

Embracing Complexity in Diagnosis: Executive Summary

Embracing Complexity is a new coalition of 38 UK charities who support people with neurodevelopmental conditions (NDCs) – conditions such as learning disabilities, autism, ADHD, dyslexia, dyspraxia, Tourette Syndrome, Down Syndrome and many more which affect how people think and interact with the world around them. We're calling for a more joined-up approach to diagnosis, services and research.

Getting a diagnosis is a vital first step in finding the right support and achieving your aspirations in life. But people with NDCs often wait too long for diagnosis and face many obstacles in receiving a diagnosis.¹ Most people with NDCs have more than one condition – for example, around half of people with dyspraxia also have ADHD traits,² whilst around 12% of people with epilepsies are autistic, have a learning disability or both.³ Yet most diagnostic pathways (the systems set up in the NHS to diagnose conditions) only focus on one condition at a time. This means that many people face lots of referrals to different specialists and it can take years to get the diagnoses and support the person needs.

However, some services across the UK are starting to diagnose multiple conditions as part of a single assessment process. This report looks at four of these emerging services: Peterborough Integrated Neurodevelopmental Service, Lambeth Paediatric Service, the Newcomen Neurodevelopmental Centre in London, and the All Wales Neurodevelopmental Diagnostic Assessment Pathway. Our report explores how each of these services were set up, the challenges they've faced and the successes they've achieved. Setting up one pathway to cover multiple NDCs can be very difficult due to funding and staffing pressures as well as the wide range of needs of people with different conditions. Yet where these pathways have been set up, they have generally reduced waiting times, saved money, and received positive feedback from families.

There is still more work to be done – these services are all for children rather than adults, and often only cover a handful of NDCs, not the wide

¹ Embracing Complexity (2019). Embracing Complexity: Towards New Approaches for Supporting People with Neurodevelopmental Conditions.

² Kadesjo B & Gillberg C (1999) Developmental Coordination Disorder in Swedish 7-Year-Old Children. *Journal of the American Academy of Child & Adolescent Psychiatry* 38(7), 820-828

³ Lukmanji S et al. (2019) The co-occurrence of epilepsy and autism: A systematic review. *Epilepsy Behav.* 98 (Pt A), 238-248

spectrum of conditions people experience. We hope that by highlighting these innovative examples, we can establish whether similar services on a larger scale are effective and viable, encourage research into which models might work best, and free up more resources to provide support to people and families during and after diagnosis. By embracing complexity in the way we diagnose neurodevelopmental conditions, we can diagnose people faster, get them appropriate support more quickly and help the limited resources we have go further.

Service	NDCs covered	Results
Peterborough Integrated Neurodevelopmental Service	ADHD, autism, learning disability	Significantly reduced waiting times and increased referral-to-diagnosis rate, capacity for post-diagnostic support and mental health assessments
Lambeth Paediatric Service	Holistic neurodevelopmental assessment including ADHD and autism	Not yet established long enough for detailed evaluation but positive feedback from professionals
Newcomen Neurodevelopmental Service, Evelina London	Multiple NDCs	Dimensional assessment useful for support, cost-saving efficiency in services
All Wales Neurodevelopmental Diagnostic Assessment Pathways	ADHD, autism	Single pathway, standards and guidance nationally

We hope this report can:

- Raise awareness of these new approaches and their potential among NHS senior leaders, policymakers and MPs.
- Make the case for more research into pathways spanning multiple NDCs.
- Empower professionals locally and nationally to understand emerging models and the principles behind them.

“I’ve been treated for other conditions most of my life, but really it’s the undiagnosed ADHD that has been the issue”⁴

You can read the full report at embracingcomplexity.org.uk.

⁴ Quote from survey respondent. Embracing Complexity (2019). Embracing Complexity: Towards New Approaches for Supporting People with Neurodevelopmental Conditions.