



THE DONALDSON TRUST

Response to the Health, Social Care and Sport
Committee's Call for Views on Stage 2 draft
amendments to the *National Care Service (Scotland)*
Bill.

September 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.

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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 Health, Social Care, and Sport Committee's *Call for Views* on the Scottish Government's amendments to their *National Care Service (Scotland) Bill*, at Stage 2. As a provider of wellbeing and development services for neurodivergent young people / adults, we maintain a keen interest in proposed reforms to the social care landscape in Scotland – and recognise the opportunity that better integration and partnership working between support services, health, and other forms of care brings.

The services that we offer (*Vibe*, *Gate*, and *Treehouse*) are registered with Care Inspectorate, or have a registration underway.

We are cautiously supportive of the changes that have been proposed by the Scottish Government in the pre-Stage 2 information pack. At this stage, it is vital that the Bill is actually delivered into law and a National Care Service becomes a reality for Scots in need of high-quality social care. We recognise (and remain disappointed) the *National Care Service (Scotland) Bill* proposes an NCS much 'slimmed-down' from initial proposals and the intentions of the IRASC; however, it *still* represents a golden opportunity to transform our care landscape. In terms of detail, the content that has been retained is more detailed and speaks to a shared goal of sustainable, rights-based, person-centred social care with more clarity than the Bill did when it was introduced.

Many of the comments in our response speak to how the Scottish Government can and should engage more effectively, more often with a broader range of groups, such as disabled people and other marginalised groups far more likely to access care. This includes people who have a lifelong, neurodevelopmental difference; for instance, an autistic person / person with learning disabilities. A priority for The Donaldson Trust is ensuring neurodivergent lived experiences are front-and-centre as the NCS begins to materialise – especially with respect to the value of inclusive communication and enabling people to know, and take control of, their rights. Initial and continued development of the structures that direct the NCS involving people with a communication difference(s) – Charter, strategies, etc. – is essential.

Strategy

Although not made explicit in the consultation question, we have included our commentary on principles here, as they are referenced in Sections 1 to 1B, too, and set the tone of the NCS, alongside strategy.

We all know that a National Care Service, if enacted, will be the most impactful change to health and care practices in Scotland since The Scottish Parliament was established; therefore, it is important the Bill speaks to over-arching themes and ambitions, such as enabling human rights, inclusion of marginalised groups and ensuring person-centred support. It is important also that bodies who have responsibilities as part of legislation will have sufficient financial resources made available to them in order to deliver it.

Section 1, *The National Care Service principles*, includes welcome clarifications and additions; in particular, the changes made with 1(1)(c) help to frame care, and a need for care, as inclusive of a range of life-long and variable conditions – for instance, neurodevelopmental differences such as autism or FASD. Explicit mention of the words *lifelong* and *neurodevelopmental* and the phrase [*needs are*] “*a result of neuro-developmental difference(s)*” in c(iii) would consolidate the improved approach. We welcome, too, the inclusion of language relevant to independent living in sub-paragraph (ii).

1(1)(e)(zi) should be amended to make reference to individual elements of the whole life experience. In addition to psychological trauma, as is mentioned, a number of other factors should now be included, such as: social isolation; poor mental wellbeing; unemployment; involvement with the criminal justice system as a victim or perpetrator; access to education, care experience, mobility, and neurodevelopmental difference. Paragraph (ea) makes reference to ensuring an individual's safety; however, there is not a reference to improving wellbeing or general quality of life in that Chapter. An amendment in that paragraph will cover this.

Inclusive Communication is arguably the most important element of improving outcomes for neurodivergent people, regardless of diagnosis or the level of the need. We are encouraged by the changes proposed in 1(1)(f) that recognise difference and the need to include a range of people for whom spoken English is not their primary or preferred method of communication, or who benefit from adjustments whilst communicating and/or receiving information from others. A sensible change to this paragraph is to add in “*and met*” to the text, such that need is recognised *and met* – and not treated as being ‘tick-box’.

1A(1) should be amended to ensure the principles are required to be reviewed every *three years*, not every *five years*; moreover, 1A(2)(b) should be reframed to ensure meaningful consultation with a wider range of individuals drawn from a wider range of groups. This should include neurodivergent people (especially

those with ‘co-occurring’ learning disabilities) and people who do not currently access a service but are (by virtue of their differences) more likely to access a service connected to the NCS in the future. *1A(2)(b)(ii)* should refer explicitly to the third-sector, given the role charitable organisations play in advocating with and for those who access a care service.

On the strategy itself, we believe that these should be co-produced by people with an interest in the success of social care in Scotland; therefore, we believe that *1D(1)(b)* needs to clarify the role that people with lived experience of care in Scotland have in developing strategy. The Bill should ensure Scottish Ministers ‘*have particular regard*’ – language that is used elsewhere in the text – for the opinions and experiences of those accessing care, the family members and/or unpaid carers, third-sector organisations, marginalised groups (neurodivergent people, for instance), and the social care workforce. *1E(1)* should be amended to ensure the strategy is reviewed every *three* years, not every *five* years – and for a requirement on Ministers to publish a progress report half-way.

