

Neurodevelopmental Disorders (ND)

Universal Factsheet



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What is ND?

ND is short for Neurodevelopmental Disorders, a diagnostic family of eight disorders. This family of 'cousins' includes Attention Deficit Hyperactivity Disorder (ADHD, 5% of population), Autism Spectrum Disorder (ASD, 1%), Language Disorder (10%), learning disability, dyspraxia, dyslexia, dyscalculia and tic disorder (including Tourette's). This is a medical model with criteria from international diagnostic manuals ICD-11 or DSM-5.

ND is not short for neurodiversity. Based in a social model, neurodiversity recognises that we are all different; our brain is as unique as our fingerprints. The term, neurodiversity, does not belong to one group in society. We are all neurodiverse and everyone is responsible for equality, diversity, inclusion and belonging. The two terms, ND and neurodiversity, work best in combination - to identify someone's profile of strengths, differences and needs through assessment, with or without a diagnosis, then plan person-centred support by making changes to our environment and enabling people around us to understand and adapt.

What is the local ND service?

The Neurodevelopmental Disorders (ND) team is a specialist service based in Neath Port Talbot Hospital. They assess ASD, ADHD or both, in children and young people (CYP) from 5 to 17y 6m old. Every case is waiting for an assessment; they are not *waiting for a diagnosis*. Every case is different; their assessment outcome will reflect their individual profile and specific circumstances.

The Welsh Government target is a six-month wait for assessment. Across Wales, waiting times are more than two years. At any time, families can ask for support from different services in the Health Board, the Local Authority or voluntary sector in a whole system approach.

What is the whole system approach?

Support does not start with a referral. Support does not change with a diagnosis.

Welsh Government has two statutory systems for all children and young people:

1. Additional Learning Needs (ALNET Act 2018); www.gov.wales/additional-learning-needs-code
2. Whole school approach to emotional health and wellbeing (2021) [WG42005 \(gov.wales\)](http://WG42005.gov.wales)

Anyone can raise concerns about a learner's progress; this can be a family member or a professional. In all cases, there needs to be a step-by-step approach that is called the graduated response. This approach is part of a whole system approach for all learners under the ALN Code of Practice. All professionals must comply with the ALN Code. That step-by-step process always comes first, before any discussion about making a referral to a specialist professional or service.

1. It starts with a discussion between parent/carers and school about a concern or lack of progress, to agree what adults at home and at school can do to help and what other support is available;

2. Once that is in place, there is an agreed time to observe and monitor progress;
3. After that agreed time, progress is reviewed again, based on feedback or outcomes from school based assessment or intervention. There might be a mixed picture of some things that have improved and other things not making the expected progress yet;
4. At this point, there should be a discussion with everyone involved to agree next steps. One of those steps might be to complete screening questionnaires for discussion or begin a referral.

Who can refer?

In 2016, Welsh Government moved ADHD and ASD assessments out of CAMHS into separate ND service. Since then, there has been no change to the national guideline that anyone can fill in and send an ND referral. There is one pack and one pathway; whoever co-ordinates the referral, the forms and process are the same. When everyone involved discusses progress and next steps on the graduated response, if there is not a collective agreement to refer, then parents can choose to co-ordinate a referral. At each stage, the priority should be what is in the best interests of the CYP, taking a practical approach and working together.

A referral is only one of many possible steps on the graduated response. It must describe the CYP's individual circumstances, the support in place to learn and progress with language, social-emotional development and behaviour. When schools need more specialist advice to help identify ALN, they can contact different professionals for different concerns. That professional advice adds to the information used in decisions about next steps. For a referral, their specialist viewpoint is separate to the school information or the evidence from home reported by parent/carers. The Autism Code of Practice expects all professionals to be able to identify ASD or signpost to assessment. As there is no equivalent ADHD Code, individual professionals must decide if they have the specific knowledge and skills to identify ADHD and support a referral.

Under NHS Wales and Swansea Bay Health Board policies, referrals must come in electronically SBU.NDReferrals@wales.nhs.uk and be added to the patient system within seven days. The email is for referrals only, not for general enquiries. With an average of 87 referrals each month, a small ND admin team and teaching staff in class, there is not enough time to request missing information. The team cannot hold incomplete referrals so these have to be declined. The office telephone number is 01639 862459 School staff will need parental consent to contact us, and from the age of 16y, young people need to give us consent to share information with anyone.

The ND team review the referral to decide if the CYP needs an assessment or not, then write to the referrer and family. They have to use set criteria and guidelines in their decision to accept or decline. They have to interpret evidence compared to overall ability or development, not just age. Another criterion is that referral evidence must come from two different settings:

In the referral, the balance of evidence from the two different settings needs to show:

- Specific examples of differences associated with ASD, ADHD or both;
- Those differences are not consistent with their overall level of ability or with another diagnosis that they already have;

- There is clear impact on how they function in social and learning environments, as well as at home.
- When symptoms are measured on questionnaires, scores are clinically significant*

For ADHD, inattention or hyperactive impulsive scores must be at or above cut-off in both settings

What about private diagnosis?

