

# Social Security Experience Panels: Disability Benefit Names Survey



# **EQUALITY, POVERTY AND SOCIAL SECURITY**



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# Introduction

In April and May 2019, the Scottish Government carried out a survey with Experience Panel members to understand their thoughts on renaming disability benefits when they are transferred from the Department for Work and Pensions (DWP) to Social Security Scotland. The research explored:

- what Experience Panel members liked and disliked about the current DWP disability benefit names;
- what Experience Panel members liked and disliked about the proposed new disability benefit names and any alternative suggestions;
- views on words Social Security Scotland should avoid using when naming a benefit;
- views on words Social Security Scotland should use when naming a benefit;
  and
- views on other proposed name changes such as staff titles.

This work was part of the Scottish Government's Social Security Experience Panels programme of research. In total, 278 Experience Panel members with experience of the relevant benefits took part in this survey (a response rate of 14 per cent). The findings of this survey reflect the views of the respondents only. This report details the findings and key themes that emerged from this work.

# **Summary**

# **DWP Disability Benefit Names**

First the survey asked what Experience Panel members liked and disliked about the existing DWP disability benefit names, with open text boxes to respond. Respondents used both questions to provide comments about they liked and disliked about the names. Therefore not all the responses to the question asking Experience Panel members what they liked about a particular name, for example, were positive.

## Disability Living Allowance (DLA) for Children

The most common thing that respondents said they liked about the name DLA for Children was that it is clear, self-explanatory and familiar. They liked that it is descriptive, stating what and who the benefit is for. Some respondents liked the word 'children' as it shows that the benefit is intended to support the child. Some respondents also said that the word 'living' is positive as it acknowledges that having a disability or health condition results in extra living costs for individuals and families.

The most common thing that respondents said they disliked about the name DLA for Children was that it includes the word 'disability'. These respondents felt that the term is not inclusive because it focuses on the disability rather than the individual.

They described it as being potentially discriminatory and stigmatising, particularly for those who do not like or identify with the term 'disability.' Some respondents felt the word labels and segregates people, and that this is particularly problematic in relation to children and young people.

Many respondents also disliked the word 'allowance'. This term was also seen to hold negative connotations. Respondents felt that it suggests a 'hand out', 'pocket money' or 'gifted sum of money' rather than a fundamental right or basic entitlement. They described it as contributing to stigma, reinforcing a notion of 'dependency'.

Some respondents said that the name DLA for Children is 'old-fashioned', 'out of date' and 'punitive'. A few respondents said that any benefits names used by the DWP held negative associations for them.

Some respondents said that it is not clear which age group the benefit applies to because it only refers to 'children'. This is seen to be excluding to teenagers and other young people.

#### **Personal Independence Payment (PIP)**

The most common thing respondents said they liked about the name PIP was that it refers to 'personal independence.' Respondents said that the word 'independence' focuses on ability rather than disability and makes clear that the financial payment is used to help an individual to live independently. Some respondents said that the word 'personal' suggests autonomy and decision making in how to use the payment, which can be tailored to individual circumstances and needs. 'Personal' was also seen by some to indicate that the payment is for an individual and is not affected by other family members' circumstances and resources.

Many respondents said they liked that PIP does not refer to 'disability' and noted that it feels more inclusive, positive and neutral.

Some respondents also liked that the name PIP is short and can be easily shortened to an appropriate acronym. They described it as easy to use, say and easily remembered. Some respondents said that PIP is self-explanatory and described it as 'clear' 'simple' and 'easy to understand.'

The most common thing respondents said they disliked about the name PIP was the past, negative associations of the benefit as administered by the DWP. Some respondents highlighted the public reputation of PIP and said the name carries 'negativity', 'stigma' and a 'bad reputation.' Other respondents said the name provoked negative memories of claiming the benefit. These respondents disliked the name PIP because of the experiences associated with the benefit, rather than the words in the name itself.

Whilst respondents who liked the name PIP mostly said this was because it refers to 'personal independence', those who disliked the name said that these words

were problematic because it may not be reflective of reality or achievable for some people. A small number of respondents said the purpose and eligibility of PIP was unclear from the name alone.

#### **Attendance Allowance**

The most common thing respondents said they liked about the name Attendance Allowance was that it is simple, short, concise and memorable. They also liked that it is familiar and easily recognisable. Some respondents noted that they liked that it is neutral and does not include potentially offensive terms such as 'disability'. Many respondents said that the name is 'fine' or 'ok' but did not provide any further information about why they thought this.

The most common thing respondents said they disliked about the name 'Attendance Allowance', was that it is not explicitly clear on what the benefit is for and who is entitled to it. Respondents described it as being 'vague', 'ambiguous' and 'confusing'.

In particular, many respondents felt that the word 'attendance' is unclear. Some respondents said that it suggests that the recipient has to 'attend somewhere', whilst others felt that the name implies that the recipient has be 'attended' to by another person at all times.

For these reasons, some respondents said that it might be unclear that the payment can be used for items and services of the individual's choosing and does not have to involve employing someone to 'attend' to them. Some respondents said that the name might suggest that the payment is for a carer. A few respondents noted that many people may not perceive themselves to be eligible for Attendance Allowance and may face difficulties when seeking information about the benefit.

A small number of respondents said that the name is outdated, particularly due to the problems outlined with the term 'allowance'. Respondents also disliked the previous associations with the DWP.

#### Social Security Scotland proposed benefit names

The survey then asked what Experience Panel members liked about each proposed new Social Security Scotland disability benefit name, with text boxes to respond.

The most common response was that they liked that the proposed new names include the word 'assistance.' Respondents felt this was more inclusive and positive than the existing term 'allowance', which was said to hold negative connotations of 'dependency' and 'charity' rather than a fundamental right and entitlement. Many respondents also described the new names as being clear and self-explanatory and liked the consistent naming across all three forms of disability assistance. Some respondents felt the names sounded more 'supportive' and 'positive' than the existing names.

The survey then asked what Experience Panel members disliked about each proposed new Social Security Scotland disability benefit name, with text boxes to respond.

The most common thing respondents disliked about the proposed new names was that they include the words 'disability', 'working age' and 'older'. Respondents felt that these words are not inclusive. As above, 'disability' was felt to be potentially offensive and discriminatory, labelling people who do not like or identify with the term. Some respondents said the word does not encompass all long term illnesses, hidden disabilities or mental health conditions and so could potentially introduce a barrier to claiming the benefit for people who are eligible but would not describe themselves as 'disabled'.

Some respondents noted that 'children and young people', and 'older people' are vague and subjective terms, and suggested that explicit age ranges should be specified. Many respondents also described their dislike of the word 'older people' and felt this could be discriminatory.

Similarly, most respondents disliked the word 'working age people.' Respondents described it as ambiguous, inaccurate and misleading. They pointed out that the benefit is intended to pay for the additional costs of living with a disability or health condition, and is not linked to an individual's ability to work. 'Working age' was also considered problematic because many disabled individuals are unable to work. Some respondents described it as 'offensive' and 'negative' to be reminded of this, as the name suggests that recipients should be working when often they do not have a choice.

Most respondents preferred the word 'assistance' over 'allowance' but a few respondents still found the term problematic. These respondents felt it may imply practical assistance rather than a financial payment which could be misleading.

Many respondents also said that the proposed new names are too long and do not allow for easy to use acronyms.

Some respondents expressed concern that changing the names of devolved benefits would cause unnecessary confusion for future Social Security Scotland clients, particularly when seeking information.

Some respondents said that they liked or disliked the proposed names but did not provide any reasons as to why.

#### **Preference**

The survey then asked respondents which they name they preferred, each new name or 'something else.'

Around four in ten respondents were in favour of the name Disability Assistance for Children and Young People (42 per cent). Almost six in ten respondents would

prefer something else (58 per cent). Of those who would prefer something else, six per cent said it should remain called Disability Living Allowance for Children. This accounted for three per cent of all responses.

Less than three in ten respondents were in favour of the name Disability Assistance for Working Age People (27 per cent). Around seven in ten respondents would prefer something else (73 per cent). Of those who would prefer something else, 19 per cent said it should remain called Personal Independence Payment. This accounted for 13 per cent of all responses.

One third of respondents were in favour of the name Disability Assistance for Older People (33 per cent). Around two thirds of respondents would prefer something else (67 per cent). Of those who would prefer something else, 20 per cent said it should remain called Attendance Allowance. This accounted for 11 per cent of all responses.

#### Words Social Security Scotland should use and avoid

The survey asked respondents if there are any words Social Security Scotland should use or avoid using when naming a benefit.

Respondents said that Social Security Scotland should use words which are short, simple, concise and descriptive and that benefit names should accurately reflect their purpose.

It was also felt that Social Security Scotland should use positive, neutral, inclusive and empowering language. Respondents highlighted words such as 'assistance', 'payment' and 'support.' Words such as these were said to highlight that people are entitled to assistance, and it is intended to give people 'autonomy' and 'independence.'

