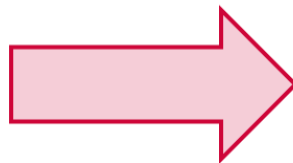


Social Security Experience Panels: Disability Benefit Names Survey

Background

The Scottish Government is becoming responsible for some of the benefits currently delivered by the Department for Work and Pensions (DWP). As part of work to prepare for this change, the Scottish Government set up the Social Security Experience Panels.

**Department
for Work and
Pensions**



**Scottish
Government**



Over 2,400 people from across Scotland have joined the Experience Panels. They all have recent experience of the benefits that are coming to Scotland.



The Scottish Government is working with Experience Panel members to create Scotland's new social security system.

2,400+
**Experience Panel
members**

About the research

This report gives the findings of the 'Naming Disability Benefits' research.



1973
invites



278
survey
responses

The research took place in



2019

The research explored:



what people liked and disliked about the current DWP disability benefit names



what people liked and disliked about the proposed new disability benefit names and any other suggestions



views on words to avoid and use when naming a benefit; and on other proposed name changes

Participants were aged between

25 – 79

years old



36%

Man or boy



64%

Woman or girl



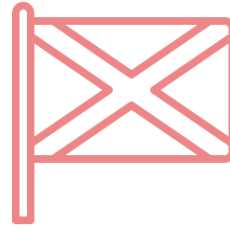
81%

lived in an urban location



19%

lived in an rural location



Participants took part in all **32** local authority areas

Most survey participants had a disability or long term health condition (87%), including:



chronic pain



severe hearing impairments



severe visual impairments



other kinds of long term health condition

More than half (57%) of survey participants were:



a carer due to **old age,**



a carer to a **child, or**



a carer to an **adult.**

This report outlines the views of people who responded to this survey. These may not be shared by all people with experience of the disability benefits.

Disability Living Allowance (DLA) for Children

First we asked respondents what they liked and disliked about the existing DWP disability benefit names, with text boxes to respond.



The most common thing that respondents said they liked about the name DLA for Children was that it is **clear, easy to understand and familiar**. They liked that it is **descriptive**, stating **what and who the benefit is for**.

“Simple and explanatory. It's direct to the point for helping children with disabilities, mental and physical.”

“Tells you who it's for and what it does.”

“It does what it says on the tin.”

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

“It's in line with the name used in England.”

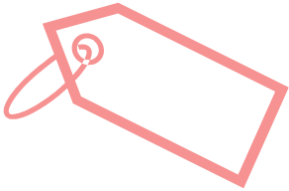


Some respondents liked the word ‘**children**’ as it shows that the benefit is meant to support the child.

Some respondents also liked the word ‘**living**’. They said that it recognises that having a disability or health condition results in extra living costs for children and their families.



The most common thing that respondents said they disliked about the name DLA for Children was that it includes the word '**disability**'. They felt it creates stigma.



Some respondents felt it is particularly problematic to '**label**' children using the word.

Many respondents disliked the word '**allowance**'.

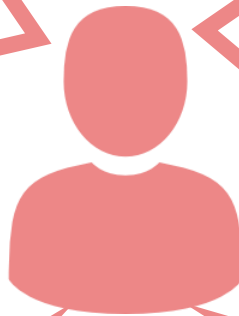
"I feel that the use of the word disability is demeaning. Children with additional needs should not be categorised."

"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."

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

"It sounds as though it is just for children but not young people."

"It focuses on disability rather as ability."



Some respondents said the name is '**old-fashioned**' and '**out of date**'. A few respondents said that any benefit names used by the DWP held negative feelings for them.

Some respondents said that it is **not clear which age** group the benefit is for because it only refers to 'children'. This was seen to **exclude teenagers**.

Disability Assistance for Children and Young People

We then asked respondents what they liked and disliked about the proposed new Social Security Scotland disability benefit names.



The most common thing respondents said they liked about the name Disability Assistance for Children and Young People was the word **'assistance'**.



Some respondents used the following words to describe the proposed name: **'kinder'**, **'supportive'**, **'softer'**, **'more inclusive'**.

