

Embracing Complexity in Diagnosis

Multi-Diagnostic Pathways
for Neurodevelopmental
Conditions

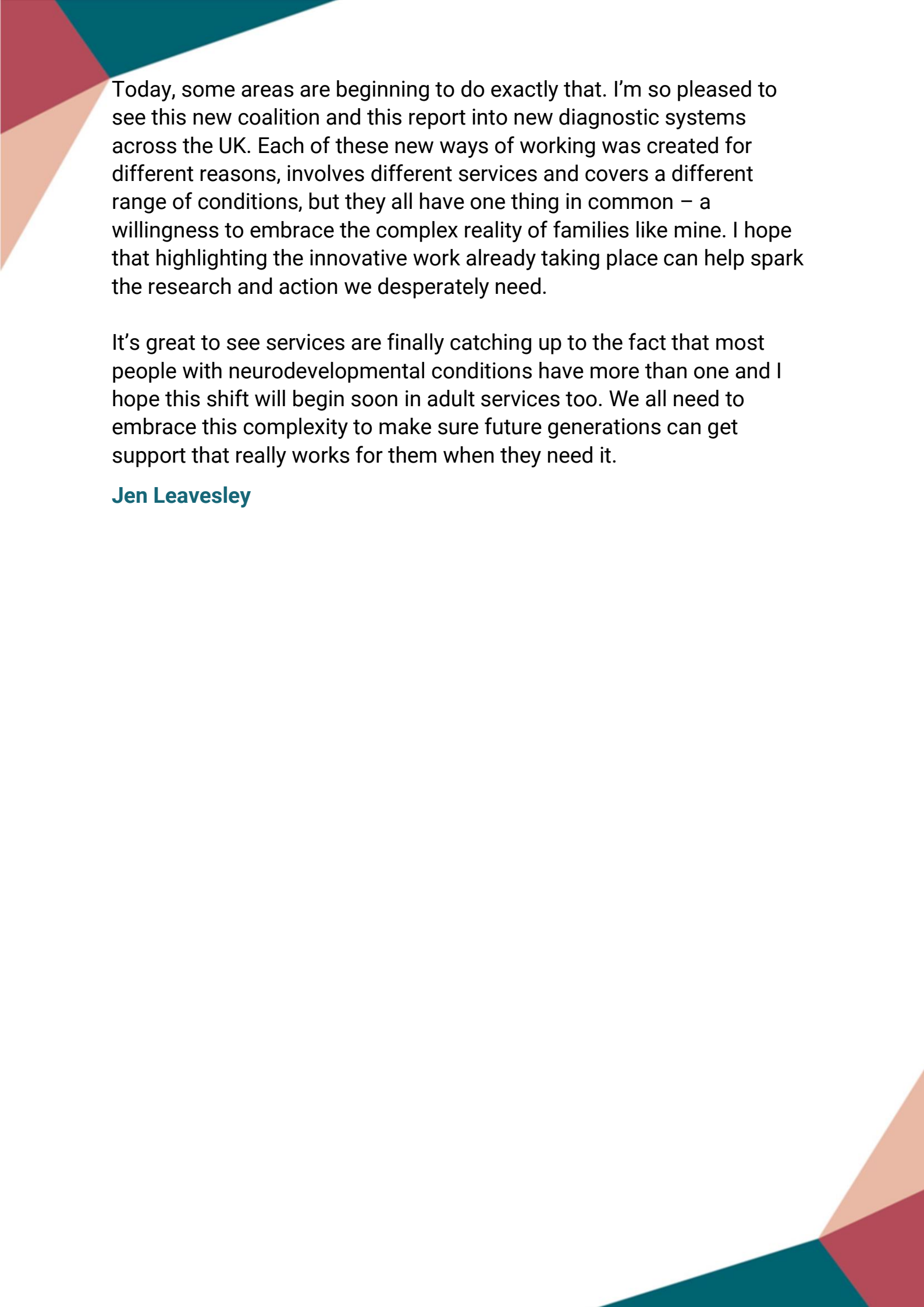
Foreword

Most services are set up to look at one condition at a time, but the people they support often don't have just one condition. To give just a few examples, I have epilepsy, autism, and hypothyroidism, my eldest daughter has autism, anxiety, and migraines, and my younger daughter has autism, ADHD, Tourette's, and Avoidant/Restrictive Food Intake Disorder (ARFID).

