



Eich cyf/Your ref P-06-1513
Ein cyf/Our ref SM/00270/25

Carolyn Thomas MS
Chair - Petitions committee
Senedd Cymru
Cardiff Bay
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29 May 2025

Dear Carolyn,

Thank you for your correspondence of 6 May in your capacity as Chair of the Petitions Committee. The Welsh Government does not support the introduction of autism specific legislation as we already have the legislative levers to deliver improvements to autism and wider neurodivergence services. We have delivered on our commitment to publish a Statutory Code of Practice on the Delivery of Autism Services, made under the Social Services and Wellbeing (Wales) Act 2014 and the NHS (Wales) Act 2006.

I would like to update the Committee on the developments in Wales since the launch of this Statutory Code of Practice on 21 September 2021.

Development of a Code of Practice on the Delivery of Neurodivergence Services

As a response to the Members Autism Wales Bill, which was rejected by the Senedd in January 2019, we published a Statutory Code of Practice on the Delivery of Autism Services and accompanying guidance in September 2021. Due to the number of people with co-occurring neurodivergent conditions we are now working with stakeholders to expand the Code to include other conditions such as ADHD and Tourettes Syndrome, the Code will also be made under the Additional Learning Needs Act 2018, which strengthens the link with education. We will publish the new Code at the beginning of the next Senedd Term.

To encourage the development of local services, Neurodivergence has also been identified as a priority for the Regional Integration Fund which is designed to promote integration across health and social care.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

To monitor progress and understand the impact of the Code of Practice for the Delivery of Autism Services we commissioned a formal evaluation. The first phase was completed in the Autumn of 2023 with a full report '[Evaluation of the Code of Practice on the Delivery of Autism Services](#)' published in April 2024.

The first phase of the evaluation evidenced that the implementation of the code is enabling us to build on an already improving service context and that the code has had a significant influence on raising awareness and training in both health and social care services, improvements in awareness raising, the provision of supporting resources and workforce training. An individual report and set of recommendations were provided to each region to ensure further improvements. The second phase examines the improvements made resulting from the recommendations from the first phase and concentrates on service user experience. This will be published later this summer.

Following the very good response to the public consultation survey on the extended Autism Code, launched on the 18 June 2024 and closed on 15 July 2024, officials identified themes for areas of inclusion in the new Neurodivergence Code of Practice. A face to face and virtual engagement programme to discuss the draft Code will commence in the New Year.

Neurodivergence Improvement Programme

In 2021 a demand and capacity review of Neurodivergence (ND) Services, was commissioned to understand the impact of increasing demand on services and children, families and adults seeking assessment and support. This was resulting in lengthening waiting times and it was apparent that there were significant gaps in services for ND conditions other than autism. The report was published in October 2022, which reflected that although the NHS Together for Children and Young People, Neurodivergence workstream which closed in March 2022, had made progress in addressing the pressure on services, further improvement was required. In response, in July 2022 a [Written Statement](#) was issued making a commitment to deliver a Neurodivergence Improvement Programme (NDIP) backed by £12M over three years up to March 2025.

The NDIP led by Welsh Government is taking an integrated, whole system and cross government approach to transformation. It is centred upon a set of guiding principles which have been reviewed by all key stakeholders through our governance structure. These have been shared with Regional Partnership Boards (RPBs) to shape the development and delivery of neurodivergence services. RPBs have demonstrated alignment with the principles as a condition of funding.

Collaboration is key to the success of the programme, and we are working closely with a number of key stakeholders. We are working in collaboration with NHS Executive on assessment pathways, with Social Care Wales and with HEIW on workforce. We also work with education and Additional Learning Needs (ALN) colleagues to support the implementation of the ALN transformation, and we have aligned with the [NEST/NYTH](#) for children's mental health and well-being. The programme is also addressing gaps in data collection and scoping digital innovation for assessment services and support.

In November 2022 we provided £1.4million to RPBs to tackle urgent need. In 2023/24 we provided a further circa £2.4 million to RPBs to bring capacity and support transformational change. In 2024/25 circa £4.8 million was provided to RPBs to further test new ways of working and sustain existing services.

