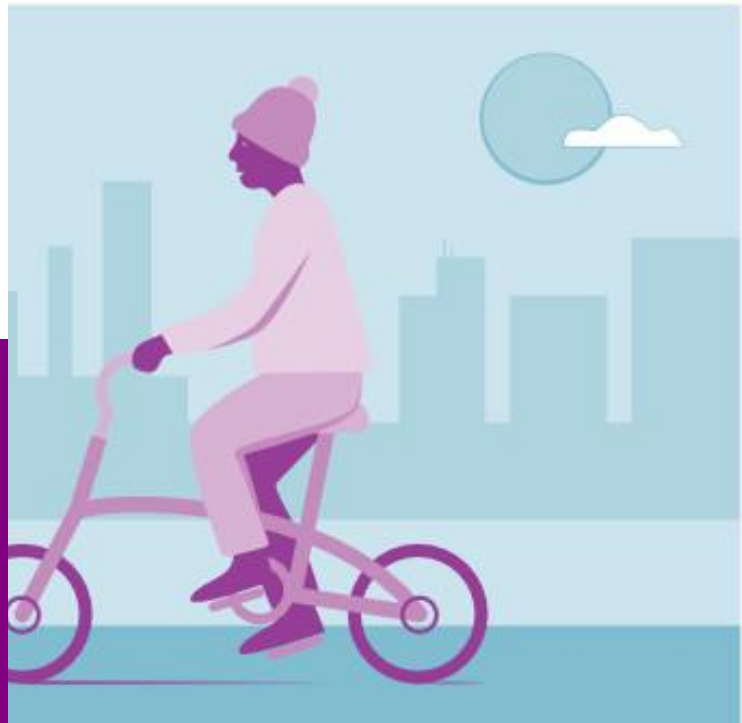




**The Health and
Social Care
Alliance
Scotland
(the ALLIANCE)**



**Adult Disability Payment:
Consultation on the Mobility
Component**

25 April 2023

Introduction

The ALLIANCE warmly welcome the many positive changes that have been put in place through the Scottish social security system. These include a greater acceptance of supporting information and the use of consultations only in circumstances where that information has not been sufficient, and on a much less formal basis than under the UK equivalent. This demonstrates a greater level of trust in applicants, affords greater dignity, and is significantly more in line with the aspiration of a human rights based system.

However, there are areas where we are concerned that there remains some distance to go towards this aspiration. In particular, the continued application of mobility criteria, including the 20 metre and 50% rules have been disappointing, and the ALLIANCE have repeatedly joined with partners across the third sector and people with lived experience to call for these to be reformed, if not abolished entirely. We welcome the opportunity to respond to this consultation and re-affirm the importance of a human rights based approach to social security.

In our response we:

- Welcome existing changes to the system including:
 - Greater acceptance of supporting information;
 - Limited use of consultations;
 - Requirement to disclose any informal observations made during consultations and to allow a response to those;
 - Removal of behavioural observations and “Mental State Examination” from the process.
- Note that the current presentation of some aspects of the mobility criteria may be confusing to people, or fail to meaningfully capture the impacts of their condition;
- Call for the removal of the 20 metre and 50% rules, which are both overly strict and arbitrary, replacing them with less rigid, more meaningful means of describing mobility;



- Call for improved understanding and accommodation of issues such as exhaustion, pain and anxiety within the criteria;
- Reiterate long-standing calls for a human rights based social security system, with specific reference to the principles laid out by the Scottish Campaign on Rights to Social Security (SCoRSS);
- Emphasise the importance of joint working between the Scottish and UK Governments to ensure that the Scottish Parliament has the flexibility to make changes to devolved payments;
- Affirm the importance of using existing revenue raising powers in the most equitable way to fund social security as an essential public service.

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

Don't Know.

Question 1a: Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

Whilst giving distances in metres may be clear and simple in a technical sense, it may be somewhat less clear in practical terms. People are not necessarily used to thinking about their mobility in terms of precise distance they can move, or able to easily imagine how far 20, 50 or 200 metres are in more meaningful terms. As noted in our response to a subsequent question, the visual aids provided for those distances are not particularly clear.

Question 1b: How could we make the moving around activity criteria easier to understand?

We answer this in more detail in Question 3.

