



Consultation Response

Social Security – A Consultation on Disability Assistance in Scotland

The Scottish Commission for
Learning Disability

May 2019



The Scottish Commission for Learning Disability (SCLD) welcomes the opportunity to respond to this important consultation. SCLD is an independent charitable organisation and strategic partner to the Scottish Government in the delivery of Scotland's learning disability strategy, The keys to life (2013)¹ and The keys to life Implementation Framework (2019-2021)². The implementation framework defines a learning disability as follows:

"A learning disability is significant and lifelong. It starts before adulthood and affects a person's development. This means that a person with a learning disability will be likely to need help to understand information, learn skills and live a fulfilling life. Some people with learning disabilities will also have healthcare needs and require support to communicate."

(The keys to life, 2019-2021, p.9)

SCLD is committed to finding new and better ways to improve the lives of people with learning disabilities and is focused on sharing innovation and good practice so that those providing services and interventions can learn from each other. SCLD also aims to be a knowledge hub and to build an evidence base, sharing how policy is being implemented and building on an understanding of what really works.

This response has been written with a focus on the Keys to Life implementation framework. To inform the response SCLD held a consultation event in Glasgow in May 2019 to hear the views of people with learning disabilities and those who support them. We also held a focus group with young people at an Additional Support Needs School in Falkirk. Our response has also been informed by engagement with third sector colleagues and SCLD's participation in the Disability and Carers Benefits Expert Advisory Group Assessment Workstream.

¹ [The keys to life \(2013\)](#)

² [The keys to life \(2019-2021\)](#)

Disability Assistance for Children and Young People

Question 1. Do you agree or disagree with the proposal to name Disability Assistance for clients aged 0-18 years old Disability Assistance for Children and Young People (DACYP).

Disagree

Question 2. If you disagreed, please could you explain why

SCLD believes the name Disability Assistance is too deficit focused and reinforces a medical model of disability. While Disability Living Allowance (DLA) focussed on an individual's impairment and the care and mobility needs arising from it, Personal Independence Payment (PIP) aimed to establish functional ability in order to assess a person's level of independence rather than whether they have a condition or not.³ In our view, the language used by the Scottish Government should provide a stronger narrative on the purpose of the new Disability Assistance and its potential to support people to overcome structural barriers and challenge negative societal perceptions of disability.

At our consultation event, people described the negative and often stigmatising language used by the current system and in wider public discourse. We believe, there is potential to communicate a much more positive message around social security as an entitlement. This could help to reduce the stigma attached to claiming disability benefits and increase public understanding around their purpose and value.

³ [Claimant experience of the Personal Independence Payment process \(2018\)](#)

We would urge the Scottish Government to use more empowering rights-based language to describe the new payments. One suggestion is: 'Independence and Equality Payment for Children and Young People'.

Disability Assistance for Working Age People

Question 3. Do you agree or disagree with proposal to name Disability Assistance for clients aged 16 years old to state pension age Disability Assistance for Working-Age People (DAWAP)?

Disagree

Question 4. If you disagreed, please could you explain why

In addition to our answer to Question 2, SCLD has concerns around the use of the term 'working-age people'. There is a risk that this name implies a link between someone's employment status and their entitlement to disability payments. At our engagement event for this consultation people did not always make a distinction between current employment related benefits such as Employment Support Allowance (ESA) and disability benefits such as DLA and PIP. Additionally, the second independent review of PIP⁴ stressed that "Claimants must have absolute confidence that being in employment does not, in any way, disadvantage them". It is critical that people with learning disabilities are neither discouraged from applying for disability payments nor disincentivised from employment.

We would urge the Scottish Government to remove the term 'working-age people'. We suggest: 'Independence and Equality Payment'.

Disability Assistance for Older People

⁴ [The Second Independent Review of the Personal Independence Payment Assessment \(May 2017\)](#)

Question 5. Do you agree or disagree with proposal to name Disability Assistance for clients who are state pension age or older Disability Assistance for Older People (DAOP).

Disagree.

Question 6. If you disagreed, please could you explain why

Please refer our answer to Question 2.

We would urge the Scottish Government to use more empowering rights-based language to describe the new payments. For example: 'Independence and Equality Payment for Older People'.

Applying for the Benefit

Question 7. Do you agree with the proposal to enable multiple application channels for Disability Assistance?

Agree.

We welcome the Scottish Government's proposal to enable multiple application channels for Disability Assistance. If the new Social Security System is to be person centred for people with learning disabilities it is essential that the application process is genuinely accessible and inclusive. There should also be clear, transparent and accessible guidance on making an application.

