

Health and Social Care Alliance Scotland (the ALLIANCE)

Response: Social Security: A Consultation on Disability Assistance in Scotland



The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has a growing membership of over 2,800 national and local third sector organisations, associates in the statutory and private sectors and individuals. Many NHS Boards, Health and Social Care Partnerships and Medical Practices are associate members. The ALLIANCE’s vision is for a Scotland where people who are disabled or living with long term conditions and unpaid carers have a strong voice and enjoy their right to live well.

The ALLIANCE is delighted to respond to this consultation, having long supported the devolution of social security entitlements to control by the Scottish Parliament. In our submission to the Smith Commission¹ we noted that social security is “inextricably linked with a range of matters which are already debated by Scottish Ministers and in the Scottish Parliament, including health, social care, housing and transport.... in order for the transfer of welfare powers to have a meaningful impact for people who use support and services however, these would need to be accompanied by the right for the Scottish Parliament to take an approach to social policy that differs from that of the UK Parliament.”

Section 1 – Disability Assistance in Scotland

Q1. Do you agree or disagree with the proposal to name Disability Assistance for clients aged 0-18 years old Disability Assistance for Children and Young People (DACYP)?

Disagree.

Q2. If you disagreed, please could you explain why.

There is a tension between the Social Security (Scotland) Act 2018, which uses medical model language (such as “disability assistance”, “impairment” and “adverse effect on the individual’s ability to carry out normal day-to-day activities”) and the social model

¹ <https://www.alliance-scotland.org.uk/wp-content/uploads/2019/05/Submission-to-the-Smith-Commission-October-2014.pdf>

language used in the consultation document (for example, that used in the Cabinet Secretary's introduction), and the shift towards a human rights based approach to social security.

We suggest something less focused on the medical/charitable model and more focused on the social/human rights model, for example:

- 'Independence Payment/Entitlement for Children and Young People'
- 'Dignity Payment/Entitlement for Children and Young People'
- 'Equality Payment/Entitlement for Children and Young People'

Q3. Do you agree or disagree with the proposal to name Disability Assistance for clients aged 16 years old to state pension age Disability Assistance for Working-Age People (DAWAP)?

Disagree.

Q4. If you disagreed, please could you explain why.

There is a tension between the Social Security (Scotland) Act 2018, which used medical model language (such as "disability assistance", "impairment" and "adverse effect on the individual's ability to carry out normal day-to-day activities") and the social model language used in the consultation document (for example, that used in the Cabinet Secretary's introduction), and the shift towards a human rights based approach to social security.

In addition to this, the new entitlement should not, in any way, be linked to an individual's employment status. Public misperceptions of both Disability Living Allowance (DLA) and Personal Independence Payment (PIP) have long been to link them to an individual's ability to complete work related activities, confusing them with the functions of incapacity benefit and ESA.

As identified in the second independent review of PIP², "Claimants must also have absolute confidence that being in employment does not, in any way, disadvantage them in the assessment for PIP; the Review has seen indications that this may not be universally the case at present."

² The Second Independent Review of the Personal Independence Payment Assessment, May 2017, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/604097/pip-assessment-second-independent-review.pdf

While we recognise that eligibility will not be determined by whether or not people are in work, use of the words “working age” in this context could be complicating. It has a dual risk of creating stigma and discouraging people who are entitled from applying. A clear communication campaign about the new assistance should set out the purpose of this entitlement in a clear and accessible fashion.

We suggest something less focused on the medical/charitable model and more focused on the social/human rights model, for example:

- ‘Independence Payment/Entitlement’
- ‘Dignity Payment/Entitlement’
- ‘Equality Payment/Entitlement’

Q5. Do you agree or disagree with the proposal to name Disability Assistance for clients who are state pension age or older Disability Assistance for Older People (DAOP)?

Disagree.

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

There is a tension between the Social Security (Scotland) Act 2018, which used medical model language (such as “disability assistance”, “impairment” and “adverse effect on the individual’s ability to carry out normal day-to-day activities”) and the social model language used in the consultation document (for example, that used in the Cabinet Secretary’s introduction), and the shift towards a human rights based approach to social security.

We suggest something less focused on the medical/charitable model and more focused on the social/human rights model, for example:

- ‘Independence Payment/Entitlement for Older People’
- ‘Dignity Payment/Entitlement for Older People’
- ‘Equality Payment/Entitlement for Older People’

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

Agree.

Q8. If you disagreed, please could you explain why.

