Scottish Commission on Social Security

Disability Assistance for Children and Young People - written submissions

Submissions have been received from the following organisations:

Citizen Advice Scotland

Child Poverty Action Group Scotland

Inclusion Scotland

Multiple Sclerosis Society Scotland

Scottish Campaign on Rights to Social Security (SCoRSS)

Scottish Association For Mental Health

Welfare Rights Officers Forum

Scotland, May 2019 https://www.cas.org.uk/publications/cas-response-consultation-disability-assistance-scotland

Submission 1 from Citizens Advice Scotland

Summary

Citizens Advice Scotland recommends the draft regulations are amended to change or clarify a number of areas to improve the social security support provided to disabled children and young people. In particular, we recommend:

- The statutory timescale for Social Security Scotland to make a re-determination should be reduced to no longer than 42 days.
- Existing case law from Disability Living Allowance should be incorporated in the regulations, to ensure no gaps in the law are created.
- The past presence requirements should be removed.
- The requirement for the needs of a child to be 'substantially in excess' of what is normally required of a child of the same age should be clarified further.
- Amendments should be made to ensure that children and young people who face barriers as a result of a mental health condition can qualify for disability assistance on a fair basis.
- If a person's claim is stopped due to entering a care home, provision should be made for their payment to be quickly restarted when they leave, rather than them having to re-apply.

Introduction to Citizens Advice Scotland and context of response

Scotland's Citizens Advice Network empowers people in every corner of Scotland through our local bureaux and national services by providing free, confidential, and independent advice. We use people's real life experiences to influence policy and drive positive change. We are on the side of people in Scotland who need help, and we change lives for the better.

Citizens Advice Scotland (CAS) welcomes the opportunity to provide comments on the draft regulations to the Commission. Advice on disability benefits are among the most common areas of advice provided by Scotland's citizens advice bureau (CAB) network. In 2018-19, Scottish CAB provided advice to clients on 6,065 issues related to the care component and 5,050 to the mobility component of Disability Living Allowance (DLA), which this new payment will replace for disabled people under the age of 18.

Many of the proposals in the draft regulations represent welcome improvements to Disability Living Allowance for children and young people, in particular in a number of changes to administer the benefit that treat people with dignity and respect.

The eligibility criteria in the draft regulations are largely copied verbatim from the existing legislation for Disability Living Allowance[1]. CAS recognises the need for a 'safe and secure transition' from existing disability benefits to a new devolved system

[1] Social Security Contributions and Benefits Act 1992 and The Social Security (Disability Living Allowance) Regulations 1991, as amended

Scotland, May 2019 https://www.cas.org.uk/publications/cas-response-consultation-disability-assistance-scotland

of assistance, and it is crucial that people do not experience a stoppage or delay to their payments as a result of the devolution process.

However, CAS also believes that a safe and secure transition should not be a barrier to more substantial improvements to disability benefits in the longer term. We encourage the Scottish Government to continue to develop proposals for longer-term changes to Disability Assistance alongside proposals for initial transition.[2]

In addition, we are concerned at the suggestion in the Scottish Government's response to the Disability Assistance consultation that "there is a risk that, should eligibility rules diverge significantly from current DWP rules, Disability Assistance may not continue to be recognised as 'like for like' for passporting purposes."[3] If eligibility criteria for devolved disability assistance must be the same as their reserved counterparts, it could severely restrict the Scottish Government's ability to improve weaknesses in the current rules, and design a suite of social security payments that enhance the rights of disabled people in Scotland. CAS would welcome clarification from the Scottish Government and DWP as to what extent policy variation is possible within these parameters.

Our comments below are structured under the headings in the draft regulations, in the order that they appear.

Interpretation

Names of benefits

The draft regulations refer to the payment throughout as 'Disability Assistance for Children and Young People' (aside from a provision in regulation 3 allowing it to have a different public-facing name, and to the benefit to replace PIP as 'DAWAP' (Disability Assistance for Working Age People). However, it is our understanding that, based on responses to the May 2019 consultation on Disability Assistance, that these names may be changed to more accessible names.

Whilst it is possible for benefits in the new Scottish social security system to have different public-facing names to their names in law (for instance Best Start Grant is referred to in law as Early Years Assistance), CAS would recommend that the public-facing names are used in the regulations to avoid confusion being caused.

Incorporation of case law

It is also unclear to what extent existing case law from Disability Living Allowance will be able to apply to disability assistance for children and young people. Many of the terms in the eligibility criteria and existing regulations have been given meaning by judgments of the Upper Tribunal and High Court.

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[2] Pages 54 – 55, Citizens Advice Scotland response to Consultation on Disability Assistance in Scotland, May 2019 https://www.cas.org.uk/publications/cas-response-consultation-disability-assistance-scotland

[3] Page 28, A Consultation on Disability Assistance in Scotland – Scottish Government response, October 2019, https://www.gov.scot/publications/consultation-disability-assistance-scotland-scottish-government-response/pages/1/

Scotland, May 2019: https://www.cas.org.uk/publications/cas-response-consultation-disability-assistance-scotland

For instance, case law has established that if a child's walking is impaired caused by anorexia nervosa, the cause is physical; that a child's discomfort from chronic diarrhoea might make them virtually unable to walk; and that the industrial injury provisions should be used to determine the degree of impairment for loss of vision or hearing.[4]

It is important that as part of a transition from the existing disability benefits to the Scottish system that individual rights are maintained and no unintentional gaps in the law are created. CAS would echo the Child Poverty Action Group in Scotland's recommendation that a comprehensive review of existing regulations, guidance and caselaw is undertaken to ensure that important detail and rights are not lost upon transition.[5]

This may require detail from existing case law to be written into the regulations, either as amendments to the eligibility criteria, as additions to the interpretations, or to specify that judgments of the Upper Tribunal and courts relating to the interpretation of DLA should be taken to apply to Disability Assistance for Children and Young People.

Residence and presence conditions

Past presence test

Whilst CAS is broadly content with the proposed approach to residency, we would recommend that the past presence test (regulation 4 (2)(c)) is removed, as it is an unnecessary barrier to people receiving social security support.

The past presence test requires a person to have been present in Great Britain for two out of the last three years to be eligible to claim PIP, DLA or Attendance Allowance, and is proposed to be replicated in the new system. However, CAS recommends that the requirement is removed.

The past presence condition is not currently included in any of the other benefits due to be devolved (with the exception of Carer's Allowance) and has not been proposed to be included in any of the Scottish social security payments introduced so far.

The condition can mean that disabled people who are in need of social security support, and who would otherwise be entitled to disability assistance would miss out. For instance, if a family living abroad had a child who became disabled in an accident and moved home to Scotland to be closer to extended family for support, they would not become eligible for Disability Assistance for Children and Young People until two years later.

The past presence condition does not seem to serve a reasonable purpose other than to reduce the number of people who are eligible to claim. This seems somewhat

[4] Pages 599 – 637, Welfare Benefits and Tax Credits Handbook 2019/20 - Child Poverty Action Group

[5] Disability Assistance consultation briefing – Child Poverty Action Group in Scotland, May 2019 https://cpag.org.uk/sites/default/files/files/policypost/CPAG-Scot-Briefing-Disability-Regulations.pdf

Scotland, May 2019 https://www.cas.org.uk/publications/cas-response-consultation-disability-assistance-scotland

at odds with the Scottish Government's welcome ambitions for the new system, as is penalising people who have recently moved to or returned to Scotland at odds with the Government's ambition to use inward migration as a mechanism to drive economic growth and counter-act demographic decline.[6] There is also a duty placed on Ministers to promote take-up.[7] CAS would recommend the past presence condition is removed to ensure that people who would be otherwise eligible to receive Disability Assistance for Children and Young People are allowed to claim it.

In addition to our comments above about the importance of retaining case law, a considerable body case law exists relating to the application of the existing Habitual Residence Test. Consideration should be given to what extent this can be incorporated into the devolved system.

Effect of UK exit from the European Union

It is unclear to what extent the UK's impending exit from the European Union will have on retained EU regulations. It may be possible that regulation 4 (7-10) may need to be revised to take account of any changes in UK immigration legislation as a result.

Care component criteria

Use of language

As the regulations setting out the criteria are largely copied from existing legislation, some of the phrasing appears somewhat outdated and arcane, and does not reflect the social model of disability (e.g. "so severely disabled physically or mentally as to require in connection with his or her bodily functions attention from another person for a significant portion of the day"). Whilst this may be a consequence of the desire to maintain parity with the existing regulations, CAS would recommend the Scottish Government review the language in the draft regulations with a view to better reflecting the social model of disability.

'Substantially in excess', 'significant', and mental health conditions

As part of a survey of CAB advisers in April 2019 to inform CAS' response to the consultation on Disability Assistance, the advisers who participated suggested a number of areas where the current eligibility rules for DLA for children could be improved upon. A number commented that the current definition of the needs of the child being 'substantially in excess' of what is normally required by a child of the same age could be clarified further, as it can be difficult to judge, given differences in children's development.

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[6] Scotland's Population Needs and Migration Policy: Discussion Paper on Evidence Policy and Powers for the Scottish Parliament – Scottish Government, February 2018 https://www.gov.scot/binaries/content/documents/govscot/publications/consultation-paper/2018/02/scotlands-population-needs-migration-policy/documents/00531087-pdf/00531087-pdf/govscot%3Adocument/00531087.pdf

[7] Part 1, Section 3 – Social Security (Scotland) Act 2018 https://www.legislation.gov.uk/asp/2018/9/section/3/enacted

> *"I think basically the idea that this child needs more help /supervision than another child of the same age is correct - but hard to judge. Needs for toddlers and teenagers with the same condition are different. Not sure how to address this. Currently young people frequently reach 16 and expect to migrate to PIP. In fact some have learnt to manage their conditions before this age (e.g. diabetes) and many no longer need the support they needed as children. There is scope for managing expectations."* CAB adviser.

A number of advisers also felt that the current rules made it difficult for children with mental health conditions to qualify, in particular children and young people on the autistic spectrum, or with ADHD (Attention deficit hyperactivity disorder). This was in part due to difficulties in being able to provide suitable evidence from schools and CAMHS (Child and Adult Mental Health Services), in part due to long waiting lists for provision of additional support.

As detailed in our comments on the 'Interpretation' section of the regulations, a number of terms are given meaning by case law. In particular, there is no definition in the regulations of what 'significant', 'severely' or 'substantial' means, which could cause difficulties for interpretation if existing case law is not to be incorporated.

