



# **REVIEW OF ALL-AGE NHS NEURODEVELOPMENTAL DISORDERS DIAGNOSIS PATHWAY ACROSS NORFOLK & WAVENEY**

RETHINK Partners  
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## **1. Purpose of the review**

RETHINK Partners were commissioned by the 5 Norfolk and Waveney CCGs and Norfolk County Council to undertake a review of Neuro Developmental Disorder (NDD) pathways across the system. The need for a review was highlighted by the system as part of a previous review of the CAMHS transformation programme undertaken in the autumn of 2018.

## **2. Background and local context**

Norfolk and Waveney do not have a single NHS service across the system for children and adults with neuro developmental disorders (NDD). There is considerable variation between the pathways currently commissioned; the focus is mainly on diagnostics with little or no pre and post diagnostic support. Referrers, young people, their families and adults seeking diagnosis and help are confused and frustrated by the existing service offer.

A recent review of Children and Young People's mental health services identified the need for a review of NHS diagnostic pathways and associated pre and post diagnosis support for children and young people. The developing Norfolk and Waveney all age autism strategy has identified similar issues for adults too. There is a lack of clarity about the requirements and offers for core associated services – such as mental health – where people with NDD are likely to have higher than average levels of need and may need some specialist support. More widely, the system has not yet embraced a “reasonable adjustments” approach for NDD for other services.

Prevalence of NDD and demand for services is increasing; waiting times for diagnosis and the support that is available have increased in recent years.

In line with national requirements, Norfolk has established an All-Age Autism Partnership. This is the only formal leadership and partnership group in the system with responsibility for services falling into the NDD category. However, whilst some of the issues are common, the focus of this group is Autism Spectrum

Disorders; it does not have a remit for ADD, ADHD or other social and communication disorders falling into the NDD category.

### **3. Scope of the review and methodology**

The scope of the review of all-age NHS NDD services was to focus specifically on the following:

- Diagnostic pathways for children and adults
- Pre diagnostic support
- Post diagnostic support
- The requirements for specialist provision in key associated services – mental health – and the relationship with key interface services: primary care, learning disability services & wider children’s services

It should be noted that an all-age approach does not mean a single service and universal pathway for all ages, but that diagnostic services should be available for all - regardless of age - and that these pathways adhere to a common set of principles. During the course of the review we used the following principles to guide our work:

- All age approach
- Equitable service offer
- NICE compliant
- Minimal waits
- Purposeful watchful waiting

The approach to undertaking the review included:

- Meetings and interviews with key stakeholders in the system involved with the pathway: commissioners, providers, clinicians, users, 3rd sector
- 3 professionals’ workshops: two to map the CYP current pathway and adults’ current pathway (respectively), and a third to inform what a good all age service would look like and what this would take to deliver
- Review of key documents and data
- Targeted insight work with people with NDD, carers, families and others (including professionals) exploring their experience of current services and their views on priority areas for improvement. The commissioned scope was to convene 2 focus groups (one for adults and one for children); 20

interviews. The review actually included 3 focus groups and 41 interviews. We found people were very willing indeed to talk to us about NDD, their experiences and how it impacted their lives. ADHD Norfolk also coordinated an online poll to give people the chance to contribute their views in their own time, especially if it was not practical for them to attend one of our focus groups in person. One hundred people responded to the poll where they had the opportunity to free text their views.

## **4. National Context**

### **The Autism Act**

It is estimated that more than 1% of the population of England have autism. However, there is no national register or record of the exact number of people with this condition<sup>1</sup>.

There has been a 25 fold increase in the diagnosis of autism in the past 30 years. It should be noted that the diagnosed prevalence is lower than population estimates as many children and adults do not have a diagnosis<sup>2</sup>.

The Autism Act was passed in 2009 and the first autism strategy for England followed in 2010. The strategy was updated in 2014. 'Think Autism' built upon the 2010 strategy and set a focus on three key areas: building communities that are aware of autism; promoting innovation in service provision and promoting integrated care. A revised governance model to support the implementation of the strategy was published in March 2018 as it was acknowledged that progress in delivering the strategy was not as quick as anticipated.

### **NHS long term plan**

The NHS Long Term Plan details the action that will be taken over the next 10 years to improve health and well being. It includes a particular focus on autism and complements the autism strategy. Specific requirements include;

- Improving awareness and support
- Ensuring providers are making reasonable adjustments

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<sup>1</sup> (Think Autism – Fulfilling and rewarding Lives, 2014 <https://www.autism.org.uk/about/strategy/2014-strategy.aspx>)

<sup>2</sup> (NICE; support for commissioning autism, 2014 <https://www.nice.org.uk/guidance/qs51/resources/support-for-commissioning-for-autism-pdf-253717885>)

- Reducing waiting times for specialist services including timely diagnostic assessments
- Jointly developing packages to support children with autism and other neurodevelopmental disorders including ADHD

## **5. The current system**

Currently services for children and young people in Great Yarmouth and Waveney are provided by James Paget University Hospital and for the rest of Norfolk services by Norfolk Community Health and Care NHS Trust. The exception is Thetford where children and young people receive their service from ICPS in West Suffolk which reflects preferred and natural pathways. The contracts with these providers do not include separate Neurodevelopmental Disorders (NDD) specifications, and services are detailed within the paediatrics specifications. Similarly there are no identified budgets for NDD as these are incorporated into various service lines within wider block contracts. NSFT provides support for eligible young people including running joint clinics across the patch. There are also specialist learning disability (LD) services for children with combined LD and mental health needs. Speech and language therapy is delivered by East Coast Community Healthcare. ADHD is particularly complex and services are delivered from all providers depending on a range of factors including but not limited to comorbidities, age and complexity.

Currently, services for adults are provided by Norfolk Community Health and Care NHS Trust for all areas with the exception of Waveney. This service is for diagnosis of autism and includes pre and post diagnostic support for those areas covered by Norfolk County Council but not for residents of Thetford and Waveney. The diagnostic service for Waveney is delivered on a cost per case basis by Anchor Psychiatry. There is also a dedicated adult ADHD service delivered across the patch by NSFT.

### **Commissioning**

The commissioning landscape is complex and feels unwieldy and fragmented. Great Yarmouth and Waveney CCG, Norwich CCG, South Norfolk CCG and the CAMHS integrated commissioning team all have commissioning input into NDD services for children and young people. Great Yarmouth and Waveney CCG,

South Norfolk CCG and Norfolk County Council all commission adult NDD services. Where an organisation commissions both services for children and young people and for adults, the commissioners within these organisations are not necessarily the same individuals. Similarly, contract management is often separate from strategic commissioning.

## **6. Context of our report**

Whilst the key findings and recommendations show that there is much work for the system to do to improve services and outcomes, it should be noted that this is a complex service area – long term transformation will be challenging and take time and resources. For example, Suffolk have been working on transformation for two years across six work streams. This is not just about resources and funding – although these are needed - but there are no straightforward solutions to what the right delivery models are. NICE guidance provides some direction on the clinical standards for diagnosis, but there are no standard models or best practice guides about how services should best be configured and delivered. Creating specialist service offers for NDD – other than for key support areas – is often not viable or desirable and the range of need is broad. Tackling stigma, equity of access, a reasonable adjustments approach to all services, and an environment in which neurodiversity is appreciated is a significant, long term challenge. There is not a clear blueprint for Norfolk and Waveney to follow. But starting this journey through improving diagnosis would be an impactful and important place to start.

## **7. Key Findings**

### **System level issues**

- 7.1 There is not a consistent definition or scope for NDD within the system that forms the basis for ensuring service provision and commissioning is well-defined. Whilst there is a strong focus on Autistic Spectrum Disorders (ASD) and to a lesser extent Attention Deficit Hyperactivity Disorder (ADHD) it is less clear how other NDD conditions or complex / similar presentations can be diagnosed or support and management secured. This also means that gaps in service provision and / or

commissioning arrangements for particular conditions or for adults or children are hidden.

**“It’s a private thing for me, it’s shameful.”**

**“Dyslexia & dyspraxia feels like they are more accepted.”**

- 7.2 There is a much stronger focus on commissioning, diagnosis and services for children and young people than adults. This bias is reflected in multiple ways – and is not uncommon across the country. However, the impact is that the provision and performance of services for adults generally is much poorer than for children, usually as a result of a lack of focused commissioning, funding and resources.