It was a huge problem for me, diagnostic overshadowing, and continues to be. One problem was always blamed for another. For example, my anxiety was blamed for my seizures. It was very relieving for me to finally get the labels I deserved, with the problems themselves teased out into their individual categories so that I could pursue appropriate help for them as best I could, once I understood what was going on.

My girls were diagnosed as autistic much earlier in life, aged 3 and 2. Knowing what their difficulties were from early on was very helpful, so that I could pursue the right educational support for them in school. However, again, diagnostic overshadowing proved to be a massive problem when it came to the younger one, whose eating difficulties were blamed on anxiety, and whose tics were blamed on autism. Yes, anxiety underpins a lot of what she has going on, but actually, the tics are Tourette's and not "just" autism, and her eating issues are a diagnosable and treatable issue of their own, not just "fussy" eating. Some of the strategies for "fussy" eating, such as star charts, backfire in ARFID, so it's critical to have the issues correctly identified as using inappropriate strategies can contribute to worsening of the issues they intended to support. Once again, having the right label meant I could pursue the right assistance for her, tailored to meet her specific needs.

Managing all those constant referrals between different services, all while continuing to go without support, is immensely stressful. It exacerbated my own anxieties around being fobbed off, which are from my own autism and being misunderstood and having my own needs dismissed. Having professionals who consider my girls as individuals rather than looking only for one set of symptoms at a time would have made a huge difference.



Today, some areas are beginning to do exactly that. I'm so pleased to see this new coalition and this report into new diagnostic systems across the UK. Each of these new ways of working was created for different reasons, involves different services and covers a different range of conditions, but they all have one thing in common – a willingness to embrace the complex reality of families like mine. I hope that highlighting the innovative work already taking place can help spark the research and action we desperately need.

It's great to see services are finally catching up to the fact that most people with neurodevelopmental conditions have more than one and I hope this shift will begin soon in adult services too. We all need to embrace this complexity to make sure future generations can get support that really works for them when they need it.

Jen Leavesley

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 spectrum of conditions people experience. We hope that by highlighting these innovative examples, we can establish whether similar services on

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

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

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

Diagnosis and the potential for multi-neurodevelopmental pathways

Diagnosis is a vital first step in helping people get the support they need to make the most of their strengths and overcome their challenges.

But people with NDCs are waiting too long for diagnosis. [Our first report](#),¹ based on survey feedback from 500 people with NDCs, found that almost 6 in 10 of them had difficulties getting their first diagnosis, with barriers including lengthy waiting lists, being told children were too young to be considered and feeling lost in the system. These experiences are borne out in the clinical literature.^{5,6}

It is the norm, rather than the exception, for people with NDCs to have more than one.^{1,7} 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

"I initially pursued DCD [dyspraxia]. In the report ADHD was mentioned but not formally diagnosed. Later I was diagnosed with ADHD then I went for a second opinion regarding autism and got a diagnosis. This happened over four years."⁴

However, healthcare services are rarely set up for the complex reality faced by people with multiple NDCs. Diagnosis pathways – the systems set up to diagnose different conditions – are typically siloed into separate conditions, such as an autism pathway or a Tourette Syndrome pathway. This leaves many people facing long, disjointed chains of referrals to different healthcare and education specialists.^{1,8} Given the overlap between conditions, a diagnosis of one NDC should ideally prompt further exploration of additional challenges and needs, but instead, subsequent

⁵ Crane L et al (2016) Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism* 20(2) 153-62

⁶ Pitts et al (2015) Impairments, Diagnosis and Treatments Associated with Attention-Deficit/Hyperactivity Disorder (ADHD) in UK Adults: Results from the Lifetime Impairment Survey. *Archives of Psychiatric Nursing* 29(1) 56-63

⁷ Gillberg C (2010) The ESSENCE in child psychiatry: Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations. *Research in Developmental Disabilities*, doi:10.1016/j.ridd.2010.06.022

⁸ Kirby A & Thomas M (2011) The whole child with developmental disorders. *British Journal of Hospital Medicine* 72(3)

diagnoses are delayed even further, adding stress, increasing cost and delaying effective support.^{9,10,11,12}

Taking a single-diagnosis approach appears to be part of why people with NDCs struggle to access diagnosis and support. It is heartening, therefore, to see new models appearing across the UK which use a single pathway for multiple NDCs.

