A Consultation on Disability Assistance in Scotland: Analysis of Responses

October 2019

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Why Research, October 2019

Acknowledgments

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1 Executive Summary

The terms of Part 3 of the Scotland Act 2016 gave effect to some of the recommendations of the Smith Commission and provided for the devolution of a range of social security benefits to the Scottish Government.

The Social Security (Scotland) Act 2018 was a major piece of devolved legislation passed by the Scottish Parliament with the intention of establishing a new social security system, based on a set of principles informed by public consultation and Parliamentary scrutiny. Social Security Scotland, an Executive Agency of the Scottish Government, was subsequently established in 2018. From 2020, Disability Assistance will begin to be delivered by the Scottish Government.

On 5 March 2019, the Scottish Government published a consultation – Consultation on Disability Assistance – setting out the Scottish Government's current policy proposals for three disability benefits. This consultation sought the views of all people, including those with living experience or a working knowledge of social security. Feedback from the consultation will inform the drafting of regulations for each form of Disability Assistance and the implementation and delivery of these benefits. The consultation closed on 28 May 2019.

1.1 Respondent Profile

In total, there were 263 replies to the consultation, of which 74 were from organisations (broken down as below) and 189 from individuals. Scottish Government officials also held a series of engagement events to raise the profile of the consultation, and to encourage participants to take part in the consultation. Where participants provided feedback and consented to its use, those responses were provided and considered as part of this report.

Table 1: Respondent Groups

	Number
Campaigning / Advocacy	13
Local authority	14
Third sector	40
Other	7
Total organisations	**74**
Individuals	189
Total respondents	**263**

1.2 Key Themes

A number of key themes were evident across questions as well as across respondent groups and summaries are provided below, rather than being outlined at each of the questions.

Views were broadly positive about the proposals laid out in the consultation paper, and a majority of respondents agreed with most of these proposals, including offering greater flexibility within the system and consideration of clients' needs on a case-by-case basis, although some respondents noted the importance of ensuring the proposals as outlined are achieved. A common thread throughout responses was the need to avoid the anxiety and stress potentially caused by having to undergo assessments, as well as the need to avoid financial hardship. Notwithstanding this broad agreement with the proposals, key themes emerged as follows:

- One thread, primarily from organisations, was criticism of the current, reserved social security system and concerns that the proposals do not go far enough in creating the change required to deliver the social security system envisaged.
- While there was agreement of a need for a person-centred approach, some respondents commented generally that the proposals did not appear to go far enough to offer this.
- While a majority of respondents agreed with the suggested names for the benefits, some felt that the suggested names were not inclusive. For example, it was felt that use of the word 'disability' is potentially divisive or discriminatory, in that it can segregate clients who do not like the label 'disability'. There were some requests for the names to focus on a social model that is perceived to be more inclusive.
- While there was general support for each of the benefits, there were some requests for one single lifelong disability benefit that is continuous and automatic with no distinctions based on age, rather than having three benefits for different age groups. For example, some respondents had concerns this could cause problems in managing the transition from one age group to another, while some noted that the definition of a young person can be subjective. Allied to this, there was agreement that benefits need to be related to need rather than age, and offer equality of access to all. Additionally, there were some requests for a mobility component to be offered to all clients.
- Overall, there was support for the role outlined for Case Managers in making decisions about entitlement for Disability Assistance, although some respondents wanted to know more about the training and guidance that would be required for Case Managers to make appropriate.
- Similarly, while there were high levels of support for Specialist Advisors and Assessors, some respondents sought clarity about the training and skills that

would be required in order for both to provide accurate advice about the impact of an individual’s health conditions.

1.3 Consultation Questions

The following paragraphs summarise the main findings from each of the consultation questions.

1.4 Disability Assistance in Scotland (Qs 1-6)

A majority of respondents agreed with the proposed new names of the three forms of Disability Assistance. That said, some respondents noted a dislike of the words ‘disability’, ‘assistance’, ‘working’ ‘older’ and ‘pension’ as these were perceived to be potentially divisive or discriminatory. There were also some comments that these names are too long and that the acronyms are not easy to use. There were some requests for the names to focus more on a social model that is perceived to be more inclusive. A few respondents suggested there should be a common name across all three benefits.

Main Findings: Applying for the Benefit (Qs 7-8)

A large majority of respondents agreed with the proposal to enable multiple application channels for Disability Assistance, with a key theme being that there is a need for choice in application channels in order to offer an inclusive system and meet the varying needs of clients.

Main Findings: Conditions relating to Residence and Presence (Qs 9-10)

A majority of respondents who gave an answer agreed with the proposal to broadly replicate the current temporary absence rules, although some felt that clients should not lose their benefits if they live with their family abroad or that clients should have the right to go travelling without losing access to their benefit. There were some suggestions that more cover for temporary absence is required.

Main Findings: Making Decisions about Entitlement (Qs 11-17)

There was consensus with the proposal to implement a person-centred approach to making decisions about entitlement to Disability Assistance by Case Managers. Some respondents sought more detail about the type of training provided to Case Managers to ensure consistency when making decisions about entitlement.

A large majority of respondents agreed with the proposed approach to the involvement of Specialist Advisors (SAs) in supporting the decision-making process, although there were comments on the need to ensure that the views of healthcare professionals are considered, and some respondents would prefer to see more detail on the future training provided to SAs. There was some reference of a need to work closely with third sector organisations, health professionals and clients and / or their carers.

A wide range of situations were cited as needing to be taken into account by Case Managers as to when an SA should be involved. The most frequently mentioned were complex / rare conditions, fluctuating conditions, multiple illnesses and instances where specialist knowledge is required.

A large majority of respondents agreed that the decision-making process for Disability Assistance for Children and Young People, and for Older People, will use existing sources of information and not face-to-face assessments, although a few respondents felt existing sources of information might be insufficient. Some respondents were critical of the age boundaries suggested and felt that the same criteria should apply to all clients. There were also some comments referring to a need for client choice and providing capacity to request an assessment.

Main Findings: Approach to Supporting Information (Q18)

Respondents cited a range of supporting information that would be relevant in assessing an application for Disability Assistance. The most frequently cited included reports from:

- General practitioners, consultants and specialists;
- Social workers; and
- Carers.

Main Findings: Duration of Awards (Qs 19-24)

A majority of respondents agreed with the proposal to have no set award durations but to set an award review date that takes account of the likelihood of that person's needs changing when a decision on a Disability Assistance application is made. There were a number of comments stating that if an initial assessment advises there will be no improvement in an individual's condition, this should be sufficient reason not to review at any point in time. A majority of respondents also agreed with the proposal to set an award review date 5-10 years in the future for a person with a condition that is unlikely to change, although there were a number of comments that there should be indefinite lifetime awards if an individual has a long term condition that is unlikely to change.

A large majority of respondents agreed with the proposal that a change of circumstances should be defined as a change which has an impact on the level of assistance that a person receives. However, there were some calls for a broader definition than that supplied in the consultation paper; and reference to the fact that some clients are unsure of what would constitute a change of circumstances that needs to be reported.

Main Findings: Redetermination and Appeal (Qs 25-28)

A majority of respondents agreed with the proposal that clients have 31 days to request a redetermination, although amongst the organisations that responded, slightly more disagreed than agreed. However, a number of respondents cited instances where more than 31 days may be required and there were requests for flexibility depending on, for example, the need to access professional support or external services, or because of hospital stays.

A majority of respondents also agreed that Social Security Scotland should have a period of between 40-60 days to consider a redetermination of Disability Assistance, although again the views of organisations were split, with some indicating that this timescale is too long.

Main Findings: Short-term Assistance (STA) (Qs 29-38)

A majority of respondents agreed that STA should not be paid to people who are not living or present in Scotland, although there were comments that this should depend on individual circumstances.

A large majority of respondents agreed that STA should not be recoverable except where it is later established that the principal assistance type was claimed fraudulently, although some respondents felt there would need to be clear evidence of deliberate fraud.

A majority of respondents agreed that STA should not be available where an investigation by Social Security Scotland has determined that the original payment was claimed fraudulently. Respondents agreed that there should be a right of appeal against any decision by Social Security Scotland that Disability Assistance had been claimed fraudulently. Additionally, some respondents indicated that if a client’s circumstances change, such that they do meet the eligibility criteria in future, this should not preclude them from claiming Disability Assistance.

A majority of respondents agreed that any deductions being made from an on-going assistance type to service an overpayment liability should also be applied to STA. However, there were also some comments that STA should never be reduced as it provides a financial safety-net, and that there is a need to give consideration to the risk of financial hardship and possible impacts on mental health and wellbeing.

A majority of respondents disagreed that for successful process decision appeals where the tribunal has overturned Social Security Scotland’s decision, STA should become available at the point the decision is overturned rather than the date of the original request. Many respondents noted that STA should become available from the date of the claim when eligibility started, or that payments should be backdated to the date of the original decision. There were also comments that a client should not be disadvantaged financially because of a mistake by Social Security Scotland.

Main Findings: Breaks in Disability Assistance (Qs 39-40)

Views were relatively split as to whether where there is a break in a client’s eligibility to receive the benefit in certain circumstances, they will cease to receive the benefit. The key theme was that there should always be financial support for those with a disability as they will still have everyday costs and removal of the benefit will leave people at risk of serious financial hardship. There was also some reference to the need to consider carers, who are still likely to be supporting the client.

Main Findings: Comments or experience of overpayment recovery (Q41)

Key themes emerging at this question were that current level of deductions are set too high by the Department for Work and Pensions and are expected to be repaid too quickly; that the current system causes severe financial hardship and that repayments should be at a level that is affordable to clients.

1.5 Disability Assistance for Children and Young People (DACYP)

Main Findings: Entitlement to DACYP (Qs 42-43)

There was broad agreement with the proposal to provide entitlement to Disability Assistance for Children and Young People to clients aged 0-18 years (initially the upper age limit will be set at 16 until delivery of Disability Assistance for Working Age People commences). However small numbers of respondents suggested the age bracket should be extended to allow for ease of transition for those aged between 16 and 21.

Main Findings: Young People aged 16-18 (Qs 44-47)

There was broad agreement with the proposal to extend eligibility, for those already in receipt of Disability Assistance for Children and Young People before the age of 16, to age 18.

A majority of respondents agreed with the approach to eligibility rules for the different components of Disability Assistance for Children and Young People, although there were a few comments that eligibility criteria do not reflect some situations accurately. For example, many respondents felt that age 16-18 is a difficult period with some challenging transition points, and that making significant life choices can be difficult for some clients; many also felt that the age eligibility could be extended to the age of 21 for those in full time education.

Main Findings: Winter Heating Assistance (Qs 48-49)

The large majority of respondents agreed with the proposal to make a £200 Winter Heating Assistance payment to families with a child in receipt of the highest rate of the care component of Disability Assistance for Children and Young People. There were some suggestions that this payment should be available to all people receiving any form of social security benefits or Disability Assistance.

1.6 Disability Assistance for Working-Age People

Main Findings: Benefit Rules: Activities and Descriptors (Qs 50-53)

A majority of respondents agreed with the proposal to use a points-based system to assess eligibility in relation to Disability Assistance for Working-Age People, although there were some comments that a points-based system lacks flexibility, particularly in relation to fluctuating conditions. Significant numbers of respondents felt that points-based systems have already been discredited, and that a ‘one size fits all’ approach is inappropriate.

When asked what suggestions they had about the most appropriate way to assess eligibility in relation to mobility for Disability Assistance for Working-Age People, respondents tended to focus on the use of medical consultants, general practitioners, experts and specialists and their reports and evidence. There was also agreement of a need for a person-centred approach and reference to the client’s own evidence, as well as seeking more information about the skills that would be required by Assessors to make an appropriate assessment of the impact of an individual’s health condition.

In terms of the full list of descriptors currently used to assess claims for Personal Independence Payments (PIP), the key themes were that the descriptors do not make sufficient allowance for clients with mental health conditions and are geared towards those with physical disabilities. There were also requests for the descriptors to be changed so they more properly reflect the impact of disabilities on daily lives as opposed to functional ability.

Main Findings: Assessments (Qs 54-59)

A wide range of informal observations made by assessors as part of a face-to-face assessment were considered to be inappropriate. These included observations relating to personal appearance, behavioural observations and movement, strength and sight tests. There were also some comments on the need for face-to-face assessments to be conducted by trained or experienced assessors with a good understanding of the condition being assessed.

In terms of what are considered acceptable distances to travelling to an assessment centre, there was little consensus, although there were comments on the need for assessments to be local to clients. Respondents also pointed out that the ability to travel is dependent on specific conditions and that this needs to be considered on a case-by-case basis.

When asked what other circumstances should be taken into account in relation to travelling to an assessment, respondents focussed on whether a carer or other support is needed, the impact on clients of having to travel and the availability and accessibility of transport options. There were also suggestions that some specific conditions should not require a face-to-face assessment.

Many respondents felt clients should be able to reschedule an appointment three times, although some respondents preferred for rescheduling to have no limits or that rescheduling should depend on the reasons for cancelling or the client's condition.

Respondents outlined a number of criteria that would amount to exceptional circumstances for failing to attend an assessment, including hospital admissions, bereavement, carer or support issues and transport issues. Again, there were some suggestions that these needed consideration on a case-by-case basis.

A large majority of respondents were positive about the audio recording of assessments, although some made caveats such as a requirement for the client's consent.

1.7 Disability Assistance for Older People (DAOP)

Main Findings: Eligibility (Qs 60-64)

A large majority of respondents agreed with the proposal that Disability Assistance for Older People is provided to individuals who have reached state pension age or above. As with the other two forms of Disability Assistance, there was some reference to the need for one disability benefit covering all age groups.

