

## **Disability and Carers Benefits Expert Advisory Group: Disability Assistance for Children and Young People Project Team**

To: Shirley-Anne Somerville, Cabinet Secretary for Social Security and Older People  
By e-mail

19 July 2019

Dear Shirley-Anne,

### **Disability Assistance for Children and Young People (DACYP)**

#### **Background**

Thank you for your letter of 7 February requesting advice on DACYP. The Group's DACYP Project Team<sup>1</sup> was pleased to consider this. In addition to core members of DACBEAG, the team involved individuals with relevant expertise to ensure the advice is thorough and well-informed. Please accept my apologies for reporting to you later than planned. This is a result of the phasing of the direct engagement meetings and limited opportunities for the project team to convene to develop and agree its advice.

Our advice is based on the best information currently available to us, but makes some assumptions about how the process of determining an entitlement to Disability Assistance will work. Should our assumptions prove incorrect, or new information become available, our advice may change.

We have had very productive discussions with your officials regarding the challenges raised in your letter and remain grateful for their support and co-operation.

We have taken part in a number of consultation sessions with legacy Child DLA applicants and recipients, mostly parents and carers of disabled children and young people, as well as some who had their claims rejected<sup>2</sup>. We are very grateful to families who gave up their time to meet us and to the organisations hosting these meetings. We present these findings and recommendations based on the consistent messages we heard. The recommendations are compiled by number, but represent composite recommendations, grouped by theme.

#### **A Holistic Support System:**

We heard that disability assistance is one important part of a whole range of support that parents and carers of disabled children need to access. The group noted that this support is provided by a wide range of voluntary and statutory services. In many of our conversations, parents and carers focused on the 'battles' they had routinely with education, health and social work services to ensure their children received the support they need. All of this takes an emotional and financial toll on family life. The

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<sup>1</sup> Project membership can be found in Annex A

<sup>2</sup> A list of the organisations hosting consultation sessions for the group can be found at Annex B

legacy system “can seem hostile on top of this.” The strongest message we heard was that applying for social security assistance should not be ‘yet another fight’.

***Example:*** Several parents spoke about the need to research and find support or services in their area, with one parent talking about being handed a ‘pack’ at diagnosis, which had contained some flyers for different groups but just leaving her to find a way to move forward after the diagnosis.

We were struck by how often parents or carers focused on common struggles with schools, health, housing and social work services, before moving onto the role of social security support. Often families face a lack of appropriate support and resourcing within these services. We heard examples of poorly understood conditions like Sickle Cell Disease, where there is a shortage of specialist knowledge within the NHS and education. This diminishes the evidence that can be drawn upon when applying for Child DLA and damages trust at the appeals stage – for example, where medical advisers have had to ask parents basic questions about the impact of such long-term conditions.

We are also aware that some disabled children, and their carers, are in contact with some services from pregnancy until transition to adult services. Many parents spoke of receiving information and support while their children were young, but this support stopped completely when they got older. Lack of support after transitions to adult services was a common concern among parents/carers. With the creation of Social Security Scotland (‘the Agency’), there is a unique opportunity to ensure that every child receives the support they need.

Referrals could be built into the Agency’s process and feed into the local delivery role that the agency is creating. This is also an opportunity for the Scottish Government to collect information about the services that are provided locally, identify gaps and look at improving local provision to be fit for purpose in the future. In this way, DACYP can be designed to serve as part of a wider system of support for children, young people and families.

#### **Recommendation 1:**

**A claim for disability assistance should be part of a larger ‘holistic assessment’ and trigger referrals to other sources of support. The Agency should ensure:**

- **Clear information about rights and entitlements to other social security payments and services.**
- **Information and signposting to Advocacy services, with clarity on how disabled children, young people and families can use appropriate advocacy support to navigate the system.**
- **Active referral pathways so that disabled children, young people and their carers can be referred to all appropriate services (including education, health, housing and transport) with monitoring of the effectiveness of different referral strategies (e.g. sign-posting,**

**appointment referral, co-located and embedded support in local settings) and take up.**

### **The Initial Application Process**

We understand the application process to include both the initial contact with Social Security Scotland ('the agency') to make a claim and the completion of a selfassessment form providing details of the child's impairment, and where relevant long term conditions.