In this report, we explore what we can learn from four such innovative models in order to build clearer and more effective diagnostic pathways to benefit the 10% of our population with NDCs. These models follow the approach of a multi-disciplinary team carrying out a holistic assessment which can deliver multiple diagnoses of NDCs at the same time. We identified these examples through interviews with professionals and researchers across the country so this is not an exhaustive list of the different models which may exist.

We should not underestimate the complexity of constructing multi-diagnostic pathways for such a wide but overlapping set of conditions. Accounting for differing developmental trajectories, ages of onset, coping strategies, levels of stigma, levels of awareness among the public and professionals, and diagnostic tools, standards and thresholds is highly challenging.

But the gains could be enormous: more timely diagnosis; more efficient use of over-stretched NHS resources; earlier intervention and support; cost savings to individuals, families and the state; and, most crucially, improved short and long term outcomes.

“Referred to ADHD pathway... told not ADHD. Referred to ASD pathway... told not ASD.”⁴

Language choices: In this report and in consultation with the charities’ experts by experience, we have used the term “people with neurodevelopmental conditions/NDCs”. There is no research on preferred language across this very large and diverse group of people and we acknowledge that this language may not be preferred by everyone represented in the report.

⁹ Brett D, et al. (2016) Factors Affecting Age at ASD Diagnosis in UK: No Evidence that Diagnosis Age has Decreased Between 2004 and 2014. J Autism Dev Disord 46, 1974-1984

¹⁰ Levy SE, et al. Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. J Dev Behav Pediatr. 31(4), 267-75

¹¹ Steffenburg H, et al. (2018) Children with autism spectrum disorders and selective mutism. Neuropsychiatr Dis Treat, Sep 06;14;2305.

¹² Gooch D, et al. (2017) Does a child’s language ability affect the correspondence between parent and teacher ratings of ADHD symptoms? BMC Psychiatry 17, 129.

Peterborough Integrated Neurodevelopmental Service

Why did Peterborough move towards an integrated neurodevelopmental pathway between CAMHS and Community Paediatrics?

There had been multi-agency work to diagnose NDCs for some time prior to 2015, but this was based largely on informal arrangements between the health service providers, Clinical Commissioning Group, local authority and education sector. Over time, as staff moved on and funding pressures continued, the paediatric service and Child and Adolescent Mental Health Services (CAMHS) began to receive a high number of ADHD and autism referrals with limited information attached, making it difficult to determine who should be accepted for a comprehensive assessment. This meant children and young people faced lengthy waiting lists without any early support, low diagnostic yield (low numbers of positive diagnoses resulting from the assessments), and very little time to provide timely support to those who were already diagnosed.

How is the pathway structured?

Peterborough Neurodevelopmental Service provides assessments and support for ADHD and autism, as well as supporting children and young people with a previously diagnosed learning disability. The service also provides mental health assessments for children and young people with these diagnoses. The team consists of consultant psychiatrists, consultant community paediatricians, clinical psychologists, nurses and support workers as well as student nurses and junior doctors. There is also support from speech and language therapists and occupational therapists available within the local service.

Referral to the Peterborough Neurodevelopmental Service is via the local Early Help Pathway and is usually completed by schools. From there, children of pre-school age see a community paediatrician for a General Developmental Assessment, before being seen by a multi-disciplinary team (paediatric psychology, speech and language therapy and occupational therapy) for further assessment, if needed, within the Child Development Centre. Older children and young people are accepted directly into the pathway if there is sufficient evidence of a neurodevelopmental condition, following a referral through the Early Help

Pathway and provision of early support including attendance at an evidence-based parent training programme.

Following assessments, diagnosis is finalised in the school-age integrated neurodevelopment team meeting (joint CAMHS and community paediatrics), and feedback is provided to parents by a member of the multi-disciplinary team. If the child also has significant mental health needs, they are then able to access CAMHS directly; Cambridgeshire and Peterborough NHS Foundation Trust manage both community paediatrics and mental health services, allowing for a seamless transition.

What challenges have Peterborough encountered in establishing the pathway?

To begin work on establishing the pathway, waiting lists were closed in 2015. This ensured the co-operation of various health, education and social care services in redesigning the pathway, but in the meantime caused some concern to families and professionals. While waiting times have now greatly decreased, staffing issues continue to cause some fluctuation.

At present, the service only covers autism, ADHD and learning disability. Commissioners envisage future expansion to certain other NDCs including Tourette Syndrome. However, this is complicated by the need for the mental health service to cover Cambridgeshire as a whole.