Respondents said that Social Security Scotland should avoid stigmatising and discriminatory words which label and segregate those in receipt of disability assistance. Respondents highlighted words such as 'disabled', 'disability', 'benefit' and 'allowance'.

#### Other name changes

The survey introduced some proposed new staff titles for Social Security Scotland and asked respondents to describe what they liked and disliked about them. The survey also asked respondents what they liked and disliked about the current DWP name decision makers.

#### **Decision Makers**

The most common thing respondents said they liked about the name 'decision makers' was that it is clear, unambiguous and descriptive. It was felt that the name

accurately describes the role of decision makers and distinguishes them from other staff who they may interact with.

The most common thing respondents said they disliked about the name decision makers was that it suggests an imbalance of power in favour of the decision maker. These respondents described it as feeling 'authoritarian' and 'judgmental'. Some respondents also felt the name implies a finality of the decision made by decision makers and said that it evokes memories of negative experiences and interactions with them in the past.

## **Case Managers**

Most respondents simply said that they liked the name case managers or that they preferred it to decision makers. Many respondents also described the name as feeling more personal and supportive, and said that it suggests less of a power imbalance between the individual and the case manager. Some respondents said that the name suggests that the case manager would be responsible for an individual's case through the entirety of the application process and so would be familiar with the case and act as a single point of contact.

Many respondents said they disliked that the name case managers appears to reduce individual people to 'cases' who need to be 'managed.' Some respondents said the name is vague and that it is not clear from the title if they are the people responsible for making the decisions on applications. A few respondents also highlighted that case manager is a term used by other services and professions, principally social work, and that this might be confusing. Some respondents noted that the name is misleading if a case manager will not be responsible for managing individual cases through the entire process or act as a single point of contact for applicants.

#### **Specialist Advisors**

Respondents said they liked that the name specialist advisors includes the word 'specialist', stating that it suggests that a suitably qualified individual with specialist knowledge and expertise will be advising on decisions. Respondents found this reassuring.

Respondents said they disliked that the name specialist advisors is vague and unclear. Specifically, respondents said that the word 'specialist' does not specify what advisors specialise in or make clear what their qualifications and experiences are. Respondents assumed that specialist advisors would be health professionals with a medical background. Some felt that medical titles should therefore be used in the name.

#### **Professional Advisors**

Respondents simply said that the name professional advisors is 'fine' and a few said that they preferred it to specialist advisors but did not say why. Like the word

'specialist', many respondents said they liked that the word 'professional' denotes knowledge and expertise.

Respondents said that they disliked that the name professional advisors is broad and vague. Some respondents felt that the word 'professional' does not necessarily indicate expertise, qualifications or specialist knowledge in health conditions and said that it describes a quality or behaviour rather than a job role or function. Some respondents also said that they expect all Social Security Scotland staff to be professional. Some respondents said professional advisors sounds 'formal' and 'corporate.'

# **Background and research methods**

The Scottish Government is becoming responsible for some of the benefits currently delivered by the Department for Work and Pensions. This includes most ill health and disability benefits: Disability Living Allowance (DLA) for Children, Personal Independence Payment (PIP), Attendance Allowance (AA) and Severe Disablement Allowance (SDA).

As part of the work to prepare for this change, the Scottish Government set up the Social Security Experience Panels. Over 2,400 people from across Scotland who have recent experience of at least one of the benefits coming to Scotland have registered as Experience Panel members. The Scottish Government is working with Experience Panel members to design a new social security system that works for the people of Scotland, based on the principles of dignity, fairness and respect.

In this research project, we used a survey to ask Experience Panel members their thoughts on renaming disability benefits. The research ran in conjunction with a Scottish Government public consultation seeking views on the proposed approach to delivery of devolved disability assistance in Scotland. The consultation, among other things, also gathered views on suggested names for the benefits. This report details the key themes which emerged from the survey with Experience Panel members. It used open text survey questions to ask:

- what Experience Panel members liked and disliked about the current DWP disability benefit names;
- what Experience Panel members liked and disliked about the proposed new disability benefit names and any alternative suggestions;
- views on words Social Security Scotland should avoid using when naming a benefit;
- views on words Social Security Scotland should use when naming a benefit; and
- views on other proposed name changes such as agency staff titles.

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<sup>&</sup>lt;sup>1</sup> Scottish Government (2019). 'A Consultation on Improving Disability Assistance in Scotland'. [Online] <a href="https://consult.gov.scot/social-security/improving-disability-assistance/">https://consult.gov.scot/social-security/improving-disability-assistance/</a>

Participants were recruited from the Scottish Government Experience Panels. All Experience Panel members who have told us they have experience of disability benefits were invited to take part in the survey.

The Social Security Experience Panels are a longitudinal research project. The panels are made up of volunteers from the Scottish population who have relevant experience. The results of this work should be regarded as being reflective of the experience and views of the participants only, and are not indicative of the views of a wider Scottish population. Percentages are given only to show a broad sense of the balance of opinion across participants.

# Survey method

Participation in Experience Panels research is optional, and in this case 278 people chose to complete the survey (a response rate of 14 per cent of Panel members with experience of the disability benefits).

Information from the survey was added to information from the 'About Your Benefits and You'<sup>2</sup> and 'Social Security Experience Panels: Who is in the panels and their experiences so far'<sup>3</sup> surveys. The demographic data collected in these surveys was linked to the information supplied by respondents of this survey as part of the longitudinal data set for the wider Experience Panels project. This data was not available for all survey respondents. The following demographic information is given to provide context to the findings from the survey.

Over one third of respondents who we have demographic information for identified as 'man or boy' (36 per cent) and just under two thirds (64 per cent) identified as 'woman or girl'.

Table 1: Gender of survey respondents (n=206)

Gender	%
Woman or girl	64
Man or boy	36
Total	100

Over half of survey respondents were aged 45 to 59 (55 per cent) and just under one third were aged 60 or over (31 per cent). 14 per cent of respondents were aged between 25 and 44, with none were under the age of 25 or over the age of 80.

<sup>2</sup> Scottish Government (2017). Social Security Experience Panels: About Your Benefits and You – Quantitative Research Findings. [Online] Available at: <a href="https://www.gov.scot/Publications/2017/11/7769/">www.gov.scot/Publications/2017/11/7769/</a>

<sup>&</sup>lt;sup>3</sup> Scottish Government (2018). *Social Security Experience Panels: Who is in the panels and their experiences so far.* [Online] Available at: www.gov.scot/Publications/2018/10/3083/

Table 2: Age of survey respondents (n=208)

Age	%
Under 25	0
25 – 44	14
45 – 59	55
60 – 79	31
80 or over	0
Total	100

Almost nine in ten respondents (87 per cent) had a disability or long term health condition.

Table 3: Disability status of respondents (n=208)

Disability status	
Disabled	87
Not disabled	13

Two thirds of respondents had a physical disability (66 per cent) and just under two thirds had chronic pain (63 per cent). One third had a mental health condition (33 per cent) and around one in ten had a severe hearing impairment (12 per cent). Six per cent had severe visual impairment and five per cent had a learning disability. Just under two thirds told us they had some other kind of disability or long term health condition (63 per cent).

Table 4: Disability types of respondents (n=208)<sup>4</sup>

Disability Types	%
Has a physical disability	66
Has chronic pain	63
Has a mental health condition	33
Has a severe hearing impairment	12
Has a severe visual impairment	6
Has a learning disability	5
Has another kind of disability or long term health condition	63

Over half of survey respondents cared for a family member or friend (57 per cent).

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<sup>&</sup>lt;sup>4</sup> The percentage is of total respondents, not disabled respondents. Respondents were able to select multiple disability types.

Table 5: Caring status of respondents (n=203)

Caring status	%
Carer	57
Not a carer	43
Total	100

Survey respondents most commonly cared for an adult friend or relative (35 per cent). 17 percent was a carer due to old age. Just one in ten cared for a child (10 per cent).

Table 6: Who do respondents care for? (n=208)

Care status	%
Cares for an adult	35
Cares for a child	10
Carer due to old age	17

Survey respondents took part from all thirty-two local authority areas in Scotland. The majority lived in an urban area (81 per cent).<sup>5</sup>

Table 7: Location of respondents (n=191)

Location	%
Urban	81
Rural	19
Total	100

Survey respondents who took part had experience of claiming or helping someone else to claim a wide range of benefits.

The most common benefits claimed by survey respondents were Personal Independence Payment (73 per cent) and Disability Living Allowance (70 per cent). The least common benefits claimed were for Funeral Expenses (8 per cent), Sure Start Maternity Grant (6 per cent) and Industrial Injuries Disability Benefit (4 per cent).