As part of this welcome progress, functionality should be built into online channels by Social Security Scotland for an online facility for both people applying for disability assistance (and those applying for them) and external Health Professionals to upload supporting evidence securely if they choose. This should also contain the functionality to switch between channels where possible e.g. scanned paper applications should be available for people to access online.

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

Agree.

Q12. If you disagreed, please could you explain why?

We agree that person-centredness is an important principle of the decision making process for disability assistance, but it is equally important that rights-based approaches to social security are also adopted. As such, decision making should not be driven by a targets-based culture or by budgetary considerations but a holistic understanding of the individual and their rights. Good awareness and understanding of human rights and rights-based approaches may well require specialised and dedicated training and ongoing support for staff and management at all levels in the new agency.

Social Security Scotland must also place a particular emphasis on training and supporting those involved in administering the system to develop and use other skills, for example in good communication, active listening and facilitation. Although these are often called 'soft' skills, they can be difficult, requiring specific and specialist training, continuous improvement/professional development, and approaches should be reviewed in regular supervision.

In order to fulfil the principle of continuous improvement, Social Security Scotland should also consider what requirement should be placed on decision makers to attend tribunals in order to learn from the approach taken and reflect on the reasons why a decision might be overturned at tribunal.

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

Don't know.

Q14. If you disagreed, please could you explain why.

It is not possible to determine the merits of this approach on the basis of the bullet point included in the command paper.

The approach taken is dependent on the aim and longer term purpose of the new entitlement. At present, PIP is a payment which aims to establish functional ability in order to assess the person's level of independence, rather than whether they have a condition or not. DLA had been a payment to recognise the additional costs of living with an impairment. As such, the approaches taken to establishing eligibility were different. Our understanding is that the Scottish Government intends that the new entitlement will take an approach more akin to PIP than DLA, but it would be helpful to get greater clarity on this.

The most frequent suggestions for change to the social security system made by ALLIANCE members in consultation on these issues has long related to the need for those making decisions about eligibility to be properly trained, qualified and supported to do so. The current approach doesn't do enough to understand the condition the individual is experiencing and isn't proactive enough at identifying when a face to face assessment may be unnecessary and dehumanising.

As we have noted in previous consultation responses³, a more joined up system would mean the new Social Security Agency seeking out key information, for example, researching an individual's medical history and connecting with processes to determine eligibility for other types of support e.g. blue badge, social care. We believe that a Specialist Advisor could play a significant part in achieving these aims, but that this needs to be clearly articulated during design and recruitment of this role – alongside a direct principle that is about how this role can ensure fewer face to face assessments. We also advise employing Specialist Advisors with lived experience of disability, long term conditions and unpaid care, as well as expertise by training.

³ https://consult.gov.scot/social-security/social-security-in-scotland/consultation/view_respondent?show_all_questions=0&sort=submitted&order=ascending&q_t=health+and+social+care+alliance&uuld=141973433

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

It should be clearly set out to people submitting applications where responsibility lies for providing further evidence to support a claim. Applicants should be able to request that Case Managers consult a Specialist Advisor on their application form (if it can be guaranteed that a specialist will actually have the requisite expertise, e.g. if it is about a particular condition or combination of conditions).

The application form could contain a question phrased along the following lines: “Would you recommend that we consult a Specialist Advisor* if there are any queries about your application? (*A Specialist Advisor is ...[definition])”.

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.

In the interests of transparency, all information provided by a Specialist Advisor should be shared with the individual as part of the notification of the outcome of a decision, irrespective of that 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.

Q17. If you disagreed, please could you explain why.

We strongly support the decision not to include face-to-face assessments for children and older people, however we recommend that the Scottish Government give greater

clarity on how the decision to retain the possibility of face-to-face assessments for individuals in other age groups has been arrived at. It is important to be able to demonstrate that this decision complies with human rights principles as well as equalities law.

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

It should be possible to use a mixture of evidence from a range of available sources. There should be no hierarchy of supporting information (e.g. evidence from a medical professional should not have more weight than from the individual who lives with a long term condition).

Where possible information provided on application forms, by GPs and other medical professionals should be enough for a judgement to be made. Some participants in the ALLIANCE's Welfare Advocacy Support Project suggested of the existing face to face assessments for Personal Independence Payments "they got nothing from my interview that wasn't there in the medical notes."

Supporting information should not be restricted to a short or rigid list but, given the Scottish Government's stated aims to achieve a person-centred application process, should recognise that supporting evidence will be individual to that person's condition, experiences and needs.

