Scottish Campaign on Rights to Social Security (SCoRSS)

DACYP regulations

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[1]. 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.[2]

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 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.

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

[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

A comprehensive review of existing regulations, guidance and caselaw should be undertaken to ensure that important detail and rights are not lost upon transition.[3]

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 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

[3] 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

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:

1. 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.
2. 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.[4] 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

[4] 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

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.

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.[5] And evidence showing that three children in every class will have experienced mental health problems by the time they're 16.[6] 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.[7] Of those receiving due to their mental health 48.4% have a behavioural disorder and 47.5% Hyperkinetic Syndrome (ADHD).[8] 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.[9]

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

[5] Kim-Cohen et al., 2003; Kessler et al., 2005
[6] Green et al 2005, Mental Health of Children and Young People in Great Britain 2004, cited in Minds key statistics
[7] StatXplore DLA Cases in Payment – Data from May 2018 [accessed April 2019]
[8] StatXplore DLA Cases in Payment – Data from May 2018 [accessed April 2019]
[9] StatXplore PIP Cases with Entitlement [accessed January 2020]

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".[10] 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.

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

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

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.[11] 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.

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