



Llywodraeth Cymru
Welsh Government

PUBLICATION

Neurodivergence improvement programme: engagement events November 2022

Report on stakeholder feedback from neurodivergence engagement events in November 2022.

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Summary

This report provides a summary of the feedback received from stakeholders who attended the neurodivergence policy engagement events held around Wales in November 2022.

Welsh Government has a strong record in recognising the needs of neurodivergent people and in leading innovation, this includes our autism strategy first published in 2008; establishing the **National Autism Team** (autismwales.org), which provides expert guidance and training and in 2016 introducing the Integrated Autism Service in every Welsh region. In 2021 we published the **Statutory Code of the Delivery of Autism Services** which sets out the roles of responsibilities of public bodies to ensure the needs of autistic people are met.

As awareness and understanding of neurodivergence is increasing we have learned that services do not have capacity to meet rising demand, particularly in accessing early support and assessment. We recognise there is also a need to address gaps in support in conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and Tic / Tourette's Syndrome. We have reviewed existing provision and in response have established a three year Neurodivergence Services Improvement Programme back by £12million, to develop sustainable integrated neurodivergence services and support.

To make sure this programme is focussed on priorities which are important for those with lived experience of neurodivergence including parents and carers we have undertaken a series of engagement events across Wales, setting out the priorities actions and seeking feedback on our plans. This report summarises the areas where stakeholders reported most urgent action was required and the outcomes they wanted to see.

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Policy background

On 6 July 2022 in a [Written Statement on Improvements to Neurodevelopmental Conditions Services](#), the Deputy Minister for Social Services published the [summary outcomes report](#) of the independent Review of the Demand, Capacity and Design of Neurodevelopmental Services and announced a new improvement programme backed by £12m up to March 2025. The [full report](#) was published on 11 October.

The Deputy Minister for Social Services also separately agreed to expand policy development on neurodevelopmental conditions from a focus only on autism to other ND conditions notably ADHD and Tic Disorders. The Neurodivergence Improvement Programme (ND Programme) set out the Welsh Government's commitment to improve Neurodivergence services in Wales.

Programme priorities

The programme addresses key areas of concern identified by stakeholders and the recommendations set out in the Demand and Capacity review. We have established three workstreams to take forward the priority areas, this is summarised below and was discussed during the engagement events.

Programme Priorities

Workstream 1: Tackling urgent need

Lead: National Autism Team

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- Set out and communicate mandate for change. Bio-psychosocial model.
- Urgent support for existing ND services – children and adult.
- Develop and pilot ND early help and support services for children and young people.
- Scoping for ADHD and Tourettes support services (all age).

Workstream 2: Building sustainable services

Lead: National Autism Team

- Waiting time pressures
- Develop specifications for a national approach for ND service reform for children, young people and adults including transition.
- Test and roll out new approaches across regions.
- Support for those not meeting assessment thresholds – missing middle.
- Improved support for co-existing conditions including mental health and well-being.
- Continuing support for families and carers.
- Support in education and employment and criminal justice.

Workstream 3: ND Infrastructure and workforce

Lead: Welsh Government

- Workforce development
- Data improvement
- Digital enablers
- Enabling innovative practice

Alongside these workstreams we have also established an expert clinical group and a wider stakeholder group. The membership organisations of the

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workstreams, the clinical group and stakeholder groups is at [appendix 2](#).

Introduction

In November 2022, the Welsh Government undertook four face to face public engagement events in, Carmarthenshire (27 attended), Cardiff (60 attended), Llandrindod (34 attended) and Llandudno (38 attended) with two online events (172 joined) on the new Neurodivergence Improvement Programme (ND Programme). The events were well attended with a total of 331 attendees.

Overall the responses supported the aims of the ND Programme with comments such as:

“Glad that we are focussing on ND – a long journey”

“Positive to see realistic views around workforce development”

“Like the idea of cultural change and partnership working”

“Really positive to see the emphasis of this work extended to under 18s”

“A general loose alignment of strong principles holding everyone together”

However, there were some concerns such as:

“Timescales need monitoring and keeping to, to make them effective, realistic and supportive”

“What’s the destination, the vision?”

“How can we ensure consistency, equality?”

“Ambitious? - too many priorities perhaps, could it be broken down/diluted?”

“Too Autism based”

Overview of findings

The engagement events asked three questions;

1. What are your views on the plans?
2. Are there any gaps in our proposals?
3. Are there examples of good practice that you can share?

