



# Nottingham and Nottinghamshire Children & Young People Neurodevelopmental Pathway Review:

## Summary Report

April 2024

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## Introduction

The aim of the neurodevelopmental (ND) pathway review is to improve outcomes for children, and young people and their families across Nottingham & Nottinghamshire. The initiative is propelled by a notable increase in referral rates for diagnostic assessments, both nationally and locally, with no indication that the demand for assessments is slowing down.

The prevalence of autism in children and young people has increased nationally from 1% to 2.78% (*Appendix A*). Locally, autism prevalence rates are 18% higher than the rate for England and 27% higher than the rate for the Midlands.

The national framework for autism assessments (*Appendix B*) indicates that a minimum service capacity is necessary to accommodate referrals and assessments for autism. Specifically, the framework suggests that for every 1.5 to 2.6% of the population, there should be referrals to an autism assessment service, and for every 1.3 to 2.3% of the population, assessments for autism should be conducted. This capacity is aimed at reducing waiting times and ensuring alignment with national policy commitments regarding autism assessment and support.

The figures below are based on the 2021 census for Nottingham and Nottinghamshire:

### Min capacity as per national framework **0-17 years Autism**

Referred for assessment 1.5% = 3438, 2.6% = 5959

Assessed for autism 1.3% = 2980, 2.3% = 5272

The prevalence of ADHD in children and young people is estimated to be around 5%, according to the NICE Clinical Knowledge Summary (CKS) ADHD Nov 2022 (*Appendix C*).

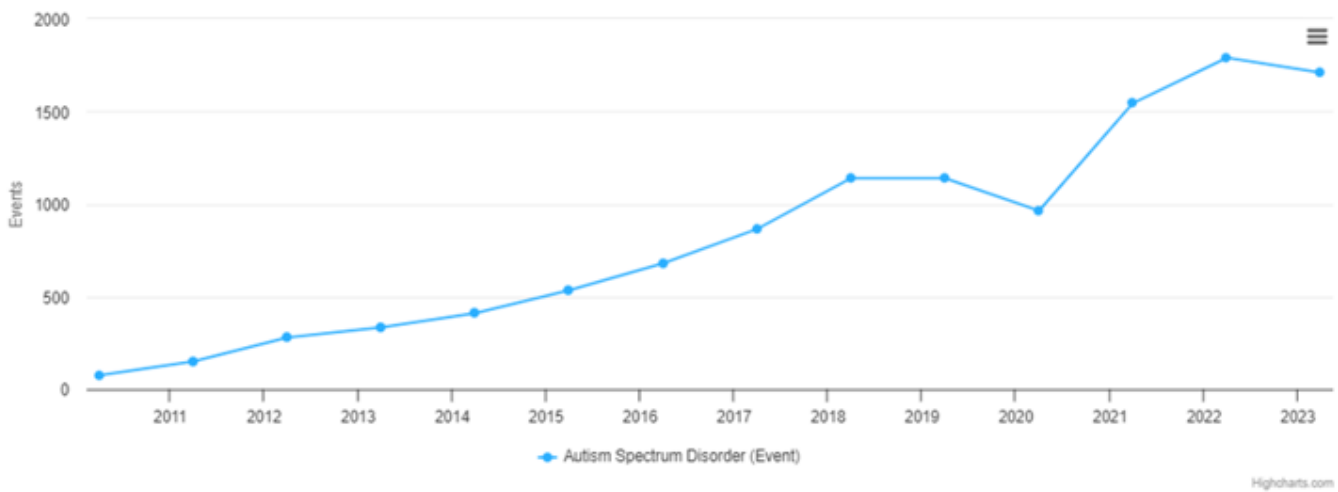
Based on this prevalence rate and the 2021 census data, there would be approximately 11,460 children and young people aged 0-17 with ADHD across Nottingham and Nottinghamshire. However, E-Healthscope data shows a slightly lower number, with 7,310 children and young people aged 0-19 identified with ADHD. This data suggests a significant number of individuals in the region who may require support and services related to ADHD.

It's important to note that the increase in prevalence for Autism and ADHD assessments since 2011 suggests a rising demand for diagnosis in the local area, as demonstrated in the graphs below. This data indicates a growing awareness and subsequent increase in the occurrence of neurodevelopmental conditions.

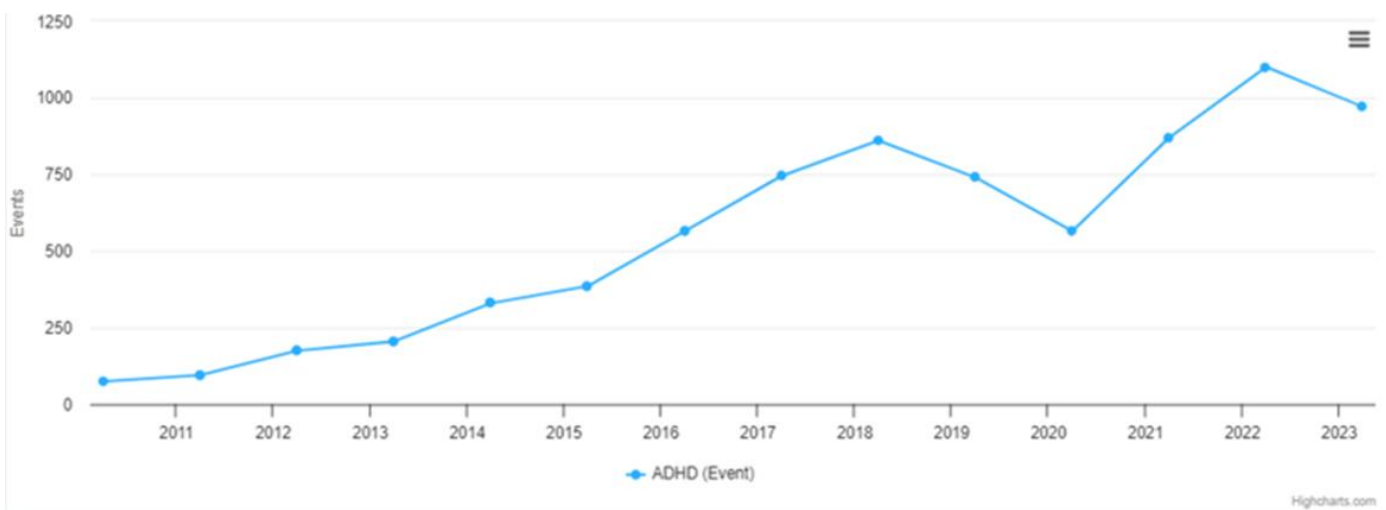
Understanding and addressing this trend is crucial for adapting and enhancing the capacity of services to meet the needs of the local population.