<sup>&</sup>lt;sup>5</sup> 17 per cent of the Scottish population lives in a rural area. Scottish Government (2018). *Rural Scotland Key Facts 2018*. [Online] Available at: https://www.gov.scot/publications/rural-scotland-key-facts-2018/

Table 8: Respondents benefit experience (n=208)<sup>6</sup>

Benefit	%
Personal Independence Payment	73
Disability Living Allowance	70
Winter Fuel Payment Carer's Allowance	32
Cold Weather Payment	32
Winter Fuel Payment	38
Discretionary Housing Payment	22
Scottish Welfare Fund	14
Attendance Allowance	21
Universal Credit	19
Severe Disablement Allowance	18
Funeral Expenses	8
Sure Start Maternity Grant	6
Industrial Injuries Disability Benefit	4

More detailed demographic information on the Experience Panels as a whole can be found in 'Social Security Experience Panels: Who is in the panels and their experiences so far' 7.

# Disability Living Allowance (DLA) for Children

Disability Living Allowance (DLA) for Children is currently delivered by the DWP. This benefit supports young people and their families to access support and care for their disability or health condition.

# **Disability Living Allowance (DLA) for Children – Likes**

We asked respondents what they liked about the name Disability Living Allowance (DLA) for Children. 234 of the 278 respondents answered this open text question. For those who provided a positive comment, a number of themes were identified.

<sup>&</sup>lt;sup>6</sup> Respondents had experience of applying for (themselves or someone else) or receiving these benefits within the last three years, but were not necessarily in receipt of the benefit at the time of the survey.

<sup>&</sup>lt;sup>7</sup> Scottish Government (2018). *Social Security Experience Panels: Who is in the panels and their experiences so far.* [Online] Available at: www.gov.scot/Publications/2018/10/3083

## **Clear and self-explanatory**

The majority of respondents said they liked that the name DLA for Children is self-explanatory and simple. It was described by some as 'clear and easily understood' and 'accurate and accessible.' Many respondents said that they liked that it is descriptive, stating what and who the benefit is for. Some respondents also liked the word 'children' as it shows that the benefit is intended to support the child.

"Tells you who it's for and what it does."

"It does what it says on the tin."

#### **Familiar**

Some respondents liked that the name DLA for Children is familiar and well known. A few respondents said that the name is easy to remember.

"There's a familiarity with it, people already know what it is and what to expect."

"I think you should stick with what is widely known in the naming of any benefit. Changing this would be an unnecessary expense and might cause confusion in the short-term."

"It's in line with the name used in England too so parents accessing support and information or on online forums will have a common descriptor rather than be confused by different titles for the same benefit."

# Positive word - 'living'

Some respondents said that they liked the word 'living'. They suggested that it makes it clear that the benefit is for living essentials and acknowledges that having a disability or health condition results in extra living costs for individuals and families.

"Disability Living' makes it clear what the purpose of the benefit is. It's for disabled people to help with the added cost of living due to their disability. Simple and explanatory. It's direct to the point for helping children with disabilities, mental and physical."

"It specifies it's for children and "Living" communicates that it is a payment to "help disabled children live."

# Disability Living Allowance (DLA) for Children - Dislikes

We asked respondents what they disliked about the name Disability Living Allowance (DLA) for Children. 211 of the 278 respondents answered this open text question. For those who provided a negative comment, a number of themes were identified.

## Negative word - 'disability'

The vast majority of respondents disliked that the name DLA for Children included the word 'disability'. Respondents felt that the term is not inclusive because it focuses on the disability rather than the individual. They described it as being potentially discriminatory and stigmatising, particularly for those who do not like or identify with the label 'disability.'

"It focuses on disability rather as ability."

"As stated far too often the word disabled defines people and their life chances, we need to stop defining people by what separates us and start looking at what makes us the same."

"Emphasising "Disability" rather than e.g. "support needs" or "Independence payment" can be stigmatising - many people do not wish to be seen as disabled, preferring to concentrate on coping / managing with their condition."

Respondents felt that it is particularly problematic to label and categorise children using the word 'disability' and some said that the name was not 'child friendly'.

"It immediately labels a child, with negative connotations."

"I think the name gives an indication that the children who receive this benefit are "different" from other children."

"I feel that the use of the word disability is demeaning. Children with additional needs should not be categorised."

Whilst respondents noted that not all individuals would describe themselves as disabled, they also highlighted that the word 'disability' itself is misleading because it does not appear to encompass all disabilities and health conditions. Some respondents said this could potentially create barriers to claiming and uptake.

"The word disability doesn't represent all applications of the allowance. Some recipients have chronic health conditions, not commonly referred to as disability."

"Pinpointing Disability in the title can be stigmatising and labels a group of people, and also can leave people with mental health disorders being disenfranchised where the same information could be inferred by calling it Care and Mobility Allowance /Assistance."

"Some people assume if you have a disability then they should be able to see it. Not all disabilities are visible."

## Negative word - 'allowance'

Many respondents disliked that the name DLA for Children included the word 'allowance'. This term was also seen to hold negative connotations. Respondents felt that it implies some form of 'hand out', 'pocket money' or 'gifted sum of money' rather than a fundamental right or entitlement. They described it as being patronising and contributing to stigma, reinforcing a notion of 'dependency'. Respondents felt that the word 'allowance' does not acknowledge that DLA for Children is a basic right to ensure that a child with a disability receives the extra income required in order to have a decent standard of living.

"Allowance kind of implies that people with disabilities are being allowed to have a life rather than an equal right to the same quality of life as those who do not have disabilities or conditions."

"The word allowance sounds like you're permitting or allowing living and independence rather than it being a right."

"'Allowance' has a certain dependency ring to it, as though the recipient should be grateful in a cap in hand manner. To allow indicates, to me at least, there's a permission needed just to exist."

"Allowance' is probably not the best word to use. It's an entitlement. A right. And Allowance gives the impression that it's not an entitlement. If we want to dramatically reduce the stigma surrounding benefits we need to change how they are perceived... they are there to assist people and boost the incomes of people that need it and it is a supportive mechanism that gives the people of this country a better life. If you are disabled you have a right to extra support in whichever form suits your needs best and you are entitled to that support, not just allowed it because the government is choosing to be kind."

#### Out of date

Perhaps related to the issues with the words 'disability' and 'allowance' discussed above, some respondents said that the name DLA for Children seems 'old-

fashioned', 'out of date' and 'punitive'. A few respondents said that any benefits names used by the DWP held negative associations for them.

"It is very old fashioned and could do with a change something that represents all children in the 21st century, something that includes all of disabilities including the hidden ones."

"It feels old, words that would be used 50 years ago."

#### **Additional themes**

A small number of respondents said the name DLA for Children is too long, and that it is unclear what the purpose of the benefit is. Some respondents also said that it is not clear as to which age group the benefit applies to because it only refers to 'children'. This was seen to be excluding to teenagers and other young people.

"It sounds as though it is just for children but not young people. Many people may think that if you are between 12 and 16 you are not entitled to this benefit."

"Children is not appropriate, when do they become young people?"

# Disability Assistance for Children and Young People

Respondents were told that the Scottish Government intends to change the name of Disability Living Allowance (DLA) for Children to Disability Assistance for Children and Young People.

# Disability Assistance for Children and Young People – Likes

We asked respondents what they liked about the name Disability Assistance for Children and Young People. 205 of the 278 respondents answered this open text question. For those who provided a positive comment, a number of themes were identified.

#### Positive word - 'assistance'

Echoing the findings above, most respondents who gave a positive comment liked the inclusion of the word 'assistance', which was perceived to be less stigmatising than 'allowance'.

"Much better as it is assisting someone to live rather than allowing them to."

"Assistance seems quite positive and not like the word "benefit" where people who do not understand the system, it does sound as if it is "earned"."

"There are no words included that strike me as negative. Assistance is a positive word. Everyone needs a little assistance at least once in their lives in some form or another. It shows that people aren't and don't have to go it alone but can be assisted to live a better and more fulfilling life."

Respondents used the following words to describe the name Disability Assistance for Children and Young People: 'sounds kinder', 'more subtle', 'friendlier', 'sensitive' 'supportive', 'softer', 'more inclusive'.

"Assistance sounds more caring."

"Disability assistance has a more supportive feeling about it."

"It sounds more welcoming and friendly."

"This title is quite positive. It implies that the claimant will be helped, rather than hindered, to apply for the benefit."

# Includes 'young people'

Respondents disliked that DLA for Children only refers to 'children.' This is seen to be excluding for young people. Respondents therefore liked that Disability Assistance for Children and Young People encompasses all 'young people', including teenagers.

"Much better. More inclusive and older young people will appreciate not being labelled as a child."

"It's a broader spectrum and covers all young people."

"It is more inclusive and doesn't leave teenagers being referred to as children."

# **Clear and self-explanatory**

Similar to DLA for Children, respondents said that they liked that Disability Assistance for Children and Young People is clear and self-explanatory. Respondents felt that it is easy to understand who and what the benefit is intended for.

"It is simple and straightforward."

"The name is better. It better describes the function of the benefit and to whom it is aimed."

#### **Improvement**

Many respondents simply noted that Disability Assistance for Children and Young People is 'better' and 'much more suitable' than Disability Living Allowance (DLA) for Children, but did not provide a reason as to why they thought this.

# Disability Assistance for Children and Young People - Dislikes

We asked respondents what they disliked about the name Disability Assistance for Children and Young People. 194 of the 278 respondents answered this open text question. For those who provided a negative comment, a number of themes were identified.

## Negative word - 'disability'

Similar to DLA for Children, most respondents disliked the word 'disability' in Disability Assistance for Children and Young People.

"It is an improvement on Disability Living Allowance (DLA) for Children, however, the stigma of the word disability still exists."

"It appears with the disability first whereas reforms such as the children's charter, places the child first. Children and young people's assistance for disability I feel sounds better focusing on the child."

Similarly, respondents felt that the word 'disability' does not appear to cover all disabilities and health conditions, and were concerned that this could act as a barrier to claiming the benefit for some eligible individuals who do not identify with the term.

"I dislike the word Disability. It is a negative label. It is difficult for people to disassociate disability and handicap, even in today's society. The name should reflect more that the benefit is for all types of impairment, whether it be seen i.e. physical or unseen e.g. epilepsy."

"The use of the label "Disability" can leave people thinking this form of welfare payment does not apply to their child or young person if they have a mental health disorder. "Care and Mobility Assistance for Children and Young People" would leave fewer people that were entitled to this payment, feeling that it didn't apply to their child or young person."

## **Too long**

Another key theme was that respondents thought the name is 'too long', 'wordy' and 'long winded' and disliked that no obvious acronym or shortened abbreviation is possible.

"Far too long winded. If you feel you have to change the name make it something shorter that is instantly recognisable. Benefits are confusing enough without giving them long winded titles."

"It's quite a mouthful...I wouldn't relish having to phone and being passed around, each time repeating this."

"It's too long and it's not worded well enough to be able to give it a shorter nickname. Benefits paid out at the moment can be shortened to easily remembered initials."

#### **Additional themes**

We saw above that many respondents were positive about the word 'assistance'. A a small number of respondents however noted their dislike of the word. These respondents felt that it is not clear that 'assistance' refers solely to financial assistance, and does not include physical or practical assistance.

"Too long. Makes it sounds like it is actual assistance not financial assistance."

"It suggests practical assistance rather than financial support. It's way too long for a benefit name. I don't like this at all. It does not say what it is. It needs to be more clear"

#### **Preference**

We asked respondents which name they preferred, 'Disability Assistance for Children and Young People' or 'something else'. Around four in ten respondents were in favour of the name Disability Assistance for Children and Young People (42 per cent). Almost six in ten respondents would prefer something else (58 per cent).

Table 9: Which name do you prefer (n=267)

Response	%
Disability Assistance for Children and Young People	42
Something else	58
Total	100

Of those who would prefer something else, six per cent said it should remain called Disability Living Allowance for Children. This accounted for three per cent of all responses. The full list of names proposed by respondents can be found at Annex A.

# **Personal Independence Payment**

Personal Independence Payment (PIP) is currently delivered by the DWP. It is designed to cover the costs of everyday life for people who have a long term illness, disability or mental health condition. It is paid to people aged between 16 and state pension age.

# Personal Independence Payment – Likes

We asked respondents what they liked about the name Personal Independence Payment (PIP). 191 of the 278 respondents answered this open text question. For those who provided a positive response, a number of themes were identified.

## Positive words - 'personal independence'

The vast majority of respondents liked that the name PIP refers to 'personal independence.' Some respondents felt that the word 'independence' focuses on ability rather than disability and makes clear that the financial payment can be used to help an individual to live independently.

"It's solution focussed - on the goal rather than on the person's shortcomings or illnesses."

"I like the implied notion of independence for disabled people regardless of their ability or disability. It conveys a very positive message."

"It stresses that independence is facilitated through access to additional resources."

Some respondents said that the word 'personal' implies autonomy and decision making in how to use the payment, which can be tailored to individual

circumstances and needs. 'Personal' was also seen by some to indicate that the payment is for an individual and is not affected by other family members' circumstances and resources.

"It indicates support to be independent and make the most of what you can do, not be dependent on others. It also reminds people that it is the individual's personal payment and not something for others to allocate on their behalf."

"The words personal and independence imply that an individual can use the payment to meet their own requirements."

## **Excludes 'disability'**

As discussed in the previous section on DLA for Children, the vast majority of respondents disliked the word 'disability.' It is perceived to be potentially stigmatising and discriminatory because it focuses on the disability rather than the individual. As a result, many respondents said that they liked Personal Independence Payment because it does not refer to 'disability'.

"The fact it doesn't push the narrative that the person in receipt of PIP may have physical limitations."

"Does not include disability: indicates person is capable sounds less discriminating."

#### **Inclusive**

By referring to 'personal independence' and not using the word 'disability', respondents said that the name PIP feels more inclusive, positive and neutral.

"It's quite a hopeful name - implies personal freedom."

"It is neutral. It doesn't stereotype people."

"I think the name has a more positive and empowering meaning."

#### Short and easy to remember

Respondents liked that the name Personal Independence Payment is short and can be further shortened to acronym PIP. Respondents said that PIP is easy to use, say and can be easily remembered. "I think this name should remain, because it is short and easily recognizable."

"Well, obviously PIP is a nice sounding acronym, and it's inclusive and positive."

"It is clear, and shortened to PIP easy to talk about."

## Clear and self-explanatory

Some respondents said that they liked that the name PIP 'tells you exactly what it is' and is 'self-explanatory.' They also described it is as 'clear' 'simple' and 'easy to understand.'

"It says what it is quite clearly; a Personal Payment to enable Financial Independence for Disabled people."

Some respondents simply said PIP is 'fine as is', 'appropriate' and 'fits the bill', but did not provide any further information on why they thought this.

# Personal Independence Payment - Dislikes

Respondents were asked what they disliked about the name Personal Independence Payment (PIP). 183 of the 278 respondents answered this open text question. For those who provided a negative comment, a number of themes were identified.

# Negative public associations and personal experiences

The vast majority of respondents said they disliked that the name PIP held negative associations and memories of the benefit as administered by the DWP. Respondents provided often emotional comments detailing their feelings about the name. They referred to both negative public associations and also negative personal experiences with the benefit.

Some respondents highlighted the public reputation of PIP, as seen in the media. They said the name carries 'negativity', 'stigma' and a 'bad reputation.' These respondents wanted new names for the benefits being devolved to Scotland.

"The scaremongering and negative media publicity it has become associated with."

"The notoriety the name now has attached to it - it's very negative."

"I don't like the name as it has become synonymous with misery."

Respondents also said PIP provoked negative memories of claiming the benefit, for example, through face to face assessments, appeals and tribunals and problems with payments. Some respondents said that the name PIP was therefore 'triggering' for them. These respondents disliked the name PIP because of the experiences associated with the benefit, rather than the words in the name itself.

"It's too triggering of the old system."

"The name 'PIP' brings up feelings of trauma, due to how badly it is administered by the DWP. I can't see the words without my heart rate increasing."

"It just conjures up all the difficulties in claiming this benefit. The process can be demeaning and very difficult for those trying to claim."

"It's become a synonym for terror, stress, and a mythical award for thousands who relied on DLA to live."

"The majority of people have had a nightmare claiming it so just hearing the name fills us with dread."

# Negative word - 'independence'

As outlined above, many respondents liked that the name PIP refers to 'personal independence.' Some respondents, however, disliked the name because of this term. These respondents felt that reference to 'personal independence' is misleading because it may not be reflective of reality. They said that, for some people, independence is not attainable.

"I disagree with the word "Independence". It is very unlikely that you will live an independent lifestyle, free from other forms of government and charity help. You are likely to need this type of support for mental and physical issues which can be ongoing. Independence is a long way off."

"Not all people with disabilities can be independent. I don't like the word independence used in this context."

"If only it did what it "says on the tin". Name gives a bigger hope of true independence than the benefit in fact supplies."

## **Purpose unclear**

A small number of respondents said it is not clear what the purpose of PIP is or who is eligible for it.

"If you didn't have knowledge of this benefit you'd likely not know what it does."

"It could mean any number of things."

"It does not tell you what it is for and who it is for."

#### **Additional themes**

A small number of respondents said that the old DWP name 'Disability Living Allowance' is better, and that the name PIP is 'impersonal' and 'patronising.' Some respondents said that they did not like the word 'payment' but did not explain why. A few respondents said that the name is too long.

# Disability Assistance for Working Age People

Respondents were told that the Scottish Government intends to change the name of Personal Independence Payment to Disability Assistance for Working Age People.

# **Disability Assistance for Working Age People – Likes**

We asked respondents what they liked about the name Disability Assistance for Working Age People. 179 people of the 278 respondents answered this open text question. For those who provided a positive comment, a number of themes were identified.

#### Positive word - 'assistance'

Repeating some of the themes identified for Disability Assistance for Children and Young People, most respondents liked the inclusion of the word 'assistance', which is felt to be less stigmatising than 'allowance'. Respondents said the name 'sounds more dignified' and is 'much nicer.'

"That is better with some feeling about it, it doesn't sound so hard."

"I like the name disability assistance, it has a more positive and empowering feeling behind it."

"The word Assistance is something that I think is more of a positive term."

A few respondents said that they liked the inclusion of the word 'working-age' because it states who the benefit is for and suggests that the benefit can be received whilst also working.

"It seems a kinder name to me. It would be an accurate description of its intended purpose. It also acknowledges that it is for people of a working age - and that you can be in employment but in needed of financial assistance due to your disability."

"Working age people, let's you know you're capable of working and fulfilling your life."

## Clear and self-explanatory

Many respondents said that Disability Assistance for Working Age People is clear, self-explanatory and easy to understand.

"It makes it clear who this benefit is for and a description of who would get it."

"More comprehensive. Explains exactly what it is and who it is for."

#### **Additional themes**

A few respondents liked that the name Disability Assistance for Working Age People is consistent with Disability Assistance for Children and Young People. Many respondents said that the name is 'fine', 'good', 'okay' or 'better' but did not provide further information about why they thought this.

"It's an improvement. I like the idea of consistency with the similar benefit for Young People."

# **Disability Assistance for Working Age People – Dislikes**

We asked respondents what they disliked about the name 'Disability Assistance for Working Age People'. 175 of the 278 respondents answered this open text question. For those who provided a negative comment, a number of themes were identified.

# Negative word – 'working age'

A key theme to emerge was that respondents disliked the term 'working age.' This was for a number of reasons. First of all, it was felt that it is not clear what age range is defined as being 'working age', and that it is a subjective term. Many

respondents said this was confusing and again, this was felt to be a potential barrier to claiming for eligible individuals.

"What age is a working age person? A lot of people now work after they are due to retire, if they are able to do so."

"'Working Age People' - You can do a paper round (work) at age 13 and the retirement ages keep being moved, so 'Working Age' is not always fixed."

"Too wordy. Disability is a very labelling word. Working age is vague - with changing pension ages it will be hard for people to know when they do or don't qualify. It might put people off applying if they are not working due to early retirement, for example, if they then see themselves as no longer of working age."

Second of all, some respondents said that the term 'working age' was misleading. They highlighted that the benefit is intended to pay for the additional costs of living with a disability or health condition, and is not linked to an individual's ability to work.

"Working? You don't stop been disabled when you hit 65."

"Why should it only be for working age people? If a person is disabled, it is usually unlikely that it will suddenly improve or disappear when they are no longer of 'working age'."

"I don't like it, as it implies that only "working" age people will be eligible."

Thirdly, respondents said that having 'working age' in the title is problematic because many disabled individuals are unable to work. They described it as 'offensive' and 'negative' to be reminded of this, as the name implies that recipients should be working, when often they do not have a choice.

"The benefits title sets a tone for people who are disabled that "working" is preferable to not working when for many people with disabilities, they have no choice about working or not working."

"Don't like the disability label and it implies that you 'should' be working even though you may not be able to."

"Do not like this, prefer P.I.P. Some disabled people of working age may never be able to find suitable employment or are unable to be employed. Reminding them of this in the benefit they receive could have a negative effect."

#### **Additional themes**

The other themes that emerged echoed what respondents disliked about Disability Assistance for Children and Young People, that Disability Assistance for Working Age People is too long, and contained negative words.

Most respondents who made a negative comment said that they disliked the name because it is too long and does not produce an easy acronym which is shorter to say and easier to remember.

"Too cumbersome and does not produce a snappy acronym."

"It's too long. Especially as the disabled person might have difficulty saying all that! I have memory problems and difficulty processing information if things are not kept simple."

The vast majority of respondents disliked names which include the word 'disability'.

"Disabled people don't like to be reminded of disablement."

"The use of "disabled" defines and pigeon holes."

Whilst most respondents preferred the term 'assistance' over 'allowance', some highlighted that 'assistance' may be confusing because it potentially implies more than financial help.

"The assistance provided is purely financial. The proposed benefits title implies all sorts of assistance, like someone coming to your home to help you out."

"The word assistance means a lot of people will think they are getting nurses, support workers etc."

#### **Preference**

We asked respondents which name they prefer, 'Disability Assistance for Working Age People' or 'something else'. Less than three in ten respondents were in favour of the name Disability Assistance for Working Age People (27 per cent). Around seven in ten respondents would prefer something else (73 per cent).

Table 10: Which name do you prefer (n=263)

Response	%
Disability Assistance for Working Age People	27
Something else	73
Total	100

Of those who would prefer something else, 19 per cent said it should remain called Personal Independence Payment. This accounted for 13 per cent of all responses. The full list of names proposed by respondents can be found at Annex B.

# Attendance Allowance

Attendance Allowance (AA) is currently delivered by the DWP. It is a benefit for people aged over 65 and is designed to help with the extra costs of living if they have a disability severe enough to need someone else to help look after them.

#### Attendance Allowance - Likes

We asked respondents what they liked about the name Attendance Allowance. 167 of the 278 respondents answered this open text question. Of those respondents who provided a positive comment, most liked that the name Attendance Allowance is simple, short, concise and memorable. They also liked that it is familiar and easily recognisable and does not include the word 'disability'. Many respondents said that the name is 'fine' or 'ok' but did not provide any further information about why they thought this. The name Attendance Allowance did not provoke as polarized responses as the other names did.

"No use of either words disability or benefit."

"Easy to remember/recognise!"

"It is a long standing name that people are familiar with and understand."

"It's discrete, and serves its purpose."

"It is concise, it says what it is and to the point."

"Short, simple, accurate."

## **Attendance Allowance - Dislikes**

We asked respondents what they disliked about the name Attendance Allowance. 160 of the 278 respondents answered this open text question. For those who provided a positive comment, a number of themes were identified.

## Unclear, particularly 'attendance'

Most respondents said they disliked that the name Attendance Allowance is not clear regarding what the benefit is for and who is entitled to it. Respondents described it as being 'vague', 'ambiguous' and 'confusing'. Many respondents did not know what the payment is for.

"The name makes little to no sense."

"It doesn't actually describe what it's for and who can claim it."

"It could mean anything."

This confusion is seen to be particularly prominent when it came to the word 'attendance'. Some respondents were not sure what 'attendance' means. Others said that the term suggests that the recipient has to 'attend somewhere.'

"Sounds like you need to attend something or go somewhere."

"It suggests the claimant has to 'attend' something which is misleading."

Respondents also said that 'attendance' could suggest that the recipient has to be 'attended' to by another person at all times, rather than provided with assistance or support. For this reason, some respondents said that the name is confusing because it may imply that the payment is for a carer rather than recipient. They felt that it is not clear that the payment can be used for items and services of the individual's choice and does not have to involve employing someone to 'attend' to them.

"The name has very negative overtones, it suggests that the looked after person needs the constant presence of another."

"To me it equates to a person that needs attending to, rather than assistance or support."

"It doesn't say what it's for, it could be paid to anyone. It sounds like it is a carer's allowance not a payment for the disabled person."

For these reasons, a few respondents noted that people may not perceive themselves to be eligible and may face difficulties when seeking information.

"It sounds vague. Anyone searching for this type of benefit might overlook it or misinterpret its meaning."

"It in no way describes what it is, many people would have no idea they can claim it."

"Probably a lot of people think you cannot claim and live on your own."

"It is misleading as the person does not have to have someone caring or attending to them for them to receive it."

#### **Additional themes**

A small number of respondents said that the name is outdated, particularly due to the problems outlined with the term 'allowance'. Respondents also disliked the previous associations with the DWP:

"It sounds outdated and allowance sounds like it's a handout like pocket money."

"Sounds old fashioned and not clear of meaning."

A few respondents simply described Attendance Allowance as being a negative name:

"Sounds dehumanizing."

"Sounds impersonal."

"I think that this name is demeaning."

# **Disability Assistance for Older People**

Respondents were told that the Scottish Government intends to change the name of Attendance Allowance to Disability Assistance for Older People.

# **Disability Assistance for Older People – Likes**

We asked respondents what they liked about the name Disability Assistance for Older People. 156 of the 278 respondents answered this open text question. For those who provided a positive comment, a number of themes were identified.