We heard that many parents and carers find the process of applying for DLA for their children to be stressful. When first faced with the claim form many individuals felt unable to complete it, were only able to provide partial information or completed it over a lengthy time period which caused them to lose entitlement.

*"Extreme problems and barriers to getting a diagnosis meant we were only able to give part of the information. It was all an uphill struggle and waiting times for support caused delays too. People settle for less as the stress is terrible".*

### **Recommendation 2:**

- **Where an individual contacts the agency to make a claim for DACYP, the date of the claim should be set at that first point of contact.**
- **The individual should be allowed as long as they need to complete the claim and assessment process.**
- **That the Agency should monitor and report on the length of time it takes from first contact to completed application.**

### **Recommendation 3:**

- **Multiple communication channels are needed to provide information about the application process and should be available as a matter of course.**
- **The preferred communication methods for applicants should be recorded and used.**
- **Accessible approaches are often widely appreciated by people in general, not just those with specific communication barriers. As we have previously indicated in our advice on the Charter, we recommend using additional, innovative methods of communication, including infographics, interactive material and audio versions.**

### **Application Form**

The group understands that the desire to make the form easier to complete must be balanced against the requirement for the case manager to get sufficient information to make an accurate determination. Where support is provided, the Child DLA form at present does allow the DWP to collect sufficient information to make a decision about entitlement, and this should not be lost when a DACYP form is developed.

However we heard that parents and carers have huge difficulties completing the application form. We were consistently told that the application process caused

additional stress to the family. It was noted that those who are most in need of help, such as those with health problems themselves, find the system the most difficult to navigate.

Difficulties outlined included:

- The language of the forms and communication currently does not encourage people to apply,

*“Make the application form more streamlined and simplified. There is far too much scope for duplication and they could cut down on repetitive questions”*

- That the form focused on the problems faced by the child. Parents felt that they had to present the ‘bleakest day’ experiences of their child, rather than allowing for a fuller description of the child’s needs and the support they would benefit from.
- Many parents described it as upsetting and crushing to look over a written summary of their child’s difficulties and challenges and also felt that this process left them more anxious, depressed and concerned for their child’s future,

*“It made my heart hurt when I looked back at the form and realised that was their life... and I felt terrified about their future”.*

- Many described completing this kind of form as an acquired skillset or that the form was not intuitive or user-friendly. It was described as dauntingly long, including sections which were not considered age-relevant for their child, and did not sufficiently allow for information beneficial to the claim to be expressed easily,

*“We applied for DLA and had to appeal 3 times. Then eventually, after 14 months, we were finally awarded middle rate care and low rate mobility- after attending a tribunal, with evidence from doctors and psychiatrists. Building a case takes a very long time because they don’t believe you and you need layers of evidence.”*

However, we also heard that where individuals had the correct support, or had previous experience of the system, they were better able to navigate the application form and process. We were told that support depended on availability, and that individuals referred to support services were, in some instances, unable to get the support that was needed:

*“Waiting times for Advice Services can be too long and they can’t always provide the specialist support needed.”*

The group understand that DWP have provided such assistance in the past, which enabled some claimants to complete the claim and assessment form. Services such as the ‘Benefit Enquiry Line’, and visiting officers, were a useful resource for

individuals making a claim for disability benefits. The group noted the distinction between advocacy, welfare rights advice, appointeeship and help with completing the application forms. While we heard some reservations from parents about placing trust in this kind of assistance being provided directly by an agency which also determines eligibility, we believe this should be tested and evaluated.

