealistic to the realities for disabled people and the numerous barriers that they face to make a journey feasible.

Section 2.3 Support for people with fluctuating conditions

11. Do you agree or disagree that the criteria for fluctuating conditions is easy to understand?

Disagree

(a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

Panel members raised the point that tribunals have ruled that government must assess whether activities, such as walking, can be sustained for a reasonable duration, without causing significant pain or discomfort, and can be repeated following brief rest intervals. But the criteria and application process still did not account for this in an easy to understand manner. It required some work by the Panel members to try and find the legal definition that is used to help with fluctuating conditions by Scottish Government, to carry out an activity, being able to find this guidance and information wouldn't be possible for everyone. Regulations related 'to a reasonable standard' means to a reasonable standard for the activity, taking account of the impact on the individual of carrying out the activity to that standard' 6. There was note that this legal definition was not helpful, as it is too 'fuzzy'. As noted by a member, "if someone has to read a definition a number of times to try and understand it, there is something wrong with the definition."

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⁶ 33.-Reliability-criteria-for-Adult-Disability-Payment.pdf (socialsecurity.gov.scot)

Panel members noted that the current system was too much geared towards guesswork and the criteria did not take into account how life was. It was "not a simple yes/no, black and white question" in terms of their conditions. Applicants are unable to predict with any certainty what would happen in the future. Also an issue with using a descriptor that talks about 50%, is that it does not take into account a person's fuller life. It can also restrict people in doing what they wish to do, in case they go against the figure as people fear losing financial support. People can't plan when their illness will affect them more or less than 50%, this was felt to be an arbitrary figure. How do people plan when they don't know which day they will be affected by their illness? Fluctuating conditions should take into consideration what and how your illness affects you with on any specific day. The 50% also doesn't take into consideration the pain and fatigue when moving around, someone may still have to walk even if they are in pain, for example if they live a certain distance from a bus, as that is the only option available to them.

(b). How could we make the fluctuating conditions criteria easier to understand?

Some suggestions were made around the evidence gathering process for deciding on awards. There was discussion amongst Panel members, for ideas like **diaries but these were discounted** as they only cover a short period of time and there are so many factors that can influence how a condition is at that point in time. The information in the diary can become outdated very quickly. It was thought that the best method, would be **face to face discussion** with someone that was an active listener and empathetic to understand the individual's needs. Whereas due to **legacy issues**, in part, there was also concern that staff would attempt to catch you out and attempt to make a lower award, so this process would have to be managed well and **building of trust** was central.

12. Are there any other issues with the fluctuating conditions criteria that we have not captured above?

Yes

(a). If you said "yes", what other issues with the fluctuating conditions criteria do you think need to be considered?

Another factor that was flagged was around issues with getting 'fresh' evidence which can adversely impact decision making. This could be for numerous reasons including waiting on the formal diagnosis, a person

self-managing thus not seeing a medical professional regularly or due to waiting lists and waiting times for appointments.

(b). In your view, what are the positive aspects of the fluctuating conditions criteria that we have not captured above?

Not applicable

13. How effective do you think the fluctuating conditions section of the application form is at helping us understand the needs of people with fluctuating conditions?

Not effective at all

It was raised that whilst the application may have 'more space to write' about fluctuating conditions now, it still had 'less space' to explain. As fluctuating conditions and the impact of these are varied and complex, the opportunity presented within the application form process is too limited.

14. Thinking about the changes we have made to how we make decisions about fluctuating conditions, what impact do you think this is having on understanding the impact of a person's fluctuating conditions?

Neither positive/negative impact

For the reasons outlined, whilst there is appreciation of a note that case managers are advised to consider cultural, social and environmental factors and staff are advised to listen. The systemic issues raised such as **legacy issues of trust** in the system, limited opportunity to express the realities of your conditions beyond arbitrary figures such as the 50% means that there is a lot more work to be done still to give people the confidence that fluctuating conditions will be considered effectively.

2.4 Other Considerations

15. If there was an opportunity to consider alternative approaches to a points-based system to understand disabled people's needs, what alternatives would you propose (if any)?

Panel members felt that a system was needed that is **based on compassion**, **health and wellbeing** and the social model of disability, when the current points system is based on the medical model of disability. Some Panel members noted the potential 'false economy' of

an existing system that is **seen as a system set up to decline applications**, but this then pushes people to other forms of support with more money coming out of, for example, local authority budgets to fund advice and support to, e.g. to contest Personal Independence Payment (PIP) claims and find other forms of financial support. This also creates a challenge in making change – as an entire system or "cottage industry" has been set up around the existing system with many organisations and people dependant on it, or working within it.

It was noted that there is still a **trust deficit** which meant that people had to believe that the consultative processes, including for Adult Disability Payment was geared towards facilitating disability assistance for those that needed it, as opposed to being a process to reduce the number of people that can claim the benefit.

Those with **lived experience** need to be at the centre of any new system. Beyond being consulted, a suggestion of a proposed model included one based on anonymised applications, where there could be a Panel for Social Security Scotland to work with, who would **review applications**. This would be for those with lived experience reviewing the decisions made, how applications were scored and if they were granted or refused, with a process to allow for reconsideration. People's privacy would have to be respected as well as ensuring the appropriate procedures and regulations, but this can be an important part of a new process.