Applying by form

At our engagement events, people with learning disabilities raised a number of concerns about the lack of accessibility and suitability of current exclusively paper based application process. For example:

- Forms are too complicated
- Forms are too long and repetitive

- The same information is requested more than once
- Forms ask insensitive questions

People with learning disabilities told us they wanted the new application form to be more straightforward, easier to understand and more personable.

Examples given at our consultation event included:

- Forms written in plain English with no jargon
- Easy read versions which are widely available and easily obtainable.
- Electronic and hard copies of the form
- Pictures and videos which explain what the application process looks like.
- YouTube video on the website telling applicants what to expect

Applying by phone

At our consultation event some people indicated that making an initial contact by phone would be preferable if they could do so with support. A number of points were made in terms of accessibility:

- It should be a free phone number
- Having direct contact with a person is important.
- Automatic systems which require people to press numbers / be on hold can be confusing and stressful

Making an application in person

For some people with a learning disability making an application in person would be preferable to doing so by form (either written or electronic) or by phone. At our consultation event people described a number of factors that would help this to be an accessible process for them. These included:

- Welcoming and friendly environments
- Staff with experience of working with people with learning disabilities
- Fully accessible buildings and locations

- Appropriate private meeting spaces

For many people with a learning disability, having support to make a claim will be critical to an accessible and inclusive application process. At our consultation event one respondent said it was important to have – *“someone to speak up for you”* another said this should be *“someone who knows me and has supported me well”* and *“someone who wants to take the time to do it”* (Consultation Respondent; 2019)

However, not everyone with a learning disability will have access to the support they feel they need. Therefore, robust signposting to advocacy and support services will be required to help people with learning disabilities give a thorough account of their learning disability and its impact. It is essential that the agency provides people with accessible information and advice on their right to independent advocacy under the Social Security Act.

Making Decisions about Entitlement

Question 11. Do you agree or disagree with the proposal to implement a person-centred approach to making decisions about entitlement for Disability Assistance?

Agree

SCLD agrees that being person-centred is an important principle in the decision making process for disability assistance. It is also important that decision makers take a rights-based approach to social security in line with the principle set out in the Social Security Act. To ensure clarity and consistency of decision making the criteria against which people are assessed must be set out in the regulations.

At our engagement events people with learning disabilities highlighted the importance of decision makers understanding their learning disability and being open minded and non-judgemental. The recruitment, training and continuous

professional development of case managers, specialist advisors and assessors will be key to their having the necessary skills, qualities and information to make person-centred decisions.

SCLD believes that the criteria and recruitment for these roles should place emphasis on strong inter-personal and good communication skills and staff should demonstrate a commitment to equalities and human rights as well as impartial and fair decision-making. The application of these skills in practice should be reviewed with regular supervision. Case managers should also receive training in learning disability awareness. This training should be co-produced and delivered by people with lived experience of learning disability.

In order to make genuinely person centred decisions a more holistic approach to obtaining information from the applicant is required. The application process should focus on collecting a full account of the person's circumstances in a way that is accessible and as easy for the applicant as possible. At our consultation event a common theme was being able to more fully describe personal experience. People said the process should:

- Build a picture of the whole person e.g. include a personal profile section; provide an opportunity to describe what their worst days look like.
- Be less deficit-focussed e.g. establish what people can do as well as what they need support with
- Be less stressful e.g. offer the option for home assessments
- Be more nuanced e.g. have a less rigid scoring system, more emphasis on non-physical disabilities, consider the experience of stigma and discrimination.

Question 13. Do you agree or disagree with our proposed approach to the involvement of Specialist Advisors in Decision Making?

Agree

We believe a Specialist Advisor can support nuanced and robust decision making by advising the Case Manager on specific points, helping to review the application or suggesting what further supporting information should be obtained. In this way, we think the role of Specialist Advisor can help to ensure that fewer face to face assessments are necessary. It is important that Specialist Advisors are accountable and transparent and that case managers have clear guidance and criteria on the role of a specialist advisor and when their input may be required.

SCLD would urge the Scottish Government to extend the criteria beyond medical professionals (doctors, nurses, occupational therapists, physiotherapists and paramedics) to include professionals with equivalent experience in social work, social care and the third sector and people with lived experience. It is our view that those with professional and lived experience of learning disability will be often be best placed to advise and assess the impact of learning disability in day to day life.

Question 15. What factors should Case Managers take into account in deciding when a Specialist Advisor should be involved?