**“It’s soul destroying when you want to put in the work to be better but you don’t know how. Or you seem to be going round in circles with little to show for it. It feels like people negatively judge and get frustrated. Like I’m lazy and weird and a bit thick. Rude and scatty. Like I’m a let down and as if I’m not trying. It feels quite overwhelming and isolating. But you don’t want to be around people because often I feel worse, burnt out and exhausted. But you do because you care.”**

- 7.3 The lived experience of local people living with NDD conditions across Norfolk and Waveney is variable but often challenging. Our insight work found many instances where their interactions with statutory services has exacerbated rather than enhanced already challenging lives; the pursuit of a diagnosis, let alone securing any additional support, is often lengthy and requires a great deal of persistence and organisation from parents and adults, and often the professionals supporting them. We also heard from many the stigma, misunderstanding and sometimes discrimination they experience in living their lives and in trying to get the support and diagnosis they need.

**“All I know is I either feel like I’m a whirl wind of scattered chaos. That feels free but doesn’t quite fit in. Or a suppressed, procrastinating over analysing person with a very busy, overwhelming mind that feels very stuck. That still doesn’t fit in. Not progressing but not creating further chaos in the short term. Thank you for this opportunity. It means a lot.”**

- 7.4 The arrangements and availability for pre and post diagnostic support – whether provided by statutory services or elsewhere - do not meet the levels of demand and commissioning and funding arrangements for offers from the 3<sup>rd</sup> sector could be strengthened. There are a number of 3<sup>rd</sup> sector organisations with a focus on various NDD conditions operating in Norfolk and Waveney; it is clear that they are a source of significant support for families and those with a diagnosis – or seeking a diagnosis. However, like statutory health and care services, these organisations are very stretched with limited resources and high demand. There is not a consistent and transparent approach to commissioning or funding for these services from the local commissioning organisations.
- 7.5 We found deeply committed and skilled staff working in challenging circumstances in the system – a common experience was that demand for services and support often outstripped available provision. There are many people with a passion and a great deal of expertise in NDD working in the system; however, they are often isolated as service provision is fragmented across multiple providers and / or they are working in non-specialist NDD settings but have some responsibility for NDD users. There is an untapped opportunity to bring people working in this area together – purposefully – to enhance joined up working, develop skills and increase the awareness of services within the system.
- 7.6 Communication with parents, adults, referrers and other professionals and practitioners needs to be improved throughout the pathway both to improve understanding of the diagnostic process and sources of support. Additional work and anxiety for parents, adults, referrers and services is caused by people not knowing what to expect, how long they might need to wait, where they are on the waiting list and pathway etc. There is a particular issue relating to communication with schools; for example there is not a consistent approach to sharing the outcome of diagnosis with schools. The role of watchful waiting is not well understood as a legitimate part of the diagnostic process. The insight and experiences of parent carers is not always appreciated or valued as part of the diagnostic process; the views of schools and teachers can carry more weight. This can be problematic when children are masking behaviours effectively at school.

“We feel everything is too dependent on parents pushing for support and understanding. Education is not allowing our children to achieve their potential. It is hit and miss what the teachers are like, some great, others blinkered, some dismissive, some think one size fits all. Parents with less ability to verbalise, too worn down to push further or simply lost for what to do are less able to support their loved ones and in turn the whole family.”

## **Adults and Children’s pathways**

7.7 Pathways are complex and are not well-understood by those not involved in delivery. This includes other professionals and clinicians as well as families, carers and adults seeking to access the pathways. This can lead to confusion and delays, people being bounced between different services and parts of the health and care system, inappropriate referrals into the wrong pathway, and inconsistent experiences and outcomes (see appendix B and C).

“These people are desperate for support and they are dangling in the ether.”

7.8 Referral mechanisms are not consistent and vary according to pathway and geography; they are not well-understood by potential referrers and for some pathways. There is an inconsistent approach about who can refer. Referrals are often poor quality; this either results in the referral being bounced back – sometimes on multiple occasions - or providers having to work with little information which may lead to inappropriate referrals, inappropriate initial assessment or delays post referral while further information is sought.

“Diagnosis is such a lottery – if there was one thing that would help it would be picking people up. Education required to spot the symptoms - there’s a nurse at my practice that wants to talk to me about how many grapes I can eat a day – it seems trivial compared to this.”

7.9 There are gaps in service provision and pathways; a key example of this is access to mental health support for people with an NDD diagnosis, particularly for anxiety, depression and anger management. This includes children, young people and adults who are often excluded from

services on the basis of their diagnosis, or reasonably adjusted services with suitably skilled staff are not available.

“Mental services – particularly around anxiety need to be looked at. The threshold for CAMHS is so high. And if you do get in you might eventually get 4-6 sessions. ASD kids struggle to talk about emotions, so they might not open up in those timescales.”

“Labelling without therapy or support is devastating.”

7.10 There is variation in services linked to geography and provider models. Some of this variation is positive; the CYP pathway in Great Yarmouth and Waveney for example had good waiting time performance and there was evidence of good joined up working between the paediatric team at the James Paget and related community health and 3rd sector services. However, in broad terms there is a need to achieve a consistent approach to pathways, delivery and performance and to reduce complexity.

7.11 We believe that none of the diagnostic pathways for adults are children are compliant with the NHS constitution 18 week standard. We have been unable to verify this through reliable performance information as this is not formally or routinely available (see section below on commissioning). However, from the information we have been able to source, through mapping the current pathways, and through talking to service users and families we are as confident as we can be that this is the case. The possible only exception being the spot purchase arrangement for a private diagnosis for adults commissioned by Great Yarmouth and Waveney CCG. There are delays in most pathways and there are hidden waits within the pathways that would be more visible through improved data collection and standards. There is not a uniformly applied approach to Referral to Treatment (RTT) / waiting time recording.

## **Commissioning**

- 7.12 Commissioning arrangements are fragmented, dispersed and incomplete; we have not identified proactive commissioning for some parts of the pathways / services particularly for adults.
- 7.13 NCC has delegated responsibility for commissioning the adults ASD pathway; whilst there are various formal mechanisms underpinning this arrangement, they are not specific to NDD but cover a broader range of integrated commissioning arrangements for community services. We believe they would benefit from being strengthened to include much more specific arrangements relating to NDD and with greater input from NHS commissioners. We have not seen evidence of routine accountability activities in place in line with best practice for commissioning clinical services under a s75. This would enable stronger support for staff working in this function.

## **Data and performance**

- 7.14 There are significant gaps in normal NHS performance and data and formal, consistent reporting is patchy; the governance process for review and decision-making is variable across services and commissioners, and whilst contract management processes do operate this can be undermined by a lack of clarity on specifications, funding envelopes and validated data sets. This inhibits the ability of both providers and commissioners to know about key issues such as waiting times and to take proactive action to improve. There is no historic validated data to inform trends and capacity planning.

We note that there has been some real improvement in recent months within the children's pathway and services provided by NCHC are now providing improved routine data. This success should be built on by formalising requirements and extending this across all services.

**"For a long time we were trying to find out what is the diagnostic pathway in the west. How long is the waiting list? We need to be telling people what's out there."**

- 7.15 There is no demand / capacity model underpinning service planning; prevalence and demand locally and nationally is increasing, but there is no forward plan to respond to this issue. Given waiting times we suspect

that services are under-resourced but it will be difficult to make the case for further investment without improved data.

## **Provision**

7.16 Provision is complex and fragmented. Provision is distributed across multiple providers both for the multi-disciplinary team required for effective diagnosis and for post-diagnosis support; whilst there is some inter-organisational collaboration in place, arrangements are often informal and not resilient. There are many instances of people seeking a diagnosis being bounced between paediatric and CAMHS services causing delay to diagnosis and treatment and wasting NHS resources. Waiting times do not transfer across when people are moved between services – which may sometimes be appropriate and necessary. This is not compliant with RTT reporting standards.

“Our children will age out of paediatric services – then what will happen? It’s almost as if they are holding off – why - to save money?” Mum has 2 children one aged 23 with ADHD and one now 15, still undiagnosed.

7.17 Staff working within the services are dedicated, professional and skilled. Their informal networks – both between commissioners and providers and with each other – are good. However, given the distributed nature of the model there is a lack of resilience in the workforce and staffing models; small pockets of service with low / single staff numbers and inadequate cover arrangements for staff absences.

## **Other Issues**

7.18 There is no obvious workforce planning in place to strengthen services or to plan for increasing demand.

7.19 There is not a clear understanding of the current level of funding on NDD; funding for services is hidden within larger block contracts.

7.20 The diagnostic processes for people with co-morbid conditions, but where LD and mental health are the prevalent issue, are undertaken within these services and appear to be timely, reasonably adjusted and use consistent diagnostic tools and processes. This is, however, based on

anecdotal evidence; light touch data collection arrangements should be put in place for these services to increase transparency and to identify problems and opportunities for improvement.

