

# **Family Voice Norfolk Consultation on the Neurodevelopmental Diagnostic Service for Norfolk County Council Health Overview Scrutiny Committee 15<sup>th</sup> July 2021**

## **Consultation**

Parent carers of children and young people with Special Educational Needs and/or Disabilities (SEND) were consulted via an online survey to inform this report. This report will be presented to the Health Overview Scrutiny Committee (HOSC) on 15<sup>th</sup> July 2021.

## **Background**

Family Voice Norfolk (FVN) is a collective of parent carers from 1150 families across Norfolk and represents over 1440 children and young people with SEND. FVN has been the strategic voice of parent carers working in partnership with Norfolk County Council (NCC) and with the Norfolk and Waveney Clinical Commissioning Group (NWCCG) since 2006. It is funded through a direct Department for Education grant (administered through Contact), by NCC and by the NWCCG.

Parent Carers were invited to complete a survey online and had the opportunity to write comments on their experiences of accessing the pathways and services supporting diagnosis of Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) and Attention Deficit Disorder (ADD). The survey ran from 23<sup>rd</sup> June to 28<sup>th</sup> June 2021. FVN received 178 responses from families living within all 7 district council areas: King's Lynn and West Norfolk, Breckland, North Norfolk, Broadland, Norwich, South Norfolk and Great Yarmouth.

The West Norfolk Branch of the National Autistic Society has collated experiences of the NDS from some of its members and shared with Family Voice Norfolk. We would like to thank them for this and have included transcripts of those experiences shared, as an addition, after the end of our survey results.

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## Key messages

### 1. LONG WAITING TIMES

Waiting times for the different Neuro Developmental Disorder (NDD) pathways are too long.

### 2. POOR COMMUNICATION

Communication with families is often poor or lacking.

### 3. IMPACT ON FAMILIES

The detrimental impact of the previous two factors is significant.

## Key findings

### 1. LONG WAITING TIMES

Over 57% of the 178 respondents first requested help over 3 years ago, and a further 24.2% have been waiting between 18 and 36 months. In effect, this shows an alarming 75%+ of families waiting in the service for more than 18 months.

For those who have received confirmation of referral acceptance, over 13% have been on the pathway to diagnosis in excess of 3 years and a total of just over 51% have been on the pathway for over 18 months.

50% of those families who had the referral refused intend to repeat the process.

Based on the lengthy wait times on the pathway, 176 responses were received to the question 'Have you ever considered a private diagnosis route?' Almost 73% of those responses indicated yes, they have considered private diagnosis because of wait times.

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Families are looking at private diagnosis out of 'desperation for answers and help'.

As one parent explained "my son needs help now and it's been nearly 3 years and they still can't tell me how much longer it will be, just he's still a way down the list".

Another parent who has experienced two very different systems told us "Although my son was diagnosed with ASD in a different county, he was diagnosed with ADHD through this service. The waiting times are appalling, this service has been reorganised a few times since on the waiting list and in that process a referral was lost in the system, departments do not communicate with each other, due to waiting lists parents are opting to pay privately as the reports are usually more in depth, a considerable amount of time is spent with the child as opposed to the NHS service and your concerns are actually taken on board rather than parent blaming. Too much parent blaming happens when a child's behaviour is being scrutinised. With private diagnosis you get much more support post diagnosis over what the NDD offers.

## 2. POOR COMMUNICATION

To the question 'are you aware of which pathway your CYP is on?', 36.7% of respondents said they did not know.

Only 37.6% said that the Neurodevelopmental Service (NDS) and the Neurodevelopmental Disorder (NDD) pathway had been explained to them by a health professional. This means an overwhelming 62.4% of respondents had received no help in understanding the pathways and services.

Encouragingly, 69.7% of families had been made aware of their CYP's referral acceptance. 11.8% of families had been advised of declined referral. This leaves 18.5% of families, however, who have received no notification.

When asked if they have been kept informed of the CYP's progress on the NDD pathway, 75% of all respondents said that they have not been informed or updated at all and 78.7% had taken action to contact the NDS themselves to get information on progress.

Almost half (48%) of the families responding stated that they had not been offered or given any help and/or advice whilst waiting on the NDD pathway.

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An overwhelming 86.9% of those families who knew their CYP's referral had been accepted had since received no communication from the NDS to explain any delays affecting them.

Being able to contact a service with ease is important to families with over 56.6% of respondents telling us they had needed to contact the NDS team but that just over 50% found that contact difficult to make.

Although there is an NDS website, over 65% of the families who replied to the question 'have you visited the NDS website?' said no, they had not.

### 3. IMPACT ON FAMILIES

There were 124 responses received to the question 'Has the time waiting on the NDD pathway had any impact on your child or young person, your family or on the educational setting?' 87% of responses indicated yes, there has been impact. This is also reflected in the responses around consideration for private diagnoses. Families have shared some of these impacts with Family Voice Norfolk and all can be seen in the appendix.

To illustrate the impact felt, three cases are listed here:

- a) " ...haven't been in mainstream education, due to her phobias, school been supportive but it has taken about 3 years. She can't be left alone die to her self-harm, suicide thoughts, she don't go outside in the sun, she slept on sofa for 2 years, she can't cope with car journeys, she's tried to jump out the car, she sees no danger, she don't stay away from home due to phobias, no days out or holidays due to phobias. She sees CAMHS, but a trainee, only because I cried and broke down begging for support, she's depressed, not motivated, I'm disabled, we have a family support worker and we are all screaming out for help but never get anywhere."
- b) "It has made it difficult for school to accept what we are saying as parents, without formal diagnosis and the GP surgery won't put him on the learning disability register

yet. Other services won't help without a diagnosis. Too much importance is put on formal diagnoses."

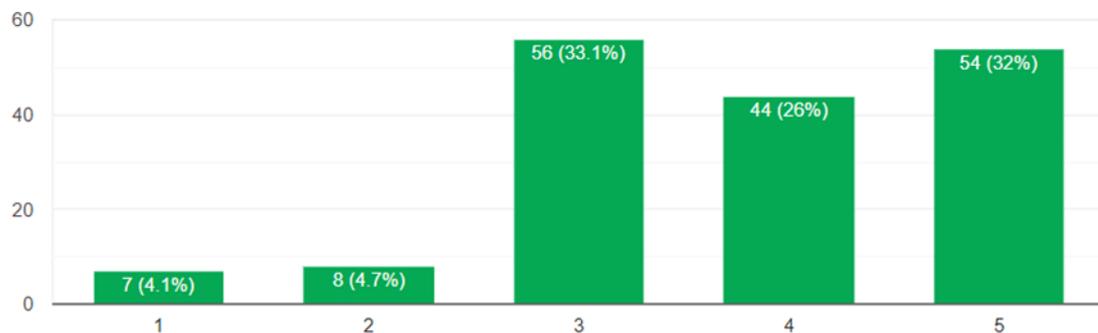
- c) "Permanent exclusion from school, mum developed anxiety disorder, reduced hours at work, child developed anxiety and school based trauma, child missed 1 year of education.

## Overall

Of 169 responses, only 8.8 percent of families rated their whole experience of NDS as excellent or good. 33.1 % rated it as average and a total of 58% said their family's experience was bad or very bad.

Overall, how would you rate your experience of the NDS service?

169 responses



1 = Very good

5 = Very bad

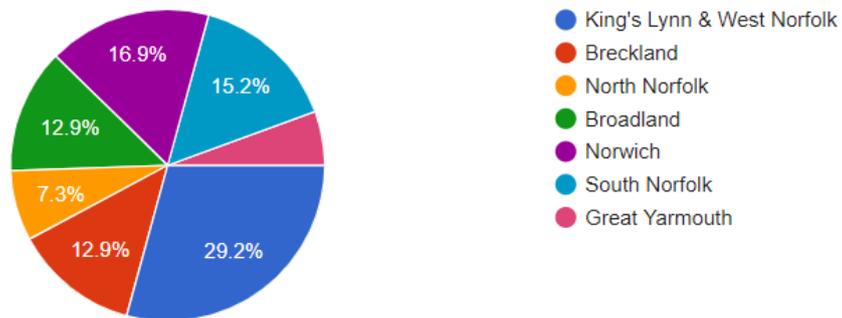
## Appendix A: Family Voice Norfolk Survey Results

(NB: Names and locations recorded in response have been redacted to protect anonymity, all other details recorded in full)

**178 responses** from parent carers of children or young people aged between 25 months and 26 years.

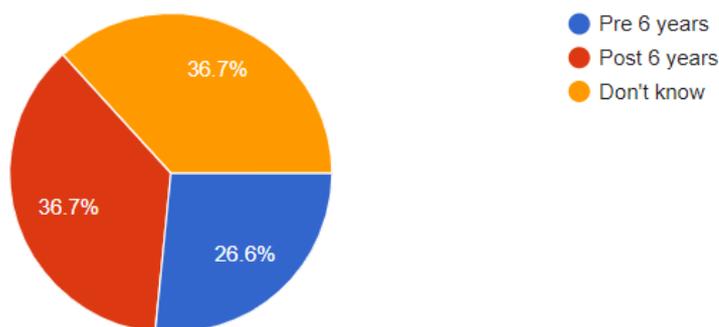
### Your location

178 responses



### NDD Pathway Route

177 responses



### Areas of concern:

85.4% ASD

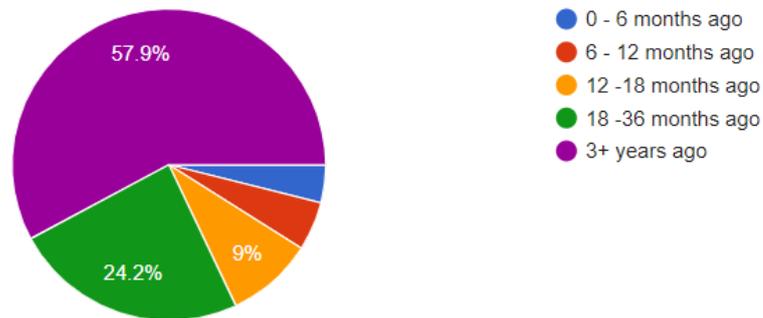
47.8% ADHD

12.4% ADD

**Also mentioned:** PTSD, Dyspraxia, Separation Anxiety, ODD, Learning Difficulties, Sensory Processing Difficulties, Trauma and Anxiety, Kleptomania, Hoarding, Meres Irellim, Dyslexia, PDA, Developmental Delay, Hypermobility, Selective Mutism, Social Communication Disorder, PICA, Self Harm, Suicidal Thoughts, Emtophoiba, Tourettes, Awaiting Diagnosis.

