Together for Children & Young People (2) Programme:

A Vision for Neurodevelopmental Support & Services in Wales

@T4CYP

We want to begin a discussion that could see Wales take a world leading approach to its support for children and young people with neurodevelopmental conditions, focusing on their **needs** rather than on **diagnosis**.

Our vision is to take a holistic, children's rights approach to providing both NHS services and wider support to a range of neurodevelopmental conditions and co-occurring needs, including attention deficit hyperactivity disorder (ADHD) and autism.

There is an opportunity to create a whole system approach that seeks to meet current and future needs by connecting and maximising resources across education, health and social care.

This briefing pack is the start of the journey and we want to ensure that **all** voices are part of this discussion, especially those of children, young people and their families.

Neurodevelopmental conditions include:

*Developmental Coordination Disorder

**Developmental Language Disorder

"My son is 15 now, but at the age of eight he started showing signs of anxiety in primary school. He was diagnosed with a medical condition, speech and language problems, autism traits, sensory processing and anxiety.

It's a very isolating experience being the parent of a child with mental health issues, and when he started to resist school towards the end of primary, I knew that I had to give up work. I was a health professional in Cardiff and Vale, but sadly I wasn't effective at my job because emotionally I was strained in work and sometimes having to come in late because I couldn't get him into school.

It impacted on my other children, who often saw meltdowns in the car and they would end up at school late. It was a negative experience for all of us.

Team work is everything, parents need to be part of that to let you know what works for our children and what doesn't work for our children… if we can get that help in early, and if George had had that help early, I don't believe he would be struggling as much as he does today, and I would probably still be in work. "

Parent

Background

T4CYP (2) Programme

Together for Children and Young People (2) is an NHS led programme aiming to improve the emotional wellbeing and mental health support available to children and young people in Wales.

The original T4CYP Programme ran from April 2015 to October 2019. During this time, the Programme supported work to establish the new Neurodevelopment (ND) Service in Wales, ND Pathway and Standards.

In November 2019, the Minister for Health and Social Services extended the T4CYP Programme until 2022 with a refocused remit on three key areas: Early Help and Enhanced Support, Neurodevelopmental Services and Regional Partnership Boards.

Our objective for the ND area of work is to further support health boards to implement the Pathway and Standards, and to support the development of a whole system response for children and young people with ND conditions, providing an early offer for children and young people and their families, who otherwise would be referred to the ND team.

Demand & capacity

The introduction of the 26 weeks waiting time from referral to treatment has now been fully implemented across Wales. The first full year of performance information is expected in Autumn 2020 but it is anticipated that the current service will struggle to meet capacity.

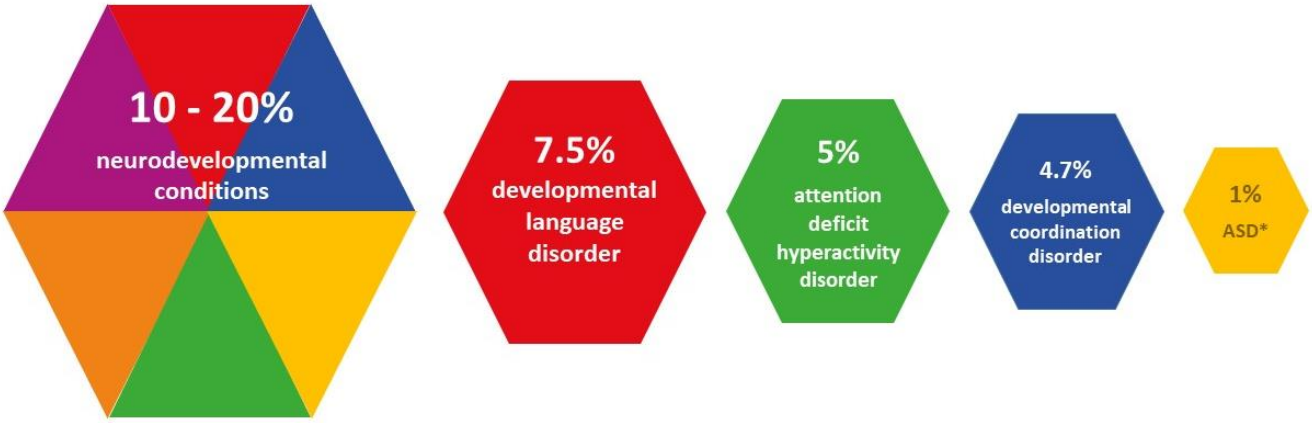
Referrals continue to increase across Wales and the impact of COVID-19 on referrals, referral to treatment waiting times, and ongoing support are yet to be fully understood. However, it is acknowledged that this is highly likely to result in an additional backlog.

