



The national carer organisations welcome the opportunity to respond to this important consultation.

The National Carer Organisations are brought together by a shared vision that all Scotland's unpaid carers will be valued, included and supported as equal partners in the provision of care and will be able to enjoy a life outside of caring. They are Carers Scotland, the Coalition of Carers in Scotland, Minority Ethnic Carers of Older People Project (MECOPP), Carers Trust Scotland, the Scottish Young Carers Services Alliance, Crossroads Caring Scotland and Shared Care Scotland.

In responding to this consultation, we have consulted with carers including an online consultation and Facebook polling and built upon numerous previous consultations and engagements with carers on social security in Scotland. A separate report detailing all survey responses will also be submitted.

## **Section 1 – Disability Assistance in Scotland**

### **Q1-6 Do you agree with the proposal to rename disability benefits?**

- Disability Assistance for Children and Young People (to replace Disability Living Allowance for Children)
- Disability Assistance for Working Age People (to replace Personal Independence Payment)
- Disability Assistance for Older People (to replace Attendance Allowance)

The national carer organisations agree in principle with this approach. Carers in our survey were in favour by 75% to 25% of this renaming of the three disability benefits. However, it is important that the names of the new benefits are clear and easily understood.

Carers in our survey expressed some concerns which we believe should be taken into account.

The terminology “working age” is worrying to some carers, noting that it could be viewed as both insensitive and something that places pressure on disabled people. Many disabled people would like to be in employment but cannot either because of their disability and conditions they experience or the barriers to work that many disabled people face.

To step away from this terminology and ensure that there is no link to employment status, the national carer organisations would suggest consideration of other names for the benefit for adults under pension age, for example, **Disability Assistance for Adults**. Alternatively, consider a simplification (and shorter name) by calling all benefits Disability Assistance and adding ages (under 18, over 18 and 65 and over).

Other comments by carers included a question on the term “disability” and suggested using terminology that is more focused on enabling independence and daily living. Suggestions including “**Independence Assistance**” or “**Daily Living Assistance**” (although disability living assistance could cause confusion with DLA).

In this respect, we are in agreement with the ALLIANCE whose response suggests a focus on a social/human rights model in naming the benefits.

Finally, there were some concerns that renaming the benefits may cause confusion. We do however understand and agree with the move away from Personal Independence Payment (PIP) in particular which has been a bruising experience for many disabled people and carers.

Whatever the names chosen, a clear and accessible public and stakeholder communication strategy will be needed to ensure that all those currently in receipt of disability benefits and their carers fully understand the change, and so too do organisations working to support them.

*“Simplify the system - one disability benefit paid to all age groups.  
Easier and more cost effective to administrate”*

*There have been too many name changes over the years already; I genuinely can't see any benefit to changing them again. The whole process is confusing enough but there needs to be lots of publicity about the changes of names so that people are aware of them*

Finally, we would note some concerns raised regarding disabled people who are reaching pension age. The current system has transfers of people on Disability Living Allowance (DLA) who are of pension age onto PIP, with the associated risks. We believe that there must be clarity in the description of the benefits for those currently of pension age and claiming PIP or DLA. It should be clear that they will be moved onto the proposed “Disability Assistance for Working Age People” rather than the lower value Disability Assistance for Older People (where they would lose the mobility component).

#### **Q7 Do you agree or disagree with the proposal to enable multiple application channels for Disability Assistance?**

The national carer organisations agree with this approach and 100% of carers in our survey also agreed. In our survey 100% of carers who responded agreed and comments focused on the need to ensure that all channels are accessible, highlighting issues such as literacy, costs of online access, language and physical barriers. The need for face to face to include home visits to complete forms is important and the role of the third and public sector, funded adequately, will be critical in supporting this approach.

*Some people may require home visits to assist with form filling. Agencies are very stretched; particularly social work and these forms can take a minimum of 2 hours to complete, depending on the abilities of the claimant giving the information.*

*Voluntary and other agencies should have good training in completing these forms and make their selves familiar with the particular illness of the person they are assisting.*

*I am aware of several carers who need assistance with reading and carers*

*who can only use their phone for internet connection when they have available data and can't afford to add more funds.*

**Q9 Do you agree or disagree with the proposal to broadly replicate the current temporary absence rules?**

In general, this is an appropriate response, however Ministers/the Agency should have some discretionary powers for individual cases, for example, if a person who has worked and lived abroad for some time returned to Scotland requiring care or to provide care. Providing care and support to disabled people saves additional costs elsewhere in the system. A lack of financial support would be a barrier and does not make practical or financial sense

**Q11 Do you agree or disagree with the proposal to implement a person-centred approach to making decisions about entitlement for Disability Assistance?**

We agree that putting the person at the centre is a vital principle in making decisions. However, critical to this is not just changing the process for making decisions but having a full and holistic understanding of the person and their needs. An interesting comment was made from one respondent which should be kept in mind when considering terminology - "people are people, not cases".

**(a) Form**

Improving decision making starts at the form. Therefore, as well as commenting on the proposals around Case Managers, use Specialist Advisors and Assessments, carers made a wide range of comments of how the forms to apply for disability benefits could be improved. Our full survey report details every response but in summary there are some clear messages:

- the length of the form must be reduced
- it must be made less complex and written in plain English (and available in easy read and other languages)
- there must be less ambiguity in questions asked
- questions must be less repetitive
- there must be better questions or a different form for people with mental health issues or learning disabilities that better reflect their needs and enables them to be better explain the issues they face.
- there must be more space to allow better and more detailed explanations
- there should be less yes/no questions, with those only in place where they serve a clear purpose.

*The PIP form at almost 49 pages is not inclusive and induces fear and worry amongst those who have to deal with it. That has to stop. Also, having to provide evidence in spades can place pressure on disabled people and their families. That said, the choice of how evidence/supporting info is provided/by whom, should be there.*

Finally, what a number of respondents made clear was that in designing the form, the Agency must understand the impact of having to repeat again and again the things a child or adult cannot do. For carers this can be deeply distressing.