“At our initial meeting with the Neurodevelopmental team, it was suggested that therapists would come and assess our son both at school and at home. We then received the questionnaires and after they were assessed he was diagnosed. I understand that the results of the questionnaires may well have been conclusive and all pointing to a diagnosis of ADHD, but I do strongly feel we would have gained so much more understanding of him and his possible comorbidities (Dyslexia/dysgraphia) if therapists had come to see him in his own environment. I think more time given to our son by therapists would have helped him, us the school and we would have been a lengthy to give him appropriate help at a much sooner time. Instead it’s been quite trial and error and we still have not had him assessed for Dyslexia or dysgraphia yet. The school have been good, there have been some issues with some teachers not understanding his diagnosis or him and his confidence and mental state dropping as a result. So more education for schools and teachers would be amazing. Our children spend so much time with their teachers, the teachers are a major influence in their lives. To have to spend every week day with someone who doesn’t understand your diagnosis and shouts at you for not being able to concentrate when you have Attention Deficit Disorder is not acceptable and could be helped by educating the teachers.”

## **8. Immediate priorities for change: 0 to 6 months**

- 8.1 Agree rapidly the scope and definition of NDD for Norfolk and Waveney and map existing service provision and contracts against this definition to identify service gaps. There is no standard agreed definition for NDD nationally or internationally – either for clinical or commissioning purposes; we have included a potential starting point for discussion in annex 1.
- 8.2 Review, reform and formalise commissioning arrangements so that there is clarity and complete coverage of NDD services and a locus of commissioning expertise and oversight for NDD in the system. This should include:

- Clarity and formalisation of lead commissioning arrangements between the NHS and NCC; whilst we would recommend an integrated approach that unifies NCC responsibilities for pre / post diagnostic support with NHS responsibilities for the diagnostic process, we believe that the current arrangement with NCC leading for the adult ASD service only should be reviewed.
  - Establishment of routine commissioning activities:
    - Collection and sharing of performance data from all providers
    - Performance and contract monitoring and management
    - Finance support
    - Clear specifications for NDD services within larger contracts
    - Reporting through to appropriate commissioning governance bodies and a clear route for escalation for performance issues
  - Whilst commissioning must be all age, it may be more practical to have a lead for children and a lead for adults. Given the current changes to CCG structures we would advocate lead commissioners sitting alongside mental health commissioning teams for Adults and Children and using the emerging leadership, governance processes and support functions for these teams to strengthen commissioning for NDD. It would also help to improve the important interface between these services. It must be clear, however, that these roles are aligned and that NDD does not become subsumed as a mental health condition, but is distinct and the particular needs and services for people living with NDD are recognised.
  - Identify funding for NDD within block contracts; review and refresh specifications for these services to strengthen commissioning activities.
  - Agree collaboratively an RTT definition / waiting time standard for the entire pathway and monitor performance against this moving forward.
- 8.3 Develop and cost an improvement plan for bringing NDD waiting times in line with NHS constitution standards, based on the local waiting time standard agreed for the pathways for adults and children (see 8.2); approach this from a total pathway perspective – not just focusing on initial assessment – to ensure delays within the pathway are not adversely impacted. Develop an improvement plan in collaboration with providers to move services towards achieving these standards over an agreed period of time (likely to be several years). This may require use of private sector capacity to clear backlogs – particularly on the adults

pathway – or a less gold-standard diagnostic process for some more routine cases. Ensure that this is developed transparently. As part of this work identify short term improvements to existing pathways to speed up flow.

- 8.4 Develop a business case to fund and deliver mental health support for children, young people and adults with NDD – particularly for anxiety, depression and anger management; people with NDD need access to these services delivered by staff who have been trained to provide therapies for this cohort. This is a significant gap in service provision and would likely have a significant and positive impact on people’s lives. A costed proposal jointly developed by NSFT and NCHC was produced last year. This should be reconsidered and redeveloped.
- 8.5 Communication: undertake a short piece of work co-produced with users, providers and commissioners to agree standards, protocols and content to improve communication and information on current service offers, how to obtain a diagnosis, outline of current pathways, waiting times, how to get support. Consider establishing a single web address for this content and also disseminate consistent content through existing channels.
- 8.6 Work together with the 3rd sector and other service providers to establish a commissioning framework for pre and post diagnostic support to create a standard, sustainable offer across the area. This could be through a collaborative framework with strong local 3<sup>rd</sup> sector providers to play to strengths around condition and location, not necessarily a single, countywide provider. This area is likely to need further investment; there is also an opportunity to strengthen self-help and advice and peer-led approaches to support.
- 8.7 Review and change current referral processes to open up routes for referral and to ensure a consistent and clearer approach. Streamline referral processes with clearly articulated criteria and good information for referrers; adopt a consistent approach across geographies. For children, ensure that information out of school can be included to capture those children who mask behaviours at school.
- 8.8 Consider bringing key staff from across the system together – with commissioners, 3rd sector colleagues, and users and families – on a more routine basis to enhance awareness of services and challenges across the region, as a forum for learning and insight, to reduce isolation of staff working in small services, and to use this group to drive forward

the required changes in services. We would recommend this happens twice a year.

## **9. Longer term transformation: 6 to 18 months**

- 9.1 Commission and deliver mental health support for children, young people and adults with NDD – particularly for anxiety, depression and anger management (see 8.4 above).
- 9.2 Implement improvement plan to bring services in line with NHS constitution waiting times / the agreed local pathway (see 8.3 above).
- 9.3 Consider the use of digital solutions to streamline processes, records and improve access e.g. for communications, for referrals, for information, advice and guidance, for personal / shared records etc.
- 9.4 Continue to develop improved communications and training over the longer term to shift perceptions and tackle stigma and discrimination; aspects to consider include:
  - education and training: awareness raising for wider children’s services, schools, other health professionals
  - GPs – opportunity to link into emerging Primary Care Networks and to identify champions / lead professionals for NDD within each Primary Care Network
  - Improve communication for parents, CYP and adults embarking on a diagnosis so that there is improved understanding of what is a complex process and sometimes legitimate delays (e.g. MDT assessments, watchful waiting); this could form part of a much wider information, advice and guidance offer for NDD which encourages peer support and self-help as well as advising of statutory duties and services.
  - Consider commissioning a support / advice line to support people through the diagnostic process and / or the role of a navigator / advocacy function; this should enable people to be more proactively involved in their own journey through the pathway.
  - Campaigns and activities to raise awareness of hidden disability and to tackle stigma; there are many resources available for example through the National Autistic Society
- 9.5 Implement a “reasonable adjustments” approach for NDD across all services so that people living with NDD are able to access the full range

of health and care services. Adapt approaches from learning disability policy and movements such as Autism Friendly environments, and Dementia Friends to help inform how NHS services (hospitals, GPs, dentists, pharmacies etc.) can make their services more accessible and fit for purpose for people with NDD.

- 9.6 Ensure that all services are operating within NICE guidelines; this includes embedded diagnostic pathways within tier 3 mental health and learning disability services, and should be extended to include any private providers within the pathway.
- 9.7 Develop a longer-term plan for service development to include capacity / demand modelling, work force plans and investment. Consider how the reliance on key members of the workforce can be improved.
- 9.8 Develop a clear transitions protocol from CYP to adult services
- 9.9 Invest in a fuller support offer for parents and carers to improve the quality of life and also to reduce demand for services
- 9.10 Develop a model to gather insight routinely and encourage commissioners and those planning services to interact with service users; develop a model for purposeful co-production and strengthen engagement mechanisms.

## **10. Relationship between CAMHS and NDD services**

- 10.1 The review of NDD services was asked to consider specifically the relationship between NDD diagnostic services and CAMHS services and whether integrating these services as part of the wider CAMHS service would improve local arrangements for children and young people. This is in part driven by the experience of children and young people locally who can be referred back and forth between these services – particularly before a diagnosis has been given, but also at other points on the pathway and post diagnosis – with no service taking responsibility for their treatment, support and needs. This leads to poor care, poor outcomes and often a deterioration before treatment and support becomes available. Equally, this a complex area and we recognise that it is not always straightforward to identify the underlying causes and conditions, particularly when someone is in crisis.