**Local Autism diagnosis rates ages 0-19 – source E-healthscope**



**Local ADHD diagnosis rates ages 0-19 – source E-healthscope**



The current CYP neurodevelopmental pathways in Nottingham and Nottinghamshire are shown in the links below:

Nottingham City

[Nottingham City Pathway](#)

Nottinghamshire County(excluding Bassetlaw)

[NST Pathway](#)

Bassetlaw

[Bassetlaw pathway](#)

The waiting time for each service up to April 24 is show in the table below. These wait times indicate the pathway journey from referral to early support services referral review and to Community Paediatric assessment services.



## CYP Autism & ADHD Assessment Waiting Times – April 2024

Pathway	Pre-Assessment Support	Average Waiting Time	Community Paediatric Assessment	Average Waiting Time	Estimated total average waiting time (Referral to Assessment)
<b>Bassetlaw</b>	A Place To Call Our Own (APTCOO) – provides support to families however doesn't provide pre-assessment activities to inform assessment with Community Paediatrics.	1 week	Community Paediatrics – DBHT GDA pathway receives referrals from early years services & schools	74 weeks	<b>75 weeks (DBHT)</b>
<b>Nottingham City</b>	Behavioural & Emotional Health (BEH) – provides support to families and initial pre-assessment screening (including school observations and collation of information to inform assessment with Community Paeds).	52 weeks	Community Paediatrics – NUH Receives referrals from BEH	25 weeks	<b>77 weeks (NUH)</b>
<b>Nottinghamshire County (Mid and South Notts)</b>	Neurodevelopmental Support Team (NST) – provides support to families and initial pre-assessment screening (including school observations and collation of information to inform assessment with Community Paeds).	61 weeks	Community Paediatrics – SFH Receives referrals from NST for Mid Notts.	10 weeks (median wait)	<b>71 weeks (SFH)</b>
			Community Paediatrics – NUH Receives referrals from BEH for South Notts.	25 weeks	<b>86 weeks (NUH)</b>

### National and Local Strategic Context

*The NHS Long Term Plan for Learning Disabilities & Autism* aims to:

- Improve community-based support
- Develop a clearer and more widespread focus on the needs of autistic people and their families
- Make sure that all NHS commissioned services are providing good quality health, care and treatment
- Reduce health inequalities
- Continue to champion the insight and strengths of people with lived experience and their families
- Make sure that the whole NHS has an awareness of the needs of people with a learning disability and autistic people

*The SEND Improvement Programme* identified actions the Nottinghamshire local area partnership should undertake to address our most important areas of improvement, how we will measure success and what difference this will make to Nottinghamshire's children and young people with SEND and their parents and carers. The plan focuses on ensuring that:

- Children and young people's needs are identified accurately and assessed in a timely and effective way.
- Children, young people, and their families participate in decision-making about their individual plans and support.
- Children and young people receive the right help at the right time.
- Children and young people are well prepared for their next steps and achieve strong outcomes.



- Children and young people are valued, visible and included in their communities.

*Priority Action 2 of the local SEND improvement plan:*

Leaders, including commissioners and providers, should act urgently to identify and address the delays and gaps in access to some health services, particularly speech and language therapy, neuro-developmental pathways, and equipment services. They should also ensure that they use available performance data to identify where gaps exist and whether actions taken to address these are effective.

The outcome needs identified:

- The needs of children and families with SEND are clearly understood so that immediate and long-term changes to health service provision can be made through effective joint commissioning  
Aim - To strengthen joint commissioning building on data, intelligence, and insight to support SEND.
- Children and Young People receive a timely assessment and treatment offer by the Neurodevelopmental Support Team (NST)  
Aim - Deliver improvements to waiting times for assessment to NST and subsequent paediatric diagnostic pathways
- For children, young people, and families with SEND experience services that are easy to navigate, free from duplication and are adaptive to their needs.  
Aims - To reduce waiting times for assessment by therapy services and to promote seamless provision of requirements, remove gaps and to reduce duplication of assessments for CYP and families

An inspection of the Nottingham City neurodevelopmental early support service Behavioural & Emotional Health Team (BEH) is imminent.

**Scope of the Review:**

Due to the need to address the actions outlined in the County SEND improvement plan, and in anticipation of a SEND inspection in the City, the initial focus of the review will include the Nottingham City and Nottinghamshire County (Excluding Bassetlaw) pathway. The review aims to assess and improve the effectiveness, accessibility, and overall quality of services provided for children and young people with neurodevelopmental assessment needs by identifying resources, agreeing on opportunities for improvement, and implementing new ways of working in a bid to reduce increasing wait times for families.

The review spans across stakeholder organisations and covers all levels of intervention to address the diverse needs in the diagnosis and care of our children and young people along the neurodevelopment assessment pathway process.

**The key elements of the review include:**

- **Identification of resources** - Understanding and identifying the necessary resources, both in terms of personnel and infrastructure, is crucial for the effective



functioning of the ND pathway. This involves assessing current resources and determining if there are any gaps or areas that need improvement.

Acknowledging the importance of the workforce in delivering quality care, the review aims to address potential adjustments in staffing, training, or roles to ensure that teams are equipped to handle the diverse needs along the diagnostic pathway. This may involve training staff in new methodologies or hiring additional personnel.

- **Opportunities for improvement** - The review seeks to identify opportunities for improvement across various aspects of the ND pathway. This includes evaluating existing processes, protocols, and workflows to pinpoint areas where enhancements can be made to better serve the needs of neurodiverse children and young people, and their families.

To achieve the desired outcomes, the review aims to implement new ways of working. This could involve introducing innovative practices, maximising benefits of technology, or adopting evidence-based approaches to diagnosis, support, and care. The goal is likely to improve the efficiency and effectiveness of the ND pathway.

The overarching goal of the ND review is to assess and improve the effectiveness, accessibility, and overall quality of services provided for children and young people, with the commitment to delivering high-quality care that is easily accessible to those in need.

- **Review financial allocations** - Financial considerations play a significant role in our service provisions. The review aims to review financial allocations a part of the review of services, indicating a recognition that proper funding is essential for sustaining and improving the quality of services provided within the ND pathway.
- **Collaboration** - The review recognises the significance of collaboration and inclusivity. This holistic approach is an initiative to incorporate input from key stakeholders involved in the care and support of individuals along the ND pathway, including those with lived experience.