We think a Case Manger should consider involving a Specialist Advisor when an individual is identified as living with a complex disability or condition, has more than one disability or condition or lives with a fluctuating condition. They may also wish to involve a Specialist Advisor where there is uncertainty on where to obtaining further evidence to support a claim.

Question 16. Do you agree or disagree that the decision making process for Disability Assistance for Children and Young People, and for Older People should use existing supporting information and not through face-to-to face assessments?

Agree

We agree that the decision making process for Disability Assistance for Children and Young People, and for Older People should use existing supporting information rather than face-to-face assessments.

In our engagement to inform SCLD's response to the 2016 Scottish Government consultation on Social Security⁵ people with learning disabilities frequently described face-to-face assessments as a difficult and negative experience.

Criticisms included:

- The period leading up to an assessment is stressful and nerve racking.
- Assessments can be traumatic and emotionally and physically draining.
- Assessments feel impersonal and can be embarrassing and humiliating.

People with learning disabilities may also struggle to articulate their difficulties clearly and effectively in an interview situation, and may also underplay their difficulties or not fully understand the questions.

Question 18. What types of supporting information would be relevant in assessing an application for Disability Assistance e.g. Social work report, medical report.

The Scottish Government's intention to significantly reduce the number of face-to-face assessments will necessitate an increased focus on obtaining the information required to determine eligibility earlier in the application process. We believe the application form should be the core piece of evidence including information from the claimant and their family and carers and supported by evidence from other third parties if necessary. In accordance with the principles of the Social Security

⁵ <https://www.sclد.org.uk/wp-content/uploads/2016/08/SCLDs-Response-to-the-Scottish-Governments-Consultation-on-Social-Security-in-Scotland.pdf>

System we believe that the starting point of the assessment process should be to presume credibility of the individual's account and build upwards in a way that supports not questions their information. It is our view that in many cases an individual's account of the impact of their learning disability on their day-to-day life should be sufficient to make an accurate and robust decision.

People at our consultation events suggested that supporting information could be provided by health and social care professionals and also come from family members. People said that it was important that they gave their permission for their personal information to be shared. They were also concerned that only information relevant to their application should be shared with the Agency. A wide range of potential sources of supporting information were identified:

- GPs
- Hospital doctors
- Specialists
- Learning disability nurses
- CPNs
- Family members
- Carers
- Social workers/social work reports
- Support workers
- Counsellors
- Third sector support organisations
- Evidence from previous applications
- Prescriptions
- Care plans
- Outcome based support plans.
- Employability advisors
- Careers advisors
- Youth workers

- Teachers

SCLD agrees that responsibility for gathering supporting information should lie primarily with the Agency. This will require a more joined up system to enable Case Managers to obtain supporting information from relevant professionals and organisation with permission from the claimant. Individuals should also be able to identify and provide sources of supporting information at the point of application if they wish. We would like to see clear, transparent and accessible guidance to help people with learning disabilities and those supporting them understand what information will be helpful in supporting an application.

While some supporting evidence will have greater impact in terms of content, no single source should be assumed to have intrinsically greater value than any other. Carers, friends and family may be in a better position than many professionals to explain the way someone's learning disability impacts their day-to-day life. The Agency should consider how best to collect this supporting information e.g. written testimonies, audio or visual recordings or by completing care diaries. There should be clear guidance to reflect the importance and value of family member and carer evidence.

Question 19. Do you agree with the proposal to have no set award durations but to set an award review date when a decision on a Disability Assistance application is made?

We welcome the proposal to have a review point rather than a set end point and for payments to continue during the review period. Under the current DWP system, individuals are required to undergo a re-assessment process at the end of their award period and people at our engagement event told us this can be a stressful and anxiety inducing process.

In order to be genuinely person centred, we believe that award duration should recognise that needs can increase and decrease overtime as circumstances change.

While a learning disability is life long, this does not mean that the level of care and mobility support someone requires will not change over time. We agree with the recommendation of the Disability and Carers Benefits Advisory Group that review periods should be “as long as possible and not as short as possible” with no minimum review period.⁶ Clear guidance should be issued to case managers on setting appropriate review dates.

We welcome the proposal to introduce light touch reviews which are supportive, person-centred and minimise stress and anxiety. However, we would like to see more detail on what these will operate in practice and suggest that the Scottish Government engages with people with learning disabilities and other stakeholders to develop this.

Question 21. Do you agree or disagree with the proposal to set an award review date 5-10 years in the future for a person with a condition unlikely to change.