*Too complex and harrowing for grieving parents coming to terms with something awfully difficult.*

*It asks for a lot of information that is repetitive. It takes days or weeks to complete. It is very emotional and stressful documenting all the things your child can't do or has difficulty with and triggers my anxiety.*

*Finally, a small section at the end inviting parents to write any positives about their child - it's very draining to write about all the negatives and things we/they can't do and would help us if we can finish on a good note (it should be made very clear, however, that the positive comments won't be included in the decision making)*

### **(b) Case Managers**

72% of carers in our survey agreed with the proposals for Case Managers. However, in recruiting these managers, there is a need to recruit sufficient numbers to ensure that they have manageable caseloads to ensure that decision making is not rushed. In addition, carers identified the need to recruit people with a depth of experience and understanding of disability, including issues such as impact of disabilities, including hidden impact and self-management. Training was identified by respondents as being critical, including disability awareness training.

*Case managers' training needs to be sufficient for them to be able to follow the criteria without bias or favour*

*Case workers with training or experience in basic health problems would be very reassuring as I have been told previously by an employee looking into my son's claim that it was doubtful my son would get DLA for his heart defect as a "heart is not a major organ!"*

*A case manager is only as good as their own life experience & the training they receive. All too often have I seen a situation that was blatantly obvious but DWP staff unable to understand how the condition can impact severely on that person's health.*

### **Q13 Do you agree or disagree with our proposed approach to the involvement of Specialist Advisors in Decision Making?**

Most carers in our survey (85%) agreed with the involvement of Specialist Advisors, however, it is yet unclear without seeing more detailed guidance on the circumstances they would be involved and what information would be requested to assist in decision making.

*Case managers should get specialist information when it is needed. However, it must be clear what the criteria are for getting specialist advice, and the specialist must know what they are, and what they are not, being asked to comment or give advice on. Specialists must have good training on their role, and*

*know the limitations of what advice they are able to give. One can envisage that there would be a range of specialists who give advice and support for specific issues, and a case manager may need to approach more than one to ensure that there is as full a picture as possible*

*Good to have "specialists" with more knowledge of some disabilities as long as they understand not all people are the same. My daughter's duplicate chromosome condition is so rare only a handful of fellow Scots have it. Her paediatrician only knows the basics. our family are the specialists. This might be the same for others.*

*I would like more information on how the specialist advisers are qualified to make such important decisions.*

Carers said repeatedly, as with Case Managers, that training, awareness and understanding are vital. This includes understanding the fluctuating nature of many conditions and that whilst two people may have the same condition e.g. MS, the impact may be completely different. More than anything there is a need to place equal value on the descriptions of the disability/condition(s) from disabled people and their carers.

*The same disability and health condition can and will affect people differently.*

*The suggestion that there is a "general" affect/impact does not reflect how every person is unique in their experience of any given disability/condition. This rigidity is harming current claimants and personal testimonies should always be remembered when life-changing decisions are made. The claimant's answers/experience will always best reflect how their health impacts on their life.*

*The specialists must have knowledge - full training would give confidence in the system.  
As things stand there are too many assessors who seem to have limited knowledge of even quite well known conditions.*

As the national carer organisations have stated often and in agreement with the ALLIANCE a more joined up system would mean the new Social Security Agency has a key role in seeking out relevant information and connecting with processes to identify eligibility for other types of support e.g. blue badge, social care, carers allowance for any carer involved, adult carer support plans and young carers statements. Specialist Advisors could play a key part in achieving this but this will need to be a clear part of the recruitment and guidance for these roles.

The roles of both Case Manager and Specialist Advisor are critical to achieving much fewer face to face assessments and there is a need to clearly articulate how this is intended to happen. Improved decision making including much fewer face to face assessments are critical to building trust in the new Scottish social security system.

**Q15 What factors should Case Managers take into account in deciding when a Specialist Advisor should be involved?**

Social Security Scotland should consider involving a specialist advisor when an individual is identified as:

- Living with a rare or complex condition
- Living with more than one long term condition
- Living with a fluctuating condition
- Where the case manager is questioning aspects of the case, such as the impact of the condition (e.g. a second opinion)

It should be clearly set out to people submitting applications where responsibility lies for providing further evidence to support a claim.

It is also important to note the relationship between Case Managers, Specialist Advisors and Assessors in supporting the local delivery aims of Social Security Scotland. The relationship between each of these roles and Local Delivery Leads will be critical in ensuring a holistic approach that supports people's varied needs, whilst also connecting people to various other supports and services available across Scotland.

Information provided by a Specialist Advisor should also be shared with the individual as part of the notification of the outcome of a decision.

**Q16 Do you agree or disagree that the decision making process for Disability Assistance for Children and Young People, and for Older People should use existing supporting information and not through face-to-face assessments?**

Agree. However, we would note that whilst more than 80% of respondents to our survey agreed that this the right approach, a few comments noted some concern and wondered whether, if a parent or older person requested a face to face assessment if they felt this was an easier/better way for them to describe impact, then this could be accommodated.

In addition, there was clear disappointment and frustration that people of working age were being treated differently. The national carer organisations share this concern.

*Why are these groups treated differently? Children don't do face to face it would be their parents, why are old people and parents more trustworthy than 57-year-old me with MRI's in hand. Or even my 30-year-old son with autism, PDA and very challenging behaviours, why does he need to go through face to face because he's 30? I thought the need for repeated face to face assessments was to be removed? Am I now being told I will have to go through a face to face for a benefit I already fought for in the old system?*

*Why does it differ from working age. This is not fair. A disabled person doesn't choose his disability in childhood or working age or old age. There is no choice. It happens when it happens. All ages need treating equally*

Q17 If you disagreed, please could you explain why.

There was clear disappointment and frustration that people of working age were being treated differently. The national carer organisations share this concern.

Q18 What types of supporting information would be relevant in assessing an application for Disability Assistance e.g. social work report, medical report?

The national carer organisations and carers in our survey believe that information should come from the widest range of sources possible. However, with guidance it should be made clear to decision makers that there must be no hierarchy of supporting information. Information from an individual and/or their carer as to the impact of a disability and condition should have as much weight as a report from a medical professional on their condition.