Consistency with terminal illness rules

Regulation 5 (3)(b)(ii) refers to an individual not being entitled to the care component if they are terminally ill, unless death is expected within a period of 6 months. This appears to be contradictory to the approach taken in the Social Security (Scotland) Act which removes any specific timescale for people who are terminally ill from qualifying for disability assistance through special rules. CAS would recommend this regulation is reviewed to ensure it is consistent with the welcome changes to terminal illness rules.

Mobility requirements

A number of the respondents to CAS survey of CAB advisers commented that they felt that the criteria for the higher rates of DLA – particularly the mobility component – were set at too high a level, and a number of children with substantial support needs were assessed at the lower or middle rate as a result.

In addition, the regulations could be amended to provide clarity that children who have a mobility impairment due to a mental health issue can qualify for disability assistance, distinct from a learning disability ('severe mental impairment') or physical condition. This could be achieved by adding 'psychological distress' to the conditions at regulation 7 (2).[8]

[8] SAMH response to Consultation on Disability Assistance in Scotland, May 2019 https://consult.gov.scot/social-security/improving-disability-assistance/consultation/view_respondent?show_all_questions=0&sort=submitted&order=ascending&_q__tex Scotland, May 2019 https://www.cas.org.uk/publications/cas-response-consultation-disability-assistance-scotland

The draft regulations also make a holding provision at regulation 10 for 'other exclusions' to the mobility conditions. It is unclear what this relates to, so additional clarity would be welcome.

Entitlement under special rules for terminal illness

CAS warmly welcomes the proposals for special rules for terminal illness, which no longer require someone to have a prognosis of six months or less to live to qualify for disability assistance without further assessment or evidence. We also welcome the decision to extend the ability to complete the verification form to registered nurses as well as registered medical practitioners, as often specialist nurses will be better placed to do so.

Effect of time spent in care homes, residential educational establishments, hospitals and in legal detention

The Policy Note accompanying the draft regulations proposes that the care component will be suspended after a child or young person has spent 28 days in a care home, residential educational establishment or legal custody. However, as drafted, the regulations appear to remove entitlement in these situations, rather than suspending it, and do not specify a process for restarting the payment when a person leaves care or custody.

CAS believes that it is important that the payment should be suspended rather than stopped, and should be resumed promptly and smoothly, as opposed to the individual having to re-apply and be assessed for the benefit again. We would recommend the regulations are amended to make provision for a suspension and resumption of the care component, rather than removing entitlement.

Despite the mention in the section heading of 'Effect of time spent in…hospitals', the regulations themselves make no mention of any effect. To avoid confusion being caused, CAS would recommend either that 'hospitals' is removed from the section heading, or a regulation is added, similar to draft regulation 18, specifying that a stay in hospital has no effect on a person's entitlement to disability assistance.

Additionally, whilst CAS considers the proposals for disability assistance for children and young people to be reasonable, we would recommend the Scottish Government consider them in developing regulations for other forms of social security assistance.

In particular, CAS would recommend that people in receipt of carer's benefit should continue to receive it whilst the person they care for is in hospital, rather than losing entitlement due to a stoppage of the disability benefit of the person they care for, which currently frequently causes problems for CAB clients.[9]

[9] Pages 24 – 25, Citizens Advice Scotland response to Consultation on Disability Assistance in Scotland, May 2019 https://www.cas.org.uk/publications/cas-response-consultation-disability-assistance-scotland

We would also recommend the rules for stoppages in hospital, care homes and custody are harmonised for the three disability benefits, as opposed to current proposals which stipulate different sets of rules for each.[10]

Payment towards winter heating costs

CAS agrees with the proposal to extend eligibility for Winter Heating Assistance to families with a disabled child. This is in keeping with our position on the Fuel Poverty Bill where we have called for more vulnerable people (including households with a disabled member of the family) to be defined as requiring an 'enhanced heating regime' and thus qualify for enhanced support-to tackle fuel poverty[11]. This is in recognition of the increased heating costs faced by families with a disabled child who are likely to be spending more time at home.

Regulation 19 (2) refers to a payment being made "to help meet the costs of heating during winter months". However, this phrase is legally unnecessary as in practice people are able to spend their Winter Fuel Payment on anything they choose rather than being restricted. This phrase could be removed as there is no need for that caveat and it may lead to misconceptions or unnecessary restrictions in practice.

The draft regulations do not prescribe when a Winter Heating Assistance payment should be made – they simply say that a payment should be made without application if the claimant is eligible. To avoid any excessive delays in receiving the payment, the regulations could also stipulate that the payment must be made within a given period of the qualifying date or the first date on which the individual becomes eligible.

In addition, the regulations require the person to be in receipt of Disability Assistance to receive the payment of Winter Heating Assistance, rather than just entitled to it. If payment was disrupted, or the person was awaiting the outcome of a re-determination or appeal, it may lead to them not receiving Winter Heating Assistance or facing a delay in receiving payment at a time when their income is already reduced. CAS recommends extending eligibility to people who are in receipt of Short Term Assistance to avoid people who are challenging a decision to reduce or remove their entitlement to Disability Assistance missing out on a Winter Heating Assistance payment.

The draft regulations set the qualifying week as being the week commencing the third Monday of September, which is the same as the current eligibility period for reserved Winter Fuel Payment. However, it may be more straightforward for people to establish if they are entitled to receive it or not if a set date was used that was more closely associated with the winter months – for instance if the qualifying period was the week containing 1 October. This would also more closely associate the payment with winter.

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[10] Ibid.

[11] Speaking up: Understanding Fuel Poverty Support Needs – Citizens Advice Scotland, June 2018 https://www.cas.org.uk/system/files/publications/2018-06-12_speaking_up_understanding_fuel_poverty_support_needs.pdf

Scotland, May 2019 https://www.cas.org.uk/publications/cas-responses-consultation-disability-assistance-scotland

Entitlement to short-term assistance

CAS warmly welcomes the introduction of Short Term Assistance, which we called on the Scottish Government to introduce, based on evidence of CAB clients being left in hardship due to a decision to reduce or remove their disability benefit on reassessment, even if they are appealing the decision. The creation of Short-Term Assistance fills this gap, by ensuring that people's payments continue until the appeal process is concluded.

As drafted, the regulation 20 (2)(a) appears to exclude people whose payments are stopped because they are suspected of fraud from receiving Short Term Assistance. CAS believes this should be amended to make Short Term Assistance available to people who are appealing a decision that their benefit claim was fraudulent.

Regulation 20 (2)(c) appears to be in draft form, but would appear to be intended to apply to people whose benefit has been stopped or suspended as a result of being admitted to a care home or who are in legal custody. We would recommend that an exception to this is made for people who are challenging a decision to stop their benefit for these reasons (for instance, because they have not in fact been in a care home for more than 28 days).

Age criteria

The draft regulations make provision for an award of disability assistance for children and young people to continue past the age of 18 if a person has applied for disability assistance for working age people but has not yet received a determination. Regulation 23 (2)(b) however makes the caveat that the payment would stop once they turned 19, even if no decision had been made on their application for DAWAP.

This risks creating a 'cliff edge' in the scenario that a decision was substantially delayed, a delay in notifying a person that they should make an application for the working age benefit, or because their application was delayed for a reason. CAS would recommend removing the caveat that the benefit would when a person turns 19, if they have applied for DAWAP, but no determination has been made on their application.

Making payments

The draft regulations make provision for a payment of disability assistance to be paid to 'another person', other than the person specified on the application, if the claim is for a person over the age of 16 (regulation 24 (2)), or where the Scottish Government considers it inappropriate to be paid to the specified person (regulation 24 (3)). It is unclear whether these relate to appointees, to suspected financial abuse, or to give people responsibility for receiving their own payment upon turning 16. Clarity over how these regulations are intended to be used, and what safeguards will be put in place to prevent their misuse would be welcome.

When an application is to be treated as made and beginning of entitlement to assistance

It is somewhat unclear what situations draft regulations 25 (4) and (5) relate to ('when an application within 6 weeks of the day on which the data required to construct a record in respect of the child or young person is submitted'). We would welcome clarification of what types of situation would be covered by the regulation.

Other situations requiring a determination without an application

In cases of suspected fraud, draft regulations 30 (1)(c) and (d) would appear to allow the Scottish Government to stop a person's benefit payment, prior to an investigation having concluded and for allegations to be proven. In a rights-based system, it is important that this only occurs once it has been proven that fraud has been committed. CAS would recommend that a payment is not stopped unless fraud is proven, or that Short Term Assistance is made available to someone challenging an allegation or decision.

Period for re-determination request

CAS welcomes the Scottish Government's decision to increase the time given to a person to make a re-determination request from 31 days to 42 days (regulation 34 (1)). We would however, recommend that full consideration is also given to decisions of the Upper Tribunal related to late reconsideration requests and individuals' appeal rights in August 2017[12]. This case law may inadvertently have the effect of making the Scottish system stricter than the current UK system in terms of the requirement for 'good reason' for re-determinations submitted after the time limit set out in Schedule 41 of the Social Security (Scotland) Act.

We are disappointed that the statutory time limit for Social Security Scotland to respond to a request has been set at 56 days.

Evidence from CAB clients has consistently shown that detriment has been caused due to lengthy waits for a decision to be made on a mandatory reconsideration request, both in terms of hardship and causing stress and worry.[13] CAS are concerned that setting the time limit at 56 days (8 weeks) is too long, given that a person will have already had to wait for an original determination on their application, and that evidence will already have been gathered in making the original determination, so will not need to be re-sought.

Additionally, the Social Security (Scotland) Act provides an option for the period to be extended with the person's consent, which would cover more complex cases and avoids a requirement for an extended period to be set because of a concern about these cases.

[12] R(CJ) and SG v SSWP (ESA) [2017] UKUT 324 (AAC) https://www.gov.uk/administrative-appeals-tribunal-decisions/r-cj-and-sg-v-secretary-of-state-for-work-and-pensions-esa-2017-ukut-324-aac

[13] Page 20 – 21, Citizens Advice Scotland response to Consultation on Disability Assistance in Scotland, May 2019 https://www.cas.org.uk/publications/cas-response-consultation-disability-assistance-scotland

CAS strongly recommends the statutory time limit to respond to a re-determination request is reduced to no more than 42 days, the same time as is given to people to make the request.