Most respondents liked the word 'assistance' and felt the name to be simple and easy to understand. Respondents said the name is 'more user friendly' than Attendance Allowance and described it as 'straightforward' and 'simple'. Many respondents said that the name is 'fine' or 'better' but did not provide any further information about why they thought this.

"It's more specific/self-explanatory than AA."

"Much more descriptive of what it is and who it's for."

"This sounds and reads better as the word assistance can help future clients not feel as though they have to have someone attending to them all the time before they can claim this benefit."

#### **Additional themes**

A few respondents said that the name is more inclusive and that they appreciate the consistency with the other proposed benefit names.

"Definitely sounds better and more caring."

"Keeps in line with name of benefits for other age groups, so easier for understanding. All age groups being referred to in same fashion will be helpful for older applicants, and their families/carers. Uptake may increase."

# **Disability Assistance for Older People – Dislikes**

We asked respondents what they disliked about the name Disability Assistance for Older People. 152 of the 278 respondents answered this open text question. For those who provided a negative comment, a number of themes were identified.

Most respondents disliked the inclusion of the words 'disability' and 'older people.' As discussed, some respondents felt that the word 'disability' is offensive, divisive and labelling.

"It highlights age and disability."

"Sounds discriminatory - disability and older."

"Disability and age is a wee bit demeaning."

Many respondents also disliked the word 'older people.' They felt that the term is vague, subjective and there is no clear definition of the age range encompassed by 'older people.' A few respondents questioned why each benefit has to be distinguished by age.

"What does 'older people' mean, i.e. at what age do you become 'older'?"

"Older People is pretty vague and many people have differing thoughts on what constitutes an older person."

Respondents also felt that referring to people as 'older' is potentially discriminatory. Some described the proposed name as being 'patronising', 'demeaning' and 'disrespectful'.

"Makes you feel old and useless."

"Labelling a person as disabled and old places them at an immediate disadvantage and can reinforce how they consider themselves."

The other themes that emerged mirrored those discussed in the sections on Disability Assistance for Children and Young People and Disability Assistance for Working Age People.

Most respondents disliked that the name was long. They described it as 'clunky,' 'wordy' and 'cumbersome'.

"This naming convention is awful. I don't like anything about it. These new terms are too long and verbose and can't be easily turned in to an acronym."

A small number of respondents said that it is not clear that 'assistance' refers to financial assistance alone and that this is misleading.

"Sounds more like a service than a benefit."

"Doesn't sound like a regular payment."

#### **Preference**

We asked respondents which name they prefer, 'Disability Assistance for Older People' or 'something else'. One third of respondents were in favour of the name Disability Assistance for Older People (33 per cent). Around two thirds of respondents would prefer something else (67 per cent).

Table 11: Which name do you prefer (n=260)

Response	%
Disability Assistance for Older People	33
Something else	67
Total	100

Of those who would prefer something else, 20 per cent said it should remain called Attendance Allowance. This accounted for 11 per cent of all responses. The full list of names proposed by respondents can be found at Annex C.

# Words used by Social Security Scotland

# Words to avoid

Social Security Scotland want to ensure the words used to name benefits are clear, easy to understand and respectful. We asked respondents if there are any words Social Security Scotland should avoid using when naming a benefit. 141 of the 278 respondents answered this open text question. Respondents said that Social Security Scotland should avoid negative, stigmatising terms such as 'disabled', 'disability', 'benefit' and 'allowance.' Words which segregate people should also be avoided.

"People with disabilities are people first and foremost so any name should reflect this. It is reductionist to have titles which reduce people to just this one set of characteristics. I think the titles should reflect accurately who and what the benefit is for."

"Disability, Allowance. Anything negative or patronising or segregating or disabling or stigmatising. The names should reflect their aim, which is to enable and to support."

Respondents also said that ambiguous words should be avoided. These can be misinterpreted and cause barriers to eligible people applying. Similarly, words should not imply that the benefit provides more than it does in reality.

#### Words to use

We asked respondents if there are any words Social Security Scotland should definitely use when naming a benefit. 134 of the 278 respondents answered this open text question. Respondents said that Social Security Scotland should use positive, neutral and empowering words such as 'assistance', 'payment' and 'support'. Words such as these were felt to highlight that people are entitled to the benefits, and that they are intended to give people 'autonomy' and 'independence.'

"Simple, matches reality of the payment."

"Stick to the positive and encouraging. Always give the impression that the agency is on the claimant's side."

"Definitely use positive words that give people a feeling of receiving something that they have every right to have. Words like 'payments', 'finances' and 'amounts'."

Respondents also said that short, simple words which are easy for everyone to understand are preferable. Names should be concise, direct and descriptive, for example, referring to explicit age ranges rather than 'older people' and 'working age'.

"Words which are easy and clear without being derogatory to the person or persons requiring the benefit."

"Make it absolutely clear what it is and who it is for. No complicated language."

# Other name changes

We asked respondents their views on other proposed name changes, specifically to Social Security Scotland staff titles.

#### Decision Makers - Likes

In the DWP, decision makers are the people who look at a benefit application and make a decision whether or not to award a benefit. We asked respondents what they liked about the name decision makers. 129 of the 278 respondents answered this open text question. For those who provided a positive comment, a number of themes were identified.

Most respondents said that they liked that decision makers is a clear, unambiguous and descriptive term. They felt that the name accurately describes the role of decision makers and distinguishes them from other staff who they may interact with.

"It is plain English. It is clear and precise. It describes the job exactly."

"Gives a better idea of who is responsible for a result."

"If they are the people deciding on claims then they are decision makers. It sets them aside from the admin staff."

#### **Decision Makers - Dislikes**

We asked respondents what they disliked about the name decision makers. 125 of the 278 respondents answered this open text question. For those who provided a negative comment, a number of themes were identified. Most respondents said they disliked that the name as felt 'authoritarian' and 'judgemental'. They described the name as feeling 'overly strict', 'ominous', 'severe', 'clinical', 'cold' and 'impersonal'.

"It sounds cold and unapproachable."

"It feels very authoritarian and impersonal."

Another key theme to emerge is that of 'power'. Many respondents said that the name suggests an imbalance of power between the individual and the decision maker. Respondents noted a feeling of powerlessness, particularly as the decision maker is responsible for making decisions which affect their income and quality of life. Many described this as feeling like their 'life is in the hands of others'.

"It sounds like you have no control"

"I feel that the name means 'power'."

"Connotation that this one person has your whole life in their power."

"It very much makes it feel like they are in control of any decisions made for you that will decide how you are able to live the rest of your life. Your life is basically in their hands."

Finally, some respondents said they disliked that the name implied a finality of decisions made by the decision makers. For these respondents, the name suggests the decision maker will also lack compromise and compassion.

"As a title it's not the kindest, it suggest to the applicant that it requires the relinquishing of all control to the "decision makers" and that the applicants input is not important. It also suggests that they cannot be reasoned with."

"Not very user friendly. Sounds like there's no room for movement/negotiation/compromise."

Some respondents said that decision makers evoked memories of negative experiences and interactions with the DWP in the past.

"Makes you think of unqualified, outside agency staff who do not know you, or care, let alone understand."

"The name is forever tainted. It now evokes images of dictatorship, inflexibility. Lack of understanding."

"It makes me think of people in offices who have no idea how a disability impacts on someone's life and they can take away money at the drop of a hat which can have serious consequences on the applicant."

A few respondents said that the name was irrelevant so long as the staff making decisions on applications show sympathy, understanding and are qualified to do so.

"As long as they have the experience and knowledge to make fair decisions on benefit applications and it is not just a paper exercise, I don't think it matters what their actual title is."

"Changing the name is irrelevant. The accuracy and sensitivity of the assessment process these people carry out, the standard of their background, training and humanity is what' crucial."

### **Case Managers - Likes**

Respondents were told that one idea for the future is to change the names of decision makers to case managers in Social Security Scotland. We asked respondents what they liked about the name case managers. 124 of the 278 respondents answered this open text question. Of those respondents who left a positive comment, most simply said that they preferred it to the current name. Many respondents said that the name is 'better' because it sounds 'gentler', 'friendly' 'more supportive', 'less confrontational' and 'less authoritarian.' They felt that it implies less of a power imbalance than decision maker does.

"It's a big improvement on decision makers. Case managers makes it sound more of a collaborative process."

"Much more user friendly. It implies a helpful attitude to the applicant."

"I like that it sounds more approachable. They are managing your case."

"I think that it is a better title. It will give people the feeling that they are regarded as real people, not just a number."

"Sounds as if they are caring for an individual."

A key theme to emerge was that many respondents used the word 'personal' to describe what they liked about the name case manager. Respondents said the name suggests that the case manager's role is to support individuals and that they would take care and consideration over their decisions.

"Sounds more personal like they are working for you not against you."

"It implies some sort of involvement/concern about the case."

"It's a lot nicer and makes it sound like they are being more considerate with decisions."