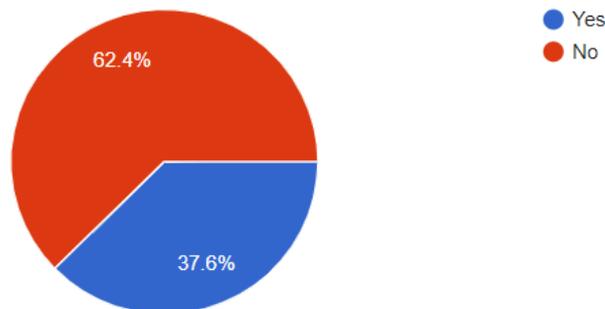
How long ago did you first ask for help from a Health Professional about your child or young person's neurodevelopmental concerns?

178 responses



Has the Neurodevelopment Service (NDS) and Neurodevelopmental Disorder (NDD) Pathway been explained to you by a Health Professional?

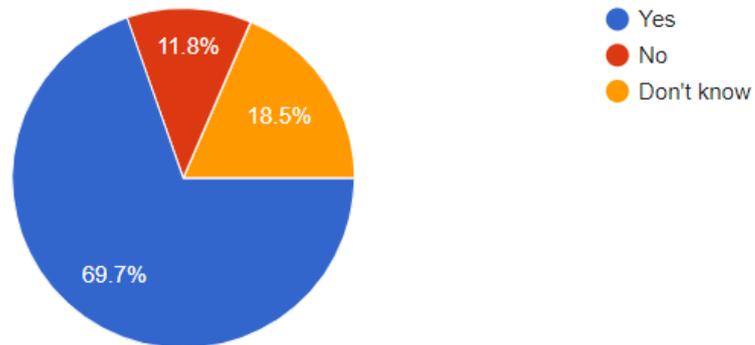
178 responses



**Of those who said yes**, 55.4% had explanation from NDS Team, 18.5% from GP, other sources mentioned were SENCO, Health Visitor, Paediatrician, Portage, School, Hospital and Teacher.

Has your child or young person's referral been accepted?

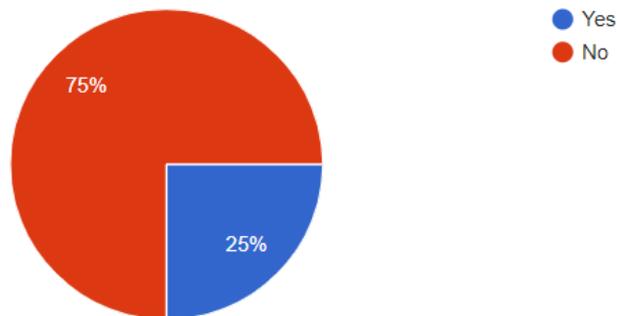
178 responses



**When asked when parent carers were told their CYP's referral had been accepted, dates varied between 2016-present day.**

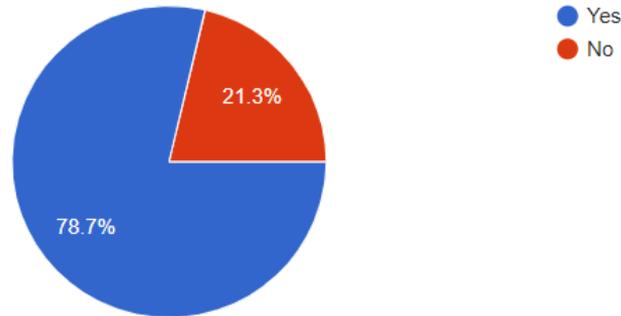
Have you been kept informed of your child or young person's progress on the NDD pathway?

124 responses



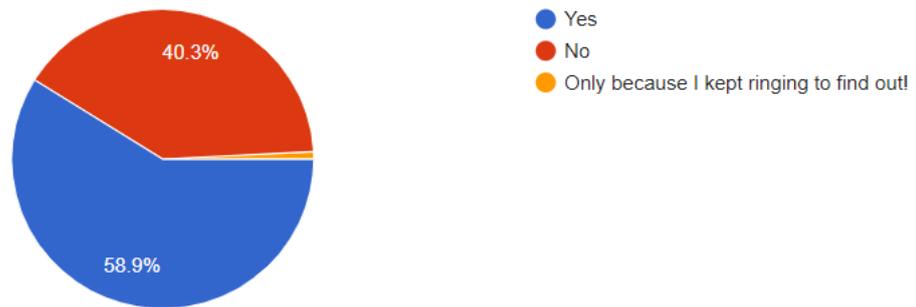
Have you made contact with NDS to find out about your child or young person's progress on the NDD pathway?

122 responses



Do you know what stage of the NDD pathway your child or young person is currently at?

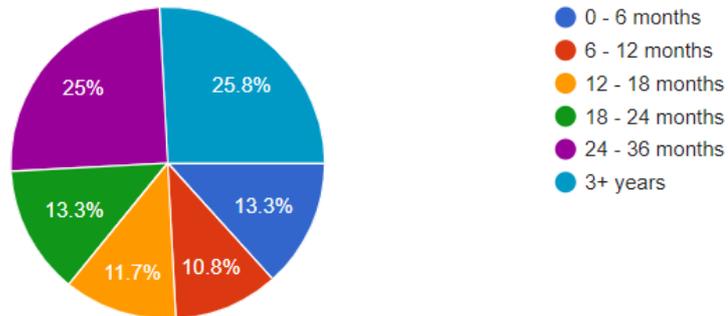
124 responses



**Those parent carers aware of the stage that their CYP is on the NDD Pathway were informed by** letter, their own contact with NDS (telephone and email), their SENCO, email from NDS, through contacting their MP, telephone call from NDS, multidisciplinary clinic and their social worker.

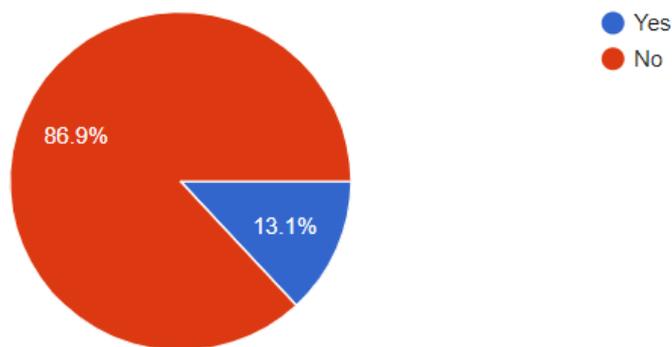
How long has your child or young person been on the NDD pathway?

120 responses



Have you received any communication to explain delays to the service?

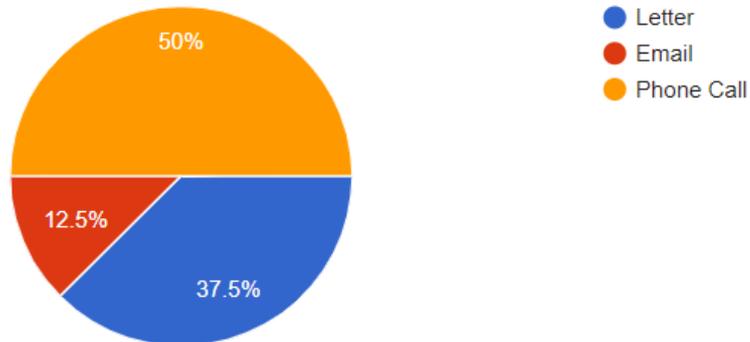
122 responses



**Those parent carers who *did* receive communication to explain delays were contacted by NDS, their paediatrician, or only received communication through direct enquiry to NDS.**

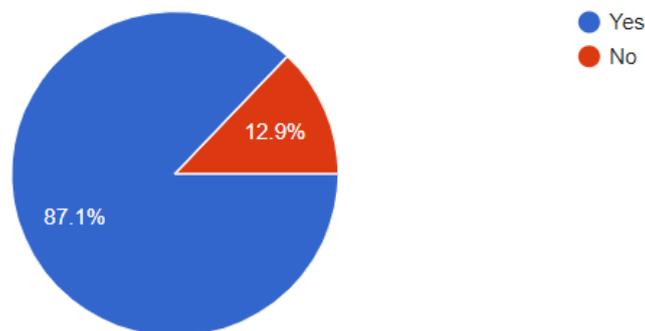
How did they make contact?

16 responses



Has the time waiting on the NDD pathway had any impact on your child or young person, family or educational setting?

124 responses



**Parent carers were asked to give details of that impact:**

I have been advise current mainstream setting is not appropriate for my child but until know if will gain ASD diagnosis or not can't have alternative school named on EHCP. This has hugely negative impact on child's mental, emotional and academic well being

It had a detrimental effect on his mental health.

It has made it harder for school to gain an EHCP

School refusal, pressure and meetings from school about attendance. Very stressful time.

Worse behaviour

In my last phonecall to ndd, I asked how long we would need to wait. The person couldn't tell me - I asked if it could be months and they said they couldn't say. I asked if it could be

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years and the person went quiet in a way that suggested this was likely. My daughter is 17 and is looking at options after A levels - she is paralyzed by the lack of diagnosis and doesn't feel ready to take next steps. With this in mind, my family have provided some of the cost of private diagnosis which we are now starting. I am very angry about this - there are a million other ways we could spend the money but my daughter is priority. She deserves better.

Impacted on trying to get him the help he needed.

Keep refusing to diagnosis, traits getting worse

People, namely daughters school have have said there wasn't much they could do as she had no diagnosis

Just want clearer answers to LO behaviour and how to support them. We feel we have been left in limbo.

Child is school refusing, still awaiting a diagnosis, impacts sibling at home, anxiety has increased.

