

Disability and Carers Benefits Expert Advisory Group: Disability Assistance for Working Age People

To: Shirley-Anne Somerville, Cabinet Secretary for Social Security and Older People
By e-mail

20th December

Dear Shirley-Anne,

Disability Assistance for Working Age People

In your letter to the Advisory Group on 31 July 2019, you asked for advice on the currently named Disability Assistance for Working Age People (DAWAP), especially how the application and assessment process can be improved to better elicit relevant information about the client's needs and functional ability, by the end of this calendar year.

We welcome the commitment by the Scottish Government to ensure safe and secure delivery of the newly-devolved benefits, and to improve the claiming process for all recipients. We understand that our advice may incur risks, implications and challenges for the Scottish Government. These will be made explicit in the current advice note and we aim, where possible, to signpost a proposed solution.

We have worked with officials to ensure that our advice is informed by information available at this time and relevant to the current policy landscape.

We have also worked closely with people with direct experience of claiming disability benefits and benefit advisers to hear their perspectives and views. We met with over fifty individuals in Kilmarnock, Dundee, Cumnock, and Glasgow in November and early December. They provided invaluable insights that have helped shape our advice and they are acknowledged at the end of this note.

Clearly, information and the current policy landscape may change in ways that cannot be foreseen at this time, so the advice we give now is with the caveat that this too may change in light of developments.

We set out below some issues arising from our discussions to which we wish to draw to your attention. Our recommendations are summarised at the end of this letter.

Priorities

We understand and appreciate that making DAWAP significantly different from personal independence payment (PIP) raises specific challenges. For this reason, we have set out our advice in terms of short, medium, and long term priorities. We have also included a short discussion section in Annex A.

Short term priorities

Changes to eligibility rules

We understand the Scottish Government is being cautious about making DAWAP eligibility rules significantly different from PIP in the short term (i.e. on day one of delivering DAWAP and before a safe and secure transition) for two reasons.

The first is that there is a danger that if payments vary too much, the UK Department for Work and Pensions (DWP) will not treat DAWAP the same as PIP for purposes of qualifying benefit eligibility and “passporting” for reserved benefits. For example, for someone to be eligible for the carer element of Universal Credit, the person they care for must be in receipt of PIP or Disability Living Allowance (DLA). If there is insufficient parity between DAWAP and PIP, the DWP may decide a person caring for someone receiving DAWAP does not meet the requirements for receiving the carer element.

The second worry is that the Scottish Government is reluctant to create a “two-tier” system during the migration process, with two different sets of eligibility criteria and rules, whilst undertaking a significantly complicated transfer process.

On the first point, it is difficult for us to advise definitively because there appears to be some vital information missing. Specifically, we do not have a clear understanding of the point at which the DWP would make the decision not to class DAWAP the same as PIP for purposes of qualifying benefits or passporting. Instead, we understand that detailed discussion between the DWP and the Scottish Government about qualifying benefits and passporting will likely begin after DAWAP regulations have been drafted.

Until we have a better understanding of what this line is, we agree a cautious approach to eligibility rule changes in the short term is required. Based on the assumption that less significant changes create less risk to PIP and DAWAP parity for purposes of qualifying benefits and passporting, we recommend:

Recommendation 1: 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.

However, this raises a different issue. Our understanding of “a safe and secure transition” includes ensuring that no one is worse off under the DAWAP system than they were before it was introduced. This means guaranteeing as a minimum that the rights people had under PIP are retained when claiming DAWAP.

To do so, it is vital that the rights established by caselaw are reflected in DAWAP. We are not aware of any commitments being made that caselaw that has looked at the PIP legislation would be binding on Scottish Tribunals making decisions about entitlement to DAWAP. If it is not binding, it means that simply copying, as much as possible, the PIP regulations over to the DAWAP regulations may not be sufficient to establish the same rights in Scotland. This creates a number of risks:

- Individuals could end up with fewer rights than claimants currently have. As well as being inherently unfair, this would potentially create the problems discussed above that may occur if there is a lack of parity.

- It would also create a lack of clarity for individuals and for Social Security Scotland ('the agency') staff. There would be a lack of clarity even if the effects of the caselaw were reflected in guidance as this would not be binding.
- It may require the intervention of the Upper Tribunals or higher courts to establish claimants' rights and provide clarity.