Some respondents liked that it **encompasses all 'young people'**.



Other respondents said that they liked that the name is **clear and self-explanatory**.

Some respondents simply noted that it is **'better'** and **'much more suitable'** than Disability Living Allowance (DLA) for Children, but did not provide a reason why they thought this.

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

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

"It is simple and straightforward."

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

"It sounds more welcoming and friendly."



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



Some respondents felt that the word does not do a good job of **covering all disabilities** and health conditions. These respondents thought the word could act as a **barrier to claiming**.



Many respondents thought that the name is **too long and does not allow for a short, easy to use acronym**.

“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.”

“It suggests practical assistance rather than financial support.”

“It’s way too long for a benefit name.”

“It is an improvement on DLA for Children, however, the stigma of the word disability still exists.”

“It’s too long and it’s not worded well enough to be able to give it a shorter nickname.”

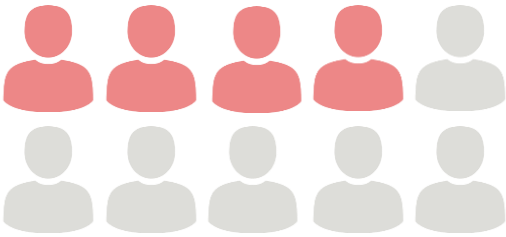


Whilst most respondents liked the word '**assistance**', a few disliked it. These respondents felt that it may suggest **practical help rather than a financial payment**, which could be misleading for people.

Preference



We asked respondents which name they would prefer, '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%).

Almost six in ten respondents would prefer something else (58%).

Of those who would prefer something else, **6% said it should stay being called Disability Living Allowance for Children**. This accounted for 3% of all responses.



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

- Living Support Allowance for Children & Young People
- Personal Living Allowance for Children
- Financial Assistance for Disabled Children and Young People
- Disability Assistance Under 18
- Disability Assistance for Young People
- Assistance for Children and Young People
- Ability assistance for Children and Young People
- Care and Mobility Assistance for Children and Young People
- Living Assistance for Children and Young People
- Assistance for Children and Young People with a Disability
- Disability Assistance for Minors
- Disability Enhanced Payment for Children
- Disability Support for Children and Young people
- Children's Assistance

Personal Independence Payment



The most common thing respondents said they liked about the name PIP was the term '**personal independence.**' Respondents said that the word 'independence' focuses on **ability rather than disability.**



Respondents liked that the word '**personal**' suggests **control** and decision making in how the payment is used.



Some respondents also liked that the name PIP is **short** and has a good **acronym.** They described it as easy to use, say and easily remembered.



Some respondents said that the name **PIP is self-explanatory.**

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

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

"It is short and easily recognisable."

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

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



The most common thing respondents said they disliked about the name PIP was the **past, negative associations of the benefit** itself.



Some respondents highlighted the **public reputation of PIP** and said the name carries '**negativity**', '**stigma**' and a '**bad reputation.**'



Respondents also said the name brought up **negative memories of claiming the benefit.**



Some respondents said that the term 'personal independence' is problematic because it may **not be achievable for some people.**



A small number of respondents said the **purpose and eligibility of PIP is unclear.**

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

"It could mean any number of things."

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

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

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

Disability Assistance for Working Age People



Similar to Disability Assistance for Children and Young People, the most common thing respondents said they liked was the word 'assistance.' Respondents said the name '**sounds more dignified**' and is '**much nicer.**'

Many respondents said it is **clear** and **easy to grasp.**



A few respondents said that they liked the term '**working age**' because it states that the **benefit can be claimed whilst working.**

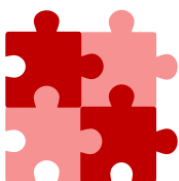
"It acknowledges that it is for people of a working age - and that you can be in employment but in needed of financial assistance due to your disability."

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

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

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

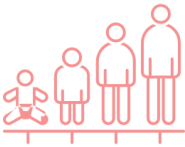
"More comprehensive. Explains exactly what it is and who it is for."



