

# Reducing demand for neurodiversity diagnosis by changing the way we support neurodiverse children and young people

*Health and Care Portsmouth priority: Pillar 2 - Children's services 0-19 (and 0-25 for young people with special educational needs or disabilities)*

## The Challenge

Of 55,000 children and young people aged 0-25 in Portsmouth, 17% - approximately 9,500 - require additional support to meet their needs, over and above universal services like maternity and schools. This figure includes over 2,000 children with Educational, Health and Care Plans, 3,500 requiring additional support in schools due to their Special Educational Needs and Disabilities (SEND), over 1,600 requiring statutory safeguarding services (including over 400 children we care for), over 1,000 children receiving Targeted Early Help services and around 1,200 receiving specialist mental health support from CAMHS at any one point. And of course, many children receive multiple services at once.

The children's services system is a £350million system, delivered by more than 3,500 adults through over 200 services - working together to improve a range of outcomes and life chances for children and young people.

When understanding what proportion of this population are neurodiverse, answers vary from a narrow definition of 1% to an expansive definition of 20% - however, the debate is important because the system's current diagnostic-led approach is designed and resourced for the 1%. This means the other 19% of children and young people are likely to appear in other costly and specialist services - from social and emotional mental health services to specialist educational and youth justice services - across the city.

This might provide an indication as to why more children and young people are joining ever lengthening waiting lists for a neurodiversity diagnosis - a problem felt in every corner of the UK. On average, children and young people up and down the country are waiting more than two years, and in some cases up to five years (where a child can make it through the whole of their secondary education on a waitlist) for diagnosis.

# The solution

## We want to be a 'needs-led' city rather than diagnosis-led.

So, in 2019, the integrated children's commissioning team in Portsmouth started a conversation between Portsmouth City Council's children's services team, children's social care, education, the NHS, and most importantly, parents and carers of neurodiverse children and neurodiverse children and young people themselves.

We learnt five things together:

1. There were long wait times for diagnosis and demand was outstripping supply.
2. Investment seemed to be skewed to diagnosis rather than support and intervention.
3. There was dissatisfaction among parents after diagnosis, with families getting referred around the system - from education to GP to CAHMS to therapy services.
4. Schools were facing significant issues in meeting the needs of a wide range of children with some level of neurodiverse needs - exhibiting itself in absence from school, behavioural issues, relationship difficulties and barriers to learning.
5. The level of understanding of neurodiversity - what it was and what can be done to make things easier for children at home, at school and in the community - was low, with children and young people experiencing discrimination, fear and intolerance.

None of this fit with our aspiration to be needs-led and prioritised assessment over meeting needs.

So, alongside our local community provider - Solent NHS Trust - we launched a major piece of co-production work lasting 18 months, featuring experts from NHS providers and commissioners, local authority, schools, the voluntary sector and of course, experts-by-experience - over 80 parents and young people - to think differently about 'profiling' neurodiversity and the evidence-based resources that can help to make life easier.

Specifically, the work focused on the coproduction of a nine-dimension model of profiling that asks what neurotypical and neurodivergence look and feels like across:

- a. Speech and language
- b. Energy levels
- c. Attention skills and impulse control
- d. Emotional regulation
- e. Motor functioning
- f. Sensory levels
- g. Flexibility and adaptability
- h. Empathising and systemising skills
- i. Cognitive ability

Our vision was to enable professionals and parents to work together to profile a child's neurodivergence using a simple-to-use tool and handbook that provided guidance, programmes and equipment to help children and families thrive.

We wanted to move away from the 'diagnose and close' model and develop a whole system 'everybody's business' approach to meeting need

# The way we work

In Portsmouth, we see 'system' before we see 'services'. Health and Care Portsmouth provides the umbrella under which we bring together partners from across NHS, local authority, education and voluntary and community sector partners so problem-solve, innovate and transform the experience of service delivery for children and families. That is how we designed the Portsmouth Neurodiversity Profiling Tool methodology, but moreover, when families said they needed a 'one stop shop' for support for neurodiverse children, we were able to deliver together and stood up a Multi-Disciplinary Team for neurodiverse children and their families.