Has the pathway been successful?

Streamlining the neurodevelopmental pathway means the number of assessments for each child has decreased, which has saved time and money. Avoiding constant re-referrals to different assessments has improved the diagnosis experience for families; the assessments are now structured and consistent. Since 2015, waiting lists have been reduced significantly; most children and young people are now offered their first appointment within 7-12 weeks, compared to waiting over a year at the time waiting lists were closed. Referrals have increased to around 50-60 referrals per month, and the referral-to-diagnosis rate has risen from 40% to 73%.

The service can now offer a wide range of post-diagnostic interventions including specialist parent training programmes such as Cygnet and the locally-developed ADHD Parent Education Group. They are able to offer timely mental health assessments with dedicated allocated time.

Lambeth Paediatric Service (Evelina)

Why did Lambeth move towards a multi-neurodevelopmental pathway?

The paediatric neurodevelopmental pathway in Lambeth was created out of dissatisfaction with a system siloed into single diagnoses, resulting in incomplete profiles and support. It was not directly driven by cost or waiting list concerns.

How is the pathway structured?

In the first instance, children below secondary school age are referred to the paediatric service, usually by their school. The service aims to provide a holistic assessment, highlighting multiple possible NDCs within the child's wider psychological, biological and family context. This assessment is not driven by diagnosis; instead, the end result is an individual profile and formulation of the child's strengths and difficulties. The child is then referred to other relevant services for formal diagnosis of possible NDCs highlighted by the assessment. The school, along with the paediatrician, remains a central point of contact for families and other services throughout the process.

What challenges have Lambeth encountered in establishing the pathway?

Lambeth's paediatric service is unable to assess all NDCs and works closely with other services such as the neurology team at Evelina London (below). As in many areas, Lambeth's paediatric service has to carefully manage challenges around capacity and funding. Combining an initial holistic assessment with formal evaluations can be challenging, and in a commissioning landscape that values clarity of pathway and time to diagnosis, making the case that this is both a desirable and efficient way of proceeding can be difficult.

Has the pathway been successful?

Although a full evaluation of this new model has yet to be carried out, anecdotal feedback from SENCOs describes this approach as "a quick and non-complicated process" producing reports which are "thoroughly written with useful recommendations" helping children to get the right support in a timely manner. 80% of SENCOs said that restriction of the comprehensive service would impact their work "very much".

Newcomen Neurodevelopmental Service, Evelina London

How is the pathway structured?

The Newcomen Neurodevelopmental Service has been running for over 30 years under the leadership of Dr Gillian Baird. Unlike the other models featured in this report, which are community services, this is a tertiary service, to which children and young people are referred for a second opinion or in the most “complex” cases with several likely NDCs including conditions such as epilepsy, distressed behaviour and mental health conditions.

Referrals are accepted from paediatricians, GPs, children’s neurologists, psychiatrists or any other medical consultant. The child then receives a multidisciplinary assessment lasting half a day. The multidisciplinary team consists of medical consultants in children’s development, neurodisability and psychiatry as well as clinical psychologists, speech and language therapists, occupational therapists and nurses. A unique feature of this service is that every child receives the same assessment. In some cases, the presence of a psychiatrist for children with mental health difficulties is included. The service does not usually offer follow-up appointments after the diagnoses are made but can provide direct intervention for a limited period in some cases. Associated services that started within and have ‘grown out’ of the neurodevelopmental service are the Evelina sleep service, feeding service and motor disorder/cerebral palsy service; all of these are multidisciplinary, tertiary and offer assessment and interventions.

What challenges have Evelina London encountered in running this pathway?

While community services are funded in set “blocks”, tertiary services such as in Evelina London are commissioned per patient, which somewhat reduces funding pressures. However, the children and young people seen by this service are amongst those with the highest levels of need, so insufficient funding always remains a possibility.

The multi-disciplinary assessment carried out by this service is staff-intensive and may not necessarily be scalable to larger community

populations; but at this stage in the pathway, such staff-intensive assessments would rarely be needed.

Has the pathway been successful?

The service regularly carries out an internal audit of families two months on from diagnosis. Families value the multidisciplinary nature of the assessments – seeing all concerned professionals at the same time and receiving a diagnostic formulation based on what is the most important problem and what interventions are advised.

