



# Listening to Neurodivergent Families in York

January 2025

**healthwatch**  
York

# Contents

**Content warning: contains reference to mental ill-health, anxiety, distress, violence, suicide and suicidal ideation, struggles with daily living and family breakdown**

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## Acknowledgements

This report would not have been possible without the support of our partners the Land, York Disability Rights Forum, York Carers Centre and Parent Carer Forum York. We are incredibly grateful to them and the people they support for sharing their experiences with us.

# Executive Summary

This report explores the experiences of neurodivergent families in York. Working with partners the Land, York Disability Rights Forum, York Carers Centre and Parent Carer Forum York, it provides an insight into the challenges these families experience.

Our key findings highlight:

- Parent blame is still prevalent in services, and also experienced from friends, family and wider society, as understanding of ND is still limited.
- Experiences are worsened by poor admin and communication.
- Services still work in silos, with families forced to play a key co-ordinating role.
- Capacity in services is limited; many are looking for reasons to say 'no' to providing help.
- Schools support varies considerably, and school behaviour codes can feel punitive to ND children and young people.
- There is significant overlap between children who are ND and who are gender questioning. Services are not geared up to appropriately support these children and may even ask them to hide part of their identity so they can access support for the other element.

Our recommendations can be found in full on page 77 but in essence we want to see:

- Research into ND friendly school behaviour charters.
- Better administration and communication.
- Training to improve understanding and awareness of ND, PDA, trauma, EBSA, and signs of autistic burnout.
- Improvements to the pathway for ND children who are gender questioning.
- A clear sleep support pathway for York.
- Better support for families, including connections to peer support at the earliest stage.

# A message from our Chair

Healthwatch exists to be the voice of local people in our health and care system. We wanted to look at the experiences of neurodivergent families in York for three main reasons:

1. Through our work we have become increasingly aware of the many challenges families are experiencing. The bulk of this report is direct quotes from individuals who agreed to share their experiences with us.
2. Through conversations with partners it is clear we share concerns about the availability and quality of support for these families.
3. City of York Council is currently beginning work to develop a neurodiversity strategy – we wanted to make sure the experiences we have heard are front and centre in shaping the strategy for our city.

This report is in essence a collection of people's stories, sharing their lives, the challenges they have faced, and the things they believe could help make those lives better. We make no apologies for this – indeed, we believe sometimes the only power we have to effect change is the power of our life stories. We hope like us reading this makes you want to be part of that change.

# Background

## What are [autism](#) and [ADHD](#)?

[Neurodiversity](#) is a term used to describe the fact that everyone's brain works differently. It is a biological fact that we are diverse in our minds.

[Autism](#) and [ADHD](#) are both examples of neurodivergence. <sup>1</sup>

[Autism](#) is lifelong and shapes how people communicate and interact with the world. [Autism](#) is not a learning disability. Whilst autistic people share certain characteristics, they do not all present in the same way. Common ways of experiencing the world that many autistic people share include: enhanced sensory perception, a preference for honesty and clarity in communication, a preference for agency, predictability and control, self-expressive body language and a passionate enjoyment of interests and hobbies (Hartman et al, 2023). <sup>2</sup>

There are an estimated 700,000 autistic adults and children in the UK<sup>3</sup>.

[ADHD](#) is a neurological condition that affects people's concentration, activity levels and impulses. The impact this has on people's lives is significant with symptoms varying for each individual. "Many patients and clinicians describe [ADHD](#) as an iceberg, where most symptoms lay hiding under the surface – out of sight but ever present."<sup>4</sup>

The [UK NICE guidelines](#)<sup>5</sup> report the adult [ADHD](#) incidence rate as between 3% and 4%. In the UK, a research survey of 10,438 children between the ages of five and 15 years found 3.62% of boys and 0.85% of girls had [ADHD](#)<sup>6</sup>. [ADHD](#) is not a mental health condition although it often occurs alongside or is mistaken for other conditions.<sup>7</sup>



There are significant barriers for women and girls to be identified and diagnosed.<sup>8</sup> There is an active discussion about whether female [ADHD](#) and female [autism](#) is under-diagnosed.<sup>9</sup>

## National picture

### Long waiting times for diagnosis.

In March 2023, in an opinion piece for the University of Edinburgh Impact bulletin<sup>1</sup>, Dr Sinead Rhodes highlighted that many children are now waiting up to three years for an assessment of ADHD, autism or dyspraxia. She highlights that whilst “the Government is acutely aware of the need to help these young people during this time, they remain largely unsupported while on lengthy waiting lists for assessment.” She advocates working to understand the strengths and challenges each child has, to upskill them with “a toolkit of strategies they can draw on” and “developing a pre-diagnostic service in the form of a ‘self-delivery with support’ programme to ensure parents and teachers feel empowered to work with the child and receive support from an expert team.”

In October 2024, the Children's Commissioner for England published a report<sup>2</sup> highlighting concerns about waiting times for assessment and support of neurodevelopmental conditions:

 This report sounds the alarm on the largely invisible crisis happening in children and young people’s community and mental health services, as well as the wider SEND system. These services have not been resourced to keep pace with the increasing need for assessment and support for children with neurodevelopmental conditions, such as autism and ADHD. 


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<sup>1</sup> [Kids awaiting neurodivergent diagnoses need more help - Edinburgh Impact | The University of Edinburgh](#) 20 March 2023

<sup>2</sup> [Waiting times for assessment and support for autism, ADHD and other neurodevelopmental conditions | Children's Commissioner for England](#) 15 October 2024



Work is ongoing to improve this situation. For example, in July 2024, NICE recommended a digital technology, the QbTest, to help speed up diagnosis of ADHD in young people aged 6 to 17<sup>3</sup>. Mark Chapman, director of NICE's HealthTech said:

 Children and young people with ADHD deserve to receive a diagnosis in a timely manner. We heard from our patient experts there are challenges with current pathways. We're committed to ensuring we get the best care to people fast while providing value for money to the taxpayer. This technology has the potential to generate tangible benefits to the lives of those waiting for an ADHD diagnosis. Evidence presented to our committee showed the QbTest could increase the number of children and young people who get a diagnostic decision within six months of starting assessment.



### **Education challenges.**

In October 2023, Dr Emily McDougal of the Anna Freud Centre hosted a webinar about neurodiversity and education. In this, she highlights that the school environment can be challenging for neurodivergent young people. Whilst every child is different, there are some common themes that help understand the adjustments needed to provide a good experience for neurodivergent people. These include sensory processing differences, executive function skills, working memory, inhibitory control and mental health challenges. She urges schools to have a whole school culture of awareness and understanding, and to tailor support in the classroom to the needs of individual students<sup>4</sup>.

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<sup>3</sup> [NICE recommends digital technology to help diagnose ADHD in children and young people | NICE](#)

<sup>4</sup> [Key challenges for neurodivergent students in school settings and how to help - THE EDUCATION HUB](#)

Without this, many young children on the SEN (Special Educational Needs) register are “falling through the cracks”. In September 2024, the BBC reported that 22% of the 2,900 children not enrolled in school or being suitably educated elsewhere are children with SEN<sup>5</sup>.

School exclusions are also rising, with 4.1 of 100 pupils being excluded in the Autumn term of the academic year 2023–24. In York this figure was 6 from 100 pupils.<sup>6</sup>

The article also highlights the knock on impact on families, stating that “According to a survey by the charity Support Send Kids, 41% of parents with SEN children say they have had to leave their jobs to spend time pursuing their children’s legal rights to support... even those with an EHCP can struggle to find specialist school places and often cannot be provided for in mainstream education.

The Family Fund’s September 2023 poll<sup>7</sup> focused on education, work and wellbeing. Of 360 carers, 57% indicated they were unable to work because of their caring responsibilities, and a further 28% were unable to work as much as they wanted to. From the same number, 54% of parent carers said they provided more than 100 hours of care per week.

## **Poverty and disabled children**

In January 2024, Disability Rights UK shared the results of a DWP progress report. The report identified that nearly half of families with a disabled child are living in poverty<sup>8</sup>. Worryingly, the figures for this

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<sup>5</sup> [Hundreds of children with SEN missing from education – analysis – BBC News](#) 10 September 2024

<sup>6</sup> <https://www.yorkpress.co.uk/news/24760283.school-suspensions-york-highest-ever-pupils-violent/> 01 December 2024

<sup>7</sup> [September 2023 Family Poll – Family Fund](#)

<sup>8</sup> [Nearly Half of Families With A Disabled Child Living in Poverty | Disability Rights UK](#) 30 January 2024



calculation were before the rapid rise in the cost of living. In September 2024, Carers UK confirmed that 1.2million carers are living in poverty in the UK, with 400,000 in deep poverty<sup>9</sup>.

Disability Rights UK also shared the [Family Fund](#)'s report from a poll of 4,264 families with a disabled child or seriously ill child. This found that nine in 10 families are struggling, or falling behind on their regular household bills and many are forced to forego living essentials such as food, heating, basic furniture like beds, flooring, washing machines and fridges, to try to make ends meet. Over half of parents and carers (54%) report skipping or cutting the size of their meals because there wasn't enough money for food and more than one in ten (13%) say they've had to cut back on essential items for their disabled children.

## **The local picture**

### **Waiting times**

Waiting times locally are lengthy. In October 2024 across Humber and North Yorkshire there were 9,849 people, adults and children, waiting for an autism or ADHD assessment, of which almost 4,000 are children waiting for an autism assessment. In December 2024, York Press reported that 6,270 people were waiting for an autism assessment<sup>10</sup>.

### **Diagnosis**

Before the age of five, when referred by a GP or speech and language therapist, children may receive a diagnosis of autism through the Child Development Centre at York Hospital. This will take up to one year. For children five and over, Tees Esk and Wear Valleys NHS Trust (TEWV) is commissioned to provide the Child and Adolescent Mental Health Service (CAMHS) for York. This includes diagnosis of ADHD, autism and other types of neurodiversity for children aged five and above. There is currently a

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<sup>9</sup> [Poverty and financial hardship of unpaid carers in the UK](#) September 2024

<sup>10</sup> [More patients in North Yorks and Humber waiting for autism diagnosis | York Press](#) 12 December 2024

significant wait for assessment. People can refer their child for assessment, or be referred by a GP or a child's school.

For self-referral, there will be a 30 minute call with the Single Point of Access (SPA) to discuss the referral. If they agree further assessment is needed, they will send out a questionnaire to families or carers and school. This is usually posted, but you can request this electronically if you prefer. The questionnaire must be completed in full, by school, by parents or carers, and with responses from the young person themselves. Once completed and returned, the form is reviewed by the team and a decision will be made on whether to assess. TEWV posts a letter informing people of the outcome. Where they agree to assess, the child will be added to the list. Recently, TEWV has begun inviting children in for a QbTest between reviewing forms and deciding whether to add children to the waiting list.

On diagnosis, families receive feedback and a post-diagnostic pack. For autism, there is no post-diagnostic support from TEWV<sup>11</sup>. For ADHD, families will also be offered two online sessions, and a further session with school staff supporting the young person. They may also offer post-diagnostic support with medication, though this involves a further wait<sup>12</sup>.

In this area, for ADHD assessment TEWV is still using the International Classification of Disease ICD-10 criteria. This does not formally recognise ADHD, but relies on assessing Hyperkinetic Disorder, or HKD. As a result only combined ADHD will be diagnosed. TEWV confirms they are in the early stages of moving to ICD-11.

### **The Right to Choose and Shared Care**

In England, patients have a legal Right to Choose who provides their healthcare. When GPs make a referral for autism or ADHD assessment, they should offer the option to choose a service to be referred to. This service must provide NHS services in England.

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<sup>11</sup> <https://www.yorksend.org/support-need/diagnosis-pathway#fivetoeighteen>

<sup>12</sup> <https://www.yorksend.org/supporting-childs-needs/adhd-diagnosis-pathway>

However, in York, some GP practices will not enter into shared care agreements with anyone who receives their diagnosis for ADHD through this route. They will only enter into shared care agreements with the Retreat for adults, and with Orca House (CAMHS) for children and young people. This means those people who are given a prescription for ADHD medications through a Right to Choose provider or private provider will need to access a medication review through York's commissioned NHS services. There is currently a significant waiting list for medication reviews.

# What we did to find out more

Through our own issues log<sup>13</sup>, we were already aware of a number of challenges facing neurodivergent families. We also heard many stories about family challenges when looking at the adult pilot ADHD assessment pathway.

In meetings with local partner organisations, we heard many more stories of people who were struggling. We agreed as a partnership to bring together these voices. We hope this will be useful for shaping the City of York Neurodiversity Strategy as this work begins.

All names have been changed.

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<sup>13</sup> See Appendix 5 for recent issues raised with us.

# Stories from the Land

## Personal stories: Lizzie

**6** School was never a good fit for Lizzie. There was so much going on it was overwhelming for her, she would get through the day but have massive meltdowns after I picked her up. Having to sit still so much was a torture, she naturally needed to move her body but this wasn't allowed. The way things were taught was not the way Lizzie learnt, she felt stupid, she knew she was "behind".