The work was led by commissioners in the Children's Integrated Commissioning Team, working across the system, working in co-production with children and families and bringing in the necessary expertise at key points in the development and delivery of Portsmouth's Neurodiversity Strategy.

Our strategy was based around four paradigm shifts:

- From disability to diversity
- From diagnosis-led to needs-led
- From clinical pathways to identifying need alongside those that know the individual best
- From a mental health agenda to a SEND agenda

And, we're conceptualising an early help response to neurodiversity not implemented anywhere else before. Through our Strategy, coproduced and launched in 2020, we're focusing on five key elements:

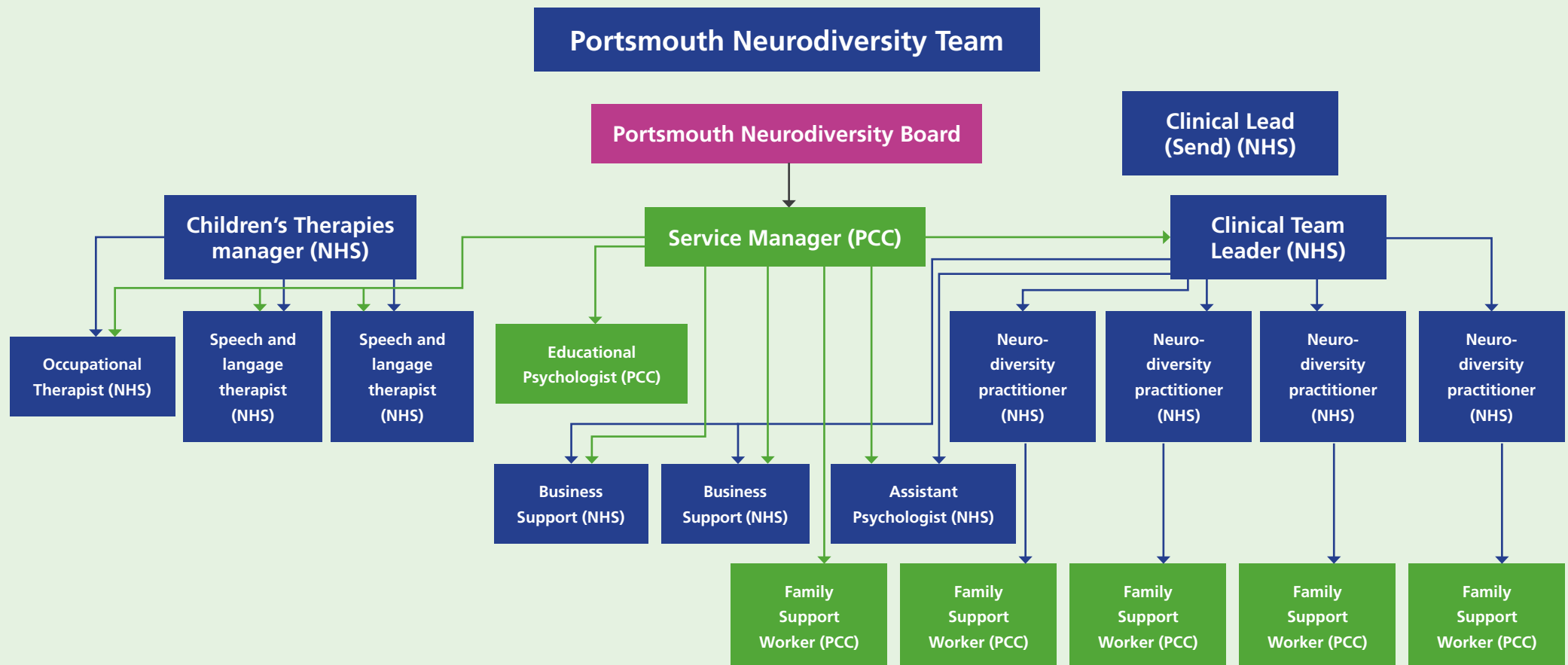
- Designing the Portsmouth Neurodiversity Profiling Tool, testing it through research, training a wide set of professionals on using it, and then distributing it across the health, care and education system.
- Developing a resource bank of advice, guidance, tools, strategies, equipment, apps, websites and more that will help families and professionals respond to child neurodivergent needs.
- Working with schools to make environmental and practical changes to enable schoolchildren wide a wide range of neurodivergent needs to feel more welcome, more comfortable and able to learn and make friendships in school.
- Implementing a neurodiversity multi-disciplinary team of professionals that bring together expertise from education psychology, CAHMS, local authority and NHS partners, to provide a 'one stop shop' for families to get support.
- Developing a neurodiversity competencies framework to ensure the skills, knowledge and competencies that everyone needs to know, to enable the city to be a truly inclusive, non-judgemental, tolerant and informed place to live for neurodiverse children and young people.