#### **Recommendation 4:**

- **The agency should trial a system of claims support provided by the agency for any individual looking for assistance to claim DACYP. A claims support service provided by the agency would have the benefit of being available throughout Scotland and provide a consistent standard of support.**
- **This would be expected to complement the system of assistance available from welfare rights and other advice providers but would ensure timely support is still available where other local provision is patchy.**

#### **Assessment Process**

There was a general consensus from the groups that we spoke to, whilst no child should be required to undertake a face to face assessment, any parent or carer should be able to request a face-to-face meeting with someone from the Agency to explain their child's needs if they feel this is the most effective way to do so. We agree that this would be a useful provision.

The group heard of many circumstances where other professionals who have contact with the child were not entirely aware of the child's full range of restrictions. Parents felt strongly that this was the case when teachers were asked to provide information about the child's needs in the school environment and many had examples of negative decisions being made and based on the information provided by teachers. We heard about 'masking' where a child has learned to present themselves as 'normal' to others in order to be accepted. Many parents, carers and kinship carers talk about a 'coke bottle' or 'pressure cooker' effect, where children try hard to fit in at school and that the stress of this may be missed by others and yet result in increased outbursts and distress at home. Kinship carers told us of the trauma-related symptoms experienced by children and young people (e.g. bedwetting, attachment anxiety) which were not visible to others. Again, we heard that many parents and carers felt that no one else understood their child in the way that they did and that they were the best person to provide a more holistic account that reflects the child's needs and capabilities across a range of aspects of the child's life.

*“He plays the joker to cover up not understanding at school, comes home and it's like a pressure cooker. He masks the problem and then comes in the door, strips off and jumps in the shower screaming, but he's “fine” at school. Then the problem looks like it's at home”*

Further testimony from parents and carers highlighted the primacy of their own supporting statements. It was also felt strongly that appropriate sources of

supporting evidence are best identified by parents and carers and then contacted by the agency.

**Example:** *One parent spoke about putting in two different applications for her two children. For one application no one was contacted in terms of her supporting evidence (she was turned down) and for the other they contacted everyone on her form and it was approved before a diagnosis was made. She therefore believed that the system was very variable and heavily dependent on who processed the application.*

The group have considered the importance of family testimony in relation to functional impacts and extra costs – for example, heating, laundry, transport. Particularly where there is a shortage of expertise around the impacts arising from an impairment or condition, the input from parents and carers need to be reflected more fully in the claims process.

The Advisory Group believe that the recommendations given in previous advice notes covering auto-entitlement and sources of evidence should apply to DACYP. The group noted that Child DLA legislation provides auto-entitlement to certain groups of claimants<sup>3</sup> and whilst we do not think this should be extended, these rules should continue to apply in DACYP. The group also noted that a claimant's entitlement to DLA is enshrined in legislation and this should be maintained in DACYP.

#### **Recommendation 5:**

- **An individual claiming DACYP should be able to request a face to face meeting with the agency to explain the full range of their child's needs.**
- **Supporting evidence should only be required in the circumstances outlined in our previous advice note. Parents and carers are best placed to identify the most appropriate supporting evidence. Case managers should be aware that professionals who have contact with a child are not always aware of the child's full range of restrictions.**
- **The rules about entitlement to DACYP should be included in legislation to ensure that individuals have the same rights as they have under the current system.**

#### **Decision Making**

We were increasingly made aware of the disparity in outcomes between families living with the same conditions. The ability to decide the limits of a condition can appear arbitrary, or based on a narrow understanding of functional impact which is often individualistic. There is a need to better reflect the range of impacts experienced and the needs that may be met through disability assistance.

Example: One parent spoke about having a nursery place for one of her two children with autism, 5 days a week. However, she is not able to reliably get on the bus with her son due to his severe distress. The distance is too far to

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<sup>3</sup> For example, some children on renal dialysis, some children who are visibly impaired or blind and deaf.

walk. On some days she takes a taxi, but this is expensive and it means her son is only able to attend nursery a couple of days a week. She did not believe criteria for assessing mobility assistance were helpful in her case.