A majority of respondents agreed with the proposed eligibility criteria for DAOP, although there were some concerns over the lack of a mobility component and several requests for this to be included, primarily from organisations.

2 Introduction

2.1 Background

The terms of Part 3 of the Scotland Act 2016 gave effect to some of the recommendations of the Smith Commission and provided for the devolution of a range of social security benefits to the Scottish Government.

Following on from this, the Social Security (Scotland) Act 2018 was a major piece of devolved legislation and the first Act passed by the Scottish Parliament dealing with social security matters. It lays the foundations for the delivery of a range of benefits that will be devolved to Scotland, and represents a substantial extension of the reach and impact of devolved legislation. It covers key areas of social security such as Disability Living Allowance and Personal Independence Payments, as well as aspects of the regulated social fund such as funeral payments and Sure Start maternity benefits. Responsibility for Universal Credit remains reserved to the UK Government, although the Scottish Parliament has been given the power to create new benefits and to top-up reserved benefits.

The Social Security (Scotland) Act 2018 was passed by the Scottish Parliament with the aim of helping to create a fairer Scotland, with a new social security system based on public consultation and Parliamentary scrutiny.

Social Security Scotland was established in April 2018 to deliver devolved benefits in Scotland. It is an Executive Agency of the Scottish Government and its purpose is to administer the Scottish social security system effectively, in accordance with the principles of the Act and the Social Security Charter. When the organisation becomes fully operational, it will administer a total of 14 benefits, supporting 1.4 million people and providing around £3.5 billion in payments every year. The organisation currently delivers Carer’s Allowance Supplement and Best Start Grants (including Pregnancy and Baby Payment, Early Learning Payment and School Age Payment).

Extensive planning is already underway for Social Security Scotland to deliver Best Start Foods, Funeral Support Payment, Young Carers Grant and Job Grants in 2019, and it will begin taking new claims for Disability Assistance, starting with Disability Assistance for Children and Young People, in summer 2020. These are complex benefits as they involve regular payments to individuals, although individuals’ circumstances may change and Social Security Scotland will have to be able to respond quickly to adjust payments. It can be complex identifying eligibility for any benefit and involves verification of identity, evidence gathering and sophisticated decision-making. The Scottish Government is legally required to introduce a system which is fair, open and transparent, and with a rights-based approach.

On 5 March 2019 the Scottish Government published a consultation – Improving Disability Assistance in Scotland – and this set out the Scottish Government’s current policy assumptions for three forms of Disability Assistance:

- From Summer 2020 **– Disability Assistance for Children and Young People** (DACYP): This will replace Disability Living Allowance for Children, which is currently administered by the Department for Work and Pensions. The Scottish Government proposes that the age criteria will be set between 3 months and 16 years, or 18 where a young person is in receipt of this form of assistance before they turn 16.
- By Early 2021 – **Disability Allowance for Working-Age People** (DAWAP): This will replace Personal Independence Payment, which is also administered by the Department for Work and Pensions. The Scottish Government proposes that the age criteria will be for adults below State Pension age.

  Summer 2021 – **Disability Allowance for Older People** (DAOP): This will replace Attendance Allowance, which again is administered by the Department for Work and Pensions. The Scottish Government proposes to align the age criteria with the State Pension age.

The consultation sought the views of all people, including individuals with lived experience or a working knowledge of social security (in particular disability benefits and experience of the application process). Feedback from this consultation will go towards informing the drafting of regulations for each form of assistance. The Scottish Commission on Social Security (SCoSS) has now been established, and part of its role is to scrutinise the Disability Assistance regulations, which will be drafted based on this feedback. The consultation was launched on 5 March 2019 and closed on 28 May 2019.

2.2 Respondent Profile

In total, there were 263 responses to the consultation, of which 74 were from organisations and 189 from individuals.

Respondents were assigned to respondent groupings in order to enable analysis of any differences or commonalities across or within the various different types of organisations and individuals that responded.

A list of all those organisations that submitted a response to the consultation and agreed to have their name published is included in Appendix 1.

As Table 2 overleaf shows, the largest organisation sub-group was Third Sector organisations with 40 responses.

Table 2: Respondent Groups

	Number
Campaigning / Advocacy	13
Local authority	14
Third sector	40
Other	7
Total organisations	**74**
Individuals	189
Total respondents	**263**

2.3 Methodology

Responses to the consultation were submitted using the Scottish Government consultation platform Citizen Space, or by email or hard copy. The Scottish Government also held a number of consultation events. Many of the issues raised at the consultation events were also raised in consultation responses, so these are not reported on separately; rather, they are referred to, where relevant, at each of the questions in this report.

The excel file output from Citizen Space formed the basis of this analysis. This excel file included respondent details from the Respondent Information Form including confidentiality details; responses to each question; and any additional information supplied by the respondent. Any responses submitted via other channels such as email or hard copy were entered into the excel file at the appropriate question(s). In this way, all responses were included in the analysis and reporting.

It should be borne in mind that the number responding at each question is not always the same as the number presented in the respondent group table. This is because some respondents did not answer every question. This report indicates the number of respondents who commented at each question.

A number of organisations referred to research or engagement undertaken and were incorporated into their response.

Where respondents did not complete each closed question but mentioned clearly within their text that they agreed or disagreed with one of the options, these have been included in the relevant counts.

The researchers examined all comments made by respondents and noted the range of issues mentioned in responses, including reasons for opinions, specific examples or explanations, alternative suggestions or other comments. Grouping these issues together into similar themes allowed the researchers to identify whether any particular theme was specific to any particular respondent group or groups.

The views presented in this analysis have not been vetted in any way for factual accuracy. The opinions and comments submitted to the consultation may be based on fact or may, indeed, be based on what respondents perceive to be accurate, but which others may interpret differently. It is important for the analysis to represent views from all perspectives. The report may, therefore, contain analysis of responses that may be factually inaccurate or based on misunderstanding or misinformation, but nevertheless reflect strongly held views. In some instances, such inaccuracies and misunderstandings will be relevant findings in themselves.

In the analysis of responses to the consultation, only those who disagreed with the proposals that were presented were asked to provide supportive commentary, although small numbers of those agreeing with each proposal also provided some commentary. As such, while a majority of respondents were supportive of all the proposals under consideration, commentary tends to focus on reasons for disagreement and allied improvements, changes or modifications that respondents would like to see.

When considering group differences however, it must also be recognised that where a specific opinion has been identified in relation to a particular group or groups, this does not indicate that other groups did not share this opinion.

While the consultation gave all who wished to comment an opportunity to do so, given the self-selecting nature of this type of exercise, any figures quoted here cannot be extrapolated more widely.

A small number of verbatim comments, from those who gave permission for their responses to be made public, have been used in the report to illustrate themes or to provide extra detail for some specific points.

3 Disability Assistance in Scotland

3.1 Disability Assistance for Children and Young people

The consultation document stated that the Scottish Government intends to replace assistance currently delivered by the Department for Work and Pensions in the form of Child Disability Living Allowance (Child DLA), with a form of assistance to be called Disability Assistance for Children and Young People (DACYP). Questions 1 and 2 asked:

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

Q2: If you disagreed please could you explain why.

As shown in the following table, a majority of respondents agreed with this proposal, although of the organisations who responded to this question, almost equal numbers agreed and disagreed.

Table 3: Q1

	Number			
	Agree	Disagree	Don’t know	No response
Campaigning / Advocacy (13)	4	6	1	2
Local authority (14)	5	7	-	2
Third sector (40)	14	10	4	12
Other (7)	2	1	-	4
Total organisations (74)	**25**	**24**	**5**	**20**
Individuals (189)	142	18	18	10
Total respondents (263)	**167**	**42**	**23**	**30**

A total of 51 respondents, across all sub-groups, opted to provide commentary in response to Q2.

A number of themes emerged. The key theme was dislike of the word ‘disability’ and a number of reasons were provided for this. Some respondents felt that this is viewed as potentially divisive or discriminatory in that it can segregate people, particularly young people who do not like the ‘disability’ label. There were some requests for this to focus less on a medical model and more on a social or rights-based model. Linked to this, a small number of respondents felt that the language used is not inclusive and / or that it is inconsistent with a rights-based approach.

"Including the term 'disabled' in the title for all three Disability Assistances may be a disincentive to take up by groups who do not consider themselves disabled, including many people with mental health problems. If the proposed names are retained the Scottish Government must ensure those potentially eligible who do not consider themselves disabled are targeted during future take up campaigns. Evidence from a Department for Work and Pensions ad-hoc study in 2013 found that only 25.9% of people who fit the DWP's definition of disability described themselves as 'disabled' with a further 11.4% describing themselves as 'sometimes disabled'. In regards to mental health we know that not everyone with a mental health problem consider themselves disabled. These issues also apply to the naming on Disability Assistance for Working-Age People (DAWAP) and Disability Assistance for Older People (DAOP)." (Third sector organisation)

Some respondents felt that this name is too long and suggested it needs shortening, while some others noted that the initials DACYP do not make for an easy abbreviation or acronym. A few respondents gave the example of PIP, which was felt to be a good acronym. A few respondents also felt that this suggested name is too complicated or confusing.

Some respondents noted their dislike of the word 'assistance', and suggested using the word 'support' instead. The reasoning for this was primarily that this would be in line with a focus on support and independent living rather than a focus on disability. A small number of respondents felt the suggested name could create a barrier to claiming this benefit as not all individuals would describe themselves as disabled. Allied to this, there were a small number of suggestions that the name needs to emphasis entitlement, for example, involving the use of the words 'benefit' or 'allowance'.

Other comments made by small numbers of respondents included:

- Some requests for a generic name which is inclusive; and some suggestions for the collective name of Disability Assistance, with only the application forms referring to age e.g. DA (CYP), DA (WAP), DA (OP).
- It is not necessary to change the name; DLA is easier to say.
- The definition of a young person can be subjective; a child can be considered an adult at the age of 16.
- The Scottish Government should delay naming until the switch from the Department for Work and Pensions, so as to avoid future confusion.

Some respondents made suggestions for an alternative name and these are listed below:

- Disability Assistance (DA).
- Child Disability Assistance (CDA).
- Disability Social Security.
- Independence Assistance for children and young people aged 18 and under.
- Ability Support.

- DAY.
- Disability Support Allowance.
- Independence and Equality Payment for Children and Young People.
- Personal Assistance for Children and Young People (PACYP).
- Scottish Disability Living Allowance.
- Living Assistance.
- Personal Support and Living Payment.
- Independence Assistance / Payment.
- Disability Payment.
- Disability Benefit.
- Disability Living Allowance.
- Disabled Assistance for Children.
- Equality Assistance / Payment for Children and Young People.

3.2 Disability Assistance for Working Age People

The Scottish Government intends to replace the current delivery by Department for Work and Pensions in the form of Personal Independence Payment with a form of assistance to be known as Disability Assistance for Working Age People (DAWAP). Questions 3 and 4 asked:

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)?

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

As shown in the following table, a majority of respondents agreed with this proposal, although of the organisations who responded to this question and gave an answer, views were relatively split with 23 in agreement and 26 in disagreement.

Table 4: Q3

	Number			
	Agree	Disagree	Don’t know	No response
Campaigning / Advocacy (13)	3	7	-	3
Local authority (14)	5	7	-	2
Third sector (40)	13	11	3	13
Other (7)	2	1	-	4
Total organisations (74)	**23**	**26**	**3**	**22**
Individuals (189)	119	43	17	9
Total respondents (263)	**142**	**69**	**20**	**31**

A total of 79 respondents, across all sub-groups, opted to provide commentary in support of their response to Q3.

A key theme emerging in response to this question was a dislike of the word ‘working’ or ‘working-age people’ and various reasons were provided. This is seen as too emotive for some who cannot work and tends to centre human values around work. Furthermore, a third sector organisation commented that there is no clarity or consistency about what constitutes ‘working age’. A very small number of respondents suggested that this misrepresents the underlying purpose of Disability Assistance which is to pay for the additional costs of living with a disability or health condition.

A few respondents noted that many disabled individuals are unable to work and that this name implies a capacity to work.

A number of the themes cited echoed those made at Q2, and these are listed below:

- The name is too long, complicated or confusing and the initials do not allow for an easy acronym or readily recognisable shortened abbreviation.
- Dislike of the word ‘disability’. For example, this would introduce a barrier to claiming the benefit for some eligible individuals.
- The need for a more social model to naming the new benefits.
- A need for a lifelong Disability Assistance.

Once again, some respondents made suggestions for alternative names that could be considered for this benefit. These included:

- Disability Assistance.
- Disability Assistance for People Aged 16 and over up to State Pension Age.

- Ability Assistance for over 16s.
- Disability Social Security.
- Independence Assistance for ….
- Assistance.
- Disability Allowance Working (DAW).
- Disability Support Allowance.
- Equality Assistance / Payment for Children and Young People.
- Independence and Equality Payment.
- Personal Assistance for Working Age People (PAWAP).
- Scottish Personal Independence Payments.
- Living Assistance.
- Independence Assistance / Payment.
- Disabled Assistance for Adults (DAA).

A small number of people noted they were happy with the proposed name but disliked the acronym.

3.3 Disability Assistance for Older People

The Scottish Government intends to replace current delivery by the Department for Work and Pensions in the form of Attendance Allowance, with a form of assistance to be known as Disability Assistance for Older People (DAOP). Questions 5 and 6 asked:

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)?

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

As shown in the following table, a majority of respondents agreed with this proposal, although of the organisations who responded to this question and gave an answer, views were evenly split with 23 in agreement and 24 in disagreement.