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

Yes.



Question 2a: If you said ‘yes’ what other issues with the moving around activity do you think need to be considered?

In the ALLIANCE’s engagement with our members, Crohns & Colitis UK raised the specific point that mobility should not be measured exclusively with regard to a person’s physical ability to walk a certain distance. Even where someone is capable of walking that distance, there may be other aspects of their condition that result in significant restrictions of their mobility.

In particular, people who are living with bowel conditions which may cause incontinence may be limited by their need to be able to reliably and easily access toilet facilities at short notice. Especially in the context of many public toilets being closed, having limited opening hours, or charging for access, some people living with bowel conditions may find their mobility limited not by their own physical capability to walk but because they cannot be assured they will have access to the facilities they need.

Question 2b: In your view, what are the positive aspects of the moving around activity that we have not captured above?

The ALLIANCE recognise and agree with many of the concerns highlighted as part of the research findings in the consultation document itself. In particular, the sense that strict distances are arbitrary, not a useful measure, and do not adequately cover progressive or fluctuating conditions has been a consistent criticism of the mobility criteria, including from ALLIANCE member input to this response.

It was particularly concerning within the consultation document to see that two-fifths of respondents to a survey were effectively discouraged from being active due to the fear they would lose their entitlement to social security. The health benefits, both physical and mental, arising from exercise or otherwise being active are well known. Disabled people already face higher barriers to accessing sport and physical activity. Further discouraging individuals from being active may have negative effects on



their health and wellbeing in the longer term, potentially including the worsening of their conditions.

In addition, social security, health (both through the International Covenant on Social, Economic and Cultural Rights, ICESCR¹) and equal participation in society (though the Convention on the Rights of Persons with Disabilities, UNCRPD²) are all recognised as human rights. Particularly in light of the Scottish Government's stated commitment to incorporate a range of human rights treaties into Scots Law, including ICESCR and UNCRPD, there should be a clear and consistent approach to human rights across society.

Human rights are interrelated and interdependent, and the realisation of one right should not have any negative impact on the realisation of other rights. Disabled people should have the confidence that they will be able to access social security payments necessary to support their additional costs, and that they can do so whilst also engaging in sport, exercise and other physical activity that may both improve their overall health and support their participation in society. Any rules relating to the mobility criteria should be rooted in human rights and dignity, rather than strict, arbitrary measurements.

Question 3: How effective do you think the moving around section of the application form is at helping us understand a person's mobility needs? Please give reasons for your answer.

Somewhat effective.

Although the image provided on the application form is intended to give a visual indication of how far the relevant distances are, due to the perspective of the image it is not particularly clear. Even the 20 metre picture is somewhat difficult to interpret, and it is significantly harder for the 50 and especially the 200 metre images. Clearer visual examples, for example with an overhead perspective, may illustrate more clearly how far the distances are. In addition, a description such as "20 metres, or about



the width of six car parking spaces” and so on may further aid applicants to interpret the criteria, and thus improve understanding of what their mobility needs are.

The inclusion of impact prompts, such as pain and breathlessness, is likely to help provide more detailed information in support of an individual’s application. However, it is not entirely clear whether their responses to these prompts are taken into consideration within the points system, even though there may be significant differences between two people who can walk the same distance unaided. If someone can walk 50 metres but is in pain or exhausted for a significant period afterwards, that should be given more weight than someone who can walk 50 metres with only mild or brief impacts.

In addition, we are not sure that defining walking as “walking on flat, level ground. It does not include walking up or down stairs or slopes.” is useful or accurate. As people will not only have to contend with flat, level ground in their daily life, consideration could be given to whether it would be relevant for a person to include further detail, for instance if they live in a hilly, or inaccessible area and would require additional support as a result.

Question 4: What impact do you think the changes to how we make decisions on the moving around activity have on understanding a person’s mobility needs. Please give reasons for your answer.

A positive impact.