She was eight years old and she felt like a failure. In a few years she had gone from being bubbly, curious, confident and engaged with life to a shell of herself. Lizzie was often poorly, tired and had a low mood.

One day Lizzie had a bit of a cold and asked to stay off school. I said she couldn't stay off just because she had a bit of a cold. She said to me "it takes everything I have got to get through the day, I just can't do it if I'm not feeling 100%".

This was like being punched in the guts. I just thought what are we doing? Is this what my daughter's childhood is going to be? What is this doing to her physical and mental health?

Lizzie never went back to school after that. It took years for her to recover, she wouldn't engage in anything that looked too much like school for a long time. We took time to figure out what she needed for her wellbeing and to learn. I had suspected she was dyslexic but the school would not engage with the idea. We had her tested and she was, so we could start a literacy program designed especially for children with dyslexia. Lizzie is also awaiting an autism assessment.

We figured out she learnt by doing, by going and seeing and experiencing things. We adapted life so she has the recovery time she

needs, she can engage in her passions (mainly horse riding) and she felt a sense of control over her life.

Lizzie is now 16, she still has her struggles and things need to be done in the right way for them to work for her, but she is thriving. She has become an expert in her area of special interest – horses. She spends most of her time caring for, riding and competing, which makes her so happy. She has completed her Prince's Trust qualification, plays in a netball team, has done her bronze Duke of Edinburgh award, sat her maths and English GCSEs, has a part time job in a café and has a place at college for September to study equine care.

She always had the potential to do well in life but we had to create the right conditions for her to flourish. We were made to feel like taking her out of school would limit her chances but I firmly believe it has done the opposite.

Due to my work giving me an insight into the system, we decided not to try and get help and support through the school system. I have seen how bad things have to get before any support is given, how damaging it is to leave a child in a situation until they are at breaking point. How many inappropriate resolutions have to be tried before proper, appropriate alternatives are provided and just how hard parents have to battle to get anywhere within the system.

There seems to be a massive problem for teenage girls at the moment. They get through for most of their childhoods masking and finding ways to cope and if they are not being disruptive it is so easy for them to go under the radar in a school. Then 14 hits and everything unravels. Just in our local area in the last year I have met two girls with anorexia – one of whom is currently hospitalized as things have got so bad. One girl who has selective mutism and is so anxious when she leaves the house she can't speak. Another girl who just broke down and couldn't hold it together any longer. All these girls were in



mainstream education until they hit breaking point. All are out of school now with really complex mental health needs. It really scares me to think where Lizzie would be now if we had not removed her from the system – I just wish I had done it sooner but it is very difficult to do something that is so countercultural.



### Personal stories: Jim

**6** Jim found starting secondary school incredibly difficult. After just a couple of weeks we were struggling to get him into the building. We tried every approach: bribery, gentle (and not so gentle) encouragement, consequences, trying to get Jim to make 'small steps'. We would sit in the car park for hours, trying to get Jim to put one foot on the tarmac before he could go home. He retreated under a blanket in the car, refusing to talk to us. In October 2022 we made a short visit to the Railway Museum to celebrate my birthday. This was the last time Jim made a trip outside. School stopped, family days out stopped, trips to the supermarket or park stopped. From that moment on life changed for Jim, and none of us knew how to react. It seemed to come out of nowhere, it was extreme and it was very scary.

At the height of burnout Jim stopped eating, reduced any contact with us, could not remember how to form letters when writing and could not tolerate visitors to the house. This had a huge impact on family life (he has an older sister) and was very damaging to immediate and extended family relationships. Jim's physical health deteriorated as well as his mental health. Jim expressed feelings of hopelessness and low mood. It was a very scary, lonely time and we felt as though we were the only family experiencing these things.

I have had to give up work so that I can be with Jim during the day. We can now, very occasionally, take a very short walk round the block at night time - he wraps himself in a blanket so that nobody can see him.

We are slowly beginning to reset, but it has been (and continues to be) a very scary, overwhelming and isolating experience. Everything has changed in our lives, and we are still trying to establish a new path for Jim.



### Personal stories: Edward



My name is Edward and I am nine years old. I am autistic with a PDA (Pathological Demand Avoidance) profile and have a diagnosis of generalised anxiety disorder, OCD, a tic disorder and PTSD.

I was a high masker in primary school and academically high achieving but had significant unmet needs. This led to autistic burnout and PTSD at the start of year 3 - I became too unwell to go to school. I stopped eating at school and became distressed every evening worrying about school. I struggled with sitting on the toilet on and off for several hours due to anxiety which meant I wasn't getting enough sleep.

I tried to ask for simple accommodations from my teachers to be told my suggestions weren't possible. My parents were told school would not support an application for an Education, Health and Care Plan (EHCP) and that we had to try different stages of support first but these accommodations were sadly too little too late.

The chronic masking had a catastrophic impact on my mental health leading to a complete loss of skills and being unable to function and complete basic tasks. I lost control of bodily functions and could not bring a cup of water to my mouth to drink without help when I was

previously fully independent. I could also not leave the house for over a year and still struggle to talk about school even though I have been out of education for 19 months.

I am slowly recovering from burnout and am the happiest I have been in a long time due to a combination of factors which include: being in a safe low demand environment at home which doesn't trigger my sensitive nervous system, having my needs met and receiving co-regulation and connection from trusted adults around me and importantly not needing to mask anymore. I was also prescribed antidepressants to help with my severe anxiety.

I have just been awarded EOTAS (Education Other Than At School) after 19 months of being out of education. This will enable my health and educational needs to be met in an appropriate way. My parents had to work extremely hard to get this and were told 'no' several times before it was finally approved.

I often need to spend time under my blankets or duvet if I become overwhelmed or feel tired. Spending time engaging in special interests and having my sensory needs met helps me to self-regulate and calm down my nervous system which is easily triggered due to my PDA profile.



### **Personal stories: Oscar**

**G** Oscar went through primary school coping well. He excelled at learning, sport, art, had a lovely group of friends and was a happy, outdoorsy boy. From a young age we saw some small sensory differences and adapted our parenting to meet his needs successfully. His teachers in primary were aware of his tendency to take time to settle in, need for genuine connection, were open to listening and collaborating. He always shone in the summer term. People often commented on what a happy, smiley boy Oscar was.

On transition to secondary school, despite a thorough handover from his year 6 teacher, regarding his anxieties and how his friendships provided huge reassurance and connection, Oscar was placed in a form with no friends. Three of his friends were placed in a form together. Oscar was sick twice on an additional transition day where they had a 'fun' BBQ and he wasn't able to eat anything and unable to speak. We spoke to the SENCO to express our concerns and request settling in support. She told us their way of working was to assess everyone in the first couple of weeks.

Oscar started secondary school – he was sick several times every morning for two weeks. We contacted his form tutor, house pastoral worker and Special Educational Needs Coordinator (SENCO) and were told we needed to practice 'tough love', he needed to develop resilience and we should 'just get him in whatever that takes'. On one occasion two pastoral workers attended our house to take Oscar to school. They sat in the front, didn't speak to him and took him straight to his lesson on arrival. Oscar was told we could be fined in court if he didn't go.

Over the next few months, Oscar's mental health deteriorated and he lost a lot of his daily functioning skills – he became unable to dress himself, his self-care deteriorated significantly, he became very angry, emotional, aggressive, destructive and was petrified of getting bad comments or detentions. He told us how staff at school did not care about him as a person, were only interested in results and how his pastoral worker called him the wrong name when he saw him. We were told Oscar was fine in school and the problem was perhaps elsewhere, that it was a behavior issue and suggested behavioural strategies (which made things much worse.)

We referred Oscar to CAMHS and he was put on the anxiety pathway (no one in school recognised this presentation as autism). He struggled to attend the cognitive behavioural therapy (CBT) sessions

at CAMHS until I suggested having the sessions outdoors. Then he struggled with the concepts being used. CBT is not recommended for autistics unless adapted by skilled professionals. Oscar completed the session in the summer holiday (when he was feeling brighter, less anxious).

Year 8 saw rapid deterioration in Oscar's health and presentation. He masked up for school and exploded when he came through the door at home. It wasn't until spring, when the early help team got involved and deemed school was the cause of Oscar's distress and burnout, the GP signed Oscar off as too anxious to attend school. He stopped playing football, seeing his friends, going out, smiling and laughing. With information gained online and from the early help team, we made a self-referral for an autism assessment.

Year 9 and we have one-to-one teaching at home, three hours per week with the wonderful Sue. They quickly connected, created safety and trust. Bingo, Oscar was flourishing. He started to see his friends again, playing football, cycling and camping. Smiling. Laughing.

End of year 9 and into year 10. Oscar transitioned to Alternative Provision (AP). The head teacher visited us at home and decided one-to-one provision would best meet his needs for his two GCSE years. Oscar steadily increased his attendance and was enjoying his lessons. He developed great relationships with his teachers and was happy. He was enjoying his learning and excelling again.

After a three year wait, in summer 2020, Oscar was diagnosed autistic by CAMHS and immediately discharged.

Year 11: We were told that AP was changing and they no longer offered one-to-one, that he would be in a group with other autistic boys who he didn't know, start earlier in the day, have much shorter lessons, be in an unfamiliar room and with lots of new teachers. We raised our

concerns and were told by the autism specialist and the SENCO that Oscar needed to start functioning in a group as 'one-to-one isn't how the real world works'. We placed our trust in the SENCO and autism specialist, they had worked with many children like Oscar. We were told otherwise the likelihood was that he'd become a boy who never came out of his bedroom. Oscar said he'd been lied to by the AP and they weren't really thinking about him in doing this. He started going to some group lessons. Once again, he really tried. Rapidly, he began to struggle. He'd intend to go, get dressed, then just completely shut down. His eyes would roll into the back of his head and he'd be unresponsive – he was dissociating. From this there was a very rapid decline in Oscar's mental health. He was hurtling into a second burnout.

The next two years for Oscar, age 16, were like this:

- Huge meltdowns, aggressive, destructive, ear-splittingly loud, significant distress.
- Self-harm – punching himself in the head and face hard. Smashing his head, hard, into walls.
- Screaming out in mental pain, begging us to kill him as he felt he was ruining all our lives.
- Huge shame.
- Sitting in his bedroom, curtains permanently closed.
- Not able to see anyone other than us.
- Devastating loss of skills.
- Started bed wetting (after many years dry).
- Stress induced shingles.
- Unable to touch most things.
- Trusting no one.
- Major toileting issues. Routinely spending seven hours to empty bowels, once 20 hours. Screaming at the distress of not knowing if he's finished / was clean.
- Unable to wear clothes.



We referred back to CAMHS and he was put on the psychiatrist waiting list. A year later, after many calls to the crisis line and police being called out by a neighbour as they thought someone was ending their life, Oscar saw a psychiatrist and a few months later started to access medication for anxiety.

He was later diagnosed with OCD and the Community Mental Health Team (CMHT) Occupational Therapist (OT) has recently explained to Oscar that he has memory loss regarding some of his life because of the trauma and that his brain has been in such a heightened state of anxiety for so long that it now perceives most things as a threat to his safety.

Oscar hasn't left the house since November 2021. He hasn't been able to wear clothes for over a year and a half.

We recently found out that Adult Social Care had closed his case without informing us.

The adult CMHT are using a trauma informed approach and collaborating with Oscar and us. Oscar has complete agency and we are all using a neurodivergent-friendly, trauma informed approach. This is what works for Oscar.

A few weeks ago Oscar dislocated his knee, was in agony and collapsed on the floor. Most people go to A&E for x-rays and treatment for this type of injury. Oscar's anxiety, trauma and OCD are so pronounced that he couldn't access a hospital so we had to wait for six hours for a doctor to ring to advise us how to assess and treat it as best we could ourselves.

The long term impact of early unmet need is devastating, impacting quality of life, mental health, physical health, self-esteem, employability, independence and Oscar's future. A tsunami of trauma has ripped through our family caused by Oscar's unmet needs.



## Personal stories: Liam



My son Liam is 12. He struggled with school from the outset. After year 1 in a mainstream primary school we realised he wasn't coping and his self-esteem was very low. Around that time we learned about {name of independent school} and decided to relocate to York in order to make it possible for Liam to attend {name of independent school.} Despite the nurturing environment and the accommodating teachers he struggled to adjust. He was withdrawn and quiet in the first year and then started being disruptive in class with loud aggressive outbursts. After reaching crisis point both at home and at school, and due to long CAMHS waiting lists, we pursued private assessments and he was diagnosed with dyslexia and autism (PDA) in 2021 and 2022 respectively. He also has sensory processing difficulties and extreme anxiety.

Over the last two academic years, it became clear that Liam requires significantly more one-to-one support to help him attend school and engage in any learning opportunities. Liam is currently struggling to access a full week of school (he has been on a reduced timetable since September 2023) due to strong emotional regulation challenges, impacted by sensory reactivity, and social engagement and learning difficulties. He attends {name of independent school} for some one-to-one tuition (two hours), social interaction in break times three days per week and {name of AP} one day per week, which we are currently funding ourselves. This is difficult considering my ability to work is severely impaired by our son's support needs and limited school attendance.