Haven't been in mainstream education, due to her phobias,school been supportive but it's taken about 3years, She can't be left alone due to her self harm, suicide thoughts, she don't go outside in the sun, she slept on sofa for 2years ,she can't cope with car journeys,she's tried to jump out the car,she sees no danger,she don't stay away from home due to phobias,no days out or holidays due to phobias. She see CAMHS,but a trainee,only because I cried and broke down begging for support.shes depressed, not motivated,im disabled we have a family support worker and we are all screaming out for help, but never get anywhere

My child needs support in school

Not getting the support he needs

Struggles with daily living tasks, anger issues, severe anxiety, self harm, biting, hitting himself, expressing to take his own life, troubling with any transitions, sensory overload, unable to regulate emotions and express what his worrying him. Problems getting him to school. Mood swings extreme. Lacks any safety awareness. Previously assessed by Psychology 4 You with diagnosis of Autism. Referral accepted for ADHD and on waiting list to see Clinician and school observation by Clinician, but long waiting list due to Covid Pandemic.

Trying to get extra support and funding at school, ehcp delays due to needing more assessments

the delays have meant his needs were never fully understood and this impacted on his education

Have now paid for a private assessment and awaiting this diagnosis to be ratified by the NHS

We feel like we are fighting the school to be heard. Our hope is that a diagnosis would help make the school take better note of our concerns. To them just being in the system is not enough.

It's hard to understand how best to support the young person without the correct diagnosis and detrimental to their own personal identity waiting for year's to understand themselves better

her behavior and development is getting a lot worse. The impact it is having on the family is not good , it causes a lot of stress for all the family. Her birth mum can no longer cope with her so visits are very short and sweet with her mum rather than sleep overs that were previously taking place. Concerned about her anger and the fact that she would go off with anyone with out hesitation is a huge concern. her relationship with food is getting worse.

My son needs an urgent assessment due to withdrawing from school due to ptsd and school "refusal". He wants to go back into the classroom but needs a diagnosis to access support.

My sons mental health and wellbeing hasnt drastically deteriorated as he is getting older and becoming more aware of his differences and difficulties, this is causing a high level of anxiety and is affecting every aspect of his life. Through not having a diagnosis he cannot access services or resources that could massively help him and us as a family to support him.

Delayed support due to no diagnosis

Mental health and support issues

We struggle with X on a daily basis, in particular with his repetitive behaviours and lack of speech which are becoming more of a problem each day. We have had to go private for speech & language therapy, occupational therapy and a diagnosis in order to try to help X's development as much as possible and this has impacted on our finances.

We as a family are struggling with our eldest son, with his behaviour not only does it affect us daily but it's also affecting him in school, his education is more important to me and I feel like his just been forgot about. We no longer can take our son out in public due to his outbursts and behaviour. His sleep is massively effected also

Moved out of county in August 2020 (for a temporary period) returned in March 2021. Told would have to go back of waiting list and start whole process again. Child was in urgent need of assessment to identify support and behaviour management. End up paying for private assessment.

Unsure of how transition to high school will go

Been excluded from school because of behaviour

It has made it difficult for school to accept what we're saying as parents, without formal diagnosis and the GP surgery won't put him on the learning disability register yet. Other services won't help without diagnosis. Too much importance is put on formal diagnoses.

My daughter has had an awful couple of years and we have no help. We don't have the knowledge of a diagnosis to help us help her.. we are 100% sure she has ADHD and an early diagnosis would have enabled us to get the medication that would help her cope in school!

We had huge issues while he was younger and treated like he was a badly behaved child by school and bullied by a teacher he had a year in secondary school where they lost his diagnosis letter and he received detention constantly every day sometimes 3 x a day

We had the diagnosis for ADHD first as that was a quicker assessment that was available. We are still waiting for an ASD assessment to be completed but are some way through that at the moment. It's the ASD part that is taking so long.

My child had no school place. No school could meet needs due to his ASD but he didn't have a diagnosis. A diagnosis was required for him to have a place at a school able to meet need. This was the situation for 18 months.

No longer able to attend school, can't get right school as no diagnosis

Has been at crisis point with school & home twice in the last 6 months

We needed to know a diagnosis so we would know how best to support him

Without knowing exactly what support my daughter needs we are left to guess what her needs are, what might help. She is now masking a lot at school and she is becoming increasingly physical at home. Needs not being met?!!!

Struggling with anxiety and lack of support - stuck in a limbo

Struggling with behaviour & aggression. Masking at school.

It delayed everything and allowed difficult behaviours to develop in my daughter. Also School didn't understand her needs so impacted school attendance. It delayed EHCP assessment. Just everything. Was so difficult.

He's in mainstream school and doesn't talk

It affects the support you can access

missing out on vital support. School have an LSP in place but don't follow it, using covid and curriculum constraints as excuses. An EHCP has now been applied for (parent) but school wasn't very supportive

Even though this team is busy, I was chasing them up to do their job to get my daughters assessments. She had one home visit. That school visit. Left me for months for no information.

Permanent exclusion from school, mum developed anxiety disorder, reduced hours at work, child developed anxiety and school based trauma, child missed 1 year of education

Behavioural issues which have had a lasting effect upon our younger children, marital strain, issues coping at school, challenging behaviour at home

High risk of exclusion - we are expecting it to take up to 2 years before he is seen, but we fear he does not have that much time to spare.

Waiting for a diagnosis was stressful

Escalating behaviour and difficulties

Their behaviour is getting worse at times, school are not helping due to no diagnosis and are trying to get rid of his EHCP

With no diagnosis no help was offered as the school couldn't give a written documentation of why extra help maybe needed.

EP assessment and EHCP evidence

Not enough support at school

Struggling to cope in school

The teachers in school are unsure of what my son needs and with no diagnosis or EHCP I do not feel I can question them

She became a full school refuser and is now in tutoring 6hours a week as she couldn't cope in main stream high school

School were slow to accept X has additional needs. Family support worker got involved and problem was resolved.

As my son didn't have a 'formal' diagnosis struggled to get school to agree to put on SEN reg, put support in place

Our child is struggling to self regulate. It means that it is guess work for the school to know how best to support. It has also made transition to high school daunting as we were hoping to be able to have a plan on place before this. We are coping but this is only because we are in the fortunate position to be able to pay for resources such as sensory toys, blankets etc and that school and that we are both school teachers with experience of teaching children with SEN. Our son is desperate to know what he has, to be able to explain it and get the

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support he needs. School is challenging for him and he has days where he comes home distressed. If we knew what he had, if we had a plan to help him life for him would be so much better and for all of our family. He also has an eating disorder which adds it's challenges. It is such a shame that the waiting lists are so long and that he can't get the help he needs.

Years without a diagnosis meant less support and understanding available at school and from other health services.

Specialist provision can not manage him and he struggles in school environment, impacting on his mental health

My son was repeatedly excluded from school or only allowed in to school for an hour a day for several years

My son's behaviour has effected our whole family and has since been diagnosed privately with severe ADHD

Not believed by school and without an assessment I can't explain to him why he is different to his peers

My son's mental health has deteriorated, he is unhappy at school and struggles with social interaction.

My sons behaviour has gotten worse, his education has suffered badly as he is not getting the help he needs - he has gotten more sensitive, developed ticks and relationships have been affected both at school and at home.

School was failing. Adhd diagnosis wasn't made correctly which had implications for years until I took her private and paid for it to be done again. This is despite nds stating she had ADHD no written diagnosis given.

Constant stress of waiting and no one listening to you so you keep backwards and forwards

He no longer believes that any health professionals will help him or are even bothered

We would like to discuss with our child but without a diagnosis, we are best guessing

It's not affected but delay in completion is delay in receiving support available

Not able to get plans into place as Nursery/School like to have a diagnosis first

My child has anxiety and is self harming. We have been told to hide medications

On medication for depression

exculsions from school

Disaster

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Lack of support, treatment, and access to services to make my child cope better

Still waiting for assessment , child struggles to keep up on school

Ended up getting a private ASD diagnosis to secure EHCP ready for transition to high school.  
Still waiting for ADHD diagnosis.

Its causing family rifts with stress and extra pressure put on sibling. The whole process is unclear and stressful no support

Now struggling to get him into a suitable school space.

It's the not knowing, he knows something isn't right

No diagnosis no further supporting evidence for ehcp

At the time of going for an autistic diagnosis my child was at the start of key stage 2, we got the diagnosis in year 7 which we really wanted before starting high school, the process took so long and there was so much chasing up to do. A very stressful time

School saw his Behaviour as negative & rude. He would get in trouble for fidgeting and calling out answers. He became very unhappy in school. This created upset at home and his frustrations would come out in meltdowns and lows self esteem.

He's struggling with school, and falling behind.

He could have had more support with his learning

Too late to put in place help at her school

Not been giving a diagnosis makes it difficult to know what you are dealing with. Stuck in limbo.

If my son was given his diagnosis earlier then he could have had more support put in place earlier

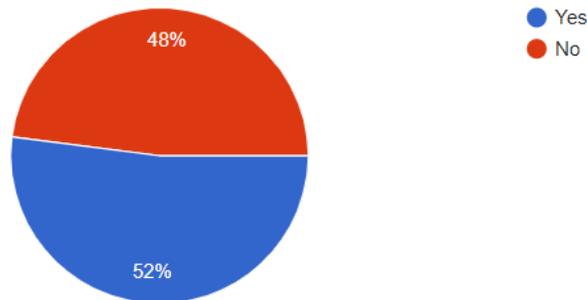
I've been asking for help and assistance for years. We finally get started and Ive only had to fill in a consent for this month in June eithen thou they except the referral in march. My son is due to go to high school in September I'm concerned on how he's going to cope and as he doesn't have a diagnosis on where the school will help with what he needs as we have not proof as such.

His condition worsened in the time and we could not access relevant support without a diagnosis

Lack of support when needed it the most. Although I am aware post diagnosis nothing happens!

Have you been offered or given any help and/or advice whilst waiting on the NDD pathway?  
For example, from Family Action, GP, educational setting, or support groups?

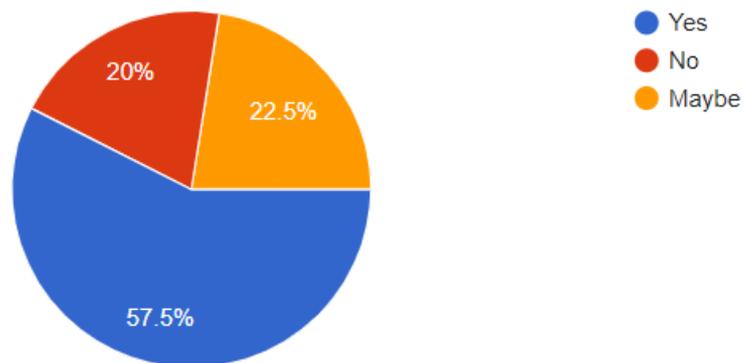
123 responses



Of those that *had* received help and/or advice the following sources were mentioned: Family Action, School, Occupational Therapist, NANSA, SENCO, SEND Norfolk, Portage, Social Services, Family Services, Educational Psychologist, SureStart Centre, SENDsational Families, Family Voice Norfolk, GP, Early Help, Health Visitor, Action for Children, SEND Norwich, SENDIAS, Swan Youth Project, FamilyLine and Point1.