In the main, we would hope that information provided by individuals and, if available, their carers on the application form and that of their GP and other medical professionals should be sufficient to make a decision on an application. It should be noted however that many individuals with stable long term conditions or lifelong conditions such as a learning disability may have little contact with GPs and consultants outwith routine appointments. Therefore, information from relevant others in such cases, for example, allied health professionals, social workers and third sector workers, along with information from the individual and their carer/family should be enough to come to a decision.

*Not all individuals with ASD have social work or medical professionals active in their lives*

In line with the intention of a person centred approach to social security, sources of supporting information should be flexible. Therefore, supporting information should not be confined to a specific list and individuals should be encouraged to consider any information that provides relevant supporting information to their application.

*The information should be drawn from as broad a range of sources as possible, social workers, support workers, community activists etc.*

*A variety of information providers should be used, depending on who the disabled person has most contact with - some may not have any Social Work input particularly if there's no 'paid' care being given. Family Carers are never assessed or supported by social work department in my many years of caregiving experience, therefore a report from them would be useless. Consultants, GP's, District Nurses, Physiotherapists & Occupational Therapists would be the main options.*

Carers in our survey made a range of suggestions including:

- information from the person and those close to them including carers, families and friends.
- information on medication e.g. a prescription list

- medical reports from medical professionals such as GPs, consultants, nursing including nurse practitioners, health visitors, Community Psychiatric Nurses (CPNs) and district nurses.
- reports from school or nursery
- reports from Allied Health professionals such as speech therapists, occupational therapists, physiotherapists etc.
- reports from third sector workers who are involved in support or care

The national carer organisations would also include reports from social workers and social care plans. However, we would urge some caution in this as social care provision is linked to eligibility criteria and as such receipt of formal care services can vary widely from area to area and does not necessarily reflect need or the impact of disability or long term conditions.

*Social reports may not be accurate or up to date! The usefulness of medical reports will vary depending on the condition which an applicant has (e.g. an applicant with autism might not be receiving any medical treatment therefore a medical report would be brief and not give much information). Speech Therapy & OT services are difficult to access with some conditions; therefore, the lack of a Speech Therapy report does not necessarily mean that a person does not have communication difficulties. Statements from friends & family should be taken into account as they are likely to be more specific and accurate.*

The collation of supporting information must be the responsibility of the Case Manager, with, as described, their role including the requirement to request reports from people identified in the individual's application. Whilst we have noted that the list of supporting information should not be restrictive, it may help to describe some of the "core" people who could help, and for example:

- Unpaid carer and family
- Doctor or GP
- Physiotherapist
- Social Worker
- Counsellor
- Support Worker
- Consultant
- Nurse
- Psychiatrist
- Community Psychiatric Nurse

**Q19 Do you agree or disagree with the proposal to have no set award durations but to set an award review date when a decision on a Disability Assistance application is made?**

Agree and disagree.

There is broad agreement from carers with the principle of an award review date rather than set award durations, particularly with carers often speaking of their experiences of the person they care for having award durations that are short and reviews happening too often.



Carers in our survey were strongly in favour (some 95%) of people receiving disability benefits under special rules because of a terminal illness being subject to no review date.

There was however considerable disquiet that those with lifelong conditions will be reviewed, even if this is for a period 5–10 years in the distance.

**Q20 If you disagreed, please could you explain why.**

The national carer organisations believe strongly that the Scottish Government should remove completely any future “review” in circumstances where an individual’s condition will not improve. There are many individuals with long term conditions and disabilities that are unlikely to change or improve and adding short review periods, even where that is 5-10 years, is of not value and likely to cause stress and anxiety to the individual and their carer. We agree with the recommendation of the Disability and Carers Benefits Advisory Group that review periods should be “as long as possible and not as short as possible” with no minimum review period<sup>1</sup>. This should be person centred and clear guidance should be issued to case managers to support this.

*Twice my wife has had lifetime awards revoked, and once myself. Both of us have long term (never going to improve) conditions. Conditions, illnesses, ailments that will be with the claimant for the rest of their life should NOT be ridiculed by continuous assessments*

*Even more reviews,? Why? Again think degenerative illnesses that are not getting better, the review will say, still not cured. I am very disappointed in this and see no difference to the old system, apart from more people knowing our health issues like social work, which is NOT a good thing. The set end point of someone with a degenerative illness, is this when we are cured or we die?*

*If someone has a lifelong condition, why are the rewards being reviewed when the needs won't change? If anything the needs increase the longer one lives with a condition and then the applicant can request they are reviewed if they feel the award should be increased*

In the circumstance of what is in effect a lifetime award, individuals with lower awards, can be reminded that there is an opportunity to come back and ask for a review if their condition worsens.

**Q21 Do you agree or disagree with the proposal to set an award review date 5-10 years in the future for a person with a condition unlikely to change**

There is broad agreement from carers with the principle of an award review date for all recipients rather than set award durations, particularly with carers often speaking of their experiences of the person they care for having award durations that are short and reviews happening too often.

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<sup>1</sup><https://www.gov.scot/binaries/content/documents/govscot/publications/correspondence/2019/03/disability-and-carers-benefits-expert-advisory-group-award-duration/documents/dacbeag-advice-to-ministers-award-duration/dacbeag-advice-to-ministers-award-duration/govscot%3Adocument/DACBEAG%2Badvic%2Bto%2Bministers%2B-%2Baward%2Bduration.pdf>

*Really sickening that currently ASD, Tourette's Syndrome & PDA are reviewed after 2 years. These are neurological conditions and won't go away.*

*Absolutely agree. I have previously had to renew my sons claim for a congenital heart defect annually despite being no cure for this*

There was however considerable disquiet that those with lifelong conditions/conditions that are unlikely to change will be reviewed, even if this is for a period 5–10 years in the distance.

**Q22 If you disagreed, please could you explain why.**

Many carers in our survey felt this was a good step forward but whilst they and the national carer organisations welcome the move away from the current system of one, two and three year awards, feel that there are a large number of people for whom any award review date is not only unnecessary and costly, but brings stress and concern. As noted in Q20 individuals in these circumstances should be able to request a review if their condition deteriorates and/or their needs increase.