The following types of evidence are often used by our members to add weight to their applications for the existing system:

- Reports from health and social care professionals including test results
- Personal testimonies from the individual and those close to them including diaries (which can be particularly useful for people living with a fluctuating condition)
- Prescription lists
- Outpatient appointment letters
- Discharge notes.

It should also be possible to use social work reports and social care plans and forms but it should be recognised that the locally applied eligibility criteria applied across Scotland means there is uneven access to social care packages across Scotland and therefore it is extremely important that eligibility for a social care package cannot be used as any form of eligibility proxy. Social Security Scotland advisors should be trained in these areas of policy so they can understand the implications of decision making in these

areas.

Supporting information should be collated by Case Managers and used to determine an individual's eligibility, not just to assistance but also to a face to face interview. At all times, the individual's preference should be sought.

Below are some examples of professionals who could be involved:

- Physiotherapist
- Social Worker
- Counsellor
- Support Worker
- Consultant
- Nurse (including specialist/condition specific Nurses)
- Doctor or GP
- Psychiatrist
- Care Co-ordinator
- Family Support.

There may be cases where referring to another professional involved in an individual's life may also be useful to them (for instance, one ALLIANCE member told us that their dentist knew their condition well and could add good supporting evidence). People should be able to nominate those who know them well who could add value to the process.

Where a face to face assessment has been determined to be required, this information should form part of the eligibility process. People accessing disability assistance should not be asked to perform tasks of which there is demonstrable proof of eligibility to maximum points in the new disability assistance criteria.

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?

Disagree.

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

We believe that the Scottish Government should ensure the complete removal of any future "review" in circumstances where the individual's condition will not change.

ALLIANCE members have previously expressed their support for automatic entitlement to certain disability payments for particular long term conditions (e.g. terminal conditions such as Motor Neurone Disease). Seldom heard people around Scotland – representing a wide variety of communities of interest and geography – repeatedly told us that people diagnosed with lifelong or life-limiting conditions should be granted lifetime entitlements⁴. 92% of respondents to an MND Scotland survey recently agreed that people should be able to access the social security system without requiring an assessment. There are many long term conditions that will not “improve” or change over time, e.g. severe spinal injuries, MS, Parkinson’s.

Where a review is considered necessary, this should be dependent on an individual’s long term condition and the circumstances around it. 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 period⁵ and that clear guidance should be issued to case managers to this effect.

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

Disagree.

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

Whilst we welcome the move away from the existing one, two or three year awards, we believe that there are a large number of people for whom any award review date is unnecessary, or should only be at the individual’s request. Experience Panel data suggests that 57% of participants felt that an award duration of five years “was not that appropriate or not appropriate at all” and that they would prefer an indefinite award if their health condition wasn’t likely to change or improve⁶.

⁴ <https://www.alliance-scotland.org.uk/wp-content/uploads/2017/10/ALLIANCE-Social-Security-Seldom-Heard-Voices-Research-Report.pdf>

⁵ <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>

⁶ <https://www.gov.scot/publications/social-security-experience-panels-award-duration-automatic-entitlement-visual-summary/>

This view also reflects research the ALLIANCE has undertaken with seldom heard groups across Scotland⁷, through which there “was a general consensus... that people diagnosed with lifelong or life-limiting conditions should be granted lifetime entitlements. They should only be required to take part in one assessment (i.e. no review or reassessment). For other applicants, reviews have to be less frequent than they are currently and take place when a major change in the person’s condition occurs, based on information from their own (medical) advisors.”

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.

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

Disagree.

Q26. If you disagreed, please could you explain why.

Many people accessing disability entitlements will require additional time to request a redetermination, possibly because of difficult personal circumstances or the nature of their illness. The timescale set out for considering a redetermination should also allow for discussion with the individual’s advice worker and/or independent advocate. Whilst we welcome the additional flexibility of up to a year (if a “good reason” is supplied), we believe that a longer period of request for redetermination should be allowed – possibly up to 62 calendar days. This would also allow further time to gather new evidence.

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.

⁷ <https://www.alliance-scotland.org.uk/wp-content/uploads/2017/10/ALLIANCE-Social-Security-Seldom-Heard-Voices-Research-Report.pdf>

Q28. If you disagreed, please explain why.

The question fails to recognise that the command paper says that this is a period of 40 to 60 **working** days meaning that this could be as long as 12 weeks before a redetermination is settled. Our members believe that this is an unacceptable time scale and would encourage the Scottish Government to set a much more challenging target of 31 days at most (if the timescale remains at 31 days for requesting a redetermination). There should be an equalisation of the acceptable timescales for people accessing social security and the Social Security Agency delivering it.