We agree there is a need to introduce longer-term disability awards to reduce the number of unnecessary re-views. These can be particularly distressing and frustrating for people with PMLD and their families. An award review date between five and ten years from the initial date of award is a welcome advance from the existing one, two or three year awards. It will be important that Case Managers are given clear guidance and training on establishing appropriate award lengths.

Question 25. Do you agree or disagree with the proposal that clients have 31 days to request a redetermination?

Disagree

Question 26. If you disagreed, please could you explain why

⁶ [Disability and Carers Experts Advisory Group Workstream – Advice on Duration of Awards \(2018\)](#)

People with learning disabilities may require additional time to seek advice or support about the meaning of a decision and whether they should request a redetermination. The timescale allowed for reconsidering a redetermination should allow sufficient time for this.

Question 27: We have proposed that social security Scotland have a period of between 40 to 60 days to consider a redetermination of Disability Assistance? Do you agree or disagree with this proposal?

Disagree

Question 28: If you disagree, please explain why

SCLD disagrees with the proposal of 40 to 60 days between a mandatory redetermination of Disability Assistance. SCLD believes the suggested period is too long and will place significant financial pressures on people with learning disabilities, who are already at risk of financial exclusion. Figures from SCLD's Learning Disabilities Statistics Scotland (2017) found that of 12,369 adults with learning disabilities, 53.3% lived in the 40% most deprived areas in Scotland⁷.

SCLD believes the proposed 40 to 60-day decision-making process will add additional stress to people with learning disabilities who may already find the process of applying for disability benefits a challenging and worrying experience. At SCLD's consultation event, respondents were clear that the process of applying for disability assistance "*... should not be stressful*". One respondent commented that due to their disability, they experienced additional challenges and that having a system which placed additional stress on them was '*awful*'. Young people we engaged with at an Additional Support Needs school said that that they thought going through the process of accessing disability payments could be difficult and

⁷ Learning Disability Statistics Scotland (2017)

inflexible. It is of note that this school was in a local authority with 24 data zones in the 15% most deprived in Scotland.

SCLD is also aware of difficulties and challenges waiting for an existing mandatory reconsideration has caused people with disabilities when challenging a decision. The Early Warning System report which published findings between 2014 and 2015 stated that the mandatory reconsideration process was found to create confusion among those claiming Employment Support Allowance. The report noted that this often led to a reconsideration process that lasted 3 months. In one reported case this resulted in one claimant having to pawn most of their possessions⁸.

These findings are supported by UK wide data from the Trussell Trust, which highlighted that 20.34% of those who accessed their service did so because of delays in accessing social security payments/ benefits⁹. In addition, figures from Citizens Advice Bureaux Scotland show that 43% of its caseload relates to social security/benefits. Significantly, over half of the 261,900 individuals who accessed its services identified as having a disability¹⁰.

While SCLD acknowledges the rates of gaining an award following a mandatory reconsideration of PIP¹¹, SCLD emphasises the importance of ensuring the correct decision is made for the individual in the first instance. The value of ensuring correct first-time decision making cannot be underestimated. One person at SCLD's consultation event compared the current system of applying for social security to that of *"...being treated like a criminal"*. Another person who attended the consultation process said that a negative aspect of the existing system was the:

"Repetitive process of assessment, cancelled benefit, appeal, success than a few months later all of those things are repeated".

⁸ [Early Warning System \(2014-2015\)](#)

⁹ [Trussell Trust \(2017-2018\)](#)

¹⁰ [Citizens Advice Bureaux](#)

¹¹ [Average of 19% to 22.2% rates of success in mandatory reconsideration of PIP award decision in May 2017](#)

(Consultation Respondent; 2019)

Given the difficulties the current system causes those who access it, SCLD stresses that it is critical the mandatory re-determination process should not become default practice or another hurdle in the *'fight'* to access an individual's entitlements, which mandatory reconsiderations have become in the current DWP system.

While SCLD supports a focus on ensuring the correct decision for the individual is first made, SCLD recognises there may be circumstances in which a mandatory re-determination will be required. SCLD would like to see a mandatory re-determination process which kept determination timescales as brief as possible. SCLD, therefore, suggests a 25 day re-determination process as opposed to a 40-60 day period suggested in this consultation document. However, SCLD is clear this support is dependent on the above and on a seamless transfer to Short-Term Assistance (STA). This is further addressed below.

Ensuring Seamless and Effective Short Term Assistance

SCLD supports the policy intention behind STA and welcomes a commitment to *"...ensure an individual is not discouraged from challenging that decision or from accessing administrative justice by having to manage, for a period, with a reduced income."*

(Scottish Government; 2019, p.31).

However, SCLD believes that further consideration needs to be given to how this policy intention becomes a reality. Previously, similar systems of hardship payments which are available following a DWP Sanction on Job Seekers Allowance have not been claimed due to a lack of awareness about the availability. This was evidenced by Barnardo's and Citizens Advice Bureaux in The Scottish Parliament Welfare Reform Committee Report (2014)¹².

¹² [Scottish Parliament \(2014\)](#)

SCLD believes that further consideration will need to be given to ensuring that people with learning disabilities are able to access STA payments and to ensure their equitable access to justice. In particular, SCLD believes the following will need to be actioned:

- Accessible information about STA payments, including but not limited to Easy Read, videos, BSL and pictorial information
- Active promotion of STA by Scottish Social Security Agency staff
- Immediate access to STA following a mandatory redetermination. These payments should be activated by the Scottish Social Security Agency and the onus should not be on the individual to ensure this
- Timely first payments of STA which is in line with expected payment dates of disability assistance.

The above is supported by comments from SCLD's consultation participants who highlighted the importance of creating a system which, *"gives people more of a chance"* (Consultation Respondent, 2019).

For consultation participants, giving people a chance means ensuring the support that is active. For example accessible information widely available and not only available following a specific request.

To ensure this, consideration must be given with regard to the following statement in the consultation document:

"In line with a rights-based approach, the Scottish Government believes that a person should have the right to choose whether they want STA, but that its availability will be as seamless as possible without the need to complete complicated forms."

(Scottish Government, 2019)

SCLD understands that the Scottish Government desire to maximise individual choice. However, there is a risk here of creating barriers to individuals accessing

their entitlements to financial assistance. SCLD recommends that anyone facing a mandatory redetermination should automatically be placed on the appropriate level of STA. Individuals should then be offered the opportunity to opt out if they choose.

SCLD believes this will reduce the administrative burden on the Social Security Agency and what consultation respondents referred to as the *'frustrating'* process of having to tell your story and answer the same questions *'over and over again'*. Crucially, this approach has the potential to reduce the likelihood of individuals reaching a financial crisis.

In establishing an opt-out system to STA, the Scottish Social Security Agency should work with caution to ensure that an opt-out STA system does not cause claimants to incur overpayments which may lead to deductions at a later date.

Time Scales for STA

Question 37: Do you agree or disagree that for successful process decision appeals where the tribunal has overturned Social Security Scotland's decision STA should become available at the point the decision is overturned rather than the date of the original request?

Disagree

Question 38: If you disagreed, please could you explain why?

SCLD disagrees with the proposal that STA is paid from the date a tribunal overturns a decision. SCLD believes this mirrors the existing system, which SCLD consultation respondents told us they felt was *"...designed to make you fail"* (Consultation Respondent; 2019).

SCLD also questions what circumstances would be deemed *'not valid'* for a late request of a redetermination. This is particularly concerning for people with learning disabilities, who could in some circumstances have to access support to place a redetermination request and may have to wait for help from a family member, friend or support agency to help them do this or who may not be aware of the need to make a redetermination if this information has not been communicated effectively.

In addition to this, limited uptake in mandatory reconsiderations has been attributed to a lack of belief in the current system. Evidence from the DWP highlighted that half of the individuals surveyed (3,514 surveyed) did not request information about a mandatory reconsideration following no award of PIP. The report goes on to state that:

“The qualitative research revealed that claimants were sometimes reluctant to contact the DWP for advice or further information after receiving their decision letter, due to concerns that it would not be impartial.”

(DWP; 2018)¹³

This lack of faith in the system may be an additional reason for late mandatory reconsideration being made. SCLD welcomes an approach which pays STA from the date a reconsideration is made, irrespective of whether or not this reconsideration is considered valid or is late. SCLD believes this approach will reduce the experience and feelings of negativity associated with *'fighting'* for your entitlements. This negative experience is best summarised by one experience panel member who said:

“Then there is an extremely long wait for a decision, and when you read it you feel as if they haven't listened to a word you said! Then another wait for an appeal

¹³ [DWP \(2018\)](#)

process. Very disheartening, and depressing. Making you feel worthless and that you are actually begging for something you are entitled to.”

(Scottish Government; 2018, p.39)¹⁴

Deductions and Overpayments

Question 35: Do you agree or disagree that any deductions being made from on-going assistance type to service an overpayment liability should also be applied to STA?

Question 36: If you disagreed, please could you explain why?