Therefore, the Scottish Government should ensure that the DAWAP regulations are drafted in such a way as to ensure that individuals who claim DAWAP have at least the same rights as have been established in PIP caselaw. As such, we recommend:

Recommendation 2: DAWAP regulations should be drafted to reflect individuals' rights as established in PIP caselaw.

It is important that this caselaw is incorporated into the regulations. This is the only way to guarantee that rights established in caselaw are binding on tribunals and case managers in Scotland.

Incorporating this level of detail in legislation:

- Provides consistency
- Provides clarity
- Provides transparency

This principle should also be used to integrate the holding of *R (CJ) and SG v Secretary of State for Work and Pensions (ESA)* [2017] UKUT 324 (AAC) into the DAWAP regulations. This case established that an applicant can appeal a decision to the tribunal within 13 months of the original decision even if the department (or with regards to DAWAP, Social Security Scotland) finds the applicant failed to have good cause for requesting a redetermination outwith the prescribed time limit.

Exactly how best to reflect the caselaw principles in regulations, as well as what caselaw must be reflected, to ensure individuals don't lose out will require further consideration and expertise the group does not feel it has at present. Therefore, the group recommends:

Recommendation 3: The Scottish Government should consider the forthcoming findings of DACBEAG's independent short-life working group of disability benefit experts, which will consider how best to reflect the rights established in PIP caselaw in DAWAP regulations. We welcome the Scottish Government's participation in this group.

Guidance and Training for Case Managers

We understand that current guidance and training in the reserved system has not adequately equipped decision makers to make consistent high quality decisions, as exemplified by the successful PIP appeal rate.¹ We therefore welcome the Scottish

¹ 73% of PIP appeals were disposed in favour of the claimant at tribunal in April-June 2019: <https://www.gov.uk/government/statistics/tribunal-statistics-quarterly-april-to-june-2019>

Government's commitment to make training and guidance for decision makers as useful as possible.

However, as discussed earlier, we believe that clear, comprehensive regulations should be drafted to include all a decision maker needs to make consistent quality decisions with confidence, including clear definitions of the reliability criteria and other principles established in PIP caselaw. This is because guidance and training are not binding on tribunals. Therefore, the failure of a case manager to follow even the most robust training and guidance will be of little use to a client who is given an incorrect decision.

As such, while we agree that guidance and training should be as clear as possible to enable case managers to make consistent high quality decisions that minimise the need for appeals, we strongly recommend:

Recommendation 4: DAWAP regulations should be drafted in a way that enable case managers to make consistent high quality decisions. Regulations should provide clarity of individuals' rights. Guidance and training should demonstrate how these rights are actualised in line with the principles of the Charter.

Delivery

While we agree that, in the short term, only changes required to ensure safe and secure transition should be implemented to eligibility rules, we also believe how DAWAP is delivered should be significantly changed from PIP to improve decisions and reduce the necessity for appeals. We are convinced that getting decisions right the first time will have a positive impact on applicants, increase uptake, and reduce redetermination and appeal costs.

We have previously advised on many aspects of DAWAP delivery including face-to-face assessments, suitably qualified assessors, and informal observations, so we will not discuss these in detail here. However, we stress that an environment conducive to making fast, high quality decisions and treating people with dignity and respect should be engendered. Additionally, we feel we must reiterate our support for a social security agency that is well integrated into the wider social support landscape. That is, we wish to see clear referral pathways between social security staff and wider support, including housing support, social work, and health services, for example. Lastly on this point, we believe a comprehensive quality assurance procedure should be put in place so entitlement decisions are regularly and independently reviewed and analysed to determine where improvements to the decision making process need to be made.

As we have already made recommendations on the other points in this section, we specifically recommend:

Recommendation 5: Regular independent reviews of DAWAP entitlement decisions should be conducted, analysed, and published to determine where decision making processes need to be improved.