Some respondents said that the name implies that there will be one case manager managing individual cases, who would follow a case from start to end, and be familiar with it.

"It makes it more personal, sounding like one person is taking ownership for decisions made about the application/award."

"This indicates a more personal service like having a key worker who individuals could contact directly about their case."

A few respondents said they liked that the name case managers sounds professional.

"It sounds more professional and suggests someone taking time and care over cases before making a decision."

### **Case Managers - Dislikes**

We asked respondents what they disliked about the name case managers. 121 of the 278 respondents answered this open text question. For those who provided a negative comment, a number of themes were identified. Many respondents said they disliked that the name case manager appears to reduce individual people to 'cases' to be 'managed'.

"We are people not 'cases'. This title is cold and uncaring, exactly what the new benefit system is trying to avoid!"

"Gives the impression it is the person that needs managed and not the case."

Some respondents said the name case manager is vague. They felt it was not clear from the title if case managers would be responsible for making decisions on applications.

"It's very vague, what does a case manager actually do?"

"It's not self-explanatory - doesn't reveal that they are the person who makes the decision on whether someone is entitled to a benefit."

"Their role is less clear than "decision maker" which is an accurate description of what they do."

Respondents also highlighted that case manager is a term used by other services and professionals who may be involved with an individual/family, principally social work. They felt that this may be confusing for people.

"Too reminiscent of social workers."

"In Universal Credit, there are case managers and decision makers, and they are quite different roles. If you use the term "case managers" for new benefits, this is going to lead to a lot of confusion. I think a completely new title should be used."

As outlined above, some respondents liked that the name case manager suggests that a case manager will be responsible for managing individual cases through the process and would act as a single point of contact for applicants. For some respondents, however, this was felt to be misleading if that will not be the service or function provided by case managers.

"Case manager implies they will follow through, know your case from start to finish and take ownership for any issues/appeals etc. If the case managers are only one part of the system then they need a different name."

"It doesn't tell me what that person does. Do I have direct access to that person to discuss my application? Can they give me advice? Where are they in the system? It's very vague and doesn't inspire confidence in the system."

Whilst most respondents who provided a positive comment about the name case managers said they liked that it sounds personal and friendly, a few respondents

said the opposite. They described it as being 'clinical', 'bureaucratic', 'official' and 'formal.' The word 'manager' was also felt to hold hierarchical overtones and suggest a power imbalance between the individual and case manager.

"Manager sounds very "authority figure" which could be intimidating."

#### Specialist Advisors – Likes

Within Social Security Scotland, sometimes decision makers might need to seek further advice or help if an application is complex or nonstandard. When this happens, they will seek help from specialist advisors. Specialist advisors will be responsible for providing decision makers with information and advice on health and social care matters - such as the side effects of a particular medication, how a specific disability impacts someone and the way in which two conditions might interact.

We asked respondents what they liked about the name specialist advisors. 118 of the 278 respondents answered this open text question. For those who provided a positive comment, a number of themes were identified. A majority of respondents said they liked the word 'specialist' as it specifies that a qualified individual with specialist knowledge and expertise will be advising on decisions. Respondents found this reassuring.

"Specialist implies they will be an expert in my condition and its effects on me."

"It informs us that these people have more medical knowledge or more understanding of how people and their lives are affected by their condition or circumstances."

Many respondents also said that they felt the name is a clear, descriptive and unambiguous. The role of the specialist adviser is to 'advise' using 'specialist' knowledge, and is therefore distinct from the decision maker.

"It makes clear they are not the decision maker but an advisor."

"It's factual and accurate. They are specialists and they advise."

A small number of respondents said the name sounds professional and positive. Many respondents described it as 'fine', 'good' or 'ok', but did not provide any further information on why they thought this.

"This is much better, and doesn't immediately make people think it's a them or us situation. I encourages disabled people to think of these staff members as helping us."

#### **Specialist Advisors – Dislikes**

We asked respondents what they disliked about the name specialist advisors. 116 of the 278 respondents answered this open text question. For those who provided a negative comment, a number of themes were identified. A majority of respondents said they disliked that the name is vague and unclear. Specifically, respondents said that the word 'specialist' is confusing as it is unclear from the title what special advisors 'specialise' in and what their qualifications and experiences are. Respondents assumed that specialist advisors would be health professionals with a medical background. Some felt that medical titles should therefore be used in the name. Other respondents noted that the word 'specialist' should only be used if the individual has specific medical and pharmaceutical knowledge of a particular health condition.

"It does not say what they do or whom they advise."

"The potential for the people in this role not to be specialists or to be consulted on an area in which they are not appropriately experienced or qualified."

"The name suggests that a person in this position would have specialist training and knowledge of all aspects of a person's condition and medication. This would be impossible since a person with complex health issues would be under the care of several health specialists, who have years of training to have the knowledge and expertise they have."

"Does not state the specialist title, not trustworthy."

"From the job description you give, claimants might get the impression that this person is medically qualified. If they are, then the job title should reflect this."

"It does not explain that they are health professionals specialised in their field, this needs to be made clear."

A few respondents said that the name specialist advisors sounds too 'official' and 'clinical.'

"It could also could be perceived as people who think they know better when that may not be the case."

#### Professional Advisors - Likes

Finally, respondents were told that an alternative to specialist advisors is professional advisors. We asked respondents what they liked about the name professional advisors. 114 of the 278 respondents answered this open text question.

Most respondents who a provided comment said that the name is 'fine' and a few said that they prefer it to specialist advisors but did not say why. Similar to the word 'specialist', many respondents said the word 'professional' denotes knowledge and expertise.

"This also makes it look like they are using professional knowledge and understanding to help and support people to the best to their ability."

#### Professional Advisors - Dislikes

We asked respondents what they disliked about the name professional advisors. 111 of the 278 respondents answered this open text question. For those who provided a negative comment, a number of themes were identified. A majority of respondents felt the name is too broad and general. They said that the title is vague and does not reflect who the adviser is and what they do. Some respondents noted that the word 'professional' does not necessarily indicate expertise, qualifications or specialist knowledge in health conditions.

"Professional in what? Disability comes in many forms and a specialist opinion is what I would be looking for."

"Professional advisors could be anything or anyone. It's too opaque."

"It is as vague as healthcare professional. It doesn't really mean much unless what the person is professional in is made very clear. Professional doesn't suggest any particular or specific knowledge or experience. It is often a term used to describe behaviour rather than experience or qualifications."

Many respondents also felt that the term 'professional' is not appropriate because it describes a quality or behaviour rather than a job role or function. These respondents highlighted that the name is misleading because not all professionals are specialists and not all specialists are professional. Moreover, some respondents said that they expect all Social Security Scotland staff to be professional so there is no need to distinguish only these advisors.

"The word professional should be in relation to all staff, their practice and behaviour and not a name for their role or job."

"Can be misleading as you can be professional without being a specialist."

"I prefer "Specialist advisers" to "Professional Advisers" because people can have a speciality without being a professional in any field. For example, someone working in a charity setting can be very knowledgeable on a particular illness, but have no professional qualification."

"It's not a good description. All the staff are supposed to be professional. 'Professional' does not mean 'Specialist'. The point of having 'Specialist Advisors' is that they should be specialists in specific fields so that they can help with difficult applications"

Some respondents described the name professional advisors as sounding 'formal', 'pretentious', 'distant', 'authoritative', 'clinical', 'corporate' and holding private sector connotations.

"It still sounds very murky, and not transparent."

"Bureaucratic. Managerial. Cold."

### What's next?

The Scottish Government will use these findings alongside responses to the consultation to inform decisions on the names to use for the new devolved disability benefits.

The Scottish Government will continue to work with the Experience Panels in the development of Scotland's new social security system. This will include further research on individual benefits in addition to work to assist in the development of Social Security Scotland.

## **Annex A**

# 'Something else' – Respondent alternative name suggestions for Disability Assistance for Children and Young People

Nine respondents suggested Disability Living Allowance (DLA) For Children, seven suggested Disability Living Allowance and six suggested Assistance for Children and Young People.

Less than five respondents suggested the following names:

**Disability Assistance** 

Disability Assistance for Young People

Disability Living Allowance for Children and Young People

Disability Living Assistance

Disability Support for Children and Young People

Personal Independence Payment for Children

Ability Assistance for Children and Young People

Ability Support for Young People

Ability to Support Allowance

Access Assistance for Children and Young People

Accessibility Allowance for Children and Young People

Accessibility Assistance for Children and Young People

Additional Assistance

Additional Support Payment for Children (APC)

Additional Support Payment for Children and Young People

ASN (Additional Support Needs) Assistance for Children and Young People Assistance

Assistance for Children and Young People to Enhance Living Life to their Fullest Ability and Potential

Assistance for Children and Young People with a Disability

Assistance for Children and Young People with Additional Needs

Assistance for Differently Abled Young People

Assistance for Young People

**Assisted Living** 

Assisting Children and Young People who are Challenged

Capability Development Payment for Under 25's

Care and Mobility Assistance for Children and Young People

Child Assistance

Child Disability Assistance Scotland

Children and Young People with Disabilities Assistant

Children and Young People's Allowance

Children and Young Peoples Assistance with Disability

Children and Young People's Living Allowance

Children and Young People's Support Allowance

Children's Assistance

Children's Independent Living Support

Children's Assistance Benefit (CAB)

Children's Disability Assistance (CAD)

Children's Equality Allowance

Condition Specific Assistance for Children and Young People

Dignity Assistance Allowance

Disability Allocation for Children/Young Person

Disability Allowance for Young People

Disability Assistance for Children

Disability Assistance for Minors

Disability Assistance for Under 16's

Disability Assistance for Youth

Disability Assistance Under 18

**Disability Benefit** 

Disability Care or Support Allowance

**Disability Empowerment Payment** 

Disability Enhanced Payment for Children

Disability Equality Allowance for Children

Disability Living Allowance for All

Disability Living Allowance for the Under 18

Disability Living Allowance for Under 16's

Disability Living Costs Fund

Disability Support Allowance for Children and Younger People

Disability Support Assistance

Disabled Children and Young Adults Help For Care

Disadvantaged Equity Award

**Enabling Assistance** 

Enabling Assistance for Children and Young People

Financial Allowance for Under 18's With Disabilities

Financial Assistance for Children and Young People who are Disabled

Financial Assistance for Disabled Children and Young People

Financial Equity

**Functionality Support** 

Health Assistance for Young People Under 16 Years Old

Help For Children and Young People

Illness Assistance

Independence Allowance for Children and Young People

Independence Payment

Junior Disability Assistance

Living Allowance

Living Assistance for Children and Young People

Living Enablement for Children and Young People

Living Support Allowance for Children and Young People

Money for Illness or Mobility for Young People

Money for Scottish Children Who Need It

Personal Assistance for Children and Young People

Personal Living Allowance for Children

**Special Needs Assistance** 

**Special Needs Care** 

Support for Children and Young People

Support for Living

**Support Living Allowance** 

Supported Assistance for Children and Young People

Supported Living Allowance

Wellbeing Allowance for Young People

Young Disabled Citizen's Payment

Young People Disability Assistance

Young People's Additional Support

Young Peoples Assistance Allowance

Young People's Independence Payment

Young Person's Disability Assistance

Young Persons Social Fund

Young Persons' Support

## **Annex B**

# 'Something else' – Respondent alternative name suggestions for Disability Assistance for Working Age People

34 respondents suggested Personal Independence Payment, 12 suggested Disability Assistance, 11 suggested Disability Living Allowance and five suggested Assistance for Working Age People.

Less than five respondents suggested the following names:

**Adult Disability Assistance** 

Disability Assistance (Adult)

Disability Assistance for Adults

Disability Allowance for Working Age People

**Disability Support Allowance** 

Personal Independence Allowance

Working Age Help

(Working Age Peoples) Additional Support Allowance (WAPASA)

A Living Support Allowance

**Ability Support** 

Access Assistance for Working Age People

Accessibility Assistance for Adults

Accessibility Assistance for Working Age People

Additional Support Payment for Adults (APA)

Adult Additional Assistance

Adult Assistance

Adult Assistance Allowance

Adult Assisted Living

Adult Independence Assistance

Adult Independence Living Allowance

Assistance for Adults with Disabilities

Assistance for Differently Abled

Assistance for Disabled Working People

Assistance for People with Disabilities

Assistance for Working Age People with a Disability

Assistance for Working People (AWAP)

Assisted Living for Challenging Lives

ASSN (Additional Support Needs) for Adults

Capability Development Payment for 25s - 65s

Care and Mobility Assistance

Condition Specific Assistance for Non Retired People Aged 16 And Over

**Dignity Assist Payment** 

**Disability Allocation** 

**Disability Allowance** 

Disability Assistance (With Stated Age Group)

Disability Assistance Aid (DAA)

Disability Assistance or Disability Assistance Entitlement for 18 to 65s or for Adults

**Disability Assistance Payment** 

Disability before Retirement Age Benefits

**Disability Benefit** 

**Disability Empowerment Payment** 

Disability Enhanced Payment for Employment

Disability Equality Allowance

Disability Equality Allowance for Working-Age People

**Disability Independence Payments** 

Disability Living Allowance for Working Aged People

Disability Living Assistance

Disability Social Allowance

Disability Support and Assistance

Disability Support Entitlement

Disability Support for Working Age

**Disability Support Payment** 

Disabled Assistance

**Disabled Citizens Payment** 

DLA Helping You to Help You

**Enabled Assistance** 

**Enablement Payments** 

Enhancing the Ability for Working Age People that need support to stay

independent

**Essential Support** 

Financial Aid to Improve Independence or Ability

Financial Assistance for Adults with a Disability

Financial Assistance for Disabled Working Age People

Financial Support for Disabled Adults

**Functionality Assistance** 

Heath Assistance Benefit for Adults

Illness/Mobility Money for Working Age People

Independence Benefit (IB)

Independence Help

Independence Payment

Independent Living Assistance

Independent Support for Working Age People

Life Elevation for Working Age People

Living Assistance for Adults

Living Assistance for Working Age People

Peoples Disability Assistance

Personal Assistance Allowance

Personal Assistance for Disability

Personal Assistance for Working Age People

Personal Independence

Personal Independence Assistance

Personal Independence Enabler

Personal Independence Money for Working Age People and Pensioners

Personal Living Support

Scotpersonal Independence Payment

Social Welfare/Social Security Welfare/Scottish Social Welfare/or Support/or

Security

Special Financial Assistance for Impairment

Support and Assistance

Support for Living

Supported Assistance for Adults

Working Age Aid

Working Age Benefit

Working Age Disability Assistance

Working Age Disability Rights Fund

Working Age Payment

Working Age People Additional Assistance

## **Annex C**

# 'Something else' – Respondent alternative name suggestions for Disability Assistance for Older People

29 respondents suggested Attendance Allowance, 10 suggested Disability Assistance and six suggested Assistance for Older People.

Less than five respondents suggested the following names:

Attendance Support

Disability Allowance for Older People

Personal Assistance for Older People

Senior Disability Assistance

Senior Disability Support

(Older Peoples) Additional Support Allowance (OPASA)

65+ Disability Allowance

Ability Assistance for Older People

**Ability Support** 

Access Assistance for Older People

Additional Support Needs for Older People

Additional Support Payment for Older People (APOP)

Adult Assistance for Mature

Age Related Allowance

All Assistance

Allowance for Extra Living Costs

Assistance

**Assistance for Carers** 

Assistance for Less Able Older People

Assistance for Older People with a Disability

Assistance Payment for Retired People Past State Pension Age

Attenders Allowance

Attending Allowance

Benefit for Mature People

Capability Retention Payment for Over 65s

Care and Mobility Assistance

Care Assistance for Older People

Care Assistance for Over 65s

Carers Allowance

Carers Support Allowance

Disability Allocation in Retirement

**Disability Allowance** 

Disability Assistance (Older People)

Disability Assistance Entitlement for Over 65s

Disability Assistance for 65 Years Old/Over

Disability Assistance for Mature People

Disability Assistance for Pensioners

Disability Assistance for People Over 65

Disability Assistance for Senior Citizen

Disability Assistance for the Retired

Disability Assistance for Those over Retirement Age

Disability Assistance Pension

Disability Assistance Retired

**Disability Care** 

Disability Fund for People Over 65

Disability Living Allowance

Disability Living Allowance for Mature Folk

Disability Living Assistance

**Disability Payment** 

Disability Rebate - Older People

Disability Social Fund

Disability Support for Older People

Disabled Older Citizens Payment

**Employment Entitlement** 

**Enabled Assistance** 

Equality Allowance for Disabled Senior Citizens

Equitable Assistance

Financial Assistance for Older Adults Requiring Extra Help

Financial Assistance for Pension Age People that need Care

Functionality Assistance for People Older than 65

Help For Older People

Homecarer and Enhanced Payment for Elderly

Illness Assistance

Independence Allowance

Independent Living Support

Living Assistance for Older People

Money for Help for Older People with Illness/Mobility Issues

Older People Additional Allowance

Ongoing Assistance for Older People

Part-Time Home Care for People past Retirement Age Benefit

Pensioners Disability Assistances

Personal Assistance Allowance

Personal Living Payment

Retirement Care, Elderly Support, Elderly Community Care, Retirement Support

Superannuation Scheme

Senior Additional Assistance

Senior Assistance

Senior Daily Care Payment

Senior Scot PIP

Seniors Support Payment

Support Allowance

Support for Living

Support for Older People

Support Living Allowance for Older People

Supported Assistance for Adults

Xtra Assistance for Older People

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