



THE DONALDSON TRUST

Response to the Scottish Government Call for Evidence
in relation to the *Independent Review of Adult Disability
Payment*.

August 2024

About Neurodiversity

Neurodiversity describes the diversity of humans' brains and minds. A person who is, for example, autistic is neurodivergent; they are in a neurological minority, not the neuro-'typical' majority.

Other neurodivergences include: ADHD, dyscalculia, dyspraxia, dyslexia, dysgraphia, misophonia, Tourette's Syndrome, or differences in cognitive function.

About Us

Our work is built on an understanding that neurodiversity is not a medical construct; rather, it lies at the intersection of culture, mind, identity formation, and socio-political action.

The Donaldson Trust envisages a society in which neurodivergent people are understood, accepted, treated fairly, and valued.

Though there is much work to be done, we believe there are genuine opportunities to change society for the better. We aim to be at the forefront of driving that change – and making a difference *with and for* neurodivergent people and their families.

As the *National Body for Neurodiversity*, we will seek to lead by example. We exist to strengthen the public's understanding of neurodiversity, develop excellence in practice, and help neurodivergent people find their voice.

Alongside neurodivergent people and our partners across the third sector and academia, we write, campaign, and persuade in order to shape the policies being made on the issues most important to neurodivergent people and families.

We improve outcomes and representation via *Connect*. Our training and consultancy is accessed by organisations looking to build a culture of neuro-inclusion. We continue to develop our free, online information, support, and guidance resources to neurodivergent people, families, and professionals alongside it.

We continue to support children, young people, and adults through a variety of services based at our Linlithgow campus, where we enable every neurodivergent person to realise their goals & aspirations:

- **Sensational Learning Centre (SLC)**

We offer individualised, skills-based learning to children and young people with 'Additional Support Needs' (ASN) including sensory and communication differences.

A 'Grant-Aided Special School' (GASS), SLC is independent of local government.

- **Vibe**

Our wellbeing service for neurodivergent people ages 12-18, Vibe offers warm, low arousal spaces for neurodivergent young people to thrive and achieve their personal goals. The service focuses on reducing anxiety, developing life skills, literacy, numeracy, and growing self-esteem / resilience.

Vibe's activities mirror the interests and skills of the young people enrolled with a wellbeing framework and personal programme of skills development.

- **Gate**

Donaldsons' skills development and training offer for neurodivergent adults, Gate has been co-designed with those who benefit from it and offers a friendly environment where neurodivergent adults can relax and be themselves. Similar to other services, Gate takes an individualised approach to ensure trainees get the most from their time with us and achieve agreed goals and ambitions.

Trainees can learn skills through activities, or enrol in a vocational and accredited course, delivered by specialist staff / tutors. This includes art, cooking, and cybersecurity.

- **Treehouse**

Treehouse is a specialist wellbeing service offering bespoke, low-arousal environments to improve wellbeing and independence. Support is centred around individual studios, with the 'home-style' settings offering individualised spaces tailored to every person's needs. That allows people we support to participate in activities they co-design alongside their Wellbeing Practitioners.

Established in the 1850's, The Donaldson Trust (formerly Donaldson's School) has provided supported education and care throughout its history and has now established itself in the neurodivergence space.

The full range of services offered by the Trust is found here:

<https://www.donaldsons.org.uk/>

**Together, we'll
find your voice.**

Overview

The Donaldson Trust is pleased to respond to the Scottish Government's *Call for Evidence*, in connection to Edel Harris' ongoing Review of Social Security Scotland's Adult Disability Payment (ADP).

Through our *Gate* and *Treehouse* services (which have a focus on wellbeing and skills development) we maintain a keen interest in neuro-inclusive social security policy. We support more than 30 neurodivergent young adults through these two services, many of whom have engaged with Social Security Scotland; they receive ADP or have applied / are applying for other working-age social security.

Overall, there is much commonality in the (often poor) experiences disabled people have when trying to apply and be assessed for a social security entitlement; however, we know neurodivergent people's experiences are aggravated by the fact there is a lack of cognizance of the impact of social-communicatory 'barriers' and other 'hidden' differences during application / assessment. The nuance of neurodevelopmental differences and the (often changeable) ways in which they manifest clashes with rigid eligibility criteria focused on physical difference over social factors.