We got Liam's first EHCP in May 2024 after going through mediation at the need to assess stage. It provides insufficient funding for the level of support needs stated in it. The fact that we choose to proactively search out better options for our son {name of independent school}, now means that we get ignored by the Local Authority and our son is falling through the gaps in the system.

The EHCP funded a course of OT treatment for Liam but we have been refused further funding for the further therapy recommended.

Our home life is often made very difficult by our son's violent outbursts and damaged property. We also have a 16 year old daughter who was diagnosed with ADHD last year.

Liam struggles with getting sleep when anxious and his usual bedtime is well past midnight. This is disruptive for the whole family and has severely impacted on my health as his mum and main carer. He was prescribed melatonin by our GP but is refusing to take it.

I have reached out to CAMHS and to the Multi-Agency Safeguarding Hub (MASH) team without any response or offer for support.



## Personal stories: Rose



I'm Sarah. My partner and I live together in York with our two children; Rose aged 13, year 9 of Secondary School, diagnosed with ADHD and Autism Spectrum Condition (ASC) with PDA traits and James aged nine, diagnosed with DCD (more commonly or previously known as dyspraxia) at primary school. When the paediatrician gave James' diagnosis, she also mentioned ADHD due to the way he presented at the appointment and how DCD and ADHD can be linked. This filled me with dread, knowing how long the waiting lists are for CAMHS assessments and knowing how totally exhausted I already am.

My partner and I are both self-employed. I made the decision to become self-employed when Rose began struggling to get into school in year 7. It had been a tricky couple of years previous with school/education due to COVID, and the transition into high school was non-existent for her. Rose is approaching year 10 now. My longer term goal was/is to complete a psychology degree with the Open University and to go into this field when the children have finished school.

James does very well, both academically and socially, at school. The head teacher is very nurturing and is always trying to make the days fun, exciting and a happy place for the children to learn and attend. Although James has DCD I haven't felt the need to engage with the SENCO as he is thriving - it's been enough to have a quick chat with his teacher if I have any concerns. However, James is going into year 5 in September and I already feel anxious about him moving up to high school in 2026.

Rose hasn't been able to attend Secondary School since November 2023. She has Emotion Based Schools Avoidance (EBSA) and is now too anxious to do anything apart from see her one friend, May (at another secondary school) who also has ASC and is primarily out of school. Rose

spends the majority of her time at home alone in her bedroom. We as her family struggle to connect with her.

The constant worry I feel is unbearable. I find myself questioning, daily, what will become of her? How did we get to this point? I worry about the impact this may have on James, and I worry that he too will become a school avoider if his future needs aren't met.

When she was in year 7 Rose begged me daily to home educate her. Some mornings I'd sit for over an hour in the car park at school trying to reassure her and relieve her anxieties. Despite her struggles I believed school was the best place for her. Every obstacle she faced could be used as a learning curve and eventually she'd settle and be able to be happy and thrive. I've always kept the lines of communication open with school and tried to work with them, and I am always very honest about Rose's struggles and the help she needs. But too often, offers come when it's too late.

If I could go back I would heed her pleas and make home education work, because now our life, her life, feels on hold. Home education isn't an option as Rose does not engage with me like she once did. I need to be her Mum, not her teacher. I couldn't possibly embark on a degree when my own child isn't receiving an education. The constant fight to secure some kind of future for Rose, while trying to run a business and home, as well as ensuring the children's wellbeing, means I just wouldn't have the headspace.

Rose doesn't always communicate in a socially acceptable way - she says inappropriate things before she's processed the consequences or possible repercussions. I have always made this clear to everyone involved in her life; we as a family have learnt to take things with a pinch of salt. We have had many incidents over the years that have caused disruption to her own and other children's learning because of her actions. I'm sad to say Rose is the child other parents tell their



children to stay away from. I've had many dealings with other parents because of things Rose has said or done. I've had to become quite thick skinned. If you haven't lived with a neurodivergent person it may be difficult to accept some actions. Some people have no idea or simply aren't interested as long as they and their family are OK. I understand this but the effects on my family remain.

After an incident on social media between Rose and some other children in November 2023, an angry parent sent me messages and we had a visit from the police. School changed Rose's timetable to put things right for another child and their family. The change was made without discussion with ourselves, without Rose's side of the story and without a plan in place to help Rose cope with such big changes to her school day.

Prior to this Rose had completed 10 consecutive days in school. This was a massive achievement. We hoped we were at a turning point. But the timetable change was the final straw for Rose - she doesn't cope well with change. Over the next few weeks I worked closely with school to try and get Rose to return, and engage with her new timetable. I worried for her wellbeing not having the social interactions with her teachers and peers. I feared she would fall further behind with her education as her attendance had been sparse since returning in September 2023.

We sanctioned at home, withdrew electronics and internet usage. At every conversation we reinforced the importance of being at school, that it was an expectation, not a choice. We were in the mindset that she won't rather than can't go. School agreed reduced timetables and offered Rose the use of the inclusion rooms etc. Rose refused to engage - she would only go back if she was given her original timetable. After weeks of disruptions in our home, I asked the school to revert Rose's timetable but was told this wasn't possible.

Within days I came home from work to find Rose drunk. She was completely dysregulated, had been cutting her arms and wrists and was saying she didn't want to be alive. I called my mum for support and called the CAMHS crisis line. I didn't get through, nobody answered. I waited and waited, but nobody picked up the phone. Rose settled eventually and I called the NHS 111 crisis line for advice and reassurance. They were a great help. The wounds were superficial but the intent was there.

Now at my wits end, I contacted MASH. They allocated us a family support worker who has a great understanding of our situation. I also reached out to other parents within the community. I learnt about Alternative Provision (AP) for children struggling in school. The general advice was to contact SENDIASS (an organisation that provides support for children and young people with special educational needs and disabilities), who have been amazing. The care and attention I have received has been second to none. I then arranged to meet with the school SENCO. I informed her of the developments in Rose's mental state and I asked about AP for Rose. She seemed visibly shocked. She said the budget was nearly taken up but agreed to look into it, as it was something that had been bouncing around in her head. We also discussed how reverting to Rose's original timetable wasn't possible as too much time had passed and the head of house had said that wasn't possible.

That evening I got a call from Rose's head of house offering her original timetable back, because we were going round in circles. This after nine weeks of Rose not attending school, of emotional turmoil for our family, and only after I mentioned AP. It came too late. Rose was in total burnout, refusing to engage in any talk of school, not even washing or looking after her own personal hygiene at this time.

Over the next few weeks, we took the pressure off Rose to attend school to concentrate on her wellbeing. We had a Team Around the Family

(TAF) meeting at school. A member of the specialist teaching team attended along with the family support worker, the SENDIASS worker, the deputy head, the SENCO and Rose's head of house. I was thrilled to be all working together to make a plan to help Rose move forward. There were discussions of a salon skills course, {names of two AP providers} and mentions of budgets due to Rose being unwilling or unable to engage. I had previously asked about an EHCP for Rose which she wouldn't have met the threshold for. I asked again and this time the school agreed.

In January 2024 we filled in the forms and I provided a letter/statement to request statutory assessment. In March the Local Authority (LA) refused to assess Rose on the grounds that the evidence provided showed Rose's lack of attendance was due to "ongoing friendship issues"... ugh, if only it was that simple!

I arranged a going forward meeting with a caseworker from LA, the SENCO, the family support worker and the SENDIASS worker. I spoke with CAMHS to keep them informed about Rose's situation and obtained letters from them prior to the meeting. The consultant psychiatrist's letter stated that Rose is highly functionally impaired by her autism. She also stated: 'We haven't identified a treatable condition right now but I would emphasise that the autism appears to be impacting on her engagement with mainstream education'.

I was told in the going forward meeting that the assessment threshold is low but more evidence was needed to take Rose's case back to the panel. I felt desperate. Every day Rose was getting more and more content with not attending school and thus receiving no education. Her sleep was sporadic, she had unhealthy eating habits and no fresh air or exercise. The whole situation is a mum's worst nightmare. I needed to prove that Rose needed the assessment to try to secure a future for her. But I didn't know what her barriers to learning were, I still don't. If I ask

“what is it you don't like about school?” the answers are always “I don't like it, it makes me sad”.

I looked through all her old school reports and any feedback ever received from teachers and staff. I considered a private OT sensory assessment to gain insight that might be helpful in securing the assessment and making Rose's life easier. The cost of this was way out of our budget and so I contacted the GP who referred on. But Rose was subsequently rejected by the triage team as it didn't appear that specialist input from OT was indicated at this time.

I mentioned to the caseworker at LA about section 19 of the Education Act at least three times – they haven't offered anything. I have now written a formal request to the Assistant Director of Education, Skills and SEND at City of York Council and await her response. I have arranged visits to {names of two AP providers} as school agreed to fund "limited time" AP to gather evidence, but Rose was unable to get out of the car to speak with staff and look around.

I asked if the LA would overturn their decision to be told a whole lot more work needed to be done on the paperwork. At which I listed what had already been provided as I felt they didn't know. I had no choice but to take the LA to mediation. I spoke with the mediators, reached out to the people I wanted to attend but the LA didn't commit to mediation within the time frame, despite the mediators chasing them up.

I moved on to tribunal. If I hadn't been on the ball we would have lost the right to appeal. I started on the tribunal paperwork and then I received a call from the LA to say the decision not to assess had been overturned. It was the letter from CAMHS that swayed it. The letter that had been presented weeks previously at the going forward meeting. So finally, a positive... yay! BUT ... there's no educational psychologist available and there is a long waiting list...

... in the meantime, I heard from May's mum that her school paid for May to attend a salon skills course, every Tuesday for the next two years. As May is the main person Rose will engage with, I thought it could be a hook to get Rose back into education. High school had already mentioned salon skills so I asked the question, "would it be possible to get Rose there on a Tuesday so she had the support and safety of a familiar face?"

After chasing this, a taster session was arranged for Rose. School and myself also put in an application to the home tuition team, so I felt hopeful Rose would be able to attend, get a qualification in salon skills and with home tuition and with the possibility of an EHCP, finish school in 2026 in good stead for further education or whatever she decides to pursue. I dared to think I could enrol with the Open University, James is happy and settled for now and things are finally turning around for Rose!

On 18 June, I took Rose to visit the course site. I spoke with the salon tutor the day before to have as much information as possible to tell Rose. The session was set up to start at 10am. We arrived late (10.30am) after quite a stressful morning with Rose saying she didn't want to go, she felt sick, she couldn't do it. I phoned ahead to apologise and spoke to the head who informed me that the high school SENCO was already there. Upon arrival, Rose, the SENCO, the head and myself had a meeting to discuss the offer. The Head explained to Rose the qualifications she could achieve and how they anticipated the course to be full in September. We booked in a further three taster sessions and discussed a start date for September. We looked around the salon, spoke to the tutor and saw May doing some work. Rose was asked if she'd like to stay and she agreed. But then I was called to collect her and sensed it hadn't gone well.

{Summary of email correspondence between family and school - confirmed tutor raised concerns about possible bullying, bodyshaming, inappropriate conversation, spending a long time in the toilets and

vaping on site; family responded highlighting extreme anxiety, providing considerable context regarding the nature of friendship between their daughter and the other person present, their shared interest in a TV programme related to the inappropriate conversation, thanking them for the opportunity, but expressing concern she was being written off too quickly.}

I received no reply to my email and started to try to move on from the salon skills offer, feeling totally miffed at this specialist provision and school for not giving Rose another chance and was left wondering who made that decision. And what else we could try?

The following week I emailed the SENCO chasing the LA decision about the home tuition team. She acknowledged receipt but couldn't give me a time frame. I contacted the LA caseworker to chase up the EHCP assessment and reiterate that Rose has had no education in eight months. I was told I need to work with school. An EHCP (if achieved) will only work with a really good reintegration plan. The likelihood of Rose being able to engage with any mainstream setting at this time or in the future is getting slimmer by the day. I asked school what the plan was for Rose if the home tuition team don't accept her and mentioned that Rose may well be in year 11 by the time an EHCP is awarded and finalised (if at all). No reply. I emailed a week later to ask the same questions, but still no firm answers. At which point it was pointed out to me the offers that Rose has been unable to engage with.

In July I received a call from our family support worker, someone who has understood our family and my struggles and has offered help and advice. Unfortunately because Rose has been unable to engage with her, there is no role and therefore she has to sign our family off. Another door shut!

She attended a final TAF meeting at the high school along with the SENCO, the high school head and myself. I was told by the head she had



made the decision to withdraw the salon skills offer. It was put that it was thought it wasn't the best place for Rose but upon reflection, Rose may still be able to attend in September! It's too late! Rose had been rejected and the task of her returning would be mammoth and too much for us all.