10.2 However, our view is that on balance, although there is a need for a strong interface and effective working relationships between these 2 service areas, we do not believe that they should be integrated. The rationale for this is:

- NDD diagnosis relies on a broad multi-disciplinary team approach. Whilst psychologist input is important the oversight and clinical skill set of paediatricians working as part of a wider team of specialist nurses, paediatric AHPs from a range of disciplines and with access to social workers, educational psychologists and other education professionals is central to an effective NDD diagnostic pathway. Separating NDD from this wider community paediatric services would be detrimental to improving diagnostic provision, and for other developmental issues to be identified and addressed by these teams.
- Whilst there are clearly children and young people with co-morbidities between mental health and NDD, there are many without them. Maintaining clarity on who does need mental health treatment and who needs support related to an NDD is an important differentiator.
- We are mindful of the significant transformation within CAMHS over the next 18 months to 3 years as services are integrated and move towards a delivery model based on THRIVE. This is a significant agenda and NDD service transformation – which is also pressing – may get lost if conflated with this agenda.

10.3 We do equally recognise the real issues that exist for local people who are bounced between services; that there is a need for CAMHS professionals to support triage, assessment and diagnosis within the NDD pathway; for people with a prevalent mental health condition to be able to be diagnosed for an NDD; and for people living with an NDD to be able to access mental health services when they need this type of support. We note that the inter-organisational multidisciplinary team arrangements work most effectively in Great Yarmouth and Waveney where NSFT works well with the paediatric team at the James Paget Hospital. This proves that the current model can work. And we know that work is underway to improve the current interorganisational model across the rest of Norfolk.

10.4 In order to continue to improve relationships, services and interfaces we suggest the following, a number of which are already in hand:

- Develop clearer specifications, protocols and resource plans to support MDT working. Referring patients on multiple occasions between services is often symptomatic of stretched services. However, over time it can become custom and practice and even when resources are more available it takes time and effort to shift the culture. And occasionally it is clinically justified. In tackling this issue it needs to be visible and accountable before a crisis is reached. Helpful measures might include ensuring that RTT measurement follows the patient, that there is escalation and accountability for children and young people who are referred between services on more than one occasion, and there are strong clinical leaders on both sides as a point of escalation, should cases become problematic.
- Consider strengthening inter-organisational working by using flexible staffing models and improved training. Consider the benefits of rotational staffing models, joint posts for key roles, improved training for community teams (particularly community paediatric teams) on mental health issues. As the THRIVE model becomes embedded in the core CAMHS services (which endorses responsibility for the mental health and emotional well-being for all children) consider the fit and needs with NDD.
- Strengthen diagnostic pathways within NSFT for NDD and ensure that this in-house specialist service is not lost (see 9.6)
- Develop and commission mental health support for children, young people and adults with NDD – particularly for anxiety, depression and anger management (see 8.4 and 9.1 above).

10.5 We suggest keeping the interface between these services under review – both through CYPMH oversight arrangements and through NDD monitoring processes. As the alliance model underpinning THRIVE develops there may be a point in the future when it would make sense to bring NDD for children and young people into these arrangements.

## **11. Implementing and sharing the report**

- 11.1 There is currently no all-age NDD group linked into commissioning governance with a mandate to oversee improvements in these services. An all-age steering group was formed on a task and finish basis for the purposes of undertaking this review. It is recommended that:
- this group is established on a more formal basis with a mandate to implement the findings of the review and to oversee service improvements and performance on an on-going basis. Consider including key providers on this group.
  - that it is connected into commissioning governance mechanisms within the CCGs and NCC so that there is a clear line of accountability and escalation to senior leaders
  - that membership is reviewed to ensure it has the relevant skills and authority to take forward implementation of the review
- 11.2 We recommend sharing this report with the following key audiences and stakeholders:
- CCG governing bodies
  - JSCC
  - NCC governance
  - NDD provider organisations
  - STP Executive
  - All those organisations and individuals who contributed to the review including the insight gathering phase. This includes user / patient representatives and groups, clinicians and professionals working within the system, 3<sup>rd</sup> sector partners and education colleagues.

## **12. Annexes**

Appendix A - Insight annex

Appendix B - Current children's pathways

Appendix C - Current adult's pathways

Appendix D - Proposed future pathway – all age

## Appendix E – Draft working definition of NDD



# **“WE’RE ON A WAITING LIST, BUT WHAT ARE WE WAITING FOR?”**

**INSIGHT**

**REVIEW OF ALL-AGE NHS  
NEURODEVELOPMENTAL  
DISORDERS DIAGNOSIS PATHWAY  
ACROSS NORFOLK AND WAVENEY**

**RETHINK Partners  
May 2019**

## **REVIEW OF ALL-AGE NHS NEURODEVELOPMENTAL DISORDERS DIAGNOSTIC PATHWAY ACROSS NORFOLK AND WAVENEY**

### **Insight, May 2019**

There's an invisible battle being fought across Norfolk and Waveney. It's making family life a struggle, staying in school impossible for some children - including those with above average IQs - and holding down a job with confidence, a challenge for many people across all strata of life.

Children and young people are confused and their confidence and self-esteem are dented; parents, carers and teachers are perplexed; employees and managers are frustrated; clinicians and professionals are continuously wondering why children and adults alike – sometimes colleagues, loved ones or indeed themselves – struggle with consistently coordinating aspects of life that seem well within their capability. This is one aspect of neurodiversity that remains hidden in Norfolk & Waveney. Many people remain unaware or undiagnosed – possibly 'high functioning' but with impaired executive function. For others, their differences and needs are more obvious and profound – although this doesn't necessarily mean that they are diagnosed sooner or receive timely help to learn about and understand their neurodiversity in order to plan, prepare and work with the challenges and opportunities that their neurodiversity presents.

The above conundrum highlights the challenges of the neurodiverse community in Norfolk and Waveney, in that it effects people in such a varied range of ways and the term itself: "neurodevelopmental disorder" encapsulates a wide range of

conditions. Commissioners from the NHS Clinical Commissioning groups across Norfolk & Waveney<sup>3</sup> and Norfolk County Council asked RETHINK Partners to conduct a review of the NHS Neurodevelopmental Disorders (NDD) diagnostic pathway across Norfolk and Waveney for adults and children to try and understand more about the experience of receiving a diagnosis of ADHD, ADD, autistic spectrum disorders (ASD) and other neuro diverse conditions. The term NDD can also include dyslexia, dyspraxia, tics, Tourette's and a range of other sensory and communication disorders.

Furthermore, there is abundant evidence to indicate that neurodevelopmental disorders tend to co-occur, rather than existing as individual conditions. This may result in an over-emphasis on just one pronounced aspect of an individual's difficulties and could lead to a diagnosis that does not capture their full profile, meaning areas of learning and cognition may go unnoticed and unaddressed.<sup>4</sup>

In speaking to local people and support organisations, we were particularly interested in finding out what their experience was of seeking diagnosis and what support they might receive. We wanted to understand the experience of children, young people and adults – and their support networks – in seeking a diagnosis and how either the absence, or presence of a diagnosis impacted on their lives and the lives of their loved ones and extended communities such as colleagues, partners and neighbours.

## **Who we spoke to**

We were asked to conduct two focus groups and undertake 20 conversations. We were guided by commissioners on which local stakeholders to initially speak to across the professional, community and voluntary sector. Most of those organisations and individuals took up the offer to either speak on behalf of themselves and their organisations; a community they believe they have the mandate to speak for; or they invited us to events they believed would provide an

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<sup>3</sup> NHS Norwich Clinical Commissioning Group; NHS North Norfolk Clinical Commissioning Group; NHS South Norfolk Clinical Commissioning Group; NHS West Norfolk Clinical Commissioning Group and NHS Great Yarmouth & Waveney Clinical Commissioning Group

<sup>4</sup> "Are neurodevelopmental disorders discrete conditions? Emilia Misheva. The Psychologist, The British Psychological Society, August 2018, Vol. 31 <https://thepsychologist.bps.org.uk/volume-31/august-2018/are-neurodevelopmental-disorders-discrete-conditions>"

opportunity to match us with people who wanted to share their lived experience of NDD. This approach ensured we found no shortage of people who wanted to tell us about their lived experience, hence we ran three focus groups and conducted 41 conversations. People lived across Norfolk and Waveney.

People spoke to us in an anonymous capacity. They spoke openly and honestly, often amongst strangers at our focus groups. For many, the act of sharing their experience at one of our focus group was a therapeutic event in itself because living with or caring for someone with NDD can be an isolating and exhausting experience: "This is the best counselling service I've had. Thank you. I feel like I've emptied my head."

People drew much comfort, validation and information from speaking to other local people facing similar challenges to themselves. For some, it was a significant moment in their own journey, of understanding there are communities of local people they could relate to; share information and experience with and learn from. For some it was an important insight to new information and potential solutions to daily challenges as they learned more about what was successfully working for others. For those in the earlier stages of their NDD journey, it was sometimes disquieting to listen to the stories of their new-found peers and to anticipate the struggle that is likely to await them to access the right support. However, becoming armed with that knowledge was, in itself, a constructive thing as people at least felt better prepared for encountering the reality of seeking or living with a diagnosis.

We ran our three focus groups at the ADHD Norfolk monthly drop-ins in Norwich and Great Yarmouth. ADHD Norfolk has a well-established brand and stakeholder network locally, with a particularly strong presence on social media. They are well connected to other specialist NDD support organisations and used their networks to promote our focus groups to the broadest spectrum of people living with NDD (not just people with ADHD/ADD). We found that most of the people who attended those events had come specifically to participate in the focus groups and share their experiences and they were living with, or caring for someone with either ASD, ADHD/ADD and a range of other neurodevelopmental disorders. Everyone we spoke with or about had also experienced mental health and emotional wellbeing issues.

Our 41 conversations took place across a range of events, meetings, phonecalls and at the Family Voice Norfolk Conference in March 2019. The Family Voice Conference included two workshops that we either sat in on or participated in. One was a workshop from service provider, Norfolk Community Health and Care NHS Trust, on their ASD pathway, which provided its history and challenges. They discussed what to expect from the pathway with regards staffing, waiting times, the assessment process, follow-up and support for families as well as a summary of the 2018 Healthwatch review finding and how the pathway has adapted to it. There was also a question and answer session with NHS Norfolk and Suffolk Foundation Trust (NSFT) on their Child and Adolescent Mental Health Services which we participated in. Finally, we shadowed Tracy McLean Deputy Director of Children, Young People & Maternity Services for NHS Norfolk and Waveney CCGs, during her speed-dating session.

ADHD Norfolk also coordinated an online poll to give people the chance to contribute their views in their own time, especially if it was not practical for them to attend one of our focus groups in person. One hundred people responded to the poll where they had the opportunity to free text their views.

## **What we spoke to people about**

We spoke to people about their entire diagnosis journey. This could be anything from months, years or indeed a lifetime. We wanted to know:

- when people first suspected they or a loved one had a neurodevelopmental disorder and at what age
- who they spoke to about getting help
- whether they sought a formal diagnosis and how they achieved this
- what kind of help, support or treatment they received
- what help, support or treatment they would have found beneficial and when
- what a formal diagnosis meant to them

## **What we found**

There is an overwhelming sense that timely access and support for the referral, diagnosis and support to understand and manage a neurodiverse condition is a lottery with very low odds. This sense is born out of the lived experience of people

we spoke to in Norfolk and Waveney, both citizens and professionals. We spoke to parents, carers and professionals about their own experiences and that of the children and young people that they care for and support. We also spoke to children and young people who spoke frankly about their experiences at home and school.

**The main shared experiences of people in Norfolk and Waveney are that they:**

1. struggle to understand clearly what NDD diagnostic and support services are available to them – and how this differed across the geography of Norfolk & Waveney
2. battle to access diagnostic services, treatment, training and support
3. are subjected to a range of prejudices both pre and post-diagnosis e.g.:
  - behaviours are misunderstood and often regarded as naughty or parenting issues
  - girls and women are repeatedly overlooked and under-diagnosed
4. are unlikely to access the right support in a timely way, often struggling with schooling and increasing the risk of exclusion and of maintaining a stable work life
5. schools and educators also have poor experiences of securing support pre and post diagnosis for their pupils, or securing mental health support for children with an NDD formal or pending diagnosis
6. there is a burden of paperwork and decision-making about referral processes falling on schools and bouncing around GPs and other agencies:
  - this delays access to support for children and young people
  - it often acts as a barrier to accessing support, particularly when a child masks behaviours at school which is common in NDD
7. the third sector in Norfolk & Waveney is providing a vital lifeline to local people and families of support to understand their conditions whilst they await referral and diagnosis as well as post diagnosis
8. diagnosis is a crucial milestone and important for people to take control of their lives; explain and understand their behaviours and traits and to self-educate, build coping strategies and plan for their future
9. interdependencies with children's mental health (CAMHS) services are fragile, with children and young people's delayed diagnosis and support for an NDD condition:
  - increasing the likelihood of needing specialist mental health services

- often meaning a longer wait for mental health services appropriate to their individual needs
10. adults receiving an NDD diagnosis in adulthood tended to have experienced mental health problems in the years leading to their diagnosis:
- they had often dedicatedly tried a number of therapies or interventions with poor outcomes – realising post-diagnosis, that their previous attempts to apply those therapies had been hampered by their executive function, due to their NDD
  - they had often eventually ended up in mental health crisis - particularly those with an ASD diagnosis had accessed tier 3 services before eventually receiving their diagnosis

## **The stamina and passion of people affected by neurodiversity**

We found that people living with or caring for someone with a neurodiverse condition are highly motivated and driven to learn about the condition and support them to achieve their potential. Some of the professionals, parents and carers that we spoke to were also living with their own neurodiverse conditions. Often, an adult diagnosis emerged following the diagnosis of their child. Some of the adults we spoke to with a diagnosis worked in the health and care sector. They reported that working within the health and care sector did not make their journey to diagnosis and post-diagnosis support any easier – they still endured the same complexity, barriers and stigma.

Nevertheless, these colleagues, as all the parents, carers and adults with NDD that we spoke to were united in one thing: an incredible drive to understand their condition, educate themselves and others on how best to manage it, to work with challenges and harness their strengths in order to be independent and achieve their potential. This self-acquired and peer-supported capability is a huge asset that could be used to greater effect. “It would help my little girl get the support that she so desperately needs as she's about to embark on her school career. She would be better understood, given adaptations to ensure a smoother transition and allow her to reach her full potential within a mainstream setting. Her little 'quirks' are beautiful and need nourishing and those people who truly know her and them can understand this and can allow her more time, space and reasoning.”

However, people are also incredibly tired of battling against an environment that discriminates, misunderstands and judges. Streamlining of the NDD service and support offer could be “life-changing” for people in Norfolk and Waveney as they would be able to channel all their energies into positive and productive actions for themselves, their families, their students, patients and clients in a proactive and timely way.

The adult diagnostic pathway for ASD was particularly elusive with sector ‘insiders’ trying amongst themselves to help guide local people into a pathway and concluding that there are significant service gaps and delays.

## **The challenges of accessing a referral and diagnosis**

People found it difficult to access the NDD pathway, indeed it wasn’t clear to both citizens and professionals what the pathway was regardless of geography. Waiting times are long, with lengthy waits at all stages of the diagnostic process with particular frustration at delays with post-assessment feedback.

People are often waiting years for a diagnosis. There was a tangible understanding for professionals working in NDD assessment services and people were patient about waiting times. Whilst people are awaiting assessment, we found that they were very driven to self-help and peer support, with many diagnosed, or parents of diagnosed, giving back time to the community to help, advise and support others. These communities are supporting thousands of families and have blossomed out of people reaching out to others in a similar position.

Although an official diagnosis is a crucial milestone for those affected and their loved ones, often, there is also resignation. Once they reach the other side of that knowledge curve, there is an understanding that the process and knowledge gained through the diagnostic process is much more meaningful and useful than the actual diagnosis: “What will you actually get at the end of it?” and “We’re on a waiting list, but what are we waiting for?”.

As people move months and often years down this pre-diagnosis stage, many begin to acquire an advanced and in-depth knowledge about NDD. Post-diagnosis

support is too little and too late. People regularly reported not being offered such support and if they did it could be anywhere from 6 months to two years post-diagnosis. By this point people had already acquired more knowledge than the training course offered: "I waited almost two years after diagnosis for parent support training, by then it was a complete waste of time."

The STEPS programme from NCC is missed by parents and carers seeking to manage challenging behavior and physical violence. This course was also viewed as a good avenue into peer support networks.

## **Culture and attitudes: discrimination, misunderstanding & judgement**

Many people reported experiencing discrimination and stigma: when seeking a referral; at assessment; post-diagnosis; when obtaining medication and in daily life. They didn't necessarily call it discrimination, but as they told us about their experiences it was evident that inequity existed across all ages and spanned gender, class and disability. We believe there is the potential for hidden harm implicit in these forms of discrimination as they lead to delayed, partial, or no diagnosis, treatment and support.

Even people on a diagnostic pathway are at risk of hidden harm due to extensive waiting times. People on those waiting lists with 'protected characteristics' as described by the Equality Act, 2010<sup>5</sup>, such as a physical disability were still waiting for assessment for years. Their protected status didn't appear to expedite that wait: "I need the diagnosis and medication I need to get on with my life." For adults, this might be whilst trying to work and run their families: "If adults have come for help, it's because we have come to a crisis point in our life. We have self-medicated for years, we've tried other treatments. I'm putting out fires all the time and I would like to do prevention."

Many parents were fighting to keep their children in an education system where they feel their children are misunderstood and labelled naughty. Exclusion rates

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<sup>5</sup> The Equality Act 2010 <https://www.legislation.gov.uk/ukpga/2010/15/contents>

are above the national average in Norfolk<sup>6</sup>. Parents described the “walk of shame at the school gate”; the denial of their child’s behaviour and simultaneous gender bias “he’s just a boy” to an apparent lack of experience of children with NDD: “we’ve never had a child like this”. We found a high number of parents who were dissatisfied with the SEN support at school. Many parents of children with an NDD diagnosis had never had any contact with their school SEN. Parents are in a perpetual cycle of advocating for their children, repeating their story and attempting to educate about their children’s behaviour and needs. For many parents this meant daily liaison with school, covering the same ground but ultimately with little understanding, and no appropriate plans with measurable goals and outcomes: “My child would understand why he behaves in the way he does. People who are in his life such as family, teachers and friends would hopefully understand him more. He could learn that he has a neurological difference and that he could now learn ways of coping with this. He would receive extra help and support through his education, and he would not end up with other mental health conditions later on in life caused by a condition which he had not been taught to manage.”

Increasing numbers of people are finding the funds to seek a private diagnosis outside of the NHS, either because of referral barriers, long waiting times, or a lack of NHS diagnosis. However, some felt they were subsequently questioned by NHS professionals with frequent reference in subsequent paperwork to the private diagnosis.

Women we spoke to struggled to get their GPs to initially take their suspicions that they had ADHD seriously, with their GPs suggesting it was menstrual issues. Although it is well known that girls often mask NDD traits, even as women, they reported that having an ADHD diagnosis felt tenuous: “ADHD isn’t a mental health issue – it’s processing and behavioural. Being a white middle class woman with ADHD is seen as quirky. Professionals don’t know what to do with it, it’s difficult to know where to go for help. When I collect my prescription, I feel like a criminal. If I was younger it would put me off.”

Age has several strands of inequity. Adults, as described above, experience a range of barriers to diagnosis, but secondary age children are also at a

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<sup>6</sup> Department for Education, National Statistics, Permanent and fixed-period exclusions in England: 2016 to 2017 <https://www.gov.uk/government/collections/statistics-exclusions#history>

disadvantage. There was a sense that preschool children are currently being seen for assessment with shorter waiting times than those in or approaching high school. Many secondary school age children have not received the appropriate assessment or diagnosis in the past but are have already become 'outliers' at school. These children wait for years for support whilst parents are caught in an interminable loop attempting to access the right support from health, care and education. Relationships with schools deteriorate without a diagnosis and these children are high risk for not meeting their potential at school, low self-esteem and exclusion.

Some parents struggled to access assessment clinics and asked if there could be a virtual offer.

## **The role of the third sector in supporting people**

The role of the third sector is crucial in supporting people through the process - and for pre and post diagnosis support, however, these services are also often fragile and are facing growing demand.

Organisations are often developed by people with lived experience who created something out of necessity when they themselves encountered a dearth of opportunities to learn more about NDD and to meet with peers and support one another. The advisory, training, pre-screening and support services they provide are so busy, against a backdrop of funding challenges, that there is a lack of capacity emerging and some rationing of support now having to take place: "Because of waiting lists, we sometimes feel we are having to play God."

These third sector services frequently receive requests from health and care professionals to "refer" patients to them, despite them being neither commissioned, funded nor being officially part of the NDD diagnostic pathway. It's clear they have much expertise and skills to support the pathway in a robust way and this would ideally be harnessed through a considered and co-designed partnership strategy. This strategy should see the third sector as equal partners in the provider mix; should dedicate business development support to help them develop a collaborative, cohesive blend of skills and services to support the pathway – and they should be supported to become a sustainable provider of services to the

public sector in supporting local people and communities to help themselves and develop a lifelong approach to understanding, planning for and adapting to their conditions.

## **How to make things better**

Everyone that we spoke to had lots of ideas about how services and their experience could be improved. Some of the key ones are listed below:

- publish and promote all NDD referral criteria for Norfolk & Waveney so local people and professionals can understand how best to access support
- allow self-referral into NDD pathways (including speech and language therapy) and permit parents to include non-school evidence where children mask behaviours at school
- for children and young people on the pathway but pre-assessment, provide a letter for schools explaining they have been accepted on to the pathway and in the meantime, listing things that could help
- provide earlier pre-diagnosis (or no diagnosis) support for parents and carers dealing with children and young people with challenging behaviours - also ensuring post-diagnostic support is immediately communicated at assessment appointments
- enable people to better understand the interdependencies with other NDD co-morbidities by providing consolidated training opportunities to local people. Much of this could be provided by the highly respected third sector in Norfolk & Waveney. Third sector should be supported to consolidate their offer to local people pre-and-post diagnosis and could be commissioned to deliver support including: information, courses and interventions for pre-diagnosis screening; workshops and training for parents and professionals to understand and manage behaviour; peer support that increases community resilience and specifically tailored training for fathers to educate, understand NDD and what support a child with NDD needs. Training for health, care and education staff should more swiftly identify neurodiverse people, understand them and put the right support in place to help them thrive
- better support people when they have stepped outside the NHS and paid for a private diagnosis - ensuring increased resilience of shared care

- arrangements regardless of where people live in Norfolk & Waveney and to eliminate any perceived stigma of a private diagnosis in the public sector
- rethink mental health support for children with NDD – providing more responsive access to specialist support – possibly drop-in clinics. Also consider the emotional wellbeing strain endured by families living with NDD
  - create opportunities for commissioners and service providers to connect with local people and hear their experiences first hand by considering the creation of an engagement programme which might include events like conferences and focus groups to come together to learn, inform, educate and reduce stigma; discuss pathways, treatments, experiences and research; reduce loneliness and isolation and foster stronger peer networks; bringing together all geographies to provide better visibility of services and service variations and best-practice shared learning

## Thanks

Thank you to the people of Norfolk and Waveney who participated in this work especially those who either joined our focus groups or spoke to us individually and took the time to tell their stories once again. Many people helped to promote our focus groups through their own social networks – so thank you for sharing and helping us reach as many people as possible.

Huge thanks to Andrea Bell and the team at ADHD Norfolk for creating space – physically and virtually – to allow as many local people as possible to have a say in this insight. Thank you for really sweating your networks and being so responsive and innovative about connecting with local people in ways that were convenient to them.

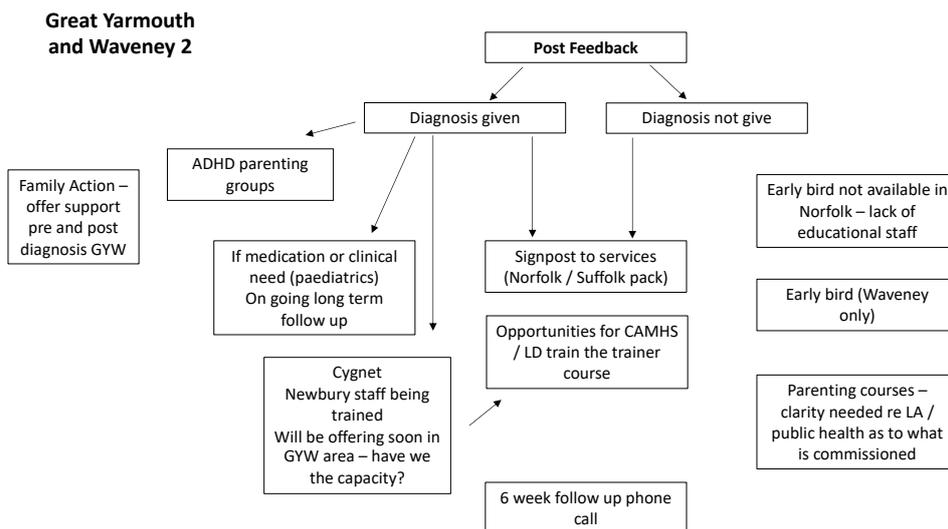
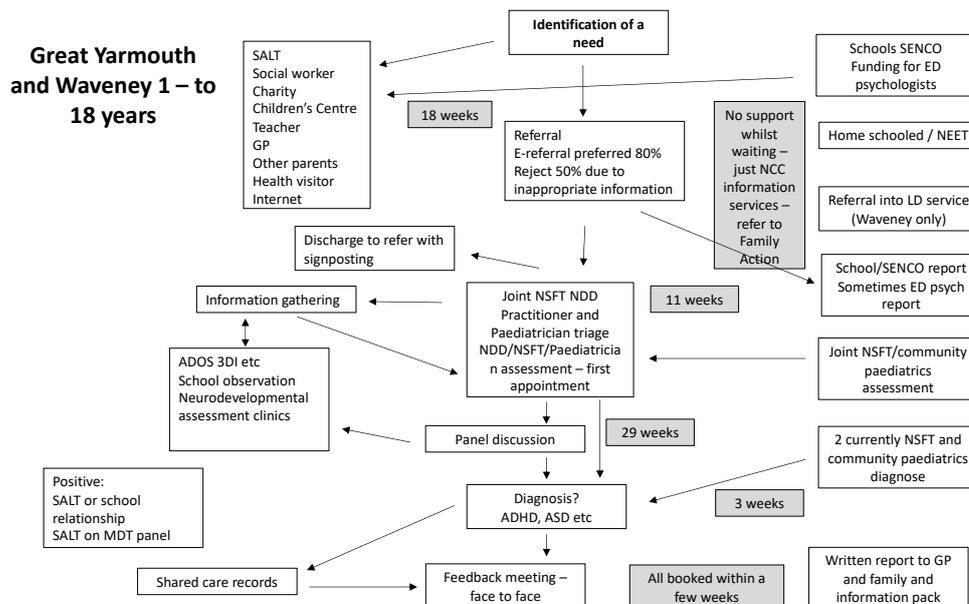
Massive thanks also to Nicki Price from SENSational Families and Bernadette Pallister from Family Voice Norfolk for connecting us with the voice of the many families you support.

Thank you Anita Millar for bringing your experience in capturing the voice of parents caring for children and young people with NDD to our final focus group. Many thanks also to Karan McKerrow from the National Autistic Society and to

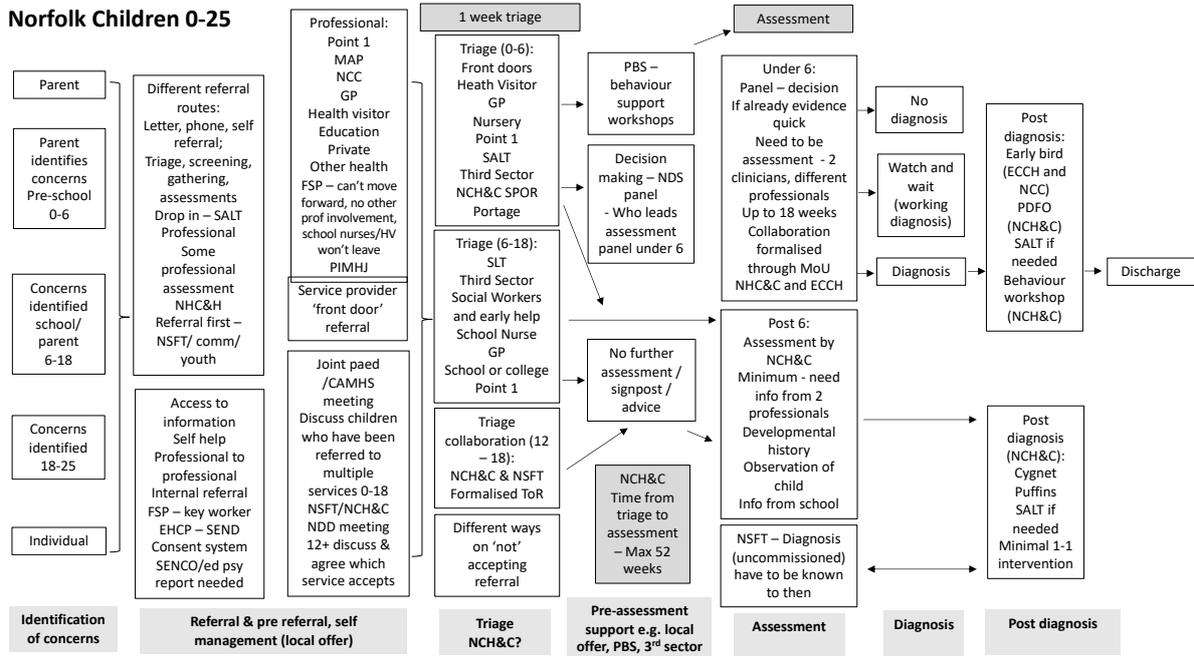
Tracy McLean from the Norfolk & Waveney NHS CCGs for joining us on the road in Great Yarmouth.

For further information please contact [irene@rethinkpartners.co.uk](mailto:irene@rethinkpartners.co.uk)

# Appendix B - Current children's pathways

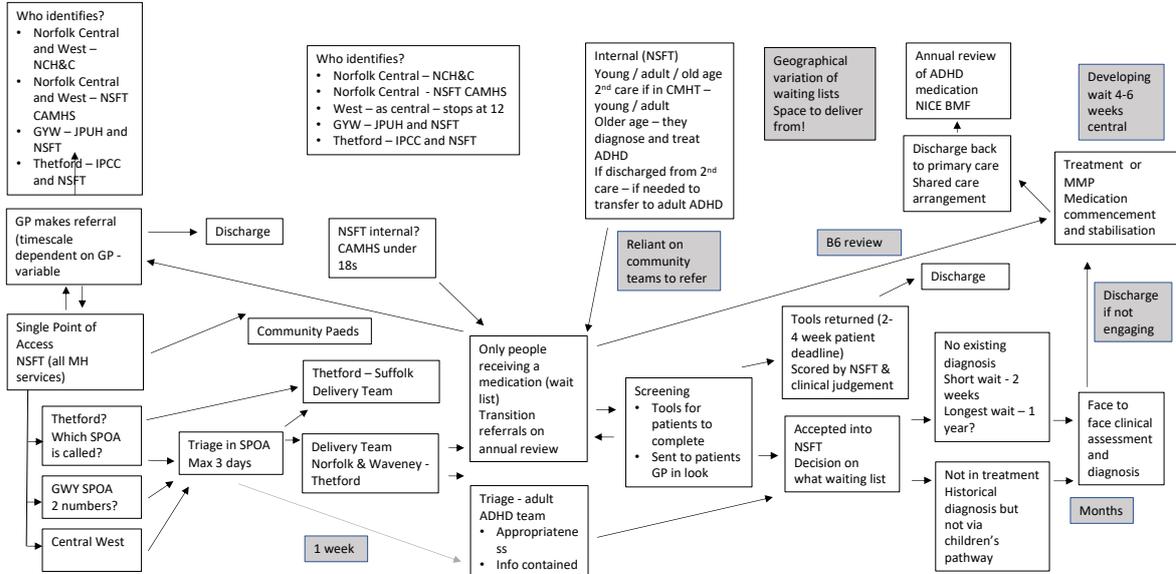


# Norfolk Children 0-25

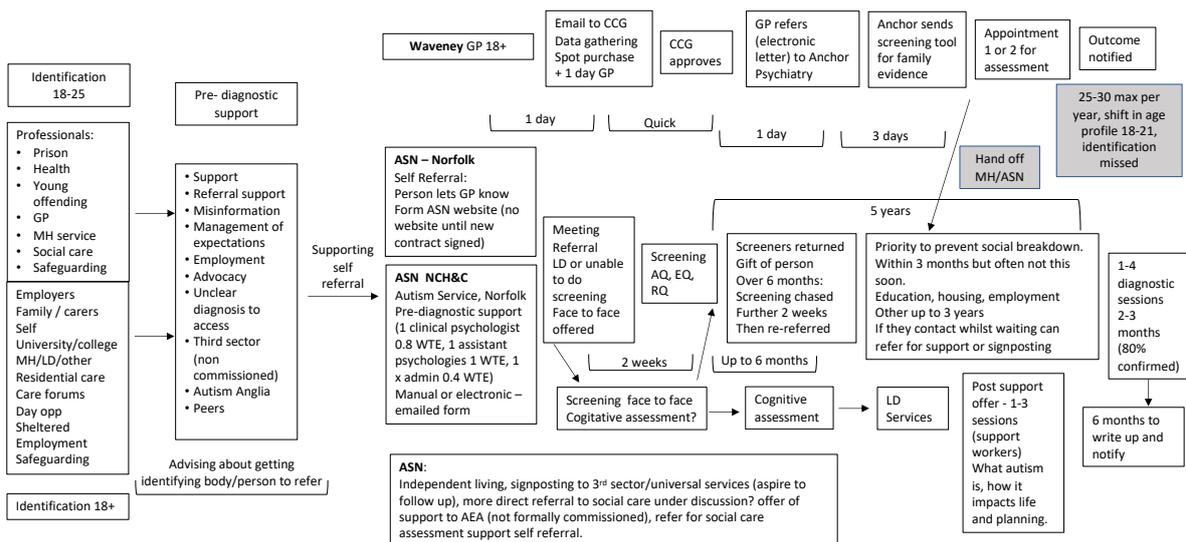


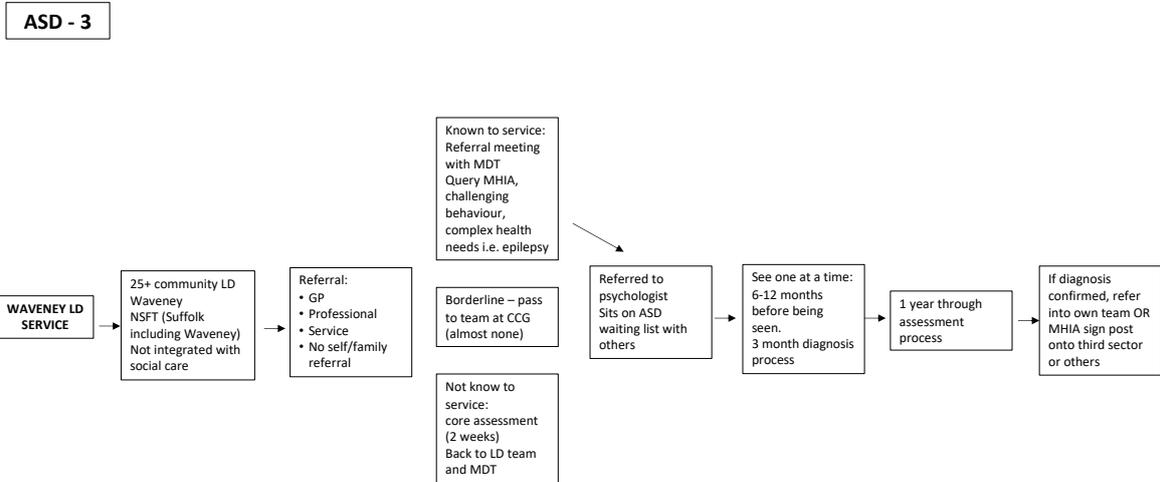
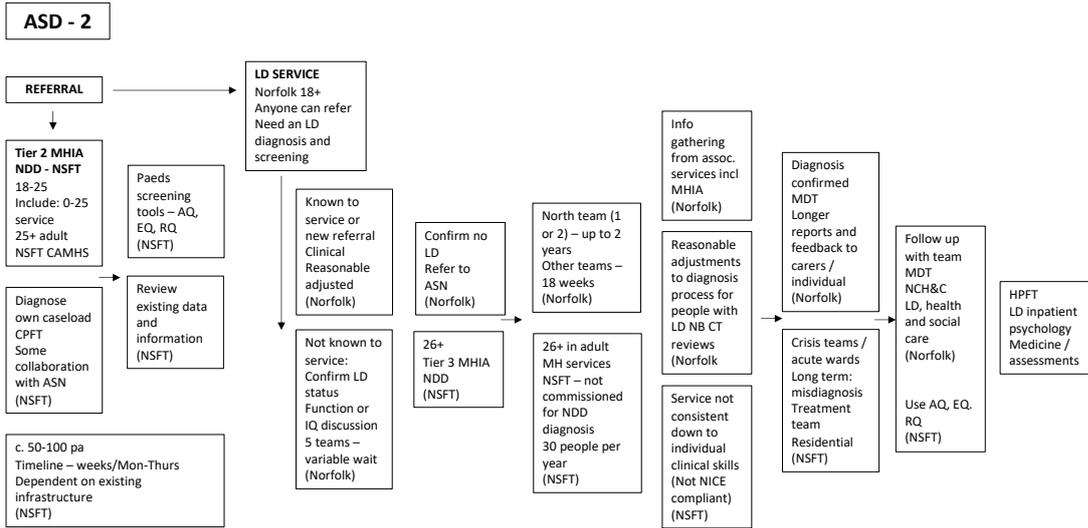
# Appendix C - Current adults' pathways

## Adults - ADHD

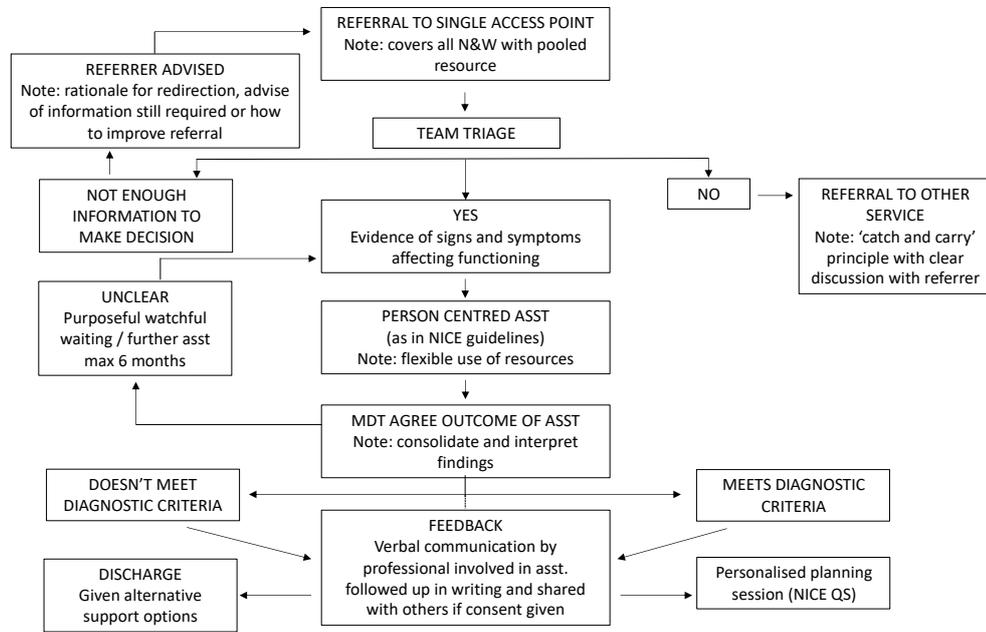


## ASD - 1





# Appendix D - Proposed future pathway – all age



## Appendix E – draft working definition of NDD

In agreeing a working definition of NDD for Norfolk and Waveney the following issues should be considered:

- There is no agreed formal definition of NDD in use in the NHS in England for either clinical or commissioning purposes. Nor is there an agreed clinical international definition. The recently published NHS long term plan includes a strong focus on services for people with a Learning Disability and for people with a diagnosis of ASD; this is a welcome focus on these service areas but NDD is broader.
- Pre-diagnosis children and adults will be presenting with a range of characteristics but will – of course – not yet have a diagnosis. The criteria for entering a diagnostic pathway therefore needs to be broad, inclusive and to describe characteristics rather than diagnosed conditions.
- There is an overlap in cohorts between those with a learning disability, those with a prime diagnosis of a mental health condition, those with ASD, and those with other NDD conditions. It is possible for someone to have all of these conditions or just one. Historically, there has been a tendency to clump these conditions together to the detriment of good service planning and recognising different needs. In recent years policy has recognised these cohorts as separate – with separate needs and interventions – but occasionally overlapping. It will be important to reinforce this view in attempting to agree a definition.

NDD covers a range of conditions that tend to share some or all of the following characteristics:

- Delay in expected features of development and possibly the presence of unusual features
- Impairments in reciprocal emotional, social and communication skills
- Behavioural issues
- A gap between attainment and underlying ability

A starting point for a local definition to inform service planning, diagnosis pathways and commissioning arrangements could include:

In scope – recognised by NICE and with confirmed guidelines:

- ASD – Autistic spectrum disorders
- AD/HD – Attention Deficit / Hyperactivity Disorder
- Potentially in scope:
- Non-specific social /communication disorders – children and adults exhibiting characteristics but not meeting a full diagnostic threshold may benefit from self-help tools, advice and access to low level support
- Sensory processing disorders
- Other communication disorders e.g. Tourettes

Closely aligned conditions – where there is a more common co-morbidity and / or potential for overlap and where people with NDD might benefit from specialist help:

- Learning disorders: dyslexia, disgraphia, dyscalcula
- Communication / language disorders: stuttering, delayed speech acquisition
- Learning disability
- Mental illness
- Sensory impairments

Out of scope – whilst these conditions may result in impaired neurological function these are not linked to impaired neurological development:

- Acquired brain injury
- Neurodegenerative diseases

It is recommended that agreeing a definition is taken forward with clinicians, commissioners and service providers and shared with service users and families.