## Key challenges

- The demand for diagnostic assessments is far surpassing the capacity of the Children and Young peoples ND services, with expectations of a sustained high demand. The primary challenge lies in the service provider capacity that was commissioned based on prevalence and activity data at the time, which is significantly lower compared to the demand now, rather than issues within the diagnostic assessment process or the design and structure of services.
- The review highlights various challenges impacting the capacity of ND services, including the need for additional clinical resource along with further administrative support being required, with the desire for a more Multidisciplinary Team (MDT) style



approach to support and meet the varying needs of children and young people in line with NICE guidance.

While some efficiencies and increased capacity may be achievable with a modest funding increase, it is acknowledged that these gains may not entirely bridge the demand-capacity gap facing ND services.

The re-design of services should therefore prioritise addressing unmet needs rather than solely attempting to close the demand & include capacity gap. Taking action to expand and restructure ND services will be essential to enhance overall capacity and better meet the needs of the community.

**In identifying the challenges, the review recognises the necessity for:**

- Adopting a whole systems approach. This includes a focus on enhancing awareness and understanding of neurodiversity, re-enforcing access to early help and support, active engagement of various sectors (such as health, education, social care and the third sector) and implementing a lifelong support approach with a “no wrong door” policy, preventing the child or young person from unnecessarily moving around services, which can ultimately lead to challenges in receiving continuous and comprehensive care.
- Furthermore, the recommended actions involve investing in, restructuring, and fostering increased collaboration between services. This aims to tackle demand & capacity gaps, including deficiencies in service provision. The goal being to establish a more holistic, needs-led approach that can effectively handle complexity, differences, and diversity.
- An emphasis on implementing short to medium term measures to enhance experiences and outcomes while alleviating the pressure on existing ND provider services. Simultaneously, there’s a consideration for exploring the development of new service models in the longer term.
- Enhancing monitoring and evaluation, with a focus on what is meaningful to service users, serves to inform decisions regarding service development, providing transparency and accountability to stakeholders.
- The programme is committed to engaging in formal communication with key stakeholders whenever opportunities for operational improvement are identified. This commitment is aimed at expediting enhancements to the accessibility and quality of provider services. Progress on implementing these improvements will be regularly reported within governance updates.
- The review aims to establish and integrate the Nottingham and Nottinghamshire Integrated Care System strategic aims and quality standards (*Appendix D*) as part of the NHS Long Term Plan (*Appendix E*) and aligning with the Nottinghamshire SEND Priority Action Plan (*Appendix F*). These standards are designed to facilitate children





and young people with or suspected with, ASD and/or ADHD in leading ordinary, fulfilling lives with the appropriate support at the right time.

- The review's focus is to establish a system-wide infrastructure for the Nottingham & Nottinghamshire ND pathway delivery model. It notes enhancements to and implementation of a streamlined data capture system as vital for efficient and consistent service review and coordination across service provider organisations.

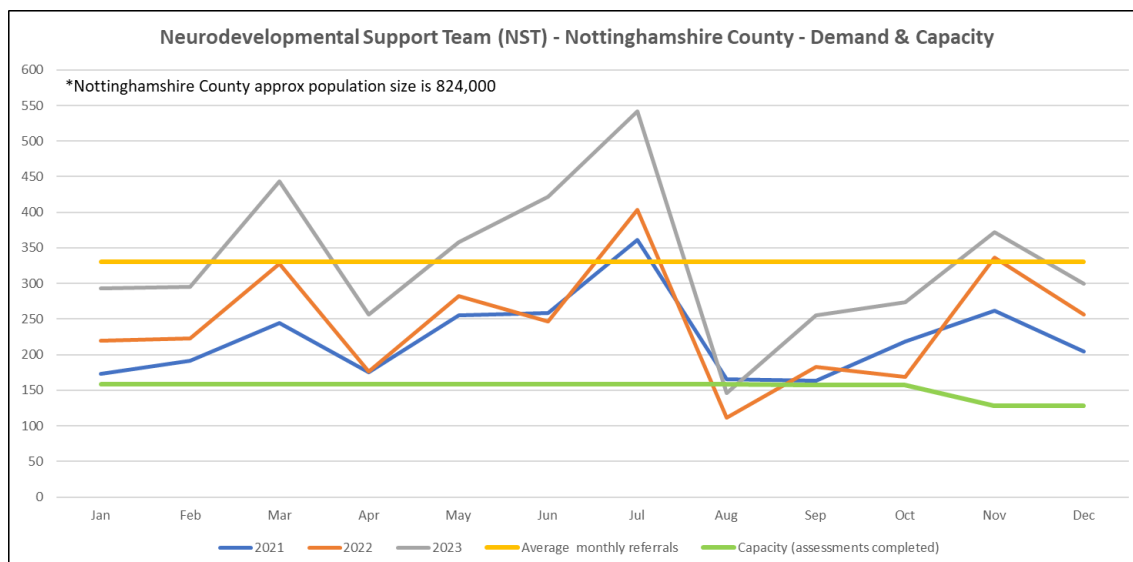
## Demand & Capacity

The escalating awareness of Autism and ADHD has led to a growing demand for diagnostic assessments. However, data reveals a significant disparity between the increasing demand and the limited capacity of children's ND services.

The graph below illustrates the imbalance between demand and capacity for our Nottinghamshire County ND Local Authority Service (NST) along with the rising prevalence of neurodevelopmental assessment requests.

Capacity is calculated based on a shortened assessment time taking on average 6.5 hrs and a complex assessment on average 12 hours.

This calculates that on average 158 assessments are completed per month, this however will fluctuate depending on staffing levels and variance in assessment type. The average demand is 330 assessments per month, therefore an increase of approx. 109% in staffing capacity is required to meet the increasing demand in requests for assessment requests within the service.