Previous to the meeting, I asked about other APs for the year 10 timetable with an option for Rose to change if/when she felt able to pick her options and a reintegration plan so that she has the visuals, time to process and the autonomy she desperately needs. I came away with an options booklet and a serious lack of trust in the school. Upset that there was no discussion again before making the decision to withdraw the salon skills offer. I was told in the meeting that they need Rose's voice, to hear what she needs but actually they haven't heard Rose's voice when it needed to be heard and this is so upsetting.

I was also told that in September the SENCO is moving to another school. This means starting again with a new SENCO who doesn't know our story.

Throughout, I've heard lots about funds and budgets. I'm starting to realise it really is all about who pays. Our lives hang in the balance because nobody wants to foot the bill.

My children are neurodivergent. I've spent quite a lot of time learning about their difficulties. As their mum, their happiness is my happiness. I question how dedicated some people are to actually helping children with SEN. Because the absolute bottom line for me is: seek to understand rather than be understood.

This isn't always the case where SEN children are involved and it needs to be. Rose isn't fitting into any box at the moment and we need to round the edges. I need a change, I need to move on and have this sorted for my children, my family and myself. Rose is going into year 10

in September, and into her GCSE years. She's yet to pick her options, the only AP she would engage with was removed after a very short trial, the EHCP assessment is no further on due to educational psychologist availability. She's 13 years old and at present she has no routine and no future to focus on.

We are just one family in York going through this hell. There seems no end in sight. It's exhausting. I'm sure there are many more families like ours. I'm hopeful if you gain enough insight and feedback that change can be made. I don't know what or how. I don't have the answer for my family at the moment. But I know there are more battles to come. I'm filled with dread to think of the future. Whatever it is that Rose needs will not be handed over easily. Even if it leads her in a positive direction, we may not receive the desired outcome. But as a mother, I'll keep fighting. I have no choice because what is the alternative?

More funding, shorter waiting times and proper hands on staff training for all teachers and staff of SEN children is needed so that our children don't become ghosts. They must receive the help and intervention they need in good time so they don't end up costing the country more in the future as adults. Adults that are out of work, struggling with mental ill health and/or addiction or worse, adults that become part of the prison population.



### **Personal stories: Mika and his transition to adult services**

Mika didn't have an active EHCP at the time of his transition to adult services. In fact he had no provision due to an acute mental health crisis and autistic burnout caused by cumulative unmet needs. We received notification from the SEND team of their intention to cease his plan. And then, before right to reply time expired, a legal cessation letter arrived to say the EHCP had ceased. It was reinstated after we contacted the SEND team and they



consulted their managers. But all this caused extra admin, stress and anxiety for us as parents.

CAMHS/CMHT - we informed the CAMHS psychiatrist when Mika reached 18 and requested a thorough transition to adult CMHT. No one from CAMHS seemed to have considered his age/transition prior to this. A planned and thorough transition needs to be the norm, especially for autistic young people. Mika was placed on the Dynamic Support Register as he was deemed at high risk of hospitalisation. This triggered assessments from CMHT and Adult Social Care. CMHT assigned him a community psychiatric nurse (CPN) who assessed Mika and quickly built trust and safety and quickly led to psychiatrist and specialist OT assessments. Mika was diagnosed with OCD and a treatment plan was agreed. He has had regular, fortnightly appointments, at home, with the specialist OT and the shoots of recovery are evident. It has been an excellent service.

Adult Social Care - during the assessment we were told by his social worker that we would be given advice and support regarding Mika's finances. But we were given none. We were told to contact them again when Mika was able to engage. So we did, to be informed his case had been closed. Neither Mika nor ourselves had ever been informed of this. This was appalling communication and caused stress, anxiety and extra work for disabled young people and their families.

Mika is rarely able to wear clothes or leave the house. His anxiety is high in public spaces which makes them inaccessible to him. There appears to be no offer for these young people.

Whilst we appreciate what York Inspirational Kids and York Ausome Kids provide, for us there is no offer which meets our son's needs.



## Personal stories: Felix and his transition to adult services

**6** We had meeting with a new in role social worker and Preparing for Adulthood Coordinator. At the meeting we were told everything for Felix would stay the same as this was working successfully giving plenty of flexibility. We discussed what Felix would like for the future and he had suggested to us speech therapy. We also suggested a cognitive assessment done in a way that would work for Felix. This was all noted and the appropriate paperwork completed for this to move forward.

A few weeks later someone from the Community Learning Disability Team contacted me regarding speech and cognitive assessment. She was really good and left me feeling really positive and like she cared about Felix's situation around communication.

A week later we found the Community Learning Disability Team had denied speech therapy despite Felix having verbal dyspraxia and having significant social issues around talking. Nothing was mentioned regarding the cognitive assessment.

Many meetings have had to be held by Felix's social worker and us to get this decision changed taking over five months and costing services more money and time. Felix is now on a waiting list with a team that only work with individuals until they turn 19. Felix is 19 in July next year and we are highly aware the waiting list means he will probably just be transferred to another waiting list by the time he turns 19. We have heard nothing regarding adult service cognitive assessment.

We had long meeting - three hours - with adult, child social worker and an NHS nurse in our home just to decide who and where the money was going to come from for Felix's social care support. This was gruelling and we were told these meetings can go on a lot longer. The energy needed to go through a meeting like this is massive and you are

looking at your child from a negative angle for hours and all their struggles etc.

We were also then asked to sign forms for Felix's budget to be paid via Salvere which we had tried years ago but their communication was poor and the flexibility was not appropriate for Felix's type of disability. We had to ring the preparing for adulthood coordinator to reassure us this would stay the same as had been agreed in first meetings, as the new social worker was unsure.

We were also completely unaware that Felix had to go through a full and intrusive financial evaluation - nobody had told us about this or the process. We rang York Carers for some back up and they supported and reassured us through this.



### **Personal stories: Charlie and her transition to adult services**

**6** Charlie, our eldest daughter, has autism, ADHD, OCD and anxiety. When we transitioned from children's health and social care to adults we were allocated a social worker who told us she was from the wrong team to deal with my daughter's team. Her team was people who can't dress and feed themselves. We were told this social worker would work on our daughter's plan and "hold" the case until she could be passed onto the appropriate team.

At the same time our daughter was discharged from CAMHS whilst suffering from suicidal ideation. We were told she did not need adult mental health services and that social care would take over things.

Her education placement fell apart at a similar time, leaving us with no education, mental health care or social care.

Social care were unable to tell us what they could offer but we were told they were working on a plan.

After a period of time with no education, my daughter got a place at an alternative provision (AP). This was a lengthy process as the first time it went to panel, they had an EHCP for her which was two years out of date. It had been reviewed but there was no record of that. My daughter's EHCP was urgently reviewed by the Local Authority.

Her social worker attended virtually. She was supportive of the change of education provision but said she was unable to put a social care plan together until education was sorted out. Around February this year my daughter began to struggle mentally and was referred to adult mental health. This was mainly around the fact that she did not know what she was going to do when her time at her education provision ended.

At her EHCP review, her education provision told us that she wouldn't leave without a plan, and that their specialist careers advisor would help. We were told that Charlie need to concentrate on getting through her qualification first, and that help would come for the next steps after that.

Charlie was subsequently discharged from social care, with no plan ever put in place. We were told that this was due to the fact that we hadn't commissioned any services from social care.

Very little help was given from Charlie's education provision about her next steps. Their careers advisor had been off sick until towards the end of the summer term. They contacted United Response about their supported employment scheme but did not hear back. They also contacted the Railway Museum to look into volunteering opportunities for our daughter, but none were available. I was told to contact Scope and given the link to the national careers service website. Scope could

only offer a couple of Zoom appointments as they're based in Leeds. If we lived in Leeds, they could have offered a lot more support.

During the final half term of the summer, I repeatedly left emails and voicemails with the specialist careers advisor service at the transition zone, as this is where a Google search had led me. By this point our daughter was regularly self harming due to the distress of not having a plan. I stated this in my messages but nobody ever got back to me. I contacted my daughters SENDO at the council, towards the end of that term too. I was told her caseworker had changed but that the new one would be in touch.

It took a while for her new SENDO to contact me, by which point things were getting worse and worse with my daughter's mental health. The SENDO I spoke to was lovely and reassured me that, although it felt like we had no support right then, we would soon be surrounded by support. I was told to make another referral to social care, and that our daughter had options open to her to either continue her education or get support to start work.

I had to repeatedly contact our daughter's SENDO after term had finished to try and get an update about what was happening. I was eventually told the SENDO had been off sick, but was working through emails and would get back to me as soon as possible.

Charlie was put on a waiting list for a social worker. This is with the Learning Disability Team, but she does not have a learning disability. There's no indication about when she will be allocated someone, or what, if any, help might be available.

I still did not hear back. Things got so bad with my daughter's self harm that she ended up needing a wound stapling back together in A&E. She now has wounds all over her arm and leg and is finding it virtually impossible to stop self harming.



By the middle of August we still had not heard back from our daughter's SENDO about what was happening. I contacted SENDIASS who told me to contact the Specialist Learning and Advice Team manager. He was on leave at the time but contacted me as soon as he got back.

We saw a careers adviser the week after we contacted him and she was brilliant. We finally had chance to go through Charlie's options. Our daughter applied for a place at a supported internship and funding was approved on 13 September.

If we had been helped sooner, she would have been able to start her internship on 9 September. It would have saved a lot of mental distress. We now have a daughter who has a huge problem with self harm. This would not have got so bad if we'd had the right help. I left multiple messages at Huntington House to speak to a duty worker but nobody phones back. I put in a request to see a GP last week and she's been put on a routine waiting list to see a GP. Apparently we will be contacted in six to eight weeks' time with an appointment to discuss support for her self harm.

The SENDO who dealt with our daughter in the summer was an interim SENDO who has now left. We were told her case would be managed by her previous SENDO. Her previous SENDO told her our daughter's case had been passed onto someone else. I spoke to the new one on Friday and she is also an interim SENDO. The whole situation is exhausting and traumatic for the whole family. We've got a young person who wants to work but needs help to do so.

We thought that having an EHCP would mean that the support would be there for us. This has not been the case at all. Our daughter is probably going to have scars for life from all the self harm this has caused.

I also have a 17 year old on an EHCP and I am dreading having to go through this process again.



## Further reflections from families

### Financial impacts

- Juggling money as a couple with children that are autistic is an absolute nightmare.
- This is also extremely embarrassing to be a family surrounded by high earners and tax payers. Your dignity is stripped back, in fact, it feels like you are not entitled to any dignity.
- Having to go to the job centre to take evidence for a claim is time-consuming and soul destroying. Then to receive advice from the Universal Credit system advising to sell your home was utterly disgusting. It's hard enough to be a carer and try to do a job then the support from the government is non-existent.

### Exhaustion

- The exhaustion, the burnout is so real. This past week alone we have had audiology appointment, speech observation, social care review, a psychiatrist appointment, social care meeting for adult services, dentist, and learning disability team meeting.
- Being able to work is impossible - juggling is real.
- The processing of new information completely derails, chasing services to do their jobs is a full time job in itself.
- All services are so stretched. Not enough money, staff rushing around like headless chickens. Trying to function - to eat, to run a home, have a life - is a juggling

act. The only people that understand are those living and breathing this roller coaster ride. Sometimes you can't breathe. You wake up anxious and ready to get on the next rollercoaster. There is only so much families can take.

## Trauma

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- I feel, as a parent, there is not enough understanding within services around trauma and autistic burnout. Placing a young child into educational environments that are not healthy for a young neurodivergent individual has a detrimental impact on their future mental health and education journey. This can and is evidenced in all the stories we hear at present. It is important we start to listen to our young people in whatever way they communicate with the world. Showing compassion and support to both child and family. If we choose not to, we will continue to see crushed individuals unable to learn, to leave their homes and not want to be here. Costing services a lot more money.

## Transition to adult services

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- As a parent of a child just transitioned to adult services it seems that there is no team set up to support neurodivergent young adults and because of this they are placed with the learning disability team. The learning disability team said to us in our meeting that there should be a separate team for individuals like our son. As a result you can end up in meetings that are not always appropriate for your child/young person.

## Audiology

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- The autism friendly audiology team does a great job. However, there are many neurodivergent children within York with auditory processing disorder. This affects their learning, socialisations and processing of information. Unfortunately these children go unsupported with families just given a leaflet.
- York's commissioners have made the decision to not recognise auditory processing disorder and the impact this has on a child. This means even if the team believes the child has an auditory processing disorder they are not directly allowed to place this in a report and have to fluff around the edges meaning families have to go private if they can then pay for the appropriate hearing device themselves.
- More awareness around this is needed. Other countries like South Africa and America are a lot more understanding around this with appropriate equipment provided.

# YDRF Report for Healthwatch: Parents of ND kids

## Introduction

York Disability Right Forum (YDRF) is led by disabled people and works to promote equal access to human rights for all disabled people who live, work, or study in York. YDRF created a Neurodivergence subgroup in 2023 in response to the Autism and ADHD assessment pilot. While campaigning for the rights of adults, the concerns of parents for their children kept coming through as a significant concern, so the ND Parent Uprising was set up in response.