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.

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.

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

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 the individual's impairment or condition improves or that their financial position is improved. For many people the income they receive will be part of a wider household income and as such may impact on the household being able to continue to pay bills and not fall into debt. Many of those directly impacted by this will be unpaid carers.

The Scottish Government should consider how eligibility can be retained for unpaid carers in relation to a range of passported entitlements whilst someone is in residential care. We believe that breaking eligibility to receive the entitlement also risks the

eligibility of unpaid carers to receive Carers Allowance in particular. There is a danger that this could have the unintended consequence of financial hardship for unpaid carers, even though their caring role would not cease after this period.

Section 2 – Disability Assistance for Children and Young People

Question 42. 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?

Agree.

Question 43. If you disagreed, please could you explain why.

Whilst we welcome the extended age bracket for entitlement until 18, we believe that this should be extended to 21 to reflect the wider recognition in Scotland that a range of tricky transition points for disabled people occur between the ages 16 and 21.

Question 44. 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.

Question 45. If you disagreed, please could you explain why.

Whilst we welcome the extended age bracket for entitlement until 18, we believe that this should be extended to 21 to reflect the wider recognition in Scotland that a range of tricky transition points for disabled people occur between the ages 16 and 21. The ILF in Scotland's Transition Fund, for example, is available for applications between 16 and 21. Extending this eligibility will allow for smoother moves between entitlement and ensure that the negative impacts of existing transition points aren't exacerbated by social security eligibility face to face assessments.

Section 3 – Disability Assistance for Working Age People

Question 50. 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?

Disagree.

Question 51. If you disagreed, please could you explain why.

We believe that a much more public conversation should be had on the relative merits of a range of approaches to determining eligibility for disability entitlements, and we are surprised to note that the command paper does not list alternative approaches that could be taken to a points based system. We understand there are concerns about running a 'dual' system, with some people transferred over from the existing social security system assessed on a points basis alongside new applicants to the Scottish system assessed on different criteria. However, in order to best reflect the Social Security Principles and welcome ambition to create a system based on person centredness, rights, dignity and respect, alternatives to a system based on points, descriptors and scoring must be explored.

To meet the eligibility criteria as set out in the command paper, 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 are concerned that, particularly in the case of fluctuating mental health conditions, this does not reflect the nature of these conditions and may disqualify some people who would not be covered by such a specific definition. Further discussion with experts in the field of mental health is required.

Question 52. Do you have any suggestions about the most appropriate way to assess eligibility in relation to mobility for Disability Assistance for Working Age People?

Social Security Scotland will need to create an approach that is not wedded to the medical model of disability but one which supports the social and human rights models and is encouraging of independent living – rather than creating a disincentive to it. Assessing mobility must be inextricably linked with Scotland's push towards people self managing long term conditions where possible – and should not create barriers to ensuring people get the support they need to continue to do so. Ultimately this is about case managers and assessors understanding the importance of support the individual receives to manage their mobility, and the risk to the individual and the state more widely if the person no longer receives support (or doesn't get support for the first time).

Members have told us that in their experience, having assistive technology that can support you to manage your condition can count against you, but these are important to ensuring disabled people's independence and can require maintenance and fixes. This results in additional costs for disabled people which need to be covered and therefore shouldn't exclude you from future support.

Question 53. Do you have any comments on the full list of descriptors (provided at page 36) currently used to assess claims for Personal Independence Payments?

The existing eligibility criteria are framed within the medical model of disability and focus too specifically on what people can't do rather than what they can do. The ALLIANCE believes that this is 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 unpaid 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, based on the social and rights-based models of disability, which sees people as being disabled because of society's social and other structural barriers, which infringe their rights.

"The 20-meter rule" should immediately be scrapped and replaced with a 50-meter substitute in the interim period, until such a time as the Scottish Government is prepared to move beyond "safe and secure transition" and challenge the existing descriptors.

Our members have expressed concern that the descriptors used at present and included in the command paper 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.

A gendered analysis of the descriptors should also be undertaken in advance of their application in order to ensure they move away from gendered assumptions as to who undertakes which role in each household. Ensuring a thorough Equalities and Human Rights Impact Assessment is undertaken should help determine which groups in society could be most negatively impacted by the proposed measures, and therefore appropriate action taken to remove them.

Question 54. What types of observations, as part of a face to face assessment, do you believe are inappropriate?

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.

Question 55. In relation to assessments, what are your views on acceptable distances to travel?