Liability for over payment

Part 14 of the regulations, relating to liability for overpayments and deductions appears to still be in development. Citizens Advice Scotland would be interested in the development of the content of this section, due to evidence from CAB clients and advisers that there are problems with the way in which overpayment debt is recovered under the current system, and that there is too little flexibility in the approach that the DWP currently takes.

Key improvements that could be made include action to minimise error, improving communications and information sharing, use of a common financial tool to assess an individual's ability to pay, introducing flexibility in how much is deducted to repay debt, limiting the level of deductions to no more than 10% of a person's total benefit payment, and ensuring that a person always has the ability to challenge a decision regarding overpayment debt.[14]

[14] Pages 26 - 29, Citizens Advice Scotland response to Consultation on Disability Assistance in Scotland, May 2019 https://www.cas.org.uk/publications/cas-response-consultation-disability-assistance-scotland

Submission 2 from Child Poverty Action Group Scotland

DETERMINATIONS WITHOUT APPLICATION (DWA)

Right to review

The draft regulations do not provide an effective mechanism to challenge a refusal to change an individual's ongoing entitlement to DACYP. This is a significant loss of rights compared to the current DLA rules. We understand that the Stakeholder Reference Group's advice on length of awards was caveated with the condition that an individual must have a right to have an ongoing award reviewed. The draft regulations do not give this right. Re-drafting regulation 30 could resolve this issue.

In DLA, if a child's condition has worsened a parent can ask the DWP to review the DLA award. If the DWP does not think it merits an increased award, the parent has a right to appeal. This is an important right to maintain. Social Security Scotland will not get all these decisions right first time.

In practice, while this is an important right, it is one that advisers take care is exercised with caution. People are not advised to ask for reviews unless they have a strong case because of the risk of losing the award they already have.

While this right exists in the UK system generally, and for DLA, PIP and AA in particular, there is an aspect of the UK system where it does not exist. This is where a person makes a repeat claim for ESA after being found 'fit for work'. Experience of people affected by the lack of appeal rights in this situation shows how people could be impacted by a similar lack of rights in DACYP. Normally people are paid while waiting to be assessed for ESA as long as they supply a fit note from their GP. But if it is a repeat claim, no ESA is paid unless they provide evidence of a new health condition or significant deterioration and the DWP decides (before the person is actually assessed) whether they are **likely** to pass. There is no route to challenge this decision. This means claimants can be left without money for long periods of time and do not have an opportunity to make their case. In the context of DACYP, it could mean people are left on the wrong award with no way to challenge it.

CASE STUDY: Having failed the work capability assessment for ESA, a lone parent reclaimed after her condition worsened. This was refused on application and mandatory reconsideration and is now pending appeal. DWP decided that the client's condition has not worsened. The client has not been paid any ESA since her new claim was made. There is no right of appeal against the determination that her condition has not worsened. #6549

Necessary DWA provisions not provided for in the draft regulations

- **Test cases.** The draft regulations contain no provision to undertake a DWA as a result of a test case. A test case is an appeal that determines a point of law. It effectively changes the law. Once decided in the courts, it can mean that other awards decided on the same point of law are wrong and should be reviewed. There are DLA regulations that allow for an award to be superseded from the date of a test case decision but no similar DACYP regulations.
- **Date new determination takes effect.** Where there is a change of circumstances that affects entitlement but was not a change that the individual was required to notify under s56 of the Act, the regulations do not say the date from which the DWA should take effect.
- **Gradual improvements in condition**. Regulation 33 allows retrospective changes to an award where an individual's condition has improved gradually over time. The date of the DWA is set by the date on which the 'change' took place (or should have been notified). It is very hard for people to know at what point their needs have gone below the threshold for their level of award. This could lead to overpayments and potential prosecutions for fraud for individuals whose condition has improved gradually over time. In contrast, the DLA rules provide that an individual's entitlement is only altered from the date of a change if it could reasonably be expected that the person knew of the relevance of the change.

Example where DWA provisions seem not to operate as intended

Regulation 30 could be split into those situations where a DWA 'must' be done and those where it 'may' be done.

- Examples of where it 'must' be done would be when requested by an individual, where a claimant leaves a care home/residential school and under the situations described in Regs 30(1)(a)(ii),(iii),(iv),(b),(e) and (g).
- Examples of where it 'may' be done would be under the situations described in Regs 30(1)(a)(i),(iv),(v) & (f).

Without this change Scottish Minister would, for example, be required to make a DWA under 30(1)(a)(v) even if the individual has made an agreement to pay back the money directly, or under 30(1)(f) in almost any circumstances.

REDETERMINATION TIMESCALES

The draft regulations (regulation 34) reduce individuals' rights and risk creating an additional complex layer of decision making.

The draft regulations reduce the time limit in which an individual can request a re-determination from 13 months for DLA to 42 days for DACYP, unless the individual can show good reason. (Note: The limit for the UK system was 1 month until CPAG was involved in a successful case that effectively extended the limit to 13 months.)

This creates an additional decision-making process to determine good reason. This kind of discretionary decision-making in the system is not only resource intensive administratively but, in our experience, disadvantages many people who struggle to navigate such rules.

CASE STUDY: A client's PIP stopped because she failed to attend a medical. She has a brain injury and did not understand the letter. She may have been able to show good reason for her failure to attend but neither she nor her carer were aware of this. Several months later she made a new claim, and was awarded PIP, but lost out on several months of entitlement.

Extending the time limit to request a re-determination to 365 days would resolve these issues. There would still be a strong incentive for an individual to submit a re-determination request as soon as possible, which could be strengthened with clear publicity and guidance to individuals and those supporting claimants.

CARE HOMES, RESIDENTIAL SCHOOLS, PRISONS, HOSPITALS AND HOSPICES

The decision to allow those who partially fund the costs of staying in a care home or residential school to receive the care component of DACYP and the decision to allow children and young people who are in detention to receive the mobility component are welcome. However, the fact that entitlement ends rather than payment being suspended, due to the way the Act is drafted, potentially causes significant problems.

1. Parents of disabled children will get less universal credit. Parents of children in residential schools or respite care for more than 28 days or for short periods less than 28 days apart will lose entitlement to DACYP and therefore also lose entitlement to the disabled child element of universal credit.

2. At present, the process for reinstating DLA when a child is ‘on leave’ from a care home or a residential school is very straightforward because payment of DLA has been suspended but entitlement has continued. Under the draft regulations, entitlement has ended so a new application is needed. A new application requires a new assessment and carries the risk of reduced entitlement. If payment is suspended, there is no risk when it is restored.

CASE STUDY: Young person with high level needs is in residential school but returns to his parents at the weekend. The mobility component of DLA can continue to be paid while he is in residential accommodation and the DLA (care component) should be apportioned and paid for the days that he is at home. #8898

This could be resolved in a number of ways, for example:

- The Act could be amended to allow the suspension of payments of assistance. This power may also be needed as other forms of assistance are rolled out, and changing the Act now would allow for that flexibility in the future. For example, carer’s allowance is not paid to people who get a full state pension, but the ‘underlying entitlement’ allows individuals with a low

income to access an additional premium in their pension credit and council tax reduction.

- DACYP care component could continue to be paid during stays in care homes and residential schools.

RESIDENCE AND PRESENCE CONDITIONS

- The Scottish Government has not taken the opportunity to relax the past presence test or create further exceptions to it. This test currently causes significant difficulty for a small number of disabled children and their families. The costs of abolishing or significantly reforming the test would presumably be small.

CASE STUDY: A 5 year old with leukaemia is not eligible to claim DLA because she has not been living in the UK for 2 years yet. #673

- There is a risk that someone could be found not to be ordinarily resident in Scotland, and also not ordinarily resident in England or Wales, or they could simply make a claim in the wrong jurisdiction. A reciprocal agreement could ensure anyone ordinarily resident in the Great Britain would be entitled to either DACYP or DLA and claim made in either would count as a claim in the relevant jurisdiction.

MOBILITY COMPONENT CRITERIA

- The Scottish Government has not taken the opportunity to relax the conditions around severe mental impairment and behavioural problems (regulation 7(2)(d)). DLA rules require the child to get the highest rate of the care component as well as have a severe mental impairment and behavioural problems. This excludes any child who sleeps through the night and has no night time needs because the highest rate of the care component is only payable if a child has needs both day and night (or is terminally ill). The removal of this rule would only benefit a small number of families. However, allowing children with high needs who cannot mobilise safely to access additional income or the Motability scheme would be a great help to those families.

CASE STUDY: Child is severally autistic. High rate mobility has been refused on the basis that the child makes a conscious decision not to walk outdoors rather than being virtually unable to walk because of physical disability. Child is not getting high rate care, otherwise may have been able to qualify for high rate mobility as someone is in receipt of high rate care and who has a severe mental impairment. #1769

- The lower rate mobility test compares the needs of a child to those of other children of the same age. Regulation 6(2) reduces what are two tests in DLA to a single test in DACYP. The equivalent test for the care component in regulation 5(2) retains both of the tests that DLA currently uses. If the drafting remains as it is, then children who need a different ***type*** of guidance or

supervision than a child of the same age, but not a 'substantially greater' ***amount*** of guidance or supervision may no longer qualify.

- The higher rate mobility test in regulation 7(1) includes a completely new requirement that a child needs 'substantially more guidance or supervision' than a child of the same age. It is not clear whether this is a deliberate policy change or a drafting error. There is no equivalent DLA provision. If a policy change, it will mean that some children who would have been entitled to the higher rate mobility component of DLA will not be entitled to the same rate of DACYP.
- The regulations do not provide a lower age limit for the higher rate of the mobility component, except where a child is entitled under the special rules for terminal illness. It is not clear whether this is a policy change or an oversight.
- Regulations 7(2)(g) and (h) provide two alternative routes to the higher rate mobility component that do not exist for DLA. Regulation 7(2)(d) closely matches the current eligibility criterion for children with a severe mental impairment, so it appears that the separate inclusion of paragraphs (g) and (h) may be a drafting error.
- The regulations do not make it explicit that a child can only qualify for one rate of the mobility component of DACYP. In contrast, regulation 5(5) only allows entitlement to one rate of the care component.
- There is no test of past and future needs (equivalent to regulation 5(3) for the care component) for the mobility component of DACYP. A child could qualify with needs lasting for just a few weeks, as the regulations are drafted.
- Regulation 7(6) which defines 'severe mental impairment' for the higher rate mobility component follows the current DLA rules. DLA rules were intended to apply to children and adults whereas DACYP is only for children. The definition is not wholly relevant to children. For example, the brain continues to develop well into adulthood.[15] There is an opportunity to simplify the rule to remove reference to incomplete physical development of the brain given that this applies to all children.