Early feedback from neurodivergence services and RPB reporting indicates more positive feedback from families that they feel more supported with greater access to information, advice and resources whilst waiting. However, referral demand is not reducing, and services

still do not have capacity to meet this ever-increasing demand. This is true for adult autism and ADHD services but is a critical situation for children's neurodevelopmental services.

In February 2025 through a [Written Statement](#) we announced a two-year extension for the NDIP programme and policy development backed by a further £13.9M of investment. We will continue to work with our partners to deliver transformational change including driving down long waiting times for children and young people.

National Neurodivergence Team

The National Neurodivergence Team is funded by the Welsh Government and hosted by the Welsh Local Government Association, it is a key partner in the delivery of the Neurodivergence Improvement Programme and wider work such as the evaluation of the Autism Code of Practice.

The team provides oversight of the development of the Integrated Autism Service and works with wider partners such as housing, police, employment services and DWP, raising awareness, providing advice, guidance and specific tools and resources to support them in their work with neurodivergent individuals.

The team is leading the development of early help and support services, this includes working with local authority Information Advice & Assistance (IAA) services, Families First, and third sector organisations to improve access to information, advice and develop models of early help. They have developed specific resources for parents of neurodivergent children with a recent addition of regular advice & consultation sessions with experts in the field of neurodivergence.

Integrated Autism Service

In 2016 we rolled out the Integrated Autism Service across all regions in Wales, providing an assessment and support service for adults. We continue to support this work, and through the ND Improvement Programme we have supported development as the demand continues to grow beyond the capacity to respond.

Digital Enablers & Profiling Tools

Digital enablers are critical in bringing greater efficiency to the provision of information, advice, and assistance, as well as better data collection arrangements and diagnostic and assessment pathways. A previous pilot commissioned in the transition from [Together for children and young People](#) (T4CYP) neurodevelopmental workstream, included the development and initial pilot of a children's neurodevelopmental profiling tool which also formed part of the referral pathway.

Advice from our digital, innovation & technology policy leads was that the initial pilot would have benefited from a discovery phase. We have now concluded a discovery project with the Centre for Digital Public Services (CDPS) on the potential of a range of digital enabler tools, they conclude that there is value in pursuing digital solutions. They have also provided us with a project proposal for an Alpha phase.

The use of the Portsmouth Neurodiversity Profiling Tool is growing across the UK. This resource is owned by Portsmouth University and NHS Trusts so is free to use, however, it is not fully digitalised so still takes a number of hours to complete a profile. At least two Health Boards in Wales are running pilots and have agreed to share their learning. We are also

exploring other tools and work such as the Autistica Research on an autism strengths and differences profile tool due out end of June, the work of Professor Helen Minnis on the Essence D tool in Scotland and work in Newport City Council on a Consideration Tool matrix.

The Neurodivergence Ministerial Advisory Group

This long-standing Autism advisory group has expanded into the Neurodivergence Ministerial Advisory Group to provide expert advice and guidance for the delivery of our policy priorities. This group meets quarterly, it is co-chaired by four people, three of whom have lived experienced of neurodivergence. Membership is varied across statutory services and the third sector, and the group has been attended by Ministers.

Outcome measures and data collection

Knowing how well services are operating is the key to identifying where we can deliver the best improvements. We are working with colleagues in the NHS Executive and Digital Health Care Wales to improve data, for children and young people we want to collect more detailed information on referral and assessment to inform service development. For adults, the Integrated Autism Service collects richer information on referrals, assessment and support.

Welsh Language

Developing a workforce that is better able to meet the growing needs of people through the medium of Welsh is a priority. We know that access to services in Welsh is important, for some clinically, as it can affect their assessment and outcomes, for others it is a matter of respect and dignity. Our Knowledge and Analytical Services (KAS) are currently looking to better understand the demand and look at the need for the availability of Welsh Language neurodivergent assessment tools. Whilst we know there are significant gaps in availability, we are pleased that the NHS Executives review of Children's Neurodevelopmental Services confirmed most Health Boards in Wales can provide diagnostic assessments in Welsh.