Carers in our survey made a number of comments on this issue, including:

*Should be more than 5-10 years. It's quite obvious when something is a lifelong disability.*

*it should be a lifelong award, why review after 5 or 10 years? This is a waste of everyone's time.*

*A condition, ailment, illness that has no end or chance of improvement should be treated as that and claimants should not have further stress added by being reassessed at any interval. If the claimant is awarded the benefit, in these circumstances the award should be for life of the claimant or that benefit is no longer applicable to claimant.*

*If the condition is unlikely to change, the review must be simplified and made a formality in practice.*

In our view, in a person centred system, it makes little sense to review people with lifelong conditions. For others individuals, reviews should be significantly less frequent than at present.

Even putting aside the human element and the impact on individuals and their carers, it simply makes no sense to the public purse in spending limited resources on unnecessary reviews.

**Q23 Do you agree or disagree with the proposal that a change of circumstances should be defined as a change which has an impact on the level of assistance a person receives?**

Agree.

Q24. If you disagreed, please could you explain why.

N/A

Q25 Do you agree or disagree with the proposal that clients have 31 days to request a redetermination?

Carers in our survey strongly agreed (some 94% were in favour) however, we have some concerns that this may be too short. Some people will require additional time to request a redetermination because of their circumstances or their disability/condition. The timescale also needs to allow for individuals and their carers to have time to seek independent advice. We welcome the fact that there will be additional flexibility of up to a year where a good reason is supplied but believe that it may be appropriate to extend the standard redetermination period further e.g. something equivalent to 2 calendar months.

This would apply equally to appeals to the First Tier Tribunal. Individuals must have sufficient time to seek advice and support and submit their appeal and we believe that 31 days is not a long enough period.

Q26 If you disagreed, please could you explain why.

See above

Q27 We have proposed that Social Security Scotland have a period of between 40 and 60 days to consider a redetermination of Disability Assistance? Do you agree or disagree with this proposal?

Disagree

Q28. If you disagreed, please explain why.

Whilst roughly two thirds of carers in our survey felt this was appropriate, the national carer organisations believe that this timescale is too long. This refers to working days which seems a particularly long period to make a decision, particularly bearing in mind that people seeking redeterminations are allowed only 31 days. We do not wish to suggest a specific timescale at present but suggest that it is equalized with that of people seeking a redetermination e.g. both equivalent to 2 calendar months.

Q29 Do you agree or disagree that STA should not be paid to people who are not living or present in Scotland?

Disagree

Q30 If you disagreed, please could you explain why.

We would need some clarity as to whether this includes individuals who may be living outside Scotland on a temporary basis.

Q31 Do you agree or disagree that STA should not be recoverable except where it is later established that the principal assistance type was claimed fraudulently when STA was awarded?

Agree.

Q32 If you disagreed, please could you explain why.

N/A

Q33 Do you agree or disagree that STA should not be available where an investigation by Social Security Scotland has determined that the original payment was claimed fraudulently?

N/A

Q34. If you disagreed, please could you explain why.

N/A

Q35. Do you agree or disagree that any deductions being made from an on-going assistance type to service an overpayment liability should also be applied to STA?

Disagree

Q36 If you disagreed, please could you explain why.

We believe that deductions should be held in abeyance until such time as a redetermination or tribunal decision is made. However, we would note that the principles that underpin overpayments and the responsibility on whom these fall should continue to made clear to both individuals in receipt of disability assistance and Agency staff.

Q37 Do you agree or disagree that for successful process decision appeals where the tribunal has overturned Social Security Scotland's decision, STA should become available at the point the decision is overturned rather than the date of the original request?

N/A

Question 38. If you disagreed, please could you explain why.

N/A

Short Term Assistance

The national carer organisations believe that Short Term Assistance should be paid to individuals throughout the appeal and redetermination process

**Question 39. Do you agree or disagree with the proposed approach that, generally, where there is a break in a client's eligibility to receive the benefit, e.g. due to being in residential care, they will cease to receive the benefit?**

Disagree. Carers in our survey were broadly in disagreement with this approach. Those who took part in polling disagreed significantly.

**Question 40. If you disagreed, please could you explain why.**

We agree with the response from The ALLIANCE, that "in order to effectively answer this question, we require for the purpose of the entitlement to be spelt out in greater detail. If, as this suggests, the entitlement is being introduced in order to ensure and encourage people to remain as independent as possible then this is an understandable aim. However, if the assistance aims to help people to cover some of the extra costs if they have a long term condition or they are a disabled person then it is less understandable."

Being in residential care does not mean that an individual's condition or financial position has improved. Equally, hospital stays are in general temporary and as such carers and the individual will continue to have both costs and needs that are not met by the NHS. For example, we know that many carers stay or spend most of their time at hospital providing support to the person they care for, particularly where person has, for example, complex needs or dementia.

Equally parent carers in our survey noted that more time is needed when a child is in residential care and that entitlement should only change when a placement is permanent.

*Some people who are in care away or hospital from home, still need an element of care from original carers - take in clothing, toiletries, do washings, help feed them. The carer benefit should not be stopped. Also when well enough to go home, but no care package is in place for them to return home, care benefits should continue/ restart.*

*For working ago people needing hospital stays but who still need the regular support of a carer (as is the case for my son as he is not safe to stay in hospital alone) it isn't right that the payments are stopped*

*"Bills don't go away and possibly household expenditure which these benefits are part of will increase due to hospital visits, transport, parking etc.*

In addition, for many people the income they receive will be part of household income and as such will impact on the household being able to continue to pay ongoing bills and not fall into debt.

In this respect it is worth noting the real struggle that carers **already face**. Over a third of carers (36%) responding to State of Caring 2018<sup>2</sup> described their financial situation as 'struggling to make ends meet'; while a further 22% said they are in or have been in debt as a result of caring. Half of those struggling to make ends meet already cut back on essentials such as food and heating to cope.

Many carers have little or nothing to fall back on to manage sudden changes in household income. Two thirds of carers have used their savings (38%) or credit cards (32%) to make ends meet, reducing long term and sometimes retirement income and storing up debt for the future.

