

## **Family Voice Norfolk update on parent carers' experience of the Neurodevelopmental Diagnostic Service**

for Norfolk County Council Health Overview Scrutiny Committee

14 July 2022

### **Consultation**

Parent carers of children and young people with special educational needs and/or disabilities (SEND) were consulted via an online survey in June 2022. They were asked to consider their experience of the Neurodevelopmental Diagnostic Service (NDS) during the previous 12 months to update survey results that Family Voice Norfolk presented to the HOSC of 15 July 2021.

### **Background**

Family Voice Norfolk is a collective of parent carers from 1230 families across Norfolk, representing almost 1600 children and young people with SEND. Family Voice Norfolk is the strategic voice of parent carers, working in partnership with Norfolk County Council (NCC), the Norfolk and Waveney Clinical Commissioning Group (NWCCG) and voluntary organisations since 2006. It is funded by a direct grant from the Department for Education, by NCC and by the NWCCG.

Parent carers were invited to complete an online survey to give their experiences of accessing the pathways and services supporting diagnosis of neurodevelopmental conditions, such as autistic spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD).

Family Voice Norfolk received 56 responses to the survey, a third of the responses received to the 2021 survey. Reasons for this may be:

- a) 'survey fatigue' from an intense period of weekly surveys on other topics just before this one;
- b) a sense among some parents that their views are powerless to improve a system so fraught with difficulty and delay;
- c) a sense among some parents that the situation is improving in some ways – if not in the length of time on the diagnostic pathway then at least in the quality of communication with the NDS. Of course, without their responses, we cannot know if this is the reason.

## What did the 2022 survey tell us?

In some ways the information parent carers gave was all too familiar, but there were changes in emphasis and some aspects that had a clearer focus than in 2021. There are seven key points that emerge from the 2022 survey responses. These are listed below and detailed more fully in the next section. Finally, narrative information from parent carers given in open text boxes in the survey is included as appendices. These give a powerful sense of the effects of the current system on individuals and their families.

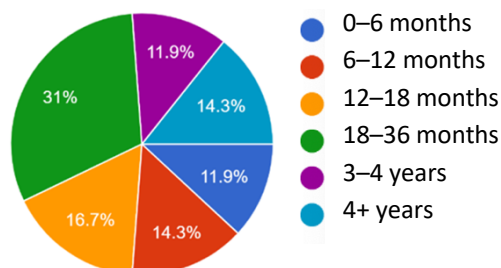
Key issues raised are:

1. LONG WAITING TIMES
2. CONCERN ABOUT YOUNG PEOPLE'S WELLBEING
3. CONCERN ABOUT TRANSITIONS AND EDUCATION
4. PARENTS FEEL DISEMPOWERED AND WHOLE FAMILIES ARE AFFECTED
5. COMMUNICATION AND SUPPORT HAS IMPROVED BUT IS STILL A SOURCE OF ANXIETY FOR FAMILIES
6. DELAYS ON THE DIAGNOSIS PATHWAY AFFECT DISADVANTAGED FAMILIES DISPROPORTIONATELY
7. LACK OF ACCURATE INFORMATION INCREASES STRESS AND LEADS TO FURTHER DELAYS

## Key findings

### 1. LONG WAITING TIMES

It is not possible to compare all statistics from last year's survey, but the length of wait is still parent carers' biggest concern. Our respondents included those who have only just begun their journey towards diagnosis, but nevertheless 26% of our respondents had been waiting over 3 years with almost 12% over 4 years. Those already on the pathway are anxious that there are still years ahead without a diagnosis and many are critical of the information they have been given about this.



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

It is not surprising that when asked how they would rate their experience of the Neurodevelopmental Service overall, parent carers' response was resoundingly negative. On a scale of 1-5, where 1 is Poor and 5 is Good, no one at all replied with a 4 or a 5.

Asked whether the Neurodevelopmental Service and NDD Pathway had been explained by a health professional, 76% of respondents said 'No' compared with 62.4% in 2021.

There are in fact two pathways – pre-6 years and post-6 years – but 62% of respondents did not know which pathway their child was on. This compares to 36.7% of respondents in 2021.

For both of these questions, results were significantly poorer than shown in our survey in 2021.

The long wait for support basically destroyed my child's education

to make parents of pre school children feel like they have to sit at home and wait for years for explanations and understandings is cruel

My child wont have completed their NDD until 16...and they wonder why so many young children suffer with mental health. We all want answers so we can educate ourselves and grow as a family.

## 2. CONCERN ABOUT YOUNG PEOPLE'S WELLBEING

We know that the pandemic has negatively impacted the mental health of children and young people. Those on the NDD pathway have an additional stress. Parent carers tell us that their child is anxious to understand themselves better and that diagnosis is part of this. As children get older their sense of being 'different' from their peers increases. It is upsetting for parents to have to tell children who are already anxious that 'one day' they will know more about why they feel as they do – but not when that 'one day' is.

My child is anxious that they will not get their diagnosis and often asks what will happen if they don't get officially diagnosed. It's causing them anxiety.