We received feedback through participating in group discussions, written notes and listening to other verbal feedback during the events. The responses were wide ranging and complex, they were analysed by identifying the key themes which emerged, these were as follows:

- education
- ADHD
- social care
- local authority
- health
- Integrated Autism Service (IAS)
- training
- employment
- transition
- workforce
- data/digital
- advocacy
- private diagnosis
- service needed

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Education

At present it was felt that schools do not meet the needs of the child with suggestions that education / schools need to be more inclusive, need to listen and acknowledge parents' concerns regarding the child.

It was also felt that there was a deterioration in Additional Learning Needs (ALN) support since the implementation of the new ALN Act with implications for families and carers.

It was highlighted that there was a need for better access to and more special educational settings for neurodivergent children without learning difficulties who are unable to access mainstream schools with support. Although this is in contrast to the need for schools to be more inclusive it acknowledges that some children / young people may not thrive in an academic school but an opportunity to learn life skills with curriculum subjects where appropriate would be more appropriate.

Comments indicated that school staff should receive appropriate training in reasonable adjustments and supporting positive behaviour for neurodivergent children in both Initial Teacher Training (ITT) and Post Graduate Certificate of Education (PGCE) training with on-going mandatory training strongly suggested.

For older learners it was suggested that work needs to be undertaken with Higher Education / Universities to understand the resources required to meet the needs of neurodivergent learners. Additionally, it was felt that older learners would benefit from support in the transition from education to work and that more training for careers services / advisors with assessments and guidelines would support this work.

Attention Deficit Hyperactivity Disorder (ADHD)

It was felt that the ND Programme didn't adequately reflect the current crisis in ADHD service provision which includes the lack of clear assessment guidance or post diagnostic support. Equally there was a suggestion that medication was always the first consideration rather than the use of therapies such as psychoeducational therapy.

There was a clear call for the GP contract to be reviewed with a view to improved shared care.

Social care

The main issue was improved training for social care staff, especially with regards to reducing the risk of children being taken into care / fines for school non-attendance.

There was also comments highlighting the need for local authorities to work better with support services.

Local authority

There is a need to look at governance structures to ensure local authorities adhere to national policies and guidelines and update their own accordingly.

Health

It was felt there was a need for some health professionals to understand the 'whole' person profile not looking at individual diagnosis.

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It was highlighted that there was a need to ensure clear adult and child national referral and assessment pathways were not only developed but also embedded within each health board. Also these pathways need to include wider ND conditions and need to consider gender bias at an early stage of referral / assessment.

When looking at developing services such as ND teams it needs to be clear that some Learning Disability and Mental Health teams do not always have the expertise to diagnose ND conditions.

Integrated Autism Service (IAS)

There is a need to look at the referral processes to IAS for consistency across Wales. Some areas accept self-referrals whilst others are consultant referrals only.

Additionally, there was interest in ND screening for adults where other ND conditions may be recognised and what service delivery is being developed for this group of people.

Training

There were specific concerns within a main training theme. Whilst some comments referred to the need for improved training for education, all public bodies including the judicial system and job centre staff, other comments suggested the need for more practical training and support rather than online / video's and leaflets and that the training should be targeted at specific workforce groups such as children or adults.

Other observations suggested revisiting educational psychology training to improve / develop the training programme to enable better help for schools to

meet ND need whilst learners await assessment.

Employment

Observations indicated the need to improve links to employment, suggesting that front line staff in employment centres need more training. Equally there were comments regarding the need for further training for employers and Department of Work and Pensions (DWP) staff not only Personal Independence Payment (PIP) staff.

It was also highlighted that there should be training available for employers with more half way support schemes to help neurodivergent employees integrate into the workplace.

Transition

Comments were made regarding most areas of transition which included; improved transition between child to adult services in local authorities, Child and Adolescent Mental Health Services (CAMHS) to Adult services in health and all stages of transition within the education system.

It was suggested that support for teenagers and young adults to allay anxieties and to help families to support individuals through the transition.

Workforce

There were constructive comments regarding the collaboration and / or commissioning of third sector organisations, stating that they have the time and expertise to offer practical assistance to families and/or individuals.

Comments regarding therapists included the need for more training for Occupational Therapists in sensory therapy, improvement in the continuity between children and young people and adult Speech and Language services (SALT).

Additionally, comments suggested that it was not sufficient just to upskill staff that would not stay in post stating there was a need to improve recruitment and retention, this included funding allocations to allow staff to be employed long enough to create sustainable change. However, it was also argued that looking at capacity issues was difficult without a nationally defined ND team. Some comments suggested the need for an integrated approach / model.

When understanding the gaps in specialist services suggestions were made to train nurses for ADHD clinics who could discuss with patients, diagnosis, possible reactions to medication and to increase training for specialist Approved Mental Health Practitioners (AMHP) to assist in the diagnosis process.