The group also wants to stress the importance of maintaining strong relationships between the agency and key stakeholders. This will be especially important when

establishing information sharing between medical and wider support professionals when requesting evidence from “official sources”. We understand that currently, the relationship between the DWP and professionals providing evidence is not particularly strong, which can have an impact on the quality of the evidence provided. The Group is keen to ensure that strong and positive relationships are developed and maintained between the Government at national and local level, the Agency and other key statutory and voluntary sector stakeholders.

For example, a lack of ongoing dialogue and engagement has been apparent within social care in many local authorities and this applies to a lack of honest conversations and breakdown of trust e.g. between commissioners and those directly practising social work, between social work management/leadership and disabled people/service users as well as disabled people’s organisations and carer’s organisations. To avoid a similar breakdown with the agency, conversations must be continual, leading to higher trust and a genuine belief that stakeholders - including those receiving benefits - can influence policies and decisions that affect them.

While we understand significant changes to the benefits themselves may not be feasible in the short term, improving the way the agency works with clients, professionals, and other public bodies will go a long way to ensuring DAWAP is delivered with dignity and respect. Therefore, we recommend:

Recommendation 6: The Scottish Government should have a clear, transparent plan to create and maintain positive relationships with clients, professionals, and other public bodies to ensure that DAWAP is delivered with dignity and respect. Service users and those affected by the policy or service area should remain at the heart of this process.

Evidence of Impact

We recognise it is difficult to predict the impacts improved delivery will have, which is itself a risk. We learned that part of the reason these impacts are unknown is because relevant data is not always collected, analysed, or shared by the DWP in a useful way. Therefore, in order to improve the ability to understand potential impacts when looking to make more significant changes in the future, we recommend:

Recommendation 7: Robust data collection, analysis, evaluation and publication procedures should be implemented to ensure future policy and practice decisions have a significant evidence base to draw upon.

When establishing what data to collect, we believe it is important to focus on a variety of potential impacts including a greater focus on positive impacts as well as the financial costs. For example, the positive impacts benefit changes may have on individuals and communities could include: improvements to health and wellbeing which also result in savings to NHS and social services; positive impacts on the local economy from increasing income; social and financial impacts associated with disabled people being able to travel, work, and live more independently; better social and financial support for unpaid carers, particularly those living in the same house as disabled people; and positive impacts on other family members. We believe collecting qualitative data regarding these issues could be helpful in making meaningful cost

benefit analyses. However, it should be noted that even more abstract impacts such as improvements in wellbeing can be quantified for comparative purposes if required using techniques such as Social Return on Investment.

Considering these wider impacts and collecting the evidence necessary to track them will allow the Scottish Government to maximise the impact of social security policy in future. For example, how policies impact people by gender, race and ethnicity and disability as well as from different places should be closely monitored to focus how policy needs to be changed to be more inclusive. How the language used to discuss social security is being received by the public and needs to be improved is another way well collected and analysed data can be effective.

Making sure the data is analysed and published in a transparent, accessible way will also be useful in building public understanding of why investing in social security is so important. We believe this will be especially important because creating a better social security system will in the longer-term require more investment, and this is something the Scottish Government must be open and honest about.

Review Date

We appreciate that there are many unknowns at this point that make it difficult or too risky for the government to make DAWAP significantly different from PIP when it is first introduced. However, we believe that if the Scottish Government is able to effectively collect and analyse a wide set of useful data, and once everyone in Scotland is safely transferred to DAWAP from PIP and DLA, it is paramount that opportunities for more significant changes are explored in detail. As such, we recommend:

Recommendation 8: The Scottish Government should set, in law, a regular review date to re-examine DAWAP. The first date should be within the next three years. This should require a consultation with people claiming DAWAP, relevant bodies and key stakeholders to explore what more significant changes could be made to DAWAP in light of evaluation evidence and a better understanding of the relationship between reserved and devolved benefits.

Medium term priorities

The group were asked to look at some of the aspects of PIP that the Scottish Government might consider changing. It was not clear if these changes would be brought in at the point of introduction or if they would be ideas to be implemented after a safe a secure transfer.

In light of our recommendation above, we believe that the best approach is for a safe and secure transition and a clear date for a review of disability assistance. This will allow data to be gathered to identify those who are not entitled to DAWAP, but may have additional costs associated with their disability and provide data to model potential changes to better understand the implications of such changes.