High anxiety for child.

Its affected my child's mental health a lot as they don't understand why they feel so different from peers and I have no explanation as no diagnosis yet.

## 3. CONCERN ABOUT TRANSITIONS AND EDUCATION

Respondents showed a particular concern about diagnosis not being available in time to facilitate transition from one educational setting to another or to access an appropriate school. In addition, although they know that schools can support without a diagnosis, neurodivergent conditions are themselves diverse and parents are concerned that provision cannot be properly targeted without a clear understanding of their child's condition.

My child is due to start school and a diagnosis is important as it needs to be in their EHCP

School had advised us at the beginning that our child needed this in place to help them move onto college or education after high school. At this rate they will have left school before assessment is finished.

School currently supportive, but we are aware specialist placement may be needed soon, which is difficult without diagnosis.

Ok for now but high school is coming and we need a diagnosis

#### 4. PARENTS FEEL DISEMPOWERED AND WHOLE FAMILIES ARE AFFECTED

Throughout the survey, parents are strongly focused on the needs of their child who is awaiting diagnosis. Fear for them and the effect that delays are having are paramount. However, in passing they mention significant impacts on themselves and on other members of the family. Among the impacts are parents having to give up work, other siblings being affected, and the whole family feeling uncertainty about whether what they are trying to do for the child awaiting diagnosis is helpful. Parents feel guilt and desperation about not being able to access what their child needs.

Frustration, upset between siblings, different parenting styles.

Overall this has caused a lot of distress to me and my child. Had they been diagnosed at an earlier age we would have known could have searched for strategies and support ... rather than living with feeling ashamed and blamed for a neurodevelopmental difference.

Our family has been torn apart

I have spent countless amounts of time and money reading, paying for private therapists to help educate myself and my child and help them manage the anxiety and other behaviours that manifest at school – it has been an unbelievable strain on our family life.

At present, it has been up to me, as their parent, to research possible conditions and try and get them support that I think they might need. I am not an expert in neurodivergence, but I have no access to an expert or medical professional who can help me understand my child better. Whilst waiting for 3 years for an expert to correctly diagnose them, my child is living a life based on a layperson's best guess at their condition.

#### 5. COMMUNICATION AND SUPPORT HAS IMPROVED BUT IS STILL A SOURCE OF ANXIETY FOR FAMILIES

Communication with families whose children are on the pathway appears to be very varied. Some have had sufficient contact from the Neurodevelopmental Service and have found ways of getting in touch with NDS when they need to, while others have had no or unhelpful contact. The same is true of contact with organisations such as Family Action. NDS appears to use a variety of means – email, face-to-face meeting, phone calls and letters – to contact families, which is good to see.

When asked if they had been offered or given any help and/or advice while waiting on the NDD Pathway, almost 63% of parents said they had, which is an improvement on the 'almost half' of parents who said this in 2021, but the recent figure is still less than two-thirds and leaves a significant proportion who feel that they have received no help or support at all.

It would be useful for a rough timeline of assessment. I have been turned down on autism awareness puffin courses as my child hasn't yet got an official diagnosis.

Leave voicemails in tears, no one responds

It was very easy to email or phone them but very hard to get a response. I had to leave numerous voicemails.

Appendix A gives more information about parents' experiences of attempting to contact NDS.

## 6. DELAYS ON THE DIAGNOSIS PATHWAY AFFECT DISADVANTAGED FAMILIES DISPROPORTIONATELY

The current system led 81.5% of all the parents who responded to consider seeking private diagnosis. Those who could afford it had gone ahead and achieved a much speedier resolution. But many could not afford it. Financial status should not be a barrier to diagnosis. Some parents spend time and resources researching conditions that their child *might* be diagnosed with, in order to be able to advocate for them more effectively in the meantime. It is parents with sufficient time, capacity and ability who can undertake research and educate themselves. Those who are not able to do this – and their children – are also potentially disadvantaged.

Lots of advice says that early intervention is best but it took months to even get to the referral stage. We have since gone private to get our child's diagnosis.

I can't think of anything more soul destroying than having a solution one cannot afford! As a parent this is beyond cruel.

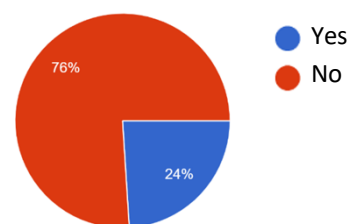
Expected to wait another 6 months on top of the already 3 years. Long waits make us want to get bank loan to help fund our child's needs for better health service and in turn future.