Question 41: Please outline any comments or experience you would like to share with us about overpayment recovery and the current DWP approach to deductions?

Please see responses to questions 35, 36 and 41 below:

With regard to servicing an overpayment liability (Question 35/36), SCLD supports pre-existing deductions being made to STA. SCLD believes this will avoid further confusion. However, with regard to Question 41, SCLD believes that overpayments and deductions are mostly avoidable and that the new Scottish Social Security system should make all efforts to ensure this practice is not carried over from the existing DWP process.

The negative impact of overpayments was well documented in ‘Social Security Experience Panels: Overpayments Survey Findings’ (2018). The stated that of 141 experience panel members surveyed: 83% identified as disabled, 69% had claimed

¹⁴ [Scottish Government \(2018\)](#)

PIP and 66% had claimed DLA. Moreover, 56% of those surveyed had experience of overpayments, of this group 62% rated the experience as 'very poor'.

Qualitative findings from the same report highlighted the issues individuals surveyed experienced with overpayments, this included:

- Accidentally spending the overpayment
- Challenges in arranging to pay back the cost owed at a minimum rate
- Having to call a paid for phone number to arrange repayment.

One particular participant commented on the negative impact the experience had on their mental health. They said,

"I experienced increased mental health problems due to the way I was being dealt with i.e. refused to be listed to...and treated as if I was totally wrong."

(Scottish Government, 2019)

This was echoed by the people with learning disabilities and those who support them who took part in SCLD consultation events and focus groups. One person told us that the current system feels like 'entrapment'. Another person said that while mistakes happen in the system, it is often the individual who gets blamed. SCLD believes this last point is pertinent when it comes to overpayments and deductions. The system makes the error (the overpayment) and it is the individual who has to arrange the repayment, potentially after the money has already been spent.

For people with learning disabilities who may struggle with money management, an overpayment could become very challenging. The potential difficulties may be intensified if an individual is experiencing an alcohol, drugs or gambling addiction. A

study from Canada by Parker et al (2012)¹⁵ suggested that adolescents with *'learning disorders'* were at increased risk of compulsive gambling.

Consideration should also be given the fact that people with learning disabilities may be at increased risk of financial exploitation from trusted individuals in their lives. Research from Gravell (2011)¹⁶ highlighted examples of people with learning disabilities experiencing financial exploitation in their community.

Taking into account the stressful process of repaying overpayments and the wider circumstances and risk of financial exploitation which can surround people with learning disabilities, SCLD would urge the Scottish Government to ensure accidental overpayments are kept to a minimum. Where overpayments do occur, it is important that the responsibility for reclaiming these payments sits with the social security agency and does not become an additional challenge for the individual.

Breaks in Disability Assistance

Question 39. Do you agree or disagree with the proposed approach that, generally, where there is a break in a client's eligibility to receive the benefit e.g. Due to being in residential care, they will cease to receive the benefit?

Disagree

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

SCLD disagrees with the proposed approach regarding breaks in Disability Assistance. SCLD believes that what has been outlined goes against one of the key themes which emerged from our consultation event. This was that one size of social

¹⁵ [Parker et al \(2012\)](#)

¹⁶ [Gravell \(2011\)](#)

security system does not fit all. This approach, therefore, goes against the person-centred policy intention of a new social security system.

SCLD acknowledges there will be circumstances in which residential services, hospitals or prisons will begin to meet the additional costs related to a disability. Where these needs are being appropriately met, SCLD sees no issue with the pausing of entitlement after a 28 day period. However, SCLD would not support the proposed stopping of an entitlement.

For SCLD, it is critical that when a person with a learning disability leaves a residential setting, hospital or prison that their Disability Assistance Payments are immediately available. Individuals should not have to re-apply and wait for a payment to be made as this could put them at risk of experiencing a financial crisis. SCLD is aware of cases in which individuals with long term ill health could leave hospital following an extended period of time, without access to their disability payments.

Moreover, SCLD is aware of the real challenges faced by individuals leaving prison. Research from Citizen Advice Bureaux in England in 2007 highlighted delays in processing payments being a potential contributory factor in reoffending.

SCLD would, therefore, welcome consideration being given to the effective reinstatement of Disability Assistance payments before a person leaves a residential setting, hospital or prison. This should be planned and should coincide with a person re-entering their community. By pausing payments, instead of stopping them the administrative burden of the individual, welfare rights officers and social security agency will be reduced. Instead, payments can be reinstated in a timely manner, and reduce the risk if individuals experiencing financial crisis.