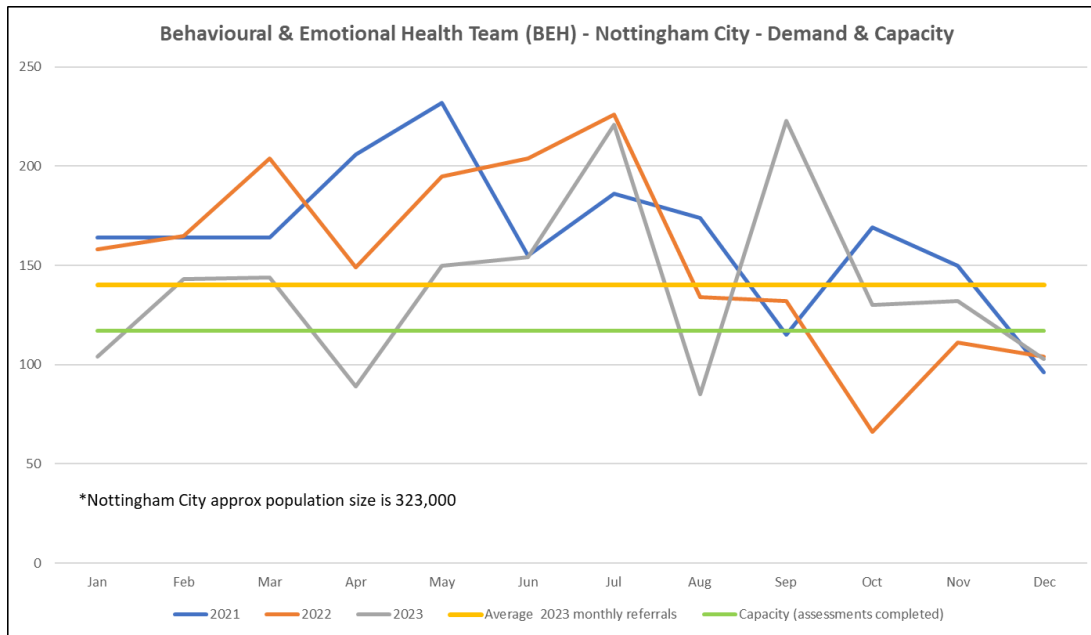
It is important to note, balancing the time needed for a quality, needs-led assessment mixed with the complexity of minimising wait times is a continuous challenge for both Nottinghamshire County and Nottingham City ND services. Thoughtful and strategic approaches are ongoing within services to ensure assessments maintain the necessary





standards of quality and comprehensiveness while also committing to support and work towards wait time reductions.

The graph below illustrates the imbalance between demand and capacity for our Nottingham City ND Local Authority Service Behavioural & Emotional Health Team (BEH) along with the rising prevalence of neurodevelopmental assessment requests.



The data for 2021 incorporates a backlog of legacy referrals from the predecessor service, coupled with an average data submission for January to March 2021 due to data not being available.

Capacity is calculated based on an average assessment time of 12 hours.

The calculation reveals that, on average, 117 assessments are completed per month. However, this figure may fluctuate based on staffing levels and variations in assessment types. Considering an average demand of 140 assessments per month, there is a need for a 19.7% increase in staffing capacity to effectively address the rising demand for assessment requests within the service.

The figures for both ND early support services in Nottingham and Nottinghamshire emphasise the urgent need to rectify the imbalance and bolster capacity. This is essential to effectively address the escalating demand for these services.

It's important however to acknowledge that while an increase in funding and subsequent capacity is valuable, it should not be viewed as the sole solution for reducing wait times. Equally crucial is the need to identify the optimal use of existing resources and procedures, making efficient use of the current capacity to its fullest potential.



It is crucial to acknowledge that the rising demand for neurodevelopmental support and assessments from our local authority provider services imposes heightened pressure on our community paediatric services. This increased demand is likely to become overwhelming for our acute services, indicating a need for a review of demand and capacity in that specific area *\*see recommendation number 4 (page 18)*.

## Collaboration across the system

**Collaboration with Nottingham University – “Nottinghamshire Neurodiversity Network” (NNN)** – The ICB is collaborating with the University of Nottingham School of Psychology & Institute of Mental Health Research Team in the ongoing review.

Establishing the "Nottinghamshire Neurodevelopmental Network," working group network has been fundamental to the review, involving key stakeholders from across the system. This group is instrumental in shaping the development of the ideal neurodevelopmental pathway for children, young people, and adults.

Comprising of health, educational, and social care professionals, the group also includes crucial stakeholders such as parents and carers with lived experiences. The collaborative effort involves proactive engagement through online review group meetings and in person workshops.

These sessions aim to evaluate the current pathway, identify strengths and weaknesses, and determine the best approaches to address challenges, with a primary focus on defining the ideal pathway. The recommendations emerging from this group will guide the formulation of the ideal neurodevelopmental pathway.

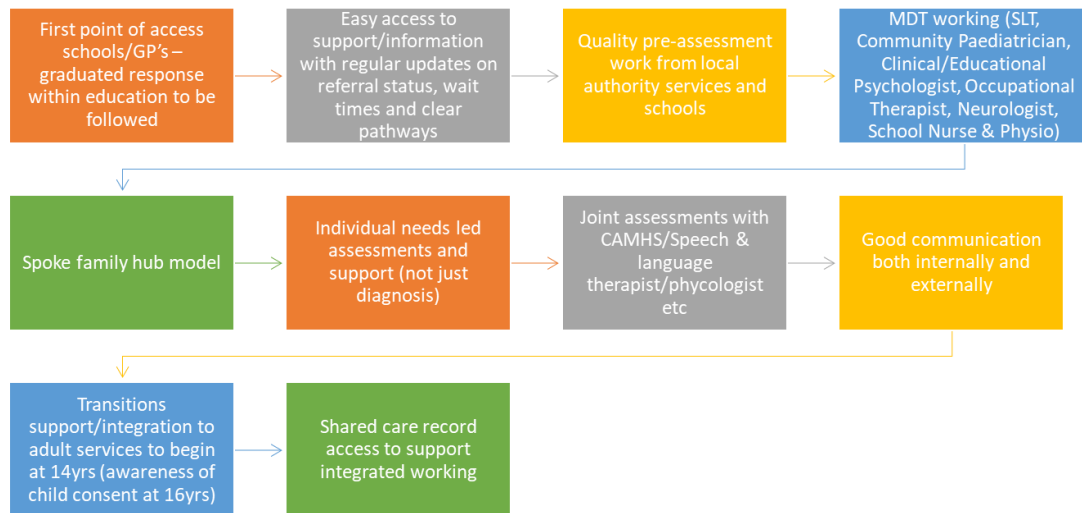
In the transformation of the ND pathway, it is crucial to prioritise effective communication and collaboration within the wider health and education system.

Robust communication support is vital for facilitating seamless interactions and coordination among diverse stakeholders within the system. The NNN therefore plays a fundamental role in shaping the design of the future pathway.

The key principles for the ideal pathway to care, and vision for ND services as outlined by the NNN stakeholder working group are below.

- Knowledge & Education
- Support
- Holistic approach
- Clarity

Each of these principles represents a crucial aspect of a comprehensive and effective ND service. The conclusions drawn from discussions regarding the ideal pathway are shown in the chart below and should be considered in future service re-design and commissioning arrangements:



To comprehend the experiences of individuals awaiting referral to ADHD or Autism support and assessment services, a survey was collaboratively developed with input from families with lived experience, service providers, and health & education professionals.

The survey aimed to gauge the support that families would find beneficial while on the pathway process. The subsequent report details the responses gathered from parents across Nottingham & Nottinghamshire.

The recent survey, with responses from 248 families, serves as valuable insight into understanding their experiences and preferences, both post-pathway and for those currently on the pathway. This survey provides insights into the families' perspectives on the support, communication, and overall experiences with ND providers. The collected data from the survey will inform contribute significantly to improving services and tailoring support based on the feedback and preferences of the families involved.