Even where diagnostic thresholds for a particular condition are not reached, families appreciate having traits described in a dimensional way and find this useful in supporting their child. Equally, receiving clear diagnoses enables the children and young people to access the support they need. The single-assessment system, using the starting point of multiple NDCs as the norm and additionally incorporating mental health expertise, leads to cost-saving efficiency for providers of services.

All Wales Neurodevelopmental Diagnostic Assessment Pathway

Why did Wales move towards a multi-neurodevelopmental pathway?

The All Wales Neurodevelopmental Diagnostic Assessment Pathway launched in 2016 as part of The Together for Children and Young People Programme (T4CYP). Bespoke neurodevelopmental teams were developed in response to concerns that existing services were not able to provide timely and equitable assessments for all those with a neurodevelopmental condition.

The decision to create multi-neurodevelopmental teams was taken on the advice provided by the T4CYP expert reference group given the existing and emerging evidence base about the co-occurrence of many NDCs. The decision also reflects the complexity of presentation and need associated with many of the children and young people seen in services.

How is the pathway structured?

Neurodevelopmental services are managed by the seven local health boards, with guidance from a National Steering Group. The pathway therefore has a loose structure largely defined by eight agreed standards alongside a guidance document produced in 2018:

1. A single point of access for diagnostic assessment of all NDCs.
2. Decisions on whether to accept referrals made only on the quality of information, rather than permitted referrers or screening questionnaires.
3. When referrals are not accepted, the referrer is provided with the rationale, advice for improving the referral and/or other services to refer to.
4. Child-centred assessments which gather sufficient information to create a profile of the child's need.
5. A timely multi-disciplinary discussion leading to a decision about the outcome of the assessment, a profile of the child's strengths and difficulties, and agreement on next steps.
6. A professional involved in the assessment process communicating the outcome to the family and, with their consent, to other professionals who support the child.

7. Next steps after assessment should be discussed with the family and, where appropriate, with the child.
8. Interventions should be based on the best possible evidence.

This pathway sits alongside the existing Integrated Autism Services. Those involved in service delivery stay in regular contact through National Community of Practice meetings and smaller Clinical Peer Support Groups.

What challenges have health boards encountered?

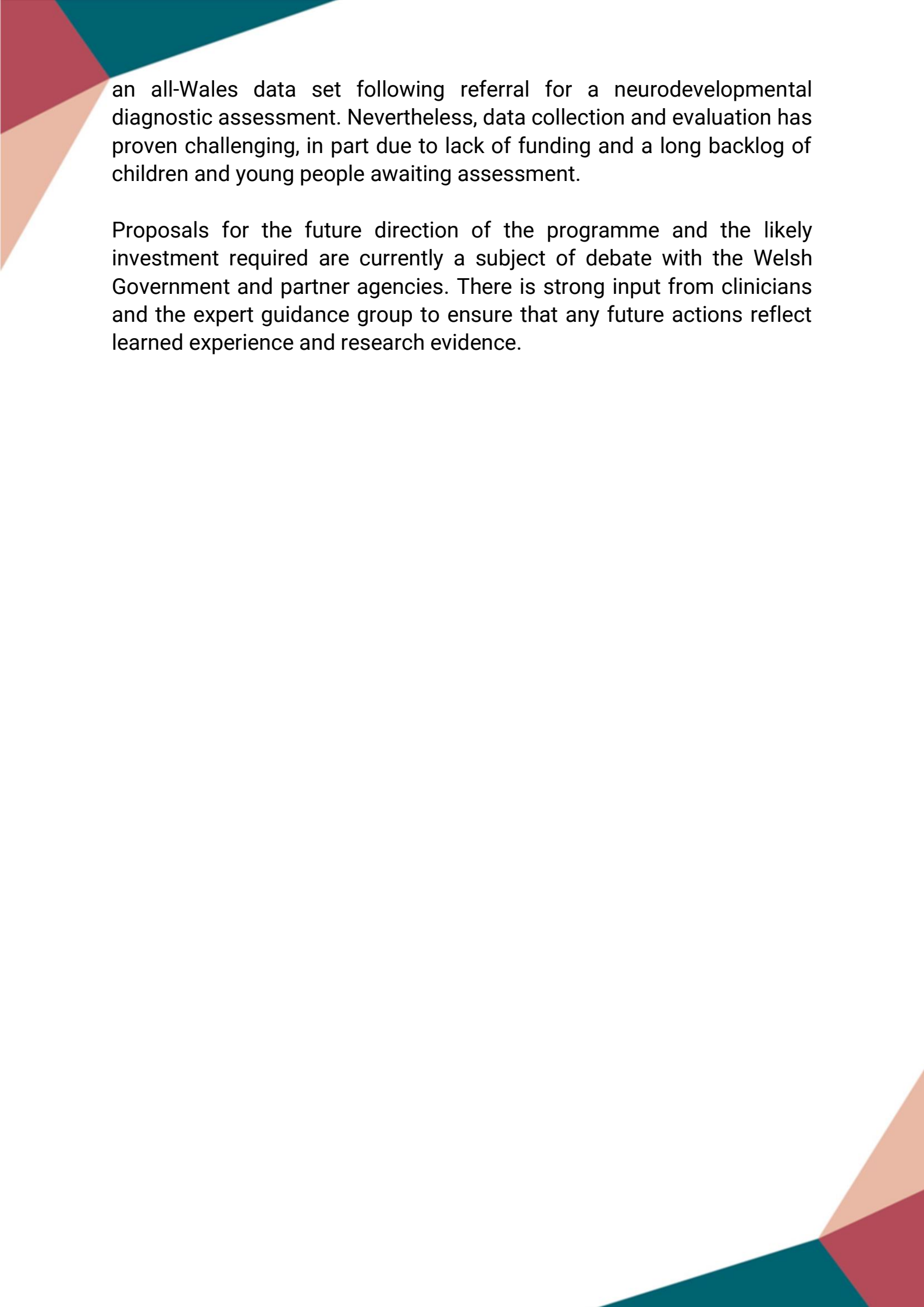
At present, the pathway only covers assessments for autism and ADHD, with learning disability also included in a separate strand to take account of changing policy elsewhere. While the intention was for the pathway to cover all NDCs, there were concerns about setting the pathway up to fail by stretching limited resources across such a large group. An initial autism/ADHD pathway was set up to ensure that initial stages could be implemented in the timeframe, creating a model for including other NDCs in future. There was also a need to align with Integrated Autism Service actions following the Autism Strategy refresh in 2016/17.