Table 5: Q5

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	3	6	-	4
Local authority (14)	6	6	-	2
Third sector (40)	12	11	3	14
Other (7)	2	1	-	4
Total organisations (74)	**23**	**24**	**3**	**24**
Individuals (189)	135	32	14	7
Total respondents (263)	**158**	**56**	**17**	**31**

A total of 65 respondents, across all sub-groups, opted to provide commentary in support of their response to Q5. Most of the themes raised in response to this question echoed those mentioned at the earlier questions. These included:

- This name is too long, too complicated or confusing and does not make an easy acronym.
- There should be one lifelong Disability Assistance, with no differentiation because of age.
- Dislike of the words 'disability' and 'assistance'.
- The Scottish Government should hold back on a new name until responsibility for delivering the benefit switches from Department for Work and Pensions to avoid any confusion in the future.
- The suggested name could create a barrier to claiming this benefit as some individuals do not perceive or describe themselves as disabled.
- There is a need for a more social model or rights-based approach to naming the new benefits.

A small number of respondents noted their dislike of the word 'older' or 'pension' and felt this could be discriminatory. A third sector organisation also noted that there is confusion over what constitutes an 'older person'.

Once again, a number of alternative names were suggested:

- Disability Social Security.
- Disability Assistance for Pensioners.
- Independence Assistance for ….
- Assistance.
- Disability Support Allowance.

- Independence Payment / Entitlement for Older People.
- Dignity Payment / Entitlement for Older People.
- Equality Payment / Entitlement for Older People.
- Financial Assistance for Newly Disabled Older People (FANCOP).
- Older People's Disability Allowance (OPDA).
- Disability Assistance for Retirees.
- Attendance Allowance Scotland.
- Independence and Equality Payment for Older People.
- Personal Assistance for Older People (PAOP).
- Scottish Attendance Allowance.
- Independence Assistance / Payment.

3.4 Applying for the Benefit

The consultation paper noted that the current application process and guidance available to clients is complicated and lengthy. The Scottish Government intends to redesign the application process to make it more person-centred and to remove repetition and unnecessary complexity. It is also intended that applications for Disability Assistance can be made via a variety of channels (either online, by telephone, or using a paper form.) There will also be clear, transparent and accessible guidance available for each form of Disability Assistance.

Questions 7 and 8 of the consultation paper asked:

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

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

As shown in the following table, all organisations and most individuals who gave an answer agreed with this proposal. The only disagreement came from a small number of individuals.

Table 6: Q7

	Number			
	Agree	Disagree	Don’t know	No response
Campaigning / Advocacy (13)	10	-	-	3
Local authority (14)	12	-	-	2
Third sector (40)	31	-	-	9
Other (7)	4	-	-	3
Total organisations (74)	**57**	**-**	**-**	**17**
Individuals (189)	151	7	23	7
Total respondents (263)	**208**	**7**	**23**	**24**

A total of 34 respondents, across all sub-groups, opted to provide commentary in support of their response to Q7.

The key theme emerging to this question was agreement of a choice in application channels as this would offer inclusivity and help to accommodate the varied needs of clients. Allied to this, there were also some comments that it is important to ensure that systems are fully accessible for all clients; with one third sector organisation pointing out the importance of these different elements being interconnected so that, for example, an individual can start to complete a form online and then print this off to send in the post alongside supporting information.

A few respondents, primarily in the third sector, agreed that the new system would require additional administration resources, that staff will require proper training and that they need to be helpful and empathetic to clients. These respondents also noted there is a need to ensure these aspects are fully implemented. There were also a few comments that clients will still need to be able to access independent support and guidance.

Some respondents referred to difficulties with the present system such as a lack of flexibility in the Department for Work and Pensions claim channels or reference to the current system for Universal Credit which is digital by default and does not suit all clients.

Other comments, each made by only one or two respondents included:

- Some clients who are vulnerable will need face-to-face assistance in their own home to complete the application process.
- External health professionals need to be able to access the application to help the client.

- Agreement that the Scottish Government should provide access to independent advocacy structures and access to specialists so that the new system will work well for all clients.
- A need to ensure there is a clear and transparent definition of the date of a claim.

There were a small number of requests for further detail in relation to this process. While members of Ill Health and Disability Benefits Stakeholder Reference Group (IHDBSRG) and Disability and Carers Benefits Expert Advisory Group (DACBEAG) have had input into the design process, a small number of third sector organisations suggested this process should be co-designed or noted they would like to be involved in the development process.

3.5 Conditions Relating to Residence and Presence

The consultation paper noted that the initial policy intention is for the Scottish system to broadly replicate the residency rules used by the Department for Work and Pensions. The current rules applicable to reserved disability benefits require the client to have been in Great Britain for 104 out of the past 156 weeks. It is intended to replicate this rule so that individuals can move freely within the United Kingdom without having to wait for two years as a result of a move from Scotland to the rest of the UK, or vice-versa. The rules relating to individuals subject to immigration control are a reserved matter (immigration law). There is also the intention to broadly replicate UK provisions in relation to temporary absences from Great Britain, which prevents the loss of eligibility for benefits as a result of short periods spent abroad. Questions 9 and 10 asked:

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

Q10: If you disagreed, please could you explain why.

As shown in the following table, a majority of respondents agreed with this proposal.

Table 7: Q9

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	4	1	1	7
Local authority (14)	12	-	-	2
Third sector (40)	16	2	4	18
Other (7)	3	-	1	3
Total organisations (74)	**35**	**3**	**6**	**30**
Individuals (189)	97	10	72	9
Total respondents (263)	**132**	**13**	**78**	**39**

A total of 27 respondents, across most sub-groups, opted to provide commentary in support of their response to Q9.

The key theme emerging was of a need to ensure that clients do not lose their benefits if they live with their family abroad or that they should have the right to go travelling without losing access to their benefit, with some suggestions that more cover for temporary absence is needed. A small number of respondents suggested a need to broaden out the definition to include a wide range of circumstances; for example, opportunities to allow more discretion to decision-makers for assessing an application under unusual circumstances, or for consideration to be given to people who have been granted refugee status but who have not lived in Scotland for two years.

Once again, a small number of respondents were critical of the current system.

3.6 Making Decisions about Entitlement

The consultation paper noted that a holistic approach would be adopted to enable all information about a client to be considered so that sound judgements can be made about the functional impact of a condition. Social Security Scotland will staff three particular roles to make decisions about entitlement to Disability Assistance. These are Case Managers, Specialist Advisors and Assessors. Questions 11 and 12 asked:

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

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

As shown in the following table, there was broad consensus for this proposal, with only a small number of respondents disagreeing:

Table 8: Q11

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	10	1	-	2
Local authority (14)	12	-	-	2
Third sector (40)	25	-	2	13
Other (7)	4	-	-	3
Total organisations (74)	**51**	**1**	**2**	**20**
Individuals (189)	167	9	5	7
Total respondents (263)	**218**	**10**	**7**	**27**

A total of 41 respondents, across all sub-groups, opted to provide commentary in support of their response to Q11.

One key theme, cited by around half the respondents who answered Q12, reiterated their support for a person-centred approach, with a small number of additional comments that there is a need to adopt a social model of disability to all aspects of social security. A few respondents noted that the current system should be person-centred but were critical that this is not actually the case, particularly when there is a need for face-to-face assessments, and this can contribute to distress and anxiety for clients.

Other issues raised by respondents who answered this question tended to focus on qualifying comments. A key theme, mentioned by around half the respondents, was agreement that all staff are properly trained and work at the same level of competence so that any decisions made are consistent, as well as being provided with updated training on a regular basis. There was also agreement of a need for the provision of clear guidance and an understanding of how a disability can impact on a client.

Some respondents also commented that this will need to be well resourced for the implementation of this proposal to be effective.

Other comments raised by small numbers of respondents included:

- Any assessments should be carried out by a GP who knows the client.
- Medical information should be of primary importance in any assessment.
- There is a need to use objective science-based evidence for decision-making.
- More information is needed on what training will be provided to assessors.

- There should be some exceptions, for example, automatic entitlement for some long term conditions such as Motor Neurone Disease.
- A need to ensure the client is consulted at all stages of the decision-making process.
- Disagreement with the implied assumption that supporting information would be required in order for a case manager to make a robust decision.

"While we agree that a holistic person-centred approach which treats individuals with dignity and respect is a positive necessity, we also recognise that the balance between person-centred and subjective is a difficult one with the potential to become discriminatory. It will be essential that training, including gender competence, for advisors addresses biases, stereotypes, and assumptions to ensure that assessors take into account the reality of women's lives. Additionally it is crucial that there are accessible and practical forms of challenges where individuals feel decisions have penalised them unfairly."

(Campaigning / advocacy organisation)

The consultation notes that for Disability Assistance for Children and Young People and Disability Assistance for Older People, it is the Scottish Government's intention to make decisions about entitlement using existing sources of information only and not through face-to-face assessments. Case Managers will have access to information and advice provided by Specialist Advisors who have professional experience in the provision of health and social care. These Specialist Advisors will provide information and advice on a broad range of matters. Question 13 and 14 asked:

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

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

The following table shows that a large majority of respondents agreed with this proposal; only a small number of respondents disagreed with the proposed approach to the involvement of Specialist Advisors in decision-making.

Table 9: Q13

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	5	1	2	5
Local authority (14)	11	-	1	2
Third sector (40)	14	2	5	19
Other (7)	4	-	-	3
Total organisations (74)	**34**	**3**	**8**	**29**
Individuals (189)	141	14	25	8
Total respondents (263)	**175**	**17**	**33**	**37**

Forty-nine respondents went onto provide commentary in support of their response. Health professionals are clearly perceived to be important in decision-making and a number of respondents commented on the need for decisions to be made by specialist consultants or healthcare professionals who know the client, with some of these respondents noting that the health professional's opinion should override that of the Specialist Advisor. A similar number of respondents also felt the client and / or their carer should be involved in any decisions as they know best about their functionality; furthermore, not all conditions affect all clients in the same way.

Some respondents had concerns that Specialist Advisors will not have the required skills and knowledge to provide information on all conditions and thus will not be qualified to make some decisions. To help overcome this, there was support for the proposals that Specialist Advisors should have condition-specific training and experience of working in the third sector or the medical profession so they have the necessary knowledge and understanding to be able to make decisions.

Some respondents requested additional information: for example, what training or medical qualifications Specialist Advisors will hold, how they will develop and maintain expertise on conditions (particularly rare conditions), or what responsibilities they will take on. One respondent requested a definition of what would constitute 'appropriate understanding'.

There were also some suggestions of the need to work closely with third sector organisations who will have the necessary knowledge and experience of specific conditions and who are experts on specific health and disability issues. Examples provided included the provision of training and the updating of skills and monitoring of skills gaps. There was also reference by a small number of respondents to the need for statutory guidance for Specialist Advisors.

Other comments made, each by small numbers of respondents included:

- The need for a balanced approach and consultation with a client's representatives; personal testimony or evidence from family members and carers is an important element.
- Queries on whether the Specialist Advisors will be independent and who will employ them to carry out decision-making.
- The need for disabled people to be able to have access to any information about them.

As at previous questions, a few respondents were critical of the current system and wanted to ensure that this proposal would not simply replicate the existing system.

The consultation paper noted that Case Managers working on all forms of Disability Assistance will have access to information and advice provided by Specialist Advisors within Social Security Scotland who have professional experience in the provision of health and social care, which may include experience gained within the third sector. The consultation paper proposed that Case Managers will take into account a number of factors when deciding whether to refer a case to a Specialist Advisor. Question 15 then went onto ask:

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

A total of 196 respondents provided an answer to this question, with many noting their support for referring a case to a Specialist Advisor in instances where the Case Manager does not have the required knowledge or expertise. A wide range of other factors were noted. These included:

Factors relevant to condition

- Complex / rare conditions. Some respondents cited specific conditions including Epilepsy, Lymphedema, Fibromyalgia, Multiple Sclerosis, Cancer, Head Injuries.
- Multiple illnesses / comorbidities.
- Fluctuating conditions.
- Conditions where symptoms vary from person to person.
- Where there are hidden or invisible disabilities.
- Where a client has a mental health condition or learning difficulty, or where they may not be able to understand and take part in the process.

Factors relevant to Case Managers

- In instances where there is contradictory evidence or inconsistencies in the evidence being presented or any doubt over the information being provided and a second opinion is needed.
- Where existing information is deficient and / or there is a lack of evidence.
- Where there are medical reports or advice from medical practitioners / health professionals.

Other factors

- In instances where a decision is negative.
- Dependent on a client's history or family background.
- If requested by a client.

There were a small number of comments seeking further details of training and / or skills that would be needed for Assessors, Case Managers or Specialist Advisors. A third sector organisation emphasised the importance of Case Managers taking into account the interconnectedness of all information.

Questions 16 and 17 then went onto ask:

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?

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

The following table shows a large majority of respondents agreed with this proposal.

Table 10: Q16

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	5	3	2	3
Local authority (14)	10	2	-	2
Third sector (40)	21	4	3	12
Other (7)	3	-	-	4
Total organisations (74)	**39**	**9**	**5**	**21**
Individuals (189)	136	32	13	7
Total respondents (263)	**175**	**41**	**18**	**28**

A total of 72 respondents provided commentary in support of their response at Q16, although most comments were made by relatively small numbers. Some of these respondents echoed what was noted in the consultation paper and welcomed the commitment to reduce the number of face-to-face assessments. Some respondents used their own experience as either a client or a carer to illustrate their response.