The primary concerns voiced by parents revolve around communication and support. While the extended waiting times were acknowledged as a barrier, many parents expressed a desire for more consistent communication and support during the waiting period.

Improved communication is sought in terms of clarity regarding the pathway, expectations, timelines, and available services. Enhanced support for both parents and young people is deemed vital, particularly in areas such as education, mental well-being, and behaviour. These insights emphasise the importance of clear communication and comprehensive support mechanisms throughout the neurodevelopmental assessment process.

Key themes from the survey were:

- Parents expressed a preference for frequent updates, ideally at one or two-month intervals, on the status of the referral, with a preference of communication via email or letters.



- Parents expressed a strong desire for specific information from services, particularly regarding waiting times and the referral process. They emphasise the need for detailed insights into what to expect during each appointment and a continuous update on the referral process. Clear guidance is sought, including visual flowcharts outlining each stage of the process. This reflects the importance of transparent communication in providing families with a clear understanding of the journey through the ND assessment pathway.
- Parents express a need for local support in various areas, including education, parenting, and information related to neurodiversity. This highlights the broader spectrum of support that parents seek beyond the assessment process. Providing resources and assistance in these areas can significantly contribute to the overall well-being of families and enhance their ability to support children and young people effectively.

Examples of some of the feedback from parents:

*“Acknowledging that it is a slow and lengthy process (for all kinds of reasons), showing the likely timescales / number of steps and clearly signposting support that’s available in the meantime. However, given the questions on this survey it feels like you know this, so I hope this is a step towards managing this issue. Thank you.”*

*“It’s taken 16 months from referral to being given an appointment with a paediatrician, but we have no idea what to expect. Will our son be assessed that day? If this just an initial appointment, how many more might there be after this and what is the timescale?”*

*“More information about how the process looks, what happens, what help or support is there for parents”*

The aim is to use these insights to guide the development of the pathway and shape co-design activities moving forward.

This approach reflects a commitment to incorporating the perspectives and experiences of families directly into the improvement and evolution of ND services, fostering a more patient-centred and responsive pathway.

## Key findings and improvements so far

- **Waiting time reduction initiatives** – additional monitoring and funding arrangements are in place to support in the reduction of wait times with collaborative efforts between commissioners and providers to reduce wait times for families awaiting neurodevelopmental ND assessments.

Regular service review meetings are in place with commissioners and providers to support in identifying service pressures and barriers, along with the monitoring of monthly data submissions to identify solutions to address these challenges.

- **Additional resource** – Allocating additional resources, including specialist practitioners, clinical psychologists, speech and language therapists, and



administrative staff, has been a positive step toward addressing the demand for ND services.

To systematically address the demand and capacity gaps, a robust plan is required for resource allocation that aligns with the current and future needs of individuals seeking neurodevelopmental services.

This approach contributes to a more sustainable and responsive system. By exploring leaner ways of working and streamlining services, the aim is to enhance efficiency and ensure timely access to assessments for families.

- **Improved communication and resource support** – Feedback from families indicates they feel forgotten once their referral has been submitted to the relevant service. Parent feedback received from a recent survey stated, *“It’s like you put the referral in and it’s turns to dust for 2 years”*.

It is subsequently noted that communication with families from services is somewhat lacking, and ultimately, children, young people, and their families' expectations and support needs are not being met.

It was therefore agreed and initiated that resource support information should be disseminated to families at the point of referral receipt, ensuring families are updated on the latest wait times and signposted to key resource support information at the earliest opportunity, ensuring they well supported whilst waiting.

It is positive to note a significant decrease in inquiries regarding service wait times and resource support, indicating that the implemented changes have contributed to a more efficient and responsive system.

It should not be underestimated how clear communication fosters transparency, trust, and reassurance with families *\*See recommendation number 7 (page 19)*.

- **Shared care record access to be introduced April 2024** – As part of the review, it became increasingly apparent the sharing of records plays a crucial role in streamlining healthcare processes by reducing duplication and preventing unnecessary assessments for children and young people.

Implementing shared care records access amongst providers from April 2024 is a positive step. It will not only significantly reduce duplication, expedite assessments, and ultimately reduce wait times for families, but it will also enhance collaboration among providers and lead to more efficient and effective care for children and young people.

- **Transitions to adult services** – the improvement of transitions from children to adult’s services to reduce the wait time for the 17+ cohort of young people has been developed through greater integration and collaboration between services.



The introduction of the practice that allows young people to transition seamlessly into the adult Neurodevelopmental Specialist Service (NeSS), starting from the same point on the waitlist they held in the children's ND service has been successfully implemented. This adaptation is anticipated to streamline the process significantly, leading to a notable reduction in wait times during the critical transition period for both young people and their families. This change in service provision aims to enhance the overall experience for those involved.

- **Direct onward referral to Community Paediatrics** – A direct electronic referral process is being implemented to streamline the referral process to the Community Paediatric Service from the Family Service Neurodevelopmental Support Team (NST) in the County to ensure equity across the system, and in line with our Neurodevelopmental support service (Behavioural & Emotional Health Team) in Nottingham City.

The implementation of this process will eliminate unnecessary GP appointments. Bypassing the need for an additional GP appointment for the family will not only ensure the GP's time is optimised more effectively, but also lead to a more direct and timely access to the specialised care provided by the Community Paediatric Service.

By streamlining the referral process, unnecessary delays can be minimised. Direct referrals can help in ensuring that those in need of prompt attention receive it without further prolonged wait times, enhancing the overall experience for the child or young person and their families by reducing the number of steps involved in accessing specialised care.

It is anticipated this change will be implemented by June 2024.

- **Collaboration with ND services CAMHS** – The review has identified the necessity for joint assessments in Nottinghamshire County between CAMHS services and the Neurodevelopmental Support Team, aligning with the principles of equity and consistency with the provision of joint assessment already established in Nottingham City services.

This support is key for identifying the primary needs of the child or young person, facilitating the creation of tailored care plans to ensure timely and appropriate care, addressing both neurodevelopmental and mental health aspects.

The ongoing discussions and planned partnership working between the CAMHS (Child and Adolescent Mental Health Services) team, and the ND service provider in Nottinghamshire County Neurodevelopmental Support Team (NST) represent a positive step toward a more integrated and holistic approach to assessing the needs of children and young people.