Data / digital

Comments included the benefits of the Welsh Community Care Information System (WCCIS) although others felt it needed further development as it adds to the non-clinical workload. In-put needs to be streamlined and more succinct and there is clearly more work to be undertaken

Agreement was across the board for the need to improve administration teams to support all health and social care teams.

There were discussions regarding why data gathering is so different across Wales, the need to standardise and the importance of collecting relevant data.

Advocacy

Attendees indicated that there was a need for advocacy services for parents to help access services and suggested the benefits of offering advocacy training for parents to enable self advocacy.

Private diagnosis

There were a few questions and comments regarding private assessments. Due to the long waiting lists individuals are looking for private assessments. We know that guidance on acceptance of private diagnosis and the standards these assessments must reach already exist in Wales. These were developed in 2017 and there has been a significant rise in referrals for assessment since then. Welsh Government intend reviewing these and updating where necessary. This will include a national approach to contracting / accepting / acting on private assessments.

Services needed

Areas where specific service development was required were:

- support after diagnosis.
- support for parents.
- need better, reliable and more committed screening.
- delivery of counselling and confidence building skills for older people who were late having a diagnosis.
- various relationship support e.g. peers, parents, spouse/partner.
- accessing talks by successful neurodivergent people to remove stigma.
- promote / develop a Buddying system and a Peer support system for individuals and their families / carers / friends.

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- jobs fair bringing together DWP and neurodivergent people.

Welsh Government conclusion and next steps

It was encouraging to see the number of attendees at the events and the positive response to the Neurodivergence Improvement Programme. We also welcomed the suggestions and constructive feedback for further development or inclusion in our plans. The feedback we received will be considered by the Ministerial Advisory Group on Neurodivergence and will help guide development of services through the programme workstreams, the clinical group and the advisory group.

We learned that there was a general consensus that all partner organisations, including the Welsh Government need to combat silo working and make strong connections to ensure equity in service provision across Wales. Making sure that all services are accessible and meeting the needs of neurodivergent communities must continue to be a priority.

As Welsh Government delivers the programme we will also ensure we continue to acknowledge and comply with legislation and guidance such as Disability Rights, Equality Act, and ensure services meet the needs of those with protected characteristics such as Black Asian and Ethnic Minority and our LGBTQIA communities. We will prioritise co-production of all aspects of work and we are currently looking at improving ways of working to ensure non-verbal people have equal access to participating in co-production. Additionally, we are committed to widening our parent engagement groups across Wales to ensure we capture as many views and opinions as possible. We will also make sure that we consider how Welsh Language services are available on an equitable basis.

We thank all the participants for the examples of good practice offered from, family centres, disability workers, peer support, mentoring, play therapists to

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examples of NHS Adult ADHD services that are working well. All these will serve as the foundations of the work being taken forward by the workstreams and will offer an insight into what neurodivergent people want and need from good services. We will continue to provide updates on the progress we are making and ensure there are many opportunities for co-production and continuing feedback.

Appendix 1: Membership of the Ministerial Advisory Group on Neurodivergence

To provide advice and guidance on programme delivery we have established a **Neurodivergence Ministerial Advisory Group**, which is co-chaired by people with lived experience of neurodivergence.

- Individuals with lived experience of neurodivergence including Autism, ADHD and Tic Disorders
- ADHD Foundation
- Autism Wellbeing CIC
- All Wales People First
- Learning Disability Wales
- Childrens Commissioner for Wales
- Tourette's Action
- Chinese Autism Support Group
- Welsh Government Neurodivergence Network
- NAS Cymru
- Advisor to the Royal Colleges (RCPsych)
- Improvement Cymru – Public Health Wales
- Black, Asian and Ethnic Minority Mental Health Group
- Cardiff and Vale UHB – ND Clinician
- All Wales Heads of Adult Services – AWASH

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- NHS Wales – Delivery Unit
- All Wales Heads of children’s Services – AWHOCS
- WLGA, Directors of Social Services
- National Autism Team
- ASD Leads Representation
- Integrated Autism Service Representation
- LGBTQIA+ representation
- All Wales Forum
- Criminal Justice representative
- Head of Probation Delivery Unit
- Head of Education WLGA
- Specialist Occupational Therapists – Tourette’s
- Autistic UK

Appendix 2: Membership of the Neurodivergence programme workstreams, clinical group and stakeholder group

Welsh Government project management and policy development membership

Workstream 1: Tackling Urgent Need

Lead: National Autism Team

- Local Authority Community Resilience Team
- Lived Experience / Complimentary therapist
- ASC Leads
- Cardiff University

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- SALT
- Swansea University
- Local Authority
- Lived Experience representative
- Childrens & Families Regional Transformation Lead for Gwent Transformation service
- Third Sector Childrens service

Workstream 2: Building Sustainable Services

Lead: National Autism Team

- Local Authority Community Resilience
- ASC Lead
- Cardiff University
- Education
- Local Authority Social Work
- SALT
- Education
- Criminal Justice
- SALT
- Educational Psychology
- Lived Experience / Home Office
- ASD Occupational Therapist
- IAS
- CAMHS
- Lived Experience / Psychologist
- LD/ MH Occupational Therapist
- ALN National Implementation Lead
- NHS
- Lived Experience representative

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Workstream 3: ND infrastructure and workforce

Lead: Welsh Government

- ASC leads
- University South Wales lecturer
- Training early years – additional needs
- Disability employment
- Swansea University
- Digital health and Care Wales
- Data Cymru
- HEIW (to be confirmed)
- SCW (to be confirmed)
- WG workforce
- NHS workforce leads
- LA workforce leads
- WG digital data
- Royal colleges
- Initial teacher training WG

Welsh Government Project Management and Policy Development: membership

Clinical group

- Clinical psychologist BCUHB
- Clinical psychologist HDUHB
- Chartered psychologist
- Forensic psychologist - Criminal justice system
- SALT Specialist Advanced Practitioner SBUHB

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- Occupational therapist ASD ABUHB
- Paediatric neuropsychologist
- Clinical psychologist / Lead for ASD /Lecturer BCUHB
- Consultant psychologist paediatrics HDUHB
- Occupational therapist CAMHS ABUHB
- Principal clinical psychologist / IAS Clinical Lead
- Speciality doctor in adult psychiatry C&VUHB
- Consultant paediatrician CTMUHB
- CAMHS / Director Family and Therapies /Lead for under 18 ND services ABUHB
- Consultant CAMHS and ND services C&VUHB
- Community paediatrician ABUHB
- Consultant psychiatrist CAMHS / Clinical Lead ND Paediatrics CTMUHB
- SALT SBUHB
- Consultant paediatrician C&VUHB
- Consultant psychiatrist CAMHS / National Clinical Lead ABUHB

Stakeholder group

- Teaching assistant
- specialist practitioner for children with complex need
- Trustee for third sector organisation
- Lived Experience
NHS Collaborative - Suicide prevention
- Lived Experience
- Early years specialist teacher
- neurodivergent individual, an Occupational Therapist, Psychologist and Psychotherapist
- Lived experience
- BPS member – Masters in psychology, Cardiff Uni SW as a specialist mentor for MH and ASD
- Welsh Assembly's Cross Party Autism Group Member

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- Lived Experience (Tourettes and ADHD)
- 3rd sector organisation
- ImROC – Implementing Recovery through Organisational Change
Lived Experience Cardiff and Vale NHS Trust, Registered Nurse
Lived Experience Grants Processor for the Welsh Government
- Graduate people & organisation Consultant, UK
Consultant graduate in organisational psychology
- International campaigner – ADHD Lived experience
- Research project
- Lived experience
- Autism Youth Advisory Group member, Lived Experience

Welsh Government cross policy working

- Education
- Housing
- Mental Health
- Employment
- Disability
- Vulnerable people
- Criminal Justice System

Appendix 3: Glossary

Terms and definitions

Additional Learning Needs Act

Is the new system for supporting supporting children and young people aged 0

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to 25 in education. It replaces the Special Educational Learning System (SEN).

Approved Mental Health Practitioner

Mental Health practitioners are practitioners who have been approved by local social services authorities to carry out certain duties. They may be social workers, nurses, occupational therapists or psychologists.

Attention Deficit Hyperactivity Disorder

Attention Deficit Hyperactivity Disorder is a neurodevelopmental condition.

Buddying systems

Encourages informal learning, development of skills, confidence and support networks through social interaction and observation.

Co-production

Is a way of designing and delivering public services in partnership with the public, giving the public control over decisions which affect their lives.

Integrated Autism Service

Represent a partnership between health boards and local authorities. The service provides adult autism assessments, support and advice for autistic adults, parents/carers and professionals.

National Autism Team

Is funded by Welsh Government and hosted by the Welsh Local Government Association with Public Health Wales.

Neurodivergence

Services and policies developed and delivered for neurodivergent communities.

Neurodivergent

Someone whose neurology differs significantly from the most commonly occurring neurotype.

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