Devon's Neurodiversity Strategy for Children and Young People (CYP) 0-25 Years

2025-2030

Proud to be part of One Devon: NHS and CARE working with communities and local organisations to improve people's lives

Introduction

Why do we need this strategy?

This strategy is the culmination of the thinking of parents, carers, NHS, Social Care and education partners. It brings together learning from experience and professionals, evidence and best practice, policy and wider strategy (including the SEND Strategies of One Devon Local Authorities) to offer a One Devon view on how together, we can better support children and young people and families who are neurodiverse to achieve their potential and live their best lives.

What is the national context?

This strategy is developed at a time of significant change in the national landscape and architecture of the NHS and Local Authorities. There are emerging legislative and policy changes, and national long-term plans and priority shifts on the horizon. Across One Devon partners must therefore maintain an ability to adjust and adapt plans to respond.

For children and young people and families, both nationally and locally, these changes will not change their immediate experiences, more children and young people are seeking to understand their neurodiversity through diagnosis than ever before, and they continue to experience long waits to access this help. Nationally, evidence is growing to ensure support and help are available with or without a diagnosis to help more children and young people to live their best lives in inclusive communities, where their needs are responded to early by integrated and co-ordinated support offers.

Who has prepared this strategy and how has it been prepared?

The production of this strategy has been led by NHS Devon, working in partnership across One Devon with experts by experience and profession. NHS Devon has long aspired to a cohesive core strategy to underpin future work. In developing this document, the intention is to ensure a One Devon, shared strategic intent, whilst recognising, through Local Authority aligned implementation plans, a local context for delivering meaningful improvement.

Strategic Drivers: Needs in Devon

Population: There are 223,736 people aged 0-17 years in Devon, making up a total of 18.2% of the population.

Prevalence of Neurodevelopmental Conditions: The estimated national prevalence for some common neurodevelopmental conditions is set in the table. This list is not exhaustive.

Condition	Estimated National Prevalence	Estimated Prevalence in Devon ICB	Estimated Prevalence in Devon CC	Estimated Prevalence in Plymouth	Estimated Prevalence in Torbay
Autism	1 in 24	9,323	6,111	2,165	1,047
ADHD	3-4 in 100	6,713 (lower)	4,400	1,559	754
DLD	7.5 in 100	17,985	11,798	4,174	2,013

Changing Prevalence of Neurodevelopmental Conditions: Estimating the prevalence of some neurodevelopmental conditions is complex because of inconsistent reporting and it changing with increased recognition. An example of the changing prevalence of neurodevelopmental conditions is autism:

- In the general population autism is frequently identified as having a prevalence of 1 in 100 people.
- A range of studies indicate significant variation in prevalence by age, one 2018 study identifies prevalence in people aged over 70 of around 1 in 6,000, whereas in 10–14-year-olds the prevalence was closer to 1 in 24.
- The 1 in 24 estimated prevalence is the most contemporary and age specific source and triangulates with national and local information. This equates to over 9000 across the ICB. A similar number would also be estimated to have ADHD (3-5 per 100).

Neurodevelopmental Conditions in Context:

- Children and young people with neurodevelopmental conditions account for the biggest group of disabled children in England.
- The South-West as a region, has the highest prevalence of children and young people with Special Educational Needs in England.
- In this context, the level of need in Devon is, overall, greater than the average prevalence in the South-West.
- Around 8.3% of children and young people with SEN have a diagnosis of autism.
- SLCN is often a primary need of many neurodevelopmental conditions. Taking the prevalence rates of language disorders and the risk factors associated with social disadvantage, the predicted level of SLCN in 0-18-year-olds is 59,919 (25.3%) across Devon ICB.

Note: Pathways of support for children with autism, ADHD and other neurodevelopmental conditions should be improved, and children and families should receive excellent support with or without a diagnosis

Current Offer In Devon

Children and young people's community services in Devon are predominantly commissioned by NHS Devon. The exception to this is services that are designated nationally as 'specialist commissioning' such as specialist inpatient care for children and young people with mental health problems and autism.

In Devon, autism and other neurodevelopmental diagnostic assessments are part of complex multi-agency and multi-organisational pathways, including services provided by:

- Livewell Southwest (LSW)
- University Hospitals Plymouth
- Children Family Health Devon (CFHD)
- Royal Devon University Hospitals (RDUH)
- Torbay & South Devon (TSD).

Devon is not alone in grappling with this complexity, nationally systems have similar local complexities and unique local solutions, this culminates in a significant national challenge understanding data from multiple national reporting systems.

In addition to this core commissioned provision, statute enables children and young people and their families to access independent sector provision, under 'Right to Choose' legislation.

At present in Devon pre- and post- diagnostic services are limited and inconsistent. In the majority of Devon, and nationally, long wait times for assessment are a persistent challenge.

Strategic Drivers: Voice of Children, Young People, Parent/Carers & Staff

Children & Young People tell us…

- they are frustrated with the long waiting times for autism assessments which negatively impacts their education, mental health, and overall well-being
- there is a need for better support in schools. They called for more understanding from teachers and tailored interventions to help them manage their needs effectively
- they want support and help which is easy to navigate and provide comprehensive support for their needs

Parents and Carers tell us…

- they want better, more regular communication and the chance to talk to someone about assessment processes
- communication about waiting times and what happens during and after an assessment were the most important information for them.
- they want details of how to get advice, support and signposting to other services, learning, groups and online resources.
- they would like peer support opportunities

Staff tell us...

- wait lists, poor experience, sustained pressure, and limited ability to recruit to vacancies adversely impact motivation and retention of workforce.
- that whilst some schools offer outstanding provision for neurodivergent pupils, this is inconsistent within and across schools, leading to inconsistent outcomes
- they identify that a lack of some types of capacity can result in increased assessment referrals

Principles: The Voice of Children & Young People & Families

Child and family centred
Needs-led rather than service-led
Consider the whole person

Child centred

Meet us where we are
Make things easier, not harder
Children, young people and families as true partners
We can work together

Work with us

The right support at the right time.It shouldn't matter where you live or who you are
People around you who understand

Early support

Seeing the whole, real person
Recognising strengths
Open up hope
Not just good enough

Aspiration

This should start early – transitions are stepping stones
Individual approach
Celebrating achievements
Consider independence

Independence

Experience of families

Families are respected, heard, considered and believed
Sharing your experience makes a difference

Inclusive communities

Communities understood and meet our needs
Misconceptions are challenged and corrected
We are not excluded

Recognise needs

More people should know and be confident about neurodiversity
Look beyond behaviour
Take aware hoops to jump through

Long term thinking

Most neurodiversity is lifelong
Planning for next steps
Impact and value rather than short term cost

Communication

Keep in touch
Give us the right information
Treat us with respect

Devon Parent Carer Neurodiversity Expert Reference Group, 2024 (see Glossary)

Principles & The Four Cornerstones

The principles identified and articulated by the Parent Carer Neurodiversity Expert Reference Group in 2024 are well aligned to the unified approach being adopted by Local Authorities, the Four Cornerstones, as illustrated in the chart below. The Four Cornerstones will form a key part of how impact is evaluated.

Welcome & Care	Value & Include	Communicate	Work in Partnership
Child Centred			
Works With Us			
Early Support			
Aspiration			
Independence			
Experience of Families			
Inclusive Communities			
Recognise Needs			
Long-Term Thinking			
Communication			

Drawing it all together to create a powerful and purposeful strategy

Vision & Purpose

Children and families who are neurodiverse can achieve their potential and live their best life.

Strategic Objective 1: Inclusive Communities	Strategic Objective 2: Identify & Support Needs Early	Strategic Objective 3: Integrated Services

Strategic Initiative 1	Strategic Initiative 2	Strategic Initiative 3	Strategic Initiative 4	Strategic Initiative 5	Strategic Initiative 6
Enhanced Universal Provision	Support for Parent Carers	Support for Schools	Needs Led Support	Integrated Diagnostic Assessment	Support If Needs Are Overwhelming

Enablers: Co-Production, Workforce, People & Culture, Finance

Principle 1 Child Centred	**Principle 2** Work With Us	**Principle 3** Recognise Needs	**Principle 4** Early Support	**Principle 5** Aspiration
Principle 6 Communication	**Principle 7** Inclusive Communities	**Principle 8** Experience of Families	**Principle 9** Long Term Thinking	**Principle 10** Independence

Foundational Elements: Alignment of Strategy, Vision and Effort
Evaluation: QI & Cultural- Four Cornerstones
(across different programmes and organisations)

Strategic Initiatives

Enhancing Universal Support:

Neurodiverse children and young people and their families will benefit from:

- Increased ND & SLCN support into family hubs
- alignment of early help and graduated approach
- Promotion of more neuro- affirming and neuro-inclusive cultures, environments and communities.

Supporting Parent Carers:

Neurodiverse children and young people and their families will benefit from support for parent carers that:

- Responds to what parent carers need through an enhanced and co-produced online offer.
-Offers Peer Led Parent Support Programmes and Parenting Support Programmes.

Supporting Schools:

Neurodiverse children and young people and their families will benefit from support for schools which that:

- Promotes neuro-affirming and neuro-inclusive cultures, is responsive to children and young people's experiences and aligns to the graduated approach
- Includes training and ND / SLCN resources through PINS and Autism in Schools Programmes, linked therapists.

Needs Led Support:

Neurodiverse children and young people and their families will benefit from:

- support being needs led and available for all, with or without diagnosis.
- This will be achieved through Neurodiversity Navigators, locality SLT, and other Early Help Services.

Improved Integration, Timeliness & Efficiency of Neurodevelopmental Diagnostic Assessment:

Neurodiverse children and young people and their families will benefit from:

- Continuing waiting list reduction activities and ensuring effective support through Right to Choose and validation of private diagnostic assessments.
- Improving integration, efficiency and effectiveness by implementing Integrated Neurodevelopmental Assessment Pathway (INAP) & <5 pathways.

Support If Needs Are Overwhelming:

Neurodiverse children and young people and their families will benefit from:

- Additional support through the National Keyworker Programme and local serious violence strategy & workforce development.

Evaluating Impact

The One Devon neurodiversity Strategy incorporates aspects of cultural change and quality improvement. Implementation Plans will include a description of the intended impact, and the metrics and measures used to understand delivery, however, wider evaluation will bring together oversight of evaluation. To understand the impact of the strategy the evaluation approach must consider understanding and evaluation of culture change (aligned to the Four Cornerstones) and, more traditional quality improvement approaches, as set out below:

Domains of Four Cornerstones Evaluation Methodology

- Welcome & Care
- Value & Include
- Communicate
- Work in Partnership

Overall Approach: Collaborative and broad qualitative insight driven approaches which track cultural and experiential shifts aligned to the four cornerstones. Iteratively and collaboratively developed.

- **Measures:** Qualitative and experiential factors
- **Mechanism**: Collaboration to be defined.

Domains of Quality Improvement Evaluation Methodology

- Experience
- Effectiveness
- Equitable
- Efficient

Overall Approach: Many small, measurable changes: Evaluation of pilots/ projects to deliver a ‘mosaic’ of changes and measures. Refining improvements through use of iterative approaches (continuous PDSA cycles) to promote continuous improvement. Include an Adopt, Adapt, Abandon reflection space to critically evaluate and collaboratively agree next steps.

- **Measures:** Qualitative and quantitative spanning experience, performance and efficiency align to healthcare quality domains
- **Mechanism**: Collaboration through evaluation and research partnership.