TERMINAL ILLNESS

- Regulation 11(8)(b) does not include a DS1500 for DLA as relevant information for treating a child as terminally ill. It is not clear why this is not relevant information. If it is not included, this could cause problems for:
  - children who transfer from DLA to DACYP;
  - children who move from rest of the UK to Scotland;
  - GPs (who may complete a DS1500 rather than BASRiS as it is more familiar).

  The regulation should be amended to include a DS1500 for any purpose ie, for DLA and PIP, as well as for ESA or UC.

- In Regulation 5(6), the reference to paragraph 2(b) appears to be a drafting error. It appears most likely that the intention is to refer to paragraph (3)(b).

[15] NMcM v SSWP [2014] UKUT 312 (AAC)

However, if this is the case, paragraph 3(b)(ii) seems to mean that the reference is redundant. If the intention of the reference is to impose a test of 'additional needs' for terminally ill children, this is a requirement that does not exist in DLA, and may restrict whether children are treated as terminally ill, even if they are expected to die within 6 months.

MAKING PAYMENTS/APPOINTEESHIP

- Section 58 of the Act only allows appointees when a claimant is deceased, or when they are incapable within the meaning of the Adults with Incapacity (Scotland) Act. There is no specific power to appoint someone to act for a child.
- Regulation 24 provides that payment is always made to the person specified in the application. This seems to lack clarity and raises the following potential problems.
    1. It appears to allow a child to make a claim for disability assistance for themselves. It is unclear if this is the policy intention.
    2. It allows Social Security Scotland a very broad discretion who to pay without any clear guidance or process for managing disputes. Such disputes may arise either between possible carers or between the child and their carers, particularly when the young person turns 16. There are potential benefits to having a system that allows the agency some discretion about who they pay, but clear guidance must be published and there must be a clear route to challenge any decision and allow an independent body, such as the SPSO, to offer an independent route to challenge decisions on who is responsible for a claim.

CASE STUDY: Child lived with his mum in England who was his appointee for DLA until he turned 16 when he decided he wanted to live with his dad in Scotland. Dad has child benefit and the UC child element in place, but mum has refused to relinquish appointeeship for DLA. Payment of DLA was suspended for 4 months while the DWP looked into the situation and eventually decided that mum should remain the appointee. There is no mechanism for disputing this decision. #8628

- For DLA a claim for a child under 16 must be made by an appointee, usually the child's parent. When a child reaches 16, the DWP procedure is to ask whether they will continue to need an appointee and usually carry out a home visit to assess the young person's capacity. It is important that children and young people in Scotland have the same degree of clarity around the processes when they turn 16, and a way to challenge any decision that is made.

DATE OF CLAIM

In regulation 25(4), which determines the date of claim, it is not clear what information is required to 'construct a record'. While this could be clarified in guidance, it would be better to have a clear legal way in which the date of claim is

established, for example by stating that any notification of the intention to claim is sufficient to secure the start date of eventual entitlement.

CASE STUDY: The Early Warning System has received a number of case studies about universal credit claimants who have initiated a claim online but it has since been closed and never put into payment. It would appear this is because they failed to provide sufficient information to progress the claim but is often unclear.

SHORT-TERM ASSISTANCE AND DACYP

If an individual is awarded short-term assistance and subsequently awarded DACYP as a result of a re-determination or appeal, it appears that short-term assistance and DACPY will both be payable for the period between the determination that reduced the award and the re-determination or appeal. This may be the issue that the draft policy note suggests remains to be settled in relation to short-term assistance.

WINTER HEATING ASSISTANCE

- Regulation 19 allows for a determination of entitlement for winter heating assistance when a child is entitled to DACYP. We believe that it should also be available to children in Scotland entitled to DLA.
- Regulation 19(3) makes reference to regulation 33 which seems to be a drafting error.
- Regulation 19 allows winter heating allowance to be paid to someone 'in receipt' of DACYP. This suggests it will only be paid to children or young people who receive DACYP themselves. This is confirmed by the accompanying policy document. If the intention is that winter heating allowance is paid to the person who is paid DACYP this would mean that in a household with two disabled children if different people were to be paid DACYP then they would receive two winter heating allowance payments. However, if DACYP for both children were paid to one person they would only receive one winter heating allowance payment.

CASELAW

At present the DACYP regulations take no account of the body of DLA caselaw. It is caselaw that defines some of the basic terms. It is far from certain that tribunals dealing with DACYP cases would apply DLA caselaw. To provide clarity for people and consistent decision making, terms established by DLA caselaw should be defined in the DACYP regulations. For example, the meanings of 'continual' and 'night' have a settled meaning in relation to DLA that are not set out in the DACYP regulations.

The Scottish Government may want to consider how future DLA caselaw may influence DACYP over time.

CASE STUDY: Tribunal judge in child DLA appeal declared that autism is not a severe mental impairment or arrested development of the brain. He also said that the child had reasonable intelligence measured by his school performance. However case law states that autism is arrested development and that IQ and academic ability

are not a measure of ability to apply intelligence to real world situations so should not come into it. #2627

BLIND AND VISUALLY IMPAIRED CHILDREN

The drafting of regulation 7(2)(f) means that the test for the higher rate mobility component is that the child is **either** blind **or** has a severe visual impairment. The equivalent test for DLA is that a child is either blind **and** deaf, or has a severe visual impairment. If this drafting is correct it seems the test for DACYP is relaxed, with no requirement to be both blind and deaf. For DLA, caselaw has established that 'blind' means 'loss of sight to such an extent to render the claimant unable to perform any work for which eyesight is essential' – it is not clear whether it is the intention to use this test for DACYP. In practice, this is obviously not a suitable test to apply to young children. The legal test should be one that is easy to provide evidence for in Scotland.

CASE STUDY: Client is getting the UC disabled child element having responded to a question asking if her child is blind. In Scotland, children are no longer 'certified' blind, but this is the legal criteria in UC and CTC. Child DLA has been refused but a mandatory reconsideration has been requested. #751

CARE COMPONENT CRITERIA

In regulation 5(3A), the reference to paragraph 5(3) appears to be a drafting error and should probably refer to paragraph 5(2). If not, then there are problems with both para 2 and para 3 of Reg 5 regarding entitlement for 16 and 17 year olds.

Applications made while in a care home

- Regulation 16 allows someone to make a new application while in a care home or residential school and have the care component paid for 28 days. This is a change from DLA regulations. (There appear to be no restrictions on making a new claim after a previous claim has ended following a DWA under regulation 30(1)(a)(ii).) It appears that someone whose DACYP award starts while in a care home, and whose entitlement ends 28 days later can make a new claim for DACYP and be entitled for a further 28 days, repeating this pattern indefinitely.
- Regulation 18 says for the avoidance of doubt, being in a hospice has no effect on DACYP care component. This could also refer to being in a hospital.

AGENCY TIMESCALES

- Regulation 34(2) gives the agency 56 days to carry out a re-determination. This timescale needs to allow the agency enough time to gather information to make the correct decision. If set too low, there will be cases where the agency runs out of time and asks the individual if they want to appeal or allow the agency an extension. While on the face of it this gives a person choice over how to proceed, in reality, allowing the agency more time does not give an extension of the time limit to appeal. The risk is that people unwittingly lose their (absolute) right to appeal. The Scottish Government should monitor

whether 56 days is the right balance between speedy resolution and sufficient information gathering eg, by collecting data on the number of cases that go to appeal under section 45 of the Act (where a re-determination is not made within the time limit) and the number of cases where the time limit is extended.

- Regulation 34(2) should be amended (to align with the The Early Years Assistance (Best Start Grants) (Scotland) Amendment (No. 1) Regulations 2019 Regulation 7) to allow, in the case where a re-determination is submitted outside the time limit, for the agency time limit to run from the date that it is accepted that the individual had good reason for the late re-determination request rather than the date the re-determination request was submitted.

GUIDANCE AND PROCESSES

There are areas where it will be important that there is clear publically available guidance to provide clarity to individuals and reassurance that the policy intention will be met.

For example:

- What duties to notify a change of circumstances are placed on people under section 56 of the Act?
- How applications for short-term assistance are made at re-determination and appeal stage.
- What processes are in place to safeguard people before making any determination to reduce or stop their payment? For example, this might be extra contact or visits for people with mental health conditions, learning disabilities or cognitive impairment.
- How power to decide against an applicant who does not respond to a request for information will be used in practice (ie, under regulation 29(2)(b) and under section 54 of the Act).
- How powers under regulation 33(2) will be used to fix a different date for a change of circumstances to take effect.

Submission 3 from Inclusion Scotland

Background: Inclusion Scotland is a 'Disabled People's Organisation' (DPO) – led by disabled people ourselves. Inclusion Scotland works to achieve positive changes to policy and practice, so that we disabled people are fully included throughout all Scottish society as equal citizens.

Key Points:

Inclusion Scotland welcomes:

- The extension of entitlement to 18 where a young person is in receipt of benefits prior to their 16th birthday
- The introduction of the Child Winter Heating Assistance
- The widening of entitlement to all those with a terminal condition
- The extension of the period to request a re-determination to 42 days

Outstanding Concerns:

- The regulations' failure to set out how existing case law on Children's DLA will be incorporated into the new regulations.
- The carry-over from Children's DLA regulations of an over-reliance on the existence and impact of physical, rather than mental health-related, conditions as determinants of entitlement.
- The lengthy, 56 day, period for a redetermination.

1 Comments

1.1 In general terms Inclusion Scotland largely welcomes the draft regulations which have been circulated to us by SCoSS.

1.2 **Age criteria:** In particular we wish to place on record our appreciation for the change in the age criteria (Part 8, para 23) which will extend entitlement of DACYP up to age 18 for those whose claims have been made before they reach age 16.

1.3 This change is very much in line with the views of the disabled people we consulted both before and during the passage of the Social Security Bill through Parliament. They and we believe that this change will provide a much needed breathing space for the majority of families of disabled young people.

1.4 At present disabled young people and their carers often face the transition between school and adult life, the handover between children and adult social care services and the assessment for adult PIP all occurring within the space of a few weeks or months at age 16. At least one of these stressful changes will now be deferred until later.

1.5 **Winter Heating Assistance:** Inclusion Scotland also welcomes the £200 payment towards Winter Heating Costs and that this assistance will be provided automatically without any further need for applications and form filling. This contribution towards heating costs will bring much needed help to families struggling with the extra costs of disability.

