

THE DONALDSON TRUST

Response to the Scottish Government consultation on proposed changes to the Adults with Incapacity (Scotland) Act 2000.

October 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 neuroinclusion. 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 Scottish Government's public consultation on amending the Adults with Incapacity (Scotland) Act 2000. The Trust is encouraged by the Scottish Government's desire – as articulated in both the Reform Programme Delivery Plan ¹ and consultation paper itself – to evolve Scotland's capacity law, such that it better reflects the intention of treaties and (current and promised) legislation and strategy.

We are emphatic that neurodevelopmental differences should be celebrated. Neurodivergence is lifelong and intrinsic to an individual's identity; it constitutes a different way of experiencing the world and, when enabled with the correct supports, brings a diversity in perspectives that is undoubtedly a strength across all aspects of our society. We do, however, know that, often due to the lack of understanding and support, neurodivergent people are much more likely than the population at-large to experience poorer mental health – and experience far lower levels of general wellbeing as a consequence ². These can include a lack of opportunity for social fulfilment and/or employment or a physical health challenge ³; moreover, and pertinent with AWI, the functional communication differences common to lots of neurodivergence will often precipitate reduced independence or decision-making autonomy if communication needs are not being met.

These inequalities are evidenced across differences, location, and gender. The rights of neurodivergent people (not just in mental health law, but in education, social care, etc.) are among those most often violated – and most often at-risk ⁴. Neurodivergent people, especially those who have a co-occurring learning disability, come in contact with mental health and capacity law too often, not as a product of necessity, but because there is an inadequate level of support from services to meet their needs.

Taking 'person-centred' approaches to ensure rights in education / social care are realised is important; taking a 'person-centred' approach to mental health

¹ 2024, Scottish Government, <u>Mental Health and Capacity Reform Programme Delivery Plan Oct. 2023 - Apr. 2025</u>

² 2021, National Autistic Society, <u>Good practice guide for professionals delivering talking therapies for autistic adults and children</u>

³ 2023, Molecular Autism, <u>Increased rates of chronic physical health conditions across all</u> organ systems in autistic adolescents and adults

⁴ An example of this would be in education, where neurodivergent young people are impacted by unlawful exclusions and part-time timetabling at disproportionate rates.



legislation is absolutely essential. We welcome a desire to "shift the focus of the AWI Act to one that truly centres on the adult" via greater focus on Supported Decision Making and the primacy of Section 1(4)(a) 5 within that Act. It is crucial that this enhanced person-centredness is apparent in changes to other mental health law addressed in the Scottish Mental Health Law Review.

Though it is not the focus of this consultation, the discussion on so-called mental 'disorder' is something we wish to briefly address, given its relevance for autistic people and people with a learning disability. We are pleased the Delivery Plan recognises 6 stakeholders' strong desire to revise the terminology that is used in the Mental Health (Care and Treatment) (Scotland) Act 2003. This will have two effects: first, to take stigmatising language out of legislation, but also to remove an ongoing tension between well-meaning rights rhetoric and the medicalised reality that (incorrectly) conflates neurodivergence and learning disability with serious mental illnesses. As the Scottish Government has correctly identified, the proposed Learning Disabilities, Autism, and Neurodivergence (LDAN) Bill could be the appropriate vehicle for delivering changes. The Donaldson Trust strongly supports a revised definition of mental disorder that will remove autistic people and people with a learning disability from the scope of the 2003 Act, except in cases of co-occurrent mental illnesses requiring professional intervention under the 2003 Act, i.e., an equity in mental health law between neurodivergent and neurotypical people 7.

Principles

Our responses in this theme focus on consultation paper questions 1-6.

Though the principles outlined in Section 1(4) of the 2000 Act remain important, both in theory and practice, we strongly agree that greater emphasis must be placed on the rights, will, and preferences of the adult in question. We support updating S1(4) for that purpose; moreover, the legislation must explicitly outline that person-centredness – in particular, the primacy of the opinions of the adult involved as articulated in S1(4)(a) – is the guiding principle of decisions that are made in accordance with the Act. We believe this could be achieved via two options. One, to state in the text that S1(4)(a) – either as it reads or as amended

⁵ Adults with Incapacity (Scotland) Act 2000

⁶ Action 2.1 - MHCRPDP

⁷ The 2003 Act states that there are three forms of 'mental disorder': mental illness, personality disorder, and learning disability (the latter is taken to include autism). That places the rights of autistic people and people with a learning disability more at-risk, solely on account of their difference and not mental ill-health they may / may not have.



post-consultation – is the guiding principle. Two, existing principles are removed from the 2000 Act where they centre the opinion of persons other than an adult directly subject to the Act, or where they look to consider factors unrelated to the opinion of that adult; for instance, with respect to S1(4)(b). Either or both of these can be applied.