That said, there are some questions officials asked us to consider we feel we can address at present.

The 50% Rule

We know that under current PIP rules, an activity descriptor is deemed to apply to a person with a fluctuating condition if it reflects how their condition affects them for more than 50% of the required period (one year). We've heard that this standard is difficult for claimants for a wide range of reasons:

- It is difficult to quantify how your condition affects you in such a discrete way.
- Disabled people may find it hard to focus on the negative impact of their impairment or condition, especially where this fluctuates over time.
- People with some unpredictable conditions, for example myalgic encephalomyelitis (ME), multiple sclerosis (MS), or epilepsy, may not always have acute symptoms that fit within this rule, but nevertheless require significant support when symptoms do occur. In addition, the effort of walking or moving can bring on symptoms such as fatigue associated with some conditions such as MS, ME, JRA etc.

As a group, we believe many of these problems arise not from the 50% rule itself; rather, they are due to decision makers failing to properly apply the other relevant rules of PIP, especially as clarified by caselaw.

Regulations state an activity descriptor applies if the client can (or cannot depending on the descriptor) carry out an activity "reliably" which is defined to mean safely, to an acceptable standard, repeatedly, and within a reasonable time period. Significant caselaw describing what these terms mean has developed in the past few years. Ensuring these rules are properly applied may, in the short term, address many of the issues discussed above.

The DWP has relied on changes to guidance and training to have these principles reflected in PIP entitlement decisions. However, as evidenced in part by the extremely high percentage of PIP decisions that are overturned at appeal, these criteria are not being correctly applied by decision makers.² This provides further reason to ensure that caselaw is integrated in to the DAWAP regulations, as opposed to relying solely on staff guidance and training.

Therefore, we recommend:

Recommendation 9: On balance, we are not persuaded that the 50% rule needs to be specifically changed in the near future. Instead the rules as they stand need to be correctly and consistently applied. However, this position is not unanimous: further discussion is set out at Appendix A.

We believe more needs to be done to ensure the changing nature of conditions is better dealt with by the system in other ways as well. Some conditions do not simply fluctuate. While more often conditions deteriorate over time, some get better. However, the cliff edge clients currently face if an improvement to their condition

² 73% of PIP appeals were disposed in favour of the claimant at tribunal in April-June 2019: <https://www.gov.uk/government/statistics/tribunal-statistics-quarterly-april-to-june-2019>

means an activity drops below the 50% threshold can be detrimental to people's health. As such, we also recommend:

Recommendation 10: The Scottish Government should explore how a tapered "parachute" payment or run on period for those whose conditions improve might be implemented in DAWAP to reduce the impacts the cliff edge of eligibility currently intrinsic to PIP creates.

We would be happy to provide more detailed advice about the possible impact of any other specific changes to entitlement the Scottish Government may have. Some of the discussions we had, and some of the ideas we raised, when looking at some of the other areas are included in appendix A. We didn't make any firm recommendations on these issues but would be happy to look at any areas in more detail if that is helpful.

Long Term Priorities

Once disability assistance is wholly in the control of the Scottish Government and how changes to these benefits will affect eligibility to reserved benefits is better understood, there will be opportunities for more fundamental changes to how disabled people are assisted in Scotland.

We believe that when this point is reached, the Scottish Government should clearly articulate what it thinks disability assistance is supposed to be achieving. Is it primarily to help with the extra costs inherent to being disabled? Is it to compensate people for the lack of accessibility exhibited by society? Only when its overall purposes and desired outcomes are better understood can we truly begin to form a better version of social security for disabled people in Scotland.

We therefore recommend:

Recommendation 11: The Scottish Government should consult with the people of Scotland to decide what the overarching purposes of disability assistance in Scotland should be, and then act on these findings.

Whatever it decides, Scotland should aim to be a world leader in this regard. This should be led first and foremost by a clear purpose and set of principles, rather than by current fiscal or political constraints. Scotland must be ready to create a new and more effective system of social security to serve the principles in the Social Security Act and Charter.

Finally, due to the uncertainty and constraints the Scottish Government currently faces in developing its new social security system, we believe there is a valuable ongoing role for an independent advisory group like DACBEAG beyond March 2021.