Parent/carers can decide to pay for an independent assessment for Attention Deficit Hyperactivity Disorder (ADHD) or Autism Spectrum Disorder (ASD). Many different companies and individuals offer diagnostic assessment outside the NHS. For ADHD, families may pay for an assessment and a trial of medication. Private prescriptions cannot automatically transfer to NHS teams; every case will be different depending on the independent report. An NHS ND team cannot make any recommendations about private providers because it has no role to quality assure other services.

When a CYP is already waiting for an NHS assessment, if parent/carers pay for an independent assessment, they need to send a copy of that report to the ND team for review. As the team accepted the original referral based on clinical need for assessment, they need to review the independent report to see if the *assessment meets the quality standards* as agreed by NHS Wales ND services. They review the method, not the outcome. The ND team has no responsibility to ratify or approve a diagnosis from another provider.

If the assessment report demonstrates those quality standards, then the CYP no longer needs an assessment. The ND team will discharge and write to the referrer and parent/carer to confirm that the independent assessment is an equivalent standard to one available from the NHS. For an independent ADHD diagnosis, families can take that discharge letter to their GP, who can then write to CAMHS to arrange a trial or monitoring of medication. If the information in the independent report does *not* demonstrate the agreed NHS Wales quality standards, then the ND team still has a duty to assess. They will write to the family to explain their decision and the CYP stays on the waiting list, unless parents ask for them to be discharged. This does not affect or change an independent diagnosis; parent/carers can still share the report freely with others.

If the CYP has not been referred for an NHS assessment and is not on the waiting list, the ND team has no reason to review an independent diagnosis of either ADHD or ASD. Any independent assessment is a parental choice and they can share the outcome as they wish. If a CYP has an independent ADHD diagnosis, some companies may offer medication. If they do not offer that but parents want a trial of medication, the GP would need to write directly to CAMHS to ask them to arrange this. The CAMHS team then to review the independent report using the same NHS Wales quality standards document. If they agree the assessment is an equivalent standard, they will agree to start medication. If the information in the independent report does *not* demonstrate the agreed NHS Wales quality standards, then CAMHS cannot take over the monitoring of the ADHD medication and they would write to the GP and the parents to explain their decision.

Universal resources to support needs in a whole system approach

Advice/support for parent carers: Special Needs Advisory Project Cymru www.snapcymru.org;
Integrated Autism Service www.autismwales.org/en/integrated-autism-service/western-bay/;
Swansea Parent Carer Forum www.swanseapcf.org; Neath Port Talbot Support Additional Needs
(S.A.N) www.dewis.wales/ResourceDirectory/ViewResource.aspx?id=16748

Attention and concentration: *with or without a diagnosis of ADHD*

www.adhdfoundation.org.uk/2022/05/30/information-booklets/
www.ed.ac.uk/sites/default/files/atoms/files/epic_adhd_parents.pdf
www.ed.ac.uk/sites/default/files/atoms/files/epic_adhd_teachers_100921.pdf

Behaviour: Behaviour Support/Wellbeing Team from the Local Authority; online resources

www.family-action.org.uk/content/uploads/2020/07/Toolkit-for-Regulation.pdf

Co-ordination and motor planning: *with or without a diagnosis of DCD or dyspraxia*

www.ed.ac.uk/sites/default/files/atoms/files/epic_dcd_teachers_100921.pdf
www.ed.ac.uk/sites/default/files/atoms/files/epic_dcd_parents.pdf

Emotional health and wellbeing: Early Help Hub; CAMHS School In Reach Team; Teen Toolbox
App and book www.caigraham.com/services/app/

Local Authority ALN services www.swansea.gov.uk/aln; www.npt.gov.uk/27472

Mental Health: Single Point of Access team in CAMHS 01639 862 744 e.g. anxiety, depression,
self-harm, eating disorders. www.camhs-resources.co.uk/downloads ; www.youngminds.org.uk

Sensory differences: Occupational Therapy: www.sbuhb.nhs.wales/children-and-young-people/childrens-health-services-swansea-and-neath-port-talbot/occupational-therapy/
www.asensorylife.com/

Sleep: www.thesleepcharity.org.uk/information-support/children/

www.thesleepcharity.org.uk/national-sleep-helpline/
www.cerebra.org.uk/get-advice-support/sleep-advice-service/
www.cerebra.org.uk/download/sleep-a-guide-for-parents/

Speech, Language and Communication: NHS Speech & Language Therapy, online resources:

Primary: www.ican.org.uk/media/3225/tct_univspeak_5-11_update.pdf

Secondary: www.ican.org.uk/media/3226/tct_univspeak_11-18_update.pdf

Language Disorder: www.radld.org/about/dld/

Universal ND strategies *with or without any diagnosis*

www.ed.ac.uk/sites/default/files/atoms/files/epic_strategy_teachers.pdf