National Care Service Board

We support the creation of a National Care Service Board; and the purpose of said Board as is drafted in Section *12E*, *The Board’s general purpose*. The Board should play a leading role in driving implementation of the principles / strategy of a National Care Service in the local boards.

The National Board should be required to outline how it will ensure meaningful participation of people on the Board (and others with whom the Board comes into contact in the course of its work) requiring reasonable adjustments in order to engage as is necessary. Training on establishing neuro-inclusive work spaces should be mandatory for all support staff involved in the administration of NCSB functions, with a particular focus on inclusive communication.

Again, we would stress the need for any co-production to be more inclusive of a broader range of individuals, groups with a stake in the success of social care provision in Scotland. *12I(2)(b)* should be amended to ensure NCSB Corporate Plans have ‘*particular regard*’ for the experiences of people who access social care in general, those likely to access a social care provision in the future, those family members / unpaid carers who support them, and Scotland’s social care workforce. In addition, marginalised groups (including neurodivergent people) and third-sector organisations advocating with and for recipients of social care can provide distinct perspectives.

Though we appreciate that the Scottish Government is planning to establish a number of additional member categories via regulations, we are disappointed that Part 4, Chapter 2 of Schedule 2C, on *Power to make provision about Board composition and appointments* does not include any mention of a third-sector representative. 2C should be amended to ensure that a right to representation for the third-sector is enshrined in primary legislation alongside those categories mentioned already.

Local Boards

Though we appreciate that the Scottish Government is planning to establish a series of member categories for the local boards via regulations connected to the 2014 Act, we reiterate what we have said with respect to the NCSB: that a third-sector representative should always sit on, in this case, a local board. This should be done in primary legislation, to give stakeholders clarity.

The inclusion of the word 'National' in the long title of the new local boards, as set out in Section 12(B)(a)(i), might cause confusion. The phrase 'National Care Service local boards' implies these are local *and* national. One alternative may abbreviating this to NCS (as is mentioned in Schedule 2C) or dropping the word 'National' from the name entirely.

Local boards should be required to articulate how they enable the meaningful participation of people on the board (and others with whom the board comes into contact in the course of its work) requiring reasonable adjustments in order to engage as is necessary. Training on establishing neuro-inclusive work spaces must be mandatory for all support staff involved with the administration of that local board's functions, with a focus on inclusive communication.

Areas of 'Further Work'

We understand that the proposed approach on *Anne's Law* – ensuring people in residential care are able to access family / friends for advocacy and support as a right – has shifted subsequent to the consultation paper's publication¹. A separate Bill will of course take months to draft; however, given the protracted development of the NCS over the space of three years (and more debates to follow) a separate Bill may offer the Scottish Government an opportunity to put *Anne's Law* through Parliament soon.

¹ 2024, Care Home Relatives Scotland, [Letter to HSCS Convener](#).

In addition, a separate Bill would give the Scottish Government the opportunity to deliver legislation on extending visitation rights to shared living facilities other than residential care / 'care homes'. That could include hospitals.

It is clear that a large number of campaigners heavily involved in bringing this topic into public consciousness are not happy with the approach taken within the Bill, as things stand.

Charter

We support the principle of a Charter that articulates the rights & responsibilities of everyone who accesses care. The extent of the change proposed makes it so important that this Bill speaks to over-arching themes and ambitions such as: enabling people to realise their rights, the meaningful inclusion of marginalised groups (such as neurodivergent people), and delivering person-centred health and social care. Alongside the principles and national strategy, the Charter will be a key determinant in the NCS' success. A robust Charter can ensure buy-in from stakeholder groups and help to ensure that the care and support on offer is individualised and human rights-focused.

The option for the Scottish Government to devolve the responsibility for drafting the Charter to the National Care Service Board is something we would oppose in principle; however, it is important that 12(4A) is not used as a pretext to either dilute the level of co-production or absolve Scottish Ministers of their obligation to deliver a successful, human rights-focused NCS regardless of who authors.

We support the introduction of 12A around communications. We would ask the Scottish Government to clarify if the Inclusive Communications work spoken to in the principles will apply to the Charter's public promotion, too. It is important that the Charter, and the national strategy, does not gather dust; rather, it must be a live document that is easily accessed and easy to employ.

Overall, we are happy with this Charter, recognising that there still work for the Scottish Government to do as part of long-running projects. This being said, the placeholders throughout the text make it harder to offer more comments. We would be keen to contribute to the ongoing work to co-produce a Charter; in particular, we would value opportunities to facilitate inputs from young people we support in service.



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