The pathway was set up in part to deal with an increasing backlog of children awaiting assessment, and the process of re-organisation and recruitment of the new neurodevelopmental teams caused further delays initially. This imbalance between demand and capacity creates a particular challenge in situations where children are referred for one NDC and the neurodevelopment team suspect an additional NDC, leaving teams to choose whether to have the child re-referred to the waiting list or delay others on the waiting list to complete a second assessment. Once teams were fully set up, they began to overcome these challenges and make progress.

Has the pathway been successful?

Despite local pressures and vast variation in local services and implementation, the programme has achieved a single pathway, standards and guidance nationally. The programme's inclusive approach and clear agreed goals enabled the development of strong cross-professional relationships and inter-agency discussion.

As part of its guidance on delivering the pathway, the Neurodevelopmental Services National Steering Group have produced data collection questions on each of the eight standards and established



an all-Wales data set following referral for a neurodevelopmental diagnostic assessment. Nevertheless, data collection and evaluation has proven challenging, in part due to lack of funding and a long backlog of children and young people awaiting assessment.

Proposals for the future direction of the programme and the likely investment required are currently a subject of debate with the Welsh Government and partner agencies. There is strong input from clinicians and the expert guidance group to ensure that any future actions reflect learned experience and research evidence.

Coming soon from RCPCH

The Royal College of Paediatrics and Child Health (RCPCH) has recently approved a new project to support community teams in developing high-quality care pathways for children with NDCs.

The project, which is currently seeking funding, will produce a comprehensive toolkit guiding commissioners, service planners and providers to work with paediatricians to develop effective and efficient integrated neurodevelopmental services. The toolkit will be rooted in the latest evidence, with engagement from all key stakeholders and evaluation built into the timeline from the start.

It is hoped that the toolkit will enable more consistency in services across the country, improve outcomes by clarifying best practice, and reduce waiting times through more efficient, sustainable services.

For more information, contact Jenni Illman at Jenni.Illman@RCPCH.ac.uk.

Where do we go now?