Some of the key gaps in service provision identified for families, and are being addressed through collaboration with the CAMHS and ND services relate to:



- **Trauma and attachment support** – there are no current provisions for children & young people with trauma and attachment related needs.
- **Talking therapies CAMHS ID** – the need for support should be recognised for children who are non-verbal or face communication and social barriers, struggle with verbalisation, or need more time to process and build relationships, presents a unique set of challenges. Additionally, if these children are closed to CAMHS due to non-engagement, alternative approaches and strategies are often therefore necessary and may not be the most appropriate support provision for the child or young person.
- **Neurodevelopmental disorders and anxiety** – It is noted the intersection of neurodevelopmental conditions and mental health issues are often complex and challenging. It is indeed recognised that neurodiverse children & young people may have a higher risk of experiencing mental health issues, such as anxiety and depression etc. However, referrals are often rejected by the CAMHS service highlighting a potential lack of understanding of the unique mental health needs of neurodiverse children & young people.
- **Neurodevelopmental referrals** - referrals to CAMHS are often declined due to the family already being on the waitlist with the NST service for neurodevelopmental concerns. This raises important considerations for a more integrated and comprehensive approach to mental health support.

The CAMHS service is actively undergoing significant development to better support the ongoing neurodevelopmental and mental health needs of children and young people. Initiatives include the creation of an autism care bundle tool which helps to support practitioners in the initial assessment process to help understand the needs of the young person and their family more clearly, along with providing a shared understanding or formulation of presenting difficulties and needs. The CAMHS service also acknowledge the need to provide additional creative therapies and allocate more time for those who may face challenges in engaging with services.

The team have also recently appointed a new single point of access (SPA) team lead to support in the triage of assessment and primary need requirements of the child/young person.

Conducting an in-depth demand and capacity review of the CAMHS service is a crucial step in supporting future commissioning arrangements. This review will provide valuable insights into the needs of the community, allowing for the development of a multidisciplinary approach and the implementation of best practices learned from other areas.

The implementation of a collaborative approach between ND services and mental health services is therefore ongoing to ensure seamless, timely and appropriate





referrals. This may involve joint training sessions and regular communication channels between the two specialties and the SPA provision.

Multidisciplinary input from both CAMHS and ND services will ensure a joined-up approach to care. This collaborative effort will lead to more effective strategies to support the child or young person in their primary need. *\* See recommendation number 10 regarding MDT working (page 20)*

- **Education** – Approximately 70% of referrals for Autism and ADHD originate from schools, underscoring the importance of evaluating the additional support required for the school's pathway process.

Current initiatives involve not only assessing reasonable adjustments but also implementing these interventions. Moreover, collaborative efforts with educational colleagues are underway to provide education and support for children and young people with Autism/ADHD.

Initiatives like the Autism in Schools project and the Partnerships for Inclusion of Neurodiversity in Schools (PINS) pilot play a crucial role in promoting understanding, acceptance, and support for neurodiverse individuals within educational settings. By working together with schools and other stakeholders, these projects can help create environments where all students feel valued, understood, and supported in their learning and development.

- **Pathway infographic** – It is clear from the review there is a definite need for the creation of a clear pathway diagram to assist and guide families through the referral process.

Pathway documents have therefore been developed for each neurodevelopmental service provider to give clear and transparent information about the entire process, outlining each step, what families can expect at each stage along with links to resource support information. The hope is this will provide much needed clarity, helping to reduce uncertainty and anxiety for families.

The pathway infographics have now been shared with families via early support providers, GP practices and educational settings.

- **Vanderbilt ADHD assessment** – As part of the review and sharing learning across ND pathways within the system, a need was identified for the Nottingham City Behavioural & Emotional Health Team (BEH) to coordinate and conduct the ADHD Vanderbilt assessment as a component of their assessment process. This now occurs before the onward referral to the Community Paediatrician for a diagnostic assessment in both the City and County ND services.

The implementation of this process has led to more timely assessments for individuals whilst they are under the care of the Community Paediatrician and awaiting a diagnostic assessment for ADHD.



- **Improved data quality and frequency** – Data capture and reporting for ND conditions has historically been challenging and variable across services. Collaboration is underway with all ND provider data leads to produce monthly data submissions of referral to assessment and referral to treatment information to support more timely performance monitoring, NHSE information requests, demand & capacity analysis, service review processes and future commissioning requirements.

The continuous analysis of data will also aim to evaluate outcomes, identify trends, informing future commissioning arrangements and improvements.

## Recommendations

The recognition that maintaining the status quo is not a viable option is an important realisation, especially when dealing with gaps in demand and capacity for neurodevelopmental diagnostic assessments.

Prolonged waiting times, delayed support, heightened distress amongst families, and missed opportunities for early intervention highlight the urgent need for improvement.

Addressing these issues is critical for the well-being of children and young people undergoing assessments and has broader implications for human, social, and economic costs. Whilst improvements during the past year have started to have a positive impact, we recognise this is the start of a collaborative journey to longer-term sustainable change and improvement for the ND pathway and services in Nottingham and Nottinghamshire. Here are considerations for addressing these challenges:

1. **Review referral threshold criteria into services** - It is crucial to establish clear threshold criteria for neurodevelopmental assessments to ensure the appropriateness of referrals and efficient utilisation of resources as part of a wider graduated response across the system. These criteria serve as guidelines for referring professionals, assisting in identifying those who would benefit the most from neurodevelopmental assessments and identifying those for whom such assessments may not be necessary.

Current referral threshold criteria should therefore be reviewed in order to contribute to reducing inappropriate referrals into the service, consequently leading to a significant reduction in wait times.

2. **Efficiency measures** – in order to meet the NICE clinical guidelines 128 for referral to assessment timelines ([Appendix G](#)), implementing ongoing efficiency measures within the diagnostic assessment process is essential. This may involve streamlining administrative processes, utilising technology for data management, and enhancing collaboration among service providers and commissioners.

We must look to consider strategies for workforce adaptability, such as cross-training staff to handle different aspects of the pathway process, along with optimising the



use of available resources. This can enhance the resilience of the workforce in responding to changing demands and increase flexibility in service capacity.

3. **Review of demand & capacity within Community Paediatrics services** - Undertaking a review of demand and capacity within our community paediatric teams at Sherwood Forest Hospital, Nottingham University Hospital and Doncaster & Bassetlaw Teaching Hospital is essential to strengthen services and effectively meet the growing prevalence and demand for ND assessment. This should be done jointly with the ICB's Children's Commissioning Team to consider and inform wider commissioning intentions for children and young people, recognising the teams' broader remit beyond ND assessments. \* *See recommendation number 4 (below)*
4. **Increased resources** Along with the need to review referral criteria and thresholds, there is a clear need in reducing the reliance on non-recurrent funding and securing consistent recurrent funding in order to retain and attract skilled workforce, thereby expanding the capacity of ND diagnostic assessment services across all areas of Nottingham & Nottinghamshire.