#1 Neurodevelopmental conditions are prevalent in the population

1 in 10 of the population are affected by neurodevelopmental conditions, such as attention deficit hyperactivity disorder, autism spectrum disorder, and learning, motor, and language problems. [1]

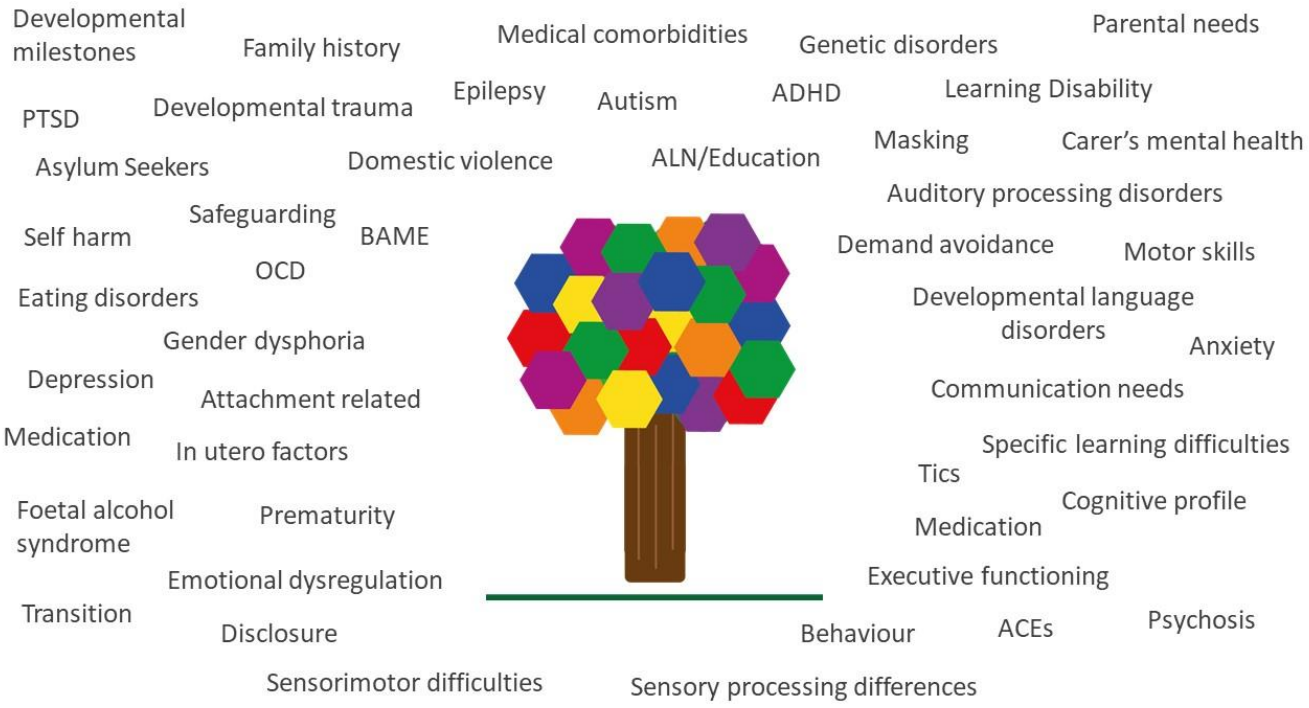
The conditions begin early in childhood and can continue through adult life. Often a child or young person will have more than one of these conditions – they 'co-occur' – and on a scale that may not fit with current approaches to diagnosis. Many conditions may go undiagnosed.

We want to begin a discussion on taking a 'neurodiverse' approach to the way these conditions are supported, which is needs led rather than diagnosis-led.



