

Written evidence from the Down's Syndrome Association (HAB0039)

The Down's Syndrome Association is a national charity focusing on all aspects of living successfully with Down's syndrome. Established in 1970, we recently celebrated our 50th anniversary year. We have around 20,000 members throughout England, Wales and Northern Ireland. The Association is in contact with over 130 affiliated local support groups and a range of professionals from different agencies. The aim of the organisation is to help people who have Down's syndrome lead full and rewarding lives.

We are the lead provider of information, advocacy, support and training to anyone with an interest in Down's syndrome. We are a membership-led organisation, with our membership comprising primarily the family-carers of children and adults with Down's syndrome and a growing membership of adults with Down's syndrome aged 18+. We are well placed to reflect the needs and views of people we seek to serve.

We have a commitment to inclusive participation and work closely with a diverse group of individuals who have Down's syndrome called "Our Voice", who come together regularly to help shape and inform our work.

About Down's syndrome

Down's syndrome is a genetic condition, caused by the presence of an extra chromosome 21 in the body's cells. Everyone with the condition will have some degree of learning disability. In addition, there are a number of associated medical conditions, which affect some, but not all, people who have Down's syndrome, meaning the services that they access from the NHS (and social care settings) are of paramount importance to their wellbeing.

The number of people in England and Wales with the condition was estimated as 37,090¹ in 2013.

The Down's Syndrome Association provides lifelong support, in the form of information and advice for people who have Down's syndrome and their parents and carers.

¹ Wu J, Morris JK The population prevalence of Down's syndrome in England and Wales in 2011 Eur J Hum Genet 2013 Sep; 21(9):1016-9. doi: 10.1038/ejhg.2012.294. Epub 2013

Some people who have Down's syndrome lead semi-independent lives in a supported environment and others, with more complex needs, will always require a high level of support. Generally needs increase with age.

With appropriate healthcare, many people who have Down's syndrome are now living to the age of 60 and beyond.

Answer to DWP Consultation Questions

1. How could DWP improve the quality of assessments for health-related benefits?

DWP could improve the quality of assessments for health related benefit by returning to in house services, rather than contracting out. In particular, training of assessors must be relevant and consistent. We still receive regular reports of assessors not understanding learning disability and its implications.

2. Are there any international examples of good practice that the Department could draw on to improve the application and assessment processes for health-related benefits?

We are not familiar with international benefit assessment and so cannot comment

3. Do the descriptors for PIP accurately assess functional impairment? If not, how should they be changed?

With regard to the PIP descriptors, we feel that these are much improved since it replaced DLA. The issues we are concerned about are more about the level of understanding of the assessor. Many will take the claimant at face value and not appreciate the complexities of any individual's disabilities, especially the impact of their learning disability.

4. Do the descriptors for ESA accurately assess claimants' ability to work? If not, how should they be changed?

ESA and UC descriptors have not been an issue. As previously stated, It is usually the assessor taking the claimant at face value and not always understanding the bigger picture of prompting and support that is a necessary component of everyday living. For many individuals who have Down's syndrome they so often rely upon a significant amount of support from families or paid supporters (if living in supported living).

5. DLA (for children under the age of 16) and Attendance Allowance usually use paper-based rather than face-to-face assessments. How well is this working?

The DLA and AA forms work only if the forms are properly filled in – there is little leeway. Problems arise when already overstressed appointees or claimants do not adequately complete them or misinterpret what they are being asked. We think it would be helpful to have a separate form for babies in their first 18 months, because the sections relevant for claiming at this time are not afforded enough space to explain additional background details on the current forms.

6. How practical would it be for DWP's decision makers to rely on clinician input, without a separate assessment, to make decisions on benefit entitlement? What are the benefits and the drawbacks of such an approach?

The issue with clinician input, rather than separate assessment, is that Down's syndrome isn't an illness and therefore (unless there were other medical conditions), the clinician may have little information to share. Sometimes a report from school or college would provide more insight. We are conscious that resources are already stretched in schools and therefore reports may not always be written and sent back on time.

7. Appeals data shows that, for some health-related benefits, up to 76% of tribunals find in favour of the claimant. Why is that?

With regard to appeals and 76% of hearings being found in favour of the claimant, the majority of appeals we support families through, are for DLA. We have found a combination of poor form completion and underestimation on the claimants/appointees side can contribute to the case reaching appeal stage. We are asked to be a representative at this stage and then prepare an appeal submission. We are able to make a case and a strong argument against the DLA decision, including case law and are usually successful in having the decision changed.