Our remit is to provide advice to Ministers on the benefits that seek to help to meet some of the additional costs of a disability, those that provide financial support for people injured or affected by "prescribed diseases" in the course of their work, and carers' benefits. As discussed above, we understand that significant variation from legacy benefits is not feasible at this time, but there is a clear appetite to explore further changes in the future. We believe an independent advisory group like DACBEAG

would be a boon to the Scottish Government when the time to look at these broader changes comes.

There is much work still to do to reshape social security in Scotland beyond the imminent safe and secure transition phase, which we understand will last into the next parliament. We therefore recommend:

Recommendation 12: DACBEAG's remit should continue into the next parliamentary term until the opportunity to more substantially shape disability and carers benefits in Scotland has passed.

Recommendations

Please see below our key recommendations.

Recommendation 1: 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.

Recommendation 2: DAWAP regulations should be drafted to reflect individuals' rights as established in PIP caselaw.

Recommendation 3: The Scottish Government should consider the findings of DACBEAG's independent short-life working group of disability benefit experts, which will consider how best to reflect the rights established in PIP caselaw in DAWAP regulations. We welcome the Scottish Government's participation in this group.

Recommendation 4: DAWAP regulations should be drafted in a way that enable case managers to make consistent high quality decisions. Regulations should provide clarity of individuals' rights. Guidance and training should demonstrate how these rights are actualised in line with the principles of the Charter.

Recommendation 5: Regular independent reviews of DAWAP entitlement decisions should be conducted, analysed, and published to determine where decision making processes need to be improved.

Recommendation 6: The Scottish Government should have a clear, transparent plan to create and maintain positive relationships with clients, professionals, and other public bodies to ensure that DAWAP is delivered with dignity and respect. Service users and those affected by the policy or service area should remain at the heart of this process.

Recommendation 7: Robust data collection, analysis, evaluation and publication procedures should be implemented to ensure future policy and practice decisions have a significant evidence base to draw upon.

Recommendation 8: The Scottish Government should set, in law, a regular review date to re-examine DAWAP. The first date should be within the next three years. This should require a consultation with people claiming DAWAP,

relevant bodies and key stakeholders to explore what more significant changes could be made to DAWAP in light of evaluation evidence and a better understanding of the relationship between reserved and devolved benefits.

Recommendation 9: On balance, we are not persuaded that the 50% rule needs to be specifically changed in the near future. Instead the rules as they stand need to be correctly and consistently applied. However, this position is not unanimous: further discussion is set out at Appendix A

Recommendation 10: The Scottish Government should explore how a tapered “parachute” payment or run on period for those whose conditions improve might be implemented in DAWAP to reduce the impacts the cliff edge of eligibility currently intrinsic to PIP creates.

Recommendation 11: The Scottish Government should consult with the people of Scotland to decide what the overarching purposes of disability assistance in Scotland should be, and then act on these findings.

Recommendation 12: DACBEAG’s remit should continue into the next parliamentary term until the opportunity to more substantially shape disability and carers benefits in Scotland has passed.

I hope this is helpful and look forward to your response.

With best wishes,

Dr. Jim McCormick

Chair

*With special thanks to those who hosted and took part in discussion groups with PIP and DLA claimants and Welfare Rights advisers:

Sarah Hammond and colleagues, East Ayrshire CAB – Kilmarnock
Lucinda Godfrey and colleagues, Dundee Carers Centre
Sarah Hammond and colleagues, East Ayrshire CAB - Cumnock
Tressa Burke and colleagues, Glasgow Disability Alliance

APPENDIX A

Issues for Further Consideration

The group understands that there are some features of PIP the Scottish Government is currently looking at changing, if not right at the point of transfer, as soon as practicable. We lay out our thoughts and some from the groups of community members and advisers we spoke to below.

These do not form part of our recommendations, but are instead discussion points aimed to flag issues that might be explored further and addressed at a later date.

The Mobility Component

The rigid nature of the mobility component is something we are keen to address. People explained they find it hard to meaningfully appreciate distance set out in terms of metres, and they felt not enough credence was given to how movement affected them. For example, someone may be able to walk 200 metres at one time, but that would mean they could not do any other activities that day.

