

NHS Right Care Pathways Proposal

Identifying & supporting neurodivergent people



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Recommendation	Develop an optimal pathway and accompanying resources to improve the diagnosis and immediate post-diagnostic support of neurodivergent people.

What are neurodevelopmental conditions?

ADHD, autism, Down syndrome, dyslexia, dyspraxia, dyscalculia, epilepsy, learning disability and Tourette's syndrome are all examples of neurodevelopmental conditions (NDCs). NDCs describe a variety of ways in which a person's brain can develop differently from the norm, affecting the way someone perceives and interacts with the world around them. **Between 1 in 10 and 1 in 20 people in the UK are neurodivergent** (have at least one NDC).¹

It is the norm, not the exception, for neurodivergent people to have multiple NDCs.² For example:

- Between a third and two-thirds of autistic people also have ADHD.^{3,4}
- Up to 40% of people with epilepsies are either autistic, have a learning disability or both.^{5,6,7,8}

The national challenge – the wrong care in the wrong place at the wrong time

Neurodivergent people face some of the worst health inequalities in society:

- On average, autistic people and people with learning disabilities die 15-20 years earlier than the rest of the population.^{9,10} Worst still, only half of those who belong to both these groups currently live to see their 40th birthday, most commonly because of seizures caused by a third NDC: epilepsy.⁷
- The rates of people with learning disabilities dying unexpectedly within the NHS is so persistent that an entire programme is dedicated to reviewing and learning from those deaths.⁸

Neurodivergent people often receive the wrong care:

- They are more likely to experience physical and mental health problems (including rare conditions)^{11,12} and have atypical responses to therapies and medications.^{13,14}
- Poor past experiences with services have left many wary of seeking support.¹⁵ Issues common in the neurodivergent community – like speech and language difficulties, selective mutism or alexithymia – make it difficult for some to advocate for their own care.

“Most of the time I feel like I am the problem, that I’m not trying hard enough to sort myself out, that nothing can be done to help, that I don’t fit the categories of help/treatment available”¹⁴

Neurodivergent people are much more likely to be seen in the wrong place:

- Neurodivergent people routinely struggle to find services willing to support them with associated health problems until those issues escalate; in part because of misconceptions that specialist settings exist to “deal with” NDCs like autism.¹⁴ They are more likely to end up in tertiary services with advanced disease and distressed behaviour that can prompt chemical or physical restraint.^{16,17,18,19}
- Despite the Transforming Care Programme, people with NDCs remain significantly over-represented in expensive acute mental health and inpatient settings.²⁰

“You get pushed from pillar to post: ‘you’re not mental health, go to learning disability, you’re not learning disability, go to mental health’”²¹

Neurodivergent people struggle to access support when they need it:

- Neurodivergent people can spend decades circulating between services without an accurate diagnosis.
- Diagnostic overshadowing is common with NDCs, with research showing that children are diagnosed years after their peers if they have more than one NDC.²² Currently, an NDC diagnosis appears to prevent, not prompt, the NHS from assessing people's wider neurodevelopmental, physical and mental health needs.

The opportunity for Right Care

Introducing diagnosis pathways reflecting the multi-morbid nature of NDCs would be a vital step towards improving outcomes for a neglected patient population.^{1,2} Currently, we systematically fragment the care of neurodivergent people between a variety of narrow condition pathways and services, even though co-morbidity is the norm.^{1,2} Identifying and assessing neurodivergent people's needs in a more holistic way could:

- **Speed up access to early support** that could prevent problems from escalating to acute emergency admissions.
*"It has got to the point where the only services we have been to access are after attempts at suicide"*¹⁴
- **Make it easier to personalise interventions** to the clinical needs of neurodivergent people, when those depend on complicated combinations of co-occurring physical, mental or neurodevelopmental conditions.
- **Help identify an undiagnosed patient population** who are heavy users of NHS services but whose needs are not met effectively. For example, a fifth of women with anorexia in eating disorder services are likely to be autistic and need alternative approaches to their care.^{23,24}

*"The Eating Disorder Service didn't recognise her food sensory issues or social anxiety. She lost rather than gained weight"*¹⁴

- **Enable the NHS to target preventive efforts** at people with particular NDCs which makes them at greater risk of health problems. For example, a dedicated health-check is currently being designed and tested for autistic people, inspired by the check available to people with a learning disability.
- **Potentially realise huge savings.** For example, the (direct and indirect) costs of poor outcomes among autistic people are estimated at over £32 billion a year (more than cancer, stroke and heart disease combined).²⁵

Other key considerations

Tackling health inequalities around two prominent NDCs is a clinical priority for the NHS Long Term Plan. NHS England will be reviewing the diagnosis and post-diagnostic support available to children and adults who are autistic or have a learning disability, making this an invaluable time to guide service improvements.

Some STPs and CCGs have begun exploring neurodevelopmental pathways locally. However, right now there is limited guidance to support those areas, other than resources focused on single NDCs like autism or ADHD.

There is data to indicate unwarranted variation in diagnosis, service use and longer-term outcomes. National datasets already exist to track the care of people with learning disabilities.^{26,27} Revisions to primary care²⁸ and mental health service data²⁹ should enable these issues to be evaluated for more NDCs.

Pan-neurodevelopmental pathways reflect the growing scientific consensus about neurodiversity. There is emerging evidence that many NDCs share a common genetic basis and that the existing diagnostic categories do not predict the mechanisms behind a person's behaviour or their response to interventions.³⁰ Researchers and clinicians in Sweden are beginning to identify people at neurodivergent and then use a framework called ESSENCE to assess clinical need, rather than focusing on what individual NDC diagnosis and symptom profiles they meet.¹

¹ Gillberg (2010). The ESSENCE in child psychiatry: Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations <[bit.ly/2CUPLbA](https://doi.org/10.1186/1745-2875-9-1)>

² Kirby A, Thomas M (2013). The ehoul child with developmental disorders...<[bit.ly/2DEJYad](https://doi.org/10.1186/1745-2875-9-1)>

³ Simonoff, et al. (2008). Psychiatric disorders in children with autism spectrum disorders...<[ncbi.nlm.nih.gov/pubmed/18645422](https://pubmed.ncbi.nlm.nih.gov/18645422/)>

⁴ Salazar, et al. (2015). Co-occurring Psychiatric Disorders in Preschool and Elementary School-Aged Children...<[bit.ly/2DeFtnF](https://doi.org/10.1186/1745-2875-9-1)>

⁵ Bolton, et al. (2011). Epilepsy in autism: features and correlates...<[ncbi.nlm.nih.gov/pubmed/21972278](https://pubmed.ncbi.nlm.nih.gov/21972278/)>

⁶ Woolfenden, et al. (2012). A systematic review of two outcomes in autism spectrum... <[ncbi.nlm.nih.gov/pubmed/22348343](https://pubmed.ncbi.nlm.nih.gov/22348343/)>

⁷ Viscidi, et al (2013). Clinical Characteristics of Children with Autism Spectrum Disorder and Co-Occurring Epilepsy...<[bit.ly/2AA2Oxr](https://doi.org/10.1186/1745-2875-9-1)>.

⁸ Tuchman & Rapin (2002). Epilepsy in autism...<[doi.org/10.1016/S1474-4422\(02\)00160-6](https://doi.org/10.1016/S1474-4422(02)00160-6)>

⁹ Autistica (2016). Personal tragedies, public crisis report. <[bit.ly/2F1fwcy](https://www.autistica.org.uk/2016/02/24/personal-tragedies-public-crisis-report)>

¹⁰ HQIP (2018). The Learning Disabilities Mortality Review Annual Report 2017. <[bit.ly/2zbWL04](https://www.hqip.org.uk/2018/03/22/the-learning-disabilities-mortality-review-annual-report-2017)>

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¹² Croen, et al. (2015). The health status of adults on the autism spectrum. <[ncbi.nlm.nih.gov/pubmed/25911091](https://pubmed.ncbi.nlm.nih.gov/25911091/)>

¹³ Spain, et al. (2015). Cognitive behaviour therapy for adults with autism...<[sciencedirect.com/science/article/pii/S1750946714002608](https://www.sciencedirect.com/science/article/pii/S1750946714002608)>

¹⁴ Robinson (2012) Childhood Epilepsy and Autism Spectrum Disorders...<[springer.com/article/10.1007/s11065-012-9212-3](https://www.springer.com/article/10.1007/s11065-012-9212-3)>

¹⁵ Autistica (Unpublished). Survey of autistic people's experiences with mental health services, conducted in Mental Health Awareness Week 2018.

¹⁶ Zerbo, et al. (2018). Healthcare Service Utilization and Cost Among Adults with Autism... <www.liebertpub.com/doi/10.1089/aut.2018.0004>

¹⁷ Allely (2018). A systematic PRISMA review of individuals with autism spectrum disorder in secure psychiatric care...<[bit.ly/2qjEJFi](https://doi.org/10.1186/1745-2875-9-1)>

¹⁸ Glover, et al. (2018). An observational study of the use of acute hospital care by people with intellectual disabilities...<[bit.ly/2OVL7Bf](https://doi.org/10.1186/1745-2875-9-1)>

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²³ Huke V, et al (2013). Autism Spectrum Disorders in Eating Disorder Populations...<onlinelibrary.wiley.com/doi/abs/10.1002/erv.2244>

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