Neurodivergent people, especially autistic people and people with a co-occurring learning disability, experience poorer outcomes across several aspects of their lives, compared to neurotypical people; for example, employment rates for autistic people have been recorded as low as 16%¹ and show little sign of improvement². We know that stems from a lack of visibility and societal failures in tackling social barriers to inclusion.

We know, too, that neurodivergent people (and their families) can be impacted significantly if they are not able to access social security as a result of an insufficient award, or none at all. That increased financial burden has negative effects on health and mental wellbeing. Access to appropriate employment and skill development opportunities (and seemingly unconnected support services) can be affected as the world around 'shrinks' – and progress is lost.

We are pleased by the Review's scope, especially the desire to address "*the activities and descriptors that determine entitlement to Adult Disability*

¹ 2021, Scottish Government, *Towards Transformation*

² 2021, ONS Census Data (England & Wales only)

Payment, including how these apply to disabled people with fluctuating conditions". We look forward to engaging with the Scottish Government around ADP (and neuro-inclusive social security policy more generally) going forward. The Trust would be willing to facilitate workshops to allow the Review to hear directly and in-person from people we support.

While preparing this response, we engaged with neurodivergent young adults who currently access a skills development, training, and wellbeing service provided by our charity, as well as service colleagues involved in the support of these young adults.

We have chosen to outline perspectives on the range of themes being considered by the Review (including perspectives of people we support) in a single organisational response, rather than facilitating separate submissions to the consultation, also.

Factors Affecting Take-Up

We are encouraged by the Scottish Government's desire to engage with under-represented people who face barriers to their meaningful engagement on this issue; however, and whilst we are mindful the example list is not exhaustive, we are concerned that the absence of 'neurodivergent people' speaks to the relative invisibility of communities with whom we advocate – and a misunderstanding of social-communicatory barriers to access. Explicit reference to neurodivergent people as a distinct 'seldom-heard group' – and a more intensive engagement with people we support on their needs as they relate to the themes discussed – would positively impact awareness of Social Security Scotland amongst neurodivergent people and the body's approach to neurodivergence.

Young adults we have engaged in producing this response had little awareness of ADP – or most of the services offered by Social Security Scotland – prior to receiving informal guidance from professionals involved in their support that it would be in their interest to apply. This advice did not necessarily come from a professional in the social security and employment sector, highlighting the role that a service provider involved in supporting neurodivergent people with wellbeing and education can play in disseminating information about Social Security Scotland. The neurodivergent people we spoke to were receptive to the idea of 'outreach' within the wider public and third sectors, including co-hosted events between service

providers and Social Security Scotland to educate staff and people being supported on their rights.

Staff in our *Gate* service agreed that there was space for partnership working between Social Security Scotland and independent service providers – such as The Donaldson Trust. The benefits of information being shared from a ‘trusted’ (familiar) voice was mentioned in our discussion, especially around giving an applicant both the confidence to apply *and* to pursue their application if the process became emotionally taxing. Though the Trust would not play a direct role in making applications (*Gate* is a day service) we would value opportunities to support people accessing our own services if possible.

Lastly, a mistrust of ‘the system’ was a motivation for some who had struggled to engage and take-up opportunities related to ADP in the past. They mentioned a general feeling that while there had been positive steps around assessment and review (in comparison to the DWP) there was still a ‘guilt by association’ effect in play; the two agencies carried similar reputations in their mind. It was thought that not enough work had been done to communicate how (and if) Social Security Scotland represents a substantial break with the processes of the DWP.

Pre-Application Support

Challenges in social communication / interaction (in comparison to neurotypical people) are fundamental to neurodevelopmental differences like autism, ADHD, and learning disability – and significantly impact on daily life and tasks perceived as routine in ways underappreciated by neurotypical peers, systems, or processes. People we support through *Gate* mentioned a number of tasks that they may have been physically able to carry out in principle, but were not able to do, including: traveling on public transportation, opening and responding to post, and preparing meals. They attributed this to feelings of low self-esteem, a lack of motivation, anxiety, poor physical health, a lack of comprehension, etc., which may vary day to day.