We also heard that the way mobility is tested now fails to take into account the realities of the client's situation. That is, the PIP distance test seems to take place in a hypothetical world of flat surfaces devoid of obstacles.

People told us they have difficulty picturing how long 20 metres is and suggested something more relatable (e.g. how many houses could you walk by) might make questions easier to answer correctly.

Additionally, we agree that how mental health conditions affect people are not given as much weight in the mobility activities as they should. This is especially evident in the "planning and following a journey" mobility activity which requires the extremely high threshold "overwhelming psychological distress".

With regards to "overwhelming psychological distress", changing the descriptors from "cannot plan/follow" to something more nuanced would better capture people who have difficulty doing these things. We heard "Overwhelming Psychological Distress" has been given a very limiting definition which requires the client to exhibit physical symptoms such as rapid breathing, sweating, retching, shaking, or rocking.

We discussed wording closer to "would experience psychological distress at some point during planning..." may be more appropriately inclusive as "overwhelming" becomes redundant when deciding whether or not a person can conduct an activity to the relevant standard.

Our discussions with stakeholders gave some further possibilities:

- Mobility descriptors could be more tailored to the client's actual experience. For example, people could be asked how they cope going to their nearest shop or what the terrain around their home is like and how they mobilise in those conditions.
- How weather or lighting affects the client's mobility could be considered.

- Descriptors should focus on how severely mobilising would affect the individual, not whether or not they can achieve a certain distance even with the “reliably” criteria.
- How much support might be required before, during, or after should be part of the descriptor (similar to DLA).

Fluctuating Conditions

While we do not believe the 50% rule needs to be changed in the short term, we do believe more needs to be done to ensure the changing nature of conditions is better dealt with by the system and to cover conditions that still require significant support but do not fall clearly under the rules as they currently exist.

We do not believe creating new activities or descriptors for specific conditions is the best way to do this, as there is a distinct possibility this will create an unhelpful precedent. We believe it is impossible to accommodate all distinct conditions and people with conditions that are excluded would feel especially alienated.

That said, there are some ways the system could become more flexible to all kinds of conditions.

For example:

- Implementing a more discretionary “safety-net” regulation to allow those not currently captured by the PIP rules to be nevertheless treated as entitled if a different threshold is met.
 - Employment Support Allowance has a similar provisions (Reg 25(2)(b) and 31(2)(b) of the 2013 regs). Its threshold is “there would be a substantial risk to the mental or physical health of any person if the claimant” is not found to be entitled.
 - The threshold could be something similar to the DLA requirements (e.g. virtually unable to walk).
- Different thresholds could be applied to different conditions similar to Industrial Injury Disability Benefit. For example, someone with fibromyalgia might only need to meet a descriptor 30% of the time in order for it to apply.
- There could be an ‘averaging’ of points. For example, if someone scores 24 pts in a bad week and 6 pts on a good week, and a bad week happen on average 1 week in four, they would average 10.5 pts.
- Returning to the more flexible DLA test as it better captured people who do not fit neatly into the more rigid PIP framework.

We are aware that there are many individuals who are not currently entitled to PIP and have great need. In the short term, changes to other forms of assistance, such as access to blue badges and travel assistance, may be a way to provide some support whilst longer term changes are made to DAWAP.

Mental Health

As we touched on above, we believe that how mental health conditions affect people is not given enough sufficient weight in the current system, especially when

compared to physical abilities. While, we believe a large part of the problem is due to the reliability criteria not being correctly applied, there are other ways mental health could be better represented in the PIP descriptors. For example, the inability to conduct an activity due to psychological distress could feature in both mobility activities, as well as some daily living activities.

We also discussed the issue that there may be too wide a gap between needing prompting and requiring supervision or assistance. We discussed the possibility of creating another descriptor that applies to people who do not need active supervision or assistance, but who need someone nearby because supervision or assistance may be required imminently, or because they would not actually complete the activity if there was not someone else in the vicinity.

Groups we spoke to suggested:

- Words to describe what's needed could include: an "additional presence", and "good peer pressure".
- How able the client is to keep the house clean should be part of the descriptors