*Disability assistance should be continued for everyone in hospital for 3 months. Commitments and disability expenses do not cease purely because a person is in hospital. The cessation of these payments also affects Carers benefits and has a hugely detrimental effect on unpaid Carers who are relying on Carers Allowance - they cannot simply go out and get an alternative form of income instantly after 28 days.*

By not reforming breaks in eligibility rules for adults and older people, the Scottish Government risks exacerbating this situation.

The national carer organisations have significant concerns over the continuation of, what is the current DWP break rules, in the new Scottish social security system. This will direct impact on unpaid carers.

*Disabled people still have expenses even when they are away from home... e.g. rent and contributions to a household. e.g. I am my son's primary caregiver, I can only work part time because of this so do not have a high income. If he was to be away from home, I could not suddenly get a new short term full time job to make up for the loss of his contribution to the household costs which we have to share between us*

The Scottish Government must consider how eligibility can be retained for unpaid carers in relation to a range of entitlements whilst someone is in residential and, particularly, hospital care. Breaking eligibility to receive disability assistance has a direct impact on carers, removing their eligibility to receive Carers Allowance and premiums. There is a real danger that this will bring greater financial hardship for unpaid carers, even though their caring role would not cease and indeed they may have more costs.

*28 days is too short a time. It seems to disadvantage anyone who is not a child and their carers because a hospital stay might go on after a major operation or accident.  
Carers lose their allowance too so it's a big deal*

**Q41 Please outline any comments or experience you would like to share with us about overpayment recovery and the current DWP approach to deductions?**

We would like to use this space to raise our concerns about the current issues with overpayments of Carers Allowance and how this can quickly become a significant issue. We would not like to see such

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<sup>2</sup> Carers Scotland, State of Caring in Scotland 2018 <https://www.carersuk.org/scotland/policy/policy-library/state-of-caring-in-scotland-2018>

difficulties extended into the new Scottish security system and would note that whilst this consultation is on Disability Assistance, difficulties in overpayments for carers have in many cases a direct impact on households with disabled people of all ages.

The UK Government's figures estimate that in 2017/18, 9,300 "recoverable overpayments" were made where carers earned over the earnings limit (£120 per week). A total of 57,000 overpayments have been recorded for this reason since 2011/12. A further 2,100 overpayments due to the full time study rule were also identified over this period. We do not yet have significant intelligence of the numbers of carers affected in Scotland, although we have heard anecdotally that carers in Scotland are receiving letters seeking repayment.

Our colleagues at Carers UK, in writing to the UK Government have noted "We hear from carers who are told that they have been overpaid Carer's Allowance. This can happen when carers did not realise the rules in relation to earnings, studying or other rules. This can be hugely stressful, particularly for those providing significant care or who are juggling responsibilities, or who are on low incomes and are finding it hard to manage financially."

The rules around the earnings threshold are complicated and exacerbated by the cliff edge nature of Carer's Allowance. Carers who earn even 1p over the earnings threshold become ineligible for Carer's Allowance (£64.60 per week) and significant overpayments can accrue in a relatively short period of time. For example, in an 8-week period this could amount to over £500. Where such small errors have occurred over a more extended period of time, or intermittently over a period of years, overpayments could amount to thousands of pounds.

The rules around full time study are perhaps equally complex. Full time study is treated as being in full-time education if students attend a course' at a university, college or other educational establishment for 21 hours or more a week. These 21 hours include not just classes, lectures and seminars, but also individual study for course work. Students are regarded as studying under supervision if you are doing course work, whether at home or at college, alone or in the presence of a supervisor. A carer may be physically attending further education classes only on a part-time basis and believe that they are eligible for Carer's Allowance (as a part-time student) but do not realise that study and work at home is included in the calculation of hours. As noted above, overpayments could very quickly mount up e.g. over a three-year period of study to over £10,000.

When overpayments occur, particularly when they go back several years it can be extremely difficult or even impossible for carers to repay. Equally, young people studying may find themselves with unsurmountable debt at the beginning of their adult life.

## **Section 2 – Disability Assistance for Children and Young People**

**Q42 Do you agree or disagree with our proposal to provide entitlement to Disability Assistance for Children and Young People to clients aged 0-18 years?**

We agree with this and carers in our survey were also strongly in agreement (95% said they agreed).

**Q43 If you disagreed, please could you explain why.**

We agree and welcome the extension of entitlement to age 18 but agree with the response from the ALLIANCE that consideration should be given to extending this to age 21. This approach would make sense for many young people and their families who would then have some certainty in income at a time where young people and their families are facing multiple transitions including e.g. in and out of further education, changes to entitlement to other benefits in the family and claiming Employment Support Allowance etc. It is worth noting that this would bring entitlement into line with ILF in Scotland's Transition Fund, which recognises the key transition points for young people as between 16 and 21

**Q44 Do you agree or disagree with our proposal to extending eligibility, for those in receipt of Disability Assistance for Children and Young People before the age of 16, to age 18?**

Disagree.

**Q45 If you disagreed, please could you explain why.**

As per Q43

**Q46 Do you agree or disagree with our approach to the eligibility rules for the different components of Disability Assistance for Children and Young People?**

In general we agree and carers were broadly in agreement (89%) with the statement that eligibility rules should mirror that of the current Child Disability Living Allowance.

- 85% agreed that the payment should start from the age of 3 months where children will be eligible for the care component.
- 84% agreed that children should be eligible for the high rate of mobility component from aged 3
- 73% agreed that children should be eligible for the low rate of mobility component from aged 5.

Around the mobility component, carers made a number of comments around how this component needs to better understand and align with children who have learning disabilities, autism etc. and be available from an earlier age.

*The higher rate of mobility component needs to make greater allowance for learning disabilities - a child might be technically able to walk but if they get distressed for any reason they can technically unable to walk.*

*More support needs to be provided to parents and carers of children with autism.  
Rules for the mobility component needs to be changed to better accommodate parents and carers of children with autism*



*The mobility rate should be set at high from age 2 as this would mean the child has more needs than another 2-year-old (most are walking by 2) this would allow parents to have a car via the Motability scheme*

We would therefore suggest careful consideration is given to eligibility for this element, working with parent carers to understand the needs of their children and young people and what would be the most appropriate age to begin the high and low rates of the mobility component.