Poor understanding and insight into the needs of a young child with a learning disability amongst assessors is quite common. Frequently the parents of individuals who have Down's syndrome are told that their child has no more needs than a "typical" child of this age, even though the information given on the form implies that they do. We have found that decision makers underestimate the importance of early intervention in the form of physiotherapy, occupational therapy, speech therapy and play therapy and that they will categorise these interventions as general play and interaction that all babies have. This is extremely short-sighted and also upsetting for the parent, as this specialist intervention given is basically ignored by DLA.

8. Is there a case for combining the assessment processes for different benefits? If not, how else could the Department streamline the application processes for people claiming more than one benefit (eg. PIP and ESA)?

For people who have a learning disability, it would be helpful to combine an assessment. Although end dates and start dates may differ for these benefits, people who have a learning disability will have needs that have been present from birth and will be lifelong. Care needs generally increase with age and there is a significantly higher risk of early onset dementia. Therefore, a report that is 12 months old would still be an accurate reflection, if needs had remained unchanged for that period – they are very unlikely to decrease.

9. What are your views on the Department’s “Health Transformation Programme”? What changes would you like to see under the programme?

Many individuals who have Down’s syndrome have parents that are appointees, who manage benefits on their behalf. This means that some are elderly and not always computer literate. Some may not have access to technology and may have to access via libraries for example. It would be prudent to always have an option for paper-based forms, or the facility to contact a person via phone until the demand for this support is no longer needed. It is an enduring issue and therefore, will not resolve over a short time.

Bringing assessments back in-house would ensure better training and consistent assessments, with a focus on the benefit being claimed, rather than an objective and sometimes irrelevant one. Training needs to be consistently updated and ongoing.

10. What lessons should the Department learn from the way that it handled claims for health-related benefit claims during the pandemic: for example, relying to a greater extent on paper-based assessments, or using remote/telephone assessments?

During the pandemic, assessments over the phone have been less stressful for many families. An assessment face to face can increase anxiety, especially if the family had to attend at a centre. Our families have many issues to deal with and so lessening the stress of a face to face assessment would be helpful. There can still be an issue with answers being misconstrued but this is the case anyway with an actual face to face assessment.

11. Most assessments for Industrial Injuries Disablement Benefit were suspended during the pandemic. What has been the impact on people trying to claim IIDB?

Not relevant to us

12. DWP believes that applications for some benefits dropped sharply at the start of the pandemic because claimants weren't able to access support (for example, from third sector organisations) to complete their applications. What are the implications of this for how the Department ensures people are able to access health-related benefits consistently?

Our organisation continued to operate during the pandemic and provided support for claims. We do receive calls from people who do not have access from other help centres. This also happened pre pandemic. This is often because demand outweighs services. If DWP provided funding for charities supporting claimants, it may enable services to keep running and employ extra staff when required.

Along with funding, signposting and accreditation from DWP for Third Sector organisations would also help

13. DWP recently published research on the impact of applying for PIP or ESA on claimants' mental and physical health. What would be the best way of addressing this?

There is no doubt that the current services need an upgrade. Claim packs should be acknowledged on receipt back at DWP and periodic updates given. It can be months in some cases before families hear an outcome. Far too frequently, when an appointee calls DWP, they have been told of a decision being made and apparently posted out. When told that they have not received a decision, the appointee is questioned about change of address and generally disbelieved. Although extra time is then given for a response, there is no excuse for this happening. In this day and age, most people, elderly parents included, have access to a smart phone, even though they may not have a computer, and as such, it may be an idea to use this as a notification source?

14. What could the Department do to shorten waits for health-related benefit assessments—especially for ESA/UC?

The only way to shorten wait times would be to assess what is causing them from an operational failure. Bringing assessment services in house would ensure that each case was traceable and updates available instantly, rather than ringing around.

15. The Scottish Government intends to introduce its own assessment process for the Adult Disability Payment, which will replace PIP in Scotland from 2022. What could DWP learn from the approach of the Scottish Government?

We do not work in Scotland and so have no comments to make on this question.

16. How effectively does DWP work with stakeholders—including disabled people—to develop policy and monitor operational concerns about health-related benefits?

We have had some involvement with DWP, this is always welcome, but this has been sporadic. It has been better of late with our members being involved in the recent Health and Disability paper consultation, where we facilitated a focus group of families for DWP staff to directly engage with. We are very keen to continue and build upon this relationship.

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