## 7. LACK OF ACCURATE INFORMATION INCREASES STRESS AND LEADS TO FURTHER DELAYS

This begins at the very start of seeking a diagnosis. In answer to the question, 'Is it clear to you what supporting information is needed for a referral to NDS?' 80% of respondents said 'No'. Information is in fact available on the SEND Local Offer website and in other places, but parents who are already worried and looking for support because their child is displaying signs of needing additional help, should not have to become experts in systems to access that help. Both GPs and schools need to be able to give parents clear and accurate information about what is involved in a referral. To parents it feels as if responsibility is passed backwards and forwards, causing further delays. Families need a sense of professionals working together for the benefit of their child. Difficulties in contact, the involvement of unconnected professionals, and the delays of the pathway itself all communicate to parents that no one cares about their child. This is profoundly worrying for parents who now have questions about the life their child will be able to live in the future and how to prepare for it.

The personnel dealing with our referral changed and it is difficult to keep up with the different services and their representatives because there are so many agencies that are

Pre diagnosis support for families is needed and this service (seemingly supplied by family action) should be integrated with NDS. More cross working between NDS, CAMHS, point one and JustOne emotional/behavioural support is needed, these services do not seem to interact with each other.



Has the Neurodevelopmental Service (NDS) and Neurodevelopmental Disorder Pathway (NDD) been explained to you by a health professional?

## Appendix A

### Parent carer responses to the request:

#### Tell us more about how easy it was to contact the NDS team.

Note: these responses have been anonymised by removing names and other identifying details. Nothing has been added to the responses and the writer's message has always been preserved.

Never answer the phone but answer emails

Leave voicemails in tears, no one responds

Never any answer on the phone lines and a long wait for an email response and even then the response was very vague.

Very difficult to speak with someone

I have generally been able to speak to someone on the phone - if I ring early or later in the afternoon.

I spent two years just raising my concerns and try to get help from a health professional, finally the health visitor referred my child for assessment, 7 months later they got an assessment with a health practitioner and 3 months later their referral was accepted since then its been 5 months and we've heard nothing, we don't know what happens next.

I used Email and contacted via mobile numbers

I rang the number on the letter but nobody answered

I contacted them about the correct procedure to refer my child for sleep issues. I was told the GP had to do it, but not that I also had to contact an organisation that dealt with sleep issues to even get them referred by the GP. This was later discovered by a member of the charity, Family Action so contacted them on my behalf.

The communication has been very poor and there has been miscommunication too. I've chased on several occasions. My child has numerous reports which they said they could use and have had a school assessment done about 2 months ago but still no further forward. We already have an ASD diagnosis. The only contact I have had in the last 12 months plus has been after I've contacted them.

Email is the best way of getting a reply. However they will not give details of progress on waiting times when I ask.

I have a named contact

Not helpful and get told different info

I have emailed.

My child's referral was rejected for being too young (you are born with neurodevelopmental disorders so how is it possible to be too young?) - instead of waiting I got a Private diagnosis at the cost of £100 and it got ratified by the NDS 6 months after they received it. If they can't even say they agree with a clinician's report within 6 months there is no hope for anyone getting seen and diagnosed within a reasonable time. They clearly rejected my child's referral to save their own waiting times.

No one ever answers and it can be weeks before a call back and in some cases just a letter is sent.

The personnel dealing with our referral changed and it is difficult to keep up with the different services and their representatives because there are so many agencies that are involved with our child's education and welfare.

Process took so long that fell behind more at school

It was very easy to email or phone them but very hard to get a response. I had to leave numerous voicemails.

Repeatedly contacted to inform of incidents, exclusions, school refusal, mental health, sleep Child was diagnosed with ADHD on almost the information we shared above and beyond the questionnaires and video call

Struggled to ever get the right support for my child who is 23 years of age no one wants to help them because they have always slipped through every net. They have mixed neuro developmental delays hearing loss, and other issues and their learning difficulties are always borderline meaning they never fitted any criteria. As a family we have all suffered and our faith of trusting professionals is nil as other than are GP they have all let them and us down. I know I'm not alone but to get the right help for them would be good, wellbeing isn't specialised in their needs and getting referrals to a psychiatrist is not impossible.

I emailed NDS on 04/04/2022, heard nothing so rang and left numerous messages, I finally spoke to someone on 19 April, I then emailed again on 05/05/2022 with a complaint, I received an email on 12/5/2022 saying my complaint had been forwarded to the complaints team - to date (11/06/2022) I have still heard NOTHING - compiling an complaint letter to my MP today - my child has been waiting 3 YEARS for diagnosis

I actually emailed the other day to ensure they'd received everything. They had but I was told not to expect to hear from them for up to 40 weeks! And that's just for the initial information. Assessment is a 3 year wait. Per the email I received.

## Appendix B

### Parent carer responses to the request:

#### How has time waiting on the NDD Pathway affected your child or young person, their family and/or their place of learning?

Note: these responses have been anonymised by removing names and other identifying details. Nothing has been added to the responses and the writer's message has always been preserved.

My child has not had to wait. Their needs for their dyslexia are met by their school. Their school are fantastic.

More at school

My child wont have completed their NDD until 16...and they wonder why so many young children suffer with mental health. We all want answers so we can educate ourselves and grow as a family.