1.6 We hope that the impact of this measure in reducing fuel poverty will be measured and that at some point, in the not too distant future, that the assistance will be extended to families with children receiving middle rate care who face similar additional costs.

1.7 **Terminal Illness:** Inclusion Scotland welcomes the extension of "special rules" applications to all those with a terminal illness. We remain concerned that what constitutes a terminal condition is to be defined in guidance rather than regulations. We accept that this is in line with what is stated in statute but believe that this provides a huge amount of leeway to future Ministers in extending, or more worryingly, narrowing the scope of special rules applications.

2 Concerns

2.1 **Existing Case law:** The draft regulations forwarded to us are silent on the issue of previous case-law decisions regarding Children's DLA. Whilst this would not normally be an issue that regulations dealt with it is a serious issue of concern in terms of whether and how existing case law is, or is not, to be utilised within the devolved social security system.

2.2 Case law has established recognised and accepted baselines for the meaning and interpretation of statute and regulations on all manner of issues related to entitlement. If existing case law is not incorporated, in some way, into the Scottish system of determination and appeals it will permit the re-determination and litigation of issues long considered as settled. This in turn has the potential to be time-consuming, and expensive. Worst of all it would introduce massive uncertainty into the system causing needless stress and worry for families and children.

2.3 Inclusion Scotland are seeking some reassurance from Scottish Government that the issue of existing case law is being addressed with a view to reducing

and, if possible, eliminating the current uncertainty as to their place (e.g. is previous case law to be binding, guiding or ignored in reaching decisions on Scottish disability assistance?) within the devolved system.

2.4 Mental Health and eligibility: Inclusion Scotland would echo the concerns expressed by SAMH about the eligibility criteria for both the care and mobility components of Disability Assistance for Children and Young People being overly focused on the physical, rather than, psychological condition of the brain.

2.5 In particular –

I. The eligibility criteria as drafted in Part 3 of the regulations do not adequately allow for people and their families to share the impact of the young person's mental health and
II. The Mobility requirements (Part 3, paras 6 through 7) are overly restrictive in relation to mental health.

2.6 We appreciate that a balance has to be struck between securing a safe, secure and hopefully simple transfer of claims and the adoption of markedly different, and more generous, entitlement criteria that might require substantial numbers of claims having to be reassessed.

2.7 However, given the current review of the Mental Health (Scotland) Act we believe that it is time for psychological determinants of ill health and impairment to be accorded their proper weight. We would thus urge the Commission to seriously consider SAMH's evidence and support a re-alignment of current care and mobility entitlement criteria that properly reflects the impact of mental health on individuals and their families.

2.8 **Redeterminations:** Inclusion Scotland welcomes the proposed increase in the length of the period in which a redetermination can be sought to 42 days. This is a vital change which will provide more time for disabled people to seek and, hopefully, secure the support of advocacy and advice services.

2.9 However, Inclusion Scotland continue to believe that redeterminations should take no more than one month (28 days) to complete – especially as the period can be extended if there is a delay in providing the information that the Social Security Agency considers is necessary for redetermination. It seems inequitable that the state (in the form of the Agency) with its far greater resources is given more time to make a redetermination than an individual is given to seek a redetermination.

2.10 The 56 day redetermination period also means that an appeal against the original determination cannot be brought for a substantial amount of time (3 months or more). We would only point out to the Commission that substantial delays in providing access to justice amounts to denying justice for a very large proportion of disabled people who, through discrimination and stigma, are forced to rely on benefits as their main or sole source of income.

Submission 4 from Multiple Sclerosis Society Scotland

About Multiple Sclerosis

Multiple Sclerosis (MS) is a chronic, neurodegenerative condition for which there is currently no cure. In MS, the body's immune system attacks myelin, the protective cover around nerve fibres. Damage, which can occur anywhere in the central nervous system, interferes with messages travelling from the brain and spinal cord to other parts of the body. Symptoms are many and varied, but unique to each person. They can include problems with balance, vision, the bladder, bowel, speech, memory, fatigue and painful muscle spasms, among many other things. MS affects over 100,000 people in the UK, many of whom experience their first symptoms during the peak of their working lives, in their 20s and 30s.

MS is both a fluctuating and progressive condition. While the progression and symptoms of MS vary from individual to individual, primary progressive MS affects around 10 to 15% of people with MS. This is progressive from the very first symptoms. The remaining 85% of people with MS are initially diagnosed with relapsing forms of MS, where people have distinct attacks of symptoms with the underlying damage building up over time. Many people with MS will go on to develop secondary progressive MS within 15 years of being diagnosed.

At present there are 13 Disease Modifying Therapies (DMTs) licenced for use on the NHS in Scotland. DMTs can help reduce how many relapses you get and how bad they are. They can also slow down the damage caused by MS that builds up over time.

About MS Society

The MS Society is the UK's largest charity for people living with MS. We're here for everyone living with MS – to provide practical help today, and the hope of a cure tomorrow. We play a leading role in research. We fight for better treatment and care. We let people with MS know they're not alone, and offer advice and support to help them manage their symptoms.

We are a member of the Scottish Campaign on Rights to Social Security (SCORSS), a diverse coalition of organisations working across Scotland with collective expertise across a range of different aspects of the social security system. Whilst coming from different areas of expertise, all members of SCORSS are united in our belief in a social security system that prevents poverty and supports those in need whilst also protecting their dignity.

We endorse the submission you will have received from SCORSS. The purpose of this briefing however is specifically address issues as they relate to people living with MS and their families and carers.

What matters to people living with MS

Over the past twenty-one months we have conducted focus groups around the country, held online sessions, engaged via social media and surveyed people living with MS to understand what their needs are from the new social security system in Scotland. Their messages have been both clear and consistent.

Ahead of the consultation on 'Improving Disability Assistance in Scotland' we conducted did a short survey ahead of our MS campaigns community. We received 550 responses to the survey, a ten percent response rate which we believe shows the strength of feeling around the issues raised in the consultation. All of this work and the stories we have heard are reflected in the issues we believe need to be addressed within the regulations:

Incorporation of case law

It is concerning that despite being raised by several stakeholders during the consultation process on 'Improving Disability Assistance in Scotland' the draft regulations do not take account of Disability Living Allowance (DLA) case law. We believe it is important as part of a transition from the existing disability benefits to the Scottish system that individual rights are maintained and no unintentional gaps in law are created. We support the SCORSS submission which covers this in more detail.

Entitlement to short-term assistance

We welcome the introduction of Short Term Assistance particularly as we heard examples of people living with MS experiencing financial hardship due to a decision to reduce or remove their disability benefit on reassessment.

Period of re-determination request

We believe the timescale of 56 days is too long. The impact of waiting on the outcome of a re-determination for someone living with MS must not be underestimated. For many people living with MS stress is a trigger factor for causing a relapse in their condition.

We were disappointed to see that despite the consultation submissions from stakeholders and the input into roundtable meetings with civil servants that the statutory time limit for Social Security Scotland to respond to a request has been set at 56 days.

We welcome the increased time for individual's to make a re-determination from 31 days to 42 days. We remain concerned however that with a fluctuating neurological condition like MS individuals may not be well enough to make a request within this time period.

About multiple sclerosis

- MS affects more than 11,000 of in Scotland
- MS is often painful and exhausting and can cause problems with how we walk, move, see, think and feel
- MS is unpredictable and different for everyone
- Multiple sclerosis (MS) is a condition of the central nervous system.

- In MS, the coating around nerve fibres (called myelin) is damaged, causing a range of symptoms.
- Symptoms usually start in your 20s and 30s and it affects almost three times as many women as men.
- Once diagnosed, MS stays with you for life, but treatments and specialists can help you to manage the condition and its symptoms.
- We don't know the cause and we haven't yet found a cure, but research is progressing fast.

About the MS Society

- The MS Society is here for people with MS, through the highs, lows and everything in between
- We have a free helpline - 0808 800 8000 and information can be found on our website www.mssociety.org.uk
- We're driving research into more – and better – treatments for everyone
- Together we're strong enough to stop MS

Submission 5 from the Scottish Campaign on Rights to Social Security (SCoRSS)

About us

The Scottish Campaign on Rights to Social Security (SCoRSS) is a coalition of organisations who advocate for a reformed social security system that reflects the five principles set out in our Principles for Change. SCoRSS (previously the Scottish Campaign on Welfare Reform) encompasses over 40 organisations from key third sector organisations, charities, faith groups, and unions. Our members have a diverse range of experience and expertise and a strong understanding of social security and its impact on the people and communities we work with. Since 2006 SCoRSS has highlighted the shared concerns of a diverse coalition of organisations in Scotland about the UK Government's welfare reform proposals. Since then, the coalition has informed debates on changes to both UK and Scottish government policy and has influenced the creation of Scotland's first social security system.

This paper sets out SCORSS's views on the draft Disability Assistance for Children and Young People (Scotland) Regulations 2020.

Introduction

Many of the proposals in the draft regulations represent welcome improvements to Disability Living Allowance for children and young people, in particular in a number of changes to administer the benefit that treat people with dignity and respect.

The eligibility criteria in the draft regulations are largely copied verbatim from the existing legislation for Disability Living Allowance[16]. SCORSS recognises the need for a 'safe and secure transition' from existing disability benefits to a new devolved system of assistance, and it is crucial that people do not experience a stoppage or delay to their payments as a result of the devolution process.

However, we also believe that a safe and secure transition should not be a barrier to more substantial improvements to disability benefits in the longer term. We encourage the Scottish Government to continue to develop proposals for longer-term changes to Disability Assistance alongside proposals for initial transition.[17]

Incorporation of case law

At present the DACYP regulations take no account of the body of DLA caselaw, this includes clarification of the definitions of some of the terms used. Many of the terms in the eligibility criteria and existing regulations have been given meaning by judgments of the Upper Tribunal and High Court. It is not certain that the DLA caselaw would be binding on tribunals in Scotland making decisions about DACYP, so it might be necessary to include the meanings of some terms as established by DLA caselaw in the regulations to ensure clarity and the smooth running of the

[16] Social Security Contributions and Benefits Act 1992 and The Social Security (Disability Living Allowance) Regulations 1991, as amended

[17] Pages 54 – 55, Citizens Advice Scotland response to Consultation on Disability Assistance in Scotland, May 2019 https://www.cas.org.uk/publications/cas-response-consultation-disability-assistance-scotland

system. For example, the meanings of 'continual' and 'night' have a settled meaning in relation to DLA that is not set out in the regulations.