We know, too, that these groups experience far higher levels of anxiety and poor mental health; for instance, autistic people have been identified specifically as a key ‘at-risk’ group with respect to suicide ³. National Autistic Society research shows that 94% of autistic adults have experienced anxiety;

³ 2018, NICE, [*Preventing suicide in community and custodial settings*](#)

almost 60% said anxiety affected their ability to 'get on' with their life ⁴. These can, in part, be attributed to neurodivergent people's struggles with (and through no fault of their own) dealing with the challenge of existing in neurotypical spaces and a lack of neuro-inclusive environments or practices.

It is clear, therefore, that lots of neurodivergent people might struggle to engage with applications and other administrative tasks for the same reason they will have made an application for ADP in the first place.

Neurodivergent people would benefit from an application process co-designed *with* neurodivergent people. The Donaldson Trust will happily facilitate sessions featuring staff members and those we support. Adjustments (communication support like 'Easy Read' documentation, in-person appointments, online service, nominated contacts, etc.) are important; however, variety in adjustment is just as important. Inclusion is not inclusion if it becomes 'tick-box'. It is worthwhile only when adjustment is personalised to a neurodivergent person, following meaningful consultation with them throughout the application process. For example, a person's differences may find them making use of more than one method for engagement depending on variable circumstances in their own lives.

The application process being seen as a long and uncertain one was a common theme in our engagement. People we spoke with highlighted a lack of certainty given for dates and on what to expect as their application was progressed. A clear, 'start-to-end' breakdown of what to expect – running from initial contact through making an application to payment and possible teething issues – would lessen anxiety. This could be done in 'Easy Read', supplemented by social stories or other visual aids.

This work is replicable for a range of differences with a similar social-communicatory basis, and maintaining a wide range of adjustments would be of particular benefit to people with several co-occurring differences; for example, people who are Deaf and Blind, or Deaf and autistic. Overall, the key point is to remember that neurodivergent people's needs are as diverse as the community itself and having several adjustments (and an honest conversation about what these are) is vital.

Gate staff noted that the skills required to see an application through from start to finish – or sometimes even to comprehend what ADP is and why it

⁴ 2021, NAS, [*Good practice guide for mental health professionals*](#)

might be an idea to apply – were skills not yet developed by the time the people we support were in young adulthood. Social Security Scotland could undertake work (if it is not already in progress) to assess, on an ongoing basis, likely recipients of ADP and other devolved entitlements in the 16-18-year-old bracket. This could allow for a better comprehension of the process amongst younger adults when the time comes to apply to ADP.

Processing Times for Applications

We do not have substantial evidence to share concerning ADP waiting times, owing to the relatively small number of ADP applicants we engaged.

To make that waiting time less anxiety inducing, we would re-iterate what we have said elsewhere: the application process is seen as a long and uncertain one. People we spoke with highlighted a lack of certainty given for dates and on what to expect as their application was progressed. A clear, 'start-to-end' breakdown of what to expect would reduce anxiety. This could be done in 'Easy Read', supplemented by social stories, or another visual aid – and chart progress from initial contacts to making an application and receiving the payment.

People we engaged with spoke about their anxieties getting to a point that it affected not only their wellbeing but their ability to process. 'Shutdown' is not conducive when managing daily living, let alone the tasks that put you in that place. That highlights the importance of timely updates and clear communication from start to end.

The common theme in our discussions was on a need for clarity over speed. A flawed process of 40 days would be worse than a correct, well-communicated process that lasted 60 days, for example. A way to remedy this may be to place requirements on Social Security Scotland to provide 'progress reports' to applicants or their advocates at set days in the process of applying; for example, 5, 25, 50 days from the application's submission.