Paid for a private diagnosis of ASC to get an EHCP and get a place in a special school. Struggling to get anywhere else though as most other professionals want to wait for ADHD diagnosis to be done by NDS before doing anything else. Child is making no progress at school and cannot afford private diagnosis of ADHD. Behaviour is very challenging and deteriorating and child is very depressed but need NDS to diagnose before CAMHS will intervene.

Can't get support

I have no idea how they can justify their wait times. My child was in year 1 when we applied, they are now year 6. Their last assessment was last October which we got the report from two weeks ago. I wish I had gone private years ago but I do not know who to trust privately. I have had enough now, there is no communication, no support, I have no idea what they are doing. I have not been able to access support from multiple channels as we have no diagnosis.

My child has been passed from teacher to teacher with no real consistency or help.

Child is unable to attend school due to high level of need and does distance learning from home provided by the school. Awaiting ehcp to decide how best to proceed.

Stressful, families need to move the process forward

Affected their ehcp reviews as there has been delays in their diagnosis thus affecting the support they are entitled to.

Ok for now but high school is coming and we need a diagnosis to get them into an autism specific school (already has an EHCP)

My child is anxious that they will not get their diagnosis and often asks what will happen if they don't get officially diagnosed. It's causing them anxiety.



We home educate and are able to differentiate learning experiences to meet the individual needs of our child. It is extremely frustrating to have been waiting three and a half years with minimal communication from the neurodevelopmental service.

Not knowing exactly where their struggles come from have meant both myself and school have to guess at how best to help and support my child.

I didnt know 90% of people with Autism have sensory disorder... for this reason these people don't offer support in this area. So besides a 3 year wait for space , more doors to go through and dealing with the here and now. Its a nightmare. Why cant these things just get done and all be under one umbrella. My child is really trying to hold it together in school, they are what I have learnt the 'fizz pop' affect and I explained this to them in one of their melt downs, so they could stop feeling so guilty. They holds it in all day (If they make school) , hates school, even the paper and pencil make them feel funny and this is just the start. Any change and they cant cope with it! Also talking about it they struggle to get their words out, explodes, needs one to one but then Senco isn't supportive and assume they are fine. So when they see me they then explode and the circle starts again. Luckily there are the odd staff member who are really caring, don't shout (my child hates shouting and certain tones of voice) I have them an ILP and a review this week but what leg do I have to stand on with no professional assessment or diagnosis. I am not a professional and I am knackered. I don't have all the answers. My child has always struggled but I never new about ADHD, Autism etc Until Covid lockdown... then it all made sense but I am still stuck and so is my child and our family. There is only so much one can do, fight for and mentally cope with. These pathways are the key to our future generations with SEN and the waiting times are not good enough, damaging.

This is a rereferral as after 6yrs under a paediatrician they discharged my child. I asked for them to be referred again a year ago as the older they've gotten the more their difficulties are evident. They are 16 and very worried about the future after leaving school.

They have deteriorated a lot. Been in 4 different schools. On medication for sleep issues. Needed social services involvement Police involved Mental health team involvement Lost friends and family members due to severity of their needs

We have had no correspondence for almost a year. Over the last three years they have had part 1 of the assessment twice and then it hasn't gone any further even though I'm told it will!

It was very difficult to find appropriate strategies for managing my child's behaviour without a diagnosis. Also we had no support at school for their additional needs.

It is effecting their learning, they are working several years behind

Negatively

High anxiety for child. School currently supportive, but we are aware specialist placement may be needed soon, which is difficult without diagnosis. As a family we are supporting this child as we already have 1 autistic child, and are knowledgeable about the best ways to support our children individually

## Worsening of behaviour

They were expelled for behaviour arising from ADHD while waiting for medication.

My child's school now say they can't meet their needs and nowhere else has places and also on wait for places

In addition to the time on the pathway we spent 4 years trying to get accepted onto the pathway. It has been very distressing not to be able to tell people the cause of my child's difficulties. I have repeatedly been blamed for my child's behaviour. I am now at the stage that my child needs to have an explanation of why they have the difficulties that they have. It is a difficult journey to navigate dealing with distressed behaviour and difficulties at school when you don't know the cause. Overall this has caused a lot of distress to me and my child. Had they been diagnosed at an earlier age we would have known and could have searched for strategies and support at a much earlier stage rather than living with feeling ashamed and blamed for a neurodevelopmental difference.

They are becoming more distressed because as they are getting older they are noticing that and will regularly say they are not the same as other people and people/ peers don't understand them. They are becoming more withdrawn and emotional. The masking strategies they used when younger are no longer working which is adding to their anxiety.

Not received the correct support required for my young person to thrive

My child is STILL out of school nearly 18 months after their needs were unable to be met by their school. My partner and I have had to take off time from work to support them and speak to professionals and those we have had contact with have been overwhelmed and sometimes unhelpful. We have struggled as a family with little regard from the services that we have been put in contact with.

Frustration, upset between siblings, different parenting styles.