- 96% agreed that the upper age limit should be raised from 16 to 18.
- 86% agreed that children and young people should have had their condition or disability for at least 3 months and be expected to have them for at least 6 months and that if they are defined as terminally ill they do not need to meet these qualifying periods.

**Q47 If you disagreed, please could you explain why.**

Carers were less sure over proposals that new claims for young people aged 16 to 18 should be for PIP until the Scottish Government introduces the new Disability Assistance for Working Age People. Two thirds agreed but as noted earlier, we would welcome Disability Assistance for Children and Young People being extended up to age 21 and made ready for new claims as soon as possible. With the difficulties that individuals claiming PIP have had with the system, the Scottish Government should do everything in its power to prevent young people from having to claim within this system.

*16 years old should not go into PIP but direct onto the new Scottish system*

**Q48. Do you agree or disagree with the proposal to make a £200 Winter Heating Assistance payment to families in receipt of the highest rate care component of Disability Assistance for Children and Young People?**

Agree.

**Q49 If you disagreed, please could you explain why.**

Whilst we strongly agree and welcome the commitment to introduce this to families with a child in receipt of the highest rate care component of Disability Assistance for Children and Young People, there needs to be careful consideration of the transition when a child turns 18 and moves to assistance for working age people.

This is a time of considerable transition for families, including impacts on other benefits in the household. If families were to also lose entitlement to the Winter Heating Allowance, despite the young person continuing to live at home, this would only exacerbate tight family finances.

We also have concerns that families with a young person who has had to make a new claim for PIP instead, because they are aged 16 to 18 (see Q46 and 47) or are currently 16 and on PIP would lose out.

We would like to see this Winter Heating Assistance extended to all people on Disability and Carers Assistance no matter their age. This is a matter the Scottish Government should seek to deliver to recognise the additional costs that carers and disabled people face in heating their homes.

### **Section 3 – Disability Assistance for Working Age People**

**Q50 Do you agree or disagree with our proposal to use a points based system to assess eligibility in relation to Disability Assistance for Working-Age People?**

Two thirds of carers in our survey were in favour of the points based system but we do not believe there is sufficient information to make a judgement at this time.

*You mean like PIP? Can't agree without knowing what points would be awarded for and at this point I have no clue about that. What will the walking rule be? It used to be 50 metres without pain, now it's 20 minutes with pain or not, ridiculous and massive difference, will you put an end to this farce? People like me fight really hard and push through pain every minute of every day and the fact that I will try to walk 20 metres to keep myself as fit as I can while suffering serious pain should not detract from how my disability is regarded. I cannot walk one foot without pain and as I type I am in pain because I have been sitting too long, I have pain at all times. Oh and I have to wear a splint just so I can walk in a semi straight line. Under current PIP rules there is a good chance of me losing benefits and I have more issues than you could know, including toilet issues.*

*Please don't make the mistake of assessing people on face value with narrow criteria, even if I could walk at a good rate for 20 metres I still require to use disabled parking and can't go anywhere with no toilets or I will have an accident, are points scored for that? Am I wasting my time typing all of this when it will likely be collated and things like this will be removed and leave us all in the same boat as always?*

*Will invisible disabilities ever be taken into account for more than just using a disabled toilet sign?*

**Q51. If you disagreed, please could you explain why**

Whilst this may be something to use in the interim to allow for safe and secure transition and new claims to be submitted for an interim period but there is much more discussion needed on what we want for the future. A broad conversation with people with lived experience on a range of approaches needs to be had to ensure that we have a system that is fit for the future.

We cannot simply replicate the points and descriptors for PIP and expect individuals and their carers to place trust in the new system.

In addition, we have some concerns over the criteria that individuals will need to have had “the physical or mental difficulty for at least 3 months and expect them to continue for at least 9 months”. We would like more clarity on how this would be applied when individuals have fluctuating conditions, particularly mental health issues.

*A points system can be too cut and dried particularly if people have conditions that fluctuate on a daily basis so there needs to be scope for further consideration to be made if required.*

**Q52 Do you have any suggestions about the most appropriate way to assess eligibility in relation to mobility for Disability Assistance for Working Age People?**

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.

*Pain, fatigue, and even the after effects of walking must be taken into account.  
The fact of walking a short distance isn't enough to say that it is manageable all the time and flare ups can come after that.*

*Pain is a factor not considered under the current system & this should be of consideration.  
The surface that people with disabilities walk upon affects their ability to walk. If you walk on sand, grass or outdoors at all, it takes more effort. Walking indoors on a flat surface takes less effort.  
Indoor steps & gradient of steps or stairs also play a part on the difficulty to use them i.e. open stairs, narrow stairs, steep stairways.*

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.

*Mobility isn't always about getting from point a to b, it should take into account the effort required, the pain caused and the long term effects of doing so. Myself for instance, if need be I can walk 500yds, however, it is agonising and I suffer for days afterwards. The current system doesn't take these into account, the new Scottish Government system should.*

*How someone moves about on the assessment day may not provide a true reflection of their illness, someone with MS may move well one day but then be floored for a number of days from that exertion.  
Perhaps documentation from a consultant or GP could verify such things.*

*If people are in pain it doesn't matter how far they can drag themselves and if they are going to poop themselves, it doesn't matter how far they can walk. Yes, mobility when toileting is an issue is important, we need to be classed as disabled to get to use those disabled parking spaces which place us nearer to any toilet. Imagine struggling with pain while you walk while trying to hold in the toilet. Disability and the effect it has on a person's life is not just about walking distances, it's also about the fact that I keep having to leave this survey to move or seize up and about the fact that my hands and arms are aching from typing, it's about how close I am to a toilet and about how many times I wanted to*

*crawl into a hole when I didn't make it. It's about having to plan meals taking into account of how long you will have to be on your feet to cook it. My disability isn't about how many steps I can take, although I can't go far, but it's more about how long I can be on my feet whether standing or walking, If I was to walk to the end of my street I could get there, about 50 yards but I would be sore the whole time, still I make a good go of it, but if my neighbour meets me and decides to chat there's every chance I can't get to the end of that street and at times it's difficult for me to get home.  
I hope this can be understand it's not about how far, it's about how long you can stand before your legs buckle under you.*

**Q53. Do you have any comments on the full list of descriptors currently used to assess claims for Personal Independence Payments?**

As noted above, the Scottish Government should develop descriptors and eligibility criteria that is about empowering people, supporting them to self-manage and

We agree with the ALLIANCE who note that these are in conflict with the Scottish Government's broader attempts to put the emphasis on asset-based approaches to supporting people who live with long term conditions, disabled people and carers (e.g. self management or the recovery approach in mental health). We believe that the Scottish Government has the opportunity to take a more progressive approach.