Overall, we consider the changes made to how the moving around criteria are described and evidenced have had a positive impact. However, this relates less to the ability of Social Security Scotland to understand a person’s mobility needs, and instead to how individuals experience the application process. A lack of dignity and respect for disabled people has been one of the key criticisms of the UK Government’s Personal



Independence Payment (PIP) reforms, including from the Scottish Government.³

We welcome the approach to the use of supporting information for ADP, which operates on a balance of probabilities basis, rather than an automatic requirement for a consultation. In addition, it is a significant improvement when compared with PIP that where a consultation does take place, any informal observations must be shared with applicants, and they must be given an opportunity to respond. By trusting supporting information to be accurate and disallowing secretive informal observations, these changes have created a more dignified approach under ADP than was the case with PIP.

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

The ALLIANCE have previously supported calls by MS Society Scotland to reconsider and review the moving around criteria, in particular the 20 metre and 50% rules.⁴ In both our manifesto for the 2021 Scottish Parliament election⁵ and our response to the ADP regulations consultation⁶, we called for the 20 metre rule to be increased to 50 metres as an interim measure and the complete scrapping of the 50% rule.

We continue to believe that these rules should be removed from the criteria. Whilst we recognise there needs to be a way to determine a person's mobility needs, we do not consider that the strict application of arbitrary measurements is the best way to do this. A more flexible approach should be taken which rather than set distances considers a person's ability to move around their own home, local area, and other places they may frequent in daily life such as their place of education or employment, shopping and leisure facilities, and healthcare services. This should account not just for physical ability to travel within those areas, but also the degree to which doing so results in pain and exhaustion, and whether there is reliable access to facilities such as toilets and comfortable rest stops.



The ALLIANCE recommends that a successor system is developed with people with lived experience to develop the specifics, but for example within the framework of a points system, the following outline may be a reasonable starting point to develop further detail from:

- Distance
 - No points – Able to move outwith their local area
 - Low points – Not able to move widely outwith their local area, but able to move unaided within it
 - Medium points – Not able to move within their local area, but able to move unaided within their home
 - High points – Not able to move within their home
- Pain and Exhaustion
 - No points – Able to move unaided within the area described earlier without pain and/or exhaustion
 - Low points – Able to move unaided within the area described earlier with mild pain and/or exhaustion
 - Medium points – Able to move unaided within the area described earlier with moderate pain and/or exhaustion
 - High points – Able to move unaided within the area described earlier only with severe pain and/or exhaustion, or not able to move within the area at all

Although this proposal moves away from the strict, arbitrary measurements such as 20, 50 and 200 metres, it may still draw a clear distinction between the capability to travel over shorter and longer distances. It may allow better reflection of individual circumstances, for example for people living in urban versus rural areas, where it should be recognised that it is not simply individual physical capability that is relevant to how an individual's mobility is affected, but additionally the infrastructure and services around them. Formal inclusion of the impacts of pain and exhaustion within the criteria is important, to recognise the serious negative effects that these can have on quality of life and wellbeing, as well as the additional costs of managing those conditions.



Question 5a: If you proposed changes, what positive impacts could these have, and for who?

For applicants with limited mobility in general, these changes may lead to a process that they feel is more supportive and understanding of them and their unique personal circumstances, rather than a perceived tick-box exercise with strict numerical measurements. In particular, applicants with chronic pain may benefit in that way from explicit recognition of pain as a barrier to mobility. Similarly, for applicants with fluctuating conditions, less strict criteria may result in them being eligible for a higher rate of payment, which is likely to improve quality of life and reduce poverty.

Question 5b: If you proposed changes, what negative impacts could these have, and for who?

It is possible that the formal inclusion of pain and tiredness in the criteria may make some applicants worried that if they are not experiencing those to a significant degree they will not be eligible for the payment. It should therefore be made as clear as possible that pain and exhaustion are additional rather than sole considerations, and that people with the most limited mobility would still be fully entitled to the mobility component of ADP on that basis alone.

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

Don't Know.

Question 6a: Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

In general terms, the following journeys criteria are easier to understand than the moving around criteria, as they are not reliant on arbitrary numerical distances that may be difficult to relate to daily life. However, we are concerned that the phrase “overwhelming psychological distress” is poorly defined, and it may not be clear to applicants what this means in practical terms.



Question 6b: How could we make the planning and following journeys activity eligibility criteria easier to understand?

As noted in our responses to other questions in this section, we would welcome a clearer definition of “overwhelming psychological distress”.

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

Yes.

Question 7a: If you said “yes”, what other issues with the planning and following journeys activity do you think need to be considered?