This approach supports the aims in alleviating wait times and addressing the escalating demand for diagnostic assessments. Prevalence and resource data for early support neurodevelopmental assessment services indicate a need for a 19.7% increase in resources in Nottingham City and a 113% increase in Nottinghamshire County compared to current demand. To reduce wait times in accordance with national policy commitments under the national framework to deliver improved outcomes in all-age autism assessment pathways ([Appendix B](#)), a minimum capacity is needed for at least 1.5 – 2.6% of the population to be referred to an autism assessment service and for at least 1.3 – 2.3% of the population to be assessed for autism:

Min capacity as per national framework		0-17 years (2021 Census City and County)	0-17 years (City)	0-17 years (County)
Referred for assessment	1.5%	3438	990	2448
	2.6%	5959	1716	4243
Assessed for autism	1.3%	2980	858	2122
	2.3%	5272	1518	3754

The appropriate resource required should be modelled against prevalence data as part of the Community Paediatrics demand and capacity review.

5. **Community education** - Implementing awareness campaigns within the community across Nottingham & Nottinghamshire is imperative to educate families, educators, and healthcare providers about early signs of neurodevelopmental concerns. The significance of a graduated response must be stressed, including Tier 1 intervention levels, before contemplating a Neurodevelopmental (ND) diagnostic referral, is crucial to ensuring families receive the right support at the right time and managing demand/expectations.



Early identification through these campaigns can streamline timely interventions and enable the provision of needs-led support.

6. **Collaboration with Primary Care** - Strengthen collaboration with primary care providers across Nottingham & Nottinghamshire to ensure timely and appropriate referrals are made, with clear guidance on the referral pathway and providing education to primary care professionals on recognising and addressing neurodevelopmental concerns, along with reaffirmation of the red flag indicators for priority referral status.
7. **Increased support for both pre and post diagnosis** – Many families report feeling “left in the dark” whilst awaiting a diagnosis and particularly following the outcome of a diagnosis. It is clear a more needs-led approach is required across Nottingham & Nottinghamshire to support individuals, and, as a result, support provisions for families should be reviewed to ensure needs are being met. The review process should be conducted through co-production with children and young people and their families to ensure that their support needs are fully understood and met.

This collaborative approach will ensure that services are tailored to meet the specific needs and preferences of CYP and their families, ultimately leading to more effective and personalised support.

The Westminster Commission on Autism, University of Bath November 2021 report ([Appendix H](#)) highlights the importance of support for families both pre and post diagnosis.

8. **Pre-diagnostic autism support provision for under 5's** – The review has identified a gap in provision concerning the increased demand for autism support for families with children aged five years and under.

The current commissioned service with the Cygnet Programme ([Appendix I](#)) is a support workshop for families of autistic children. This provision however is currently only commissioned for families of children aged five years and upwards.

Autism workshops designed for families with children under 5 years old can offer a holistic approach to support, encompassing education, skills, and a sense of community. Early support intervention is essential and has the potential to positively impact the developmental trajectory of children with autism, contributing to the overall well-being of their families.

The commissioning of a pre and post diagnostic autism support programme for families of children under five years, should therefore be considered.

As part of the threshold considerations, the review also recommends that for children under 5 years of age, the initial appointment be conducted by a Community Paediatrician on the pathway, rather than pre-assessment services. This approach



aims to ensure a thorough examination to exclude other medical and developmental disorders.

9. **Parental workshops** - It's important to consider the feedback from families and actively address concerns about the potential implication of blame on parents for their child's behaviours related to Autism and ADHD.

Feedback has been particularly evident concerning the name of parental workshops, suggesting that parents are responsible for their child's neurodiverse behaviours and subsequent education is required in their parenting skills. This demonstrates a commitment to fostering a supportive and understanding environment, avoiding any unintended stigmatisation or misconceptions.

The November 2023 report from the University of Leeds ([Appendix J](#)) highlights the significance of understanding and addressing the prevalence and impact of allegations related to Fabricated or Induced Illness (FII) on families.

It also highlights the need to assess workshop descriptions and potential content to prevent any misunderstanding in parenting skills. This approach ensures the workshops provide accurate and helpful information without contributing to misconceptions.

A workshop name present a supportive and collaborative offer. Here are some alternative names that aim to avoid any implication of blame and focus on understanding, support, and collaboration:

- Navigating Together: A workshop for Autism/ADHD support
- Building Bridges: Empowering Parents in Autism and ADHD
- Parenting Partnerships: Supporting Children with Autism/ADHD
- Strength in Support: A workshop for Parents in Autism/ADHD

10. **MDT working** – The pathway review has identified the need to embrace and continue to work towards a Multi-Disciplinary Team (MDT) style approach to neurodevelopment assessments to collaboratively address complex issues and provide comprehensive care.

This approach is geared towards fostering joint working and decision-making, emphasising the significance of integrating expertise from diverse professionals to ensure a thorough evaluation and more timely assessment. The intention is to prevent the child or young person from being passed around services, promoting an ethos of a team around the child for a more cohesive and supportive approach.

MDT working for neurodevelopmental assessments offers several benefits, particularly in the comprehensive evaluation and support of children and young people along the diagnostic pathway, which has been seen through the introduction of the Clinical Practitioner and Speech and Language roles in Community Paediatrics



Neurodevelopmental conditions often present with overlapping symptoms, MDTs can help reduce diagnostic ambiguity by considering multiple perspectives, leading to more accurate and timely diagnoses.

Regular communication and coordination among team members facilitate a cohesive approach to assessment and intervention, ensuring that information is shared, and everyone is aligned with the goals of supporting the child/young person, and their families in accordance with NICE clinical guidelines 128 ([Appendix F](#)).

The NHS Health England Multi-Disciplinary Toolkit ([Appendix K](#)) and the November 2021 National Library of Medicine article ([Appendix L](#)) highlight the benefits and approaches to MDT working.

- 11. Hub and spoke model** – As above, with an MDT approach, the hub and spoke model facilitates collaboration and networking among different “spokes”. Professionals from various locations can share best practices, exchange knowledge & information, and collaborate on solutions to individual assessment needs.

Having ND spokes in different locations, individuals can access ND support services more promptly. Timely interventions are crucial for addressing developmental needs and providing support during critical periods. This flexibility allows for a more customised, inclusive, and responsive approach to ND support for families.

Spokes can also play a key role in preventative and early intervention strategies. Identifying ND challenges early on and providing appropriate support can prevent issues from escalating and should therefore be considered as part of the review, particularly in cases such as looked after children, where this particular cohort may often experience additional delays to accessing services, recognising they may have changing living arrangements for example.