Decisions, Re-Determinations, and Appeals

As we note throughout our response, neurodevelopmental differences are often 'invisible' to others and/or not immediately associated with 'Disability' or a long-term health condition that affects everyday life; moreover, these vary in presentation, not just between individuals but day-to-day for the same person. This means that a neurodivergent person's need for and entitlement

to ADP can easily go un/under-acknowledged where there is a lack or misunderstanding of differences and how they impact people.

This being said, understanding of neurodivergent presentations is important during the application process and *after* a decision has been made. Appeals (and, later on, reviews) are an important route for neurodivergent people who do not think that there has been due consideration of the importance of their social-communicatory differences on their ability to complete tasks or go from one place to another.

This is not universal, though. Some young adults we spoke to mentioned the 'high risk' factor of re-determination, and a perception that they were likely to lose what they had if they 'rolled the dice' on what they had, even though they truly believed that they were incorrectly assessed. Negative memories of the initial assessment and the anxieties this created compounded their unwillingness to engage with re-determination regardless of the validity of the case they thought they / their advocate could make. A guarantee against recovery of payment would be an effective tool for giving those applying the confidence to do so, i.e., Social Security Scotland being required to guarantee application of the initial decision in the event the re-determination offers a poorer outcome to the applicant for ADP.

Finally, we know that applicants often see re-determinations as futile. Social Security Scotland should look to ensure enhanced awareness of the benefit of re-determination. This could be achieved by outlining a clear, 'start-to-end' breakdown of what to expect. This could be done in 'Easy Read', supplemented by social stories, or another visual aid – and chart options from when they receive the decision to opportunities for Tribunal Appeal. That information can be made available and shared direct with an applicant even before the initial decision is conveyed.

Change of Circumstances

We do not have substantial evidence to share concerning changes of circumstance other than to stress that neurodivergent people have an increased tendency to strictly follow process, procedures, and rules. That has implications for self-advocacy.

For instance, a neurodivergent person may not be comfortable or willing to disclose information around change in their circumstances, even if it would

be advantageous for them to do so, owing to their own interpretation of what 'change' means and what the 'rules' might mean.

We heard from one individual during our engagement that they would struggle to submit a change in circumstances (irrespective of the impact their condition was having on them) if they had been judged previously to qualify for no award in not dissimilar conditions.

Reviews

We are encouraged that Social Security Scotland recognises indefinite awards for entitlements are appropriate in circumstances where an applicant's condition is such that it is unlikely to change. Though we recognise that the way neurodevelopmental differences present might be variable, we believe the baseline need for ongoing support highlights minimal engagement with the review process is both sensible for Social Security Scotland and beneficial to the wellbeing of neurodivergent people.

Neurodevelopmental differences like ADHD and autism are *lifelong*. We know that presentations will vary person-to-person, and every person will have strengths and weakness unique to them; indeed, the way that their neurodivergence presents can vary and is dependent on the level of support offered.

We are not arguing that indefinite awards are the answer to the challenges a lot of neurodivergent people face engaging with ADP applications; rather, we believe a parallel process for all applicants with identified social-communicatory differences (and making an application on the basis of these differences) is practical. For example, an assessment made without face-to-face interview, supplemented by testimonies from health professionals and advocates. Over time, a folio of evidence could be gathered by Social Security Scotland that gives an assessor, with professional experience of supporting neurodivergent people, a fuller picture of fluctuating and consistent needs. Additionally, that process could feature in-person 'check-ins' with advocates without the neurodivergent applicant present.

Other Considerations

People we engaged with spoke to their apprehension about making 'progress', knowing that that progress was not a given and that it would often fluctuate. The idea of being assessed on a 'good day' was of particular concern, especially given that neurodivergent people can often struggle to

articulate needs not immediately visible to others – and such need is often dependent on variable social factors. There was consensus that support – whether that came via ADP, another entitlement, or opportunities made possible by financial independence – being suddenly withdrawn will reverse progress made. Tapering-off of an entitlement over the long-term to a baseline level of support, or the introduction of a great number of tiers beyond ‘Standard’ and ‘Enhanced’, is a feasible solution.

One applicant we spoke to thought that there was a *de facto* means-testing of ADP, as their ability to persevere through negative changes to their circumstance was a product of ongoing, informal supports from family.



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