A rights based approach to this consideration would ensure that a tailored approach is taken dependent on the individual's impairment/condition(s), and experiences, in order to establish acceptable distances that they may be required to travel.

The nature of the Scottish landscape means that an acceptable distance to travel will also be dependent on the locality area and the availability of local public transport. The existing DWP process is based on minutes travelled rather than distance. They have set an arbitrary 90 minute period (determined via journey planning websites), which we believe is too long to expect someone to travel for a consultation or assessment.

We believe that the Scottish Government should not require anyone to travel longer than an hour to get to an assessment. There will be some circumstances where this is not appropriate, however, and any calculation should be based on the availability of public transport, determined in discussion with local transport providers.

Question 56. What other circumstances should the Agency take into account?

It is worth noting that distance to travel is only one of the elements that will determine an individual's likelihood to attend a consultation or assessment. If the roads surrounding an assessment centre or local delivery office are inaccessible or if the building itself is not adapted to their particular needs (e.g. no accessible parking or accessible toilets) this is likely to be a determining factor in whether the individual will be able to take part in any face to face assessment.

Question 57. In relation to assessments, how many times do you think an individual should be able to reschedule, or fail to attend, an appointment?

The ALLIANCE does not believe there should be such a limit. The feeling of being disbelieved in relation to health problems may be a serious source of stress for people who are already likely to be vulnerable or living in poverty. Additional stress may inhibit an individual from managing their health issues effectively.

Social Security Scotland should be prepared for flexibility and rules which recognise that appointments can result in stressful situations which impact on an individual's ability to

attend e.g. people with continence issues or who have issues with medications may find that they are not well enough to travel. A flexible, compassionate approach is required to ensure people have the confidence to report being unable to attend.

Question 58. In relation to a missed assessment. do you have any comments on what should amount to exceptional circumstances (e.g. hospital admissions)?

If such a limit was applied the criteria for a missed appointment would need to be extremely broad in order to take account of the daily, and often fluctuating impact, of long term conditions on an individual's life. Seeking to fit a 'one size fits all' list of exceptional circumstances within a person-centred system is not advisable. It may be possible to provide 'examples' of what is meant by an exceptional circumstance, but it should always be tailored to the individual.

Question 59. Please provide any comments you wish to make about the audio recording of assessments.

Recording face-to-face assessments is likely to help with some of the issues people have experienced in the existing assessments for Personal Independence Payments.

The Scottish Government should clearly set out what type of recording it accepts as legitimate, particularly where a home assessment has been undertaken, and how new methods of recording e.g. through digital means, can be used. There will also be circumstances where disabled people do not wish for their assessment to be recorded and rules should allow for them not to consent to any form of recording.

We believe that the Scottish Government should consider the viability and potential for video recording of assessments in future. This is currently being piloted for PIP assessments across the UK⁸ and the Scottish Government should monitor and respond to the results of this pilot accordingly.

Section 4 – Disability Assistance for Older People

Question 60. 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?

Agree.

⁸ <https://www.disabilityrightsuk.org/news/2018/june/video-recording-be-standard-part-pip-assessment-process>

Question 62. Do you agree or disagree with the proposed eligibility criteria for Disability Assistance for Older People?

Don't Know.

Question 63. If you disagreed, please could you explain why.

We believe that Disability Entitlements for Older People should be extended to contain a mobility element. Many people over pension age will wish or require to continue to work and having access to mobility component that can support them to either purchase a vehicle or acquire the type of support they require to get to a work could support them to continue their participation in the labour market.

For some people, the use of mobility component may be the only way that they can travel and they will require it for a range of reasons that contribute to their independent living and contribution to society (e.g. using a car to go shopping, visit family or participate in social activities). This is particularly important in remote and rural areas where a personal vehicle is often required for regular travel. The Scottish Government has also recently published an isolation and loneliness strategy⁹, which states that: *“Accessible transport is vital to people being able to meet face-to-face and stay socially active, particularly for those in rural areas or later in life.”*

Public clarity is also required on how the Scottish Government will support older people (65+) who are currently on DLA/PIP. Whilst there is currently only one component for Attendance Allowance, and it appears that this will continue with Disability Assistance for Older People, moving these people from DLA/PIP to Disability Assistance for Older People would mean they were financially worse off.

We welcome the commitment in the Partial Equality Impact Assessment in the Disability Assistance Consultation document that Government plans to explore work to assess how they can better meet the mobility needs of older people who are not currently eligible for mobility when in receipt of Attendance Allowance. We believe that a mobility component should be included in the Disability Allowance for Older People so that applicants, if they need, can access the planned Scottish Motability Scheme and the benefits that come with that.