#### **Recommendation 6:**

- **The group sees scope for revisiting the criteria for decision making following the safe and secure transition to DACYP.**
- **The dichotomy of balancing individual needs against the need for a transparent and consistent system means the Group would see this as something that would need to be monitored and reviewed.**

#### **During the Decision Making Process**

We heard that many individuals felt lost during the decision making process. Often they faced long delays and felt there was a lack of information available about their claim. The group would welcome a commitment to clear timescales. Often claimants talk about a mismatch in terms of deadlines, with more of the onus and pressure on applicants than the decision-making body. We are mindful of the need to balance timely responses with accurate decision-making and clear communication.

The group considered the proposed change under the Scottish system, so that a request for redetermination must be made within 31 days of the date of the determination, unless there is good cause for a later request. This new determination can then be appealed within 31 days, unless there is good cause for a later request. The Agency would have 40-60 days to carry out the redetermination. In contrast, in the GB reserved system, a claimant can request a 'mandatory reconsideration' within a month of the decision. A 'late' request can be made up to 13 months after the date of the decision. If the DWP refuse to accept a late request then the claimant has a legal right of appeal directly to the tribunal against the original decision. In practice this means that in the GB legacy system a decision can be challenged up to 13 months after a decision is made without having to show 'good cause'. The current proposals mean that individuals in the Scottish system would have more restricted appeal rights. We believe that individuals in the Scottish System should have the same rights as they currently have under the GB system.

We considered if it would be useful for the applicant to be given contact details of someone working on their case within the Agency. We are also mindful that we don't want to introduce additional delays into the process, and that there may be an obligation for different members of staff to deal with a claim at different points in the determination, re-determination and appeals process. However, we are aware that this is often a distressing time for families and having a point of contact at the agency may be useful for individuals and allow greater accessibility and transparency. Many parents said they felt ongoing communication with updates on progress would be helpful and reassuring.

#### **Recommendation 7:**

- **That the Agency has clear policy and guidance in terms of how applicants can be kept informed about their claim.**

- That the time allowed to ask for a re-determination is extended beyond 31 days to ensure that applicants in Scotland retain the rights that claimants of DWP disability benefits currently have.
- That the application of 'good cause' should be broad enough to ensure that individuals have the same rights as they currently enjoy.
- That the Agency runs an evaluated trial giving claimants contact details within the agency to provide them with updates and any relevant information during the claim process and reflecting their preferred communication method.

## **Stigma**

Parents and carers told us about the stigma they often felt around claiming social security benefits. Within the stakeholder sessions, repeated reference was made to people reporting that they felt distrusted in the application process or that the system was set up to 'trip them up'. Even when they were awarded benefits, this wasn't always enough to allay their suspicions. Many parents noted that they felt the need to justify what they did with the money.

***Example:** One parent noted that when the money arrived in her account it was before the letter informing her that she would receive it. She was scared to spend it.*

Claimants repeatedly mentioned feeling judged by peers, medical professionals, those delivering social security and, in some cases, agencies that were providing support including schools, because often other people are not familiar with the needs of their child,

*"I feel like we're being blamed or judged- not believed and listened to. I had to give up my job as it wasn't possible to balance caring and working so money is already tight. I feel guilty that I can't save up...for ...extras compared with working parents but we need it to live- to pay for the clothes, the transport, the heating- basically the extra costs of disability"*

This stigma around social security is a barrier to some claimants making an application, and causes stress and worry for claimants during the process of claiming.

We recognise that the stigma associated with social security is felt by claimants across the range of benefits, and is not only an issue for DACYP, and we support the emphasis placed by the Scottish Government and the agency on reducing that stigma. In doing so, we advocate that communications incorporate a focus on the importance and value of supporting disabled people and children to fulfil their potential. The group welcomed the work that has been done by the Scottish Government to promote uptake of benefits for older people with the intention of challenging the stigma that has been created around claiming social security by use of a rights based approach.

## **Recommendation 8:**

- **The way that the Scottish Government communicates in terms of social security payments plays a key role in fighting stigma. The group recommends the continued use of open communication as well as advertising of payments**
- **A clear message is needed about Social Security as an investment in the people in Scotland and specifically, that disabled people and children face additional costs and require assistance to have a life with dignity and reach their potential. This would be consistent with the distinctly Scottish approach of designing and delivering social security alongside people with direct experience, rooted in human rights.**

### **Training of Social Security Staff**

A large part of the attitude towards those claiming benefits will be set by the Agency in the language used, communication methods and approach to engaging with applicants.

In addition to feedback from Experience Panels and Client Insight, there is a desire among Disabled People Led organisations as well as parents and carers to engage directly in training sessions with agency staff.

Direct participation has been found to be an effective and powerful tool in creating a respectful and responsive service which can be built on better understanding of people's needs, as embedded in the Christie Commission recommendations. In this way, people's lived experience can help to build understanding, insights and an improved quality and consistency of service provided by agency staff, especially assessors.

Young people with learning disabilities aged 15-18, taking part in a discussion hosted by the Scottish Commission for Learning Disability (SCLD), identified the qualities they wanted to see in social security staff:

- Using the right language for the right person e.g. BSL, Makaton
- Clear language, broken down: "don't use fancy words"
- Staff who "understand us" including some with experience of disability personally or within their families
- Being friendly, respectful, kind, honest, positive and mature in the way they speak
- Asking about your interests, not focusing only on disability

### **Recommendation 9:**

- **People with lived experience of disability- in this case disabled children and young people, their parents and carers - should be fully involved in designing and delivering training to agency staff, both face-to-face and making use of existing resources <sup>4</sup>.**

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<sup>4</sup> For example, film clips produced with disabled children, young people, parents and carers by Mindroom: [http://www.mindroom.org/index.php/help\\_and\\_support/resources\\_for\\_parents](http://www.mindroom.org/index.php/help_and_support/resources_for_parents)

### **Peer Support and Welfare Advice**

Given the issues around stigma and take-up, parents reported that access to peer support for them and their children is an essential support mechanism. Most often the best information and practical advice comes directly from those with lived experience and parents/young people are more likely to trust those who share similar barriers and challenges:

*“Parents themselves know best- look to them and learn, as they’ve been through it ahead of us”*

The group noted that the support peer-to-peer organisations can provide is invaluable and that there is a need to provide this type of support system and assistance to parents at what is often a stressful and isolating time.

Welfare rights advice is needed to help individuals understand their entitlements and particularly when a claimant is unhappy with a determination or wants to challenge a decision. It is essential that such Welfare Rights advice is freely available, fully accessible and understanding of the particular needs of parents/carers, many of whom are themselves disabled people

### **Recommendation 10:**

**That the Scottish Government continues to support the work of peer support organisations, whilst developing a system to support applications within the Agency. Social Security Scotland should provide:**

- **Information about peer support organisation to ensure information about support, services and wider rights reaches those who need it.**
- **Information about peer support organisations which celebrate positive role models of both disabled children and young people and parents/ carers to offer hope and ‘know-how’ in terms of accessing wider opportunities.**

### **Recommendation 11:**

- **People with direct experience of disability and caring should be encouraged to work with Social Security System as employees as well as volunteer advisers. Drawing upon their expert insights would actively build greater trust in the system.**

### **Take Up**

The group is aware that there are families who would be entitled to disability assistance and who do not current receive it. They welcome the commitment, enshrined in the Social Security Act, through a strategy to increase take up.

During consultation events, the Group heard that many eligible parents and carers do not consider themselves carers or their children disabled.

**Example:** *One parent spoke about the difficulty of accepting this type of label for her child. She had struggled to accept a comment from her sister and had only really understood that there was something wrong with her child when the Health Visitor had sent her to a support group.*

The group felt that different advertising messages may work better for different elements of the population, and that tailored messages for parents and carers of disabled children and young people will be needed.