Learning as within weeks of medication they moved on but over 3 years is disappointing as now my child has to catch up so it's frustrating you know your child and when I knew there was something delaying treatment causing more problems

Thankfully I have been supported by their nursery I'm also a Social Worker by profession so I felt confident in self-referring them for an EHCP and it was accepted this has helped a great deal

We have felt 'stuck'. Lots of advice says that early intervention is best but it took months to even get to the referral stage. We have since gone private to get our child's diagnosis.

Our family has been torn apart, one child become a young carer, another not been in school for nearly a whole school year come September, that's just the start of it, partner unable to work so financially struggling badly one wage pressure on me, damage to property, multiple school exclusion, injuries

Its affected my child's mental health a lot as they don't understand why they feel so different from peers and I have no explanation as no diagnosis as yet.

Had to remove from mainstream and home ed.loss of self esteem.loss of self understanding

Very worried and let down

I have spent countless amounts of time and money reading, paying for private therapists to help educate myself and my child and help them manage the anxiety and other behaviours that manifest at school- it has been an unbelievable strain on our family life ( their sibling is ASD/ADHD and SPD took just under 3 years to diagnose pre COVID). Despite school accepting they are SEN every year we have the same struggles with the new teacher NOT understanding their needs. They are a VERY bright child but struggles with attention, impulsivity and anxiety and the teachers tell them off for not concentrating, for their hand writing, etc which then impacts on their sense of worth ( they have HUGE rejection sensitivity dysmorphia) and has self harmed because of the pressure school puts on them ( been through all the NHS point one referrals etc which were so long or useless that we have seen private therapists)....my marriage has been pushed to breaking point, both my husband and I are on antidepressants ...and if I hear one more time from the school " they don't show any signs of anxiety at school, they just need to buckle down!!!!!!!!!!!!!!one more time it may be the straw that broke the camels back. My child goes to High school in September and i am desperately worried about that HUGE step but NDS dont seem to care, all I need is confirmation they are ADHD so that I then have a diagnosed "stick" to wave at schools to get them to listen to me, as them just being on the SEN register is NOT enough

Horrendous. No diagnosis - absolutely no support. More battles. More judgement. More ignorance. Currently battling for an EHCP.

## Appendix C

### Parent carer responses to the question:

### Where has help and/or advice come from while you have been waiting on the NDS Pathway?

Note: these responses have been anonymised by removing names and other identifying details. Nothing has been added to the responses and the writer's message has always been preserved.

No due to my child having ASD already no one helps

Nothing from GP, School, Senco etc All been my own research!

I had to find it myself. I have received two useless and patronising leaflets from NDS in the last 12 months.

Just one Norfolk

Family action emails have been good for advice however I have been unable to make any coffee morning etc due to work commitments.

Norfolk Community nurse was able to offer advice on services to contact

Family Action/ children centre

Family action

Leaflets with referral letters

We have a lot of experience of asd and adhd in our family so we haven't needed to ask for support.

Family Action

Only through support groups etc but they are not the answer, just a plaster that keeps falling off.

Leaflets and a phonecall.

NDS.CAHMS.ISS.school.Action for children. Support groups.Social media.

Family voice, support groups

Family Action, ASD Helping Hands

I think when we got a letter telling us the wait was approximately 3 years we got a list of contacts.

Family action - who sent us some links to resources (including suggesting looking into PDA for our youngest, which we agreed is a likely profile for them, and had already been putting in place PDA strategies such as using declarative language and lowering demands) all of which we knew about

anyway. We have had no support apart from that - to be honest, it feels pointless asking for anything as we have already accessed most things they can point to us.

GP and school

Asd helping hands, family action. Newbold hope, bild - it took me 4 years to accidentally find my way to these services.

In the way of offering advice I mean I was sent a sheet with a list of phone numbers and websites on. We were referred to family action over 4 years ago and were told that at that time they wasn't much else they could help us with and that my child needed to be assessed by NDD, because of this i didn't bother contacting them again.

Family voices, Point One, ASD helping hands. All remotely or by post and not in a useable form of support.

School

Nursery, complex case nurse, salt, sen coordinator at school where my child will start reception in September.

Family action in first year

Swaffam family action, was advised in letter to call then which I did they have been amazing support.

GP

GP, school but have to push for it all the time, private dyslexia testing

We were sent some charity links.

## Appendix D

### Parent carer responses to the question:

#### Have you ever considered a private diagnosis route?

Note: these responses have been anonymised by removing names and other identifying details. Nothing has been added to the responses and the writer's message has always been preserved.

My child has been screened for dyslexia and received what they need through their mainstream school. They do not need a Neuro Developmental Service.

Can't afford private

I cant think of anything more soul destroying than having a solution one can not afford! As a parent this is beyond cruel. The waiting time should not be so long in the first place, nor should my childs needs have been missed throughout their education settings all this time! The professionals are to blame in these settings. If it wasn't for my research during 1st lockdown my child would not have what little understanding and support I am able to give them now but there is years and years of their life that they haven't had any support or understanding (due to my lack of knowledge.. I had never even heard of Extreme social anxiety / Autism or ADHD) and it has effected them, our family, their education and probably done more harm to their mental health than if this would of been picked up in their schools etc (You need a de code book for all the abbreviations used.) What is NDS .. for example.