A few respondents liked that the name is **consistent** with Disability Assistance for Children and Young People. Many respondents said that the name is 'fine', 'good', 'ok' or 'better' but did not explain why they thought this.



The most common thing respondents disliked about the name Disability Assistance for Working Age People was the term **'working age.'**



Firstly, respondents said the word is **vague** and it is **not clear what age range** it covers.



Secondly, respondents said that 'working age' is **misleading** because it **suggests the benefit is linked to a person's ability to work.** Thirdly, respondents said 'working age' is not good because it **suggests that that recipients should be working,** when many disabled people are unable to.

The other things that respondents disliked about the name were the same as for Disability Assistance for Children and Young People. Most respondents said the name is **too long** and that they disliked the word **'disability.'**

"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."

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

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

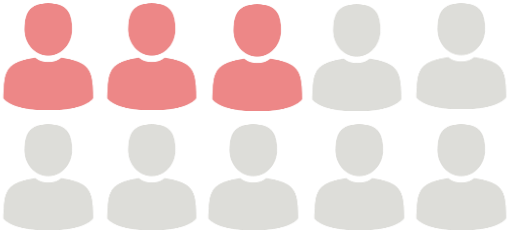
"The benefits title sets a tone for people who are disabled that "working" is preferable to not working when for many people with disabilities, they have no choice about working or not working."

"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."

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%).



Around seven in ten respondents would prefer something else (73%).

Of those who would prefer something else, one in five (**19%**) **said it should stay being called Personal Independence Payment**. This was 13% of all responses.



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

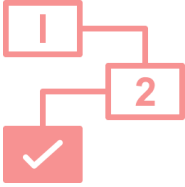
SCOTPIP

- Accessibility Assistance for Adults
- Assistance for Working Age People
- Disability Support for Working Age
- Independent Support for Working Age People
- Financial Assistance for Disabled Working Age People
- Financial Support for Disabled Adults
- Disability Support Payment
- Living Assistance for Adults
- Assistance for People with Disabilities
- Additional Support Payment for Adults (APA)
- Independent Living Assistance
- Disability Assistance Payment
- Disability Assistance (Adults)

Attendance Allowance



The most common thing respondents said they liked about the name Attendance Allowance was that it is **simple, short** and **concise**.



They also liked that it is **familiar** and **easy to recognise**.

Some respondents noted 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 explain why they thought this.

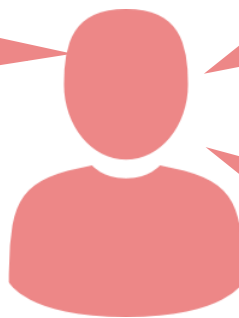
"It is a long standing name that people are familiar with and understand."

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

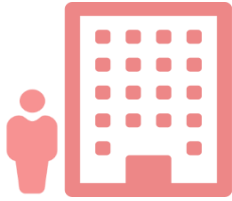
"Short, simple, accurate."

"Easy to remember/recognise."

"No use of either words disability or benefit."



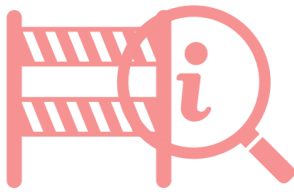
The most common thing respondents said they disliked about the name Attendance Allowance was that it is **not clear what the benefit is for** and **who is entitled to it**. Respondents described it as being '**vague**', '**ambiguous**' and '**confusing**'.



Many respondents said the word '**attendance**' is particularly **confusing**. Some respondents said that the word suggests that the recipient has to '**attend somewhere**'.



Others said 'attendance' suggests that the recipient has be '**attended to**' by another person at all times. Some felt that the **payment could be for a carer**.



Some respondents noted that many people may not think they are eligible because of this. They may then find it difficult to find out about Attendance Allowance.



A small number of respondents said that the name is **outdated**, especially the **word 'allowance'**. Respondents also disliked the previous associations with DWP.

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

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

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

"It sounds like it is a carer's allowance not a payment for the disabled person."

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

Disability Assistance for Older People



Similar to the other names, the most common thing respondents said they liked about the name Disability Assistance for Older People was the word **'assistance'**.



Respondents said the name is **'more user friendly'** than Attendance Allowance and described it as **'straightforward'** and **'simple'**.

"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."

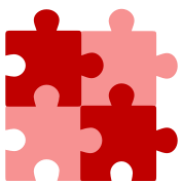
"It's more specific/ self-explanatory than AA."

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

"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."

"Definitely sounds better and more caring."

Many respondents said that the name is **'fine'** or **'better'** but did not explain why they thought this.



A few respondents said that the name is **inclusive**. A few liked the **consistency** with the other proposed benefit names.



The most common thing respondents said they disliked about the name Disability Assistance for Older People were the words **'disability'** and **'older people.'**



WHO?

Respondents said that the word **'older people'** is **vague** and that it is not clear what age range the assistance covers.

Respondents also felt that referring to people as 'older' is **disrespectful.**

The other things that respondents disliked about the name were the same as for Disability Assistance for Children and Young People and Disability Assistance for Working Age People.



Most respondents thought the name is **too long.** They described it as **'clunky,' 'wordy'** and **'cumbersome'.**

Similarly, a small number of respondents said that it is not clear that the **'assistance'** is a financial payment.

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

"Doesn't sound like a regular payment."

"Sounds discriminatory - disability and older."

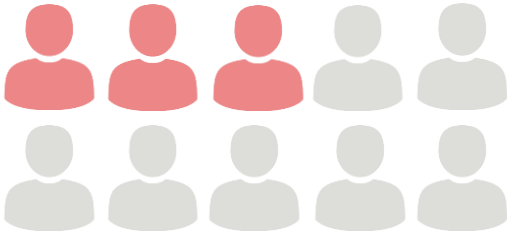
"Older People is pretty vague and many people have differing thoughts on what constitutes an older person."

"These new terms are too long and verbose and can't be easily turned into an acronym."

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%).

Around two thirds of respondents would prefer something else (67%).

Of those who would prefer something else, one in five (**20%**) **said it should stay being called Attendance Allowance**. This accounted for 11% of all responses.



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

- Disability Assistance for Pensioners
- Disability Assistance for People Over 65
- Care Assistance for over 65s
- Senior Assistance
- Disability Allowance for Older People
- Senior Disability Assistance
- Disability Assistance
- Disability Assistance (Older People)
- Home Carer and Enhanced Payment for Elderly
- Ability Support
- Care and Mobility Assistance
- Illness Assistance
- Disabled Older Citizen's Payment
- Support Allowance
- Disability Payment
- Senior ScotPIP

Words Social Security Scotland should use



We asked respondents if there are any words Social Security Scotland should definitely use when naming a benefit.



Respondents said benefit names and words should be **short, simple and concise**. They should be **descriptive** and **reflect their purpose**.

“Simple, matches reality of the payment.”

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



Respondents said that Social Security Scotland should also use **positive, neutral, inclusive and empowering language**. Some highlighted words such as ‘**assistance**’, ‘**payment**’ and ‘**support**.’

“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’”

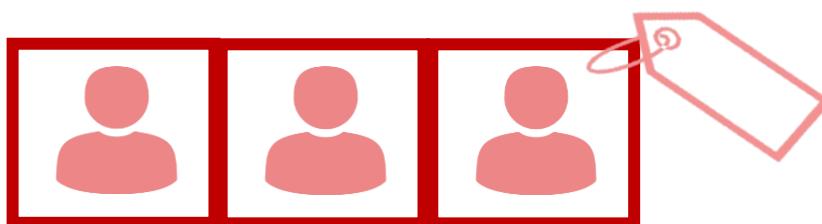
Respondents said words such as these highlight that people are entitled to the assistance, and it is supposed to give them ‘**autonomy**’ and ‘**independence**.’

Words Social Security Scotland should avoid



We also asked respondents if there are any words that Social Security Scotland should avoid using when naming a benefit.

Respondents said that Social Security Scotland should **avoid stigmatizing** and **discriminatory** terms which **label** and **segregate** those in receipt of it.