The key comment was agreement with the consultation paper in that existing supporting information might be insufficient in terms of lacking detail or being out of date, which could make it difficult to make a decision without a face-to-face assessment. Allied to this a few respondents also commented that some conditions might need a face-to-face assessment or that a face-to-face assessment will be needed for first time applicants. Conversely, a similar number of respondents felt that a face-to-face assessment should not be used for some conditions such as autism where an individual is likely to have communication difficulties, sensory issues, poor levels of social interaction or suffer extreme anxiety. Respondents suggested individuals with some other conditions may not require a face-to-face assessment, for example, individuals with a diagnosis of Myalgic Encephalomyelitis, Parkinson's disease or hearing loss.

Some respondents were critical of the age boundaries being suggested and noted that being younger or older does not make a client more reliable. These respondents felt the same criteria should apply to people of working age as the condition(s) from which they suffer will not vary according to their age.

The issue of client choice was mentioned by some respondents who suggested clients should be offered a choice of attending a face-to-face assessment if the Case Manager would otherwise be likely to make an adverse decision on an application based on the application form alone.

Other comments made by small numbers of respondents included:

- Agreement of a presumption against face-to-face assessments.
- Information or evidence from general practitioners or NHS specialists should negate the need for a face-to-face assessment.
- The use of supporting evidence is unintrusive to clients and enables dignity, fairness and respect.
- Face-to-face assessments can cause acute anxiety, stress and confusion to clients.
- Agreement that Social Security Scotland should collate evidence through the application process and specialists who are involved in their care to ensure the process is as unobtrusive and straightforward as possible.
- Agreement that Assessors should take a proactive, holistic approach to gathering information, using other channels in order to ensure a person-centred approach.
- Agreement that face-to-face assessments should only be used in instances where medical details do not provide full information or if there is a change in circumstances.
- Face-to-face assessments are necessary to avoid fraudulent claims being made.

3.7 Approach to Supporting Information

The consultation paper outlined that the intention is for Case Managers to use existing information where possible to support decision-making and, where possible, Social Security Scotland will assume responsibility for gathering information. Case Managers will give equal weight to supporting information that is most relevant for each case. Where individuals choose to gather information, Social Security Scotland will provide clear and transparent guidance about what information will be helpful in supporting an application and what information is not as useful. Question 18 went on to ask:

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

A total of 228 respondents answered this question and a wide range of supporting information was cited. This included evidence from those within the medical profession, those who are in close contact with clients and those involved in other forms of care provided to clients. Suggestions provided by respondents included:

- Medical reports / information from health professionals.
- Social work reports.
- Reports from GPs.
- Reports from consultants, specialists, specialist nurses or any professional involved in the client's care.
- Reports from Occupational Therapists, Occupational Health or physiotherapists.
- Reports from psychiatrists or educational psychologists.
- Information from carers, family or friends or someone who knows the client well.
- Information from support workers.
- Information from care packages, care plans and support plans or school / nursery / college educational support plans.
- Information from the client themselves or their diaries outlining the impact of a condition on their day-to-day living.
- Evidence from Speech and Language Therapists (SALT).
- Third sector, voluntary or charity reports.
- Evidence from Child and Adolescent Mental Health Services (CAMHS).

Small numbers of respondents noted concerns that some clients have little contact with clinical services and may not have ready access to supporting information, or had concerns that there may be a charge for a clinical report or that it can take a while for a healthcare professional to supply the required supporting evidence. One organisation noted concerns around patient confidentiality; another that individuals should be able to see the supporting information so they can check its accuracy.

3.8 Duration of Awards

The consultation paper noted that the Scottish Government has taken advice from Experience Panels, a short-life working group and the Disability and Carers Benefits Expert Advisory Group and is committed to introducing longer-term disability benefit awards in the form of rolling awards where the client's condition is unlikely to change. These awards will be allocated a review point rather than a set end point and payments will continue during the review period. For a person with a condition that is unlikely to change it is proposed that Case Manager's Guidance will recommend that an award review date is set between 5 and 10 years from the initial date of award. Questions 19 and 20 asked:

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?

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

The following table shows a much higher level of agreement with this proposal than disagreement, across all sub-groups:

Table 11: Q19

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	2	4	2	5
Local authority (14)	8	2	1	3
Third sector (40)	18	4	5	13
Other (7)	2	1	-	4
Total organisations (74)	**30**	**11**	**8**	**25**
Individuals (189)	122	40	18	8
Total respondents (263)	**152**	**51**	**26**	**33**

A total of 83 respondents provided commentary in support of their response at Q19. These comments were also echoed in responses to question 21, so comments for both questions are reported after Table 12.

Questions 21 and 22 went on to ask:

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?

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

As shown in the following table, a higher number of respondents agreed than disagreed with this proposal. However, the views of organisations were relatively polarised, with 26 in agreement and 23 in opposition to the proposal. Higher numbers of local authorities agreed than disagreed; and higher numbers of campaigning / advocacy organisations disagreed than agreed.

Table 12: Q21

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	1	8	-	4
Local authority (14)	9	2	-	3
Third sector (40)	14	12	1	13
Other (7)	2	1	-	4
Total organisations (74)	**26**	**23**	**1**	**24**
Individuals (189)	108	62	9	9
Total respondents (263)	**134**	**85**	**10**	**33**

A total of 106 respondents provided commentary in response to Q21.

Key themes emerging across these two questions were agreement that if initial assessment advises there will be no improvement in the applicant's health or if their condition is unlikely to change, this should prevent further reassessment in the future. There was also agreement from some respondents that if a condition is likely to change, it would be appropriate to have an award for a limited period of time. There were requests from over half of those respondents commenting at Q21 that there should be indefinite lifetime awards if an individual has a long term condition that is unlikely to change, or where there is unlikely to be any significant change in the foreseeable future; a small number of respondents suggested there could be a light touch review rather than a full review in instances where circumstances do not improve.

A few respondents made suggestions as to the appropriate timescale for reviews but there was no consistency in these suggestions; suggestions included for more than two years, a minimum of three years, a minimum of seven years or five to ten years. There were also a small number of comments that review periods should be as long as possible rather than as short as possible. Some respondents made suggestions for specific review periods, and these ranged from five to fifteen years, with the most opting for a minimum of ten years.

Small numbers of respondents noted benefits to the proposal to have no set award durations but to set an award review date when a decision on the Disability Assistance application is made, although one third sector organisation commented that this could still be interpreted by many recipients as being an award duration.

The main benefits for clients would be the introduction of a system suited to the long term nature of their condition and removing the anxiety associated with having to undergo a reassessment, which can in turn worsen the client's condition. The key benefit to Social Security Scotland staff would be that claims could be handled less frequently which would mean greater efficiency and a reduction in Social Security Scotland's administration and overheads.

The consultation paper then went on to note that a change of circumstances should be considered as a change which has an impact on the level of assistance a person already receives. For example, there would be no need for a review where there has been any change in employment status or a change of personal details is reported. Questions 23 and 24 asked:

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?

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

As shown in the following table, a large majority of respondents agreed 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.

Table 13: Q23

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	4	2	-	7
Local authority (14)	11	-	-	3
Third sector (40)	20	2	5	13
Other (7)	3	-	-	4
Total organisations (74)	**38**	**4**	**5**	**27**
Individuals (189)	135	30	16	7
Total respondents (263)	**173**	**34**	**21**	**34**

Two key themes emerged in response to this question. First, that the consultation paper provided too limited a definition of a change of circumstances and that cases can be more complex than this suggests, with some comments that some clients are unsure what constitutes a relevant change of circumstances; so at the least there needs to be a clear definition or guidance of a change of circumstances that will require changes in the level of support.

The second key theme was that what constitutes a relevant change of circumstances would depend on what the change – and the scale of change – is to warrant a review. For example, if there is an improvement in someone's condition, this would constitute a relevant change of circumstances and therefore require a reassessment but a change of address would not.

Some respondents also commented that the definition should not say 'how much assistance a person receives' but how much assistance a person requires, with a suggestion that change should be defined as 'a major change in their condition which impacts on their ability to carry out tasks'.

A few respondents noted a concern that most conditions do not have a strict, constant and precise relationship with functional capacity or daily activity and are likely to fluctuate to a degree. In addition, a small number of respondents noted that there may be a need for more care because an existing carer can no longer provide the same level of care to a client.

Relatively small numbers of respondents noted specific points and these included:

- Agreement that Social Security Scotland will not treat taking up employment as a relevant change of circumstances.
- There is a need for clear statutory guidance which outlines what constitutes a change in circumstances.
- Agreement that requests for supporting evidence would be in line with the principles of dignity, fairness and respect.
- Agreement that there will be flexibility within the system, and examination of the issues on a case-by-case basis.

3.9 Redetermination and Appeal

The consultation paper explained that the Social Security (Scotland) Act 2018 provides a right for an individual to challenge a decision made by Social Security Scotland if they believe it is not correct. The Scottish Government is proposing that a redetermination request relating to Disability Assistance should be made within 31 calendar days of being notified of the determination. If there is good reason for a request being made late, a request for a redetermination can be considered at any point up to a year after being notified of the original determination. Questions 25 and 26 asked:

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

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

As shown in the following table, overall, a much higher number of respondents agreed than disagreed with the proposal that clients have 31 days to request a redetermination. However, the views of organisations were equally split, with almost equal numbers in agreement and disagreement with the proposal. Higher numbers of organisations within the third sector and campaigning / advocacy organisations were in disagreement with this proposal.

Table 14: Q25

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	3	5	2	3
Local authority (14)	7	4	1	2
Third sector (40)	10	14	3	13
Other (7)	2	1	-	4
Total organisations (74)	**22**	**24**	**6**	**22**
Individuals (189)	112	50	18	8
Total respondents (263)	**134**	**74**	**24**	**30**

A total of 94 respondents opted to provide additional commentary in support of their response to Q25.

The key theme emerging – primarily from respondents who disagreed with this proposal – was that accessing professional or external services can be challenging and take a long time; even once a request is made for evidence to be provided, it can take time for professionals to then prepare this.

Another key theme was that clients may need longer than 31 days to submit their evidence because of personal circumstances such as being in hospital for some or all of the 31 days, or an individual with learning difficulties may find it challenging to gather any information and require external help.

There was also agreement from some respondents of a need for extensions to be allowed, providing a delay can be adequately explained and that there will be a need for flexibility for some clients because of their situation or the nature of their condition.

A number of respondents felt that the time limit could be longer. While some did not provide any further detail, others cited timescales of 6 weeks, 2-3 months, 3 months and 6 months. One organisation suggested there should be no time limit in cases where clients argue their original award was based on an error of law.

A small number of organisations were concerned that the time limit of 31 days could deter some clients; for example, people with mental health illnesses might not engage with the processes involved in challenging a decision. One organisation suggested the redetermination process should operate along the lines adopted for housing benefit appeals where a client completes an appeal letter and the local authority reconsiders the decision. Another organisation noted the need to communicate to clients their right to advocacy and support through the redetermination process. One third sector organisation felt that disabled people should have the option to go straight to appeal with no requirement to undergo redetermination.

The consultation paper then outlined that it is likely that additional evidence may need to be obtained during the redetermination stage and proposed a timescale of between 40-60 working days for a redetermination of Disability Assistance. Questions 27 and 28 asked:

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?

Q28: If you disagreed, please could you explain why.

As shown in the following table, overall, a higher number of respondents agreed than disagreed with the proposal that Social Security Scotland have a period of between 40 and 60 days to consider a redetermination of Disability Assistance. However, the views of organisations were markedly divergent, with almost equal numbers in agreement and disagreement with the proposal. Higher numbers of organisations within the third sector and campaigning / advocacy organisations were in disagreement with this proposal. Higher numbers of local authorities were in agreement with this proposal.

Table 15: Q27

	Number			
	Agree	Disagree	Don’t know	No response
Campaigning / Advocacy (13)	2	6	1	4
Local authority (14)	9	3	-	2
Third sector (40)	10	12	3	15
Other (7)	2	1	-	4
Total organisations (74)	**23**	**22**	**4**	**25**
Individuals (189)	114	48	17	9
Total respondents (263)	**137**	**70**	**21**	**34**

A total of 85 respondents opted to provide additional commentary in support of their response to Q27. The key theme, cited by respondents in all sub-groups other than local authorities, was that this timescale is too long and should be quicker. A number of respondents – again, across all sub-groups other than local authorities – cited concerns that the applicant should not be short of money during the redetermination period and others noted that this is a stressful time for clients[1] (cited by respondents across all sub-groups).

Some respondents provided their own suggestions for a more suitable timescale and these ranged from 28 days or fewer, to as long as 60-90 days, although more of these respondents suggested a timescale of up to 30 days than over 30 days.

A third sector organisation disagreed with any mandatory redetermination process and suggested that all necessary information should be collected at application stage so that there is no need for redetermination.

3.10 Short-term Assistance

The consultation paper explained that the Scottish Government has committed to providing Short-term Assistance (STA) where Social Security Scotland has made a decision to reduce or stop an on-going benefit and that decision is subject to a request for redetermination or an appeal. Where there is a successful appeal, an individual's entitlement would be adjusted from the point at which it was reduced or stopped or from the point as decided by the tribunal. Given that the principal assistance type will have required an individual to meet clearly stated residence requirements, the Scottish Government proposes that STA should not be available if the individual is no longer living or present in Scotland. Questions 29 and 30 asked:

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

Q30: If you disagreed, please could you explain why.

As shown in the following table, overall, a large majority of respondents agreed with the proposal that STA should not be paid to people who are not living or present in Scotland. Across organisations, the highest levels of agreement came from third sector organisations and local authorities.

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[1] STA (Short-term Assistance) will be available where an award is reduced or stopped by Social Security Scotland, to provide a safety net.

Table 16: Q29

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	2	2	2	7
Local authority (14)	11	1	-	2
Third sector (40)	15	3	4	18
Other (7)	2	-	-	5
Total organisations (74)	**30**	**6**	**6**	**32**
Individuals (189)	135	16	29	8
Total respondents (263)	**165**	**22**	**35**	**40**

Only 40 respondents opted to provide additional commentary in support of their response to Q29, and the largest single comment was that this should depend on individual circumstances. Examples included if someone has to live with their family elsewhere for their care needs to be supported for a short time or if there is a need to move for work for a period or that it depends on how long someone will be out of the country and whether they will be returning.

A small number of respondents felt that a refusal to pay STA in certain cases was discriminatory as it would place restrictions on the movement of disabled people not experienced by non-disabled people, that it would restrict personal mobility, or damage life chances. There were a small number of suggestions for exceptions to the proposal, for example, if someone has retired elsewhere but paid their taxes in Scotland, or for individuals who wish to go travelling.

A small number of respondents agreed with the proposal, noting that STA money should stay in Scotland and STA should only be available for those who are resident in Scotland.

A small number of respondents requested more detail or information, such as how STA might be rolled out in the future or how presence / living criteria will be defined.

3.10.1 Recovery of STA

The consultation paper explained that as the purpose of STA is to ensure an individual is not discouraged from challenging a decision or face hardship while doing so, the Scottish Government proposes that STA should not be recoverable. The exception to this would be where the principal assistance type was found to have been claimed fraudulently and Social Security Scotland was not aware of this at the time STA was awarded. Questions 31 and 32 asked:

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?

Q32: If you disagreed, please could you explain why.

As shown in the following table, a large majority of respondents agreed with this proposal; and all organisations agreed.

Table 17: Q31

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	8	-	-	5
Local authority (14)	12	-	-	2
Third sector (40)	21	-	2	17
Other (7)	2	-	-	5
Total organisations (74)	**43**	**-**	**2**	**29**
Individuals (189)	155	9	17	7
Total respondents (263)	**198**	**9**	**19**	**36**

Only 19 respondents opted to provide additional commentary in support of their response to Q31, and the largest single comment was that clients who have given fraudulent information should be liable to make repayment in full. That said, a small number of respondents felt that there needs to be a distinction drawn between deliberate fraudulent behaviour by clients, errors or mistakes made by clients, and mistakes made by Social Security Scotland.

[….] STA should not be recoverable except in cases of fraud. Any recovery beyond cases of fraud would undermine the purpose of STA in supporting someone financially, for example during appeal, as it would be a disincentive to challenge decisions regarding their Disability Assistance. Where someone has been found to have claimed their original Disability Assistance award fraudulently, we believe that the Agency in line with the principles of the Act should take a human rights and person centred approach to recovery of STA. Rates of recovery should be set to a level that would not leave the person destitute." (Third sector organisation)

3.10.2 Fraud Investigations

The consultation paper explained that during a fraud investigation, the overarching principle is a presumption of innocence and an individual's payments will not be stopped or reduced unless Social Security Scotland has investigated and obtained evidence that, on the balance of probabilities, show that the assistance has been paid incorrectly. The Scottish Government proposes that in these circumstances, STA would not be payable even if the individual has requested a redetermination or an appeal. Questions 33 and 34 went on to ask:

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

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

As shown in the following table, a majority of respondents agreed with the proposal that STA should not be available where an investigation by Social Security Scotland has determined that the original payment was claimed fraudulently:

Table 18: Q33

	Number			
	Agree	Disagree	Don’t know	No response
Campaigning / Advocacy (13)	2	2	1	8
Local authority (14)	11	1	-	2
Third sector (40)	12	2	5	21
Other (7)	2	-	-	5
Total organisations (74)	**27**	**5**	**6**	**36**
Individuals (189)	131	23	25	9
Total respondents (263)	**158**	**28**	**31**	**45**

A total of 38 respondents provided an answer to Q34. The majority of respondents’ views on the issue were supportive of the policy intent set out in the consultation paper, and the Scottish Government’s current plans are already intended to implement a policy that meets the respondent feedback.

As at the previous question, some respondents differentiated between genuine mistakes, errors on the part of Social Security Scotland, and fraud, with comments that if payment of STA is because of a genuine mistake in the initial application, or as a result of a mistake by Social Security Scotland, it should not be recoverable and the claimant should not be penalised.

“The consultation does not seem to make a clear distinction between fraud and error, referring both to an award being paid incorrectly and to fraud being identified. The rules for STA should make it clear whether it is not available in both situations or only in cases where there is evidence of an offence having been committed.”

(Campaigning / advocacy organisation)

Other comments made, each by small numbers of respondents included:

- There is a need to consider the definition of fraud (as opposed to overpayments) and who is deciding if fraud has been committed.
- Clients are innocent until proven guilty.
- The decision should be made by the Court and not Social Security Scotland; there is a need to follow the correct legal process; and a need to clarify what types of recoverability exist.

3.10.3 Servicing an Overpayment Liability

The consultation paper explained that there may be situations where deductions are being made from an individual's on-going assistance to service an overpayment liability and the Scottish Government proposes that these deductions should also apply to STA. Questions 35 and 36 asked:

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

Q36: If you disagreed, please could you explain why.

As shown in the following table, a majority of respondents agreed with this proposal:

Table 19: Q35

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	2	4	-	7
Local authority (14)	9	1	-	4
Third sector (40)	11	4	4	21
Other (7)	1	-	-	6
Total organisations (74)	**23**	**9**	**4**	**38**
Individuals (189)	84	33	61	10
Total respondents (263)	**107**	**42**	**65**	**48**

A total of 49 respondents provided commentary in response to Q36. The key theme emerging was that STA should never be reduced as it provides an essential safety-net, and that recovering overpayments of STA would defeat the purpose of paying it in the first place. Another key theme was that there is a need to take into account the risk of financial hardship as well as the negative impact on health and wellbeing of clients. Allied to this, a small number of respondents noted that recovery of STA can be unduly punitive.

"By definition, short term assistance is being paid at a point where Disability Assistance would otherwise be interrupted and may be about to cease. Further reducing the income for the person claiming the assistance (and their family) at this point undermines one of the stated objectives of this type of assistance, which is about removing barriers to challenging decisions. We know that even small ongoing reductions in household income can make it harder for people (especially people

with disabilities or with caring responsibilities or both) to take on the extra tasks or costs associated with challenging decisions."

(Campaigning / advocacy organisation)

Some respondents suggested that a decision to make deductions from social security benefits should be done on a case-by-case basis based on affordability to repay the amount to be recovered, or that any repayment should be at a low level so that it will not affect the client's quality of life.

A similar number of respondents also felt that overpayment should not be recovered if the overpayment is the fault of Social Security Scotland.

Other comments made, each by small numbers of respondents included:

- Requests for additional information such as what happens if someone relocates to England for six months.
- Agreement that Social Security Scotland staff will be fully trained.
- Agreement of a simple right of appeal against a determination.

3.10.4 Process Decision Appeals

The consultation paper noted that the 2018 Act provides appeal rights for what are termed as process decisions (where Social Security Scotland refuses a request for a redetermination, either because it views the request as not being validly made, or where a request is made outside of the time limits without a valid reason). Appeals against these decisions are not routed via Social Security Scotland and the individual is responsible for lodging an appeal themselves with the Tribunal within the timeframes set out in s. 61 of the Social Security (Scotland) Act 2018. Questions 37 and 38 asked:

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

Q38: If you disagreed, please could you explain why.

As shown in the following table, a majority of respondents, across all sub groups, disagreed with this proposal:

Table 20: Q37

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	1	4	1	7
Local authority (14)	2	9	1	2
Third sector (40)	4	16	4	18
Other (7)	1	1	-	5
Total organisations (74)	**8**	**28**	**6**	**32**
Individuals (189)	47	99	29	13
Total respondents (263)	**55**	**127**	**35**	**45**

A total of 132 respondents provided a response to Q38 and the key theme, cited by over half of those responding to this question, was that STA should become available from the date of the claim when eligibility started so that a client is not out of pocket because of an incorrect decision that is subsequently overturned. Around a third of respondents also noted that payments should be backdated to the date of the original decision that was then subsequently overturned. One organisation in the third sector noted that this proposal would create the potential for a client to be financially penalised for errors made by Social Security Scotland in adjudicating on their claim. An organisation highlighted issues in relation to devolved powers:

"The earliest date possible should be used under powers of STA or existing benefits but given we do not control all of this it will be difficult. We could use similar processes like when appealing ESA when this is re-instated at appeal.
As we may see individuals lose out we cannot risk this so the earliest date should be appropriate." (Representative organisation)

Once again, there were some references to the unfairness of penalising a client because of a mistake by Social Security Scotland and that this should not result in detriment or financial hardship to the client.

Other comments, each made by small numbers of respondents included:

- The proposal would cause unnecessary hardship anxiety and stress to clients.
- The appeals process is too lengthy.
- This proposal does not fit with the fairness, dignity and respect principles of the Scottish Government in the delivery of social security.

3.11 Breaks in Disability Assistance

The consultation paper stated that the Scottish Government proposes that breaks in Disability Assistance will continue to impact on eligibility so that where there is a break in a person's eligibility to receive the benefit after 28 days, whether that is due to residency or other issues, they will cease to receive the benefit. Questions 39 and 40 asked:

Q39: 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?

Q40: If you disagreed, please could you explain why.

As shown in the following table, views across all respondents were relatively polarised, and 92 respondents agreed compared to 103 who disagreed. Among organisations specifically, a higher number of respondents disagreed (26) than agreed (17).

Table 21: Q39

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	2	7	1	3
Local authority (14)	7	5	-	2
Third sector (40)	6	13	5	16
Other (7)	2	1	-	4
Total organisations (74)	**17**	**26**	**6**	**25**
Individuals (189)	75	77	28	8
Total respondents (263)	**92**	**103**	**34**	**33**

A total of 121 respondents provided further commentary in support of their response at Q39.

The key theme which emerged was that there should always be financial support for those with a disability as they will still have everyday costs and removal of the benefit would leave people at risk of serious financial hardship. One organisation noted that the benefit is likely to be factored into a household's overall income and thus the client and their family will be reliant on its payment. Linked to this, some respondents also noted that Disability Assistance should cover the additional costs of a client's disability or health condition; and provided the leasing of adaptive equipment or the employment of a personal assistant as examples of costs that will still need to be met. Furthermore, some respondents also commented that there is a need to consider carers and that removal of the benefit should not impact negatively upon them, particularly if they are still providing support to the client.

Around a quarter of respondents agreed that there is a need to be able to pause payments and have quick reinstatement of these without a client having to reapply for the benefit; some of these respondents suggested there needs to be a fast track return to payment of the benefit, and some referred to the need for automatic reinstatement. A very small number suggested there could be a capacity for short-term suspensions.

A few respondents commented that it will depend upon the reason for a break in payments and decisions made on a case-by-case basis. While a relatively small number of respondents felt that the proposal is acceptable if a client will permanently be in residential care and will not require the benefit for the original purpose of its payment, a similar number noted that if the reason for eligibility to receive the benefit is temporary, perhaps for two months, then the client should still receive the benefit. Similarly, a small number also noted that sometimes the benefit will be needed to help pay for residential care and services needed while the client is in residential care[2], while a similar number also commented that some people are unable to leave hospital because of a lack of a care package and should not lose the benefit in these instances.

A few respondents also noted their disagreement with Disability Assistance being stopped after 28 days in hospital, with suggestions that this needs to be extended to 56 days or three months, which would offer a more person-centred approach.

Finally, at this question, a few respondents requested further information or clarification on specific points such as how benefits would be reinstated or the circumstances for an adult in education, on remand or in prison.

3.12 Overpayments and Deductions

The consultation paper noted that policy on overpayments for Disability Assistance will follow wider policy for Social Security Scotland. Where an overpayment is made as a result of Social Security Scotland error, it will not be pursued unless there are exceptional circumstances, such as a large and obvious overpayment. Where it is made as a result of client error, Social Security Scotland may seek to recover the overpaid assistance, but in doing so will have regard to the individual's financial and other circumstances they consider relevant.   Question 41 asked:

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

To an extent, the responses to this question largely echoed many seen in responses to earlier questions. Three key themes emerged.

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[2] If a client is on a low income and has little/no capital, then they will qualify for local authority or NHS support for their care needs. Self-funding individuals should not have their payment stopped as there is no 'double' public funding of care.

1. First, deductions are set far too high and are expected to be repaid too quickly, which is punitive for clients. Linked to this, some respondents commented that this causes ill health, anxiety, depression and stress to clients.

2. Second, the current system causes severe financial hardship, increased debt levels and can lead to increased reliance on food banks.

3. Third, the issue of repayments should be discussed with clients and set at a level that is affordable, with some suggestions that recovery of the overpayment should be means-tested and, if a client is suffering from financial hardship, the repayment should be deferred until such time as the client can afford it. A few respondents suggested there should be a maximum weekly amount that is recoverable, with some suggestions that this could be in line with Housing Benefit where a maximum of 10% of the total benefit entitlement is recovered. A small number of respondents noted a need to strike a balance between the interests of clients and the impact on their family, and the interests of the state.

4 Disability Assistance for Children and Young People (DACYP)

4.1 Entitlement to DACYP

It is the Scottish Government's intention that Disability Assistance for Children and Young People will be payable between the ages of 3 months and 18 years. All eligible children may be eligible for the care component. To be eligible for higher rate of mobility, eligible children will need to be at least three years old; and at least five years old to claim the lower rate of the mobility component. Individuals aged 16 or over will apply for working age benefit (PIP) initially with the Department for Work and Pensions, until Social Security Scotland commences delivery of Disability Assistance for Working Age People (DAWAP). At that point, the upper age limit for DACYP will be extended to age 18. Individuals in receipt of DACYP before age 16 may, however, continue to receive DACYP until 18 years of age, provided they continue to meet the qualifying criteria. Questions 42 and 43 asked:

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?

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

A majority (seven in ten) of respondents agreed with the proposal to provide entitlement to Disability Assistance for Children and Young People to clients aged 0-18 years. Only very small numbers (one in fifty) of respondents disagreed:

Table 22: Q42

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	10	-	-	3
Local authority (14)	10	2	-	2
Third sector (40)	21	-	1	18
Other (7)	3	-	1	3
Total organisations (74)	**44**	**2**	**2**	**26**
Individuals (189)	136	4	5	43
Total respondents (263)	**180**	**6**	**7**	**69**

Only 15 respondents provided comments at Q43. These were similar to those provided at Q44, so these comments are jointly commented on after Table 23.

4.2 Young People Aged 16-18

The Scottish Government would like to introduce continuity of receiving DACYP up to the age of 18. Questions 44 and 45 asked:

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?

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

As shown in the following table, the overwhelming majority of respondents (particularly individuals) agreed with the proposal, with only small numbers disagreeing:

Table 23: Q44

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	4	3	-	6
Local authority (14)	12	-	-	2
Third sector (40)	18	1	1	20
Other (7)	1	1	1	4
Total organisations (74)	**35**	**5**	**2**	**32**
Individuals (189)	140	5	2	41
Total respondents (263)	**175**	**10**	**4**	**73**

Only 19 respondents opted to provide comments in response to Q45.

The key comment from respondents was agreement that DACYP should be extended to age 18, as that this would provide a seamless transition to adulthood or that it would be more consistent with age limits for other types of welfare support.

Small numbers of respondents thought that the age bracket should be extended further than 18, citing tricky transition points for disabled people between the ages of 16 and 21 as this would take account of several transition points across health and social care services, employability services and the Scottish ILF Transitions Fund age limits. Additionally, the years between 16 and 21 can be a difficult transition period, e.g. because of significant life choices being made at this stage and people not needing to be burdened with dealing with disability benefits or assessments. There were also comments about the need to dovetail this with other supports which are available beyond 18, e.g. CB/CTC until 19, throughcare help until age 25, and ILF Scotland Transition Fund between 16 and 21.

Small numbers of respondents suggested that Disability Assistance for Children and Young People should be payable from birth if a child is born with a serious health condition, whilst a similar number of respondents suggested that all young children require constant care.

A small number of respondents considered that the eligibility restriction should be maintained at 16 as this is the age at which people are considered (lawfully) to be an adult or young adult.

The consultation paper noted that it is anticipated that broad eligibility rules for DACYP will remain similar to Child DLA and explained what criteria are required for lower, middle and high rates. Questions 46 and 47 asked:

Question 46: Do you agree or disagree with our approach to the eligibility rules for the different components of Disability Assistance for Children and Young People?

Question 47: If you disagreed, please could you explain why.

As the following table shows, the majority of respondents agreed with the proposed approach to the eligibility rules for the different components of Disability Assistance for Children and Young People, although substantial proportions either did not know or did not answer. Only a small number disagreed:

Table 24: Q46

	Number			
	Agree	Disagree	Don’t know	No response
Campaigning / Advocacy (13)	2	1	2	8
Local authority (14)	12	-	-	2
Third sector (40)	13	5	3	19
Other (7)	3	-	-	4
Total organisations (74)	**30**	**6**	**5**	**33**
Individuals (189)	107	3	36	42
Total respondents (263)	**137**	**9**	**41**	**75**

Only 23 respondents provided comments at Q47. Many of these reinforced their general agreement with the approach whilst elaborating on various aspects of the criteria for eligibility.

The main theme on which respondents chose to focus was that of eligibility criteria failing to reflect some situations adequately. A variety of examples were given including the following:

- The impact of mental health issues or serious behavioural difficulties on the ability to plan and follow a journey safely.
- Some conditions (e.g. Sickle Cell Aanaemia) not being understood by assessors.
- Criteria for the higher rate of the DACYP mobility component needing to be altered for under 3's who require bulky medical equipment.
- Criteria assume conditions fluctuate only within a day / night cycle (often not the case).
- There is a big disparity between the criteria for children and those for adults in terms of available services.

A few respondents wanted to keep eligibility criteria similar to those applying for Child DLA, at least to begin with, for continuity and consistency reasons. Other respondents stated that the Scottish Government should review the criteria after a transition period, taking an evidence-based approach. A third sector organisation suggested that when a child is born with an impairment that will affect their mobility and / or support needs, they should be immediately eligible to apply rather than having to wait three months for the care component or three to five years for the mobility component.

A need for explanations of the criteria was mentioned, with a few respondents saying they did not understand the rules; and others requiring clarification on terminology (e.g. whether 'day and night supervision' means constant 24 hour supervision or at various points in the cycle).

4.3 Winter Heating Assistance

The consultation paper explained that the Scottish Government is committed to providing Winter Heating Assistance to families with children in receipt of the highest rate of the care component of Disability Assistance for Children and Young People to supplement winter heating costs for families. Questions 48 and 49 asked:

Question 48: Do you agree or disagree with the proposal to make a £200 Winter Heating Assistance payment to families in receipt of the highest rate care component of Disability Assistance for Children and Young People?

Question 49: If you disagreed, please could you explain why.

As demonstrated in the following table, the majority of respondents agreed with the proposal and only one in ten respondents disagreed:

Table 25: Q48

	Number			
	Agree	Disagree	Don’t know	No response
Campaigning / Advocacy (13)	3	2	2	6
Local authority (14)	8	3	1	2
Third sector (40)	19	3	2	16
Other (7)	3	-	-	4
Total organisations (74)	**33**	**8**	**5**	**28**
Individuals (189)	120	19	7	42
Total respondents (263)	**153**	**27**	**12**	**70**

A total of 41 respondents made comments at Q49. Many of these respondents made alternative suggestions as to eligibility for the Winter Heating Assistance, with the highest numbers saying that the assistance should be available to all people with any disability payments or benefits (e.g. PIP, DLA):

“It should be all levels of care. Given the additional costs and especially at home it should be reflected in support with winter heating assistance for all recipients of personal care.” *(*Campaigning / Advocacy Organisation)

Significant numbers of respondents made the following observations about groups they thought should be eligible for the Winter Heating Assistance payment:

- Those on the middle rate care component of DACYP (and upwards) should be eligible.
- Eligibility should be means tested i.e. based on income or family finances. Those on the highest rate care component are not necessarily at the greatest risk of poverty.
- There is no need for a blanket payment as it may not be needed by all.
- Those on the higher rate mobility component should be eligible (more prone to feeling the cold as they are immobile).
- Eligibility should be extended to those of working or pension age.
- Eligibility should be extended for families receiving the DLA highest rate care component during any transition period.

Concerns were expressed by a few respondents that people not on Disability Assistance should have prioritised heating assistance, perhaps by expanding the cold winter fuel payment; examples were given of the elderly or housebound adults who need heat on 24/7 while disabled children may be out at school or a day centre during the day.

5 Disability Assistance for Working Age People (DAWAP)

5.1 Benefit Rules: Activities and Descriptors

The Scottish Government is proposing that the criteria for awarding DAWAP will be determined on a 'points-based' test against a list of daily living and mobility activities. Each activity will have a list of descriptors, describing different levels of need in undertaking each of the activities and points will be awarded on the descriptor that best meets the needs described by an individual. Questions 50 and 51 asked:

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?

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

As shown in the following table, almost half of all respondents agreed with this proposal to assess eligibility, with only one in five disagreeing:

Table 26: Q50

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	1	4	2	6
Local authority (14)	7	2	2	3
Third sector (40)	13	6	4	17
Other (7)	2	1	-	4
Total organisations (74)	**23**	**13**	**8**	**30**
Individuals (189)	102	45	26	15
Total respondents (263)	**125**	**58**	**34**	**45**

A total of 94 respondents gave their opinions in response to Q51. The most commonly mentioned theme, cited by a third of respondents, was that a points-based system lacks flexibility to determine levels of disability or the fulfilment of entitlement criteria and is thus unfair. An issue specific to this topic was that a points system cannot give consideration for conditions which have day-to-day fluctuations in abilities.

Significant numbers of respondents perceived that points systems have been discredited and do not work. Comments around this theme included:

- All people are different or every case is different.
- People are not ‘tick boxes’.
- A one size fits all process doesn’t work.

“I’ve yet to see a points-based system I agree with and that actually works. A points based system doesn’t have a person-centred approach, it’s just a way of gathering metrics. The points-based system is all well and good, however, some folk can have good days and bad. Some may be able to walk x amount of distance because of no other option (no family or carers to help) but then suffer later. The conditions need understanding and how this affects the person and family and lifestyle.” (Third sector organisation)

Other negative comments, drawing attention to problems with a points-based system, were made by significant numbers of respondents and included the following:

- The points system is too binary or black and white in nature (for example it is possible to score either 8 points or zero for a descriptor, but without an option in between).
- Negative experiences of the PIP points-based assessment system, including lack of consideration of whether an individual can complete an activity safely, inaccurate application of individuals’ experience and evidence against the descriptors, and high numbers of successful appeals against decisions.

Suggestions for alternative bases for an assessment system were made, each by significant numbers of respondents, and included the following:

- The system should be based on the input of professionals taking part in care (e.g. general practitioners, consultants, social workers) and not just one assessor or decision-maker.
- The system should include a qualified or trained assessor’s input, assuming they have the appropriate expertise.
- The system needs a more person-centred approach, and not just a medicalised understanding of disability.
- A system alternative should be based on medical evidence rather than points.

Additionally, a preference for the previous Disability Living Allowance rules for adults, based on frequency of assistance day and night, was expressed by a few respondents.

A few respondents said they were generally in favour of a points-based system. Other small numbers of respondents suggested tweaks and alterations to any (existing) points based system. These included the following:

- Clarity on how to apply a points system using the assessment method.
- Revising the descriptors to increase fairness (e.g. abolishing the 50% rule that is applied to descriptors).

- Allowing an element of interpretation or discretion to be used.
- Taking adequate account of the impact of mental health issues on individuals.
- Having the same points system makes sense during any transition phase, as long as changes are made in the longer term to ensure the same or greater rights as individuals are entitled to under the UK system.

Question 52 then went on to ask:

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?

A total of 185 respondents provided suggestions.

Large numbers of respondents chose to focus on the sources of evidence they thought should be used to assess eligibility. The greatest number (one in four respondents making a response) recommended the use of medical consultants, experts, and specialists and their reports and evidence. Types of specialists mentioned included occupational therapists and physiotherapists. Small numbers of respondents cited the use of medical reports and evidence without specifying sources.

Additionally, significant numbers of respondents recommended the use of reports, other medical evidence or mobility assessments produced by the patient's own general practitioner. Smaller numbers also suggested using the evidence of peoples' families, carers and other personal contacts, or social workers' assessments and other evidence.

A broader theme, raised by nearly one in four respondents answering the question, was agreement that the assessment process needs to be person-centred in terms of paying more attention to the person's own evidence, circumstances and needs in terms of transport and movement.

"Assessment of mobility needs should be person-centred and based on:
- *the client's account of how their condition affects their ability to get around safely including the risks to which they are exposed when getting around as a result of their condition; and*
- *a good understanding of the condition in question."*

(Third sector organisation)

Significant numbers of respondents (and notably one in four responding organisations) thought assessors themselves needed to improve in the following ways:

- Requiring specialist or medical experience.
- Needing a better understanding of disability conditions.
- Considering all the evidence, not just that gathered on assessment day.
- Not just considering use or non-use of disability equipment.

Large numbers of respondents chose to focus on various criteria that they considered were under-accounted for in assessing eligibility in relation to mobility for DAWAP. There were a significant number of respondents who commented that more account should be taken of mental health or mental illness, particularly in terms of its effects on physical health. Examples of conditions considered in this context were psychosis, paranoia, depression, allodynia and anxiety issues. Suggestions made to help incorporate these conditions into assessments for eligibility included giving sufferers extra support or counselling, producing paper-based reports to reduce face-to-face stress and taking into account the physical side effects of medication used by those with mental health or illness problems.

"Even following the reversal of the 2017 changes to the PIP regulations, only two descriptors (Planning and following journeys (b) and (e)) used to assess mobility have clear relevance to mental health. In both instances these refer to psychological distress to people in regards to making "any journey". We believe this is overly restrictive and does not cover the full circumstances where someone's mental health may impact their mobility. For example, this may be due to the side effects of medication. New mobility descriptors should be co-produced with people with mental health problems as well as expert stakeholders."

(Third sector organisation)

A similarly high proportion stated that more account needs to be taken of fluctuating conditions. Examples of these were noted including Multiple Sclerosis, Lupus and Ehlers-Danlos Syndrome. Suggestions for incorporating these conditions more effectively included taking an average day as the analysis point or considering symptoms on a 'worst' day rather than 'best' day.

A wide variety of other criteria considered under-accounted for in assessments were cited by smaller but still significant numbers of respondents, and these included the following:

- A greater number of 'hidden' disabilities or health conditions than allowed for currently (e.g. Dyspraxia, Myalgic Encephalomyelitis, Epilepsy).
- Presence of fatigue-related conditions (e.g. Fibromyalgia), including the amount of effort undertaken to do an activity or recovery time required.
- The impact of pain in undertaking mobility tasks (whether or not successfully completed).
- Learning difficulties (e.g. Autism, Down's syndrome, neurological health conditions, anxiety and sensory impacts), including understanding things like distance, measurements, and navigation.
- Ability or inability to use public transport or plan journeys.
- Chronic or degenerative conditions (i.e. conditions which will not get better).
- Place lived or housing location (e.g. whether urban or rural, road status for disability access, hilliness).

Significant numbers of respondents commented on the rules and tools used to compile the points assessment system. Most frequently mentioned (including by one in three responding organisations) was agreement that the 20 metre threshold for qualifying for the enhanced rate of the mobility component is problematic. Reasons given were that it is too limited a distance to be of use, that it was designed to reduce peoples' benefits or prevent them leading a full quality of life, or that it was better to return to the "virtually unable to walk" test which was used to establish entitlement to the higher rate of the mobility component for Disability Living Allowance. Similar numbers of respondents wanted to see the 'distance moved' rule to be scrapped entirely on the grounds that it is too simplistic or arbitrary and doesn't account for things encountered in everyday life such as navigating furniture.

"The adoption of the 20 metre rule has had an impact on disabled people's ability to work, participate in family and community life and increased costs and social isolation. In addition though a blind person might be able to physically walk 20 metres their ability to do so safely without putting themselves and others at risk is minimal." (Third sector organisation)

A focus on whether everyday activities can be undertaken, in line with current requirements, safely, reliably and repeatedly without risk of harm was suggested as an assessment tool by significant numbers of respondents (including one in four organisations). Similar numbers made a point about needing clarity over how to account for usage of walking aids or travel enablement requirements (such as wheelchairs or vehicle adaptations) in assessment criteria. Finally, there were a few mentions of needing a change in descriptors or how eligibility is assessed generally in order to encourage independent living.

Question 53 went on to ask:

Question 53: Do you have any comments on the full list of descriptors currently used to assess claims for Personal Independence Payments?

A total of 116 respondents gave an answer. A large majority of comments were general in nature, applying to the descriptors as a whole rather than individual descriptors, with only a small minority (less than one in ten) making general positive comments couched mostly in terms of them being clear, mostly fair or a good starting point for assessment.

There were two themes mentioned most frequently (each by over one in four of those replying to the question). Firstly, that the descriptors do not make sufficient allowance for, or are not relevant to, those clients with mental health conditions or are geared towards those with physical disabilities only. A variety of mental health conditions were put forward as affecting physical ability as follows:

- Psychological health conditions.
- Neurological disorders.
- Depression.
- Schizophrenia.

- Bipolar disorder.

As two organisations put it:

"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. …They need to realise that cognitive impairment is just as disabling in many ways as physical." *(*Third Sector Organisation)

"…the only descriptor that is used to apply to those with mental health conditions is the "requires prompting to carry out this task". This descriptor only carries two points which means that no matter the significance of the condition, an individual with a mental health condition can only ever score 2 points in the majority of the activities." *(*Campaigning / Advocacy Organisation)

Secondly, a general theme was made about the descriptors needing to be altered so they more properly reflect the impact of disabilities on daily lives as opposed to functional ability. Respondents cited a desire to empower people or make them focus on what they are able to do rather than the negatives associated with disability.

"The current descriptors tend to focus on negatives - what a person cannot do - rather on what a person could do with the right support. Disabled People have told us that this focus on the negative can impact on wellbeing and mental health."
(Third Sector Organisation)

Other themes, all cited by significant numbers of respondents, focused on other factors perceived as not being taken into account sufficiently by the descriptors. These included the flowing:

- Descriptors not encompassing or making allowances for fluctuating conditions (e.g. Multiple Sclerosis, Epilepsy).
- Descriptors not making allowance for those with learning disabilities or memory issues.
- Descriptors not taking levels of fatigue or exhaustion encountered while doing activities into account.
- Descriptors not taking pain levels into account.
- Descriptors need to be changed to account for specific conditions (e.g. Visual disability, Epilepsy).
- Descriptor points not adequately catering for the amount of care or supervision required (e.g. for night time care).

Several examples were given by respondents including the following:

"…we have been working with one person with vision impairment who accesses our services who was registered as partially sighted … following a brain injury and has not worked for ten years, but nevertheless his application for PIP was not

successful. This decision is currently being appealed. He received no points against the descriptors used for his assessment because their application completely failed to recognise properly his daily living needs. Because he said he was able to prepare a bowl of cereal for himself, this was assessed as his being 'able to prepare and cook a simple meal unaided' – despite the fact that when he had attempted to cook a meal on another occasion items in the kitchen were burned presenting a fire risk. The assessment of his functioning vision failed to take account of the fact that his neurological vision impairment causes him to hallucinate. His problems dressing were not taken account of, nor did he receive any points on mobility despite the fact he requires a cane to negotiate any journeys. …We believe it is extraordinary that someone living with this level of vision impairment would receive no points after an assessment, but this is not an isolated case as we have highlighted." (Other organisation)

General negative comments about the nature of the descriptors were also made by significant numbers of respondents as follows:

- They are too vague or generalised, such that they cannot be applied to all medical conditions or situations.
- They are confusing or difficult to understand.
- They are designed to make people fail eligibility.
- They are too prescriptive or inflexible and do not allow for discretion.

Small numbers of respondents cited a need for any changes to the descriptors to be evidence-based, following, for example, a consultation with users and relevant organisations.

A very small number of respondents foresaw a need for automatic entitlement being available for those with severe, chronic, or terminal illnesses (e.g. if supported by available evidence).

Small numbers of comments were made specifically about the mobility descriptors; the largest number agreed that the 20 metre threshold is problematic because it is regarded as:

- Inaccurate as it fails to encapsulate mobility needs; and
- Punitive as it excludes clients from financial support thereby affecting their quality of life.

5.2 Face-to-Face Assessments

5.2.1 Informal Observations

The consultation paper noted that during assessments, assessors are permitted to make informal observations about the individuals they are assessing, and respondents were asked:

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

Comments were made by the majority of respondents, 184 in total. Many different types of observation were cited as inappropriate by significant numbers of respondents, while about one in seven said that all or almost all observations are inappropriate.

“The key underpinning purpose of a face-to-face assessment should be the intention to support individuals to tell their stories so that assessors can make accurate, robust decisions. It is critical that this is also how the individual being assessed perceives the process.
… all types of observation undermine this approach as, by their very nature, they are opaque and lack clarity about what is being ‘observed’ and ‘why’. They create an adversarial relationship and an atmosphere of distrust, in which there is an expectation that the agency is trying to ‘catch you out’. Furthermore, they undermine the credibility of people’s lived experiences. Individuals claiming Disability Assistance are experts in their own lives and should expect to be believed and trusted.” (Campaigning / advocacy organisation)

Furthermore, similar numbers regarded face-to-face assessments generally as inappropriate, with many saying medical evidence or reports should be key to decision-making.

Among those specifying particular types of informal observation as inappropriate, the greatest number (one in four of those respondents answering the question and two in five answering organisations) cited observations relating to personal appearance (or appearance of the home if a home assessment). Consultees referred to a well-dressed, clean or well-nourished appearance as resulting in harsh judgments as to eligibility for support.

“'Client well kempt and wearing clean clothes'. Surely this is a default condition and not worth commenting on? The converse i.e. scruffy and dirty, is in contrast worth commenting on as it may indicate self-neglect.” (Local authority)

A number of other informal observation types considered to be inappropriate were also stated by significant numbers of respondents, as follows:

- Movement, strength and sight tests (if unsafe or painful).
- Behavioural observations (e.g. mood or demeanour, body language or ability to engage with the assessor).
- Judgemental observations or assumptions made by the assessor (i.e. observations unsupported by any other evidence).
- Informal observations inappropriate to certain conditions or disabilities (e.g. autism, Asperger’s syndrome, memory problems, mental health, brain injuries, depression, neurological issues, hearing loss).

- Observations about how the individual travelled to or arrived at the assessment appointment (e.g. with or without an aid).
- Observations where medical evidence already exists to back up the effects of the condition (or only have observations where they are supported by medical evidence).

"Behavioural observations such as maintaining good eye contact, whether the individual is sweating, rocking back and forward or fidgeting are inappropriate, as are comments on appearance. The assumption that an individual must be rocking back and forward and dress unconventionally perpetuates the stereotype that individuals with a mental health condition must look and act a certain way. We also often see reports that claim that the individual does not have an anxiety disorder as they were able to sit still and engage with the assessor despite the ability to sit still not being a basis for diagnosis of anxiety. How an individual behaves in an official face-to-face assessment where there are established societal rules for engagement can in no way be taken as an indicator of how they behave in social circumstances." (Campaigning / advocacy organisation)

Smaller numbers of respondents also cited demographic observations (e.g. about race, gender, age), physical examinations and questioning or observations that may cause distress (e.g. about suicide or end of life care) as being inappropriate forms of informal observation. Observations taken while the client is in the waiting room or waiting for their appointment time were also regarded as inappropriate by a small minority of respondents.

Significant numbers of respondents made comments about how they perceived assessments should be conducted. The largest proportions focused on two areas: firstly, that face-to-face assessments need to be done by trained or experienced assessors with a good understanding of the condition or conditions of the people being assessed; and secondly, as per the Scottish Government proposal, that informal observations need to be discussed openly at the time to be transparent.

"A particular issue with current PIP face-to-face assessments is that observations made by assessors are included in the assessment report without the client having any opportunity to explain them. This can result in the observations being made being an inaccurate reflection of the impact of a person's condition on their daily living and mobility, and ultimately be a source of inaccurate decisions being made on eligibility." (Third sector organisation)

Other comments relating to perceived problems with the assessment process were made, again by a significant number of respondents. These issues included the following:

- Detrimental assessments caused by clients masking or underplaying their conditions.
- A need to ensure that questions in relation to the assessment process are clear and easy to understand.

- Fluctuating conditions causing unrealistic assessments based on only a snapshot of the day.

Finally, a very small number of respondents (one in twenty-five of those responding) considered that all observations are appropriate within the context of the assessment.

5.2.2 More Choice when a face-to-face assessment is required

The Scottish Government are proposing that individuals are provided with choice and flexibility, taking into account the distances people are expected to travel and their location preferences, when they are invited to an assessment. Question 55 asked:

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

A total of 204 consultees responded to Q55. Around two in five of these suggested maximum acceptable distances or times to travel to assessments, while the vast majority of respondents (including those suggesting times and distances) cited provisos or problems with travel.

Among consultees who suggested maximum acceptable distances to travel, there was little consensus, with respondents citing distances ranging from less than 5 miles up to 30 miles in fairly equal measures. However, all but one consultee who gave a maximum acceptable time of travel stated times of between half an hour and one hour, these times being given by equal numbers of respondents. Table 27 provides a breakdown of acceptable distances and times outlined by respondents.

Table 27: Q55

	Number		
	Total	Organisations	Individuals
< 5 miles	7	1	6
5 miles	10	1	9
5.1 – 10 miles	12	2	10
10.1 – 20 miles	10	1	9
20.1 – 30 miles	7	2	5
Total respondents (distance given)	**46**	**7**	**39**
½ hour	17	3	14
1 hour	18	9	9
1 & ½ hours	1	-	1
Total respondents (time given)	**36**	**12**	**24**

Among the comments received, one in three respondents were of the opinion that assessments had to be local to the client, in terms of being within their local area, town or city. Various venues were suggested to help enable local assessments as follows:

- GP surgeries.
- Council offices (with disabled access).
- Health centres.
- Libraries.
- Hospitals.
- Social Security Scotland Offices.
- Community Halls.

One in three of those responding (including more than one in two organisations) made a point that the ability to travel depended on the particular condition or disability or health status of the client at the time of assessment, with the implication that decisions on distance to be travelled should be taken on a case-by-case basis.

Significant numbers of respondents cited other problems with travel to assessments:

- Travel for many is dependent on transport availability or accessibility (e.g. public transport, having own transport, having someone available to help, taxi availability).

- The Highlands and Islands and other rural areas have particular problems with distances and transport availability.
- Distance travelled is not the main issue - often it is the amount of effort and stress incurred in travelling to assessments which is the problem.
- Unaffordable travel costs, with requests that these should be limited, subsidised or reimbursed.

Significant numbers of respondents stated that assessments should preferably be at home depending on the client's condition, while small numbers of individual respondents said their assessments would have to be at home as they were incapable of travel or totally housebound. Small numbers of respondents suggested that flexibility to enable attendance is essential, or that there needs to be an option for an individual to choose a venue that meets their access and travel needs.

Question 56 then went on to ask:

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

A total of 171 respondents gave a response to Q56. A wide variety of other circumstances surrounding travel and ability to attend assessments were suggested. The most frequently mentioned of these was whether a carer or other support is required to help with travel, cited by one in four respondents. Various potential difficulties were mentioned including carer availability and responsibilities and the amount of support needed.

"It is not just about the distance to an assessment centre, Is there disabled parking? Is there a bus stop nearby? How far will someone have to walk to get to the centre? Once there does the centre have disabled access? Does it have a lift within it? All these factors can contribute to the stress and anxiety of travelling for an assessment." (Third sector organisation)

Other circumstances to be considered were raised by smaller, but still significant numbers of respondents as follows:

- Accessibility and / or the environment of the place of assessment (e.g. reduced visual acuity, wheelchair access, noise levels, temperatures, toilet arrangements, pavement maintenance, parking availability, hearing loop).
- Appointment timings needing more flexibility (e.g. early mornings are very difficult for those with certain conditions and there is a need to take account of the time required to get ready, bearing in mind pain management or medication times).
- Home visits being needed where there is an inability to attend.
- Help and support availability for travel for those in rural areas or remote locations.
- Costs and affordability of travel to assessments.

Significant numbers of respondents agreed with the consultation paper that a person-centred approach was required, given that everyone has different circumstances (e.g. multiple conditions).

Significant numbers of consultees chose to specify various conditions for which they thought there should be no or very few face-to-face assessments undertaken, given their nature or the difficulties faced by sufferers in doing so. These included:

- Autism.
- Asperger's.
- Global developmental delay.
- Sensory processing disorder.
- Attention Deficit Hyperactivity Disorder.
- Some mental illnesses resulting in difficulties processing questions or articulating answers.
- Degenerative and chronic conditions.
- Terminal illness[3].

The consultation went on to explain that for efficiency reasons there will have to be a limit to the number of assessment appointments that individuals can cancel or fail to attend. Question 57 asked:

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

A total of 205 respondents responded to this question. The majority (approximately three quarters of respondents) expressed an explicit number of times an assessment can be rescheduled, but these were often caveated with reference to exceptional circumstances that may mean an individual has to cancel several appointments.

More than two in five cited three occasions, out of all those giving a number. More than one in four cited two times. However, nearly one in five respondents (particularly third sector and campaigning / advocacy organisations) thought rescheduling should have no limits.

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[3] If the appropriate form is received from a client's healthcare professional, there is no need for assessment as they will automatically be awarded the relevant form of DA (no matter their age).

Table 28: Q57

	Number		
	Total	Organisations	Individuals
Once	8	-	8
Twice	37	5	32
2 /3 times	9	3	6
Three times	59	9	50
More than 3 times	5	-	5
No limit / as many times as needed	24	9	15
Total respondents	**142**	**26**	**116**

A total of 94 respondents gave their opinions in response to this question, and two in five said that rescheduling should depend on the reasons for cancelling, and nearly one in four that it should depend on the particular individual which echoed the need for a person-centred approach.

Smaller but still significant proportions of respondents cited the following caveats for deciding whether an assessment can be rescheduled:

- It should depend on the client's illness / disability / condition.
- There is a need for flexibility and choice when making or rescheduling appointments (taking into account factors such as support availability or lengthy notice being required).
- Repeated failure to attend should result in a home appointment or telephone or paper review or some other alternative solution.
- If many appointments are missed a good reason needs to be provided (e.g. sick note or letter of support from client's GP or health team).

Further to missed assessments, respondents were asked:

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

A total of 187 respondents made comments or suggestions as to situations which should amount to exceptional circumstances in relation to missed assessments. The highest proportion (nearly half) repeated the suggestion in the question, i.e. hospital admissions. Almost as many cited client illness as an exceptional circumstance, particularly if related to flare ups of the client's disability (e.g. epileptic fits, seizures, asthma, pain).

High proportions (nearly one in three respondents) mentioned bereavement as an exceptional circumstance, in many cases specifying family bereavement; there were also a few mentions of funerals.

One in five respondents affirmed carer or support availability issues; reference was mainly made of cases where the carer of the client was unavailable, but mention was also made of instances where the client has carer responsibilities. Childcare unavailability issues were also mentioned in relation to this theme.

Other medical issues were referred to by smaller but still significant numbers of respondents, including:

- Hospital appointments (because of rescheduling difficulties).
- Other medical appointments such as for doctors, dentists or psychiatrists.
- Illness in the client's family (e.g. children, dependents).
- Stress or anxiety, in cases where mental health conditions are involved (e.g. Meniere's attacks, schizophrenic episodes, autism, Attention Deficit Hyperactivity Disorder).
- Physical incapacity or severe mobility restrictions.
- Inability to open, read or remember the appointment letter (because of memory loss or lack of capacity).

A significant number of respondents mentioned transport issues on the day, including transport cancellations, breakdowns or other transport disruptions. Small numbers of respondents pinpointed adverse weather conditions affecting travel (e.g. snow or ice); a few respondents also mentioned an inability to pay for travel.

Other circumstances, as cited by smaller numbers of respondents, included the following:

- Emergencies generally (e.g. accidents).
- Work commitments.
- Other family-related occasions (e.g. graduations, weddings, holidays, house moves, once in a lifetime events).
- Court attendance or jury duty.

Significant numbers of respondents also cited general caveats about situations which might amount to exceptional circumstances. In particular, nearly one in five of those respondents answering the question said that missed assessments need to be looked at on a case-by-case basis:

"…we think that the key question should be what impairments/health conditions does this person have and how might that impact on their ability to attend an assessment on a particular day. This is a more holistic approach and gives the person making a determination on non-attendance more discretion as to whether it was reasonable for the person claiming the benefit not to have attended the assessment as scheduled." (Third Sector organisation)

Additionally, small numbers of respondents stated that the circumstances surrounding a missed assessment should depend on the nature of the client's illness, condition or disability, while others maintained that there was a need to show proof of the circumstances (e.g. written confirmation by the client's GP or hospital).

5.2.3 Face-to-face Assessments will be Audio Recorded as Standard

The consultation paper explained that the Scottish Government is committed to introducing the audio recording of assessments as standard. Question 59 asked:

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

A total of 168 respondents gave their thoughts on the introduction of standard audio recording of assessments. A large majority of comments were positive in nature; nearly two in five respondents welcomed the idea in general, and one in five reinforced that recording should be carried out as standard or made compulsory.

Significant numbers of respondents specified areas in which they perceived that audio recordings would be a positive step forward. Chief amongst these themes were that: audio recordings will help to resolve areas of contention as they will give an accurate account of proceedings; and audio recordings will help assessments be fair and transparent and so will help safeguard both clients and Social Security Scotland staff.

Small numbers of respondents also perceived that audio recordings will be useful if an appeal is required, or to help build trust in the system.

"Frontline advisers suggest this would be a welcome step in ensuring transparency of the assessment. All advice agencies … regularly report clients telling advisers what they said during their assessment is not what is reported by the assessor. Therefore an audio recording would safeguard all involved and should contribute to a reduction in the need for appeals when an adverse decision has been received and the challenge relates to 'false' evidence contained within the report."

(Local Authority)

However, significant numbers of respondents, although broadly positive in their remarks about audio recordings, made caveats about audio recording of assessments. The most frequently mentioned of these, cited by one in five respondents (including half of responding organisations) who answered the question, was that the recordings should only be made with the client's consent or that clients should have the right of refusal. Additionally, small numbers of consultees said the recordings should only be made as long as all parties consented.

Further provisos, each made by a significant number of respondents, stated that recordings should be made:

- As long as they are made available to the client (either just after the assessment or with the decision letter).
- As long as they are made available to the client (not specified whether at the tribunal stage or another time).
- As long as they are made available to all involved.
- As long as all parties are informed beforehand (about the purpose of the recording).
- As long as there are strict rules in place (e.g. about retention, use, security, data management, confidentiality and destruction).
- In line with GDPR requirements.

Around one in ten of the 166 respondents answering the question stated a preference for a video recording to be made, either as well as or instead of an audio recording, in order for example to see how individuals present themselves or to capture non-verbal communication.

"In addition, the Scottish Government should give consideration to whether video recording of assessments would further enhance trust and transparency in the process. This would be particularly important if an assessor was permitted to make informal observations. The Department for Work and Pensions previously announced plans to pilot video recording of PIP assessments with a view to making it a standard part of the assessment process across Great Britain."
(Campaigning / advocacy organisation)

A small number of respondents foresaw a need to make allowances for deaf people, suggesting the provision of transcripts or a British Sign Language DVD.

There were a small number of comments suggesting types of acceptable recording devices: digital equipment, MP3 format equipment, CD's and USB drives were recommended. A few respondents stated that clients should be allowed to make their own recordings.

Only small numbers of respondents were negative about audio recording of assessments. The main concern was that recording may cause clients to be uncomfortable or anxious, particularly if they suffer from mental health problems; a few mentions were made questioning their necessity, claiming that all relevant information should be available anyway, or citing their invasiveness as an evidence-gathering method.

6 Disability Assistance for Older People (DAOP)

It is the Scottish Government's intention that eligibility for Disability Assistance for Older People will be largely based on the rules for Attendance Allowance and aligned with state pension age. Questions 60 and 61 asked:

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

Q61: If you disagreed, please could you explain why.

As shown in the following table, a majority of respondents who gave a response, across all sub-groups, agreed with this proposal.

Table 29: Q60

	Number			
	Agree	Disagree	Don't know	No response
Campaigning / Advocacy (13)	7	-	1	5
Local authority (14)	11	2	-	1
Third sector (40)	15	2	2	21
Other (7)	3	-	-	4
Total organisations (74)	**36**	**4**	**3**	**31**
Individuals (189)	141	9	6	32
Total respondents (263)	**177**	**13**	**9**	**63**

Only 22 respondents provided further commentary in support of their response at Q60; only small numbers of respondents made specific comments and some of these echoed points made at earlier questions.

A small number of respondents suggested that a mobility component should be included. A small number also made suggestions for alternative ages for this benefit with examples being for anyone aged 50 plus or at the same age as the bus pass. There was also concern that State Pension age can change over time and thus this benefit should not be linked to State Pension age.

The consultation paper then noted that it is anticipated that eligibility rules for the benefit, and the components that make up the benefit, will remain similar to Attendance Allowance. Questions 62 and 63 went on to ask:

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

Q63: If you disagreed, please could you explain why.

As shown in the following table, there were higher levels of agreement than disagreement with this proposal.

Table 30: Q62

	Number			
	Agree	Disagree	Don’t know	No response
Campaigning / Advocacy (13)	2	1	2	8
Local authority (14)	10	2	-	2
Third sector (40)	11	5	2	22
Other (7)	1	-	1	5
Total organisations (74)	**24**	**8**	**5**	**37**
Individuals (189)	95	13	43	37
Total respondents (263)	**119**	**21**	**48**	**74**

A total of 33 respondents provided further commentary and the key theme which emerged was concerns over mobility allowance and requests for this to be included.

7 Additional comments

Finally, in this consultation, respondents were invited to provide any further comments relating to Disability Assistance benefits not covered by the consultation document.

Some of these respondents welcomed the opportunity to respond to this consultation; and some provided background on their organisation to set the context for their responses.

Overall, a number of these respondents welcomed the emphasis on a person-centred approach to Disability Assistance as this will help to achieve a service that offers dignity, fairness and respect to all individuals receiving Disability Assistance.

One thread throughout the consultation was criticism of the current system and while respondents were largely positive about the proposals being presented in the consultation paper, some respondents hoped that the negative impact(s) of the current system will not be repeated under Social Security Scotland.

A number of respondents wanted the Scottish Government to move away from a points-based system. Overall, there was perceived to be a lack of transparency in the current system, which is also perceived to be punitive and respondents commented on a lack of trust with Department for Work and Pensions.

One third sector organisation commented on the timescales for applications and payments for benefits and suggested that Social Security Scotland should set clear processing targets for Disability Assistance, with regular reporting on its performance. They also commented on the need to ensure a smooth transition from the current system to the new system.

Many of the issues raised reiterated points made at earlier questions. Other issues included:

- A need for greater clarity around the nature of the transitional arrangements between Scottish Government and Department for Work and Pensions.
- A need to conduct a comprehensive review of existing regulations, guidance and case law to ensure that important detail and rights are not lost upon transition from reserved to devolved social security benefits.
- How the roles of guardians and appointees will operate within the Scottish social security framework and how they will interact with the role of independent advocates.
- A need to offer higher number of home visits and outline when these will be offered.

8 APPENDIX 1: Respondent Organisations

Aberdeenshire Council
Action on Hearing Loss Scotland
Advocard
Age Scotland
Blackwood Homes and Care
BLESMA
Child Poverty Action Group (CPAG)
Children's Hospices Across Scotland (CHAS)
Citizens Advice Scotland
Contact
Convention of Scottish Local Authorities (COSLA)
Deaf Action
Disability Equality Scotland
Down's Syndrome Scotland
Dumfries & Galloway Council
Dundee Fairness Commission
ENABLE Scotland
Energy Action Scotland
Engender
Epilepsy Connections
Epilepsy Consortium Scotland
Epilepsy Scotland
Falkirk Council
Glasgow City Council
Glasgow Disability Alliance
Grampian Opportunities
Haemophilia Scotland

Health and Social Care Alliance Scotland (the ALLIANCE)
Highland Council
Inclusion Scotland
Law Society of Scotland
LEAD Scotland
Let's get on with it together (LGOWIT)
Macmillan Cancer Support
Marie Curie
MND Scotland
Mobility and Access Committee for Scotland (MACS)
MS Society Scotland
National Autistic Society
National Carer Organisations
National Day Nurseries Association
National Deaf Children's Society
National Association of Welfare Rights Advisors (NAWRA)
NHS Ayrshire and Arran Health Board
North Ayrshire Health and Social Care Partnership
North East Sensory Services
North Lanarkshire Council
One Parent Families Scotland
Parkinson's UK Scotland
Perth CAB
Perth & Kinross Council
Poverty Alliance
Rights Advice Scotland (RAS)
Royal National Institute of Blind People (RNIB)
Royal Blind and Scottish War Blinded
Royal College of General Practitioners

Royal College of Paediatrics and Child Health, Scotland
SAMH (Scottish Association for Mental Health)
Scottish Borders Council - Sensory Services team, Social Care & Health
Scottish Borders Council - Customer Advice and Support Service
Scottish Commission for Learning Disability
Scottish Independent Advocacy Alliance (SIAA)
Scottish Older People's Assembly
Scottish Women's Convention
Shetland Islands Council
Social Work Scotland
South Lanarkshire Council
THAW Orkney
The Royal Caledonian Education Trust
Together for Short Lives
UNISON Scotland
West Lothian Council
Youth Link Scotland
+ 189 individuals

How to access background or source data

The data collected for this <statistical bulletin / social research publication>:
☐ are available in more detail through Scottish Neighbourhood Statistics

☐ are available via an alternative route

☐ may be made available on request, subject to consideration of legal and ethical factors.

☐ cannot be made available by Scottish Government for further analysis as Scottish Government is not the data controller.

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