Have got a private diagnosis of ASC but cannot afford private ADHD diagnosis and ongoing support.

Can't afford it and no where nearby

I would love to have a meeting with you guys as I need advise what to do :)

I can't afford it.

I have considered private diagnosis due to length of wait just being referred and then wait within the service and child's level of need/ being unable to attend school. Currently awaiting ehcp outcome to decide on next steps to take to support my child.

Current finances will not allow this

I have so far been waiting for an appointment for 3.5 years.

We have been on the NHS list for 3.5 years. After this long we are determined to stick it out. We have no doubt that our child is Autistic and also has ADHD and have considered a private assessment, but the cost is prohibiting.

After 3 years on the waiting list and my child significantly struggling. I decided to go private as I felt we wouldn't wait another year or 2 as they would be going to secondary school. I wanted to make sure as much was in place before then.

Again (I have done one of these for my child) Offering the answer for your child with something you can not afford is soul destroying and wrong. I also need a de code.. what is NDS?

Unfortunately we had moved from another county to Norfolk and both rely on school reports these haven't always supported the child so considered going private but can't afford that option at the moment and have to be careful where I go because some people I know so could be classed as conflict of interest.

I can't afford it though

Expected to wait another 6 months on top of the already 3 years. Long waits make us want to get bank loan to help fund our child's needs for better health service and in turn future

Because of the horrendous waiting times in Norfolk. But too expensive and we hear private diagnoses are often not accepted by publicly funded agencies (NHS,, LA etc)

We paid around £400 for a private diagnosis for sensory processing disorder as this is not available on the NHS in Norfolk. This was taken into account when they were diagnosed with ASD.

We did consider going private and got so far as to speaking to a doctor but unfortunately I was diagnosed with a serious illness so put it on hold.

Expensive

Ended up going private and NDS referral was rejected due to lack of evidence from school We looked into it, but are already going to be paying for sensory integration therapy and don't think we can stretch to a private diagnosis too!

We have sort additional help via the Adoption Support Fund

We had to get the assessment done privately.

Ccg will pay for private adhd assessment if wait is more than 18 weeks but because so many parents have done this there is now a massive wait to go private

I have now booked private assessment which I am paying for with my childs DLA money which it took me years to realise they were entitled to. It has taken 7 years in total of waiting for me to reach this point. I have made this decision due to increasing difficulties at school and complete lack of support from school in terms of waiting over 18 months for educational psychologist and still counting.

I have explained above how after my child's referral was rejected instead of waiting for a new referral then being on NDS waiting list for up to 3 years I went and got my own diagnoses for my child who is severely autistic

We have bumped around the system for years now. I first asked NSFT to consider whether my child had autism in 2015. That seemed to get lost in their systems literally, when they changed over to a new operating system or Lorrezzo. ( my child and I did subject access requests to try and understand what was recorded and happening ) Since then I raised my concerns several times with health professionals and schools /college. My child was referred to Children's NDD pathway unfortunately only a few weeks before their 18th birthday. All seemed to minimise my concerns. My child believes they have Asperger's. ( they are not bothered by the history behind the name re the Nazi connection ) I looked into a private diagnosis but it was very expensive and impossible for me to fund it and at the same time my child's education ( they are above average IQ ) has suffered greatly and I have not received any extra funding that would have come with a diagnosis.

Couldn't afford it!

Both my children have private reports and they were referred and accepted by the paediatric consultant team.

We went privately in January as the wait was almost years!

Have considered a private diagnosis due to the 18 month to 2 years plus waiting list, however costs are too high.

It is overwhelming and eye watering expensive.

Going round in circles no one gets back to me. Being ignored, was told 18 weeks from letter which was a year ago. Private is so expensive.

Thought about it but can not afford it

We have gone private and this has been ratified by the NDS. This was for my mental health and well-being as I was so worried about not knowing how to support my child.

Only reason can't afford it as one wage due to not being in school and price

If we could afford it I would have gone down the private route, we were refused twice the 3rd time accepted so it feels like it's been going on such a long time and I feel private may have been a lot quicker.

But can't afford it.

Beyond financial means but would have if had money



We have been told it's not possible to have a private NDD assessment and the wait is 3 yrs  
Can't afford the £2500 for private right now. But it will certainly be an option after Christmas.

## Appendix E

### Parent carer responses to the question:

#### Is there anything else you would like to tell us of the Neurodevelopmental Service in the past 12 months?

Note: these responses have been anonymised by removing names and other identifying details. Nothing has been added to the responses and the writer's message has always been preserved.

I think this survey may need to be headed differently NDD covers a lot of conditions and not all if these require a medical diagnostic route. Lots of children will have a neuro-developmental disorder but will not health expertise as their main barriers will arise in accessing education.

Its a phone call with then a waiting list of about 3 years and an email for other doors to try and get your answers/ help/ support...

I emailed them and told them I had been really patient but that My child will be drawing their pension before they diagnosed them. The email back with an apology saying we were on the list for assessment and it would be done ASAP. I have been a busy mum/work last few years but I am now on the case. I am currently studying level 2 Certificate in Understanding Autism. I have learned a lot so far. I am looking at places to get private help but do not know which places are trusted. We have had out EHCP approved and is with the commity for finance. I am now applying for DLA (40 page form!) as access card / CEA / blue badge / etc do not take us seriously without DLA, we have not needed to apply for it so didn't. I also thought we could not apply until diagnosis. The kids with ASD are being failed by the NHS. They should have 18 months max to help diagnose these children with drop in centres and people to explain in plain english what is going on. All the acronyms and terms are a nightmare. They are also putting all the kids a one bucket. None of us these children receive blood tests to look at levels and variations. I only last week found about AFRID. a food/eating disorder. This has never been mentioned by NHS yet they were accessed to ensure nothing physically stopped them eating. I feel the NHS have really let us down, without a diagnosis how do you know what to action in order to best help. I could rant on all day! We are lucky and have a great school. x

I have no idea when to expect the next stage of my child's referral. They have 2 years left of primary school. They missed nearly 2 years of learning due to no understanding of their needs in school then 2 years up and down due to covid. I am highly concerned for their education. They are very bright and can become obsessed with certain subject but struggles with their reading writing, spelling and concentration.

They clearly need more staff!

We are 18 months into the expected 3 year wait for diagnoses. In the meantime, it feels like I have had to diagnose my child with ASD in order to get them into the school they need to be in. This is absurd. Perhaps they don't have ASD or maybe they have additional disorders which are not being addressed? They are currently failing in their current school as it cannot support them. Perhaps if they had been assessed by an expert in the NDS, we would fully understand

their condition and be able to meet their needs. At present, it has been up to me, as their parent, to research possible conditions and try and get them support that I think they might need. I am not an expert in neurodivergence, but I have no access to an expert or medical professional who can help me understand my child better. Whilst waiting for 3 years for an expert to correctly diagnose them, my child is living a life based on a layperson's best guess at their condition. Three years is a huge proportion of their childhood and I have to wonder, is my child getting the support they really need? I do not know, because their condition has not been fully assessed and diagnosed. Therefore their needs cannot be fully met until we fully understand what their needs are. My child is being failed and I see the impact that this is having on them every day. They are not thriving or even meeting their potential and until we get a diagnoses I am unsure how their needs can be truly met.

Having had very little contact from the NDS over the past few years, we wrote to our local MP about the state of the service in this area. The MP then contacted the NDS. I then received a phone call from [a senior person who] offered lots of apologies and excuses. They said that the current waiting time until discharge from the service was at that time (Feb 2022) 3 years and 6 months. They also said that although they couldn't say exactly when our child would reach the 'top of the waiting list', they would be quite concerned if it wasn't at some point this year. They then wrote to our local MP saying that they had personally spoken to me about my child's case. I haven't heard another word from them since that call in February. They provide a very poor service.

It would be really useful if parents were given a realistic time scale for waiting times. More support in place whilst we are waiting (I had one call from family voice - lady I spoke to was lovely, but ongoing support would have been nice). *[NB Family Voice does not offer support or advice. The writer may have been thinking of Family Action.]*

Sort the waiting times out. From the phone call there should be an appointment to get things going. Not more plasters!

I think its ridiculous the pathway and the criteria for it we've been waiting a year since moved back to norfolk. Just because a school doesn't see traits or they do but communicate different it's crazy and the fact my child's crisis team worker and the eating disorder team trying to liase with them I call it a "ping pong ball effect"

Wait is too long. Very disappointed with the lack of service. I feel I as a parent have made most of the contact to get answers. Complained to CCG regarding the poor service. No face to face help./Support

No, we are still waiting to be called for an assessment.

My child is due to start school and a diagnosis is important as it needs to be in their EHCP

I'm still waiting for my child's referral (4 years)

Pre diagnosis support for families is needed and this service (seemingly supplied by family action) should be integrated with NDS. More cross working between NDS, CAMHS, point one and JustOne emotional/behavioural support is needed, these services do not seem to interact with each other. In general where a family is dealing with emotional/behavioural difficulties integrated support including mental health support and support for parents/siblings (as needed) is needed. Right now these services are fragmented and very hard to access. Unfortunately in Norfolk we are used to services being rubbish and just accept the situation but this should not be the case.

It took intervention from West Norfolk NAS to get my child on the NDS diagnostic pathway in 2018. They were finally diagnosed with ASD earlier this year.

Absolute shambles

I think it's disappointing that if the school report doesn't show anything the referral is rejected, many children like my child mask extremely well at school and these children are slipping through on that basis, we recently went private and received a diagnosis of Autism and PDA. The wait and lack of contact is awful. Any contact we have had has been purely down to me repeatedly emailing, but they have failed to answer questions about waiting times. Emails take on average a week to be replied to, which is frustrating. There is no point in ringing I have found as no one ever answers the phone. Apart from being sent the questionnaires at the beginning of the process we have had nothing else from them. We are fortunate that my child was added to the pathway when under 6, so is still on the pre-6 list as apparently that is a bit shorter a waiting time, but at almost 2 years with 0 meaningful contact, no phonecalls or emails to see how we are as a family, no further contact from the community paediatrician who initially put in the referral or anything else, we are becoming very disillusioned with the entire process, and feel that we have been left to struggle by ourselves. I have been left to find my own support groups and resources (Newbold Hope has been the most helpful and I would recommend that that was added to resources suggested to families while they're left waiting for years!!), pay for my own learning/training and support for my children. Right now I have very little to say about the NDS that is even slightly positive.

Covid probably hasn't helped the service but we have had very little contact from them

The long wait for support basically destroyed my child's education.

There needs to be change newspaper article needs to shame the service and highlight the failings

We decided to stop seeing a paediatrician when my child was around 9 years of age. This was due to my being convinced that there was abuse of power, untrained staff and poor use of restraint going on. This was not in Norfolk where we now live. However we suffer from national issues.

I am sure that they are very good at what they do (I wouldn't know as I haven't seen them) it is a typical case of under funding to meet the demand and lack of training of the number of appropriate professionals to complete assessments

The NDS in our county is a complete and utter failure. They are failing children. Children who don't get diagnosed young struggle to get their children an appropriate education - how can the EHCP outline a child's needs if they don't have a diagnoses? How can early intervention be applied if you don't have a diagnoses? How can families expect to live their lives and meet their childrens needs without a diagnoses? Imagine If your child had Down's syndrome but you had to spend the first 6 years knocking on doors trying to get a diagnoses? You had no language or OT or physio - or way to explain your child to doctors and friends and school - because you had no diagnoses. The system is honestly a disgrace - if they are underfunded and have unacceptable waiting lists they should just say that - to make parents of pre school children feel like they have to sit at home and wait for years for explanations and understandings is cruel.

Most recently I phoned them in desperation . They got back to me withing a few days . They have been helpful but the previous information I had ie within the last twelve months had been confusing especially around how to achieve a priority assessment The Gp and college were also really unhelpful. My childs education and health and Wellbeing has deteriorated and our relationship has too The lack of knowledge and understanding of ASC is very concerning especially amounts they VSCE wider so called support services eg For parent carers of young adults /adolescents . To many people still saying " we're all have some autistic traits ". And or "they may have some but I don't think it is Autism " " they look me in the eye so I don't think they have " (SenCo ) They didn't look the SenCo in the eye and she only met them for about 15 minutes ! They present well (for a short time but really struggled with their executive functioning. They are then judged negatively without a diagnosis.

Just wish they would finish my child's assessments that they started in January/February 2020 when they came to the top of the waiting list and not blame the pandemic as to why they haven't been seen since! Surely if they were being assessed then, they should have been one of the first to continue with their assessments once things got going again. Your not telling me that over the whole pandemic no consultations or assessments were carried out!!

There is a severe lack of communication from the NDS during referral. It feels like you are just left to wait without any reassurance or communication that things are being done.

Worst service I have ever experienced

It would be useful for a rough timeline of assessment. I have been turned down on autism awareness puffin courses as my child hasn't got an official diagnosis

My child has been let down massively throughout the entire process...

My child was referred to the NDS in November 2021 by a paediatrician. I heard nothing from the referral and eventually contacted them in March 2022 to query whether the referral had

been accepted. I was told that due to an 'oversight' my child wasn't even on the list and the referral had been misplaced. At this point I gave up and pursued a private diagnosis which was completed within four weeks.

Feel sorry for the lovely ladies that answer the phone they are so nice but constantly delivering bad news. Have put complaint in in the pa

The system is broken. Far too difficult to get help for clearly struggling young people. Was told no longer than 3 years in system took nearly 5 years to get a diagnosis. Shockingly bad form start to finish

Like everything it's a fight. After years of pushing my child was moved to the 'special' class in high school who quickly said they would like them to have an NDD referral for autistic tendencies. They referred them Oct 2021, school got an appointment for Dec 2021 but this was cancelled due to NDD team staff sickness. School got another appointment for late Jan 2022, they expected this to be an assessment but it turned out just to be a phone call from NDD telling them they are not accepting referrals from schools due to the backlog caused by Covid. We lost 3 months waiting for them to tell us that, not good enough!!!! School advised us to go to our GP as GP referrals cant be ignored, we did this straight away and we got a letter in March 2022 telling us our child joined the waiting list on 09.03.22 and to expect the process to take 3 years. School had advised us at the beginning that our child needed this in place to help them move onto college or education after high school. At this rate they will have left school before assessment is finished. I understand how hard all our professionals, medical and education have worked during covid but this back log is not acceptable. Extra staff need to be employed to meet the needs of our young people. Struggling all their school career and repeatedly being let down by the system has already taken a great toll on our child.

It needs better communication with families, check in with parents, updates on progress etc.