ND Parent Uprising is a project started in recognition of the fact that parents of ND kids often feel isolated and alone in their experiences. Constantly fighting systems (schools, local authority, GPs, CAMHS, and many others) means that parents have limited time, energy or motivation to maintain social connections with those who may not understand. We believe that parents coming together in solidarity and sharing their experiences is transformative.

For this report, parents spoke to us directly and reflected on their experiences. Parents fed back that they felt this was a therapeutic exercise as they felt validated and heard, sometimes for the first time. We offered anonymity to ensure the psychological safety of both the parents and their children when engaging in projects such as this one. Below we have grouped quotes from the parents under key headings.

Website: [www.ydrf.org.uk](http://www.ydrf.org.uk) Email: [ND@ydrf.org.uk](mailto:ND@ydrf.org.uk) Social media: [@yorkdrf](https://twitter.com/yorkdrf)

## Early indications of neurodivergence

“Early indications were an inability to nap/rest/stop through the day from a very early stage. He is adopted so we had awareness of prenatal ill health and substance abuse so that could also have been a factor. He did not reach standard milestones, was late to walk, speech delayed and over

the years had 6 different speech and language interventions, each for new challenges. He was incredibly impulsive, with no danger awareness and was 100 miles per hour, even before walking. He did not play inventive/imaginative games and did not really play fully until much older, 6-7+ and reenacted as opposed to imagined. In pre-school and early years, it was clear he was not at the same development stages as his peers by a long way and now aged 10 chronically often is much younger emotionally than peers."

"Early indicators were a little hard to figure out. We had a lot going on post adoption (9 months)! Difficulties have been clearer the older she is and the more that is expected. Her play and social skills have always been different to others."

"We've got two children, a boy and a girl. Our girl is older (20) boy is younger (17) and have had really different presentations. The girl's ND sort of crept up on us and didn't really start presenting till maybe mid-teens, but looking backwards now we've done the assessments, I can see it more. She's doesn't have many close friends, and that's probably been all the way through. She was having panic attacks in school after going back after lockdown. Nothing anyone was doing was helping because we were going on the anxiety and nobody was joining up the dots or even thinking about neurodiversity. We as a family were going through a very acrimonious divorce at that point so that distracted too."

"Early indications – inconsolable tantrums, suicidal thoughts, conscientiousness, impulsive behaviour (taking things, biting), vocabulary at a young age (loves talking), no spatial awareness, falling often. GP stigma, child psychologist – didn't think of these as unusual, they were stressful, but the norm."

"I've got two kids, both neurodiverse. My daughter's the younger one, it was her that I first had concerns about from about the age of five, because academically she wasn't at the same level as other children her age, and certainly not in terms of comparison with her brother at that stage. So

throughout primary school I had concerns about my daughter, but I didn't have any concerns about my son at all. He was academically very, very bright. My only concerns with my son were towards the end of primary school when I realised he was struggling with friendships and was never invited to birthday parties."

"My son, he's definitely autistic and I didn't know, but he was a biting child when he was very little, he had meltdowns all the time, all of primary school, he would have meltdowns. It's just a sensory overload now, looking back, total sensory overload. There was a lot of self-harm as well, when he couldn't work out why he was feeling that way or somebody told him off. I remember him having a tennis table tennis bat and he was hitting his head. It felt like it was all my fault, all my fault. My friend was shocked, she said 'I've never seen anything like that before'. It hasn't been until the last, maybe five years that we've actually been thinking more about neurodivergence, we've just been thinking he'll grow out of it. I just knew he was different, and he needed different things. I just wasn't thinking autism. Now I am and so it's blatantly obvious. He's very compliant, very, very compliant, he will try his best and then have burnout afterwards. He's quite obsessive as well. So, dinosaurs, Pokémon, Xbox. They are his things and he's getting more of them, but more adult things now."

### **Experiences with Systems**

"The good clinicians, the ones who listen, they stick with you and they change your life. It's sad that these experiences are rare."

"It really doesn't help when systems don't talk to each other. It might be one appointment for you but when it comes with 6 questionnaires to fill in first and some of them are the same questionnaires of 90 items that you've already filled in for another professional in the same week, it's exhausting. Giving the same negatives over and over again is an absolute drain."

"Please stop suggesting parenting courses to exhausted parents who are trying to juggle a host of appointments already."



“We're lucky that we have been able to afford some private assessment and meds for ADHD. She would probably have been excluded from school otherwise. We worry for those who can't afford this, it shouldn't be this way. Parent blame is alive and well!!”

“We've experienced so much stigma and a complete lack of understanding from systems. People wanting/thinking they're helping but actually causing harm. They seem to want to link with childhood trauma. Extremes of either wanting to 'fix' everything or that I'm 'mad' for trying to advocate for him (as a woman/mum).”

“The parent guilt never ends and society is so ready to dump that on you.”

## **Education**

“School was very supportive for both of them. The college support was oversubscribed but the individual course leader was very supportive for my daughter.”

“I feel like I'm forever, throughout their education, hitting my head against a brick wall, trying to just fight for their needs constantly.”

“Secondary school said your son's got ADHD which was a surprise. Neither of my kids fit into the stereotypical ADHD – you know people think of that naughty little boy? They never fitted into that mould, so they went a bit under the radar.”

“School wanted the child to come and “touch the gate” to “keep connection with school” which was an appalling thing to encourage. How many people connect with a cold hard gate which is designed to keep people out and children in? Again this shows me how out of touch the professionals are with the needs of children and what actually works for them, not to mention trauma.”

“My son started getting a lot of codes at school not because he was naughty, but because he had the wrong equipment because he was

disorganised and wasn't allowed his bag with him, so he was forgetting things. I was told he was disruptive in class, so I asked at parents evening, what do you mean he's disruptive? And they said 'he keeps putting his hand up and asking questions or telling me the time's wrong on the clock or telling me the date I've written on the board is incorrect.' So I said, well, was it incorrect? 'Well, yes it was. But that's not the point.' So, hang on, you're punishing my child because you've written the wrong date on the board?"

"School were doing their best with my son but struggling, so they suggested he go to {Name of AP provider} one day a week. I was initially against it, but he loved it. Then instead of the school phoning to say he was doing things wrong, I was getting calls saying your son's a really clever kid, your son's a delight to teach, your son's amazing. One day a week turned into two days a week, and then they decided he could go full time at {Name of AP provider} for half a term. He was actually doing his academic GCSEs and he absolutely loved it. And then he had to go back to mainstream because that half term had come to an end. I told them it wasn't going to work and it didn't, straight away he was suspended. After a lot of back and forth, the Local Authority made an exception because it was only two months before his GCSEs. He passed every single one, he did brilliantly."

"School and the Senco are woefully out of touch with what works for the needs of the child, and are possibly driven by attendance targets, and fear. I was asked directly "do you think he'll prefer alternative provision to school". The other factors not taken into consideration, despite my many conversations on it, and input from the Ed Psych and other professionals, was transition and attachment needs...

The first alternative provision we were offered and tried was within the academy. It involved 4 transitions there and back, in a taxi from school, and then a return directly to school for a further transition into the final 50 minutes of the school day which was not ideal. It was sold as low demand, free flowing etc yet in reality was timetabled, not as outside focussed as

stated, and had a key man dependency so if they were off sick or their kids were, the provision could not run.”

“Where to start with school? We’ve had 3 Sencos over 7 years, the first would not pursue an EHCP and my experience is they “managed me” as opposed to supported interventions to support my child. I now know what should be picked up in the EYFS and believe all signs were ignored and our voice was too. Then Senco 2 came in and she was amazing. She grasped the needs of our child, understood and heard what was happening at home and arranged an Ed Psych assessment, which was the beginning of things being supported. She created a sensory room within the school, ensured teachers understood needs and had simple effective ways to meet them e.g. where a child was sitting in the classroom. She also supported getting an EHCP and 121 help...

Senco 3 has been supportive in some ways, however I do not feel has listened to us as we entered into the difficulties which began in Year 4 and imploded in Year 5. I stated several times we would start to see an inability to come to school, that the timetable was too heavy, that he was being othered, and in December 2023 the Ed Psych attended a review and agreed. I was also visibly upset at this time and whilst it’s absolutely ok for a parent to be upset, this was out of character for me and I was open about the stress we were dealing with at home and the impacts to all of us. I do not think it is ok to ignore a parent in this way and continue to say a child is “fine in school”...

At this time afternoon support was also not in place when it should have been, so afternoons were a hotspot for him. This was reintroduced in January 2024 however probably too late. During the Spring term of that year, I continued to say things were not ok, he was not ok and nothing was done. I had been asking for an alternative provision to help with his capacity but to no avail. Alongside this however the Senco submitted a request for increased EHCP funding, so I question this in the sense of on 1 hand that shows the child has higher needs, yet our challenges were not being responded to...

The funding increase was agreed. By which point, he had reached his limit and was not able to attend. When this happened, I was sent the SEND

graduated pathway by another parent which highlights what interventions should be looked at in each stage. When I showed this to the Senco she said "I am aware of that document", and I wondered why on earth it had not been used within the last 6 months of us continuously saying things were not ok. We were at stage 5-6 of 7 by the time any of the interventions recommended in this were implemented, and even then that was via a large number of conversations and repeated requests."

## **CAMHS**

"My son really didn't like CAMHS. He really, really didn't like them and he refused medication outright. He said 'I don't want to be turned into a zombie. I don't want meds.' He was still doing drugs at this point, and so they just discharged him. They didn't want to know."

"My son got very, very depressed, almost suicidal, about a year ago. I phoned CAMHS and I just said 'I'm really worried he's still on the waiting list, what do I do?' And actually, a psychologist called me which I was quite impressed by. She couldn't do anything about the waiting list or see him any earlier, but at least she called me. He's not suicidal anymore, but he does get very down and I think he could quite easily have suicidal tendencies."

"VERY mixed experiences with different professionals. Notably, we've seen a lot of diagnostic overshadowing: 'she's adopted so it must be Foetal Alcohol Spectrum' (it isn't). CAMHS discharging her from the ADHD assessment list to do life story work because she is adopted without even asking if we had done life story work (of course we had) then not accepting her back on the list since she had been discharged. A conversation would have been so helpful."

"CAMHS gave my son some mental health support, a group session of kids his own age where they share their concerns and their worries. And in that group was one of the boys who bullied him. So of course he didn't want to go there. I told CAMHS my son will not open up because there's one boy in that group session who bullies him. They said they could maybe take him

out and put him forward for a future one in a few months. I said we need help now. Can't you do any one to one stuff with him? Oh, no. This is all we can offer you. He never completed the course, he did a few more which I had to drag him to kicking and screaming and pay him to attend. And then he just said I'm not going to anymore and I didn't push it."

"We are within CAMHS currently, after I had to contact them frequently to put him on their ADHD medication waiting list. They kept us in limbo whilst debating whether our NHS-but-funded-by-the-CCG diagnosis was sufficient for them to take him (after they refused to assess some time before). In the end I requested with insistence that he go on the list whilst they decided, so time did not tick on, and we also had to contact the emergency line a number of times because the situations we were dealing with at home were completely untenable. When I have interacted with CAMHS, I've had a very mixed experience. From "it's 4.45pm so the person can't take your call" to quite a helpful ADHD session with their team and other families. That said, it was clear some of the professionals in that session did not realise how difficult the reality for some families is."

"It's heart breaking to hear your son tell you he can't take it anymore, that he doesn't want to be alive, that he wants to kill himself."

"My daughter went into an absolute mental breakdown and depression, not getting out of bed type of thing. She had to stop going to 6th form. The GP referred her to CAMHS for depression and anxiety. They did an assessment of four areas and she was in red plus plus in all four. They told her to choose one area to go through the CAMHS counselling and at this point she was 17 ½, so she did some OCD work and ignored everything else as there was no scope to expand that."

"We're still waiting for CAMHS. We keep getting automatic letters saying 'you're still on our books, here are some web links if you require them, blah blah'. I contacted them recently and said please I don't want to get forgotten. He's already 17 1/2. Please don't forget. They've said that they will

not discharge him and won't pass him on to the adult services until they have seen him."

### **Health Professionals**

"The GP has washed her hands of us. She's tried two lots of SSRIs which worked for a short amount of time to lift her mood to get her out of bed. But then the anxiety just overran that. So she just stopped because the anxiety was worse than having the SSRI."

"Doing right to choose was a bit difficult because it wasn't a provider that the GP was aware of, so she said she would contact the ICB to see if we can use them. I said, well, if you give me the ICB contact as well, I will contact them as a parent. I got a reply within a week as a parent and when we went back to the GP, they were still waiting for a response. So the GPs, even though they are the clinical professional, are not getting the response from the ICB."