As per our response to question 2a, ALLIANCE member Crohns & Colitis UK raised specific concerns about how mobility criteria do not currently account for the impacts of bowel conditions that may cause incontinence. The need to plan for access to toilet facilities may represent an additional further difficulty for many disabled people, with uncertainty around whether facilities will be open, accessible, free to use, and of good quality liable to contribute significantly to feelings of anxiety about planning journeys.

Question 7b: In your view, what are the positive aspects of the planning and following journeys activity that we have not captured above?

The ALLIANCE recognise and agree with many of the concerns highlighted as part of the research findings in the consultation document itself.

“Overwhelming” indicates a very high bar for distress, when lower levels may still significantly impact a person’s ability to plan and follow a journey. It may be more useful to talk in terms such as anxiety, fear of getting lost and fear of encountering hostility, but to do so in a non-stigmatising way that doesn’t suggest it’s unreasonable for people to be anxious or have such fears.



It is also not clear that there is a meaningful distinction in practice between planned and unplanned journeys, particularly for people with fluctuating conditions. The same individual may feel quite capable of carrying out an unplanned journey on one day, and feel so anxious as to be unable to undertake a planned journey on another.

Question 8: How effective do you think the planning and following journeys section of the application form is at helping us understand a person's ability to plan and follow journeys? Please give reasons for your answer.

Somewhat effective.

The examples given of the difference between familiar and unfamiliar journeys are reasonably clear and useful, if that distinction is to continue to be drawn. In addition, the prompt with a list of mental health conditions that may result in anxiety about traveling may help make clear to applicants there are legitimate and understood reasons they would feel that way, although these could be supplemented with specific reasons people may feel anxious as outlined in our response to the previous question.

However, the binary nature of the “can you leave your home at all?” question may fail to capture the nuance of fluctuating health conditions. It is unclear from the consultation paper whether individuals are asked about fluctuating conditions in relation to this specific point, and this may impact on the ability to understand whether people with fluctuating mental health conditions are able to plan and follow journeys.

Question 9: What impact do you think the changes to how we make decisions on the planning and following journeys activity has on understanding a person's ability to plan and follow journeys? Please give reasons for your answer.

A positive impact.



Overall, we consider the changes made to how planning and following journeys criteria are described and evidenced have had a positive impact. However, this relates less to the ability of Social Security Scotland to understand a person's mobility needs, and instead to how individuals experience the application process. A lack of dignity and respect for disabled people has been one of the key criticisms of the UK Government's Personal Independence Payment (PIP) reforms, including from the Scottish Government.⁷

We welcome that stigmatising behavioural observations and the "Mental State Examination" have been removed from the process, and agree with the points made in the consultation document that these perpetuated unhelpful stereotypes. Similarly, the commitment to ensure that where a consultation is necessary in relation to mental health or learning disability, the person conducting it will have relevant experience, and therefore be more capable of understanding the applicant's condition. These changes have helped to create a process that is more dignified and less stigmatising.

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

In line with responses to earlier questions, a threshold less strict than "overwhelming distress" should be put in place for determining how mental health conditions impact people's ability to travel. This should include suitable recognition of fluctuating conditions and provide further examples of the kind of mental health conditions or reasons that may contribute to anxiety.

Question 10a: If you proposed changes, what positive impacts could these have, and for who?

These changes may have positive impacts for applicants with mental health conditions in general, if they feel that the process is more supportive and



understanding of them. For applicants with fluctuating conditions, less strict criteria may result in them being eligible for a higher rate of payment.

Question 10b: If you proposed changes, what negative impacts could these have, and for who?

We do not foresee any negative impacts arising from such changes.

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

Disagree.

Question 11a: Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.

The ALLIANCE heard general statements from some of the members who responded to our call for input that they found the criteria for fluctuating conditions unclear. This related in part to the feeling the form itself did not allow for appropriate understanding of their conditions, and that it could be difficult for individuals to quantify whether they were being impacted in certain ways a majority of the time.

Question 11b: How could we make the fluctuating conditions criteria easier to understand?

As discussed in our answers to other questions, an approach which aims to identify how people are impacted by their conditions on their worst days is likely to better reflect the necessary level of support. It would also be easier to think about only the worst days, rather than expecting people to try and quantify how often they are affected and in what ways.