It is important that as part of a transition from the existing disability benefits to the Scottish system that individual rights are maintained and no unintentional gaps in the law are created. A comprehensive review of existing regulations, guidance and caselaw should be undertaken to ensure that important detail and rights are not lost upon transition.[18]

Past presence test

The past presence test requires a person to have been present in Great Britain for two out of the last three years to be eligible to claim PIP, DLA or Attendance Allowance, and is proposed to be replicated in the new system.

The Scottish Government has not taken the opportunity to relax the past presence test or create further exceptions to it. This test currently cause significant difficulty for a small number of disabled children and their families. The costs of abolishing or significantly reforming the test would be minimal.

There is a danger that someone could be found not to be ordinarily resident in Scotland, and also not ordinarily resident in England & Wales, or they could simply make a claim to the wrong jurisdiction. A reciprocal agreement could ensure anyone ordinarily resident in the Great Britain would be entitled to either DACYP or DLA and claim made in either would count a claim in the relevant jurisdiction.

Terminal illness

We welcome the proposals for special rules for terminal illness, which no longer require someone to have a prognosis of six months or less to live to qualify for disability assistance without further assessment or evidence. We also welcome the decision to extend the ability to complete the verification form to registered nurses as well as registered medical practitioners, as often specialist nurses will be better placed to do so.

The regulations (Reg 11(8)(b)) do not include a DS1500 for DLA as relevant information for treating a child as terminally ill. It is not clear why this is not relevant information. If it is not included, this could cause problems for:

- children who transfer from DLA to DACYP;
- children who move from rest of the UK to Scotland;
- GPs (who may complete a DS1500 rather than BASRiS as it is more familiar).

The regulation should be amended to include DS1500 for DLA, as well as for ESA or UC.

Reg 11(4) appears to allow backdating of a DACYP claim to the date a BASRiS and DS1500 form is completed, even if the DACYP application is made after this date. If this is the policy intention it is welcome, but it would be preferable to also allow

[18] Disability Assistance consultation briefing – Child Poverty Action Group in Scotland, May 2019 http://www.cpag.org.uk/sites/default/files/CPAG-Scot-Briefing-Disability-Regulations.pdf

backdating for claims which are not made on the basis of a terminal illness, if the child met the entitlement conditions before claiming.

Effect of time spent in care homes, residential educational establishments, hospitals and in legal detention

The decision to allow those who partially fund the costs of staying in a care home or residential school to receive the care component of DACYP and the decision to allow children and young people who are in detention to receive the mobility component are welcome. However, we are concerned that a child or young person's entitlement ends rather than being suspended if they have spent 28 days in a care home, residential educational establishment or legal custody. We understand that due to the way the Act is drafted the regulations must *remove* entitlement in these situations.

The fact that entitlement ends rather than payment being suspended potentially causes two problems:

3. Carers of children in residential schools/respite care for more than 28 days or for short periods less than 28 days apart will lose entitlement to DACYP and therefore also lose entitlement to the disabled child element of UC.
4. At present, the process for reinstating DLA when child is 'on leave' from a care home or a residential school is very straightforward. Under the draft regs a new application will need to be made.

This could be resolved by one of the following routes.

- The Act could be amended to allow the suspension of payments of assistance. This power may also be needed as other forms of assistance are rolled out, and changing the Act now would allow for that flexibility in the future. For example, carer's allowance is not paid to people who get a full state pension, but the 'underlying entitlement' allows individuals with a low income to access an additional premium in their pension credit and council tax reduction.
- DACYP care component could continue to be paid during stays in care homes and residential schools. This could either continue to be paid to the person who was getting the payment, or payment could be made to care home or residential school. There are knock on effects with either choice.

An alternative option would be:

- To resolve issue 1 – make an agreement with the DWP that the UC disabled child element is still paid when a claim has been stopped due to the child being in a care home or residential school for 28 days or more; and
- To resolve issue 2 - add a category of DWA so that when a child is 'on leave' and their previous entitlement to DACYP Care Component has ceased then DWA is made to reinstate the entitlement.

Payment towards winter heating costs

SCORSS agrees with the proposal to extend eligibility for Winter Heating Assistance (WHA) to families with a disabled child.

Reg 19 allows for a determination of entitlement for WHA when an individual is entitled to DACYP. We would welcome further information on how a determination for WHA is to be made for an individual who is in Scotland and entitled to DLA.

Reg 19 allows for WHA to be paid to some 'in receipt' of DACYP. This suggests it will only be paid to children or young people who receive DACYP themselves. This is confirmed by the accompanying policy document. If the intention is that WHA is paid to the person who is paid DACYP this would mean that in a household with two disabled children, if different people were to be paid DACYP, then they would receive two WHA payments, if the DACYP for both children were paid to one person they would only receive one WHA payment.

Entitlement to short-term assistance

We welcome the introduction of Short Term Assistance, particularly in light of evidence of CAB clients being left in hardship due to a decision to reduce or remove their disability benefit on reassessment, even if they are appealing the decision. The creation of Short-Term Assistance fills this gap, by ensuring that people's payments continue until the appeal process is concluded.

As drafted, the regulation 20 (2)(a) appears to exclude people whose payments are stopped because they are suspected of fraud from receiving Short Term Assistance. SCORSS believes this should be amended to make Short Term Assistance available to people who are appealing a decision that their benefit claim was fraudulent.

Regulation 20 (2)(c) appears to be in draft form, but would appear to be intended to apply to people whose benefit has been stopped or suspended as a result of being admitted to a care home or who are in legal custody. We would recommend that an exception to this is made for people who are challenging a decision to stop their benefit for these reasons (for instance, because they have not in fact been in a care home for more than 28 days).

Age criteria

The draft regulations make provision for an award of disability assistance for children and young people to continue past the age of 18 if a person has applied for disability assistance for working age people but has not yet received a determination. Regulation 23 (2)(b) however makes the caveat that the payment would stop once they turned 19, even if no decision had been made on their application for DAWAP.

This risks creating a 'cliff edge' in the scenario that a decision was substantially delayed, a delay in notifying a person that they should make an application for the working age benefit, or because their application was delayed for a reason. We recommend removing the caveat that the benefit would when a person turns 19, if they have applied for DAWAP, but no determination has been made on their application.

Making payments
The draft regulations make provision for a payment of disability assistance to be paid to 'another person', other than the person specified on the application, if the claim is for a person over the age of 16 (regulation 24 (2)), or where the Scottish Government considers it inappropriate to be paid to the specified person (regulation 24 (3)). It is unclear whether these relate to appointees, to suspected financial abuse, or to give people responsibility for receiving their own payment upon turning 16. Clarity over how these regulations are intended to be used, and what safeguards will be put in place to prevent their misuse would be welcome.

s58 of the Act only allows appointees when a claimant is deceased, or when they are incapable within the meaning of the Adults with Incapacity (Scotland) Act. There is no specific power to appoint someone to act for a child. The Act should be amended to allow this.

The regulations (regulation 24 (1)) provide that where payment is made to the individual, payment is always made to the person specified in the application. This seems to lack clarity and raises the following potential problems:

- It appears to allow a child to make a claim for disability assistance for themselves – it is unclear if this is the policy intention.
- It allows Social Security Scotland a very broad discretion as to whom disability assistance is paid – without any clear guidance or a process for managing any disputes. Such disputes may arise either between possible carers or between the child and their carers, particularly when the young person turns 16. There are potential benefits to having a system that allows the agency some discretion as to whom they make payments, but clear guidance must be published and there must be a clear route to challenge any decision and allow an independent body, such as the SPSO, to offer an independent route to challenge decisions on who is responsible for a claim.

When an application is to be treated as made and beginning of entitlement to assistance
It is somewhat unclear what situations draft regulations 25 (4) and (5) relate to.

The regulation that determines the date of claim (Reg 25(4)) lacks clarity as to what the information required to 'construct a record is'. Whilst this could be clarified in guidance it would be better to have a clear legal way in which the date of claim is established, for example by stating that any notification of the intention to claim as sufficient to secure the start date of eventual entitlement.

Determinations without an application (DWA)

Right to review
We are concerned that the draft regulations do not provide an effective mechanism to challenge a refusal to change an individual's ongoing entitlement to DACYP. This is a significant loss of rights compared to the current DLA rules. We believe there must be an absolute right to either get a review of your ongoing award, or be able to appeal a decision not to review an ongoing award. The draft regulations (Reg 30) do

not give this right. The problems this create are illustrated in the areas of the UKs social security system where this right does not exist, for example in certain situations regarded ESA and WCAs.

A person making a repeat claim for ESA, who has already been found "fit for work" will only get ESA pending their work capability assessment, or subsequent mandatory reconsideration or appeal, if they can provide new evidence to suggest their condition has got worse or they have a new health condition. (Normally, ESA is paid on the basis of a fit note from the GP pending assessment.) The DWP decides whether their health condition has substantially deteriorated or they have a new health condition. There is no route to challenge this decision. This means claimants can be left without money for long periods of time and do not have an opportunity to make their case.

In the context of disability benefits, if a child's condition has worsened a parent can ask the DWP to review the DLA award. If the DWP does not think it merits an increased award, the parent has a right to appeal. This is an important right to maintain. Social Security Scotland will not get all these decisions right first time. In practice, while this is an important right, it is one that advisers take care is exercised with caution. People are not advised to ask for reviews unless they have a strong case because of the risk of losing the award they already have.

Suspected fraud

In cases of suspected fraud, draft regulations 30 (1)(c) and (d) would appear to allow the Scottish Government to stop a person's benefit payment, prior to an investigation having concluded and for allegations to be proven. In a rights-based system, it is important that this only occurs once it has been proven that fraud has been committed. We would recommend that a payment is not stopped unless fraud is proven, or that Short Term Assistance is made available to someone challenging an allegation or decision.

Other DWA

There are no powers to undertake a DWA as a result of test cases, the current DLA regulations allow for an award to be superseded from the date of a test case decision.

Where there is a change of circumstances that affects entitlement but wasn't a change that the individual was required to notify under s56 of the Act, the regulations do not say the date the DWA should take effect from.

We are particularly concerned that regulation 33 allows retrospective changes to an award where an individual's condition has improved gradually over time. The date of the DWA is set by the date on which the 'change' took place. This could lead to overpayments and potential prosecutions for fraud for individuals whose condition has improved gradually over time. It contrast, the DLA rules provide that an individual's entitlement is only altered from the date of a change if it could reasonably be expected that the person knew of the relevance of the change.