"The speech and language team were excellent and one of the few professionals I have connected with over the years who had a good understanding of Foetal Alcohol Spectrum and tailored their sessions perfectly to meet the needs of the child – e.g. using a ball to throw in the exercises so it wasn't sitting still and trying to process. They also had a strong link with school and so that worked in terms of sharing the interventions and school could then do them within his timetable."

"The GP has always completed any referral we've asked for which has been helpful. The paediatric team at York hospital were good to a point, and did complete an important referral to a specialist clinic in Surrey for assessment, and the CCG agreed to fund it. I found the consultant didn't fully grasp the system nor the day-to-day challenges he faced. She expected things like an EHCP to be granted without issue, and did not agree that starting school later would have been helpful for him. Similarly, before starting school, we met with portage, nursery, the school early years teacher and queried waiting a further year, all advised to start school within his age group. I do not believe this was the right advice."



## Local Authority

“The local authority continue to be a challenge. We have been thrown around different teams/social workers/case workers over the last couple of years and not had consistency of support. We've recently requested Learning Support Hub intervention for not being able to attend school, which was from April last year, and were told we don't meet the threshold because they count from the start of the academic year. I do not feel the LA understand the needs of the child, nor follow the SEND law and guidelines. Everything feels like a push or a fight to get what should be legally provided.”

“Poor experience of social care since pre adoption.”

“With my son I had to contact the Local Authority a few times. First of all, school changes because of the bullying and so on. Then we had early help when he was 13 when he was doing drugs and starting to truant from school. Looking on his phone I saw that he was being offered drugs via text messages from some much older people and adults. I spoke to the school but they didn't want to know because they said, that's outside school, that's nothing to do with us. I was too scared to go to the police so I contacted early help and I just said look, I'm worried about my child and what do I do? They gave me an early help support worker, a man, and he was no help whatsoever. My son didn't like him. He made no effort to try and get a relationship with my son and he turned around to me and he said 'I don't know why you need our help, lots of children take drugs.' Then we went into lockdown and that's when I needed this guy the most, but he turned around and said, I can't do any face to face visits and if your son's not going to engage with me, there's nothing I can do for you. So he closed the case. My son really went off the rails then, left home and got addicted to class A drugs during lockdown...

After lockdown, my son was really anti-school; he'd had a summer of doing what the hell he wanted and was a drug addict by then. Within two weeks of going back, his best friend died of a drug overdose. His world fell apart. He'd never had a best friend before. That was his first ever best



friend, and it was a very, very short-term relationship. He couldn't go to the funeral because of the COVID measures. He wasn't offered any counselling at school or anything, and I was trying to do my best at home, but I had an awful relationship with him at that point. He used to climb the fences and escape school to go to the graveyard and just sit smoking at his best friend's grave for hours. I'd get a phone call from school. 'He's escaped again.' Right. I bet I know where he is, drove to the graveyard and he was there...

In desperation, I contacted social services again. He was already in trouble with the police and was caught with class A drugs. Suddenly, social services wanted to know; I was assigned a social worker, and I was given help and support. The social worker was brilliant and cared. It took a while, but my son eventually built up a rapport with the social worker. He was great. He was also assigned a youth justice worker who, again, was brilliant. And because I had a great relationship with the youth justice worker and the social worker, between us all, we started turning him around. Youth justice helped us get his assessment fast tracked and he was assessed and diagnosed straight away."

"The local authority in terms of post adoption support have been great and we've been able to receive funding and access for the therapies we felt would work and have had two experiences of post adoption therapeutic interventions. (Sadly one was stopped by the pandemic)."

"We have had some support from the Virtual School Team/Social Worker, and they have answered any questions we've had, made recommendations and are on hand if needed. The alternative provision that we now have in place have a positive offering, however we have had to initiate transition and attachment-based approaches after 7-9 weeks of the child struggling to attend and stay without a parent. We now have a graduated transition plan in place to try to support this."

"I wanted to make sure that my daughter was on the SEND register and that she would get support going forward. So I contacted the Council and

I just said, can you see whether she's been flagged up as SEND and they told me the primary school had registered her a few years previously, but never bothered telling me."

### **Community Groups**

"I know in a couple of the YDRF ND parent sessions that we've had I've been in tears a couple of times and I know some of the other mums have. I don't think any of us would regret having those discussions or anything. I think the reason that we're crying is because it's just so nice to get it out and talk about it and it's a relief."

### **Impact on parents and wider family**

"Our child's experiences have had a major impact on us all."

"I haven't told my family because of the stigma."

"I'm so tired all of the time. I'm determined to give my son the life he deserves."

"The impacts on us have been big. Both children have suffered as a result of additional needs, school trauma and the dysregulation brought about by that. Our house has been damaged repeatedly, we have been injured and been in fear of one of the children getting seriously hurt. My husband has experienced a particularly severe episode of depression with suicidal ideation and had to be signed off from work, funded private counselling and increased/changed his medication to Prozac. I have had periods where I do not feel I can see people socially and have had to maintain focus on day-to-day needs. We are both struggling to exercise and have time for our own health and self-care needs. We do not see friends and family as much as we don't have the capacity to navigate what's needed as well as manage day to day."

"My son told his dad about being autistic and he said 'you're not autistic, you can't possibly be because you're not rocking in a corner, and you're

not hyperactive, so you can't be anything'. He is not supportive. We don't have a relationship at all."

"Support from my side of the family is more or less non-existent. I don't think they really get neurodiversity, so I don't talk about the kids. I haven't talked to them at all."

"I told my mum my son was diagnosed with ADHD and she turned around and went 'well, who's faults that then? Who's he caught that off of?'"

"I told my brother and his response was "all the best people are"."

"When my son left home, my mother-in-law took him in for a while. She was elderly. She was in her early 80s at that point and she just said if he won't come home, he can come and live with me. But he started bringing dodgy people back to her house so it impacted on her as well. My parents didn't want to know him. It's a shame, he's sort of like an outcast to a lot of the family."

"For 8 months I have done every single bedtime and evening routine mostly, as he can't tolerate someone else doing it. Our eldest child has suffered and would describe his experiences from his sibling as abusive. We've had daily aggression and upset to deal with which has been incredibly stressful. Our eldest child is also at risk of barriers to attendance so we are trying to manage that and his needs within all of this. (and ensure our voice is heard with his school). I should add the positive side of this is that since not attending school, and once a severe burnout was recovered from, our child is considerably more regulated and whilst we still have to manage outburst and aggression at times, this is significantly lower than when he was in school."

"When my son went off the rails, it was very, very difficult because it impacted the whole household. My daughter was a lot younger, she was probably about 10-11 years old when everything was going on. She knew there was a lot of arguments and slammed doors, trashing of his bedroom, all this sort of thing. She used to have a lovely relationship with

her brother when they were little, but they have no relationship at all now. She will never forgive him for what he did to his family.”

## **Work/Finances**

“Our life is changed and feels incredibly bleak at times. Every single day is a struggle. The anticipation of the explosion which we often see the minute she wakes, it does dreadful things to be in a constant state of negative anticipation. Work is really important to both of us but there's guilt in having a job and we've had issues with the amount of time we need off.”

“It's been hard financially. I've always been the main earner, but on a part time salary. I used to work extra for financial things knowing that my ex-husband was at home, but not anymore. I'm working 32 hours a week and I feel scared to increase my hours or to change my job because the kids need me.”

“I'm fortunate to have understanding employers and have managed to progress my career alongside being a single parent - I won't ever apologise for the commitments I have as a parent and I advocate for that. I do have to leave work at times to ensure I can be there to sooth and comfort - he might get told off at school and the aftermath is immense - people don't understand the masking that goes on. Both with him and with me.”

“We have constantly had to research methods that work to keep everyone regulated, to change styles to meet the varied needs of both children and cannot leave our youngest child with any other adults so have to do things separately or all together. I have spent hours reading, researching, watching webinars etc to try to educate myself on our rights, on the law, on what should be offered. We then have countless meetings, calls, emails etc, the list is endless. It is practically a nearly full time job in itself.”

“With my daughter, the fighting with school took up a lot of my time outside my full-time working hours. But with my son, I had to give up work. School were phoning me every 5 minutes. Every day there was something

going on, so there was no way on Earth I could have gone to a physical office and held down a job, so I had to give up work.”

“I have had to give up 1 of my jobs, and reduce my working hours considerably, to 2 evenings per week, Fridays when my husband doesn’t work and Saturday mornings. I have been able to do this as I am fortunate enough to be self-employed however were I in a different position, I would have had to stop working completely. So our income is much lower, and my needs as an independent adult have had to be vastly adjusted. We have been given DLA which has gone some way to help here. We have privately funded a specialist dyslexia assessment because the primary school were not listening to our worries about reading ability and challenges there either.”

### **Social Connection**

“Sometimes I feel I can’t be myself with my friends, because I can’t talk freely, you know.”

“I can’t talk about it to any of my friends. In fact, I don’t really have that many friends anymore because relationships with other parents got a bit strained. The few friends I’ve got, their kids are non-neurodivergent goody two shoes. Kids that comply with what their parents tell them to do and everything so you can’t have conversations with them about anything. Or I can, but they don’t understand.”

“Dating was incredibly difficult – being a single parent, your stigmatised as it is – being a single parent with a child with additional emotional needs is hard. I’m incredibly proud to be his mum and I always state that. He’s an asset. But the emotional burden of supporting a child with the needs that he has, that could be considered baggage – I’ve spent a very long time feeling so shit.”

## Impact of waiting

"I think we've had to wait for every single intervention pretty much, apart from speech and language because they kept us on their records and so rereferrals were picked up quickly."

"I think we're so used to having to wait now, it is simply part of our day to day lives."

"Waiting is really mixed. Currently we have the opposite struggle that everything came at once and we can't space it out or keep up. We are told 'there is no option to delay, or you lose the funding and we have to start again with the application.'"

"I know my son, I know about ND, I know my sons struggles, and I know he's ADHD - what am I waiting for? The diagnosis doesn't come with the support, but it comes with the understanding - even when people don't want to understand - schools etc have to offer that additional support. The additional support doesn't truly come without the diagnosis, stigma and judgement comes with the self-diagnosis - not support."

"It's very frustrating because my daughter has already been through CAMHS and they didn't join up the dots. If they joined up the dots then she wouldn't still be waiting. Now, we've had to go through private counselling and medication that wasn't appropriate. We've gone through all these things because she's been waiting."

"My son is just telling people he's autistic because he is and he's finding it very frustrating that he just can't speak to somebody officially about it. The waiting is very, very frustrating. The letters that you get from CAMHS, the standard letters, that every time we go 'oh, hooray, we've got an appointment!' But, no, we haven't, it's just another useless letter. Oh, it's painful. It's painful."

"With my son it all just went a bit wrong because his support was too late, because by then his mental health was in really, really bad shape. He

ended up getting in with the wrong crowd and he ended up doing drugs and all sorts.”

“We had to wait and/or push for CAMHS to take him onto their waiting list – so a wait to be in the waiting! This is ongoing and means we’re delayed in looking at medications – although what we have asked for is a conversation about medication, so we can learn and understand the benefits and challenges and make informed decisions from there.”

“The wait for the FASD/ASC/ADHD assessment was about 3 years however was also impacted by lockdown and we knew that would be the case, however it was worth it in terms of having all aspects assessed in 1 go, and the detail of the assessments and reports has been excellent.”

### **Changes that could have made a difference**

“Had my son received the diagnosis early on when we first went for it, and not waited 4 years+, he would have received the correct educational support. He would have received additional emotional support. I wouldn't have experienced the stigma I have. He would have received the school place in the school we'd selected for his needs. Because of this he experiences emotional ill health due to educational pressures that I know will live on with him. Not having the recognition of a diagnosis has risked his educational future. Education isn't everything but it's such a huge part of their lives as they're growing up. Children feeling like they're failing continuously and being told off constantly for things they simply can't help – it kills their confidence.”

“I think the first one is to be heard, for professionals to be curious, even when they have experience and knowledge. Secondly for school to follow guidance, to have reduced the timetable and implemented other alternatives sooner. I also think conversations between the LA and the Senco, without our involvement have not helped. Our voice has not been included so we are then given a response back via the Senco which doesn't align to the processes we believe are in place nor the law around SEND provision. I then have to contact places like Sendiass to unpick what



has happened and advocate for what should have happened. Meanwhile the child continues to struggle in the middle of it all. I do not feel it is ok for professionals to ever say a child is “fine in school” in response to a parent saying a child is not ok. This is also whilst they are seeing the child not being able to come into the building etc. There needs to be much more knowledge on ND in schools. Teaching assistants who are 121s should have mandatory training and they should be required to have knowledge and awareness. Schools need to shift their thinking to create simple, and often without any money required, changes to support children in school. A relationship first approach will work with all children.”

### **Key messages**

“Listen. Please stop diagnostic overshadowing. Adopted kids can be neurodivergent too!!!”

“The diagnosis process is degrading – don’t ask deficit-based questions in front of the child you’re assessing.”