We are concerned that further clarity is required to reassure people over the age of 65 that their eligibility for their existing entitlement will continue and they will not be moved

⁹ <https://www.gov.scot/publications/connected-scotland-strategy-tackling-social-isolation-loneliness-building-stronger-social-connections/>

to Disability Assistance for Older People against their wishes. We would like to see reassurance placed in regulations that people who currently receive PIP or DLA but who are over the age of 65 will go on to receive its replacement entitlement (which in many cases will include a mobility component).

Question 64. 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.

Clarity of Purpose

At present, Personal Independence Payment is a payment which aims to establish functional ability in order to assess the person's level of independence, rather than whether they have a condition or not. Disability Living Allowance had been a payment to recognise the additional costs of living with an impairment. As such, the approaches taken to establishing eligibility were different.

Much of the stigma related to disability entitlements at present is drawn from a lack of understanding of their value and purpose.

The Scottish Government should set out, clearly and in advance of the roll out of these entitlements, what the overarching purpose of each of these entitlements are. This will give the public a much greater understanding of each entitlement, and would address concerns about stigmatisation of applying for entitlements that the general public do not understand the purpose of. Our recommendation is that the purpose be aligned to the social and human rights models of disability.

Language

The Scottish Government should review language used in reference to social security in order to move it away from stigmatising language such as "welfare" and "benefits". The ALLIANCE, and many of our members, were supportive of the initial announcements from the previous Minister for Social Security, Jeane Freeman MSP, that the Scottish Government would review the use of the word "benefits" in relation to the new system. We have, therefore, been disappointed to note that this review has not reflected on the need to guide public opinion away from stigmatising language towards more rights-based wording e.g. entitlements.

The command paper also makes multiple references to people's "needs" but disappointingly omits reference to people's human rights. This is central to a person-

centred, rights based approach to social security and amendment should be considered as the application process and regulations become established.

Safe and Secure Transition

A safe and secure transition of social security powers should be a given. Lifting and laying the existing eligibility criteria does not necessarily represent safe and secure transition of social security entitlements in Scotland (particularly as the Scottish Government is proposing some amendments to existing rules e.g. extension of children and young people's entitlement to 18 and potentially amending the 20-metre rule.)

We believe that a fundamental review of disability assistance is required and that the Scottish Government should outline the timescale within which "safe and secure transition" will end and we will move on to consider how the approach to social security in Scotland can best reflect the principles of the Social Security (Scotland) Act 2018.

Regulations

Current entitlement to social security across the UK is based upon decades of legislation, caselaw and guidance, which are all required for smooth running of the system. At present an individual's entitlement to social security could flow from primary legislation, regulations or caselaw. We agree with the Child Poverty Action Group in Scotland that the Scottish Government must ensure that, at the very least, the legal rights claimants currently have will continue for individuals who claim disability assistance in Scotland.

This can be achieved by including the current legislation and the meaning of important words, as established by caselaw, in the Scottish disability assistance regulations. This would, for instance, clarify what is meant by the word "regularly" in relation to the criteria. This is in keeping with the internationally recognised human rights principle of non-regression.

Application process

During our consultation with ALLIANCE members, they made a range of suggestions in relation to application forms. These highlighted that the current application forms for PIP, in particular, were daunting and needed modified to become less complex. Suggestions included:

- Shorter, less repetitive questions that seem designed to catch people out

- Forms/ an online process which is available in a range of different and accessible formats
- Online application forms should allow for magnification and a spoken version which can be used simultaneously (you can only do one of these at a time currently)
- Advice and support should be made available, and regular signposting to these throughout the process
- Forms should have the ability to be tracked throughout the system. Some people told us they had experienced forms being “lost” in the post in the existing system.
- Fluctuating conditions need to be better represented
- There needs to be clarity over the term “reasonable” and “safely” as they are used within the existing process

Responsibilities of Case Managers/Specialist Advisors/Assessors

The ALLIANCE is unsure on the proposed approach of Case Managers, Specialist Advisors and Assessors remaining as separate roles in the new social security system. Whilst the Case Manager will make the overall decision, it seems counter productive that the individual may never meet the Case Manager and could result in a faceless decision making process with a lack of accountability at its heart. We believe that the Case Manager and Assessor role could be, at least, more closely linked if not merged together.