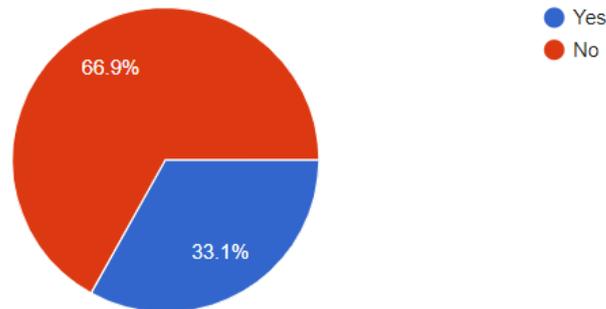
Do you feel COVID 19 has affected your journey on the NDD Pathway?

120 responses



Have you received any communication from the NDS team during the COVID 19 pandemic?

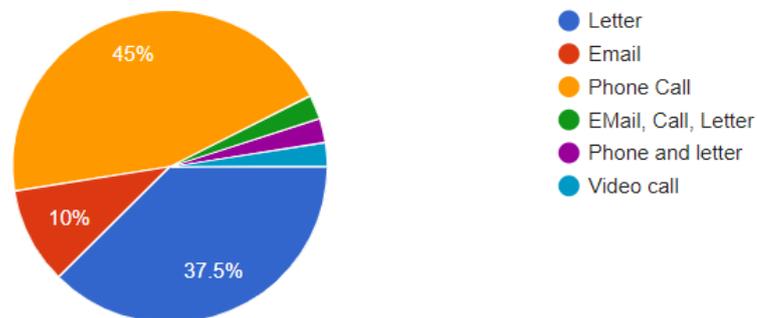
121 responses



**Those parent carers who *did* receive communication were contacted by** NDS, SENCO, Occupational Therapist, Paediatrician, EHCP co-ordinator, CAMHS, Family Action and SaLT.

How did they make contact?

40 responses



**When asked if reasons for delay and what to do next were explained, parent carers responded:**

We were told the reason he couldn't be referred for an ASD assessment was because he already had a diagnosis of a deletion on one of his chromosomes and that it wasn't possible to have a second diagnosis. We weren't told what to do next.

The letter only stated that she didn't meet the criteria but didn't explain what that was.

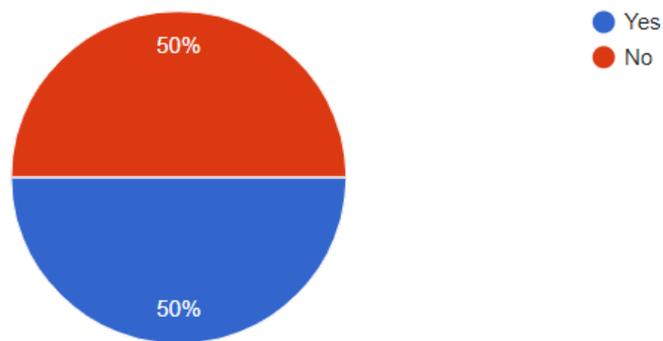
Reasons yes but not specifically what to do next

Told why (no difficulties at school) but not what to do next. We went private instead

I was told any referral had to come from school by my GP

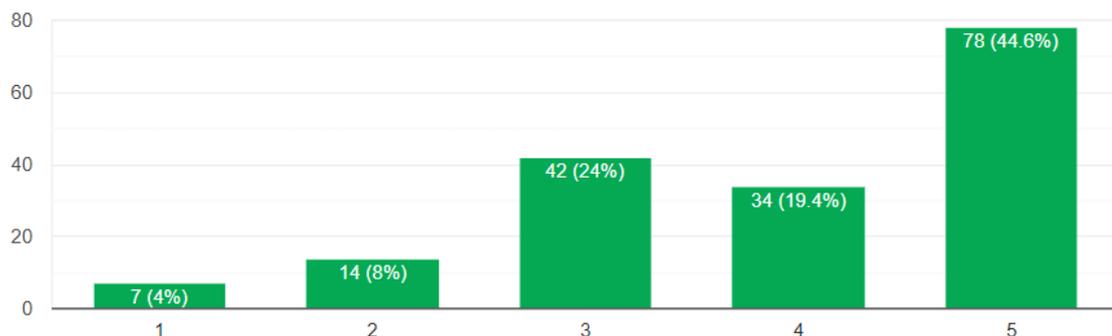
Are you intending to repeat the referral process?

20 responses



Can you rate the referral process?

175 responses



1 = Very easy

5 = Very difficult

**When asked to explain their rating parent carers responded:**

Nursery advised GP referral to seek diagnosis so they can apply for additional funding but provided no supporting evidence . GP made referral but this was declined on basis of insufficient supporting evidence from nursery

As always the onus is on the parent to keep ringing up to keep updated, send in relevant reports and extremely stressful To be waiting over two years whilst child is suffering

Unfortunately with the cuts there is a long waiting time to be seen

Had to get a private diagnosis, then get the NHS to accept it !

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Still waiting to be seen by someone

I am at the very early stages

My son masks at school so it's very difficult to get a report from school supporting a referral. We had numerous reports from over the years but a referral always seems to hinge on school support. Thankfully we managed to persuade school to write a letter during lockdown stating a report from them would be so delayed that it wouldn't be appropriate to wait that long, which helped, and we sent in a long, detailed report of everything we witness with our son. Not every child displays at school. Parents should be believed. Nobody would make this up!

Because my son was also in the process of having an EHCP, the NDD team were able to use the needs assessment reports; EP, SaLT & OT, to inform their assessments and give him a diagnosis of ADHD. I asked for this to be considered though, but they were very responsive and saw the merits of sharing current assessments across all services.

Not enough information given

A long wait for a diagnosis

The process is absolutely fine and it's obvious the team work hard and are doing all they can for families, but it's the time scale that is the problem. My son was first referred by the GP in May 2018 and I received a phone call from NDS in January 2021 to say his last assessment is likely to be another 2 years. That is not acceptable.

Our first referral was rejected as we didn't have the right type of evidence- There wasn't enough evidence from school, even though at school there are no issues and the majority of the challenges we face are at home. It felt like our experiences weren't valid (something that has happened continuously throughout this process.)

A the start of the referral everything was explained to me

No support for parents and slow process for child

The wait wasn't terrible like others have had

It's awful! The length of time you have to wait is ridiculous! My son had an ADHD diagnosis within weeks when it was done through CAMHS.. I don't understand what takes so long with the NDD team! Having to wait years for a diagnosis is ridiculous especially when years can have such an impact on a child's future

It seems like no professional listens to your concerns and just find more hoops for you to jump through. No one clearly explains what is required and it's always a fight and this should not be the case. I have decided to go private for a diagnosis because the process is so unclear, unhelpful and stressful.

Long waiting list of 3 years I was advised.

It's hard unless someone agrees with you

I havent heard from since September 2020

The first time round we finally saw someone after nearly two year who then lied on his report about what was said and pretended there are no problems. This left us with the school insisting we try again as there is so clearly a strong problem. Now having the stress of waiting all over again.

It was a lengthy process with no support while it was ongoing. We paid for private speech therapy (and still do) to plug the gap. Our son was non-verbal but with speech therapy support now has age-appropriate speech. We would not have received any support via the NDS or other NHS services.

It takes far too long to get a diagnosis and the children are the ones that are suffering

It was easy to get the referral accepted but the waiting with no explanation was not easy

My child was initially discharged by Community Paediatrician without diagnosis in 2017. With help from the school and Ed Psych and Clinical Psych reports the school arranged privately the referral was accepted and moved on to the NDS multi disciplinary team in early 2018.

No communication at all

ASD referral declined by health, so I went privately and they diagnosed him very swiftly and was shocked that Health declined referral and so was my GP. ADHD referral has been accepted but still waiting to be seen have been told its a long wait

Just absolutely disgusted

blocked from all avenues

I ended up going private as wasn't willing to wait years and see my child miss crucial early years support. We got as far as a NHS triage phonecall and I think we are now on a 'post diagnosis pathway' since our private diagnosis.

Not much info or contact, lack of guidance or knowing whats going to be put into place. We still done no Looking at home schooling as he's been kept back a year in reception and there thinking of doing the same again

It's the length of time that it take to get seen. Even once one person has been out to observe, the wait for the next person is another 18 weeks at least if not longer. With no help, and no recommendations or support

When we started down a diagnosis route there seemed some confusion from the school as to who should refer and what was needed, and since being referred we have been waiting over 2 years with absolutely no progress.

After asking for referral, we needed to fill in a few forms and then we received a reply that our son is being accepted for ASD assessment, but we haven't been given any date or expected waiting time.

It was easy but I believe things are more tricky now in that you need an ep report already etc it is sitting on the waiting list for years for a single assessment appointment which is difficult.

I've been waiting for 5 years to get someone to listen to me. Even now I'm being listened to it's taking an age and it's not helping my child who has 2 years left in primary.

We were initially turned down, but we were given an appointment anyway where he had a quick assessment, and history was taken, but not all info was recorded.

Actual initial appointment with paediatrician at the hospital was quick and he agreed a referral was needed but rest of it very slow and lack of information

it seems to take so long to get to a point where child is seen and helped unless you work in the hospital and then the process is moved so much quicker.

A lot of standardised questions, doesn't give a rounded picture of the child. Had to go through several other professionals before a referral was made.

Too long, little to no communication, no support suggested during that time, lots of places refusing to accept child is SEN with out formal diagnosis

It was difficult enough to convince the GP to put in the referral I then had to gather a whole heap of evidence to send to the Neurodevelopment team

Was rejected three times before accepting. No contact since then and when I phone I am just told she is not anywhere near the top of the list.

The referral process is appalling, especially as my son's referral got lost then we had to start the process and waiting list again.

I can't even remember how I initially referred it was that long ago now but there has been lack of communication, I've had to do all the chasing and have only received answers through frequent phone calls and emails to them. I feel like I have to keep them on task, there are always different case holders for each part and no one has the overall responsibility of supporting my son to receive a diagnosis or keeping me in the loop. It is a slow, form filled exercise and hasn't even completed after going on almost 4 years now

Takes a very long time from seeing a professional to getting a referral to NDS

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to get to this stage can have huge consequences on child given the time frame

It takes time to convince school and GP that there is an underlying problem

Never happened!

It's not until you get rejected to then find out what evidence is required

No body is interested

I have a younger child and I'm trying to avoid the nds pathway at all costs. Given he has 3 siblings who both have dual diagnosis he needs assessing but honestly I don't rate it. A particular issue is it doesn't pick up children who mask, it will only accept information where school identify a problem. However if a child is not disruptive the setting don't overly pick up on it. They have no separate process for these children that I'm aware of ( maybe this has changed) and so it makes everything delayed.

My Son was referred but nothing happened so consultant had to re refer as his information got lost on the system by the sounds of it

Very complicated process. Needed evidence from school but unable to attend school. Didn't offer any other pathway to get OT support

My daughter has suspected add however because she masks at school and sendco havent seen her difficults a referral can't be made

I was told to wait by many health professionals as my child was so young (under 1), but once it was accepted then it was smooth

The doctor put the wrong focus of the referral first time round then I had to get them to correct the main focus and resubmit.

no one really seems to know what to do and it seems like it's a battle to even get on. Yet alone get to see or talk to anyone

No help no explanation family GP didn't really understand the process either. There was no follow up from the GP we just got the refusal letter via them and that was it, there wasn't a next steps or an alternative procedure to follow or that I was made aware of at the time. School and school Senco were also of no help or support.

It took years to even get a referral, the sit and wait process is detrimental to the outcomes for children and young people

Such a long wait

The process takes far too long, too much damage is done in that time. Too many years this system has been too slow

No one knew how so Cahms referred us across after realising they were the wrong team. Wasted their time and ours.

Although it took a while the GP made sure she had as much evidence as possible before sending the referral in

GP did the refer

No communication

Was referred to child services after a delay just before 18th Birthday having first raised concerns in 2015

My son was diagnosed in 2012 we were lucky to receive a diagnosis and get support in place very quickly.

2 year wait for diagnosis appointment

Lack of explanation of process

Long, drawn out, little explanation or support, not being kept up to date, covid being used as an excuse

Simple process for our son and the referral accepted quickly-delays predominately from that point though

Child masks so appears to cope in school so they would not support my claim through lack of evidence

Health visitor suggested drop in SALT went to one they referred got a diagnosis 11 months later

I feel absolutely disgusted with the whole thing. The waiting time is an absolute joke, and when ringing up to find out what's happening you just get told, yes his on the waiting list. Can't give no time frame what so ever, although his teacher was told we was looking at March yet still not heard nothing.

Child been referred multiple times by multiple settings since age of 2 & always been turned down until daughter's psychiatrist got involved through fsp & supported the referral. Been told process could take 2 years so would have been helpful to have been accepted on waiting list before now so gets DX

Lack of communication & wait is far too long

It's a difficult process unless you are knowledgeable about the service and neurodiversity.

It is a stressful time.

The constant refusal to see my child and having to go back and get referred over and over

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We seem to be on endless waiting lists for everything. No communication in the meantime.

Made to put off throughout the referral process- barriers constantly put in our way etc

I believe there is a discrimination towards hidden disability which are not taken as seriously as physical disabilities by health professionals. Lack of understanding & awareness is obvious. There seems to be no urgency in supporting & helping a family. Many are forced to raise the funds themselves for a private diagnosis leading me to believe that this part of The NHS went private years ago.

My GP didn't want to know when I approached them. My son's school was also very difficult to give help as they were not seeing the same behaviours in school. We eventually were referred to Just one Norfolk but was going to be discharged without any further help from the school nurse even though it had been agreed there were some concerns.

No one explains anything, no one offers help or support, especially in health services.

My child has issues and I have been told because of Covid he doesn't meet the criteria

Too slow

As long as you communicate well with school and gp, it seemed quite straight forward.

Time consuming to get all of the views but the primary school and GP were both great.

Took 5 years

Took until he was over 6 to get a diagnosis, and a year from that to get medical help

My son was never accepted and was diagnosed via CAMHS when he was in complete crisis

At nursery's request, the Health Visitor referred X to the community paediatrician in June 2020 who, subsequent to our online video appointment on 3 November 2020, further referred X to the NDS who accepted him on 25 November. The process was straightforward enough - however even in those early stages it took 6 months just for this to be achieved - and since then (another 7 months down the line) we've heard nothing from the NDS.

Because of the old head teacher it was always denied even though it was really lies

To actually get referred took 10 years and now we are on the waiting list

Too slow for children who need their diagnoses in black and white

Nothing is easy

It's such a long process and takes ages for them to contact you

I am answering this questionnaire both as a parent of a child awaiting diagnosis and also as the SENDCo of a school where children have been waiting for over a year with little to no contact. Also referrals in Great Yarmouth can only be made through the GP, not school.

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The whole process is unclear and stressful as well as too long

Going to the GP and sending referral in was straightforward

We didn't really have any issues from referral to diagnose

Very confusing

Nothing was made clear. The first referral was rejected.

Getting support and just getting referred was difficult

Referral accepted easily, but waiting time is terrible

School or GP didn't know the referral criteria and assessments/reports needed. I eventually found it by searching online.

This is our third attempt to get onto the process and without the family worker support I think we'd still be trying.

It takes too long for the children who need it most

The school wouldn't refer so I had to go through GP

Its a nightmare

They don't keep you informed you just left hanging

Both daughters have been waiting for over 4 years

Can never get an update to know what's going on.

It's hard to get support I had to fight for yrs

No communication and the process takes to long

I have been trying to get help for near 5 years now and it seems nobody is listening to me. I have had starfish on board now for about 6 month and they have not told me anything new.... still waiting on a diagnosis after all this time

First spoke to gp when he was 2 and asked for a referral but was told that as a first time mum I was over reacting! I finally got a referral when he was about 4.5 but only because his teacher at the time backed me up in my concern.

I was constantly having to call to be updated

We started the referral at 7 and he's now 10

Never had any luck until now getting support

It wasn't difficult for us to be accepted as we have evidence. However the lack of communication, updates, and long waiting times to hear whether you have been accepted or not are frustrating

It takes so long and is so complicated unless you get a really helpful professional who guides you through, we were lucky to have a fantastic speech therapist who initially got things started

it was too late and no support offered

First referral was rejected

Our GP made it very easy to refer us, it was everything else that delayed things after that

Long winded, no updates

I didn't have no input

It's all confusing and nothing is explained I was told at one point my daughter didn't have Adhd and then in a meeting with my daughters school and NSFT alot of her behavior was blamed on Adhd which they have now decided that my daughter does have. But I have nothing to explain if she has her diagnosis or not.

We were never referred re: ASD. For ADHD it was an incredibly difficult process with the Paediatrician not wanting to recognise ADHD. It took work and evidence from Starfish to be presented to him for him to consider that this was a diagnosis and that medication was required.

No one wants to know

referral made via GP

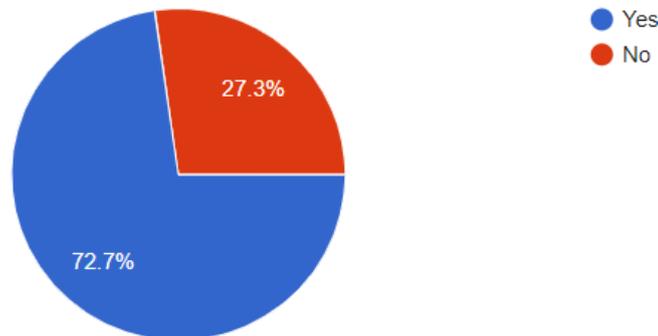
The delay in his diagnosis is effectively delaying better choices of schools

As a parent it feels complicated and criteria for assessment is too narrow.

terrible delays

Have you ever considered a private diagnosis route?

176 responses



**When asked to explain this answer, parent carers responded:**

Concerns around the wait as my son is already at High School

So we know as whether my son has adhd, but have decided to not go down private route as school has assured us we will be supported by them.

Because of the wait and my child was suffering

I've thought about it, however the reality is I don't have £1200+ and even if I did NCC and the NHS refuse to accept private diagnoses.

But it costs too much for private and if you do get one the local gp etc won't accept it

I feel the delay in diagnosis has delayed my sons learning

Desperation of getting help

I heard no good news about getting a diagnosis . I have supported a friend that took 4years to get diagnosis and then ECHP . A further 4Years to get a place in specialist school.

I met poeple that gave been trying years including one mother still trying to get help with a son of 27 .

I feel lost. A system that seems broken . And difficult to navigate .

I looked up Anglia autism to find the private diagnosis waiting list close . My son was rejected for an EHCP as has no diagnosis . His school didn't take any notice of him asking for help and okayed dorm the idea he had autism . His best friend has a diagnosis ( not this area . But manchester before moving to norfolk . They are very similar but my son has gone from being grade as Nine and in too 2% in cCAT test aged 13 to not being able to attend school for the last six months and essentially will now fail his AI Levels .

It's so much faster and they seem to be more honest about the problems that are present. They are not trying to make the government figures look better than they are. The cost is the only problem

Very slow process. Didn't feel they took parents view into consideration at all

I would have preferred to go privately so he could have been assessed and diagnosed quickly, unfortunately it was far too much money.

To get it done faster

Because we are truly suffering without the support us as a family are finding it very difficult to cope being unknowingly how to help deal and support my daughter she is suffering chronic sleep apnea due to lack of support when we ask for it.

Because the NHS had done a micro array test, and then ruled out ASD as well

It seems the only way to ensure a diagnosis is attained in a timely manner

Long waiting times - but is too expensive

Over 4 years to get to a diagnosis

Because the private route seems to be the only way to get a diagnosis for my child quickly rather than have to fight and wait for years. The repeatedly going back to GP and then referrals is an impossible and stressful process for me and my child

I did go private because the wait of 3 yrs+ is obscene. All the while my child was in school fully unsupported and that was not fair!

Because nobody is telling me anything.

The lack of communication, the timescale, not having any idea how much longer it would be before my son was seen. Rumours of the process taking 3 + years

I paid for ASD assessment privately but can't afford to do adhd one

My son needs help now and it's been nearly 3 years and they still can't tell me how much longer it will be just hes still a way down the list

I honestly do not think that the nds will believe parents if school say different. Therefore they won't assess and it just reinforces the view that your child has no difficulty. A private assessment is quicker and would give a professional opinion as to other options for us if our child wasn't fitting criteria rather than writing it off as a behavioural issue or poor parenting. A private diagnosis would be a lot quicker and help us get help quicker - which in terms of my child's development and early intervention is really important.

Because it seems that nothing has happened or changed anything. That they just throw meds at him and the nds pretty much said he didn't tick enough boxes

Because EVERY child matters!

Because my son is due to go to high school it's took me years to get to wear I am and the fact is if I had money and could afford to go private I would have had answer by now and be getting my son the support he needs.

As NHS services are so scarce

To get a definitive answer

NDS take far too long

length of time waiting and then informed child would be placed at back of long waiting list !!! following a tempary stay outside of county.

Camhs and psychologists are not interested and CS are useless

Only way to get an answer

In order to receive a diagnosis and acceptance from school

To get appropriate diagnosis, help, advise, spoke to a private company and with info i provided they agree diagnosis is needed and to go straight for final assessment

Sick of waiting

Early years is crucial for neurodevelopment. As a primary teacher I knew what my son needed and wasn't willing to wait and miss the under 5's years. Felt incredibly guilty that I can afford it and others can't but my hope was by us going private it opened up a space for another family.

Speed of diagnosis

Waiting too long - felt i had no other choice

My son is suffering mentally and struggling to understand who he is and why things affect him differently, I can't tell him it's because he is autistic as I dont 'officially' know that! If I could afford £2000 for a private assessment I would do it in a heartbeat.

I got ADOS and assessment done private to try and speed up referral diagnosis time

Because it's taking years and as the years go by my daughters are struggling more and more as we all our.

Private seems to be the only way to get help quickly! But the cost and the fact that a private diagnosis isn't always accepted by the NHS means it could be pointless.. plus we shouldn't have to go private!

To get my son seen sooner

because it would help the whole family and her I dont want her to be feeling the way she does for longer then needed.

only reason we haven't is the cost of it.

Because so many people told me early intervention is key. The fact is he was on the pathway from 18 months - finally diagnosed at 6 privately. This is my opinion is far too late to start the interventions & subsequently his Autism became a lot more challenging & obvious when it didn't need to.

My son is 14 and we didn't want to wait until college before he was assessed. He needs the support now. We've been fighting for assessment since he was 3. We saw a doctor at CATS (a few months after our son was accepted for NDS) who referred my son for a private ADOS, which showed scoring for ASD. We didn't take it any further because we felt the doctor was the wrong fit for our family and our son really didn't like her

Want to get help for my son, but we can't afford it

X has been waiting since 2018 and the process is painfully slow. 1+ year between each part of the process, made worse by covid means he is missing out on support and the transition to high school is going to be made more difficult

Private would be quicker

It's a lot quicker, the only problem is the NHS will not always pick your child back up again if you get a private diagnosis

Although my son was diagnosed with ASD in a different county, he was diagnosed with ADHD through this service. The waiting times are appalling, this service has been re-organised a few times since on the waiting list and in that process a referral was lost in the system, departments do not communicate with each other due to waiting lists parents are opting to pay privately as the reports are usually more in depth, a considerable amount of time is spent with the child as opposed to the NHS service and your concerns are actually taken on board rather than parent blaming. Too much parent blaming happens when a child's behaviour is being scrutinised. With a private diagnosis you get much more support post diagnosis over what the NDD offers.

Because child's mental health was suffering

Speed of diagnosis

My concerns were around the length of time it took from first our GP agreeing to refer to the paediatrician and the diagnosis process. Now, I'm concerned at the lack of support, understanding and services for my child and family.

Can't get any supportive help for my young person since he left high school

It seems the only way to ensure a diagnosis is attained in a timely manner

If cost wasn't an issue, I just want the best help and support to give my child a happy and fulfilling life.

Costs too much money

Because it would be faster

Because it would be easier to be heard and taken seriously.

The wait for assessments is too long and the referral process is impossible

Such long waiting times

Had to go private to get help needed before high school

Insufficient NHS funding and priority for young children needing this support. Concerns about finding the right high school and whether a diagnosis will be in place in time

Because I don't think anyone understands how hard it is. And as I say the amount of time we have waited already is an absolute joke

To speed the process up.

Out of desperation for answers and help

We are desperate for X to receive the support he needs and we are very concerned about the next stage - which is applying for a school place for him for September 2022. He is non-verbal and still in nappies and he needs 1:1 support which we think would only be achieved if he has an EHCP in place by then. That is also a long process and we could be turned down at any stage. So we thought that a diagnosis would help us in receiving the support that X will most definitely need when he goes to school.

We did go down the private route. The NHS took far too long, we desperately needed an EHCP to get my daughter some help in school. It was so mentally draining not knowing where we stood with the NHS and we as parents wanted to ensure that she got the help she needed and the earlier the help the less she would struggle.

Speed. Told waiting list (once on it) was three years long

I felt I wasn't being listened to

From seeing the Gp several years ago, to being referred to the hospital, we then moved and had to go through the referral process again

No help or support.

I want things in place before my son starts high school.

The waiting times are outrageous. There is no other free help or support available.

I needed to get diagnosis in place before she started High School so she could have allowances in place for issues with uniform, eating and anxieties.

To get a diagnosis without waiting for years.

Because it took a long time to get medication

Because it's taken so long. He has been given spd diagnosis but we believe it's more complex! Feel it's a tick box exercise

Because 8-12 weeks wait is better than 2 years

At the time it was suggested to me by a family member, but I could not afford it, and had to have faith in the public sector

ASD referral declined by health, so I went privately and they diagnosed him very swiftly and was shocked that Health declined referral and so was my GP. I went privately to get my son the correct support he needs

The waiting times and the support is ridiculous

Waiting times were too long, child was unsupported with deterioration of mental health

Because the autism was diagnosed but the adhd diagnosis was messed up and no written diagnosis given so despite every letter saying adhd we couldn't get support or medication. Had to pay private years later to get it. This had an awful effect on my child and family as a whole.

He has been turned down for help although everyone seems to know there is issues

Quicker and essential for evidence to meet sons current needs

I have heard that the whole process can take 3 years + and as our daughter is getting older she needs the support sooner rather than later, we need the diagnosis for school to take us seriously and if it takes this long it will be too late to help her, and also too late to help support us as a family .

To get the diagnosis we need to move forward. It was not affordable though and concerns that the NHS may not accept the private diagnosis anyway

Because had multiple referral turned down & was negatively impacting child

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Over two years is such a long time to wait and until has assessment can't name alternative school. So I am currently homeschooling two half days a week and bringing child home for lunch everyday.. this is only way he can survive a week on mainstream education

Because of the timescale

I feel it's my only choice to get my son the help and support he needs at school

Although I am at the early stages, I feel that the road ahead will be a long and stressful one.

For quicker results

I felt I was given no choice but to seek a private diagnosis as I couldn't bare to watch my daughter struggle any longer both her physical and mental, emotional health was in tatters being in a mainstream school with no help no understanding and no support and academically 5 years behind her peers. No friends not able to read social Q's in order to assist her to help make friends but also being used as an escape goat by others for doing things in school for example stealing and then blaming her and my daughter excepting the blame as she was unable to defend herself as she didn't know what was actually going on.

I took my daughter for a private diagnosis in March 2019 and she was given a full diagnosis in the July which I believed helped us to secure the correct outcomes in section B,F & I in her EHCP and securing the correct education establishment for her in January 2020.

have considered but cannot afford

To speed up the process, but it's too expensive

I've been waiting 4 years now for a diagnosis appointment cancelled or moved 6 months behind

To get help sooner but can't afford it

The process takes too long, however we cannot afford a private diagnosis

Because it's just busy and too much for them to handle. Not an experience I ever want to go through again just to get my daughter the help she needs

I have had to book a private SLT ax because my self referral was declined. Despite my daughter being 2 and completely nonverbal.

The NDS route was very lengthy and involved so many assessments, sometimes years apart. We wanted a diagnosis ASAP for our child so they could start to receive more support and understanding from others and for their own personal understanding.

Due to delays.

NHS /LA referrals take a very long tine to come to fruition so need to speed up the process if we can.

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Waiting times. Non beneficial help for my child so what is the actual point in the services?

Because its quicker

We desperately wanted answers but we decided to wait in the end as it was a lot of money that we then decided could be used for other purposes such as music lessons, forest school and the other activities that our child deserves.

The waiting list is ridiculous. My child needs help now not in 3 years time! I am very concerned about the knock on effect on his mental health and education without appropriate professional support.

To avoid the long delay! Almost two years at school before we have a diagnosis despite being flagged by nursery at the age of 3

If one pays privately I feel there would be a complete and full assessment and all family information would be listened to and not dismissed. The young person would be listened to also. Sadly all disciplines seem to work hand in glove and just agree with each other. They really have no interest in the individual it is just a box ticking exercise. No one has the foresight to look beyond what has been written before. So sadly any chance of a true investigation and out come is blighted as is the young person's future.

It saddens me beyond belief and that is why my daughter will become a statistic.

The assessment my daughter had was incomplete only one part of the speech and language section was carried out.

I should have followed the official complaints procedure but our experience over the years has put me off doing this as sadly our experience has been that one professional will not speak out against another.

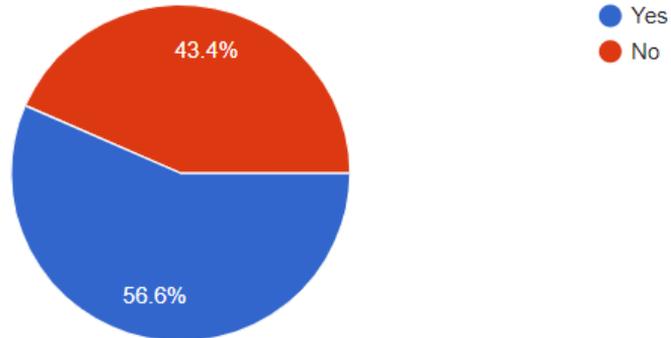
Sadly I think I have now run out of time to make a complaint.

I've been waiting 4 years now for a diagnosis appointment canceled or moved 6 months behind

The wait is to long

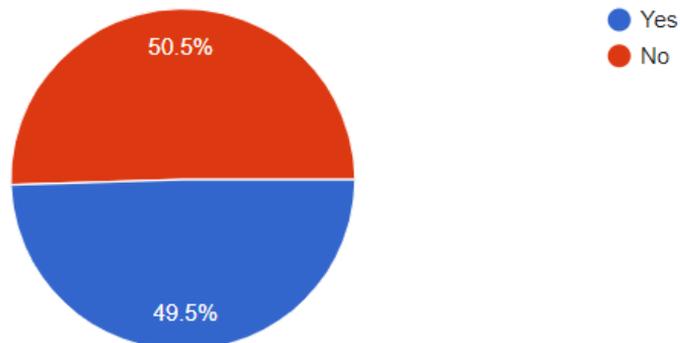
Have you needed to contact the NDS team?

175 responses



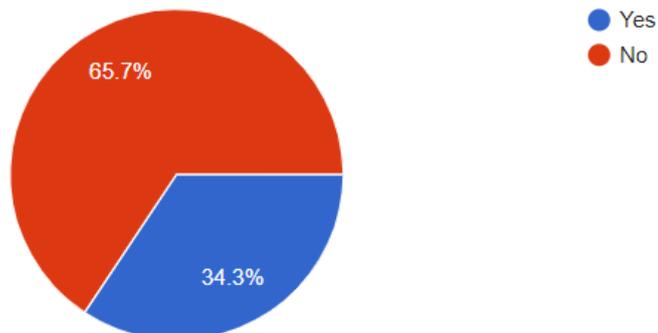
Did you find the NDS team easy to contact?

95 responses



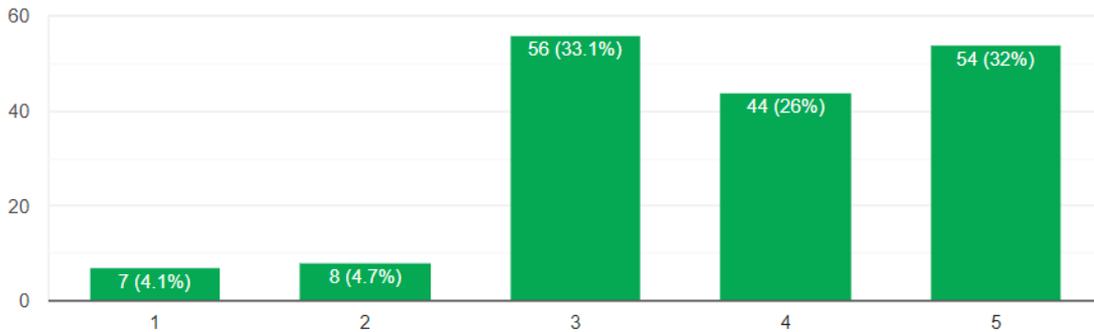
Have you visited the NDS website?

172 responses



Overall, how would you rate your experience of the NDS service?

169 responses



1 = Very Good

5 = Very Bad

**Parent carers were then asked if there was anything further they would like to share about their NDS experience. They responded:**

Poor communication. Waiting list is far too long

I was lucky to speed up my sons journey by having other ongoing needs assessments. If this hasn't of been the case, I know my son would probably still be waiting, as COVID hit and waiting time for face to face engagements had to stop. Luckily for us my son now has the support he needs from health and his new school. The wait times for referral and first appointments was extremely long and caused anxiety all round. More communication to keep families updated would at least help you feel that you haven't been forgotten! I feel for families now starting their journey with the current wait times in Norfolk.

I was left floundering looking for help my son was rejected twice despite as no assessments being done in thetford he only saw a paediatrician for assessment

I've just discovered that the wait to be seems is over 3 YEARS. By this time my son would have aged out and have to restate the wait in the adult service. This means it's likely he won't get a diagnosis until he hits his MID TWENTIES!!!

The waiting list is ridiculously long

Just long waits. incredibly hard if you are struggling with your child .it's really affected My health.

It has just been confusing as my son is now suffering with his mental health too. If health professional can't distinguish which is which how on Earth am I expected or acted too. At present he has not recieved help with either other than being put on anti Depressants. It

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has now been over a year since he was referred for support with his mental health and nearly 2 years since discussing possible ASD with his GP who encouraged him not to worry about getting a diagnosis as this could help him with struggling with A levels and poor health at the time ... November 19 .

The back log feels intentional to hide the true scale of the problem and to put people off getting the support they need

The service is underfunded and understaffed for the volume of referrals but the quality is excellent

My son clearly has ASD but because of his complex LD they said they couldn't diagnose ASD. We went private and he was diagnosed straight away

Recently asked for son to be tested for SPD got told they don't test for that anymore

I don't even know what they offer fully.

They kept telling me they were short staffed and were recruiting new practitioners to support the service I haven't really seen any evidence of this, I provide any information they require instantly but it doesn't seem to help anything go faster we just pale into the background as my son is only 'low-level disruption' status at school

I would think that their actual practice around diagnosis is pretty good - my daughter has a clear plan of what should happen. Unfortunately the time it takes is destructive and leaves children/families struggling without diagnosis or appropriate help for years.

Rubbish, they wanted to rule out his other diagnosis as being his only one ?

It has been incredibly frustrating. It doesn't help that no one can give me any idea whatsoever about how much longer we are going to have to wait. The only time we have had 'updates' or communication is when I have chased. I feel as though I am letting my daughter down because I cannot afford a private assessment.

While the diagnosis itself was fine to get, there's no support and very little signposting on where to find support. We have no idea on what to do next or whether we should be in contact with the health services and feel we've been left to it on our own - I'm sure the pandemic has exacerbated this, but even with a pandemic some level of support should have been surely offered. We are still paying for private speech therapy as that's the only help our son gets. This is making a huge difference to him, but it's stretching us financially.

Lack of communication is very poor and wait times are horrific

Seems like you wait for eternity then you get diagnosed and are discharged straight away. Like a factory conveyor belt.

Just that parent need to be informed more.

**Family Voice Norfolk consultation on NDS for Norfolk County Council HOSC**

The original referral was rejected as it coincided with myself and my husband separating. Whilst on the pathway the only contact received was to take some very basic demographic information and tell us they didn't know how long till the next stage but it would be a long time. Professionals working with us including SENCO, social worker, crisis support workers tried to get information on timescales and nothing was available. After having the private diagnosis ratified by the NHS (all within 8 weeks of seeking it). We eventually received information about post diagnosis support for parents. On trying to book into these we were told there was no availability. Far too little much too late. Professionals involved with us didn't really know if it was possible to have a private diagnosis accepted by schools or services. Although my son now has a place at a specialist ASD school he is struggling to attend. Not surprising after so much time out of school. I have been unable to work (as an SEN teacher) since January 2018

It takes too long, damage is done in that time

There is a particular issue about identifying girls who need assessment. They treat girls and boys the same and yet their presentation is very different.

They put all children in a box

I KNOW it's about lack of funding from central government; I KNOW it's about inadequate staffing levels; I KNOW it's not County's "fault". But how does ANY of that help our children?

Why is the process such a long and complicated process?

very limited very unhelpful

The assessment process of the computer based work for parents is very hard going and emotionally draining

The wait is unacceptable. Children's lives are being damaged.

They seem lovely in the small communication I've had. Just so frustrating they're so overstretched!

No guidance, questions not answered, future isn't clear

I think my overall experience once we got to diagnosis stage was good, as I had gone in to say I thought my son had ADHD and SPD, so I think they were pointed in that direction so it was more straightforward. I know a number of families who are struggling getting full diagnoses with multiple issues.

The time scales are ridiculous and children are suffering because of them! The NDS team obviously need more funding and more resources to help resolve this problem!

Lack of communication

**Family Voice Norfolk consultation on NDS for Norfolk County Council HOSC**

A late diagnosis for a child can have a detrimental impact on their future especially ASD children! Early intervention is essential but can't happen when the waiting time is so ridiculous

It took 2 years to get a diagnosis and when we got that, we were thrown out the door with a good luck in the future and no further support!

it seems as if there is not enough staff to cope with the work load.

I really don't see the point of a service that doesn't appear to be helping anyone? You can of course see most of these NDS Doctors privately for around £2000. It is a disgrace that they take the NHS money on top of this as well. Very wealthy Doctors & Very poor, desperate parents with declining children. An absolute SHAMBLES of a service. Where IS the care? Who really DOES care when there is so much ££££££ to be made out of children's complex neurological conditions & heartbroken parents, eh?

Waiting list is unbelievable

unacceptable delays. no formal report from a feb 2020 school visit. children's' well being massively impacted. unaware of any other nhs service which is so slow.

You shouldn't have to constantly fight to get what your SEN child needs, there is no support for parents and very little support for the children involved!

Give parents more credit they know their children much better than someone that has only spent 15 minutes with them in an appointment where they can seem "normal".

The NDS service could improve by having better communication between different professionals, having open communication with parents, a suggestion is offering those children with ASD/ADHD yearly health check ups. Offering more support than just sign posting to charities/different organisations. Cutting the waiting times for referral/diagnosis and ensuring the parent is kept in the loop with decision making processes. And this system where the child's behaviour is blamed on parents need to stop.

Diagnosis was spot on, all the professionals and staff we spoke to/ had appts with could not have been more passionate/professional/helpful/caring just too overwhelmed and under funded/staffed

I don't like the way once you have the diagnosis you are pretty much left with just a few leaflets. No further help no further investigations into other comorbidities.

Still waiting with no correspondence

Minimum amount of contact so based on the phone call and 2 letters was ok given information at that time

I understand the back log due to Covid but my Son was referred long before Covid and nothing has seemed to have happened until his Consultant contacted them

Once you get through the process has been OK so far. However getting accepted onto the referral has been a challenge. It feels like it's a challenge for people to take us seriously

Previous experience with eldest child was positive - 3 years ago but we did not wait long, had contact throughout and felt listened to. It's hard to say whether our experience this time is good or bad really due to the complete lack of communication and having failed to have our child seen, spoken to or assessed by anyone since referral was made by community paediatrician. Child was under 6 at time of referral - it was never explained to us that he would remain on the same list even after he turned 6 and when we were trying to contact the nds team to find out if that was the case it was very difficult to get hold of anyone, and the information we were given was vague. I understand that covid 19 has made everything more stretched and increased waiting times, but they were appalling before the pandemic too. I understand that it is not the fault of those who are part of the NDS team, and that underfunding and understaffing for the level of need is at fault, but for families who are left waiting without any answers this isn't much comfort.