This report highlights four examples of diagnostic pathways spanning more than one neurodevelopmental condition. Given the lack of robust research into these service models and the need for services to reflect local needs, we are not advocating for these specific models to be replicated. Rather, we aim to raise awareness of these new approaches and their potential among policymakers, professionals, researchers and people with NDCs and their families. The current system is not meeting everyone's needs and we urge all involved in diagnosing NDCs to consider how we can diagnose people faster, more accurately and making more efficient use of NHS funds.

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

Expanding these emerging diagnostic pathways

Although there is much more work to do, it appears that multi-NDC diagnostic pathways have generally been received positively by individuals, families and clinicians. Despite initial challenges, these pathways often appear to reduce costs and waiting times in the long term.

While we were able to identify a number of multi-NDC diagnostic pathways in specific UK regions, all of them only include a small subset of NDCs and, in most cases, have been driven by motivated local professionals rather than a wider strategic, evidence-led approach. All those involved in diagnostic pathways must now work together to understand whether integrated, holistic pathways are clinically effective, cost-effective, acceptable to professionals and people undergoing diagnosis, and scalable.

The pathways we examined are all for children but we need to look across the lifespan. There are more adults with NDCs than children and many are undiagnosed – even those with formal diagnoses of one or more NDCs may have further undiagnosed conditions. Just as with children, adults

with NDCs are also highly likely to have multiple conditions but we have not been able to identify any combined adult diagnostic pathways. Co-occurring mental health issues should also be considered.

Commissioners and diagnosticians need to consider how borderline/sub-threshold diagnoses can be reflected in both diagnostic reporting and subsequent support. Accounting for high but sub-clinical traits of NDCs alongside clinical diagnoses needs further careful thought.

There needs to be more shared responsibility across health, education and social care systems. Wider support structures, such as SEND departments in schools, can begin assessment of neurodevelopmental differences before a referral for diagnosis is made. This would enable support to be offered based on the person's individual strengths and challenges. Consideration should be given to how to support staff in these settings to understand the pan-neurodevelopmental approach.

Research and evidence

There is little research into how multiple NDCs could be combined into joint pathways, which conditions can feasibly be assessed together and how multi-NDC pathways fit with the ways in which parents and people with NDCs may first express concerns and seek help.

Further research into these emerging models should be guided by both scientific evidence and NDC community views.

- Existing multi-NDC pathways should be evaluated robustly to establish their effectiveness and cost-effectiveness. Evaluation and research measurements should ideally be factored into costings from the start.
- Research funders, charitable and state service providers and community-led groups should collaborate to understand how multi-NDC pathways would affect the individual and family experience of diagnosis, both positively and negatively.
- NHS England and health services in the devolved nations should consider the implications of multi-NDC pathways for service design, workforce planning and training, resource allocation and health information.

- Policymakers, providers and research funders from other countries may be useful sources of international comparisons for multi-NDC pathways.

Integrating support and diagnosis

Multi-NDC pathways may provide an opportunity to test the effectiveness of relatively simple supports before the point of diagnosis which are not specific to one particular diagnostic outcome. This could for example cover ways to improve communication, achieving everyday tasks, mood, anxiety and resilience to stigma, all of which affect large numbers of people with NDCs.

Funding, commissioning and communication

Services are unable to effectively plan for the long term without the security of continued funding. When commissioners are considering these new models, they should take into account the need for sustained funding and the need to collect robust value-for-money data.

Once a new pathway is agreed, effective models depend on good communication across all levels of services involved in the diagnosis process, as well as other relevant bodies such as schools. Practitioners should consider how they can strengthen links with professionals in other areas of public services to ensure these new models can work most effectively.

In a system largely set up to focus on one NDC at a time, it is relatively uncommon for professionals to be comfortable assessing multiple conditions. Bodies such as Health Education England and the Royal Colleges should consider how to ensure the workforce is prepared for multi-NDC pathways.

Our members

Action Cerebral Palsy
ADHD Foundation
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Autism Alliance
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The Brain Charity
Brain & Spine Foundation
British Dyslexia Association
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RADiANT Research Consortium
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Sunshine Support
Tourettes Action
Williams Syndrome Foundation
Young Epilepsy

Embracing Complexity is a coalition of 38 leading UK neurodevelopmental and mental health charities working together to think differently about the 10% of the UK population with neurodevelopmental conditions (NDCs). Our first report, published in May 2019 following a survey of 500 people with NDCs and families, found significant overlap in the challenges faced by people with a wide range of neurodevelopmental conditions. We're calling for a more joined-up approach to diagnosis, services and research.

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