As noted above the "20-metre rule" should immediately be scrapped and replaced with a 50-metre substitute in the interim period.

We are also concerned, and agree with the ALLIANCE, that the current descriptors don't work for people living with fluctuating conditions (particularly the emphasis on doing "these safely, to an acceptable standard, as often as you need to and in a reasonable time" – which can change depending on the nature of a fluctuating condition). We are also concerned that for each descriptor the only mental health consideration taken into account is "a lack of motivation" which does not appropriately describe the nature of mental health problems and their broader impact on a person's daily living.

*Not all illnesses and disabilities can be scored, some can differ from day to day so need more details than this.*

*They need to realise that cognitive impairment is just as disabling in many ways as physical.*

**Q54 What types of observations, as part of a face to face assessment, do you believe are inappropriate?**

Carers noted that informal observations were not necessarily of any use and in their experience were made on issues that were not relevant, did not take account of the different environment, of care provided by an unpaid carer or the fact that such an assessment is only a given point in time and does not reflect an individual's day to day experience.

*I am a carer. My wife has mental illness and I make sure she's dressed and clean. You wouldn't know she had a illness unless you see her when unwell. I feel because I look after her and take care of her she can be judged on her appearance which doesn't take account of her mental state.*

*You can do this in this environment you must be able to do it on every day life. With autism, the ability to function can change dependant on many different factors.*

*Whether a person "looks" tired/in pain or not is irrelevant to how they feel. Chronic illness means people get good at looking much better than they feel; this helps feeling normal. How a person is dressed is irrelevant; whether a person makes eye contact or not; whether a person can pick up a bag/pen etc.; strength and grip can go up or down, e.g. during flare up.*

*Body language - people are generally very nervous. Ability - someone could be having a good day in regards to walking, social skills etc. and be seen as more able than they are. Positive language/personality - a claimant should not feel that they have to go "cap in hand" and miserable to be deserving. Being positive is how most of us get by and we shouldn't have to force ourselves to be depressed to gain the panel's pity*

To this end, we believe that informal observations should never be included as part of any face to face assessment. Any observation made during the assessment should be discussed with the individual and become part of a formal discussion as part of the record of the decision made about the individual's eligibility.

#### **Q55. In relation to assessments, what are your views on acceptable distances to travel?**

Carers in our survey were clear that this needs to be as local as possible and in general no more than 10 miles away. It was also clear that this must be personalised and based on individual circumstances, the person's disabilities, transport availability and where they live. Any assessment centre must be fully accessible with sufficient parking, including disabled parking spaces. This includes accessibility into the and within the building itself.

Many felt that, as face to face assessments are expected to be minimal, home visits were more appropriate.

#### **Q56 What other circumstances should the Agency take into account?**

Distance is only one issue to consider. As noted above, the individual's disabilities or condition, where they live and local transport availability are all relevant circumstances to take into account. Issues such as recent illnesses should also be relevant.

**Q57 In relation to assessments, how many times do you think an individual should be able to reschedule, or fail to attend, an appointment?**

Carers offered a range of options ranging from twice to as many times as is required. This reflects the fact that, as above, we believe that individual circumstances must be taken into account. We would suggest that Social Security Scotland be as flexible as possible.

*As long as valid and documented reason e.g. hospital, doctors, illness or due to issues with a child or young person or elderly person for e.g. where you still have responsibilities to these people. Four or five times as the current two strike no third appointment is too strict and not flexible at all. Less stress about restrictive timings the better.*

**Q58 In relation to a missed assessment. do you have any comments on what should amount to exceptional circumstances (e.g. hospital admissions)?**

Carers noted a range of circumstances that should be included, a hospital admission being only one of many. This includes recognising that individuals and their carers have other responsibilities and issues such as illness of a child should be taken into account. Our key message is that if a limit is going to be in place, the circumstances that should be allowed for a cancellation should be as wide as possible to take account of fluctuations and flare ups, family circumstances and more. As noted in the response, in a new social security system, the Agency should trust individuals that cancellations are genuine rather than expect them to be “exceptional circumstances”.

*Caring for someone is tough. A difficult night, a particularly bad episode or incident and everything is up in arms. There needs to be an element of trust here.*

**Q59. Please provide any comments you wish to make about the audio recording of assessments.**

We welcome the commitment to recording face-to-face assessments which we hope will address the issues that people have experienced in Personal Independence Payments. Individuals should though have the right to request that an assessment is not audio recorded.

We agree with the response from the ALLIANCE that the Scottish Government should consider the potential for video recording of assessments in future.

#### **Section 4 – Disability Assistance for Older People**

**Q60 Do you agree or disagree with our proposal that Disability Assistance for Older People is provided to those who are state pension age or older?**

We agree with this proposal and there was strong agreement (96%) from carers in our survey. However, some comments were made on the impact of equalisation of state pension age on women and suggestion that disability assistance for older people should be available from age 60.

Q61 If you disagreed, please could you explain why.

N/A

Q62 Do you agree or disagree with the proposed eligibility criteria for Disability Assistance for Older People?

We agree in part

Q6. If you disagreed, please could you explain why.