There was also a suggestion for the Independent Review to look at other **systems from across the world**, with the aim to build a positive model that is genuinely built on principles of the social model of disability, **beyond the United Kingdom**. There has been previous research carried out by the Scottish Government comparing disability benefits across countries ⁷ to really look for best practice and a model focused on compassion, the Scottish Government also needs to go beyond the European Union.

There needs also to be a better join up of **existing data and systems** as well which will help improve access to disability assistance,

%2BInternational%2BComparison%2Bof%2BDisability%2BBenefits%2B-%2BReport.pdf

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www.gov.scot/binaries/content/documents/govscot/publications/foi-eir-release/2018/07/foi-18-01623/documents/foi-18-01632-international-comparison-disability-benefits-report-pdf/govscot%3Adocument/FOI-18-01632%2B-

particularly for those with vulnerabilities. With different departments sharing information, so that they know immediately if someone is eligible and so people don't have to share their stories so many times.

(a). If you proposed changes, what positive impacts could these have, and for who?

It was felt that the current system based on points is undignified and not person centred and relates to the medical model of disability. People go through some of the assessments and feel really bad at the end of them. The system faces a **legacy issue**, which is "adversarial by design and suspicion was the default".

This was not the majority view, as there were a small number of Panel members that preferred a points based system to decide on applications.

- (b). If you proposed changes, what negative impacts could these have, and for who? N/A
- (c). If you proposed changes, which of these would you prioritise?

Those with lived experience being central to the design and implementation of any new system of disability assistance.

16. Other than changes to the eligibility criteria, are there any changes you think we could make to Adult Disability Payment to support people's mobility needs (if any)?

Award levels, additional monthly costs of being disabled are high. There is a gap between Adult Disability Payment and the additional cost of being disabled. The Adult Disability Payment award needs to better reflect the higher costs. ⁸

The Scottish Government and Social Security Scotland also need to be better at learning, when tribunals make decisions, they need to demonstrate learning from these decisions and evidence this. For example, Panel members thought that particularly in the DWP system, when decisions were overturned at appeal, these were looked at from an individual case perspective, rather than as a wider issue that needs improvement and highlighted, which limits learning and improvement across an organisation.

⁸ https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag/

17. How can the independent review ensure that any recommendations it makes are both deliverable and affordable? Please give reasons for your answer.

In terms of ensuring any recommendation is affordable, this requires more accessible information and transparency on Scottish Budgets and future projections and scrutiny of this by the independent review.

Priorities are for the Scottish Government, however the Panel felt that Adult Disability Payment was an investment in the people of Scotland and a key form of disability assistance that can assist in measures to reduce poverty and inequality. The Panel also thought that everything that was raised was deliverable, but required prioritisation and focus of Adult Disability Payment as a benefit aligned to the social model of disability for change to occur.

18. How can the independent review consider the impact of any recommendations on existing "passporting" arrangements?

The Panel believes that a key focus for the Independent review would be to move to a single system of disability assistance in Scotland at a level that meets the needs of individuals, without needing to rely on 'passport' processes for premiums or top up payments. Rather than perpetuating different processes which can be viewed as two parallel systems that heightens confusion and stress for individuals interacting with these. The focus should be on moving to a model of assistance that has fairness and compassion at the core.

3. Conclusion

This submission on behalf of the Experts by Experience Panel has highlighted key issues, including:

- Serious concerns that the moving around criteria does not take into account the **context** as well as the individual impact of moving over a distance for disabled people and the different levels of recovery required. Measures such as use of a 20 metre criteria was unfair to disabled people.
- The moving around criteria as it stands is a model that focuses on the limitations and weaknesses of disabled people, is not attuned to those with lived experience and is exclusionary

rather than inclusive. Many felt the current points system was not person centred and related to the medical model of disability.

- There was a significant issue with the planning and following journeys activity, as it asked if an individual can plan and follow a journey, not if they would be able to complete it.
- The criteria for planning and following journeys as it stands is unrealistic to the realities for disabled people and the numerous barriers that they face to make a journey feasible.
- The process as currently noted for fluctuating conditions is based on arbitrary figures such as 50%, a 'fuzzy' legal condition and the application process does not allow an individual to give a realistic picture of their fluctuating condition.
- There were significant legacy issues related to trust.

Recommendations from the Experts by Experience Panel included:

- Moving away from a system that is based on the medical model of disability to one that is based on a social and value based compassionate model. This is where disabled people are valued for their choice and a system that understands the systemic, discriminatory and attitude based stigma disabled people face, before designing any processes for disability assistance.
- Develop **new criteria for the 'moving around' and 'planning and following journeys'** that considers the realities and context of living as a disabled person.
- Ensure that those with lived experience are central to the design and development of a new system of mobility disability assistance.
- To tackle legacy issues due to experiences with other social security agencies in particular, work to build trust with disabled people, including evidencing change in Adult Disability Payment in Scotland.
- Ensure that **the level of awards are increased** to reflect the costs disabled people face.