*Autism Spectrum Disorder

A clinician's view - factors to consider when assessing a child or young person

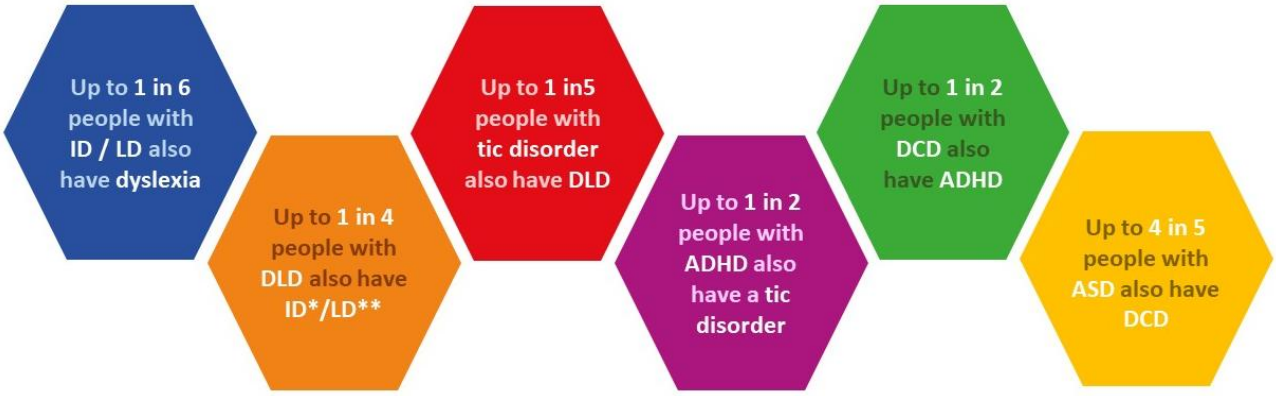


#2 Neurodevelopmental conditions are not distinct from each other and typically overlap

Research has shown that different neurodevelopmental conditions typically overlap with each other or co-occur; for example, many people with autism will have ADHD, intellectual disability and motor difficulties. [2]

These overlaps are the rule, not the exception.

Children do not fit into single, distinct entities but services are currently structured towards this approach.

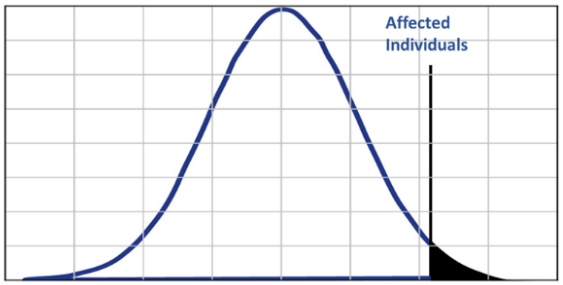


*Intellectual disability
**Learning disability

Source: Cleaton & Kirby (2018) in Journal of Childhood & Developmental Disorders

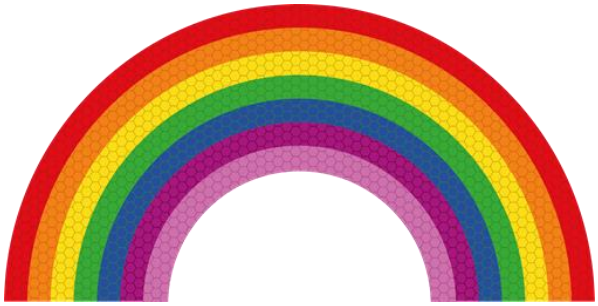
#3 Neurodevelopmental conditions are on a scale - there is no 'Yes' or 'No' diagnosis.

Neurodevelopmental conditions behave like continuous traits along a continuum, such as height or blood pressure. [3] [4]



There is not a clear cut-point on this continuum beyond which adverse outcomes appear.

For example, someone who does not show enough autism symptoms to fulfill criteria for a diagnosis could have worse outcomes than someone who meets diagnostic criteria, because of poverty or an additional mental health problem.



Genetics

- ADHD and ASD are highly heritable.
- Multiple different genes contribute.
- Environmental factors co-act with genetic predisposition.
- The same risk factors influence different neurodevelopmental disorders, so different family members may have different diagnoses. [5] [6]

#4 A balanced approach where support & resources are not dependent on diagnosis

We currently expect children and families to navigate complex services and agencies to receive a 'treatment' - something that is done to change the child and focuses on a 'deficit' model.

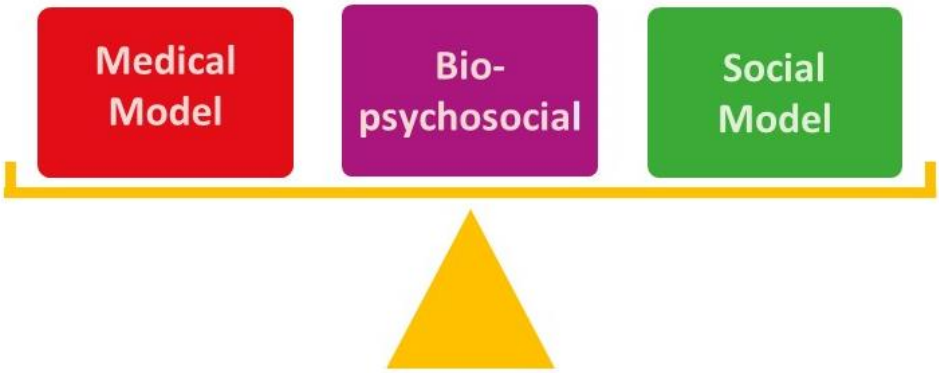
This means people wait for a long time for expensive assessments without intervention, by which time secondary problems will have arisen e.g. depression, anxiety or school exclusion.