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

Don't Know.



Question 12b: In your view, what are the positive aspects of the fluctuating conditions criteria that we have not captured above?

The ALLIANCE recognise and agree with many of the concerns highlighted as part of the research findings in the consultation document itself. As noted in response to earlier questions, we have previously called for the 50% rule to be scrapped, in part as this may not give an accurate indication of the impact of a person's condition. Understanding how people are impacted on their worst days would likely be more useful, both in terms of determining support that may be necessary and reassuring applicants that their experiences are valid and will be taken into account. In addition, the nature of fluctuating conditions is such that it may not be possible for people to predict or estimate how frequently they will be impacted.

We also agree that it would likely be confusing and exclusionary to provide condition-specific descriptors. Disabled people, and the ways in which they are impacted by their condition and by societal barriers, are incredibly diverse, and it would be difficult to capture all possible conditions and impacts. General categories and indicative examples within existing descriptors would be more flexible.

Greater flexibility on fluctuating conditions in general would be welcome, potentially on the basis suggested by the Disability and Carer Benefits Expert Advisory Group. However, it is possible that averaging over a number of weeks may result in additional complexity rather than simply flexibility, and it may be difficult for people to quantify the impacts of their condition over an arbitrary timescale.

Question 13: How effective do you think the fluctuating conditions section of the application form is at helping us understand the needs of people with fluctuating condition? Please give reasons for your answer.

Not very effective.



Although the creation of a legal definition of what it means to carry out an activity to an acceptable standard seems on the face of it to give greater clarity, there is very limited information as to what this means in practice on page 37 of the consultation document. In particular, the example given from the application form seems to be very simple. It is therefore difficult to make a meaningful assessment on the basis of the information given.

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

A positive impact.

Changes to how decisions are made about fluctuating conditions relate less to the ability of Social Security Scotland to understand a person's mobility needs, and instead to how individuals experience the application process. A lack of dignity and respect for disabled people has been one of the key criticisms of the UK Government's Personal Independence Payment (PIP) reforms, including from the Scottish Government.⁸

We welcome the more flexible approach taken to consultations, with a focus only on the relevant areas of the application, without unnecessary questions, and to no standard duration. Supporting people to discuss their condition and how it impacts them at their own pace helps to ensure a more dignified process, and minimise the stress and pressure put upon them.

Question 15: If there was an opportunity to change any specific aspects of the fluctuating conditions criteria, what changes would you make (if any)?

As stated elsewhere in this response, we believe the 50% rule for fluctuating conditions should be removed. Instead, seeking to understand how people are impacted on their worst day is likely to give a better indication of the kind of support that they need. Alternatively, a more



flexible approach that considers frequency as well as severity of impact, without an arbitrary threshold, may represent an improvement.

Question 15a: If you proposed changes, what positive impacts could these have, and for who?

Removing the 50% rule and replacing it with something more flexible or representative may have a positive impact on applicants with fluctuating conditions in general, if they feel that the process is more supportive and understanding of them. In addition, less strict criteria may result in more people being eligible for a higher rate of payment.

Question 15b: If you proposed changes, what negative impacts could these have, and for who?

We do not foresee any negative impacts arising from such changes.

Question 16: If there was an opportunity to consider alternative approaches to a points-based system to understand disabled people's needs, what alternatives would you propose (if any)?

The ALLIANCE has consistently advocated for a human rights based approach to social security, including through our membership of the Scottish Campaign on Rights to Social Security (SCoRSS). The 2020 report “Beyond a Safe and Secure Transition”⁹ lays out the SCoRSS vision on the future of social security in Scotland, calling for a social security system that follows six core principles:

- Has a clear purpose
- Is human rights based
- Supports equal participation in society and independent living
- Is adequate
- Provides whole-of-life support
- Interacts well with future social security developments and is well connected to other services



Whilst a points based system may be easy to administer, it does not necessarily sit well with a human rights based approach to social security or with the provision of adequate support. Whether fairly or not, people may perceive a points based system to be rooted primarily in controlling costs for the government, rather than ensuring the right support is given to disabled people. In particular, there is potential for serious psychological distress where individuals fall only marginally short of a required number of points, risking giving the sense that they are “disabled, but not disabled enough” to justify support.