A hub & spoke model would ensure adaptable assessment processes, ensuring the accommodation of the needs and schedules of children in care are supported.

- 12. Shared care protocol ADHD medication** – Implementing a shared care model for ADHD medication distributing responsibilities among GPs and Community Paediatricians, should be considered. It's important to note that while this scheme is currently in place, and voluntary, some GPs are participating, but many are not due to existing pressures across Primary Care.

The intervention of shared care across the system will allow Community Paediatricians to allocate more time to assessments, diagnostics, and addressing complex cases, making the best use of their expertise, and ensuring efficient use of resources, particularly given the current pressures Community Paediatric services are facing.

As well as creating a more collaborative and integrated approach between Primary and Secondary Care services, shared care arrangements make it more convenient for patients. This will enable them to receive medication prescriptions, dosage





adjustments, and routine monitoring from their local GP, reducing the need for frequent visits to specialist services.

Funding implications need to be carefully considered regarding the allocation of resources for monitoring processes, including consultations, assessments, and communication between primary care and specialist services. This consideration should be included as part of the Community Paediatric demand and capacity review.

- 13. Sensory processing needs provision** – The review identifies the need and a gap in sensory therapy support for neurodiverse children and young people. Despite the evident rise in demand and need for such services, Nottingham and Nottinghamshire do not currently commission a sensory therapy service, however the spot-purchase of sensory assessments is considered on an individual basis through a number of different routes including the CYP Keyworking Service, continuing healthcare, personal health budgets and individual funding requests.

Sensory therapy offers a range of benefits that contribute to a child or young person's well-being, development, and overall quality of life. The provision of sensory support aims to create environments that accommodate the sensory needs and preferences of neurodiverse children and young people. Therefore, the coordinated commissioning of such provision should be considered to ensure that the necessary support is in place.

- 14. ADHD - Quantitative Behaviour (QB) testing** – It is recognised that the provision of recurrent investment for QB testing is needed across Community Paediatrics Services to support in significantly reducing ADHD assessment times.

This testing method, offers valuable quantitative data, facilitating a more efficient and objective evaluation. This, in turn, has the potential to expedite the assessment process and may reduce the need for additional diagnostic appointments for individuals undergoing ADHD assessments.

The implementation of QB testing on a trial basis within the Community Paediatrics Team at Nottingham University Hospital (NUH) has demonstrated significant benefits, particularly in the reduction of wait times. The outcome from this trial indicates the potential positive impact of incorporating this approach more widely across Nottingham and Nottinghamshire Community Paediatrics Services.

It is worth noting that Bassetlaw previously trialled QB testing with funding for two years. However, it was not considered particularly beneficial due to the economies of scale and the small population in Bassetlaw. Therefore, the costs could potentially be justified in other more densely populated areas such as Nottingham City and the South and Mid-Nottinghamshire areas of the County.

The NICE briefing demonstrates the benefits of this intervention ([Appendix M](#)).

The 2017 QB Test Demonstrator Project as part of the East Midlands Health Academic Science Network ([Appendix N](#)) also highlights the merits of QB testing,





with the project winning the 2018 Health Service Journal (HSJ) Award for innovation in mental health.

15. **Tic & Tourette's - service specification design/implementation and review of pathway** - A review of the current pathway is required to identify where areas can be streamlined or improved to enhance efficiency in service delivery. The design and implementation of the service specification are necessary, along with the development of a business case to support future commissioning and workforce arrangements.

16. **Behavioural & Emotional Health Team (BEH)** - Changing the service name of the Nottingham City ND Local Authority service provider "Behavioural and Emotional Health Team" (BEH) could have several potential benefits. The choice of a service name is significant as it shapes perceptions, communicates the scope of services, and influences the way individuals engage with the service.

A new name for the BEH Team may provide greater clarity about the focus and purpose of the service. The objective is to highlight the service's focus on neurodevelopmental support. Adopting a name that explicitly reflects this focus could potentially reduce ambiguity for both service users and referring professionals. Crucially, it may contribute to a decrease in inappropriate referrals into the service.

17. **Doncaster & Bassetlaw Neurodevelopmental Pathway** – Conduct a review of the current neurodevelopment support and assessment service process in Doncaster and Bassetlaw.



## Summary

Overall, the ND pathway review aims to identify and address challenges, enhance collaboration, allocate resources effectively, and ensure timely and appropriate support for children and young people with neurodevelopmental conditions.

The commitment to collaboration at a system-wide level in addressing and implementing the required changes and recommendations outlines the importance of a coordinated and comprehensive approach to support children, young people, and their families.

By working collaboratively across the system, the review aims to ensure that necessary changes are identified, communicated, and effectively implemented.

This commitment reflects a holistic perspective, acknowledging the collaboration of system stakeholders is key in achieving the ultimate goal of providing the right care at the right time for children and young people of Nottingham & Nottinghamshire.

## Next Steps

The next steps for the ND pathway review should involve a strategic action plan to implement changes and improvements based on the findings and recommendations.

The review findings should be shared with system partners across Learning Disabilities and Autism and SEND for review and comment.

The review aims to seek continued commitment from partners to work collaboratively to implement improvements, develop an overarching strategic implementation plan as part of the newly structured Neurodevelopmental Assessment Working Group, along with informing commissioning intentions for 2025/2026.

A detailed implementation and improvement plan should be developed, outlining specific actions, timelines, and responsibilities for addressing the recommendations.

Throughout the process of improvement and change, the aim is to foster a culture of continuous improvement within the ND pathway, encouraging ongoing learning, flexibility to adapt to changing needs, and a commitment to enhancing services based on feedback and evolving best practices.



## Appendix

Appendix A - [Data & Statistics on Autism Spectrum Disorder | CDC](#)

Appendix B – [NHS England » A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards](#)

Appendix C - [NICE CKS Attention Deficit Hyperactivity Disorder](#)

Appendix D - [Integrated Care System Strategy](#)

Appendix E – [NHS Long Term Plan](#)

Appendix F – [SEND Priority Action Plan](#)

Appendix G – [NICE clinical guidelines 128](#)

Appendix H - [Support Surrounding Diagnosis: An inquiry into Pre and Post Support for the Autism Diagnostic Pathway](#)

Appendix I - [Cygnet Programme](#)

Appendix J – [The prevalence and impact of allegations of Induced Illness \(FII\)](#)

Appendix K - [NHS Health Education England Multidisciplinary Team Toolkit](#)

Appendix L – [Pathway for Multidisciplinary Neurodevelopmental Assessment and Diagnosis in Children and Young People](#)

Appendix M - [NICE briefing QB Testing ADHD](#)

Appendix N - [East Midlands Academic Health Science Network - QB Test Project](#)