Once families receive a diagnosis, they then receive interventions from highly trained specialists and can become eligible for resources – yet we know children and young people who do not fully meet the criteria for diagnosis can have worse long-term outcomes.

We think diagnosis is still useful but on its own presents an overly narrow and scientifically outdated concept of ND conditions.

We believe that interventions need to start early with tailored profiles that build on a child or young person's strengths and offer strategies to target difficulties, not just to be provided once you receive a diagnosis.

We need a balanced approach.



What are the different models?

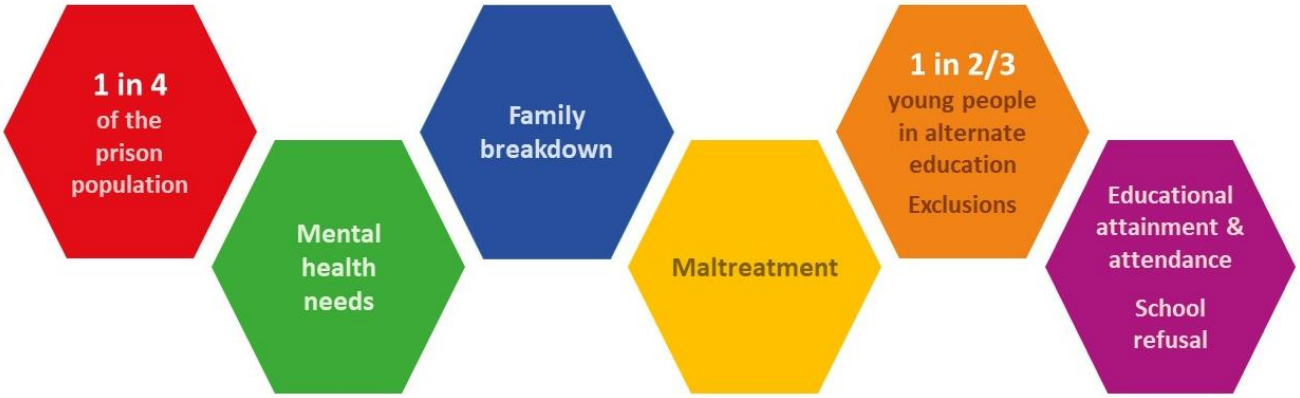
- **Medical Model:**
  Neurodevelopmental conditions are impairments of the growth and development of the brain and/or the central nervous system. Diagnosis can lead to treatment to 'change' the child or young person's symptoms.
- **Bio-psychosocial:**
  Considers neurodevelopmental conditions in terms of biological, psychological and social factors.
- **Social Model:**
  Focus on skilling up society to adapt **around** people with neurodiverse conditions, rather than focus solely on trying to change the young person through treatment for a diagnosis.

#5 The way we currently support neurodevelopmental conditions has an enormous personal and societal impact

Children with ND conditions experience high rates of school exclusion, educational failure, family breakdown, substance misuse, mental health conditions such as depression and anxiety, and are more likely to end up in prison and die early.[7 8 9 10]

They are also more likely to be maltreated[11 12] and are over-represented in looked-after groups[13].

As well as being the source of enormous suffering for children and families, the cost of ADHD and ASD alone in children and adults in the UK is over £40 billion per year in treatment, education, lost earnings, care, and support.[14 15] The total economic impact is unknown, although it is reasonable to suggest it will be significantly higher than reported here due to known prevalence of co-occurring conditions.



#6 A whole system approach would ensure a child or young person receives the support they need, when they need it

A whole system approach could break down barriers between different services and between services, schools and families. Parents and young people repeatedly report this is a current key problem.

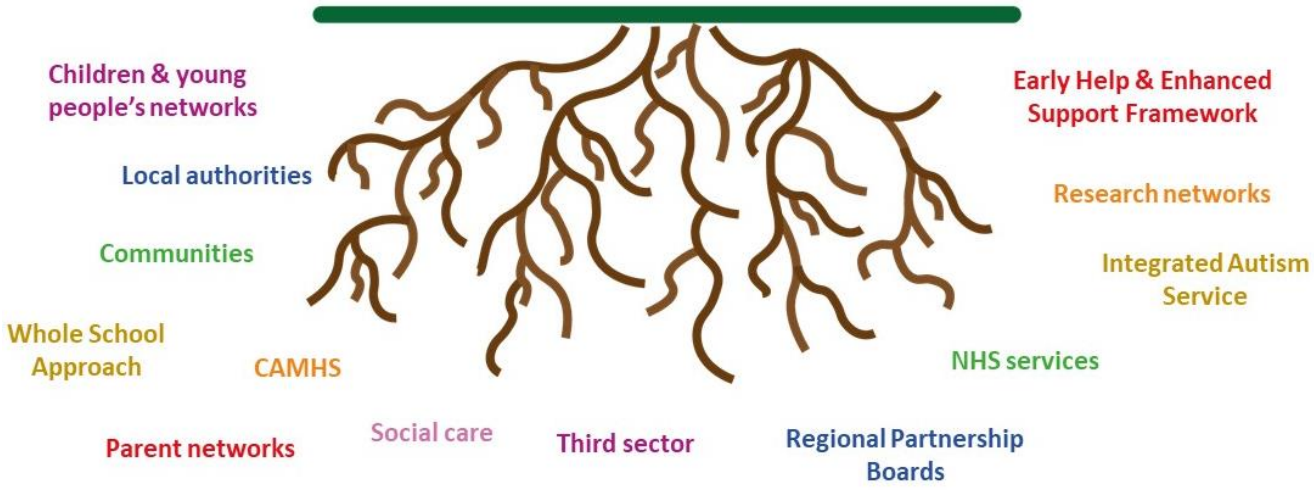
Key to this would be linking the Welsh Government's Whole School Approach, ALN Act, the new curriculum in Wales and the Early Help and Enhanced Support Framework being developed by the T4CYP (2) Programme for roll out through Regional Partnership Boards.

Providing early interventions for neurodiverse children via schools and families is crucial, because we know that children with neurodevelopmental problems are at a very high risk for future difficulties, including mental health disorders such as anxiety and depression. For example, there is good evidence that modifying the whole school environment improves pupils' mental health[16 17]. These approaches need to incorporate the needs of neurodiverse children too.

As a nation, we also need to adopt a life-long approach for **all** neurodiversity - beyond school into higher education and employment. Children with ND conditions grow up and although many continue to have difficulties with transitions, studies show that others find their 'niche' in suitable occupations and adapt well[18]. For example, considering an extension of services to a 0-25 year olds model, could reduce the number of service transitions and better manage those in place. This

would bring the service in line with the new ALN provision.

To be successful, these ambitions require the involvement of children and young people with lived experience and their families - not just professionals. There also needs to be an increased emphasis of working with the third sector and charities across Wales.



Wales has an opportunity to take a world leading approach to its support for children and young people with neurodevelopmental conditions

What could good look like?

- **A new cross-sector approach, co-produced with children, young people, and their families.**
- **Moving away from diagnosis-focused support, to a strengths based approach with a blend of support that offers choice**. We do not propose that we dispense with diagnoses but rather that these should only be needed for medical categorical decisions, not for decisions on educational and social resources that should be provided according to an individual child's needs.
- **Education and awareness raising with organisations and families,** to better understand the new ideas and language of neurodiversity that moves us away from a sole focus on the traditional medical model. To tackle stigma and embrace differences based on a strength based model.
- **Providing early intervention for neurodiverse children** because we know that children with neurodevelopmental problems are at very high risk for future difficulties including mental health disorders such as anxiety and depression.
- **Equipping families and schools** with the necessary knowledge and skills to provide 'team based' support to neurodiverse children.

- **Adjusting and shaping educational and social contexts** to better suit children with neurodiversity and recognise the profile of a child's strengths, not just their differences from other children.
- **Breaking down barriers** between different services, and between services, schools and families.
- **Embracing complexity**. Children need to be profiled along multiple dimensions or traits rather than by a single category alone, as reflected in the 'Embracing Complexity Report'.
- **A Lifelong approach.** As a nation, we need to adopt a life-long approach for **all** neurodiversity -beyond school into higher education and employment.

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Diolch yn fawr!

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Further reading

T4CYP (2) Programme - the journey so far

Guidance and standards for neurodevelopmental services in Wales developed during the first phase of the T4CYP Programme 2015 - 2019:

- Guidance on the delivery of Neurodevelopmental services in Wales
- Neurodevelopmental Services in Wales: Position against the standards for guidance on the delivery of neurodevelopmental services
- Guidance on the delivery of neurodevelopmental services in Wales - Suggested data collection/audit questions

Reports & References

- The International Classification of Functioning, Disability and Health
- Embracing Complexity Report: Towards New Approaches for Supporting People with Neurodevelopmental Conditions - The Embracing Complexity Coalition
- No Wrong Door - Children's Commissioner for Wales

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