We believe that consideration should be given to the addition of a mobility component for older people. This would connect social security with Scottish Government policies to enable older people to connect with their communities, reduce isolation, retain independence and social connections. This also includes recognising the particular challenges of older people in remote and rural communities where public or community transport is limited.

*Claiming the Mobility component needs to be extended to those of pension age.*

*Disability assistance should be the same for all adults regardless of age*

Equally, carers are concerned about those older people who are currently in receipt of Disability Living Allowance or Personal Independence Payment and that these individual's entitlement to these working age benefits continues under the new system, including when a request is made to consider increased care or mobility needs. This must be made crystal clear in legislation and guidance.

*Again, why copy the current system? How will those currently on DLA/PIP be treated if they are older/reviewed? Will they forced to move onto DA for older people with no mobility component?*

Q64 If you have any further comments you would like to make relating to Disability Assistance benefits not covered by this consultation document, please provide them below.

### **Immediate and longer term changes to disability assistance**

Whilst we agree that a safe and secure transition of social security powers is vital, there needs to be some immediate changes, beyond those which are outlined in the consultation. As noted earlier, the 20-metre rule must be immediately increased with further work undertaken to consider how mobility needs can be identified and supported through Disability Assistance.

To this end, we agree wholeheartedly with the ALLIANCE and others that the Scottish Government as part of this consultation should lay out a timescale for a fundamental review of disability assistance, beyond safe and secure transition.

*I truly congratulate you on your efforts to implement a fair, just and compassionate system that allows disabled people to engage in life as far as their condition allows. Please don't over generalise or be too rigid with qualifying criteria - remember that it is individual human beings with complex, ongoing conditions whose vulnerability and susceptibility to falling through the safety net is an ever present threat. You genuinely could hold their very life in your hands.*

## **Application**

As noted earlier, carers had clear messages for the improvement of the application forms.

- the length of the form must be reduced
- it must be made less complex and written in plain English (and available in easy read and other languages)
- there must be less ambiguity in questions asked
- questions must be less repetitive
- there must be better questions or a different form for people with mental health issues or learning disabilities that better reflects their needs and enables them to better explain the issues they face.
- there must be more space to allow better and more detailed explanations
- there should be less yes/no questions, with those only in place where they serve a clear purpose.

## **Face to Face Assessments**

Carers continue to have significant concerns over proposals for face to face assessments. Whilst the Scottish Government appears to be clear that these should be reduced significantly, the criteria for circumstances where a face to face assessment would be required feels too broad.

*This survey seems to talk a lot about face to face assessments yet I was under the impression these would be reduced. There should be no need for face to face assessments for people who can provide a consultant's diagnosis. This would save money spent on these assessments and that money could go into paying for benefits or social care. I thought that was the idea behind our own social security system. Save money cutting out red tape and paperwork, admin, assessors, case workers by using what is at your disposal, our well trained consultants.*

Carers also noted inequality in the proposals for face to face assessments, where working age people were being treated differently from children, young people and older people. This included noting that a disability or condition does not change just because a person reaches adulthood. This should also be seen in the light that people with disabilities and long term conditions of working age also often have to face assessments for Employment Support Allowance.



*Why are these groups treated differently? Children don't do face to face it would be their parents, why are old people and parents more trustworthy than 57 year old me with MRI's in hand.*

*Or even my 30 year old son with autism, PDA and very challenging behaviours, why does he need to go through face to face because he's 30? I thought the need for repeated face to face assessments was to be removed? Am I now being told I will have to go through a face to face for a benefit I already fought for in the old system?*

*My query is this. Why should people of working age have to experience a face to face assessment when others don't?*

*Why does it differ from working age. This is not fair.  
A disabled person doesn't choose his disability in childhood or working age or old age.  
There is no choice . It happens when it happens. All ages need treating equally*

Some carers in our survey suggested it should only be required when an individual requests it or as part of redetermination or appeal.

*Unless requested by the person*

*Why have you taken the choice away from parents of a face to face if they wish for this?  
If you actually mean 'ordinarily the two above benefits will be assessed by the information presented to the assessor, but a face to face may be requested by the parent if they feel this will better present their case' then I would agree to that.*

*I disagree. I think it only right & fair that this group have a fail-safe to have the chance of a face to face if they feel it is warranted*

*But only if there is an option for right to appeal.*

Simply put, there is simply not enough detail to understand how the Scottish Government will turn warm words into reality. We have real concerns that unless this is clearly articulated and genuinely a minimum, there is a risk of immediate lost of trust in the new Scottish social security system.

## **Rates of payments**

As we have noted in the past, we believe that all forms of Disability Assistance and Carers Assistance should be uprated in line with the Retail Price Index (the inflationary measure with constitutes the most accurate measure of the real cost of living). Using the Retail Price Index, would be an important measure in ensuring that households with someone of any age with a disability or long term condition and their carers do not continue to fall behind the rest of society.

## Qualifying periods

All forms of disability assistance are proposed to require a condition to have existed for at least three months. We believe that this period should be shorter as in most circumstances it is clear from an early stage that an individual will need support. The ALLIANCE has suggested a qualifying period of 4 weeks which we feel is an appropriate timescale. This will help support individuals and their carers at a time where income can drop dramatically e.g. individuals only receiving statutory sick pay, carers having to give up work to care, taking significant periods of time off because a child or adult is in hospital.

For example, in Cancer's Hidden Costs<sup>3</sup>, individuals with cancer and their carers reported that the costs of a diagnosis were often immediate and significant. Almost one in three (30%) people living with cancer experienced a loss of income as a result of their diagnosis; those affected lose, on average, £860 a month. A third of respondents (33%) stopped working either permanently or temporarily.

All forms of disability assistance should have the same qualifying period.

*6 months is too long - you try living being newly blind for 6 months and see how you get on!!!*

## Conclusion

The national carer organisations welcome the Scottish Government's considerable efforts in providing both this consultation and supporting policy intention papers. We hope that our response, supported by the responses from many carers, will help in refining Disability Assistance in Scotland and ensuring that it truly meets the policy and public intentions of the legislation.

## For more information

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<sup>3</sup> Macmillan Cancer Support (2017) Cancer's Hidden Price Tag: Revealing the costs behind the illness