Regulation 30 could be split into those situations where a DWA 'must' be done and those where it 'may' be done. Examples of where it 'must' be done would be when requested by an individual's, where a claimant leaves a care home/residential school and under Reg 30(1)(a)(ii),(iii),(iv),(b),(e) and (g). Examples of where it may be done would be under 30(1)(a)(i),(iv),(v) & (f). Without that the Scottish Minister would, for example, be required to make a DWA under 30(1)(a)(v) even if the individual has made an agreement to pay back the money, or under 30(1)(f) in almost any circumstances.

Period for re-determination request – agency timescales

Evidence from CAB clients has consistently shown that detriment has been caused due to lengthy waits for a decision to be made on a mandatory reconsideration request, both in terms of hardship and causing stress and worry.[19] Some members of SCORSS are concerned that setting the time limit at 56 days (8 weeks) is too long, given that a person will have already had to wait for an original determination on their application, and that some evidence will have been gathered in making the original determination.

We note that the Social Security (Scotland) Act allows a determination to be done after this period. An individual may be told that they can choose to wait for a redetermination before appealing, but in practice they should always appeal within the attached 31 day time limit. If they do not, there is no legal obligation for the agency to make a determination.

We do note however that in order to avoid unnecessary appeals it is important that this time limit is long enough to allow the agency to gather sufficient information to carry out the re-determination. Because the determination will not be able to be changed once an appeal has been passed to the tribunal, if further information or evidence is received after the deadline has passed the agency will not be able to carry out a re-determination unless the individual has waived their appeal rights.

Regardless of the time limit that is set the agency should collect data on the number of cases that go to appeal under S45 of The Act (where a re-determination is not made within the time limit), publishing statistics on how many cases miss the deadline, how many voluntarily extend the deadline and how many are won at appeal. This will allow the agency to determine how the timescales are working.

Period for re-determination request – individual timescales

The draft regulations (Reg 34) reduce individuals' rights and risk creating an additional complex layer of decision making.

The draft regulations reduce the time limit in which an individual can request a redetermination from 13 months for DLA to 42 days, unless the individual can show good reason. This creates an additional decision-making process - to determine good reason. The Act allows individuals to appeal a decision to refuse to accept redetermination request outwith the 42 day time limit, which will involve funding tribunals to consider this question.

[19] Page 20 – 21, Citizens Advice Scotland response to Consultation on Disability Assistance in Scotland, May 2019 https://www.cas.org.uk/publications/cas-response-consultation-disability-assistance-scotland

Extending the time limit to request a redetermination to 365 days would resolve these issues. There would still be a strong incentive for an individual to submit a redetermination request as soon as possible and clear publicity and guidance to individuals and those supporting claimants should ensure that the agency is able to balance their workload.

Eligibility criteria and mental health

Eligibility criteria as drafted in Part 3 of the regulations do not adequately allow for people and their families to share the impact of the young person's mental health.

- Part 3, section 5 – Care component criteria – should be amended to include 'psychological distress' in relation to daily activities as an eligibility criteria.
- The term "significant danger to the individual or others" (Part 3, 1(b)) should be defined in the regulations. The Definition should not be left to guidance.

Part 3 6-7 -Mobility requirements – are overly restrictive in relation to mental health, in regard to psychological distress and mobility. The test will still be that the child requires supervision even if psychological distress is included – should we therefore be asking to remove the supervision test? This would be a significant change but potentially more likely to be useful in these cases?

- The definition of "severe mental impairment" in Part 3, 7 (6) of the regulations should be amended to remove reference to brain development and functionality.
- The Definition of and "severe behavioural difficulties" in Part 3, 7 (7) should be amended to include definition of terms such as "extreme"
- Part 3, 7 (1) should be amended to include 'psychological distress' resulting from making journeys as an eligibility criteria for the higher rate mobility component

Mental Health – Care Component

We know that mental health is a significant issue for young people in Scotland, with half of all mental health problems in adulthood beginning before the age of 14; and three quarters before 25.[20] And evidence showing that three children in every class will have experienced mental health problems by the time they're 16.[21] Despite this the current case load for young people in receipt of DLA shows that only 22.5% of DLA recipients in Scotland between the ages of 0-18 receive the benefit due to their mental health.[22] Of those receiving due to their mental health 48.4% have a behavioural disorder and 47.5% Hyperkinetic Syndrome (ADHD).[23] This contrasts with the adult case load for PIP where 39.1% of people in receipt of PIP in Scotland

[20] Kim-Cohen et al., 2003; Kessler et al., 2005

[21] Green et al 2005, Mental Health of Children and Young People in Great Britain 2004, cited in Minds key statistics

[22] StatXplore DLA Cases in Payment – Data from May 2018 [accessed April 2019]

[23] StatXplore DLA Cases in Payment – Data from May 2018 [accessed April 2019]

receive it due to their mental health – higher than any other group of conditions or disability.[24]

We are concerned that eligibility criteria as drafted in Part 3 of the regulations do not adequately allow for people and their families to share the impact of the young person's mental health. For example the criteria for the care component (5 (1) (a) – (c)) focuses on the need for support or attention in connection with "bodily function" or continual supervision of the person to avoid "substantial danger to the individual or others".[25] We believe this is overly narrow and does not take into account factors such as psychological distress in regards to daily activities. We would like to see the regulations amended to include eligibility in respect to the impact of psychological distress, including when not related to bodily functions or risk of danger to others.

It is also essential that terms such as "significant danger to the individual or others" are defined clearly and incorporate previous case law where relevant. We would strongly recommend that definitions be made in the regulations themselves to give them legal authority rather than solely in guidance.

Mental Health – Mobility Component

In regards to mental health the draft regulations outline that someone will be eligible for the higher rate mobility component if they require substantially more guidance or supervision than would be typically be expected of someone that age, due to:

- "(d)the individual is entitled to the highest rate care component of disability assistance and has a mental impairment, accompanied by significant behavioural difficulties arising from the impairment
- (g) the individual has a severe mental impairment,
- (h) the individual has severe behavioural difficulties."

This is a further test not applied to DLA and represents a restriction in entitlement which we would not support. We also note that the above may be drafting errors. If not, (d) is irrelevant – a claimant will meet (g) and (h) before they meet (d).

We also believe that the definitions for both "severe mental impairment" and "severe behavioural difficulties" are overly restrictive.

In particular the definition of severe mental impairment is tied to brain development or functionality. We see no rational for this, with many mental health problems not having a dependence on brain development or functionality.

Similarly the definition of severe behavioural difficulties is overly restrictive with its dependence on behaviour requiring physical restraint and constant supervision. Terms such as "extreme" also require careful definition. We strongly recommend that this should be outlined in the regulations themselves to give them legal weight rather than relying on guidance alone.

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[24] StatXplore PIP Cases with Entitlement [accessed January 2020]

[25] Scottish Government Draft Statutory Instrument The Disability Assistance for Children and Young People (Scotland) Regulations 2020 Part 3 5-(1)

We believe that the regulations should be amended (Part 3, 7 (1)) to include 'psychological distress' resulting from making journeys as an eligibility criteria for the higher rate mobility component. This should be tested with the Experience Panel.

The Scottish Government have not taken the opportunity to relax the conditions around severe mental impairment and behavioural problems (Reg 7(2)(d)). The DLA rules require the child to get the high rate of the care component as well as having severe mental impairment and behavioural problems. This excludes any child who doesn't have night time needs, as the high rate of the care component is only payable if a child has needs during both the day and night (or is terminally ill). The removal of this rule would only affect a small number of children, but allow these families, whose child has severe difficulty mobilising safely, to access help with mobility either by providing additional income or access to the Motability scheme.

Mobility criteria

The low rate mobility test - which compares the needs of a child to those of other children without the same impairment (Reg 6(2)) - reduces what were two tests for DLA to a single test. The equivalent test for the care component (Reg 5(2)) retains both of the tests that DLA currently uses. If the drafting remains as it is, then children who need a different ***type*** of guidance or supervision than a child of the same age, but not a 'substantially greater' ***amount*** of guidance or supervision may no longer qualify.

The high rate mobility test includes an additional requirement that a child needs 'substantially more guidance or supervision' than a child the same age (Reg 7(1)), as well as the existing DLA tests or entitlement. It appears that this is a deliberate policy change – as there is no equivalent DLA provision. If this is the case, it will mean that some children who would have been entitled to the high rate mobility component of DLA will not be entitled to the same rate of DACYP.

The regulations do not provide a lower age limit for the higher rate of the mobility component, except for where a child is entitled under the special rules for terminal illness. If this is a change in policy it would be welcome.

Case Managers and Specialist Advisors

Part 10 of the Scottish Government's Policy Note, published with the draft regulations states that regulations will set out so that Social Security staff making decisions about Disability Assistance entitlement must undertake training as required by the Scottish Ministers, with Specialist Advisors having prior experience of providing health or social care whether through paid employment or voluntary work, for at least 12 months.

We welcome this commitment but believes that all three aspects of the Suitably Qualified Assessor provisions of the Social Security (Scotland) Act 2018 should apply. This includes the assessor having held "a particular position", as well as having training and experience.[26] We believe the Scottish Government and Agency should take further advice from health and disability experts, as well as people with

[26] Social Security (Scotland) Act 2018 Section 13

lived experience to determine a list of particular positions that Specialist Advisors should hold to meet the criteria under the Act as suitably qualified.

We believe that Specialist Advisors, with specialist training, experience and professional experience in mental health should be used for all applicants where the person's main condition relates to their mental health and where there is a gap in information or discrepancies in their evidence relating to their mental health.

Submission 6 from the Scottish Association For Mental Health

Introduction

This paper sets out SAMH's views on the draft Disability Assistance for Children and Young People (Scotland) Regulations 2020. This to help inform SCORSS's response to the Scottish Commission on Social Security (SCoSS) request for comment on the draft regulations.

Key Points

SAMH welcome many aspects of the regulations including: The extension of entitlement to 18 where a young person is in receipt of benefits prior to their 16th birthday; and the introduction of the Child Winter Heating Assistance,

Below are the key changes SAMH would like to see. A fuller discussion of key points related to mental health follows this at the end of the paper.