We believe that the principles should continue to be legally binding for people who take action in accordance with the Act. That must apply to principles that are currently in place – the five mentioned in the Act – as well as principles that emerge post-consultation. This should cover both newly drafted principles and amendments to any of these existing principles.

Whilst we do not have an especially strong opinion on language in the context of capacity law, we would concur that language of *rights*, *will*, and *preference* is preferred to *wishes* or *feelings*. A move to terminology used in the EAP's report 8 better expresses, we believe, feelings of urgency and obligation (to facilitate decision-making that substantively involves the adult in question) than the texts of the 2000 Act as it is currently. Rights are just that: rights. Rights are not optional 'extras' to be discarded if convenient.

In cases where the will and preferences of the adult cannot be followed – such as when acting contrary to the wishes would be a "proportional and necessary means of effectively protecting... rights, freedoms and interests" 9, or where it is not practical to act – we believe it would be appropriate to require all parties acting in accordance with the legislation to demonstrate how they considered an adult's will and preferences to the greatest extent possible. This may include placing a duty in the revised legislation to see parties' prepare statements that outline actions leading up to and the actions taken since acting, including: the steps taken to support the communication / decision-making of the adult (and their respective efficacy); a timeline of events, and which decisions taken were contrary to the will / preference of an adult and which were not. Parties should not be able to act unless that is all clearly demonstrated – and made available to others with professional or personal interests in that adult's wellbeing.

We agree that compliance with the principles, old and new, is essential if there are to be positive practical implications for the realisation of the rights of neuro-divergent people. We believe that, through a combination of legal obligations

 $^{^{8}}$ 2016, $\underline{\textit{Towards Compliance with CRPD Art. 12 in Capacity/Incapacity Legislation across} \underline{\textit{the UK}}$

⁹ 2024, Adults with Incapacity Amendment Act Consultation



set-out in the Act and role-appropriate training that can be achieved. Training is central to provisions in the Learning Disabilities, Autism, and Neurodivergence ('LDAN') Bill, and we believe that the 'LDAN' legislation can be utilised to make change in the mental health law space beyond a revised definition for 'mental disorder'. If the Scottish Government felt that it would be more appropriate for capacity-related training to be delivered through this capacity legislation – we think a requirement for this to be offered and undertaken must be enshrined in law – we would support that, too, provided that it contained materials related to neurodevelopmental differences and communication.

The Trust supports the Scottish Government's proposal, in LDAN, to broaden the scope of public-sector training in relation to neurodivergence. We believe that could include every professional who has taken actions or may have cause to take actions in connection to AWI. The Scottish Government correctly identifies the need for practitioners and services to be skilled at enabling neurodivergent people in the LDAN consultation paper ¹⁰:

"Public sector staff who work directly with members of the public have confidence and skills in being able to understand the needs of neurodivergent people and people with learning disabilities, resulting in improved services and communication and reduced health inequalities."

As outlined above, neurodivergent people will often require additional support in order to communicate most effectively. This is especially true of those with a learning disability. We are pleased that the Scottish Government has engaged people with experience of supporting the communication needs of those who require supports. We trust that has, and will, continue to include neurodivergent people. The Trust is eager to engage on this work in order to contribute a neuro-affirming perspective from our staff and the neurodivergent people we support to any practitioner training under development.

We know that differences in social and functional communication, both verbal and non-verbal, are an integral part of the lived experience of neurodivergent people, especially autistic people and people with learning disabilities. Though differences in communication styles are shared experiences, the nature of the differences varies person-to-person. Neurodivergent people do *not* lack 'social skills' or actively choose *not* to communicate needs; rather, they utilise different

¹⁰ 2023, Scottish Government, <u>Learning Disabilities</u>, <u>Autism</u>, <u>and Neurodivergence Bill</u> <u>Consultation</u>



strategies ¹¹. This might include an indirect gaze and repetition. Neurodivergent people might have intermittent or delayed speech, too – or not use speech at all. They may choose to communicate via vocalisations, physical gestures, and Augmentative and Alternative Communication.

Whilst communication differences present barriers to realising will / preference, Supported Decision-Making, and greater neuro-inclusion overall, we know that overcoming these is central to delivering human rights and equity in the mental health law space. This begins with robust, mandatory, and role-specific training that ensures practitioners are equipped with the necessary knowledge.

¹¹ 2018, <u>Being versus appearing socially uninterested: Challenging assumptions about social motivation in autism</u>



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