While those professionals we have had contact with have been helpful and supportive, the time it takes to access this time is horrendously long

Communication is terrible. Not kept up to date what's happening

I understand from various forums I am a member of that the waiting list for a diagnosis with the NDS is currently around 3 years' long which is ridiculous. How are our children supposed to be receiving the support they so badly need with a 3 year' waiting list? Even more worryingly, I also understand that once a diagnosis is given, there is no support to follow (except maybe a training course for the parents). There is no OT available on the NHS in Norfolk and the NHS SALT currently has a 1-year waiting list. We have been using our savings to access SALT and OT privately, but obviously our resources are limited and there are so many families who can't access this at all. There should be so much more help available for SEN children and their families than there currently is and we feel completely let down by the system.

Too long waits, little to no information on help

Speed Up. There are part of the country who can diagnose a child in 8 to 10 weeks, just increase the quantity of clinicians to get the job done and get children the help they need.

Follow ups would be nice to know what is happening. I have had a telephone appointment and filled in questionnaires to be told I am on another waiting list

Slow

The staff are dedicated and helpful when you see/speak to them but the length of time the process takes is shameful.

Waiting times poor and other children getting seen before just because they are severe it should be first come first serve

The waiting time for diagnosis is way too long. Children are struggling in school, and with it taking so long to get help and a diagnosis many children are missing out on an education. Families are also struggling to cope, without answers for their child's difficulties and support with this.

Every step is a battle to get support. If they don't see what I see then it can't be happening. But it is and it does. We were FORCED to go down private route. I knew he was autistic but MY evidence is not good enough!!! He was diagnosed ASD and most probably SPD but we couldn't afford for the formal diagnosis.

The NDS staff have always been very pleasant and helpful, although I never really got to use their services. The waiting time though is just abysmal and shocking that children are missing out on vital support. 3 years in the life of a child is a huge amount of missed opportunities.

It seems impossible to speak to anyone from the service and certainly not the same person more than once.

I'm still waiting for someone to get back to me.. I know we've been in lockdown but some acknowledgement that he is still on the system would be appreciated.. Year 4 is looming.. Back and fourth since nursery..

still waiting on assessments

Our paediatric doctor is amazing and has done everything she can to speed things up. She's an absolute rock!

We used this service 9 years ago. The mistakes made have rippled out until I took my daughter private. 7 years of heart ache and stress could've been avoided had the correct paperwork been done.

Expect to wait 2 years plus

Now we are on the pathway we have been pleased with the service. The professionals we have spoken to have been helpful and listened to us. Getting onto the Pathway took time, although not necessarily their fault. We have been informed our daughter will be getting an observation at school by an OT but I feel that we could do with one at home too to help us provide the right environment here for her.

The admin team have always been extremely efficient, supportive and helpful whenever I have contacted them.

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It needs to speed up, hard enough trying to cope with the demands and needs of children with additional needs without the hassle of waiting and having to keep chasing things

It's difficult to add additional information to support a referral. The doctors posted some evidence via internal mail which did not arrive. Had to be sent via direct email after speaking with the service. Doctors also did not have an up to date list of items needed for referral eg they said we needed to have a CAF. This was checked and out of date. Doctors need to be a bit more aware of the process to support families in understanding the steps that will/could be taken.

The waiting times are ridiculous. I phoned up to see when my daughter would be seen and I was given a two and half year wait time.

We have had no involvement with NDS and had no idea they existed until this survey.

too late and no support

It wasn't difficult to get the referral, but waiting for the assessment takes really a long time.

Didn't know it existed

I'm just glad I never have to go through this system again

I was never even signposted to the service at all!

I understand it takes a while but 4 plus years isn't good especially when the only person suffering is my child

I don't understand why the face to face school visits are happening now

Sensory Processing Difficulties need to be recognised and children and families need to be supported by OTs specialising in Sensory Integration. Ultimately there needs to be much more funding to support children with additional needs.

N. D. S should deal with the assessments themselves instead of passing it onto starfish plus to deal with who really have no interest and just read a few pieces of paperwork and carry out a cursory assessment then a year later produce a woefully inadequate report.

more information is needed to be given

The wait is miles to long

## Appendix B: Email to Family Voice Norfolk

"I wanted to give feedback on the NDS but the questionnaire isn't really appropriate. But I had amazing service from NDS a couple of years ago 2018-2019. I can't comment now, but we were referred to Silverwood centre by a paediatrician. They identified ASD behaviour in **Family Voice Norfolk consultation on NDS for Norfolk County Council HOSC**

my daughter and wrote a report and requested a referral to the NDS, she explained it was a diagnose and discharge service and made it clear what we should expect. We were seen by a doctor within a couple of months and he agreed. It was then only approx 4 months after that she had the observation in school and then a further 3 months roughly to have the results/feedback appointment. I believe we got the diagnosis early in 2019 less than a year since our first appointment. I can't fault any of the professionals we saw. All the reports were detailed, clear and accurate and the staff were polite, empathetic and friendly."

## Appendix C: Quotes from members of the West Norfolk Branch of the National Autistic Society

- They desperately need more resources. Expecting the current NDS to be able to cater for the amount of children who actually need their services is like expecting a whale to live in a goldfish bowl. I know this is probably beyond their control though. Honestly I think the bigger issue is with the community paed's who refer into the service in the first place, although I believe they're part of the service too. It concerns me that information from the paediatrician who wasn't even going to refer my child is apparently going to be used instead of a proper ADI-R taken by a clinical psychologist.
- All I can say about the neurodevelopmental service is that they need to learn to communicate between the departments, right hand does not know what left hand is doing. Service is poor, they lost my child's ADHD referral a few years back even though they knew my child was home educated they called up asking when they could assess my son in school! No support post diagnosis, no support if there is also severe anxiety present with the ASD unless they are suicidal which how many of us want our children to get to that point before they are seen. I can't comment about waiting times for ASD in Norfolk as my son was diagnosed in Hampshire but that was over 2 years waiting. Services for ASD etc. is atrocious here in Norfolk. Sign posting you to just Puffins Parenting course post diagnosis is laughable using outdated footage from years ago the content I myself would have easily researched via the internet. I know it will never happen because of budget constraints but I would like to see 6 monthly/yearly health check-ups/developmental check-ups etc. a phone call maybe from an assigned ASD/ADHD nurse to see how things are, if there are any concerns etc. like you would have if you were diabetic for example, if that makes sense.

- Took me a year to get a referral accepted for my child because school or GP were not aware of the criteria. It was only because I found a document online that I realised we needed a report from an Educational Psychologist. Referral accepted around March 2019. Received telephone call in December 2019 and spoke with person who was very understanding and informed. Received forms/questionnaires to complete in Jan 2020 and then told next step would be for someone to come and observe child at school (which they said was a long wait – and then Covid hit). I needed a diagnosis for child before they started high school this September so ended up going for a private assessment Dec 2021 and got child ASD diagnosis. I passed on the private diagnosis report to NDS and they sent a letter accepting the diagnosis along with a lot of photocopied leaflets of organisations who can offer help.

- My god where do I start? NDS service has been absolutely ridiculous for us. Finally referred onto them 3 years after constant fights. They then did my child's assessment through Zoom chat with a speech and language therapist which was utterly ridiculous and child did not want to have anything to do with it. They claimed due to Covid they couldn't see her but we still managed to go for a pointless standard hearing test at the hospital 2 meters away from the people conducting it. Anyway we had the pointless assessment and the pointless outcome where they said my child will be discussed at the next meeting. This was January 2021, they then delayed the meeting month after month. I rang every single month to be told sorry it didn't go ahead but I promise child is top of the list and will be discussed. I rang again April for the 4<sup>th</sup> month to be told the meeting went ahead but my child was not discussed. I made a formal complaint that I didn't hear back from for weeks, when they did call they profusely apologised and said child would be discussed at a priority in May's meeting and will call me straight after. Well we haven't heard a word from them since this day. We've been fighting for 4 years now for a diagnosis but nobody cares. We are now going down the private route because we are struggling too much and we feel that the NHS has failed our child too many times now.
- Absolutely crazy wait times! I went private in the end. I was lucky enough to just about be able to afford it.
- It took 4 years for one child and 5 for another to get a formal diagnosis relying on me constantly harassing NDS as they are incapable of keeping you abreast of updates. Having been thrown the diagnosis of asd with one and moderate adhd with asd with the other the only after support I have is a list of websites I can refer to. Meanwhile I have 2 children I have had to de-register from school as they weren't coping. 2 children that don't want to mix with others. Power struggles. One that chews their fingernails off and one that can't focus on anything etc. etc. No support at all and NDS just say we are only a diagnostic team and we have finished with you now. Shameful service that clearly does not do what it says on the tin. Quite frankly I'm unsure as to how they are allowed to continue whilst offering the useless services they do.
- I felt my child might have ASD when they were 7. They are now 12 and we got an assessment with the help of the NAS this year. Unfortunately my child had a meltdown and they couldn't do it. I was told they would come to the school to do it. I heard nothing, but then a couple of weeks ago my child said a lady from the NHS had come to see them at school. No-one had told me! So we are still awaiting the outcome. Sounds like it will be many months....

- Four and a half years for diagnosis...Puffin course not available till after diagnosis...and I am still on the waiting list for the course...we as carers need the courses to educate ourselves at the start not at the end of the process.
- 5 years to get a diagnosis for 1 child, 4 for the other and after getting asd and adhd moderate to severe, all the help I've had is a list of websites to refer to. Wish I hadn't bothered – achieved nothing in the end.
- Not fit for purpose pretty much covers it.
- Well the lady I spoke to was lovely and very supportive but it's 3 and a half year wait for the ASD assessment and when I asked if I could ask the NHS to fund a private assessment, it was a no.
- Child was in Year 1 when the service accepted the referral for assessment from the GP. All I have had is the initial parent phone assessment and I would call and chase monthly throughout child's time in year 2. Eventually when child started year 3 I decided to go private and child was diagnosed in December last year. I have sent my reports in to be NHS ratified and still waiting. I understand the resources are right etc. but communication would help. I would've made the decision to go private a lot sooner which isn't really OK as not everyone has the financial ability to do so.