Section 2 – Disability Assistance for Children and Young People (DACYP)

Entitlement to DACYP

Question 42. Do you agree or disagree with our proposal to provide entitlement to Disability Assistance for Children and Young People to clients aged 0-18 years?

Agree

Young People Aged 16-18

Question 44. Do you agree or disagree with our proposal to extending eligibility, for those in receipt of Disability Assistance for Children and Young People before the age 16, to age 18?

We support the proposal to extend eligibility for those in receipt of DACYP from the age of 16 to 18. This period is commonly a period of significant change for young people with learning disabilities. They are likely to transition from child/school to adult services, assume greater autonomy in many different areas of their lives and adjust to new experiences, expectations, processes, places and routines.¹⁷ These transitions can present particular challenges for young people with learning disabilities. Extending eligibility to 18 can support a smoother move between entitlements and help ensure that the negative impacts of existing transition points are not exacerbated by social security eligibility face to face assessments.

For new applicants aged 16 we support the proposal not to open eligibility for DACYP due to the likely disruption involved with individuals then being required to apply for a working age benefit when they turn 18. We therefore support intention that brand new Disability Assistance applicants aged 16 or over will apply for working age Disability Assistance.

¹⁷ [Facing the Future Together - ARC Scotland \(2017\)](#)

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

Agree.

Disability Assistance for Working Age People (DWAP)

Question 50. Do you agree or disagree with our proposal to use a points based system to assess eligibility in relation to Disability Assistance for Working-Age People?

We understand the imperative for the Scottish Government to secure a safe and secure transition of social security payments in Scotland and the intention to retain a points-based system during this period. However, in the longer term we would welcome a wider debate on the alternative approaches to a points based system for determining eligibility criteria for disability assistance. We believe there may be potential to introduce more flexible eligibility criteria that are better aligned with a person-centred and rights-based approach to social security.

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

In order to assess mobility appropriately, case managers and assessors must have a sophisticated understanding the importance of the support an individual receives to aid their mobility and the barriers they will face without this. This is essential to an approach which supports the social and human rights and promotes independent living.

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

At our consultation events respondents felt that the current PIP descriptors were overly focussed on a person's physical disabilities and may not adequately capture the impact of learning disability on day-to-day life. They also stressed that key words need to be clearly described to enable people to provide the correct information.

Respondents at our consultation event made the following suggestions:

Preparing Food

- Descriptors need to take account of support required in planning meals.
- Descriptors needs to be more specific about what meals a person can prepare.

Washing and bathing

- Descriptors need to take account of not only the physical task but also the ability to do this safely.

Dressing and undressing

- Descriptors need to take account of whether person can dress themselves appropriately.

Communicating verbally

- Descriptors need to take account of whether a person finds it difficult to communicate with friends and family.

Planning and following journeys

- Descriptors need to take account of the support that is required to establish an independent journey and the knowledge of this routine.
- Descriptors need to take account of whether the person is able to deal with disruptions to journey.

Moving around

- Descriptors need to take account of whether someone can go out independently and safely.

On 'Managing therapy or monitoring a health condition' one support worker described two people with similar levels of support and care needs but who had different PIP scores because one of them was not required to take any medication.

Respondents also suggested a number of additional factors that could be considered as part of the descriptors currently used to assess claims for Personal Independence Payments:

- Understanding written information
- Being able to tell the time
- Time management
- Memory
- Stress/anxiety levels

In the longer term, SCLD believes there is an opportunity to take a more progressive rights-based approach which is less deficit-focused and takes greater accounts of the social and other structural barriers which infringe people's right to independent living. This would align better with the Scottish Government's wider policy agenda which promotes asset-based approaches to supporting people.

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

We believe all observations made during face-to-face assessments should be governed by a set of core principles to ensure that individuals are treated in line with the values of the Social Security Agency and its obligations. This requires observations made during the assessment to be discussed with the individual and become part of the formal discussion and record of the decision made about an

individual's eligibility. Individuals should also have the right to respond to informal observations at the time they are made.

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

A tailored approach should be taken which takes account of an individual's barriers and experiences. What is an acceptable distance for one person may not be acceptable for another. This will depend on a range of factors including geography and the availability of local public transport which is accessible, whatever someone's condition. The length of journey as well as distance should also be taken into account.

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

The accessibility of the travel routes to local delivery offices or assessment centres and of the buildings themselves will also be a determining factor in whether an individual will be able to attend a face to face assessment.

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

We think the system must be flexible and apply rules which recognise that assessments can cause stress and anxiety for people that may impact their ability to attend. It should also recognise that people may be unable to attend a particular appointment due to transport costs or a lack of support.