“If you're a parent with an ND child – lean on the support you have and don't feel guilty for it. It's for you and for your child. Also advocate, advocate, advocate. Be the pushy 'neurotic' mum. Even if people don't listen, your child will know you have their back. They need a safe space. If it makes things better for them, that's the aim. If the systems don't listen at first, make them – you know what your child needs.”

“Asking for help is hard – make it easier.”

“There is such a lack of understanding of the parent’s point of view and a lack of support and knowledge for us. Parents not being able to work as much because you’re trying to look after your child for whatever their need is. And feeling guilty, so guilty, because you know, you've got to finance the household. But actually you are treading that tightrope all the time thinking ‘how are they now, can I do some extra shifts, can I not?’”

“It's awful for parents because you can never let go. You can let go to a degree, but you can't let them go on their own fully. So you're always preparing for the future and that's the hard bit.”

“Diagnosis can be life saving. It's not for everyone and in some instances it's not helpful. But when someone is asking for it – there's a reason for that.”

“Listen to parents. Believe us when we say there's something wrong, no one knows our kids more than us. Trust that if we're saying we think they need support, just listen to us and believe us and work with us. We're not doing it for the attention or anything. We're doing it because we're trying to help our child, and if we can get the help for our child that they need, that's going to help everyone. If my son hadn't got the help that he needed, he'd be dead by now, or in prison.”

“I would like people to know that is very hard, however having seen the difference in my child from being a desperately unhappy and frightened to much more settled and able to enjoy their life has been an eye opener. With hindsight and the knowledge I now have, I wish I had taken steps to push for either flexi-schooling with alternative provision much sooner, and not been afraid of it myself. If professionals had this knowledge, they would be able to help so many more children and families before things get so severe more issues come into things. It shouldn't have to be a fight to get the support that is needed, especially when all the evidence is there.”

“If a parent is speaking up for their child, listen – they're not doing it for fun.”

“Services need to pull their socks up and get organised. Don't ration support for children! What are you doing!? These kids are going to be our bankers, councillors, social workers, farmers – why would you hold them back from what their capable of? The North/South child funding divide is criminal.”

“People need to value neurodivergence and support people to live their full selves - ND people, when supported to live fully, have a LOT to offer - my sons a legend and I have no doubt he'll excel, just provide him with the right opportunities to do so.”

“Employ commissioners that value, are informed and care about equity and diversity.”

# Stories shared with Healthwatch York

Personal stories: Mary



I grew up in York. About age 15 I went to my local GP with multiple issues. I was struggling with my mental health and they thought it was anxiety and depression.

I was a good student, although I was always anxious. I also had stomach issues, but nothing was done. Later I realised that all my symptoms were related to ADHD but at the time I didn't know and the doctors didn't investigate or suggest anything other than anxiety / depression.

I started playing ill at school as I didn't want to be there. I was doing a lot of masking (I can see that now) and then I was able to be normal at home. I was referred to CAMHS but I never had an appointment and after that I didn't try again.

I went into sixth form with no support and struggling. I had a lot of depression and anxiety around my A levels and was prescribed Propranolol which didn't work and then Sertraline before my A levels.

When I went to university (outside York) I didn't have a diagnosis, just a prescription and had to ask my new university GP to write a letter to the university so I could access the appropriate support.

The Sertraline also didn't work and I was prescribed Mirtazapine and tried that for a year. At this time, again there was no investigation that my issues could be something else and no discussions about wider issues.

I began sleeping all the time and decided to stop all medication.

In the September of my third year at university (2023), a friend said they thought I might have ADHD. I thought I was more likely to be autistic as I needed time out and alone. I asked my university GP for a reassessment and was sent a questionnaire. I missed the deadline and had to restart the process. I had to wait for an appointment until the January when I was diagnosed with ADHD via Psychiatry UK on the NHS.

It took five months to titrate the medication, but we got to a point where it was working for me. In this time I moved back to York and they sent the medication to me at home.

The medication made a huge difference and meant that I could be in control of my life. Before I had 20 things whizzing through my head. With the medication, it is more like four things and they move much more slowly. I am exhausted without the medication, but with it, I can cope and am not so tired by everything.

By December 2023 my medication was working and Psychiatry UK said to get a Shared Care Agreement with the GP practice (close to York). I was planning to do some travelling and when I told them, they said to wait to sort the medication until I got back.

I checked with Psychiatry UK about medication, but they said no. So, I went to New Zealand for two months without medication.

When I got back I started to look into getting the medication again. I know what I need as it was working really well before. I went to my GP who said that I needed a new agreement. Psychiatry UK said I needed to fill in the forms again. I did that and was told by both the GP and Psychiatry UK that I had to go to the back of the waiting list. That was two months ago. I heard from Psychiatry UK last week who said they will arrange a meeting for me about getting back on the

medication/titration. I don't have a date for the assessment, but I do have the pre-assessment forms so I am hopeful it will be soon. But I am not sure what happens after that with the Shared Care Agreement to make sure I can continue to get the medication that helps me so much.



## Personal stories: Ray

**6** Ella shared her experiences supporting her child Ray. They are female leaning non-binary, born male. They came out aged 12 in the middle of distressing autistic burnout. There were no signs of gender questioning in early childhood so this came out of the blue for the family, but they are doing everything they can to support Ray and reduce their distress.

The path to autistic burnout began in year 6 as a reaction to a lack of flexibility in the teaching process. There were further incidents at school including another parent making inappropriate contact with their child. Parents were led to believe this was dealt with, but with benefit of hindsight wish they had taken the matter to the police. This led to autistic burnout at end of year 6, and a complete breakdown in year 7. Then lockdown happened.

Ray told Ella in March of their new name, Ray, and their new gender and pronouns. A few months after, as they were in burnout and non-verbal Ray communicated by What'sApp that they did not understand why their parents had not got them hormone blockers. Ella confirmed she wouldn't know how, and Ray sent them a link to Gender GP.

Ella informed CAMHS of what was happening – CAMHS were visiting monthly at this point. Staff visiting were really unsupportive and disapproving of Gender GP. Ella understands this, but feels there were no other choices made available to them. Every day Ray said "if you don't do this I will kill myself." One of the staff members responded with

"I guess they will just have to learn to sit with it." There seemed to be no compassion or understanding around what hearing this would feel like for a parent. A referral was made to Tavistock clinic but there was a four year waiting list.

In August there was an MDT meeting where it was agreed to take a watch and wait approach. In November without parents' knowledge CAMHS made a referral to the Safeguarding team. In December the family received a call as an urgent safeguarding referral following the November meeting. Other people at the MDT meeting do not remember a discussion about referring to safeguarding.

A doctor at the gender clinic in Leeds provided very supportive feedback regarding the actions the family had taken. As well as concluding there was no safeguarding issue, the safeguarding lead asked to share this advice with the rest of the team anonymously as it would be helpful for such referrals in future. The family is grateful they resolved this quickly as it could have negatively impacted on care had it not been.

The crux of the issue for the family is this - they are facing a new situation which they don't know how to do the things that they need to do. They want help, a professional to walk alongside them, help them work through options who they can talk to and who knows their child and wants to help. The family feels like they have no option but Gender GP but everything costs money, from £7 just for a chat to getting blood tests done. They know things are going wrong - blood tests show that their cholesterol is high, their blood pressure is high, but they have no one to talk to about what might help. There is no gender care at the GP, no specialist, no lead. They are being refused shared care as the doctor won't do anything private.

TEWV has said they will put training in place, but in three years the family has seen no evidence of a change in their behaviour which has



been judgemental, stigmatising and unsupportive. At the very least health services need to do no harm, but the family feels that by invoking safeguarding at such a time they increased the potential for harm to occur. They are also concerned about the quality of advice around autism – if they had followed the advice provided by TEWV they believe that this would have damaged their child's wellbeing further. They feel there is an absolute failure to understand their child and what good support would look like for them. Workers need to patiently build trusting relationships.

The family wants to know, given the situation with the Tavistock Clinic, the long waiting lists for gender identity clinics, and the increasing number of young people identifying as trans, what are commissioners doing to meet this gap. Are they working to establish leads in all provider services, GPs, hospitals, mental health services, with additional knowledge / specialisms? It is clear services are not ready but at this time it seems that people lose their basic humanity when interacting with trans individuals.

When their child was diagnosed with autism, they wrongly thought someone would tell them what this meant, but in reality they had to figure it out by themselves, find their own information sources. They don't think it should be like this for trans individuals and their families. There is nowhere to go and just talk to someone helpful.

The family would also like to see clear information on shared care and how this can be put in place. The system is all about box ticking, have you had this assessment, jumped this hurdle. Not about “are you ok? Is this having an impact on your mental health?” “All families want is people they can trust, who care about their child. Currently it appears this is too much to ask for.”





I have a number of health issues. When my children got diagnosed with ADHD (after a five year wait for a CAMHS appointment), I realised that I probably had the same.

I was diagnosed with ADHD when I was 48. I feel it is a similar experience for other women with peri-menopause as this seems to make the ADHD symptoms much worse. In fact the worst times for my ADHD have been hormone related: puberty, pregnancy and after birth and menopause.

My children also have ADHD, but they are not on medication.

My son Charlie was diagnosed just before he was 16. The issues for him got particularly bad at secondary school where teachers suggested he probably had ADHD. He was fast-tracked to Alternative Provision (AP) which was a very positive experience.

The school helped with the referral to AP and social care was involved. After diagnosis, he refused medication. As he was over 16, we were not allowed to input into this and were told that his decision had to be respected, so he was discharged. I don't think he should have been discharged as he still needed support from CAMHS even if not medication.

My daughter Daisy was 10 when we realized she was struggling. I thought she may be dyslexic. The school did not support this, so we went ahead with a private diagnosis which identified dyslexia. The assessor also thought that she might have ADHD. I mentioned this to the school who said that yes, she definitely had ADHD.

The symptoms and evidence of ADHD were very different for my son and daughter. Daisy was good at school and quiet, then at home could be a tom boy whirlwind or zombie. But she struggled at school (due to

the dyslexia) and was put on the table with the naughty children, but wasn't naughty. She was very unhappy about that as she really tried.

At 10 she was referred to CAMHS where there was a long wait. She was booked for a pre assessment but the psychologist had been double booked so she had to see someone different. She saw a male nurse who said that as she also had Irlen Syndrome and was changing schools that we should wait and see if it all settled down. I agreed but I didn't realise this meant my daughter was being discharged.

When Daisy had been at secondary school for a year, I rang CAMHS to follow up and found she had been discharged. I asked about a re-referral and was told it needed the school's support. The school refused. I went to the SENCO who contacted the teachers about evidence but every teacher just said 'no signs of ADHD'. But what they were seeing was no classic male signs.

At home Daisy could be one of two things, a zombie or manic. When I took her to a GP appointment when she was 10 to ask about ADHD, the GP and a trainee responded as if I was stupid saying 'what on earth makes you think it is ADHD ... if she had ADHD she would be banging her fists on the desk and rocking in her chair'.

Daisy really struggled during Covid and we moved her to a different school. I talked to the SENCO and explained the situation. The SENCO met Daisy and said that she definitely had ADHD and the school would support a referral as soon as it could (six months later).

Daisy was diagnosed at 15 and was on a waiting list for medication. She was offered a medication appointment the week before her GCSEs which I thought was not helpful, so I asked for it to be delayed. The new appointment came when Daisy was ill and so I emailed to ask for the appointment to be changed. However, instead Daisy was discharged and told she would need a new referral for medication consideration in

the future or to wait until she is 18 and get an adult referral to the Retreat.

My family have had no support at all.

Knowing I have ADHD is important as it explains why my head works in the way it does. I want medication and my psychiatrist and GP to communicate and work together. When I went to the GP to talk about HRT and mentioned ADHD I was told that the GP doesn't deal with that, but they are connected.

There are also issues with shared care agreements for ADHD medication at GPs in York. I feel that this is the GP rejecting ADHD diagnoses.



## Personal stories: Ben



When Ben started mainstream school at four, I was concerned that he might be dyslexic as there was a strong male line of dyslexia in my family. Ben had excellent spoken language skills and had started to talk when he was relatively young, but he had shown no interest in books.

In reception his teacher suggested getting his eyes tested because he wasn't looking at the board. But no one was worried as his language was so good.

At five he had a partial assessment for dyslexia as it was so clear he was dyslexic. But his school wasn't supportive. They were trying to get him to do more of the things that weren't helping him and put him in a group with other children who were struggling, but struggling for very different reasons.

When Ben was seven, he was aware of what he couldn't do and some felt his behaviour was about self-confidence. There was an autistic boy

at the same school who Ben was friendly with. So, Ben's behaviour was seen as situational when he was with the other boy.

When Ben was seven, we moved to York. This was a difficult time for him, he had broken his arm and was getting over chicken pox. My mum was also planning to move as well but didn't. It also marked the break-up of our family as Ben's dad had still been involved in his life, but wouldn't be as much once we moved.

Ben started at {Name of Independent school} after moving to York. The school was focused on exams and students going to university and was not supportive of Ben having an assessment, so we went private. ADHD was flagged but there wasn't the evidence and so it wasn't followed up. The focus was on his dyslexia.