Ultimately, we are working towards a reduction in demand for formal diagnosis, but not a complete removal, as we are aware that many families will continue to benefit from formal diagnosis.

# How we work

Our team supporting neurodiverse children in Portsmouth is made up of 16 officers, employed by Portsmouth City Council and Solent NHS Trust, who report into the Assistant Director for Children, Families and Education at Portsmouth City Council.

We align funds and resources to deliver the service through a Memorandum of Understanding and Service Level Agreement. There is a multi-agency Steering Group that determines the work of the team, that reports into the Portsmouth Special Educational Needs and Disabilities Board.



# The impact

There has been an 89% reduction in requests for formal diagnosis for neurodiversity since the Profiling Tool and multi-disciplinary team officially launched in September 2022.

This bucks the national trend significantly, and while there will continue to be national drivers to getting a formal diagnosis (through additional support in UK universities for example), we are seeing needs being met in Portsmouth without relying on the previous clinically led model.

This significant reduction in diagnosis is due, in large part, to:

- More than 500 people working in schools, early years settings, health services, the voluntary sector and social care who have attended training on how to use the Portsmouth Neurodiversity Profiling Tool.
- An online toolkit on Family Assist (digital platform) being accessed by families and professionals regularly
- The core team of 14 staff and three additional matrix-managed staff who make up the expert neurodiversity co-located multi-disciplinary team. The team includes neurodiversity clinicians, family support workers, speech and language professional, occupational therapist, education psychologist, consultant paediatrician, consultant psychiatrist and business support.
- 15 schools working to adapt and change to be inclusive for neurodiverse children and young people. We've worked with school senior leadership teams to encourage culture change, adapt teaching styles, share strategies, improve parent/carer engagement and enhance staff skills, and are developing a model of change to be rolled out across all 60 schools in the city.

- Our work on competencies to define what professionals need to be able to do and what they need to know to meet the needs of children and their families depending on their involvement. For example, those who have a specific remit to work with neurodiverse children and young people (i.e. SENCOs, health visitors, school nurses, social workers etc.) may need different training than those who are likely to be regularly seeing neurodiverse children and young people but may not have a remit to support them (i.e. GPs, teachers, early years professionals, police officers, youth workers)



# Lessons learned and next steps

The feedback we've received from young people, parents, teachers and professionals has been outstanding with extensive national interest in the model we have developed. Portsmouth now leads a National Community of Practice on needs-led neurodiversity models, and we have presented the model to over 40 other areas - from Cornwall to Cumbria, London to Wales.

Our three key learnings are:

## 1. People create change

- Families are our (and children's) biggest asset, and we must co-produce services with them
- It is absolutely essential to bring NHS clinicians, joint commissioners, local authorities and schools together in order to think differently
- Partnership and integrated working - when well facilitated, led and genuinely valued - is the true bedrock of true innovation and transformation

## 2. Coproduction needs time

- Co-production is essential, but it's likely to take longer than anticipated
- Allow space for people to define their own outcomes - they almost certainly won't be the same things we currently measure!

## 3. Focus on needs

- Unmet needs around neurodiversity affect far more children, and are almost certainly more significant, than you may think
- Focusing on needs, rather than activities or processes is vital to addressing poor outcomes for children due to unmet neurodiversity need
- We should also focus on care groups and not individual outcomes - as health outcomes, education outcomes and wellbeing outcomes are interdependent

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Health and Care Portsmouth is a partnership between:

