

## Exec Committee Meeting

<b>Agenda Item No.</b>	
<b>Date.</b>	<b>22<sup>nd</sup> May 2023</b>

<b>Title</b>	Neurodevelopmental Deep Dive
<b>Lead Director</b>	Richard Watson
<b>Author(s)</b>	Jamie Mills/ Garry Joyce
<b>Purpose</b>	Report back on the outcome of the deep dive into the NDD pathways and agree with the following recommendations for service development.
<b>Recommendations</b>	<ol style="list-style-type: none"> <li>1. That the proposed new way of working for Suffolk is approved and implemented without delay</li> <li>2. That the new coordination function structure is approved.</li> <li>3. That the procurement for the coordination function can begin immediately</li> <li>4. That the existing contract with Barnardo's is extended to 31<sup>st</sup> March 2024 to allow for the procurement to be undertaken.</li> <li>5. That the support services delivered by Families Together, Green Light Trust, Noise Solutions, Beans, Suffolk Family Action and Suffolk Family Carers have the contracts extended by the plus 2 years included within the original contract offer</li> <li>6. That the support service delivered by the Befriending Scheme is not extended</li> <li>7. That £26,525 is put out on the framework for additional support service to apply.</li> <li>8. A single service clinical delivery model is developed.</li> <li>9. Additional investment to address increased demand on clinical diagnostic services.</li> <li>10. Introduction of Shared Care agreements for ADHD in relation to private diagnosis</li> </ol>

### Executive Summary

An update report was taken to SOAC committee on 7<sup>th</sup> November 2022 to provide detail around the first 6 months of full operation of the new NDD pathways in Suffolk and North East Essex, following a number of questions and concerns, predominately focussed on the Suffolk pathway, we were tasked by the committee to undertake a deep dive into the pathways and report back by June 2023. There remain considerable challenges with the NDD pathway, particularly around the demand for services, which is impacting upon RTT across the respective services.

The report primarily focuses on Suffolk but does include a section concerning NEE and will cover the historical background relating to the establishment of the pathways, the way they have been working, the current issues relating to delivery and the proposed solutions.

The deep dive focused on key areas where it was felt the most improvement could be made and a series of workshops (detailed in section 6) were organised to dig deeper into those key areas, all of which will be covered by a revised communications drive which will include updating the Local Offer website, the key areas were:

- Referral form and process
- Coordination function
- Triage process
- Clinical model
- Pre diagnosis support

Referral form and process – following a number of group sessions with system partners and the Suffolk Parent Carer Forum a number of minor changes have been made to the referral form and it is now ready to go live. The biggest change to the referral process that is being suggested is to restrict the pathway to Autism and ADHD diagnostic referrals only, this will ensure that only appropriate referrals are being accepted.

Coordination function – the current function is just an admin team that have been accepting too many non-NDD referrals on to the pathway as they have been trying to help everyone that contacts them. This has resulted in a significantly lengthy information gathering process, as well as a resources of emotional support for parents. However, this has led to a backlog of over 1000 referrals that had not been triaged, a recovery plan was enacted to resolve this and has resulted in the redesign of the coordination function. The proposed new coordination function will have a clinical lead with a background in NDD which will alleviate pressure on the triage process. The current contract expires at the end of October 2023 and we are recommending a procurement process to commence immediately with an extension to the existing contract of 6 months to cover the procurement period.

Triage process – this is a multiagency panel, with representation from colleagues from Education, Social Care, West Suffolk Community Trust, The Educational Psychology and Therapy Service and Suffolk and Norfolk Foundation Trust. This was designed by clinicians to triage all referrals coming through the pathway. The deep dive has shown that the triage panel rather than quickly deciding on whether a case should be accepted or, is frequently going into detailed debate which is limiting the number of cases they are able to review and creating a backlog. We recognise that multiagency clinical debate is required and are suggesting that the inclusion of a clinical lead within coordination function. The clinical lead will be able to screen the majority of cases prior to triage and then forward the remaining more complex cases to triage panel, which will be chaired by the clinical lead, for discussion.

Clinical model – Across Suffolk, currently there are 3 separate services within 2 providers that provide the clinical assessment and diagnosis for ASD and ADHD. Following a group discussion with those services the preferred option from provider colleagues was for a single service model. They felt this would be a better way of delivering the clinical elements of the pathway and that is what we are proposing we move towards. Whilst this is the preferred option for provider colleagues, the current service challenges are considerable and therefore this option and others, such as a single provider for all elements need to be considered.

Pre diagnosis support- one of the key themes identified at this point was providing CYP and their families' information and guidance. The 'Universal Support' offer was initially commissioned to support families, irrespective of diagnosis. However, there has been a considerable demand, in excess of the anticipated demanded, on occasions where other services may be more appropriate. This has in turn generated a waiting list for support for all but one of the voluntary sector organisations. It has been recommended to ensure these services are not overwhelmed and referrals are focussed on the supporting those families who have been referred through the diagnostic process.

On 5<sup>th</sup> April NHSE released new guidance for ICBs relating to frameworks and operational guidance for Autism pathways which we have used when considering the redesign of this

pathway (link attached <https://www.england.nhs.uk/publication/autism-diagnosis-and-operational-guidance/>)

## Recommendation:

### The committee are asked to approve the following set of recommendations:

1. That the proposed new way of working for Suffolk is approved and implemented without delay, this includes the following changes:
  - Adopting the revised referral form by 30<sup>th</sup> June 2023 (see Appendix A)
  - Creating guidance documents for CYP, parents/carers and professionals to ensure the referral process and requirements are understood by 30<sup>th</sup> June 2023
  - Introducing a profiling tool and associated training (timeframe tbc)
  - Introducing a parent/carer resource pack by 30<sup>th</sup> June 2023
  - Restricting access to Autism and ADHD assessment and diagnosis only by 30<sup>th</sup> June 2023
  - Publishing revised narrative on the local offer detailing accessibility criteria by 30<sup>th</sup> June 2023.
  - Screening is undertaken by the proposed new clinical lead. This will be dependent upon the decision from the ICB Executive, however preference would be for the clinical lead to start immediately.
  - Adoption of a pre assessment screening tool, specifically in relation to ADHD assessments by October 2023
  - Triage panel focus on the cases with more complexity only. This would be implemented once the clinical lead is in post
  - A single service clinical delivery model is developed and agreed by 30<sup>th</sup> June 2023
2. That the new coordination function structure is approved, which includes
  - The addition of an 8b clinical lead post. The recommendation is this would be mobilised immediately whilst the procurement exercise was undertaken
3. That the procurement for the coordination function can begin immediately
4. That the existing contract with Barnardo's is extended to 31<sup>st</sup> March 2024 to allow for the procurement to be undertaken.
5. That the support services delivered by Families Together, Green Light Trust, Noise Solutions, Beans, Suffolk Family Action and Suffolk Family Carers have the contracts extended by the plus 2 years included within the original contract offer. 2 of these contracts are due to expire at the end of August and the remaining 5 the end of October.
6. That the support service delivered by the Befriending Scheme is not extended
7. That £26,525 is put out on the framework for additional support services to apply, this could include increasing existing support services already contracted.
8. A single service clinical delivery model is developed.
9. Additional investment to address increased demand on clinical diagnostic services
10. Introduction of Shared Care agreements for ADHD in relation to private diagnosis

## Financial Summary

Description	Amount	Funding identified
Suffolk Coordination function	£411k	Yes
Suffolk Resource Pack	£4,500	No
Profiling tool – Suffolk only	Not quantified	No
Suffolk Clinical service growth	£783k	No
NEE Clinical service growth	£182k	No

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## 1.0 Background

When referring to neurodevelopmental disorders, whilst not an exhaustive list some of the conditions with onset in the early developmental period are outlined below:

- May include a known medical or genetic condition
- Intellectual Disability, social skills difficulties and Autism Spectrum Disorder, Attention and Concentration difficulties and ADHD
- On a developmental continuum with overlapping features
- Pervasive through the lifespan, and across different settings

### Factors affecting Neurodevelopment:

- Prenatal factors – stress, domestic violence, smoking, alcohol, congenital lesions
- Prematurity – increased risk of learning difficulties, attentional problems, social skills difficulties, cerebral palsy, specific learning difficulties.
- Perinatal – hypoxic ischaemic encephalopathy – seizure disorders
- Genetics – Down syndrome, 16p deletions, strong family history of developmental difficulties
- Environment – post natal depression, neglect, abuse
- Brain Injury – head injury (infective / traumatic)

1.1 Historically within Suffolk, CYP and their families did not generally have a positive journey and experience through universal and specialist services when seeking support, guidance and diagnosis around Neurodevelopmental conditions eg. attention-deficit hyperactivity disorder (ADHD), autism (ASD). Children with neurodevelopmental disorders can experience difficulties with language and speech, motor skills, behaviour, memory, learning, or other neurological functions. Some other conditions can share similar signs and symptoms to NDD, differential diagnoses can include intellectual disability, OCD, anxiety, developmental and relational trauma, as well as other communication and language disorder and sensory processing difficulties.

1.2 At the time the services were being reviewed in 2018 it was estimated prevalence of NDD conditions among children in England was between 3-4%. ADHD being the most common neurodevelopmental condition in the UK affecting 1.6% of CYP. ASD affecting 1.2% of CYP in the UK with prevalence higher among males than females. Applying these prevalence at the time the number of CYP aged 0 to 18 in Suffolk suggests there is an estimated 2,580 CYP with ADHD and 1,935 CYP with ASD in the county.

1.3 A multi-agency Steering Group was established in 2018 with the objective of reviewing the universal and specialist offer. It subsequently co-produced an inclusive NDD model, designed to meet the needs of CYP and their families in Suffolk. The draft high level model had previously been agreed.

1.4 The Steering Group completed baselined activity that mapped the services CYP and their families may come in contact with during their NDD journey. This included services that offer support, assessment and diagnosis for NDD conditions. The mapping activity identified a complex service offer with multiple pathways and providers including services from the voluntary sector, early years, early help, education, community paediatrics, wellbeing and specialist diagnosis services. There were 34 different services identified that a CYP may have contact with in relation to NDD. Of those services, there were 9 different providers identified.

1.5 Qualitative research showed that both professionals and families find the current offers and pathways difficult to navigate. This led to CYP being passed between services and getting held in pathways that are unable to meet their needs. Ultimately this resulted in significantly delayed waits for initial contact, assessments and diagnosis and generally poor patient experiences.

1.6 In May 2019 a number of immediate implementation projects were developed to address concerns raised by families and professionals. The projects aimed to provide CYP and their

families with a more supportive and enhanced pre and post assessment and diagnosis offer, they commenced in September 2019. The lessons learnt formed part of the detailed early support function.

## 2.0 Implementing the original model

2.1 To turn the model into reality the Steering Group recommended 3 distinct parts,

- Support services
- Coordination function
- Clinical diagnostic pathways

### Support Services

2.2 One of the key themes identified at this point was providing CYP and their families' information and guidance on NDD to provide support at any point during a family's NDD journey. The 'Universal Support' offer was initially commissioned to support families, irrespective of diagnosis, with the following organisations commissioned:

- Families Together
- Suffolk Family Action
- Suffolk Family Carers
- Beans
- The Befriending Scheme
- Noise Solutions
- Green Light Trust

2.3 The desire to offer this support to CYP as an early intervention was designed to provide help to develop the skills of the family and the universal workforce around the CYP, thus reducing the need for referrals to specialist services.

2.4 Initial estimates, based on the demand at the time (around 700) anticipated that the demand for support services would be around 2000 families per year.

2.5 The prevalence data at this time suggested that in Suffolk there were around 4500 children and young people with presenting conditions that will fit within the remit of the NDD pathway.

### Coordination function

2.6 The coordination function was commissioned to be the key link for CYP, families and services to ensure that consistency of support and information is embedded in the system.

2.7 The coordination function was designed to be a single point of access for information around what support is available, a function that families or services can contact for advice and finally. A function that could coordinate the diagnostic pathway from triage to diagnosis.

2.8 The coordination function was initially created imitating learning from other sites that have already successfully launched similar pathways and could include the following roles:

- Coordinator (CAMHS LD trained) Band 7
- Assistant Coordinator – Band 6
- Admin support – Band 4 x 2

2.9 Barnardo's were commissioned to deliver this element of the pathway and act as the coordination function. This has been agreed until October 2023, with a procurement exercise taking place to confirm the longer-term commissioning of this service.

### 3.0 Clinical diagnostic pathways

3.1 The planned scope of the pathway was redesigned to ensure that a multi-agency/professional triage process and diagnostic panel,

3.2 The new triage process was designed to ensure that all referrals to the new pathway identified any early interventions that may be needed as well as ensuring that the most appropriate assessments are undertaken, removing the existing processes where a child may be assessed under one pathway before being directed to another.

3.2 The diagnostic panel process was be used to consider multiple diagnosis and have a broad range of professionals in attendance, including education psychology which Suffolk County Council have been requested to provide without charge (it is a traded service).

3.3 All existing staff within the current pathways for ADHD and ASD were due to form part of the new multi-agency/professional triage and diagnostic panel.

3.4 These recommendations came into place in April 2022, following agreement by the then CCG Governing Bodies.

### 4.0 Current pathway

4.1 The current NDD pathway has now been in place for a year and involves a number of elements.

#### Voluntary organisations

- **Families Together Suffolk**
- **Family Action**
- **Suffolk Family Carers**
- **Beans**
- **The Befriending Scheme**
- **Noise Solution**
- **Green Light Trust**

**Barnardo's** – Coordination function to receive referrals to access support services and consider access to formal diagnostic pathway.

#### **West Suffolk Foundation Trust (Suffolk wide Integrated Community Paediatric Services)**

- Provides formal assessment for Autism Spectrum Disorder up to age 11yrs.
- Post diagnostic workshop is offered to all CYP diagnosed.
- Support and intervention is offered according to clinical need thereafter.
- Pathway is supported by Paediatrician's, Specialist Health Visitors/Nursery Nurse, Specialist Nurses, Clinical Psychologists, Speech and Language Therapists and Occupational Therapists.
- The pre-school pathway is not accessed via the NDD coordination function

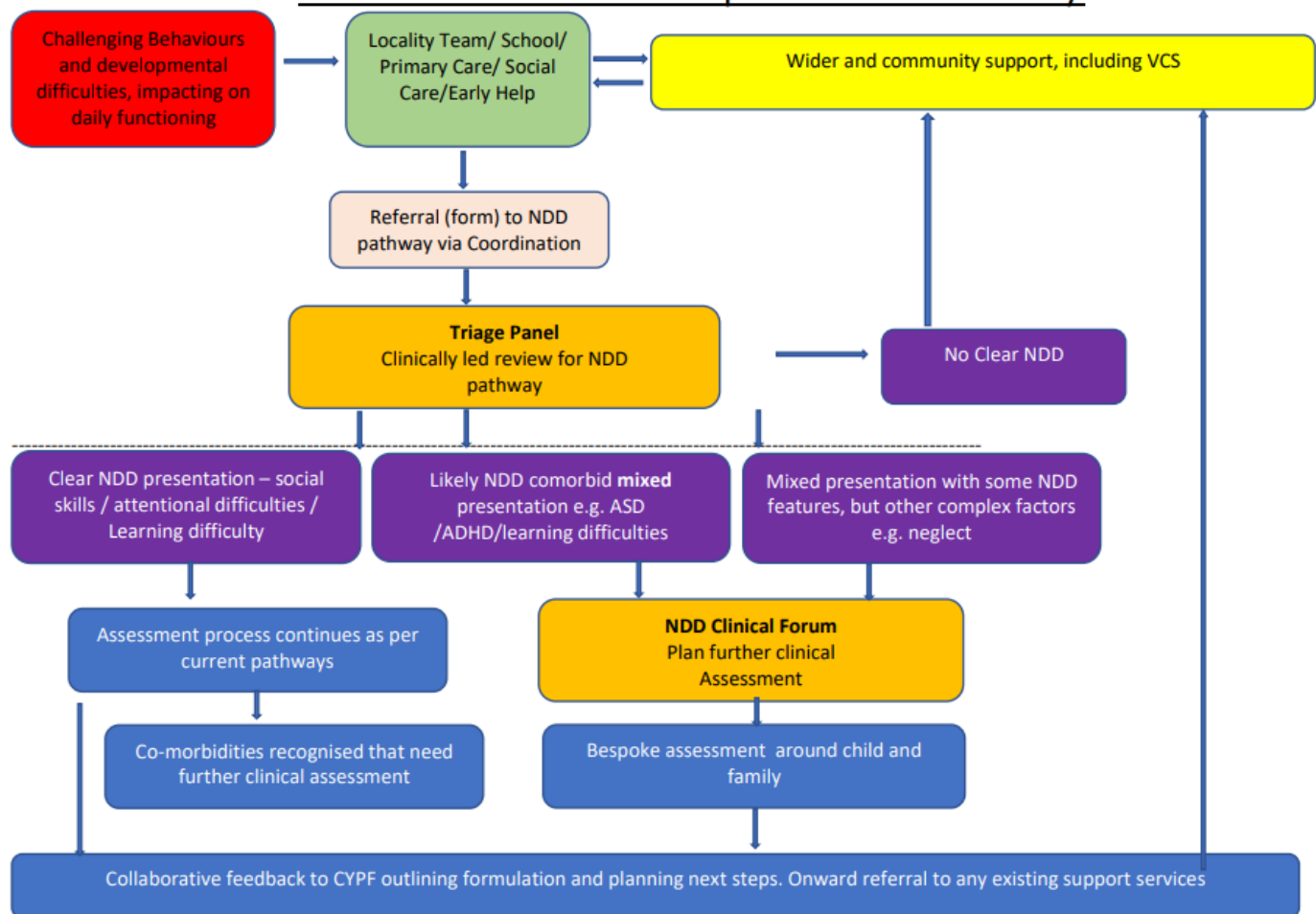
#### **Norfolk and Suffolk NHS Foundation Trust**

- Emotional Wellbeing Hub and Specialist ADHD and over 11s Autism Services for CYP across East and West

A visual outline of the pathway is provided below



## Suffolk Neurodevelopmental Pathway



4.2 Referrals relating to NDD are completed by parents/carers or a lead professional and sent directly to the coordination function which is currently hosted by Barnardo's.

4.3 Barnardo's co-ordinate the child or young person's journey from enquiry/referral to ensure a coordinated approach to delivering the care and support required. This also includes the parent carer mental health advice line.

The function of the coordination function currently includes the following

- Being a single point of access for the NDD pathway
- Receiving all referrals and confirming receipt
- Providing advice and support for families around local support offer
- Coordinating all triage meetings and associated paperwork
- Coordinating the request for assessments / onward referrals
- Coordinating effective, informative and timely feedback to families following MDT panel decisions
- Being the point of contact for families at any point during the pathway process
- Ensuring that consistency of support and information is embedded in the system.

The parent carer mental health advice line covers:

- Providing mental health advice to parents / carers when they phone seeking advice and guidance as defined within the iTHRIVE framework.

4.4 Once a referral is received into the coordination function it should be processed, via Barnardo's and if appropriate sent directly to the Triage Panel for consideration as to whether to take forward for assessment for ASD or ADHD. Should the request be purely to access voluntary organisations



this would be processed through to the respective organisations, without the need to go through to the Triage Panel.

4.5 Voluntary organisations offer a wide range of support, currently delivered irrespective of diagnosis. The current commissioned voluntary services are:

- **Families Together Suffolk** – Visit families at their own invitation to provide support services up to the age of 11 years.
- **Family Action** – Informs and empowers parents/carers by providing a "menu" of information and group or individual support. Age up to 25
- **Suffolk Family Carers** – Work collaboratively with the whole family or with individuals where appropriate offering a holistic, bespoke non-clinical needs led support. Age up to 25
- **Beans** – With families to provide positive change through bespoke social groups, workshops and volunteering and mentoring opportunities. Age up to 25
- **The Befriending Scheme** – Service supports difficulties young people and families face when transitioning from child to adult services. Age 14 -25.
- **Noise Solution** – Music mentoring based on self-determination theory.
- **Green Light Trust** – Intensive person-centered approach within a woodland setting. Age 5 – 25

Barnardo's will liaise with the family and having considered the referral, subsequently make recommendations regarding the most appropriate voluntary service to access.

4.6 The Triage Panel has representation from a variety of professionals including clinical reps from Norfolk and Suffolk Foundation Trust (NSFT) West Suffolk Foundation Trust (WSFT) Suffolk County Council via representatives from Social Care, Education and Educational Psychology and is facilitated by Barnardo's.

4.7 Should the panel consider the child or young person requires assessment for ASD/ADHD or both the referral will be agreed and taken forward through to the clinical pathway via the respective organisations.

## 5.0 Current challenges

5.1 Whilst the pathway itself has been operational for just about a year there are a number of challenges, both at a national and local level which are impacting upon the performance and timeliness of the NDD pathway. Some of the key areas identified initially are:

### **Increasing demand for ASD and ADHD assessments in both North East Essex and Suffolk**

5.2 Whilst this is a national challenge as highlighted within the new guidance published on 5<sup>th</sup> April 2023, it is important to note there has been a considerable increase in requests for both ASD and ADHD assessments. NHSE are now recommending that all commissioned services relating to the diagnosis of Autism should be commissioned at a rate of up to 2.6% of the population, currently we commission at around 1.4%. The national prevalence rate is around 1.7% and to reduce wait times in accordance with national policy commitments, 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.

5.3 Another factor which may have led to an increase in requests for diagnosis relates to the misunderstanding about the need for a diagnosis to get an Education, Health and Care plan (EHCP). Schools and parents often believe that an EHCP is required in order to access additional funding for schools, although in Suffolk High Needs funding is available for individual pupils with or without an EHCP.

### **Recruitment challenges for providers, impacting on development of long term plans to address this increasing demand**

5.4 Whilst there has historically been non recurrent financial support offered to providers to address recruitment challenges, posts have been unable to be filled due to the lack of permanency being offered. This in turn means providers are unable to staff adequately to address the increasing demand for ASD and ADHD assessments. This creates a further backlog and if we do need to commission as per national guidance then this is likely to worsen, as every area will be trying to recruit from the same limited clinical pool.

### **Development of consistent data recording, to inform service developments**

5.5 One of the key areas of challenge relates to the mechanisms in place to capture data both from a service performance perspective and also to forecast potential future demand. Existing recording processes work independently from one another meaning individual discussions are required with providers rather than considering the wider system demand.

### **Referral demand to voluntary sector organisations**

5.6 Whilst considerable non recurrent investment has been made for voluntary organisations to provide support for CYP and their families irrespective of diagnosis, demand has been significant. 6 of the 7 voluntary services have exhausted the commissioned spaces and are operating waiting lists.

Support service	Referrals (YTD)
Noise solution	57
Families Together Suffolk	166
Family Action	95
Befriending Scheme	0
Green Light Trust	50
Access CT/Beans	217
Suffolk Family Carers	455

### **Within Suffolk and North East Essex ensuring the offer compliments and feeds the wider SEND agenda across SNEE**

5.7 Whilst the majority of the challenges within SNEE relate to the Suffolk NDD pathway, there has historically not been a joined-up approach towards addressing both the challenges and best practice across the footprint.

### **Service performance and reporting**

5.8 Collectively across local ASD and ADHD services, NHS 18-weeks referral to treatment compliance remains at a low level, with school age diagnostic pathways facing the most challenges and demand, with reports of some children waiting up to 59 weeks for assessment for under 11s ASD assessment and wait times for over 11s ASD assessment and ADHD assessment remaining a significant area of concern. A particular area of challenge is the 10% referral to diagnosis rate in ADHD service which influenced by large numbers of inappropriate referrals that could be supported in the wider community by more suitable options being considered rather than ADHD, as acknowledged in the ADHD recovery plan provided by NSFT.

5.9 As part of the ongoing developments relating to the SEND agenda a localised health dashboard has been developed which reflects current RTT for both ASD or ADHD.

ADHD

## 8.1 Children and young people have access to ADHD treatment within expected timeframes

Data Source: NSFT

ADHD (RTT) - Under 25s

Age Band		Apr-22	May-22	Jun-22	Jul-22	Aug-22	Sep-22	Oct-22	Nov-22	Dec-22
5-9	RTT - Incomplete	50	71	69	88	85	95	95	101	109
	Average Weeks Waited	13.4	10.6	10.6	10.9	13.3	14.5	15.2	14.4	15.1
10-15	RTT - Incomplete	33	38	46	56	57	56	60	71	85
	Average Weeks Waited	24.8	16.2	13.6	11.4	14.4	14.1	14.6	15.3	15.5
16-17	RTT - Incomplete	9	13	11	12	12	15	14	14	12
	Average Weeks Waited	18.3	15.4	17.4	17.1	18.2	18.7	18.2	20.6	18.6
18-24	RTT - Incomplete	76	77	95	129	156	187	211	212	231
	Average Weeks Waited	15.4	18.3	17.3	17.2	17.7	18.4	20.6	23.6	25.4
Total	RTT - Incomplete	168	199	221	285	310	353	380	398	437
	Average Weeks Waited	16.8	15.0	14.4	14.1	15.9	16.7	18.2	19.7	20.7

ADHD (RTT - Incomplete) - Under 18s



ADHD (RTT - Incomplete) - Under 25s



## ASD under and over 11's

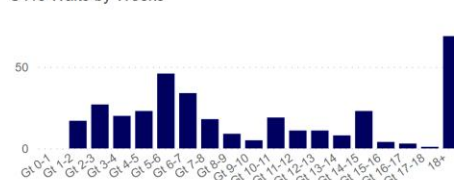
## 8.2 Children and young people have access to ASD assessment within expected timeframes

Data Source: Integrated Community Paediatric Services (ICPS)

Patients identified as having Socio-Communication difficulties (Under 11s)

Month	Total Waiting	Max Waiting Time (wks)	Average Waiting Time (wks)	No. Waiting over 18 Weeks	% Wait over 18 Weeks
Dec-22	348	54.71	10.77	61	17.53%

U11s Waits by Weeks



% Waiting Over 18 Weeks

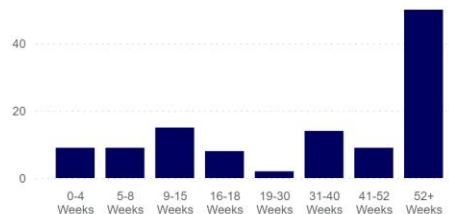


Data Source: NSFT

Youth Autism (11-18s) - Weeks Waiting for Assessment

Month	0-4 Weeks	5-8 Weeks	9-15 Weeks	16-18 Weeks	19-30 Weeks	31-40 Weeks	41-52 Weeks	52+ Weeks	Total
Feb-23	9	9	15	8	2	14	9	50	116

Youth Autism Waits by Weeks



5.10 Nationally, recent increases in the numbers of children diagnosed with neurodevelopmental disorders such as autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD), has led to growing demand on clinical services (Male, Farr and Reddy 2020). Diagnostic rates of ASD in the UK have seen an exponentially increase of 787% between 1998 and 2018, and a suggested 400% increase in individuals seeking an ADHD diagnosis since 2020 respectively (ADHD foundation). This pattern of increasing referrals seeking assessment for possible NDD has also been seen in Suffolk, with an 80% increase being seen in some local services. The NHS Long Term Plan expresses the desire “to test and implement the most effective ways to reduce waiting times.... achieving timely diagnostic assessments...[and] support children with autism or other neurodevelopmental disorders including ADHD”. However, demand for assessment has resulted in

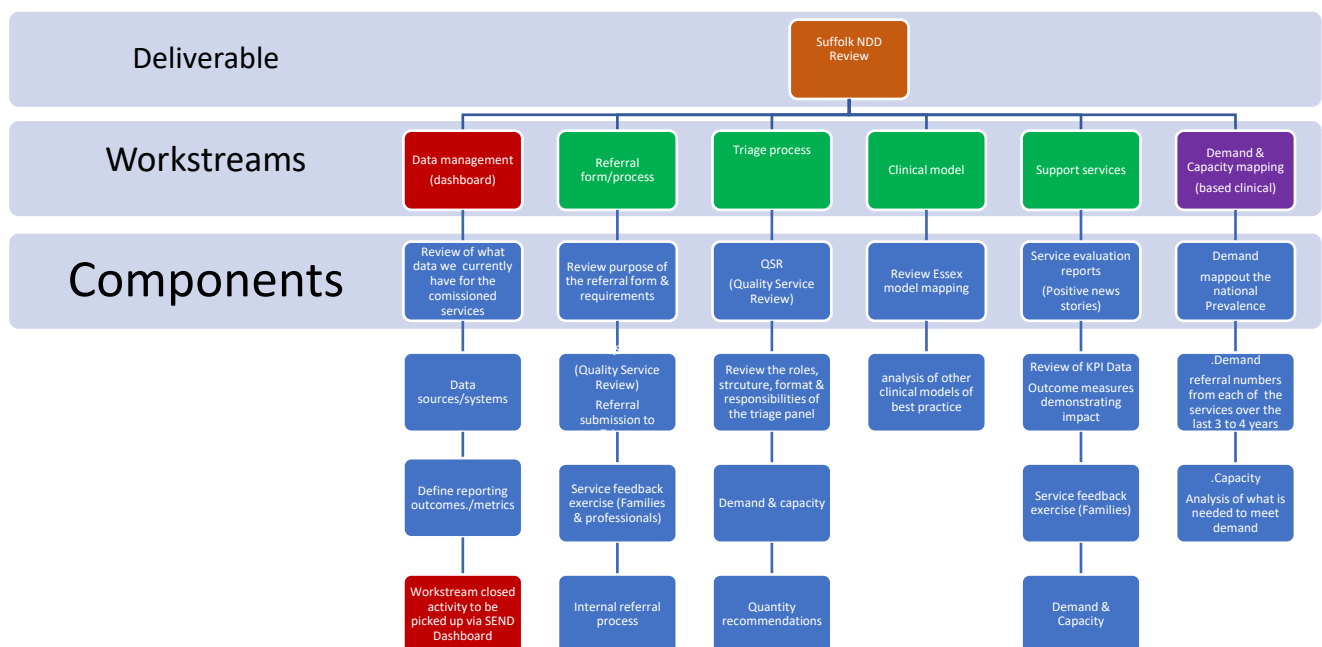
greater waiting times within the NHS as resources become increasingly stretched, compelling service to examine their processes in order to improve accessibility.

5.11 Nationally there is an increase in families seeking a private diagnosis for ADHD and without “shared care” agreements in place we are unable to accept these diagnoses and instead must put these children on the current ADHD waiting list for an NHS assessment.

## 6.0 Addressing the challenges

6.1 Taking into consideration the initial concerns shared with SOAC in November and highlighted in this report, it was agreed an NDD Deep Dive would be undertaken to gain a greater insight of the challenges within the system, in turn ensuring any recommendations could be made with confidence. It was important to ensure this work was undertaken in the spirit of coproduction. Therefore, partners from WSFT, NSFT, Suffolk County Council colleagues, including those from Social Care, Education and the CYP Engagement Hub all contributed to the discussions where appropriate.

6.2 The deep dive itself was divided into a number of workstreams as outlined below. Whilst these are all interlinked it was felt it would be more manageable to break it down into sections.



### Data Management

6.3 One of the key areas of concern related the mechanism and processes around capturing data across the ICB, regarding reporting information relating to ASD and ADHD. As these are captured across via differing contract and reporting mechanisms it made it challenging to gather consistent information on a regular basis.

### Referral Form and Process

6.4 One of the primary areas of focus related to both the referral form itself and the supporting processes around expectations for referral. Currently referrals are completed by a professional who knows the child or young person, in most instances the school SENCO. However, there are also instances where referrals are completed by the GP or the parent/carer. Referrals are supported by a variety of different forms of evidence including school reports, observations from

other professionals, however there is not a consistent expectation regarding additional information to support the completed referral form.

6.5 The referral form and process were identified as an immediate priority. To address this a working group was established with representation from the following groups:

- ICB
- WSFT
- NSFT
- Suffolk County Council- Inclusion Services, Social Care and the Engagement Hub
- Suffolk Parent Carer Forum
- Secondary High School

6.6 The group met on 4 occasions and identified the following issues with the referral form and process, in addition to a professionals survey to capture a wide range of views. The initial focus was to ask the group to identify challenges their teams had experienced with the referral process in order to inform where consistent gaps were being found. A comprehensive summary is contained within the appendices, with some examples of the challenges summarised below:

- Not aligned to current diagnostic criteria for ASD and ADHD
- The need for clearer instructions and explanation of each part of the form
- Reports of low completion rate on the young person section (some children not sure how to respond)
- Lack of clarification as to who qualifies as a lead professional and who is required to complete the referral forms
- Lack of understanding around the responsibility of the lead professional completing the referral
- Sometimes challenging for professionals to complete the form and provide evidence when they may not see the same behaviours being referenced to
- It is felt there is a lack of communication/updates once the form has been submitted. Referrers are unsure what the referral status is
- Form is not user friendly, too vague and unclear what information is being sought
- Some concerns, parents are struggling to complete their parent section due to their own learning difficulties
- Lack of opportunity within the current form to give schools an opportunity to show what they already have in place for the pupil, with or without support from Specialist Education Services (SES)
- Perception that SES involvement appears to be an expectation now. The thresholds for this are specific and not all children with communication and interaction difficulty will meet these
- Additional information is often requested at Triage, which is not captured within the referral form.
- Reports referenced in the referral, are then requested which takes time to chase and on occasions do not add value to the decision making process.
- Lack of detail within the referral form- often the forms have very brief description of the concerns
- Welling hub- how the NDD pathway compliments CYP. On occasions it is felt if there is a sign of NDD, despite other needs displayed (anxiety, low mood), child is automatically signposted to the NDD pathway.
- Overcomplicated the form and in some cases it's not clear why referral has been made and what refer is asking for.
- Current form does not take into consideration the age and individual circumstances of the child or young person.
- Challenge of quantifying the requirements of 3 different services together, as well 2 conditions plus support services, with varying requirements.
- Lack of clear and robust comms, guidance was needed around the pathway, which has generated additional confusion.
- Lack of time to bed in some of the principles around what pathway is and what it isn't, which has caused additional confusion for service users.
- SPCF advised families may find it hard to quantify what support they are looking for. Most families aren't looking for support, they refer because they want their child's needs identified and met.
- Concerns around the referral information is being stored and is not visible to the wider system (other services).

6.7 We also undertook a random sample of 10 different areas around the country to compare pathways being offered elsewhere, what was covered, how they screened/triaged and conditions covered.

6.8 During this process it became apparent that a focused piece of work around the coordination function was also required.

### **Coordination Function**

6.9 Several meetings were organised to understand the issues faced by the coordination function which included detailed understanding of the waiting list within this part of the pathway. In summary it uncovered that just over 1000 referrals had been made to the pathway that had not been reviewed and as a consequence those families had not been informed if the referral had been accepted, effectively leaving them in limbo.

6.10 An urgent piece of work was undertaken to review all of those cases initially by Barnardo's but with support from a clinical team from the ICB.

6.11 The clinical team from the ICB reviewed in detail around 400 cases, from those cases only around 45% appeared to be appropriate referrals. The remainder appeared to be relating to the need for some alternative level of support that should be provided through schools as part of the graduated response or requiring mental health support. It would appear that the NDD pathway is being used as a "catch all" by referrers rather than trying to resolve low level issues.

6.12 The clinical team from the ICB also reviewed the processes with the coordination function and helped with designing a new SOP (Standard Operating Procedure) for the coordination function to follow when making decisions around acceptance on to the pathway, however they also recommended that a full redesign of the coordination function was needed to ensure effective delivery for the future of the pathway, including the creation of a clinical lead post.

6.13 Barnardo's have introduced a new pathway for referrals which has been instigated immediately to ensure that any referrals with safeguarding issues are identified and all referrals are screened within 10 days as per contract requirements (see appendix B)

### **Triage Process**

6.14 The current triage process was established as a multiagency/professional panel which would meet on a weekly basis for 3 hours to review all referrals received in the previous week to determine if they were appropriate for the pathway and potential clinical diagnosis. It was initially estimated that 50 referrals per week would need to be reviewed by the panel.

6.15 A working group was established as part of the deep dive to consider some of these challenges, taking into consideration the experience of panel members as well as feedback from parents/carers, who view the panel from a different perspective.

6.16 The group met on 4 occasions, highlighting both the challenges facing the triage function, in addition to some potential solutions. A comprehensive summary of the meetings is captured within the appendices, however a summary of some of the key areas for consideration are recorded below:

- Frustrations from Schools/families don't always understand how and why decision was reached.
- The information and how it is requested need to change. Development of a process that allows SENCOs/lead professionals to give enough information first time round. This is connected to ensuring the referral form is accessible and user friendly.
- Equally weighting in the decision making the within the triage panel – joint decision being made. Lack of chair means, on occasions the panel are unable to reach timely decisions

- Lack of representation from mental health services at Triage panel, either via representation at the panel or a clear lead in through, creates additional confusion and responsibility for the panel
- The outcome letter doesn't always give clarity on the steps needed to move forward. This in turn is confusing for families
- Sometimes by the time a referral reaches triage the information is too old/out date – CYP circumstances have changed e.g changed schools
- No pathway/sufficient provision to support challenging behaviour needs, which causes additional confusion and frustration

6.17 The panel are meeting weekly but only reviewing around 15 cases per week. A number of officers, including clinical, have attended panel meetings to understand why the numbers are so low. Effectively, whilst the panel has some incredibly skilled professionals, the lack of chair or clarity regarding responsibility for decision making is creating a situation where cases are debated. In addition the request for additional information is almost pre-empting diagnosis rather than making a decision on whether to accept on to the pathway.

6.18 Workshop meetings have been arranged and the reflection in 6.16 has been accepted by the clinical representatives from system partners that both attend triage and the workshop meetings. However, they also stated that as there is no clinical screening of referrals before triage and also the fact that a large number do not relate to the pathway they almost felt duty bound to debate each case in detail either to identify if indeed this pathway was correct or to identify alternative services for the child and or family.

## **Clinical Model**

6.19 As part of the deep dive we looked at 10 different areas around the country to seek out best practice around clinical diagnostic models, the findings demonstrated that there is not a standard model of delivery, however, what we did find was that most areas are limiting the pathway to ASD and ADHD.

6.20 On 5<sup>th</sup> April 2023 NHSE released new guidance for ICBs in relation to frameworks for the design of ASD pathways which does take into consideration the inclusion of ADHD as a potential around dual diagnosis.

6.21 Clinical leads from the 3 existing clinical pathways came together with officers from the ICB and had a discussion, facilitated by Andy Vowles, around what would be the best clinical model look like. The session was extremely insightful with all agreeing that a single service model would be the best option for future delivery.

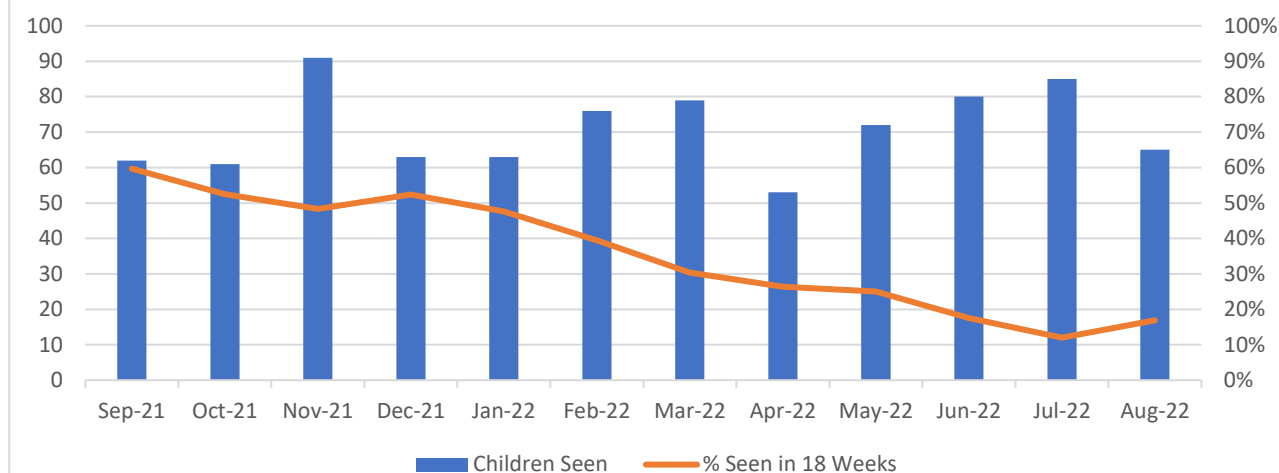
6.22 A new model of delivery which has been developed by Portsmouth is being looked at by many different areas around the country as is currently being spoken about by NHSE as having potential to reduce referrals. The main components of this model are very similar to the model we have in Suffolk but there are additions which we should consider, they are:

- The introduction of a profiling tool and a significant training programme for schools etc in how to use it. (See Appendix C)
- The introduction of a resource pack (we already have this in NEE but not in Suffolk and there is a cost to introducing this as well as some resource in pulling it together)

6.23 There remains a significant, ongoing issue in addressing the increasing backlog of cases within both ADHD and ASD assessments. Whilst investment has previously been agreed for West Suffolk Foundation Trust this has not being fully utilised due to recruitment challenges. It is recommended an additional 200k recurrent investment is committed to look at how the ASD under 11's service can address this but this needs to be finalised with the service. This has previously been requested via the Financial Request Prioritisation Model but was declined along with every other case due to the financial position of the ICB. (awaiting current data)



### 18 Week RTT for Paediatric Consultant-Led Services



6.24 We have already committed an additional £393k for a two year period in October 2022 to address the waiting list for the ADHD service but this will require the funding to become recurrent to ensure the demand is managed.

6.25 The ASD over 11 service although has an increased demand currently have not requested an increase in funding, however based on the capacity and demand review that is being undertaken (see extract below) we can clearly demonstrate that an increase in capacity is needed and we would suggest an amount of £200k to match the under 11 ASD service.

#### Service Caseload Growth

		2023-24	2024-25	2025-26	2026-27	2027-28	2028-29	2029-30	2030-31	2031-32	2032-33
Children ADHD East Suf	New patients onto caseload	82	82	81	81	80	80	79	79	78	78
	Patients turning 18 and discharged	25	28	31	33	36	38	40	42	44	46
	Patients no longer needing treatment by service	2	3	3	3	3	3	4	4	4	4
	<b>Service caseload</b>	<b>501</b>	<b>552</b>	<b>599</b>	<b>644</b>	<b>685</b>	<b>723</b>	<b>758</b>	<b>791</b>	<b>821</b>	<b>849</b>
Children ADHD West Suf	New patients onto caseload	81	80	80	79	79	78	78	78	77	77
	Patients turning 18 and discharged	30	33	35	38	40	42	44	45	47	48
	Patients no longer needing treatment by service	3	3	3	3	4	4	4	4	4	4
	<b>Service caseload</b>	<b>591</b>	<b>635</b>	<b>676</b>	<b>714</b>	<b>750</b>	<b>783</b>	<b>813</b>	<b>841</b>	<b>867</b>	<b>891</b>
Youth Autism	New patients onto caseload	79	79	78	78	77	77	77	76	76	75
	Patients turning 18 and discharged	0	4.41	8.53	12.39	15.98	19.32	22.44	25.35	28.05	30.56
	Patients no longer needing treatment by service	0	0.40	0.77	1.11	1.43	1.73	2.01	2.27	2.52	2.74
	<b>Service caseload</b>	<b>79</b>	<b>153</b>	<b>222</b>	<b>287</b>	<b>347</b>	<b>403</b>	<b>455</b>	<b>503</b>	<b>548</b>	<b>590</b>

\*Figures provided by the services

6.26 In order to address this immediate pressure the proposal is to commit this funding to recruit additional roles, potentially looking at a different approach. Initial consideration has been given to developing the pre-school pathway through recruitment of assistant psychologists, whilst a longer term preferred clinical model is developed with the provider, through a coproduced staffing model and approach.

## 7.0 Options and solutions

### Data Management

7.1 In light of the developments around the SEND Dashboard, which is capturing similar information, this workstream has been stood down. Colleagues from Quality and Transformation teams will work through the Dashboard to capture future reporting, this will ensure consistency of reporting and at the same time meet the local reporting arrangements relating to the SEND health dashboard.

### Referral Form and Process

7.2 The development of a revised referral form, coproduced with colleagues at NSFT, WSFT, SPCF, SCC and the Engagement Hub has been completed and is ready for implementation / roll-out across the system.

7.3 Development of a guidance document to support the referral form, to ensure lead professionals are clear around responsibilities and required information.

7.4 The referral process should follow the new guidelines published by NHSE relating to Autism which call for referrals to be submitted by a professional that knows the child well and does list a number of expected referrers (see appendix D)

7.5 The scope of the pathway should be limited at this moment in time to just suspected ASD and ADHD, this will bring the Suffolk pathway in line with the NEE pathway. The launch only focused on ASD and ADHD so we would not be losing any diagnostic pathway, it just means that the coordination function will only deal with ASD and ADHD.

7.6 Update the narrative published on the local offer (see appendix E) and also indicate that there are waiting lists and include estimated wait time, this will help with managing expectations. Where a referral is not deemed appropriate there will need to be a crossover with partners, such as education to ensure any response compliments the work of our partners. In addition, this will be communicated via Suffolk Parent Carer Forum, to ensure it is undertaken in an appropriate manner.

7.7 Reinforcement of the new referral form and process, via workshops with School staff, Suffolk County Council colleagues, ICB colleagues and via Primary Care.

7.8 Introduce a profiling tool and a training package to support its introduction and make the training manual available for download for parents to help with the understanding of what is considered.

7.9 Introduce a resource pack for parents/carers and make it available for schools etc. Use the resource pack from NNE as the guide for this.

### Coordination Function

7.10 The existing contract is due to finish in October 2023 and due to the financial value over the life of the contract we cannot offer any further extensions without considering the options relating to procurement as detailed in section 11.

7.11 Based on the findings of the clinical team from the ICB we want to add a clinical lead post to the coordination function which will enable effective screening of all referrals sent in to the pathway and provide a dedicated chair for the triage panel when discussing the more complex presenting

cases. This will involve additional financial commitment which will be detailed in the finance section below.

7.12 Once the final sign off of the SOP from clinical quality team within the ICB has been completed then it needs to be adopted and followed by the coordination function, future delivery and oversight will be undertaken by the proposed clinical lead.

7.13 As we have identified funding to support the introduction of a clinical lead post we would like to start this as soon as is practically possible and would recommend putting in place a clinical lead from the ICB to lead the process. This will ensure the SOP and other changes are fully embedded which will support the procurement process as well as assist in implementing the other recommended changes. This post would work alongside Barnardo's in the interim.

## **Triage Process**

7.14 All agreed the contributions and value of having a multiagency triage panel were considerable, particularly where there are more complex situations.

7.15 With the introduction of the clinical lead post within the coordination function the triage panel will be able to continue meeting on a weekly basis. However, with a driven focus from the clinical lead as chair and the fact that only the more complex presenting cases will be discussed, it will allow for informed clinical debate to be undertaken without resulting in a growing backlog of cases waiting for triage.

7.16 The clearer cases would be filtered and referred directly to the respective services by the clinical lead, ensuring only those more complex cases would be taken through to discussion.

## **Clinical Model**

7.17 With the significant challenge and inconsistency around wait times and diagnostic rates across SNEE for both ASD and ADHD assessments a concern, a change in approach is required to ensure these issues are addressed.

7.18 A clinical system meeting took place on 13<sup>th</sup> March 2023 with the preferred option outlined of a clinical diagnostic service as a single team covering both ADHD and Autism based services. Focused around functioning while using a wide skill mix which will map needs and may lead to a diagnosis. This can be achieved by either moving all services to a single provider or by identifying dedicated time for each service to work in a colocated manner with the other services, effectively collocate the three existing services for a set period of time each week to work as a single team.

7.19 Consideration also given to adopting a single provider to deliver all ASD and ADHD assessments across Suffolk. This would allow for a clearer model of service delivery with one set of KPI's and the ability to resource on a greater scale. Providers felt this was a potential option, but felt they could work collaboratively without the need to go through this route.

7.20 The new NHSE guidance for ICBs relating to frameworks and operational guidance for Autism pathways also suggests adopting an MDT approach which could be delivered as a single team.

7.21 A clinical model outcome specification is currently being developed and will be shared with services for input and agreement which should be finalised by 30<sup>th</sup> June 2023.

7.22 Tightening up of the referral process and the introduction of clinical screening will ensure that more appropriate referrals are accepted on to the clinical model for potential diagnosis.

7.23 The introduction of a pre-assessment questionnaire is also being recommended by the clinical teams, the suggestion is to use the Development and Well-Being Assessment (DAWBA) as part of the referral process. In NEE for ADHD services they use QB testing which has resulted in 80% of referrals that are accepted on to the pathway end up with a diagnosis, Suffolk ADHD services currently has no pre-assessment and has a referral to diagnosis rate of only 10%.

## **Options**

7.24 Taking into consideration the complexities of this situation there are a number of options available for decision:

<b>Option 1: Maintain existing arrangements</b>	
<b>Advantages</b>	<b>Disadvantages</b>
<ul style="list-style-type: none"> <li>• Would ensure services continue, with no disruption</li> </ul>	<ul style="list-style-type: none"> <li>• Would not address the current challenges and would lead to increasing wait times for assessment</li> <li>• Continuation of the fragmented approach towards commissioning of services</li> </ul>
<b>Option 2: Implement a single team across NDD, consisting of staff from NSFT and WSFT</b>	
<b>Advantages</b>	<b>Disadvantages</b>
<ul style="list-style-type: none"> <li>• Would allow for joined up working through dedicated team, who could offer peer to peer support.</li> <li>• Would ensure all clinical staff work together as a single colocated team.</li> <li>• Clear clinical model to support provision across appropriate disciplines</li> <li>• Clinical and governance structures will be in place to support different disciplines.</li> </ul>	<ul style="list-style-type: none"> <li>• Would need considerable commitment to implement, with clear expectations outlined from the outset</li> <li>• Would need a signed MOU that outlines time and staff commitments.</li> <li>• Other staffing pressures may mean staff are pulled from this team to support individual organisations</li> </ul>
<b>Option 3: Implement a single service model across Suffolk through service transfer to a single provider</b>	
<b>Advantages</b>	<b>Disadvantages</b>
<ul style="list-style-type: none"> <li>• Would potentially ensure more consistency of service with the ability to staff and resource more efficiently.</li> <li>• Would be a dedicated service delivery team.</li> <li>• Potential to grow income stream using ERF if it were a physical acute trust funding through the contract to support future demand growth.</li> <li>• Would only require transfer from one provider to another</li> <li>• Clear clinical model to support provision across appropriate disciplines</li> <li>• Clinical and governance structures will be in place to support different disciplines.</li> </ul>	<ul style="list-style-type: none"> <li>• Potential that some staff would not want to transfer and leave gaps in service provision.</li> <li>• Disruption to service provision while service transfers.</li> <li>• Complexity around identification of correct level of funding and staff to transfer.</li> <li>• Probably take 12 months to complete</li> </ul>
<b>Option 4: Implement a single service model across Suffolk through procurement to a single provider</b>	
<b>Advantages</b>	<b>Disadvantages</b>
<ul style="list-style-type: none"> <li>• Would potentially ensure more consistency of service with the ability to staff and resource more efficiently.</li> <li>• Would be a dedicated service delivery team.</li> <li>• Potential to grow income stream using ERF funding if a physical acute trust were to bid through the contract to support future demand growth.</li> <li>• Clearly identified contract budget for future monitoring purposes</li> <li>• Clear clinical model to support provision across appropriate disciplines</li> <li>• Clinical and governance structures will be in place to support different disciplines.</li> </ul>	<ul style="list-style-type: none"> <li>• Potential that some staff would not want to transfer and leave gaps in service provision.</li> <li>• Disruption to service provision while service transfers.</li> <li>• Complexity around identification of correct level of funding and staff to transfer.</li> <li>• Potential impact on two providers if contract award is not to existing provider.</li> <li>• Probably take 12 to 18 months to complete.</li> </ul>

7.25 From the options listed we feel that the creation of a single team under one provider would be the best solution, however there are a number of considerations that need to be taken into account to determine whether it is option 3 or 4, they are:

- The agreement with NSFT to move the services (ADHD and ASD over 11's) out of the organisation.
- The agreement of the financial value of the services to move, this also includes the ASD under 11 service.
- Identification of staff that may be TUPE transferred.
- The willingness of WSFT to take on the NSFT services.
- Would there be a challenge to delivery from ESNEFT as they deliver both ADHD and ASD services for NEE.

7.26 With the increase in private ADHD diagnosis we need to ensure that there are appropriate "shared care" agreements in place with GPs.

## 8.0 Finances

8.1 The NDD pathway is funded through various streams due to the complexity of the delivery. The clinical teams are funded through the existing NHS contracts with NSFT and WSFT. The support services are funded through individual contracts with a total value of £700k per year and the Coordination function which includes the Parent Carer mental health advice line is funded through MHIS and re-aligning of funds from EWB hub.

8.2 The coordination function requires additional investment to enable the recommended changes to be implemented which is the addition of a clinical lead post. The additional investment has been identified from new SDF funding from NHSE, see table below:

	Existing funding	Proposed funding
MHIS funding	£166k	£166k
Re-aligned funding from EWB hub	£172k	£172K
NHSE CYP LD&A SDF funding	-	£73k
<b>Total</b>	<b>£338k</b>	<b>£411K</b>

8.3 ICB costings for 8b including on-costs are £71k (bottom of grade) to £83k (top of grade) and the additional funding available is £73k which is from NHSE and is dedicated SDF funding for LD and Autism for CYP. Although this is £10k below the top of the grade as we will be undertaking a procurement process then the total envelop available will be the maximum for contract award purposes which will include the additional post of clinical lead.

8.4 The clinical delivery model is currently financed as part of the block contract arrangements with both NSFT and WSFT. Future funding where possible to meet the increase in demand should be met by funding this service through ERF. Under contracting arrangements we are suggesting that the assessments are coded to create outpatient procedures which will create an income source for future investment, however this will require a change in recording processes and an alternative will be needed for NSFT.

8.5 The cost of introducing a resource pack has yet to be quantified, however in Essex we recently funded a new print of the resource pack at a cost of £4,500

8.6 The cost of introducing a profiling tool has yet to be quantified, however the quickest way and probably best from a research perspective would be to copy the Portsmouth model as they have already undertaken research relating to effectiveness of the tool, the cost would probably involve a payment to Portsmouth for intellectual rights but we would also need to quantify the training requirements required for its introduction.

8.7 Based on expected growth in demand as referred to in section 6.23 to 6.26 we are also requesting additional investment in clinical services of £783 for Suffolk. This is broken down as follows:

- £200k ASD under 11 estimate based on new NHSE guidelines asking ICBs to commission at around 2.3% to 2.6% of prevalence
- £200k ASD over 11 as above
- £383k ADHD based on recovery business case funding being made recurrent

## 9.0 North East Essex

9.1 The pathway in NEE is much simpler in design and delivery than in Suffolk although follows the same principles. The pathway has two main components delivered as follows:

- **HCRG** – Coordination function to receive referrals to access support services and consider access to formal diagnostic pathway.
- **ESNEFT** – Specialist ASD and ADHD formal assessment, diagnosis, support and signposting for children and young people

9.2 The NE Essex element of the NDD deep dive focussed on the following challenges that were identified in the original presentation to SOAC in November 2022;

1. Developing more established links with mental health services.
2. Development of consistent data recording, to inform service developments.
3. Referral demand to voluntary sector organisations and for clinical assessments.
4. Within Suffolk and North East Essex ensuring the offer compliments and feeds the wider SEND agenda across SNEE.

9.3 The Methodology undertaken focussed the work on the Early Support Services in the NDD pathway. The deep dive looked at the existing service specifications, contract discussions and reporting and evaluation requirements. A workshop was held with the four early support providers

- The Maze
- Families in Focus
- Autism Anglia
- Essex Child and Wellbeing Service

where the current challenges were discussed and the feedback from the workshop fed into the findings and recommendations for the deep dive.

9.4 What we found:

1. Links between the NDD early support services providers and mental health services was inconsistent and reliant on individuals understanding of wider service offer. A number of community based emotional health & wellbeing services were not being utilised as services were defaulting to a SETCAMHS referral. These were often inappropriate and resulted in not meeting the threshold and CYP and families being bounced around the system. There was also a lack of awareness about support systems that were available in the system to support practitioners including consultation lines in Children & Families services and SET CAMHS for professionals, weekly early help drop-in sessions, Effective Support Directory and Team around the Family Support Officers (TAFSO). We also found that there was a lack of understanding of the role of Mental Health Schools Teams, and emotional health & wellbeing hubs and how services could support families in accessing these support services.
2. Data recording across the four providers was inconsistent which resulted in the ability to monitor the effectiveness of each service and the pathway as a whole difficult. The data and reporting were focussed on outputs (numbers, waiting lists etc) with little emphasis on outcomes for CYP & families.
3. Providers were increasingly reporting that they were seeing a significant increase in referral demand, this was mirroring the Suffolk and National picture however when we delved a bit deeper we found that the advocate services in particular were supporting families with needs that were not directly related to early support for NDD. With a number of families supported to address housing and employment issues, or with families currently open to

social care, these were often taking up a lot of resource and time for the advocacy services to navigate these complex systems.

4. There were also levels of inconsistency among our early support providers in understanding the wider SEND landscape across Essex. All the providers are represented at the SEND quadrant meetings however more work needs to be established to ensure that the NDD early support services contribute and compliment to the overall SEND work across NE Essex and wider Essex.

9.5 Demand for clinical assessments remains high in NE Essex and this is consistent across the Essex footprint. A data advisory group has been established to ensure there is a consistency in data collection, forecasting and reporting for ASD referrals and waiting lists. This will formulate a collective approach to addressing increased demand and support a system wide approach to resourcing and utilising collective resources rather than costly outsourcing to meet increased demand and pressure.

9.6 Current demand as outlined below demonstrates a continuing increase in requests for assessments for both ASD and ADHD



## ADHD

Ref	Metric				
		Q1	Q2	Q3	Q4
<b>CYP ADHD 1.0</b>	No. weeks from referral to CYP/family receiving first line intervention	<b>27.0</b>	<b>30.4</b>	<b>36.3</b>	<b>42.7</b>
<b>CYP ADHD 2.0</b>	No. new referrals received and accepted onto the ADHD pathway	<b>384</b>	<b>185</b>	<b>336</b>	<b>377</b>
<b>CYP ADHD 2.1</b>	Total no. CYP accepted onto the ADHD pathway and awaiting specialist diagnostic assessment				
<b>CYP ADHD 2.2</b>	No. weeks from acceptance of a referral onto the ADHD pathway to completion of ADHD diagnostic assessment	<b>30.1</b>	<b>39.9</b>	<b>43.8</b>	<b>51.4</b>
<b>CYP ADHD 3.0</b>	Percentage of referrals resulting in ADHD diagnosis	Percentage	<b>75.3%</b>	<b>78.7%</b>	<b>69.0%</b>
		Numerator: no. interventions that led to a positive completion	<b>131</b>	<b>107</b>	<b>129</b>
		Denominator: Total no. interventions completed	<b>174</b>	<b>136</b>	<b>187</b>

## ASD

Ref	Metric					
			Q1	Q2	Q3	Q4
<b>CYP ASD 1.0</b>	No. weeks from referral to CYP/family receiving first line intervention		<b>25.7</b>	<b>30.1</b>	<b>25.2</b>	<b>26.7</b>
<b>CYP ASD 2.0</b>	No. new referrals received and accepted onto the ASD pathway		<b>268</b>	<b>229</b>	<b>257</b>	<b>192</b>
<b>CYP ASD 2.1</b>	Total number of CYP on the ASD pathway awaiting specialist diagnostic assessment		<b>1030</b>	<b>1068</b>	<b>1104</b>	<b>1113</b>
<b>CYP ASD 2.2</b>	No. weeks from onto the ASD pathway to completion of ASD diagnostic assessment		<b>47.0</b>	<b>46.4</b>	<b>47.3</b>	<b>48.1</b>
<b>CYP ASD 3.0</b>	Percentage of completed pathways resulting in ASD diagnosis	Percentage	<b>81.4%</b>	<b>85.4%</b>	<b>81.8%</b>	<b>84.1%</b>
		Numerator: no. pathways completed with positive diagnosis	<b>136</b>	<b>175</b>	<b>166</b>	<b>206</b>

		Denominator: Total no. pathways completed	167	205	203	245
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9.7 The recommendations that came from this work are all listed below and have already been implemented as they were felt to be small changes that would improve the delivery of this pathway and associated services to families.

1. Early Support Services sighted on system wide early support offer (including emotional health and wellbeing support) through engagement in Early Help Drop in Sessions, Start Well (Feel Well Sub Group) and through regular networking opportunities.
2. Consistent reporting and recording system that satisfied national and local reporting needs across all providers. Reporting also focusses on the outcomes for CYP & families that have been achieved as a result of the service support. Outcomes and reporting are aligned to the four agreed ASD ADHD Outcomes and Effectiveness Measures for Essex which have been developed and agreed in conjunction with Essex Family Forum on behalf the families they support. Aligned reporting to ensure that we can demonstrate the impact of individual services and the wider system. Greater scrutiny in contract meetings on performance with support and challenge provided where necessary. Propose quarterly themed face to face meeting to strengthen partnerships, discuss issues concerns and support strategic thinking.
3. The extension of the grants for a further 2 years in September 2023 provides the opportunity to work with the providers to tighten up the current service specifications and add clarity to the support that the service offers and avoiding ambiguity. Early support services to utilise the wider system support mechanisms more effectively and manage the referrals more appropriately. They should be considering signposting to additional support services, e.g. City and District Authorities for housing and employment related concerns where there are resources in place to support, thus alleviating the burden on NDD providers and freeing them to work to support CYP and families NDD needs.
4. NDD early support services to continue to influence the wider SEND agenda across Essex, supported by Essex Family Forum to ensure CYP and families needs and concerns are captured effectively. NDD Oversight Group to report directly into SEND Quadrant meetings and highlight areas of success, development and concern.

9.8 Assessments for ASD are continuing to be outsourced to reduce the backlog. ESNEFT have recently committed to an additional 200 assessments through this mechanism. Whilst this addresses some of the short-term issues, it does not alleviate the continuing increase in demand and inability to staff at a level to meet the increased demand needs.

9.9 To address these challenges investment is required to address the significant increase in demand for ASD assessments delivered by ESNEFT. The service has seen a significant level of increase in demand for ASD Assessment, with the activity data for the years since 2017 in the table below;

Year	Capacity	Demand
2017	416	385
2018	416	399
2019	416	538
2020	416	654
2021	416	872
2022	416	1038

9.10 There has been ongoing dialogue with ESNEFT who have been proactive in developing a recovery plan to support the reduction in waiting lists. They have also invested in outsourcing ASD assessments to reduce waiting times in the short term. However, this proposal will provide a longer term solution to the increased demand.

9.11 When viewing the RTT position and the waiting lists for ASD assessment, it is recommended that the service requires investment in additional staffing.

The request for investment would be to support the additional staffing of;

Band 8 a Psychologist at a cost of £64,798

Band 7 SALT Therapist at a cost of £58,217

Band 7 Neuro Developmental Nurse ( complex caseloads) at a cost of £58,217

Total cost £ **181,232 pa**

9.12 Funding is requested on a recurrent basis or alternatively for a minimum of 2 years.

## 10.0 Support Services

10.1 There are seven support services currently open to families, irrespective of diagnosis. These are commissioned via non recurrent funding, with schemes coming to an end between August and October 2023. Schemes are outlined below:

Service name	Age range	Offer	Location	Value py
Access Community Trust	5 to 25	BEANS support, LEAF network 700 individuals (Community Circle approach)	All Suffolk	£147,655
Families Together Suffolk	<11	60 families py. Home visits, training, What's App group	Not Ipswich	£121,754
Family Action	5 to 25	150 families 1:1 support, 60 families for groups, courses and workshops	West Suffolk	£149,867
Suffolk Family Carers	5 to 25	360 families py Various levels of support, groups, courses, workshops	All Suffolk	£148,734
Green Light Trust	5 to 25	40 CYP over 2 yrs 12wk Woodland courses nr B St Ed and Ipswich	East and West Suffolk	£55,964
Noise Solution	>11	24-26 py 12wk music mentoring programmes virtual/F2F	All Suffolk	£49,500
The Befriending Scheme	14 to 25	260 slots (was 24 ind py) Community Farm experience to support transitioning YP	Sudbury	£26,525

10.2 All but one of the support services are currently operating waiting lists, which means there are families who may benefit from the interventions unable to do so.

10.3 Services are in their infancy and were initially commissioned with consideration of how they may potentially need to evolve over time to reflect the needs of CYP and their families.

10.4 The Befriending Scheme is not being accessed as we would hope and despite meeting on several occasions remains well below capacity.

10.5 Regular individual contract reviews in addition to end of year reviews have taken place with each provider and are available on request. They have indicated services have been appreciated by families, however there is a desire from providers to grow and develop their individual offers.

## Options

10.6 Taking into consideration the end of year reviews and service demand, there are a number of options available for decision:

<b>Option 1:</b> Extend all services <b>with the exception of</b> the Befriending Service which requires further discussion in relation to underperformance/suitability. Services would only be provided for those considered under the NDD pathway, ensuring capacity is prioritised.	
<b>Advantages</b>	<b>Disadvantages</b>
<ul style="list-style-type: none"><li>• Would ensure services continue, whilst reducing the potential demand to access services</li></ul>	<ul style="list-style-type: none"><li>• Whilst not a disadvantage this option would need to have clear protocols in place to ensure referrals to voluntary services are agreed via an appropriate route</li></ul>
<b>Option 2:</b> Extend all NDD support services in their current format.	
<b>Advantages</b>	<b>Disadvantages</b>
<ul style="list-style-type: none"><li>• Would allow for continuity of services, in line with the initial commissioned model</li></ul>	<ul style="list-style-type: none"><li>• Would not take into consideration the issue with The Befriending Scheme places not being used.</li></ul>
<b>Option 3:</b> No longer commission the support service organisations	
<b>Advantages</b>	<b>Disadvantages</b>
<ul style="list-style-type: none"><li>• Would reduce the financial commitment from the ICB</li></ul>	<ul style="list-style-type: none"><li>• Would result in families waiting on the NDD pathway being unable to access any support services at a time of growing demand</li></ul>

### Preferred option

10.7 Option 1 would allow for the continuation of support services, whilst taking into consideration the fact that one, the Befriending Scheme has not been accessed to the extent hoped. This option would also allow for the families to where possible “wait well” whilst they are going through the NDD pathway.

## 11.0 Procurement

11.1 The contract for the coordination function will end in October 2023 and will need to go through a procurement process which will commence in May 2023.

11.2 The value of the contract will be £411k per year as per finance section above (8.2) and we would expect the new contract to be a minimum of 5 years plus an option to extend of a further 5 years. Total contract value for 5 years would be in the region of £2,055k plus annual uplifts when agreed and similar for the 5 year option to extend.

11.3 We will be potentially advertising the contract through the framework that is already established, however there are alternatives to this listed in the options below.

11.4 We have developed a revised service specification based on the recommended changes and in its draft form which has not been coproduced is included in Appendix F for information only as it is likely to change.

11.5 After discussions with the procurement team there is an option to direct award to SCC who have already indicated a willingness to deliver this service as part of the SCC health offer.

11.6 An initial discussion with Barnardo's has taken place around their intention relating to future delivery of the function and they are also keen to deliver the function in the future.

### Procurement options

<b>Option 1</b>	<b>Through the framework</b>	<ul style="list-style-type: none"><li>• SCC will be excluded from this option.</li></ul>
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		<ul style="list-style-type: none"> <li>• Day 1 release opportunity</li> <li>• Day 35 receive tenders</li> <li>• Day 65 complete moderation and evaluation</li> <li>• Need sign off before awarding – so if below £3M can go to Exec Committee (weekly) but if over £3M total contract then it will need to go to Board which sits bi-monthly</li> <li>• Then up to 3 months mobilisation with TUPE</li> </ul>
<b>Option 2</b>	<b>Open market tender</b>	<ul style="list-style-type: none"> <li>• SCC will be included in this option.</li> <li>• Day 1 release opportunity</li> <li>• Day 49 receive tenders</li> <li>• Day 79 complete moderation and evaluation</li> <li>• Need sign off before awarding – so if below £3M can go to Exec Committee (weekly) but if over £3M total contract then it will need to go to Board which sits bi-monthly</li> <li>• Then up to 3 months mobilisation with TUPE</li> </ul>
<b>Option 3</b>	<b>Direct award to SCC</b>	<ul style="list-style-type: none"> <li>• Release PIN (best to do this but don't have to) asking for interest – 30 days – this then informs whether we can award through a VEAT as tells us who is /isn't interested</li> <li>• Assuming no interest – release VEAT (Voluntary Ex-Ante Transparency Notice) 10 days</li> <li>• Assuming again no interest award through a waiver and release contract notice.</li> <li>• Mobilisation of service and TUPE up to 3 months</li> </ul>

11.7 Due to the fact that there are more than one interested organisation in providing this function we have no option other than to recommend option 2 as the preferred option.

11.8 We will begin the initial stages of the procurement process from May and expect completion by 31<sup>st</sup> March 2024. Although the timeframe quoted in option 2 suggests that we could complete the process by February we feel that tying it in with the new financial year not only makes sense but also gives 4 to 6 weeks slippage should it be needed.

11.9 The current contract with Barnardo's is due to expire in October 2023, we are recommending it is extended to 31<sup>st</sup> March 2024.

## 12. Communications Strategy

12.1 A consistent theme which has been highlighted through each of the workstreams and via parents and carers is the need to have a transparent communications strategy to ensure the pathway is clear and understandable for both families and professionals. Whilst this was not initially highlighted as an area of focus within the deep dive, it was clear that in order to ensure the pathway is understood a comprehensive and consistent communications strategy would need to be considered. Initial conversations have taken place and a communications strategy will be completed as a matter of urgency.

12.2 Clear and comprehensive outline of the NDD pathway on the Local Offer Website, including waiting times and an overview of the pathway. This would need to compliment the work of colleagues within Suffolk County Council, such as the Specialist Education Team and the Psychology and Therapy team. This is particularly relevant in light of the number of referrals who are not appropriate for the NDD pathway and require support from partners.

12.3 Proactive communications with colleagues in Primary Care and schools to ensure any agreed amendments are understood across the system. This would include interactive workshops, supported by written communications.

12.4 An update re the outcomes of the Deep Dive provided to the Suffolk Parent Carer Forum and a regular update given to families so they are aware of the system pressures. Families have reported a worry that not knowing what is happening causes an additional pressure during an already challenging time.

12.5 Recommendation that this strategy is coproduced with service users and other professionals to ensure the language and structure of the information is helpful and include campaigns and advice as recommended through Public Health.

## Appendix A



All referrals should be made using this referral form, completed by a professional who has met with the child and family.

In order that we are in the best position to understand a child or young person's needs it may be that this form is completed by one or more professionals (such as health and education) and is supported by parents/carers or there is liaison between the networks or people involved.

It is always ideal for the professional who knows the family best to complete the referral form.

*Please consider if you have the best professional knowledge of this young person if not it may be appropriate to ask the professional who knows the young person best to complete this referral?*

**Please note a referral for an autism or ADHD assessment does not preclude input from other services if there are identified needs that warrant support.**

In order for this referral form to be processed all sections **must** be completed. School observations and additional reports can be provided for additional supporting information only. Please reference guidance for further details.

### REFERRAL REQUEST

Please tick all that are relevant.

- ☐ Autism Assessment - Complete **All** sections.
- ☐ ADHD Assessment - Complete **All** sections.
- ☐ Support Services

### SECTION ONE: Lead Professional and referrer's details

Lead Professional's name:	
Job Title:	Agency:
Address:	
Email Address:	Contact Number:
Date of request:	
As the lead professional I understand that I and/or my service hold the primary responsibility for the young person's care and for actioning any onwards referrals and recommendations from this request, whether the young person is accepted for a NDD assessment or not.	
Referrer Signature:	

### Other referrer's details (if applicable)

Referrer's name:	
Job Title:	Agency:
Address:	
Email Address:	Contact Number:

### SECTION TWO: Child and Family Details

#### CHILD/ YOUNG PERSON'S (CYP) DETAILS

Full Name:	Date of Birth:
Name they prefer to be called if different:	Age:
NHS Number:	Religion:
Gender at birth:	Ethnicity:
Gender young person identifies as:	
Preferred pronouns: (e.g., he/his/him, she/her, hers, they, them, theirs)	
Address:	
Postcode:	1 <sup>st</sup> Language (if not English): Interpreter required? Yes/no

#### PARENT/ CARER INFORMATION

Full Name:
Address:
Relationship to CYP:
Holds full parental responsibility? Yes / No
Phone number:
Email address:



Preferred mode of contact (letter, telephone, email):
---

If parent/ carer(s) above do not hold full parental responsibility, provide details of person who does or who parental responsibility is shared with:

Full Name:	Relationship to Young Person:
Address	
Phone Number:	

<b>GP</b> Name and address: ..... Tel No:.....
---

### SECTION THREE: Consent

#### CONSENT

Is the child / young person aware of this referral to Children and Families Autism Service and is consent given? Yes / No. If no, details:

Is the parent / carer aware of this referral and is consent given? Yes / No. If no, details:

If the referral does not meet Children and Families Autism Service criteria, are the family happy for us to pass it on to any other relevant agency? Yes / No

#### Consent to Contact

The service will assume parental consent for the autism/ADHD service to contact other professionals (to include education and health) for additional information to support the referral, if you **do not** wish the service to contact other professionals identified above. Please indicate below:

☐ All relevant services

List specific services/ professionals: .....

Please indicate below for parental consent to receiving correspondence from the service electronically via email

☐ Yes

☐ No

If yes please provide email address: .....

### SECTION FOUR: EDUCATION

#### SCHOOL/EDUCATION

What academic year is the young person in: Year.....

What educational provision is the young person at (please tick the appropriate box below):

Mainstream education:	Specialist education:	Home school:	Not in education:
-----------------------	-----------------------	--------------	-------------------

Current school/nursery name and address with postcode:	Contact details for SENCo: Name: Telephone: Email:
--	---

Any known previous education provision name and address and postcode:	Name: Telephone: Email:
---	-------------------------------

Is the young person due to move education settings within the next calendar year?	YES/NO
---	--------

If YES, please state where and for what reason: (e.g., transitioning to secondary school)	Name: Telephone: Email:
--	-------------------------------

#### Academic attainment

For a complete picture of the child, it is critical that education information is provided where the young person attends nursery school or college. please attach an educational report or explain why if none is attached

Estimated reading age:	Estimated spelling age:
------------------------	-------------------------

Do you have the results of any educational test or assessments the young person has recently undertaken? If available, please provide a copy of the assessment with this referral.

Is the young person academically on target which is in line with their peers?	
---	--

Does the young person have any known learning difficulties or disabilities?	
---	--

Does the young person require learning and/or behaviour support in school?	
--	--

If the young person is not in education, what other services are involved with supporting the young person's education?	
---	--

Has the young person got an Education & Health Care Plan in place?	YES / NO
--	----------

If YES, when was it last reviewed?	Date:
------------------------------------	-------

Has the young person got an Education & Health Care Plan in progress? Please provide details of stage reached.	YES / NO
--	----------

## SECTION FIVE: Service Involvement

### OTHER PROFESSIONALS AND SUPPORT INVOLVED

Please tick, and provide details and reports, if the following agencies are involved or referred to currently or in the past:

Please provide contact details for any selected details of involvement

- ☐ 0-19 Service (health visitor/ school nursing)  
☐ CAF/TAF  
☐ Family support, Early Help, social care  
☐ Paediatrics (acute or community)  
☐ ASD Service (Integrated Community Paediatric Service/ADYSS)  
☐ ADHD Service  
☐ Speech & Language Therapist  
☐ Audiology  
☐ Educational Psychologist  
☐ Learning and/or behaviour support services in school  
☐ Occupational Therapy  
☐ Dietitian  
☐ Child and Adolescent Mental Health Service (CAMHS)  
☐ SES  
☐ Analysis of Additional Needs Tool (AANT)  
☐ Youth Offending Service  
☐ Other, please indicate .....

Please provide details of involvement below:

## SAFEGUARDING & RISK

### SAFEGUARDING

*Please ensure to follow your own organisation's safeguarding policies and protocols. Please note a referral for an autism or ADHD assessment does not preclude input from other services if there are identified needs that warrant support.*

Are there any or have there ever been any safeguarding concerns in relation to the young person and/or their family? YES/NO

If YES, please give brief details below, including agencies involved:

### RISK

Are there any identified risks to self or other? YES/NO

If YES, please give brief details below, including risk management plan:

Has the young person historically or do they currently engage in self-harming behaviours? YES/NO

If YES, please tick and provide brief details below:

Cutting	Pulling hair	Picking or Scratching at skin	Burning their skin	Misusing substances such as medication, drugs and/or alcohol
Hitting self or walls	Biting	Over or under eating	Over or under exercising	Intentionally engaging in risky behaviours

#### Details of self-harm:

(Please include information about the length of time, intensity, and frequency of the behaviour(s))

## SECTION SIX: Assessment

### Referral Reason

Please identify all areas of concerns for the young person in the below boxes:

*Please tick all that are applicable*

- ☐ Social Skills  
☐ Communication and language skills  
☐ Behavioural difficulties  
☐ Intellectual/learning disabilities  
☐ Concern about learning  
☐ ASD  
☐ ADHD  
☐ Mental Health

Please provide information about the child with reference to strengths and difficulties within identified areas. Examples must be given for each point provided, for example referrer's own observations. This information is important to ensure a timely process.

### Social Communication

Please provide information from your own observations and experiences of the young person's ability to communicate reciprocally with others both verbally and non-verbally. You may wish to consider:

- Does the young person integrate non-verbal communication (eye contact, gestures, facial expressions, body language) with their spoken language?
- Is there anything unusual about the quality, intensity, or frequency of the young person's non-verbal communication?
- Is there anything unusual about the young person's speech? Consider their use of language, tone, pitch, pace, and volume.
- What is the young person's expressive language like (use of words, gestures and writing to convey meaning and messages to others)? Does this appear exceptional or different to their peers?

Please give your specific examples below:

### Social Interaction

Please provide information from your own observations and experiences of how the young person interacts with peers/adults/family/professionals. You may wish to consider:

- Can the young person engage in a reciprocal conversation? Are they able to participate in the back-and-forth conversation?
- Does the young person show interest, understand, and respond appropriately towards others?
- How does the young person respond to the opinions, thoughts, and feelings of others? Is this in keeping with their age and peers?
- Does the young person seek company of others?
- Are they able to make and maintain friendships? Are their friendships of a similar age? Do they share similar interests?
- Do they or have they experienced any difficulties within friendships? Do they appear to be very loyal to a particular friend?
- Does the young person have social awareness? Can they modify their behaviour to social situations? For example, are they overly formal or inappropriately familiar?
- Do they have an awareness of socially expected behaviours such as greetings, farewells, sharing, personal space, correcting teachers or others.
- Do they appear overly mature/immature in comparison to their peers?

Please give your specific examples below:

### Rigid Behaviours and Thinking

Please provide information from your own observations and experiences of the young person's areas of interest, factors that could affect the child, rigid cognitions, ability to manage change. You may wish to consider:

- How does the young person respond to new experiences? Consider change in both familiar environments such as home and school, as well as their responses to unanticipated events.
- Does the young person have fixed routines? For example, precise timings, certain orders to complete tasks in, how do they respond if this is changed?
- Does the young person have a strong adherence to follow rules or a strong sense of justice? E.g., rules when playing games or at school.
- Has the young person ever had any repetitive or stereotyped movements? Such as hand flapping, spinning, body rocking, finger flicking.
- Does the young person have any ritualised behaviours with no external purpose? E.g., lining up or sorting of objects.
- Has the young person ever had an unusually strong attachments to particular objects (excluding comforters)? Have they ever collected or hoarded objects?
- Does the young person have one or more specific interests that are overly focused or unusual? Do they have a particular interest that they have specialist in-depth knowledge about which brings them great pleasure?

Please give your specific examples below:

### Sensory

Please provide information from your own observations and experiences of areas of sensory interest or sensitivity they have noticed e.g., taste, smell, texture, visual, hearing. You may wish to consider:

- Does the young person have excessive and persistent over or under reactive responses to sensory stimuli? This may include actual or anticipated sounds, lights textures (clothing and/or food), odours and tastes, heat, cold or pain.
- Does the young person have an unusual interest in certain sensory stimuli?
- Does the young person find pleasure in certain sensory experiences?

Please give your specific examples below:

### Attention/Concentration

Please provide information from your own observations and experiences of how the young person demonstrates a persistent pattern (e.g., at least 6 months) of inattention symptoms and how this is impacting on their academic and social functioning. You may wish to consider:

- Does the young person have difficulty sustaining attention to tasks that do not provide a high level of stimulation or reward?
- Does the young person become easily distracted by stimuli or thoughts not related to the task at hand?
- Does the young person appear to have difficulties listening when they are spoken to directly?
- Does the young person frequently appear to daydream or have their mind elsewhere?
- Does the young person often lose things?
- Does the young person have difficulty remembering to complete upcoming daily tasks or activities?
- Does the young person have difficulty planning, managing, and organising schoolwork, tasks, and other activities?
- Does the young person produce schoolwork to a high calibre?
- Does the young person appear to be a 'model' student?
- Are these behaviours evident across a range of situations or settings (e.g., home, school, with friends or relatives)?

Please give your specific examples and timeframe for how long these behaviours have been present below:

#### Impulsivity

Please provide information from your own observations and experiences of how the young person demonstrates a persistent pattern (e.g., at least 6 months) of hyperactivity and how this is impacting on their academic and social functioning. You may wish to consider:

- Does the young person demonstrate excessive motor activity, such as leave seat when expected to sit still, often runs about, has difficulty sitting still without fidgeting (younger children), restlessness, a sense of discomfort with being quiet or sitting still (adolescent and adults).
- Does the young person have difficulty engaging in activities quietly; talks too much.
- Does the young person blurt out answers in school and/or difficulties waiting turn in conversation, games, or activities? Does the young person interrupt or intrude on others' conversations or games?
- Does the young person have a tendency to act in response to immediate stimuli without deliberation or consideration or risks and consequences (e.g., engaging in behaviours with potential for physical injury, impulsive decisions)?
- Are these behaviours evident across a range of situations or settings (e.g., home, school, with friends or relatives)?

Please give your specific examples and timeframe for how long these behaviours have been present below:

**Other Information-** Please provide details of any other diagnosis, support plans etc. Please provide dates of diagnosis or any actions taken to date

#### Developmental History

Were there any known pregnancy or birth complications? For example, prematurity born <37 weeks, preeclampsia, gestational diabetes, infection, low birth weight, birth trauma or injury.

Has the child or young person experienced any significant life events? For example, bereavements, marital/family breakdown, parental mental health concerns, domestic violence, bullying, abuse, addiction etc.)

At what age did the young person achieve their developmental milestone for:

Walking:

Talking:

Toileting:

Where you aware of any developmental delays, if so what:

#### Medical History

Has the young person experienced ever any significant illnesses or injuries? If so, please provide details and timeframe.

Is the young person, or have they ever been prescribed any long-standing medication? If so, please include any previous and current medication, dosages and when it was started/stopped. Along with any side effects or reasons why a medication was discontinued. Please also include details of current prescriber e.g., GP.

Is there a family history of neurodevelopmental disorders within the family? Please state what relation they are to the young person and if they have received a formal diagnosis.

## SECTION SEVEN: Parent/Carer's Views

### Referral Reason

Please identify all areas of concerns that you are concerned about for your child in the below boxes:

Please tick all that are applicable

- |   |   |
|---|---|
| <input type="checkbox"/> Social Skills                      | <input type="checkbox"/> Concern about learning |
| <input type="checkbox"/> Communication and language skills  | <input type="checkbox"/> ASD                    |
| <input type="checkbox"/> Behavioural difficulties           | <input type="checkbox"/> ADHD                   |
| <input type="checkbox"/> Intellectual/learning disabilities | <input type="checkbox"/> Mental Health          |

### Describe current difficulties/ needs

It would be helpful to understand the how your child or young person's presents in more detail, e.g., what are your current main worries- this may be at home, school or elsewhere. When did these concerns start to occur, what context, what was/is the response, the intensity.

### Timeframe of current difficulties

Please provide information around longevity of the difficulty/need. What age did these concerns begin? What areas have previously been tried e.g., accessed workshops, strategies, support services? What difficulties have not improved despite the use of appropriate interventions and strategies?

### What could be better?

At present, what would be the most helpful areas of need to address that would help the young person.

### Is there anymore that you can add to provide a picture of your child?

For example, likes/dislikes, their social skills, routines, friends/attachments, sleep or eating patterns, what makes them happy/anxious/sad. Their strengths and aspiration.

## SECTION EIGHT: Child/Young Person's Views

This section is optional and for young people 11+

This form is all about you!

Below are some questions that will help us understand what you like and don't like and how you feel.

You can draw or write and can share as little or as much as they would like.  
(Please leave blank if do not want to complete it)

### What is important to me e.g., hobbies, friends, family, every day?

### Am I safe?

### What is good now? This may be at home, at school or elsewhere.

### What could be better? This may be at home, at school or elsewhere.

### What are my main worries? This may be at home, at school or elsewhere.

### What would I like to gain from having an assessment?

### If I need an assessment:

#### What things will make the assessment go well?

Such as, things you do or do not want to happen on the day, any help you need with the assessment(s), how you want people to communicate with you.

### What things will make the assessment more comfortable for you?

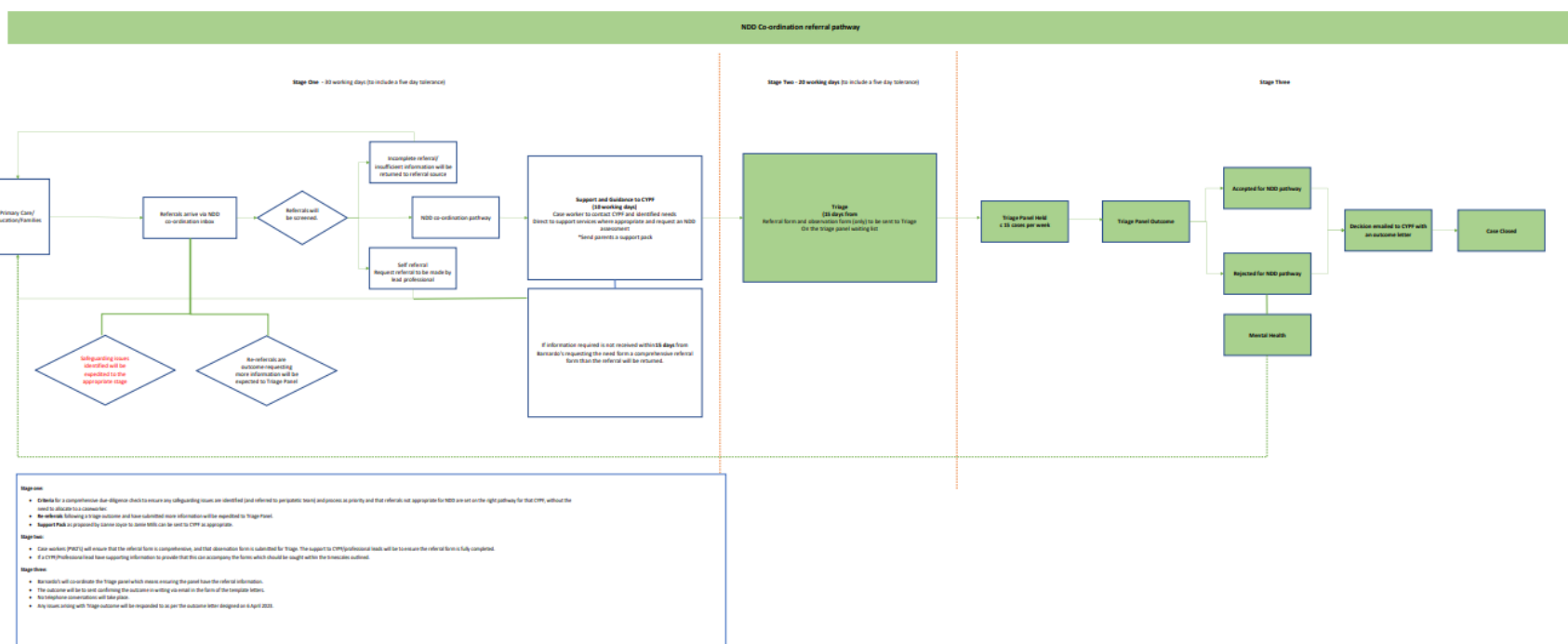
Such as lighting, certain sounds to help me feel calm or not too much noise, things to help me feel calm in the room, things for me to play with in the room, things on the wall for me to look at, not too many things on the walls, certain people or objects being with you.



## Appendix B



Process%20Map%20  
Excel file %20-%20NDD%20co



## Appendix C



Portsmouth ND  
Profiling Tool - Trainir

## Portsmouth Profiling Tool



### Portsmouth ND Profiling Tool - Main Profile

Name and DOB of young person:

Names and roles of people completing this form & Date Started: DD/MMM/YYYY

		Average				
Speech and Language Ability	Low					High
Energy Levels	Low					High
Attention skills (O) and Impulse Control (X)	Low					High
Emotion Regulation Skills	Low					High
Motor skills	Low					High
Sensory Needs	Low Needs					High Needs
Flexibility and Adaptability	Low					High
Systemising and Empathising	Low					High
Cognitive Abilities	Low					High



## Portsmouth ND Profiling Tool - Main Profile



\_\_\_\_\_ is at their best when:

It is more difficult for \_\_\_\_\_ when:

Sensory Description

What else can explain (name of the child)'s profile:

Other comments:

Resources/strategies and adaptations required:

This plan will be reviewed -

**Signed Agreement that the party member has fully read through the profile and will agree to work on the resources an strategies mentioned above**

**Professional Signature**

**Professional Name**

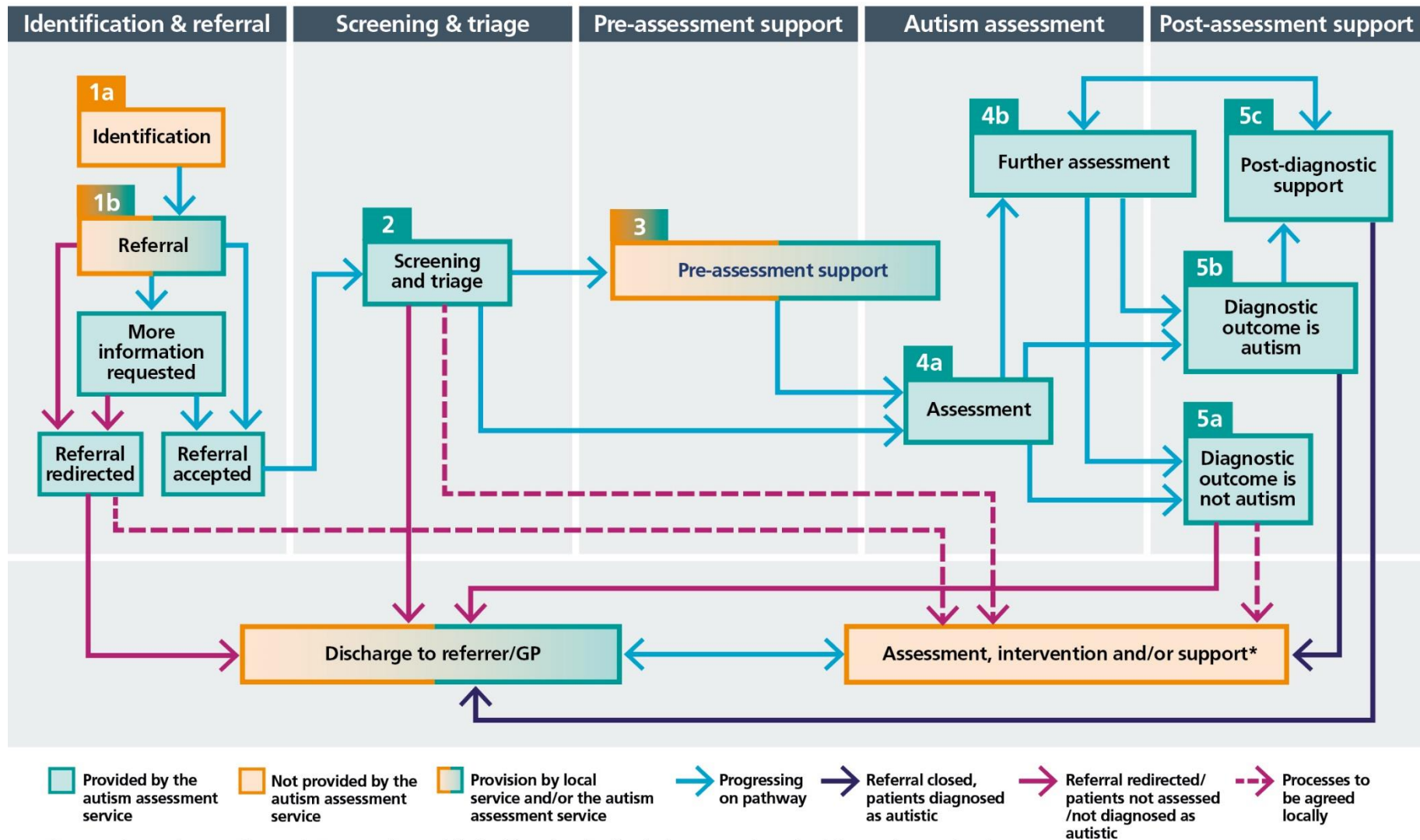
**Parent/Carer Name**

**Parent/Carer Name**

## Appendix D

Setting	Professional
Health	GPs Paediatricians Psychiatrists Nurses Clinical, counselling or forensic psychologists Occupational therapists Speech and language therapists Health visitors
Social care	Social workers Occupational therapists Speech and language therapists
Education	Educational psychologists Speech and language therapists Special Educational Needs Co-ordinators Teachers at schools or colleges Nursery teachers
Criminal justice	Probation officers Professionals working in court Forensic psychologists

# The Autism Assessment Pathway



## Appendix E

### Potential wording for Local Offer

#### NDD relaunch

Introduction to the relaunch of the Neurodevelopmental Pathway for Families in East and West Suffolk, we are launching the revised Neurodevelopmental Pathway which will replace the old separate pathways for Autism and Attentional Difficulties (ADHD). This document will explain why the pathways are changing and how the new pathway will operate.

#### Why are we making changes?

Autism and ADHD are both medical diagnoses and are by far the vast majority of referrals that are coming in to the pathway. To decide whether a child or young person meets the criteria for either condition, they need to have a comprehensive assessment to see if their difficulties meet the diagnostic criteria. This is always done by a multi-disciplinary team that considers information from a range of different settings. In East and West Suffolk, we have always had three separate pathways, one that looks at the diagnostic criteria for Autism under 11, one that looks at the diagnostic criteria for Autism over 11 and one that looks at the diagnostic criteria for ADHD. These pathways have worked well for many children and young people. There have however been several children and young people who have presented with difficulties linked with BOTH conditions, and sometimes it has taken a long time for them to have their difficulties fully assessed and understood. The new Neurodevelopmental Pathway will be able to assess for both conditions at once, ensuring that children and young people get a single assessment that fully explores all their strengths and difficulties.

#### What does Neurodevelopmental mean?

The term “neurodevelopmental” refers to a collection of problems that are linked to the way the way the brain has developed, since birth. The two most common neurodevelopmental disorders are Autism and Attention Deficit Hyperactivity Disorder (ADHD). There are other neurodevelopmental conditions, such as Sensory Processing Disorder, Developmental Co-ordination Disorder (dyspraxia), specific learning difficulties, Foetal Alcohol Spectrum Disorders, tic disorders such as Tourette’s and many others. **The East and West Suffolk Neurodevelopmental Pathway is not currently commissioned to assess for these conditions.** We are only able to accept referrals where the main presenting difficulties are suggestive of Autism or ADHD or both. These include significant and persistent difficulties with:

- Understanding other people’s thoughts and feelings.
- Emotional regulation.
- Listening and attending to the teacher in school.
- Getting on with peers and maintaining friendships.
- Controlling impulses and making safe choices.
- Speech, language, and communication.
- Flexible thinking and coping with change.
- Behaviours that are rigid, repetitive, or obsessive.

If these difficulties are neurodevelopmental in nature, they will have been present at some level throughout childhood. For example, if a child presents with Autism, there are usually indicators of some degree of difficulty in the first three years of the child's life, although the difficulties might not cause a problem until the child is older. There are however other reasons why children and young people might demonstrate some of the behaviours above. These reasons can include learning difficulties; developmental trauma; exposure to a stressful home environment; an illness or brain injury; and many others.

The role of the Neurodevelopmental Pathway is to undertake a comprehensive assessment to develop a better understanding of a child or young person's needs, including whether a child or young person meets the diagnostic criteria for a diagnosis of Autism, ADHD, or both.

## Referral Process

To access the Neurodevelopmental Pathway, families will need to ask a professional to work with them to complete the Neurodevelopmental Referral form. You can download a copy of the referral form here (***Insert link***). This is a detailed form that will gather information about how your child or young person presents, their difficulties and strengths, both at home and in their school. The ideal person to help you complete the form is the Special Educational Needs Co-ordinator (SENCo) in your child or young person's school. We use the information included on the referral form to decide about whether further neurodevelopmental assessment is indicated. It therefore needs to include as much information as possible, and it is important that we have a picture of how your child or young person is getting on both at home and at school. If the school SENCo is unable to complete the form, you could ask another professional who knows the child or young person well such as their class teacher, school nurse, speech and language therapist, Paediatrician, or family support worker. We ask that you include any historic reports that professionals have completed about your child or young person. If your child or young person has ever met with a psychologist, advisory teacher/SEND support worker, Portage worker, speech and language therapist or paediatrician in the past, their letters or reports often contain valuable information that we need to be aware of.

## Multi-agency Neurodevelopmental Pathway Triage Panel

Once the referral has been completed, we ask that you e-mail it into the Neurodevelopmental Team (***Insert link or email address***). The referral form will then be shared with all the members of the multi-agency Neurodevelopmental Pathway Triage Panel. The panel is attended by representatives from ***health, etc.*** The panel will consider the information included in the referral form alongside information that is held about your child or young person by the services represented. The panel will use all the available information to decide whether your child or young person needs a neurodevelopmental assessment. The panel will also consider what other sources of advice and help might be useful and how it might be accessed. The panel will then write a brief report explaining whether your child or young person has been accepted onto the Neurodevelopmental Pathway and all the suggested recommendations. Once your child or young person has been accepted onto the Neurodevelopmental Pathway, there is likely to be a wait until the assessment begins (***insert waiting time***). We work through all new referrals in the order that we receive them. During this wait, advice and support may already be available or may be sought from the support system outlined below (***list support services and links***).

## 1 SCHEDULE 2 – THE SERVICES

## A. Service Specifications

Service Specification No.	1.0
Service	CYP NDD Coordination Function & Mental Health & Wellbeing Helpline
Commissioner Lead	SNEE Integrated Care Board
Period	March 2024
Date of Review	TBC

## 1. Population needs

Within the new guidance published on 5th April 2023, it has been recognised there has been a considerable increase in requests for both ASD and ADHD assessments. NHSE are now recommending that all commissioned services relating to the diagnosis of Autism should be commissioned at a rate of up to 2.6% of the population, currently we commission at around 1.4%. The national prevalence rate is around 1.7% and to reduce wait times in accordance with national policy commitments, 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.

Nationally, recent increases in the numbers of children diagnosed with neurodevelopmental disorders such as autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD), has led to growing demand on clinical services (Male, Farr and Reddy 2020). Diagnostic rates of ASD in the UK have seen an exponentially increase of 787% between 1998 and 2018, and a suggested 400% increase in individuals seeking an ADHD diagnosis since 2020 respectively (ADHD foundation). This pattern of increasing referrals seeking assessment for possible NDD has also been seen in Suffolk, with an 80% increase being seen in some local services.

Based on the helpline demand over the last year, it is envisaged the helpline will receive in the region of 350 calls a month. We are seeing a breath of call type queries but with most callers making enquiries regarding support and information on ASD, anxiety, ADHD and NDD pathway & Hub referrals.

## 2. Key Outcomes

1.1

1.2 **NHS Outcomes Framework Domains & Indicators:**

Domain	Description	Applicable
Two	<b>Enhancing quality of life for people with long-term conditions</b>	
Four	<b>Ensuring people have a positive experience of care.</b> 4.1 Improving people's experience of outpatient care. 4.4 Improving access to primary care services. 4.9 Improving people's experience of integrated care	4.1 4.4 4.9
Five	<b>Treating and caring for people in safe environment and protecting them from avoidable harm</b>	

1.3

1.4 **Local Defined Outcomes:**

### 3. Scope

This is one service, operating two functions Neuro Developmental Disorders coordination function (NDD CF) and Mental health (MH) & Wellbeing helpline. The service will in most cases be the first point of contact for families and professionals entering the neurodevelopmental pathway and will be responsible for co-ordinating all activities from referral enquiry to triage outcome. Which sits in the 'getting more help' quadrant. The MH & Wellbeing Helpline, which sits in the 'getting advice' quadrant and will support families, children and young people with initial support and signposting for mental health and wellbeing queries.





The Thrive Framework is an integrated, person centred, and needs led approach to delivering mental health services for children, young people and their families that was developed by a collaboration of authors from the Anna Freud National Centre for Children and Families and the Tavistock and Portman NHS Foundation Trust

#### **Aims and Objectives of the Service:**

- Will support families in understanding and navigating the neurodevelopment pathway.
- Will guide families through the referrals process and help identified appropriate support for families whilst they are on the pathway.
- Will work with other system pathways and partners where appropriate to redirect and support incoming referrals.
- Will develop a robust understanding of Suffolk support services and their offer, particularly related to mental health, wellbeing and NDD.
- Will foster and develop positive relationships with Suffolk's services including but not limited to (VCSE, NHS Trusts, local authority services)
- To be a visible and accessible resource that will enable families to approach their care the way they want and more positively, nurturing their confidence.
- To empower callers through information to make their own choices about how their healthcare needs may be met.
- To promote mental wellbeing and reduce stigma.
- Help families identify appropriate support before reaching crisis.
- Increased resilience of parents and carers and CYP

#### **Service description/care pathway:**

**The service will work in line with the developed standard operating procedure (SOP) and will cover following but not limited to.**

- Work as part of a wider multi-disciplinary team (MDT).
- Will work with the clinical lead to check the neurodevelopmental pathway is appropriate for the child or young person who has been referred in and, in the case, where they may not be, signpost them to more appropriate services.
- With oversight from the clinical lead will provide information and guidance where needed on completing the referral form.
- With oversight from the clinical lead, screen referrals and identify where a need for an (NDD) assessment is clear and apparent, to send directly to the identified assessment pathway.

- With oversight from the clinical lead prepare referrals for Triage panel, where more complex needs have been identified and that require (MDT) review and input.
- Provide advice and support for families around available commissioned NDD support services and wider local support. (NDD commissioned support services should be accessed on the basis of a referral being accepted on to the NDD pathway).
- Will provide accurate and timely responses to queries.
- Keep families and the lead referrer up to date with where the referral submission is in the pathways and the outcome of the referral.
- Will record all enquiries and agreed actions.
- Coordinating all triage meetings and associated paperwork, including logging triage outcome, and forwarding referral form and supporting information to assessment pathways where required.
- Coordinating and communicate triage outcomes to family/lead refer (as directed from the Triage panel and clinical lead).
- Coordinate and respond to all complaints and queries dissatisfaction. Where clinical input is required, the coordination function should seek guidance from the clinical lead.

## **MH & Wellbeing Helpline**

The Helpline is a function for those looking for general wellbeing information, guidance, and resources to address common emotional wellbeing issues, such as, anxiety, low mood or stress, or if they are looking for self-help support to stay emotionally well or need help signposting to useful support services.

- To listen to families, children and young people's and understand their needs and desired preferences for support.
- To provide accurate and high-quality Information, advice, and guidance to assist with meeting their needs.
- To have a focus on early intervention and prevention with the priority of keeping children and young people safe.
- Signposting means alerting a young person or their family to resources external to that of the person giving the advice. This support should build on existing family resources.
- Inform individuals of the possible options available and the possible benefits.

The service will **not**:

- Be responsible for completing the referral form or adding to the information. Incomplete referral forms will be sent back to the referrer.
- Be case holding. Health and Care professionals involved with the family will retain professional responsibility within their own area of practice.
- Provide diagnosis of Neurodevelopmental disorders (NDD)
- Attempt to give clinical advice or input to referral enquiry or outcome.
- Should not fast track any referrals unless risk has been identified and approval from the clinical lead is given.
- Provide services for (NDD) (the coordination function will liaise with those who do).
- The helpline will not initiate referrals on behalf families/CYP.
- The helpline is not a clinical service and does not have access to medical records and cannot give clinical or medical advice.

### **Access to service:**

Referrals for the Neurodevelopmental pathway will come mostly via school professionals but in some cases health and social care professionals and emailed into the coordination function.

### **Acceptance criteria:**

Over 25 years old, not registered with a Suffolk GP. Incomplete and inappropriate referrals (these are referrals that do not require ASD and/or ADHD assessment or support) forms will be returned to the referrer. Excludes Waveney. The pre-school pathway is not accessed via the NDD CF.

**Workforce:**

The service will: Ensure staff are recruited with the appropriate skills to meet need and requirements of the service. The staffing structure meets demand, the requirements of the service. Staff will cover each other's annual leave and long-term sickness or maternity exceeding 3 months will be covered with bank/agency or fixed term practitioner.

There will be an expectation the service will include a clinical lead role.

(The staffing is dependent of the current level of funding allocated to the service, there may be future opportunity to be flexible with the design and makeup of team).

**Days/Hours of service**

09:00 -17:30, Monday-Friday (excl. bank holidays)

**4. Applicable Service Standards****Applicable national standards:**

- NICE Guidance for children and young people with Autism (2014)
- NICE Guidance for children and young people with ADHD (2014)
- NICE Guidance applicable to children and young people mental health and emotional wellbeing
- National Mental Health strategy (2011)
- Every Child Matters (2003)
- Children and Families Act (2014).
- Future in Mind (2015)
- SEND code of Practice (2015)
- [National strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026)
- [NHS England » National framework and operational guidance for autism assessment services](https://www.nhs.uk/clinicalguidance/national-framework-and-operational-guidance-for-autism-assessment-services/)

**Applicable local standards:**

- Joint Strategic needs Assessment (JSNA)
- Suffolk's SEND Strategy 2021– 2023 and any updated versions: [Suffolk InfoLink | SEND Strategy 2021-2023](#)
- Any other applicable Local Offer

**Consent and Confidentiality:**

The provider will ensure that all staff are made fully aware of their responsibilities and obligations to respect confidentiality and are supported by the policies of their employer.

**Staffing:**

The Service provider shall supply professionally trained; staff qualified to meeting requirements of the defined service. The Provider must ensure that all staff receive a comprehensive induction and are aware of the services policies, procedure and standards.

**Monitoring information requirements:**

The provider is to provide monitoring reports on performance measures, and service experience feedback from young people, families, and carers.

**Safeguarding:**

This service is part of local safeguarding systems. The service will adhere to national and local procedures and guidance to safeguard children and young people and will also adhere to the local policies. All staff working with children and young people will have undertaken an enhanced Disclosure and Barring Service check. The Service will also contribute where appropriate to safeguarding training.

## 2 5. Information and Technology

The Provider must ensure that there are sufficient systems and databases in place to support the Service requirements, including but not limited to:

- The service should have the ability to store and record referral information and supporting information in line with GDPR protocols, as well as having the ability to supply referral information and data on request, if required.
- Is sufficient to manage the volume and type of information/data.  
The service will also be required store referral forms and any supporting information provided, on system one.
- Supports service user information to be transferred back to the commissioner /a new provider at the end of the Contract at no extra cost to the ICB.
- The service will be required to use and interface with System one
- Support requirements of the Data Protection Act 2018, and Freedom of Information Act 2000
- Provide a telephony system.
- Identify and map out appropriate call behaviour scenarios (routing options)
- Interoperate with our hosts Interactive voice response (IVR) system if required.
- Greetings/voicemail functions

## 6.Applicable Quality & Reporting Requirements

### Local quality, information & performance requirements

Locally reported as defined under Schedule 4 and 6 of the contracts, to be shared with commissioners and contract manager at least one week prior to the relevant Service Performance & Quality meeting.

### Report on and/or demonstrate the following:

- Service demand - referral data & throughput (including but not limited to referrals numbers, source, age, request type i.e., ASD and/or ADHD)
- Family & CYP outcomes
- CYP Journey (Where the CYP is in the pathway).
- Wait times, in line with KPIs developed.
- Where families have been signposted to in the system for support.
- Risks, emerging issues, and trends
- Staffing position/workforce report
- Financial position/ underspend
- % of children, young people and their families who have given the service a good or excellent satisfactory rating.
- Incidents, safeguarding, compliments, and complaints.
- Quality assurance of processes including quality assure phone calls for training and development purpose.
- Ability to monitor and/or record call length.

### Outputs/Activity:

The service provider will complete the following outputs as agreed with the ICB commissioners:

- Monthly scorecards/KPI report
- Service activity reporting (including Demographics)
- Case studies
- Service user satisfaction survey (by at least 20 percent accepted onto the pathway and callers into the helpline)

### National Reporting requirements:

Not applicable.

However, the provider will provide regular progress and assurance updates as and when requested by the commissioners and/or NHS England.

## **7.Location of Provider Premises and Accessibility**

The service(s) will be based in the organisation's premises or remotely and with service predominantly activity taking place via email, phone and in writing.

### **Equality and diversity**

The Service Provider will treat all people in a considerate and respectful way and show sensitivity towards a person's beliefs, background, way of life, personal needs, and circumstances. This applies to anyone that the service encounters, or has access to (in person, over the telephone and in writing).

The service provider must demonstrate how it complies with all equality law when recruiting and managing its workforce.

The service will have an Equality Impact Assessment in place to ensure that it meets the legal requirements of the equality framework and to ensure equalities to service users within service delivery.