Even were the points system to be retained, there is scope for reform to make it more flexible and minimise barriers to accessing support. Many of the existing rules, as highlighted throughout this response, relate to arbitrary numerical values, for example of how far people can walk, or how much of the time their condition affects them. Considering approaches such as scaling support across a range of points rather than a sharp, cliff-edge where people either qualify for a given level of support or don't may help to build a system that is more responsive to individual circumstances and feels less like a box-ticking exercise.

Question 16a: If you proposed changes, what positive impacts could these have, and for who?

An approach such as scaling support may result in more disabled people and people living with long term conditions being able to access social security, potentially reducing poverty and improving mental health and wellbeing.

Question 16b: If you proposed changes, what negative impacts could these have, and for who?

We do not foresee any negative impacts arising from such changes.



Question 18: How can the independent review ensure that any recommendations it makes are both deliverable and affordable? Please give reasons for your answer.

The ALLIANCE believe that Scotland’s social security system should be human rights based, providing adequate support that helps to reduce poverty and ensure participation in society, in line with the principles set out by the Scottish Campaign on Rights to Social Security.¹⁰ Decisions about social security should be taken on a human rights basis, rather than being led by cost considerations. However, we recognise the financial limitations facing the Scottish Government, and that these have grown significantly in recent years.

We also welcome the positive work so far in developing the Scottish approach to social security. In addition to treating people applying for and receiving social security payments with greater dignity, the approach will also lead to an increase in the number of people qualifying for payments, and that the Scottish Government have committed to additional funding for social security over and above what would have been the case had the UK system continued unchanged.

It is important that social security is not considered simply in isolation, and instead as part of a whole-government approach. Careful consideration should be given to how to best raise and maximise the revenues available for public services. Although the ALLIANCE does not have a position on the exact rates or forms of taxation that should apply in Scotland, we recognise that a comprehensive social security system must be adequately funded, and would encourage the Scottish Government to approach budgets and revenue raising from the perspective of what services will promote wellbeing and human rights in society, rather than what level of taxation may be seen as “appropriate” and only then fitting public service provision to that arbitrary level.



Question 19: How can the independent review consider the impact of any recommendations on existing “passporting” arrangements?

Engagement with the Department for Work and Pensions, the Treasury, and the wider UK Government at the earliest opportunity should be a priority. This should be both with a view to understanding their thinking on how to manage passporting arrangements in light of potential changes to Scottish social security, and to re-affirming that the principle of devolution means that the Scottish Government should have complete control over existing devolved powers.

Whilst the financial impacts on the UK Government of the Scottish Government’s decisions should be carefully and sensitively considered, it would be against the letter and spirit of devolution to seek to impose restrictions on what changes the Scottish Government can make. It is important for people receiving social security payments that the system puts their human rights and dignity at the centre, and is not subject to partisan disagreements between governments.

Question 19a: How much of a priority to you is maintaining the current “passporting” arrangement?

Very high.

Question 19b: Please explain why you chose this answer.

Passporting is an important component of the social security system, allowing individuals to access a wider range of support they are entitled to without having to go through the onerous process of applying separately for each entitlement. If passporting arrangements were to be disrupted, this could have serious negative impacts on people’s health, wellbeing and financial security.

However, we do not believe that it should automatically be the case that significant changes to how Scottish social security works leads to the ending of passporting arrangements. As the consultation document itself notes, where decisions by the Scottish Government or Parliament result in



additional liabilities for the UK Government administered components of social security, those additional costs can be recovered from the Scottish Government.

With appropriate partnership working between the governments, this mechanism could be used to allow the Scottish Government to pursue further changes to Scottish social security whilst maintaining passporting by assuming liability for any additional costs arising for the UK Government. In line with our responses to other questions, this should form part of a human rights based approach to social security, and be paired with measures to maximise revenues available for public services.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:



- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

Contact

Allan Faulds, Policy and Information Officer

E: allan.faulds@alliance-scotland.org.uk

Rob Gowans, Policy and Public Affairs Manager

E: rob.gowans@alliance-scotland.org.uk

T: 0141 404 0231

W: <http://www.alliance-scotland.org.uk/>

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