- While we welcome the extension of the period to request a re-determination to 42 days, we believe the period for the Agency to undertake a redetermination is too long. We would like Part 10 34(2) amended to reduce the period for the Agency to undertake a re-determination to 28 days.
- Eligibility criteria as drafted in Part 3 of the regulations do not adequately allow for people and their families to share the impact of the young person's mental health.
    - Part 3, section 5 – Care component criteria – should be amended to include 'psychological distress' in relation to daily activities as an eligibility criteria. Psychological distress should not be tied to bodily functions.
    - The term "significant danger to the individual or others" (Part 3, 1(b)) should be defined in the regulations. The Definition should not be left to guidance.
- Part 3 6-7 -Mobility requirements – are overly restrictive in relation to mental health.
    - The definition of "severe mental impairment" in Part 3, 7 (6) of the regulations should be amended to remove reference to brain development and functionality.
    - The Definition of and "severe behavioural difficulties" in Part 3, 7 (7) should be amended to include definition of terms such as "extreme"
    - Part 3, 7 (1) should be amended to include 'psychological distress' resulting from making journeys as an eligibility criteria for the higher rate mobility component

Mental Health – Care Component

As outlined in our response to the Social Security: A Consultation on Disability Assistance in Scotland we have a number of concerns about young people with mental health problems access to DACYP.[1] We believe these concerns still apply to the regulations as drafted.

[1] SAMH Response to: Social Security: A Consultation on Disability Assistance in Scotland 2019

We know that mental health is a significant issue for young people in Scotland, with half of all mental health problems in adulthood beginning before the age of 14; and three quarters before 25.[2] And evidence showing that three children in every class will have experienced mental health problems by the time they're 16.[3] Despite this the current case load for young people in receipt of DLA shows that only 22.5% of DLA recipients in Scotland between the ages of 0-18 receive the benefit due to their mental health.[4] Of those receiving due to their mental health 48.4% have a behavioural disorder and 47.5% Hyperkinetic Syndrome (ADHD).[5] This contrasts with the adult case load for PIP where 39.1% of people in receipt of PIP in Scotland receive it due to their mental health – higher than any other group of conditions or disability.[6]
SAMH is concerned that eligibility criteria as drafted in Part 3 of the regulations do not adequately allow for people and their families to share the impact of the young person's mental health. For example the criteria for the care component (5 (1) (a) – (c)) focuses on the need for support or attention in connection with "bodily function" or continual supervision of the person to avoid "substantial danger to the individual or others".[7] We believe this is overly narrow and does not take into account factors such as psychological distress in regards to daily activities. SAMH would like to see the regulations amended to include eligibility in respect to the impact of psychological distress, including when not related to bodily functions or risk of danger to others.
It is also essential that terms' such as "significant danger to the individual or others" is defined clearly and incorporate previous case law where relevant. We would prefer definitions to be made in the regulations themselves to give them legal authority rather than solely in guidance.

Mental Health – Mobility Component

In regards to mental health the draft regulations outline that someone will be eligible for the higher rate mobility component if they require substantially more guidance or supervision than would be typically be expected of someone that age, due to:

- "(d)the individual is entitled to the highest rate care component of disability assistance and has a mental impairment, accompanied by significant behavioural difficulties arising from the impairment
- (g) the individual has a severe mental impairment,
- (h) the individual has severe behavioural difficulties."

The regulations provide the following definitions for both "severe mental impairment" and "severe behavioural difficulties":

> *(6) An individual is to be taken to have a severe mental impairment, for the purposes of paragraph (2)(g), if the individual has a significantly impaired capacity for judgement because of suffering from*
>
> *(a) a state of arrested development as a result of a failure of the individual's brain to grow in the way normally expected, or*
>
> *(b) a deficiency in the functionality of the brain as a result of its incomplete physical development.*

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[2] Kim-Cohen et al., 2003; Kessler et al., 2005

[3] Green et al 2005, Mental Health of Children and Young People in Great Britain 2004, cited in Minds key statistics

[4] StatXplore DLA Cases in Payment – Data from May 2018 [accessed April 2019]

[5] StatXplore DLA Cases in Payment – Data from May 2018 [accessed April 2019]

[6] StatXplore PIP Cases with Entitlement [accessed January 2020]

[7] Scottish Government Draft Statutory Instrument The Disability Assistance for Children and Young People (Scotland) Regulations 2020 Part 3 5-(1)

(7) An individual is to be taken to have severe behavioural difficulties, for the purposes of paragraph (2)(h), if the individual exhibits disruptive behaviour which—

(a) is extreme,

(b) regularly requires another person to intervene and physically restrain them in order to prevent physical injury to the individual themselves or another person or damage to property, and

(c) is so unpredictable that another requires to be awake and watching over the individual while they are awake.

SAMH feels these definitions are overly restrictive. In particular the definition of severe mental impairment is tied to brain development or functionality. We see no rational for this, with many mental health problems not having a dependence on brain development or functionality.

Similarly the definition of severe behavioural difficulties is overly restrictive with its dependence on behaviour requiring physical restraint and constant supervision.

Terms such as "extreme" also require careful definition. This should be outlined in the regulations themselves to give them legal weight rather than relying on guidance alone.

We believe that the regulations should be amended (Part 3, 7 (1)) to include 'psychological distress' resulting from making journeys as an eligibility criteria for the higher rate mobility component. This should be tested with the Experience Panel

Case Managers and Specialist Advisors

Part 10 of the Scottish Government's Policy Note, published with the draft regulations states that regulations will set out so that Social Security staff making decisions about Disability Assistance entitlement must undertake training as required by the Scottish Ministers, with Specialist Advisors having prior experience of providing health or social care whether through paid employment or voluntary work, for at least 12 months.

SAMH welcomes this commitment but believes that all three aspects of the Suitably Qualified Assessor provisions of the Social Security (Scotland) Act 2018 should apply. This includes the assessor having held "a particular position", as well as having training and experience.[8] We believe the Scottish Government and Agency should take further advice from health and disability experts, as well as people with lived experience to determine a list of particular positions that Specialist Advisors should hold to meet the criteria under the Act as suitably qualified.

We believe that Specialist Advisors, with specialist training, experience and professional experience in mental health should be used for all applicants where the person's main condition relates to their mental health and where there is a gap in information or discrepancies in their evidence relating to their mental health.

[8] Social Security (Scotland) Act 2018 Section 13

Submission 7 from the Welfare Rights Officers Forum

The Welfare Rights Officers Forum (WROF) is a fully constituted body whose aims are to support members to deliver welfare benefits advice, assistance and advocacy and to disseminate good practice. We also provide information on practices and interpretation of legislation on a Scotland-wide basis and aim to raise matters of mutual concern, on behalf of our members, with statutory authorities.

Membership is open to any person that is providing welfare benefits advice, assistance or representation, without charge to service users, working within the Housing sector. Membership can also be granted to others providing free advice and assistance in other sectors.

The following document outlines our response to the main sections of the draft legislation. Whilst much of the legislation is largely a replication of existing DLA regulations, we acknowledge some welcome changes.

In consultation with members the following points have been highlighted:

1. We are heartened to see that proposed legislation appears consistent with the principles in the Scottish Social Security Charter as laid down in the Social Security (Scotland) Act 2018. The introduction of the following elements are very much appreciated:
    - The intended payment of Short Term Assistance (STA) during the period where a determination is being challenged is most welcome. This will prevent sudden 'cliff edge' loss of income for claimants who find themselves facing negative decisions which may well be overturned through the appeals process.
    - We also welcome the introduction of the Child Winter Heating Assistance. This will help families with disabled children and young people and reduce the likelihood of fuel poverty for those groups. We would question if this should be restricted to only those claimants in receipt of the highest rate of the care component. Should it be extended to those with high rate mobility and/or middle rate care component too? We also would express some concerns about the timing of this being based on entitlement for a date in September. Is the proposed date the most suitable and could some exceptions be made, perhaps for those diagnosed with terminal illness?
    - The extension to age 18 in some instances can be useful, but for some young people this could be problematic if a claim for Personal Independence Payment (PIP) would actually be more beneficial. Is this something which has been considered? Could a young person choose to claim PIP at age 16 (or its replacement in future) or will they be excluded from this by these new rules?

2. We particularly welcome the changes proposed in relation to terminal illness.
    - It is hard to imagine anything worse than a parent facing the death of their child. This change to the existing definition in DLA legislation is very much needed. When faced with the news that your child has a life limiting illness the last thing one needs is having to put a time frame on that. This will allow help to go to families at the most difficult time and is in keeping with a system which protects the dignity of those claiming assistance.
    - The addition of an automatic award of high rate mobility as well as high rate care component for those accepted as terminally ill (and over the age of 3) under this new definition is a positive development, as is the regulations which mean payments will not stop during periods a child or young person is hospitalised or in a hospice, for example.
    - How successful this approach will be depends largely on how well informed the registered medical practitioners are of this change. Most practitioners will be aware of the 'six month rule' from DLA and PIP claims and the DS1500 forms. It is important that the Scottish Social Security Agency ensures training is provided for relevant practitioners to avoid unnecessary confusion over this issue.

3. Amendments to the rules pertaining to dialysis are also an improvement on the existing DLA Regulations. This is a costly and difficult time for families of children who require such intensive treatments and this would ease the financial strain often experienced. It also means there will no longer be additional stress of proving that the child's care needs meet the required thresholds during this period, resulting in a much simpler claim process.

4. With regards to residence conditions, the following comments were given:
    - When transferring to another part of the United Kingdom a 3 month run on of DACYP is allowed. If a claim for UK based DLA is not processed within that timeframe could that be extended? Regulation 39 allows for Scotland to accept a UK DLA award. Is it possible to have reciprocal agreements with UK DWP to accept a Scottish Social Security award in the same way?
    - It is welcomed that there will be no additional habitual residence test for those moving to Scotland from within the common travel area (CTA) and that ordinarily resident would suffice in addition to habitual residence within CTA.

5. In terms of specific Regulations, the following observations were given:
    - Regulation 33(2) which allows for some flexibility in the treatment of changes in circumstances is viewed a positive change. This recognises that there may be occasions when notifying of a change in

circumstance timeously may be affected by conditions beyond a claimant's control and therefore it would be unjust for them to be penalised.

- There is some confusion around mobility Regulation 7(2) and (3) in relation to claimants with amputated legs/feet and it was felt that the existing DLA Regulation 12 (1) b and (4) seemed to be clearer. If the intention is the same why has the wording changed? If the intention is to change this then it was felt this is not clear.

In summary, the general response from our members is that the proposed legislation is broadly similar to existing DLA legislation, but where there have been changes these are positive changes which are welcomed and are consistent with the aims of the 2018 Act.