In discussion with our members they believe that these roles are key in encapsulating and operationalising the principles outlined in the Social Security (Scotland) Act 2018, and should be particularly focused on compassion, respect, human rights and person centredness at their core. This will be key in recruitment and ongoing support for these roles. As such, the job description, recruitment processes and ongoing CPD for each of these roles should include reference to the need for well developed inter-personal, interviewing and good communication skills like active listening; impartial and fair decision-making; and equalities-related training. There should be regular ring-fenced support and supervision for staff at all levels, with opportunities for reflective practice built in.

We welcome moves to ensure Case Managers will be responsible for gathering evidence in support of a claim. This is a welcome change from the existing system, whereby the onus of responsibility for gathering further evidence “should sit with the claimant”¹⁰. In many cases this has led to people applying for Personal Independence

¹⁰https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/604097/pip-assessment-second-independent-review.pdf

Payments to bearing the costs of gathering evidence from GPs, as per the BMA's guidance on the matter¹¹. Social Security Scotland should work closely with the BMA and other relevant bodies to establish close working relationships between healthcare professionals and case managers/other decision makers to avoid charges for obtaining supporting information where possible. These costs should never be borne by the applicant.

Social Security Scotland should outline clearly and transparently the skills required to be an Assessor, including what mandatory training they must take. This information should be made available on the Social Security Scotland website and signposted to applicants in advance of any face to face assessment.

When a face to face assessment is required

The criteria outlined in the command paper on when a face to face assessment will be required has been left too broad as to allow for informed comment from consultees. We believe that the "The Agency may identify other circumstances" in which a face to face assessment is required is far too broad and does not allow for consideration of the full criteria under which a face to face assessment may be required.

Reducing the number of face to face assessments

We believe that the Scottish Government should draw together a strategy for reducing the number of face to face assessments over time and should set a series of targets that ensures that this is achieved. We are disappointed to see that the consultation doesn't go into enough detail on the level/scope of face to face assessments and hope for further clarity on how the number of face to face assessments will be managed in future.

Home assessments

We are disappointed to note that the consultation does not allow for further discussion of the process to determine whether or not someone is applicable for a home assessment. The command paper notes a home assessment will be provided "when necessary". We believe much stronger guidance should be published and consulted upon to determine the approach to home assessments – outline the Scottish Government's criteria and offering people the opportunity to comment on whether or not is appropriate. In our view a home assessment should be available if an applicant wants

¹¹ <https://www.bma.org.uk/advice/employment/fees/benefits-certification>

one in any case when supporting information determines that an individual may require one.

Independent Advocacy

The inclusion of a right to access independent advocacy for everyone going through face to face assessments for disability assistance is a welcome move. We believe that this right must be communicated directly to all claimants ahead of any claim for disability assistance in order that any interaction with the agency can be supported by an independent advocate. Further information on a responsible individual who should inform people of their rights to access advocacy and advice should be laid out in guidance and information to people applying for disability assistance.

Rates of payments

The ALLIANCE believes that all forms of Disability Assistance should, in future, be uprated in line with the Retail Price Index (the inflationary measure which constitutes the most accurate measure of the real cost of living). Ensuring the use of the Retail Price Index, would be an important means to ensure that low income households do not continue to fall behind the rest of society.

Figures extrapolated from a Parliamentary Answer by Steve Webb MP, Minister for Pensions on 28 June 2010¹², suggest that as a result of the UK Government's 2010 decision to link benefits to the Consumer Price Index rather than the Retail Price Index has led to:

- People in receipt of Disability Living Allowance or Attendance Allowance being £184.60 worse off in the financial year 2015-2016
- People in receipt of Carers Allowance being £135.20 worse off in the financial year 2015-2016
- People in receipt of Employment Support Allowance being £132.60 worse off in the financial year 2015-2016
- People in receipt of Industrial Injuries Disablement Benefit will being £361.40 worse off in the financial year 2015-2016
- People in receipt of Job Seekers Allowance being £132.60 worse off in the financial year 2015-2016
- People in receipt of the basic component of Bereavement Benefit being £332.80 worse off in the financial year 2015-2016

¹² <http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm100628/text/100628w0008.htm>

This has had a cumulative impact for the significant number of people who receive more than one of these benefits.

Qualifying periods

The command paper outlines that qualifying periods for Disability Assistance for Children and Young People (DACYP) and Disability Assistance for Working Age People (DAWAP) will require the person to have had their condition for at least three months. We believe that this is too long and could continue to leave people living with long term conditions and disabled people without support at a critical time.

As such, we believe any qualifying period before someone can be eligible for applying for disability assistance should ideally be set at 4 weeks, but no more than three months in any circumstance. We believe that 3-6 months is too long to wait for a support.

We also believe that there should be no difference in the qualifying periods between the three types of disability assistance.

People who have been sentenced or are on remand

The command paper identifies a difference of approach to breaks in disability assistance that will impact on eligibility between working age people and older people – noting that DAWAP will stop for anyone sentenced or on remand after 28 days but DAOP will be stopped immediately.

Around 30% of the prison population have some form of social care requirement¹³, and many will be disabled people. We believe that the proposed approach is discriminatory and should be equalised to 28 days across working age and older people's entitlements.

Easy read versions of consultations

We were disappointed to note that no easy read version of the command paper was published alongside the full version. It is essential for the full participation of people with learning disabilities and the wider community of people who low levels of literacy than easy read versions are provided at the same time as any other versions.

¹³ <https://socialworkscotland.org/wp-content/uploads/2019/03/A-New-Vision-for-Social-Care-in-Prison-Report-.pdf>

Evidence from unpaid carers

We welcome the Scottish Government's decision that there should be no 'hierarchy' of supporting information and data. Some forms of evidence are not currently given sufficient weight with evidence from health care professionals. Supporting guidance should clearly set out that this applies to information from unpaid carers and other family members as well as the individual who is applying for the entitlement. This becomes important where, for example, a carer has guardianship and the individual is unable to communicate their condition or needs.

Audit, assurance and quality improvement activity (including scheduled review of operation of Disability Assistance)

We are disappointed that the consultation paper did not set out the terms of any future review of the three Disability Assistance entitlements and we believe that the Scottish Government should outline a draft timetable for close consideration of the long term success, or otherwise, of the disability assistance in meeting the principles set in the legislation should be established.

Taking a human rights based approach to social security, as set out in the Social Security (Scotland) Act 2018, requires for the duty bearer to ensure that accountability is central to the approach, and therefore that independent scrutiny and oversight is built into the process. As such, we believe that criteria should be set out for measuring consistency between Disability Assistance cases in order to provide assurance that assessments are producing fair outcomes. Monitoring and measuring consistency should consider the following:

- Support received by applicants for Disability Assistance.
- The level of supporting information required to be supplied by applicants for Disability Assistance.
- Intersectional analysis of applicants (including those refused entitlement to Disability Assistance).

Promotion of various entitlements

During our consultation with ALLIANCE members they told us that many people were unaware of Personal Independence Payment and that they may be entitled to make a claim. Social Security Scotland must work closely with other organisations, including in the statutory sector, to make sure that everyone eligible is able and encouraged to

access these entitlements. Alongside this there needs to be wider checks built into the system that people are in receipt of their entitlements. This should include other statutory entitlements such as council tax reductions.

Simplify and better co-ordinate communication products to provide a clear explanation of user responsibilities and ensure accessibility for all. This should include the use of digital media to provide claimants with real examples of what functional information they should submit as part of their claim.

It is also vital that people receive clear, unambiguous information related to their eligibility, or otherwise, for Disability Assistance. This should include information on the basis on which the decision was made and should signpost all unsuccessful claimants to further sources of relevant support (including customer service advice from Social Security Scotland).

Information sharing

In health and social care, the sharing of personal data for research and clinical purposes is highly controversial and contested. ALLIANCE members often express the view that the sharing of information about them by organisations involved in their care and support would be of significant benefit in reducing bureaucracy and the need to re-explain conditions, symptoms or level of independence to numerous different clinicians, assessors and other parties.

However, systems at present are not built around people who can or want to own the data that health and social care actors hold on them; rather they are built around those who can't or don't want to be. Confidentiality remains a concern, but in our view the person themselves is the best guardian of their data and the level of sharing needs to be a free decision based on the individual view of the person themselves.

Therefore, the new social security system should be flexible enough to enable the individual to give consent to open up access to their data to whatever level stipulated by the individual.

It is also clear from the current system that there is significant variation in the quality of the responses from professionals approached for supporting evidence. Often this is dependent on the individual professional involved. We believe that Social Security Scotland should set out a clear, structured process for communicating supporting information and should be directly discussing this with professional bodies such as the Royal College of General Practitioners and the Royal College of Nursing as soon as possible.

Rejected applications

Data should be collected on rejected applications to consider the impact on particular groups and the possibility of putting in place other types of interventions that can support them. This could play a preventative role in ensuring people don't eventually reach the need for costly support later on.

Where applications are rejected, subject to redetermination or appeal, applicants should be sent a copy of all the information that has been used to make this decision and a full explanation.

For More Information

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