#### **Recommendation 12:**

- **The Scottish Government should trial a routine enquiry where all parents are referred for a benefits check at certain key milestones. This should be developed with people with direct experience and other expert stakeholders and, if successful, be rolled out across Scotland.**
- **This would be in addition to tailored communications, designed alongside disabled children, young people parents and carers, to address the diverse needs of the population.**

#### **Transition**

The group felt that clear communication from the agency was important at any moment of transition and will be the most important element of the transition from the UK system to the Scottish system to minimise stress. We would like to emphasise the importance of stability, the need for open and transparent provision of information in advance, and the requirement for a system to help as quickly as possible anyone who falls through the net.

Parents welcomed the proposed increase in DACYP eligibility to age 18, but some felt that the upper age limit for DACYP should be at least 21, which fits with the age limit for accessing the Scottish ILF Transitions Fund. Parents experienced so many different age related transition points and were keen to see these streamlined as much as possible.

In terms of the child to adult transition from what is currently Child DLA to PIP, the group feel that any of 18, 21 or 25 years could be supportable, and welcomes the automatic extension of Child DLA to 18 years whilst the system is being transferred. We propose that the impact of setting the new threshold at age 18 is evaluated and subject to review.

It was noted that this child to adult transition will also be affected by the needs or ability of the child to take on financial responsibility. There will be children who are covered by 'guardianship' (where the parent or carer has legal responsibility for their financial and other affairs) alongside those who have capacity to manage their own money and can take responsibility for their benefits.

The group considered the current 'appointee' system, where children under 16 are represented by an adult. At age 16 the DWP makes a decision about whether the child can manage their own affairs. The group noted that although this appointeeship system works well for many families, we have also heard evidence

from young disabled people and their parents that this can lead to unintended consequences in the longer term. Kinship carers in particular noted that the transition to working-age disability benefits at 16 can add an extra level of complexity to the family relationship based on the transition of benefits and with it more independence, or their ability to remain actively involved in decisions such as schooling. Whilst kinship carers voiced concerns as to the ability of young people turning 16 to be able to take on this responsibility (including concerns over vulnerability to financial coercion from others) they also noted the difficulty of the transition from carer of a disabled child.

The appointee system can appear arbitrary and largely unchecked. In addition, meanings of appointeeship and guardianship can become confused. Decisions about who manages benefits at age 16 can result in someone having rights over all decisions for the rest of another person's life. This can lead to young disabled people who do have capacity to manage their affairs - with support - being held back in terms of fulfilling their potential to lead independent lives therefore undermining human rights – for privacy, for home and family life as adults, for their own adequate standard of living through work or benefits and across the whole range of life opportunities.

#### **Recommendation 13:**

- **Further evaluation and exploratory work around the appointee system and potentially family mediation is needed to balance support for parents and carers with protection of the rights of young disabled people to fulfil their potential, have autonomy and live their lives as independently as possible.**
- **The impact of raising the transition from DACYP to DAWAP to age 18 should be evaluated fully and kept under review.**

#### **Terminal condition or illness**

We have not yet been able to draw upon direct evidence from families of children and young people with a terminal condition. We will continue to review this, and if we are able to provide any potentially useful insights, will prepare a follow up note in the future.

I look forward to your response and we would be pleased to discuss this advice report with your officials.

With best wishes,

Jim McCormick  
Chair

**Project Members:**

Lorne Berkley  
Tressa Burke  
Etienne D'Aboville  
Ewan MacDonald  
Jim McCormick  
Ed Pybus  
Frank Reilly  
Andrew Strong  
Carol Tannahill

**List of Consultation Sessions:**

- The Hope Project/Contact – [redacted]
- DIFFERabled – [redacted]
- Family Fund – [redacted]
- Glasgow Disability Alliance – group of parents and carers of disabled children and young people – [redacted]
- Mindroom – [redacted]
- [redacted]– consulted parent and expert through experience
- In addition, we have drawn upon the findings of a consultation session arranged by the Scottish Commission for Learning Disability (SCLD) with pupils from Carrongrange High School – with thanks to [redacted].