We have also funded a post within the National Centre for Welsh Learning to develop national health and social care neurodivergence terminology, bringing together professionals to provide a pool of Welsh language expertise for assessment and diagnosis across Wales. The National Neurodivergence Team is also linked in with Nottingham University, which has developed a new adult autism diagnostic tool, ACIA. This is currently being translated into Welsh.

Neurodivergence & Mental health

The evaluation of the Autism Code provided recommended that RPBs place a higher level of scrutiny on the delivery of support to neurodivergent people through mental health services. We know that neurodivergence and mental health related issues/conditions are often co-occurring, and we work across government to align neurodivergence and mental health policy, such as the NEDST/Nyth framework for improving mental health for babies, children and young people and their families.

The National Neurodivergence Team, continue to develop training and resources to support individuals, including those with mental health needs, families, and services. They have already developed a CAMHS toolkit for practitioners, e-learning models for all staff, which includes the latest addition to support professionals to adapt their practice when undertaking any type of formal assessment with neurodivergent individuals. These are

readily available via Health Boards training infrastructure and on the National Neurodivergence Team website.

Transition

Transition related issues from child to adult are not an issue exclusive to neurodivergence related services. Nevertheless, we continue to see services have difficulties in managing issues relating to transition, as evidenced by the NHS Executive children's services review. Where necessary, the NHS Executive has provided specific recommendations for improvement to individual Health Boards. The NHS Executive has also provided an overarching recommendation of developing national standards. We have brought these issues to the attention of our Clinical Advisory Group for further consideration.

Women & ADHD/ASD

Neurodivergent conditions present differently in each individual. We know girls and women are more likely to mask their difficulties than boys and men, often mimicking others to appear to fit in. Current screening and assessment tools have been revealed to be biased towards what is often defined as male presentation; however, clinicians understand this and are skilled and able to work with additional evidence bases to make an expert diagnosis. The National Neurodivergence Team has offered training, recently, Dr Jo Steer, Consultant Clinical Psychologist, presented at a Community of Practice on Women and ADHD.

We know that the differences presented by women are being recognised. We have data from the Integrated Autism Service which demonstrates an increase in referral rates for women for both diagnosis and support. Awareness and skills in identifying neurodivergent traits in girls and women is clearly growing resulting in this increase of referrals for women. The national Integrated Autism Service now receives more referrals for women than it does men.

Criminal Justice System and Improving Services in the Secure Estates

Following the UK Government led report 'Neurodiversity in the Criminal Justice System – A Review of Evidence', the Welsh Government has worked collaboratively with the UK Government Ministry of Justice and the Welsh Government Criminal Justice Team to ensure appropriate levels of support are provided to neurodiverse individuals within the non-devolved secure estate across Wales.

There is now a Neurodiversity Support Manager (NSM) post in every prison in Wales. NSMs are responsible for implementing improved processes for supporting prisoners with neurodivergence needs, ensuring they have the access to tailored support in areas such as education, advice, and work opportunities. We have also undertaken the following work to support the Criminal Justice system:

- The National Neurodivergence Team has developed a basic autism awareness training for emergency services. This has been piloted with North Wales and Dyfed Powys Police. North Wales Police also employ an autistic person as their Equality Officer who has developed further resources that have also been shared.
- Staff from Berwyn Prison have accessed North Wales Integrated Autism Service training.
- Work with probation and the Integrated Autism Services (IAS) has been ongoing throughout Wales.
- Specific housing guidance in relation to supporting autistic tenants has been produced and this resource is available to Resettlement Officers.

- We are engaging with cross-government colleagues responsible for the Prison Health & Social Care Oversight Group and have requested representation on this group.

Adult ADHD Pathway

The Clinical Advisory Group, which sits under the Neurodivergence Ministerial Advisory Group, is leading on the development of an adult ADHD pathway. Initial advice has been disseminated through Regional Partnership Boards on the required delivery and establishment of ADHD services, this includes expectations regarding their alignment with other services, and integration with post diagnostic support and psycho-educational arrangements.