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

We think that where an individual fails to attend an appointment, the agency should establish if they are willing to attend an assessment, and a new appointment should be arranged. The Social Security Act gives the powers to make a 'negative determination' of someone's entitlement if they fail to attend a face-to-face assessment. In our view, making a negative determination of an individual's entitlement solely because they have failed to attend an assessment does not accord with the principles of the Social Security Agency. Where an individual is unable to attend an assessment the agency should make every effort to obtain the necessary information by different means. Where someone refuses to attend an assessment a decision should be made based on the information that the agency already holds.

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

We believe that individuals should always have a right to choose whether or not to have the assessment recorded. To inform this choice, there must be clear and accessible information explaining the purpose of recording the assessment. At our consultation event it was suggested that copies of the recording should be made available to applicants on request.

Decision makers should be given training to ensure they understand the limitation of an audio-recording e.g. not capturing non-verbal communication. We believe there is potential to consider the viability of video recording of assessments in future. This is currently being piloted for PIP assessments across the UK¹⁸ and the

¹⁸ <https://www.disabilityrightsuk.org/news/2018/june/video-recording-be-standard-part-pip-assessment-process>

Scottish Government should monitor and respond to the results of this pilot accordingly.

Section 4 – Disability Assistance for Older People (DAOP)

Question 60. Do you agree with our proposal that Disability Assistance for Older People is provided to those who are state pension age or older?

Agree.

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

We are concerned that Disability Assistance for Older People does not contain a mobility element. For some people, the use of the mobility component is essential to realising independent living (e.g. shopping, visiting family or participating in social activities). The Scottish Government’s isolation and loneliness strategy¹⁹, states that: *“Accessible transport is vital to people being able to meet face-to-face and stay socially active, particularly for those in rural areas or later in life.”*

A large number of people who currently receive PIP or DLA are over the age of 65 and are eligible for both the care and mobility elements. We would like to see further clarity to reassure people over the age of 65 that their eligibility for this existing entitlement will continue in the transition to the new system.

¹⁹ <https://www.gov.scot/publications/connected-scotland-strategy-tackling-social-isolation-loneliness-building-stronger-social-connections/>

Question 64. If you have any further comments you would like to make relating to Disability Assistance benefits not covered by this consultation document, please provide them below.

Communication

In addition to multiple application channels, it is critical that Social Security Scotland also offer multiple communication channels in relation to Disability Assistance. At SCLD's consultation event the following points were made:

- It would be helpful receive a reminder a couple of days before an appointment. There should be a choice of a phone call, an email, or text.
- There should be more effective ways of information sharing for people who do not use verbal communication e.g. visual aids, emotion cards,

Young people at the Additional Support Needs School said that staff at the Scottish Social Security Agency should:

- Be good communicators.
- Use the language for the right person, for example Makaton or BSL.
- Use clear language and communications tools and cards.

Social Security Offices

At SCLD's consultation people said local offices and assessment sites should:

- Offer welcoming atmospheres
- Have friendly and patient front of house/reception staff.
- Staff should understand the needs of people with learning disabilities.
- Have clear signage and be easy to navigate
- Be placed in areas with good public transport links

Social Security Staff

At SCLD's consultation event people emphasised the personal qualities social security staff should possess and the importance of listening, being open minded, using appropriate language as well as positive body language and eye contact.

People also said that staff should:

- Have training in learning disability awareness delivered by people with learning disabilities and communication techniques.
- Have experience of working with people with learning difficulties or have a disability themselves.
- Be recruited with someone who has a learning disability on the panel.

Young people at the Additional Support Needs School thought the staff should be: friendly, respectful, kind, honest, positive and mature.

Home assessments

For some people the preferred option would be to have an assessment in a familiar environment. In our view a home assessment should be available if an applicant requests one and where supporting information indicates an individual may require one. We would like to see stronger guidance on this accompanied by consultation on the approach and proposed criteria.

Face to Face Assessments

The consultation document states that "The Agency may identify other circumstances" in which a face to face assessment is required. We believe this is far too broad and does not allow for consideration of the full criteria under which a face to face assessment may be required. We would like to see the clarified.

The skills required to carry out assessments should also be clearly and transparently outlined alongside what mandatory training assessors are required to undertake.

At our consultation event people said assessors should be understanding, non-judgemental, open and honest, allow dialogue, and have knowledge and proper

training. People also said they should have empathy, be friendly and keep good and accurate records.

Contact us

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