Respondents highlighted words such as **'disabled'**, **'disability'**, **'benefit'** and **'allowance'**.

“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.”

“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.”



Respondents also said that **ambiguous words should be avoided**. These can be confusing and cause barriers to eligible people applying.

Other name changes – Decision Makers

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

In 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 and disliked about the name decision makers.



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



Some respondents said the name accurately **describes their role** and **sets them apart from other staff**.

“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.”



The most common thing respondents said they disliked about the name decision makers was that it felt **‘authoritarian’, ‘impersonal’** and **‘judgmental’**.



Many respondents said the name suggests an **imbalance of power**, where the **client has little control**.



Respondents also said the name suggests that the decision made by decision makers is **final** and there is **no room for compromise**.



Some respondents said that the name brought up **memories of negative experiences** and interactions with decision makers.

“As a title it’s not the kindest, it suggests 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.”

“It sounds like you have no control.”

“It sounds cold and unapproachable.”

“Not very user friendly. Sounds like there’s no room for movement, negotiation, compromise.”

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

Case Managers

We told respondents 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 and disliked about the name case managers.



The most common theme was for respondents to simply say that they **preferred** case managers to decision makers.



Many respondents described the name as feeling **more personal** and **supportive**. They felt it suggests **less of a power imbalance** between the client and the case manager.

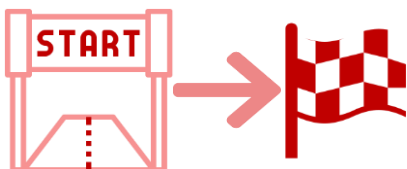
“This indicates a more personal service like having a key worker who individuals could contact directly about their case.”

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

“It’s a big improvement on decision makers. Case managers makes it sound more of a collaborative process.”

“It’s a lot nicer and makes it sound like they are being more considerate with decisions.”

“It makes it more personal, sounding like one person is taking ownership for decisions made.”



Some respondents also said that the name hints that the case manager would be responsible for an client’s case from start to finish. They thought they would be very **familiar** with each case and act as a **single point of contact** for clients.



The most common thing respondents said they disliked about the name case managers was that it seems to **reduce individual people to 'cases' who need to be 'managed.'**

Some respondents said the name is **vague**.

“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’s very vague, what does a case manager actually do?”

“Too reminiscent of social workers.”

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

“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**, 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 process and act as a single point of contact for clients.

Specialist Advisors

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'.



We asked respondents what they liked and disliked about the name specialist advisors.



The most common thing respondents said they liked about the name specialist advisors was the word '**specialist**'. Respondents felt it shows that a **qualified** person with **specialist knowledge and expertise** will be advising on decisions.

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

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

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

"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."

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



The most common thing respondents said they disliked about the name specialist advisors was that it 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 experience are.



Respondents assumed that specialist advisors would be health professionals with a medical background. Some felt that **medical titles should then be used** in the name.

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

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

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

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

Professional Advisors

Finally, respondents were told that an alternative to 'specialist advisors' is 'professional advisors'. We asked respondents what they liked and disliked about the name professional advisors.

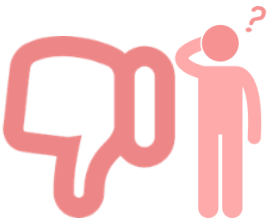


The most common theme was for respondents to say that the name professional advisors is **'fine.'** A few said that they **prefer it** to specialist advisors but did not say why.



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

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



The most common thing respondents said they disliked about the name professional advisors was that it is **broad** and **vague.**

"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."



Many respondents said the word '**professional**' does not necessarily show expertise, qualifications or specialist knowledge in health conditions.



Some felt 'professional' **describes a personal quality or behaviour** rather than a **job role**.



Some respondents said that they **expect all Social Security Scotland staff to be professional**. There is no need to set apart only these advisors as being professional.

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

“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 said professional advisors sounds '**formal**' and '**corporate**.'

“Bureaucratic. Managerial. Cold.”

What's Next?

The Scottish Government will use these findings 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.



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