We are in the early stages of developing and piloting a minimum viable data set to begin to understand the true demand for adult ADHD services. Whilst the referral demand for diagnostic assessments is significant and continues to rise, we are also aware of the significant challenge the prescribing and dispensing of ADHD medication, and are working with our colleagues in Primary Care to bring improvements and explore different ways of working to increase availability in the community.

Tourettes Syndrome

Tourette's Syndrome has seen a surge in awareness across Wales. We have continued to meet with families of children with Tourette's Syndrome, and are actively engaging with Tourette's Action, who provide us with advice on best practice models, interventions, and access to e-learning modules. We recently supported the awareness raising campaign for Tourette's Awareness Month, we funded the translation of their posters into the Welsh Language so that these could be shared across Wales.

Several training sessions have been facilitated by the National Neurodivergence Team on Tourette's Syndrome, which provided opportunities to upskill and train our current workforce. The National Institute for Health and Care Excellence (NICE) have agreed to look at developing agreed Pathways, this will provide best practice guidance for service development for Health Boards.

Education and Additional Learning Needs (ALN)

There remain barriers to collaborative working and good communication between education and health services and this is an area of concern. Families tell us that the education system, notably schools have a central role in the pathway to ND assessment and support. We are therefore ensuring that the development of the Statutory Code of Practice on Neurodivergence Services will also be made under the ALNET, to strengthen education requirements.

We are supporting the implementation of ALN transformation, supporting colleagues in Pedagogy, Leadership & Professional Learning to develop an improved offer of professional learning to education staff. This work is being undertaken with Bangor University and the National Neurodivergence Team and aligns child development and neurodivergence with the Whole School approach. This includes inset days, undergraduate training and management.

Third Sector Grant Scheme

Two ND organisations have received funding through the Social Services Third Sector Grant Scheme, which is currently in its fifth and final year of the current grant round.

National Autistic Society Cymru

The National Autistic Society has developed the peer support available for autistic individuals. This has been achieved by establishing new branches and social groups in local communities and provide the support autistic adults need to form and run their own social groups.

We know autistic individuals will often experience feelings of loneliness and isolation. By setting up or just attending a peer social group, they will be in a safe environment where they meet others with similar interest and life experiences. These newly established groups will make a real and positive difference to the lives of autistic people by providing person-centred community activities and reduce the loneliness and social isolation that they experience and help members to grow in confidence.

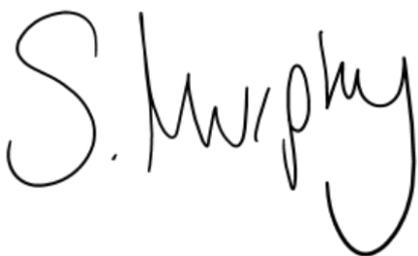
Autism Spectrum Connections Cymru (ASCC)

ASCC provide a one stop shop - a responsive, flexible, person centred support for autistic adults in the areas of pre-employment and benefits, they offer a programme of regular targeted activities to support autistic individuals, these include employment workshops, face to face sessions around benefit support, support to access education/training courses, employability support, support to retain existing employment and to achieve volunteering or work-based experience.

ASCC has established joint working with the Integrated Autism Service (IAS) in Gwent and Cardiff and the Vale. The work that ASCC relieves the pressures on the IAS around employment and benefit support. They have developed simple referral pathways with the IAS ensuring support is focused and not duplicated. Outside the scope of the grant, ASCC also supports autistic individuals to access social opportunities and provide wellbeing activities and drop-in services.

I am confident that the Committee can agree that the evidence of progress and improvement demonstrates effective delivery and the significant impact of the Welsh Government policy approach, strengthened by the introduction of the statutory Autism Code of Practice. Our focus has been to direct available resources in the continued delivery of improvement on the ground, rather than taking forward primary legislation which is not required. We will continue our transformation of ND services through the delivery of the NDIP programme and development of the Statutory Code of Practice on the Delivery of Services.

Yours sincerely,

A handwritten signature in black ink that reads "S. Murphy". The signature is written in a cursive style with a large, looped 'S' and a long, sweeping tail on the 'y'.

Sarah Murphy AS/MS

Y Gweinidog Iechyd Meddwl a Llesiant
Minister for Mental Health and Wellbeing