Also, the structure at the school effectively supported Ben. I did a lot of research and together Ben and I found ways to cope at home so we didn't feel the need to pursue a diagnosis. I thought Ben might have autism with a PDA (pathological demand avoidance) profile and inattentive ADHD.

The lockdowns in 2020 and 2021 exacerbated things and I recognised that we would need other things in place for when Ben was sitting exams. The school SENCO referred Ben to CAMHS. This was a dual referral. I believe we only got this as I know how to fill in forms! However, the process was very repetitive with two sets of forms to be completed with much of the same information, then two very similar Zoom interviews, followed by a face to face meeting.

At this stage Ben had self-identified with ADHD and that seemed the priority as it was affecting school.

However, at the face to face meeting we were told that CAMHS would not pursue a diagnosis as Ben's behaviour did not show any risk taking

and he wasn't physically hyperactive. The referral to the autism team would still happen.

I was very frustrated. If I had known that these traits were needed for the diagnosis, I would not have continued as I knew he would not fit the CAMHS criteria. Because of this experience I questioned whether there was any point bothering with the autism referral.

While the assessments were happening, Ben moved to another school. They were asked to fill in paperwork for the ADHD referral and did it too late to be considered. The feedback did say the school felt Ben had ADHD.

For the autism referral the school said that he had normal interactions and they did not think he is autistic. They also commented on his behaviour out of school even though they were not aware of it as Ben had only been at that school for a year.

However, the psychiatrist we met for the assessment said that he is autistic. They said he communicates in different or unusual ways and commented on his use of American terminology (due to watching a lot of US television). The psychiatrist could see autism in several things. I feel that Ben presents with a style of autism more associated with female presentation.

The assessment was again frustrating for me as there was no consideration of Ben's ADHD and autism working together and presenting differently to others. There was no understanding of the interplay between the two for him and how this impacted on him and his day to day life.

The assessment process was all about challenges and crisis rather than looking at what was working and how Ben (or others) were currently coping. This meant it was skewed and not at all holistic.

After the diagnosis the school asked me if I was shocked and then asked how they could help – two months before Ben’s GCSEs!

Ben went on to college, but I was disappointed that college wasn’t as supportive as it could be. However, Ben did not want to be singled out so he didn’t seek help. I feel the college wasn’t equipped for the variety and complexity of student needs and the number of students that need different support.

Society and the education system are making it harder for neurodiverse young people to fit in, particularly with the increasing use of technology and the lasting impact of lockdown.

If Ben had to navigate the current assessment process it would have been debilitating. The process and assessments were inaccurate and outdated when he was going through them and they haven’t improved. It all lacks clarity and honesty.



### **Personal stories: Freddie**



My son is amazing. Kind, caring, sweet, affectionate, and very, very funny. He has an infectious laugh that you can’t help but join in with. He’s bright, curious, joyful, friendly. I’ve also suspected he has ADHD from a very early age.

We’re still at the start of our journey and in many ways we’re really lucky. Our school has been supportive. They’ve provided lots of extra help at school – from one to one support for reading, writing and basically anything that you need to concentrate on, sessions with the Emotional Literacy Support Assistant (ELSA) to improve his ability to manage his emotions, to breaks part way through tests so he can burn off some of his ‘fizz’ and then come back to it. They suggested we should work on the forms for an ADHD referral at about the earliest



stage you can because there are issues we need to work on that they'd welcome specialist input on.

I think for me the biggest challenge is that it always feels like you are flying blind. He's my only child, he's all I know, but I am expected to know whether what we're experiencing is usual or unusual. Where do you go for a conversation on the 'acceptable' level of violence from a school-age child? There's no place for real conversations about what to be worried about and what to accept. Instead, you find yourself documenting only the worst of their behaviours so you can persuade health professionals there's something they should be helping with. But I am also surprised at how little co-ordination there is between services, and that it's up to me to keep them all informed, usually having to share quite difficult personal information in front of Freddie, which has a clear emotional impact on him.

We actually got rejected for an ADHD assessment before we even asked for one – long story short there was a miscommunication about some other tests we needed to have done. But when we first really put the referral in for assessment through school we got a straight no back, plus forms to complete for a possible autism assessment. He definitely has some autistic traits, but they're not the issue that's most concerning for us right now. However, as all of this is done via forms without ever seeing anyone you don't have the opportunity to explain any of this. I immediately challenged their reason for rejection and lo and behold they'd made a mistake. He's since had a QbTest and been put on the ADHD waiting list with an autism 'clip-on'.

We made a request when making the referral to have the forms by email, to have letters by email and to get responses by email, but we always get written to. I don't know what class of post they use but it weirdly seems to take several weeks after the date on the letter. So for example we received the original ADHD forms just before school broke up for summer, and we then had to wait until September to work with

school on them. It seems to make a mockery of all the early intervention talk when the process itself seems to involve stalling tactics over and above the lengthy delays for assessment.

We're just hopeful we get an assessment within the one and a half to two year timeframe they've suggested, so support can be well-documented before he goes to secondary school.



# Partner statement from York Carers Centre

Many of these stories are truly harrowing and we should all be affected by reading them. York Carers Centre supports families who are experiencing an increase in their caring role due to a reduction in services and support, and the demand on the services available. The complexities involved in accessing and navigating services adds a burden on to families who already have enough on their plate. Support is meant to be just that; services are meant to be there to help the people who need them, not cause further distress.

When a family is left to care for their child with limited support there is a significant impact on family relationships, finances, the physical and mental wellbeing of family members, the ability to work or study, and the opportunity to connect with others. It is vital that parent carers and their children have quality support and choice so they can create a life that works for everyone in their family and is one they can sustain.

We believe this is about more than finding ways for children to be in education. It is about changing our approach to understanding what families need and finding ways to deliver this. It is clear from some of the case studies that things need to change, and we need to stop causing further trauma to families and children, but work with them, hear them and support them to find meaningful ways forward in the best way possible.

# Partner statement from Parent Carer Forum York

The Parent Carer Forum York is an independent charity who is commissioned to represent the voice of parent carer lived experience in York. We represent parent carer views to Education, Health and Social Care to inform development of services for young people with additional needs aged 0-25.

This powerful report captures the journeys and stories of many families whose experiences are reflected in the common themes heard by PCF York. We urge all decision-makers to take the time to read each story, as they describe the wide impact on both the children and their families.

York Local Authority and Health Services have a genuine interest in working with us to shape strategies and services with lived experience. We hope that this report will inspire innovation and drive meaningful change, both locally and within national systems, to better support neurodivergent individuals.

If you would like to find out more about how your family experience can inform current and future plans, or support us in the work we do please email: [connect@pcfyork.co.uk](mailto:connect@pcfyork.co.uk)

# Key findings

- Societal awareness and understanding of ND is still low, and parents experience stigma from friends, family and services.
- Parent blame is still often the first thing parents seeking help experience.
- Parent experiences are also worsened by poor administration and poor communication from services.
- Support is still focused in silos, with thresholds for support, making finding the right help for a range of lower-level issues challenging. Capacity in the system is overstretched, leaving many services looking for how to say “no” to providing a service.
- Some schools are still not considering the needs of neurodivergent children at times of transition. Others support transition well but do not maintain support beyond transition and fail to see the signs when a child begins to struggle.
- School behaviour charters often ask for behaviour that is impossible for neurodivergent children. This reinforces negative views many neurodivergent people already hold about themselves – that there is something wrong with them and they are not good enough. There is a significant challenge in setting behaviour codes that maintain a good environment for all pupils without punishing ND pupils. However, meeting this challenge is vital. Low self-esteem increases the problems many neurodivergent children grapple with, but there are many strengths associated with neurodivergence which need to be recognised, valued and celebrated.
- There is significant overlap between children who are neurodivergent and children who are gender questioning. Our systems are not geared up to support these young people. Many are asked to choose which they want support with, and may also be advised to ‘hide’ part of themselves to receive support with the other element of their identity.

# Recommendations

Recommendation	To
<p>Consider how to embed across the health and care workforce the importance of connections, and signposting to peer support at the first moment people approach for help. Make sure this includes not just parent carer awareness but recognises young sibling carers too.</p>	<p>All York system partners including City of York Council, York Health and Care Partnership, Tees Esk and Wear Valleys NHS Trust, York &amp; Scarborough Teaching Hospital Foundation Trust and Primary Care leads.</p>
<p>Make a commitment to stopping parent blame.</p>	<p>All York system partners as above.</p>
<p>In partnership with local ND and parent carer groups, seek funding and support through local research networks to develop a Neurodiversity friendly schools charter and encourage local schools to adopt this, covering:</p> <ul style="list-style-type: none"> <li>• ND training for educators.</li> <li>• How to recognise the signs of EBSA, burnout and school trauma.</li> <li>• Developing a best practice mental health pathway where such signs are observed.</li> <li>• Developing school behaviour models that do not discriminate against people who are neurodivergent.</li> <li>• Transition planning and help to support young people through transition and beyond, with a menu</li> </ul>	<p>All York system partners as above.</p>

<p>of potential reasonable adjustments that can be accommodated within the school environment.</p> <p>This will rely on identifying funding to support such research. This should also consider the links to the Human Rights schools approach in York.</p>	
<p>Develop local expertise around neurodivergence and gender identity. Put in place a clear policy around shared care arrangements and an escalation process for those whose GPs cannot or will not support them.</p>	<p>HNY ICB, York's PCNs, TEWV</p>
<p>Develop and deliver local training around PDA for health, care and education professionals.</p>	<p>HNY ICB, LD MH &amp; Autism Provider Collaborative, City of York Council</p>
<p>Bring York into line with the wider ICB by making sure there is a clear sleep pathway that offers behavioural support and further specialist help where this does not address the problems experienced, including identifying who will prescribe melatonin where this is clinically assessed as right for the child, and how the transition to adulthood will be managed. Provide clear information about the offer for the workforce and parent carers.</p>	<p>HNY ICB</p>
<p>Improve access to information for parents whose children become unable to access the school environment. This must include, as above, making them aware of peer support and statutory rights.</p>	<p>All York system partners as above.</p>



<p>Make sure all services comply with the Accessible Information Standard and that providers seek to understand the communication needs of parents and children and respect requests for information in particular formats. This duty sits with providers, not families.</p>	<p>All York system partners as above.</p>
<p>As per the recommendation in our Children’s Mental Health snapshot report, improve administration processes for paperwork related to the formal assessment and diagnosis pathway in secondary care. As above, this must include seeking to understand and respecting people’s communication preferences. Checking preferred communication methods should form part of any initial SPA conversation.</p>	<p>Tees Esk and Wear Valleys NHS Foundation.</p>
<p>Consider ways to improve support for families of neurodivergent young people. This must include considering how existing services such as school SENCOs, SENDIASS, Local Area Co-ordination, Family Navigators and Social Prescribers can play a role connecting families, and consider how integrated approaches and multidisciplinary teams can address the challenges families experience, with more proactive and co-ordinated support.</p>	<p>City of York Council, VCSE partners.</p>

# Initial response from Humber and North Yorkshire ICB

The Humber and North Yorkshire Integrated Care Board (ICB) and Mental Health, Learning Disabilities & Autism Collaborative were anticipating the opportunity to develop this report together with Healthwatch York and as such would have welcomed more time to consider the draft content describing the local picture and findings. Receiving the report just before Christmas has limited the time to digest, discuss and respond. The findings will be discussed at a future Executive meeting of the Mental Health, Learning Disabilities & Autism Collaborative, which will enable a more comprehensive response to the recommendations and reflect these in programmes for neurodivergent families. We would like to develop this response in partnership with Healthwatch York, voluntary sector organisations, and representatives of children, young people, and families.

Moving forward the Integrated Care Board is committed to building sustainable and equitable services, balancing diagnostic capacity with appropriate support and ensuring that the right interventions are in place across the system. This demands careful planning, collaboration and a long-term strategy. We are working with both regional and national teams to address the demand for autism and ADHD (Attention Deficit Hyperactivity Disorder) services, while our Mental Health, Autism, and Learning Disability Collaborative drives pathway improvements. This includes learning from other regions, taking direction from NHS England's national team and sharing resources to better manage demand and meet the needs of the population.

A number of key workstreams have been identified as part of our programme of work include:

- Reviewing waiting lists to ensure accuracy and transparency.
- Creating unified service specifications for both adult and children's assessment services.

- Developing consistent thresholds for assessment eligibility across the system.
- Ensuring diagnostic tools are applied consistently.
- Aligning transition policies between children's and adult services.
- Mapping commissioned and non-commissioned pre- and post-diagnostic support services to identify gaps and assess levels of need.
- Piloting early identification and support initiatives.
- Expanding peer support networks and community advocacy programs.
- Planned development of a central website hub for autism and ADHD resources.

These initiatives aim to address the complexities of autism and ADHD pathways by improving access, quality and outcomes. While this report focuses heavily on autism and ADHD, in York, we are also undertaking several key workstreams around other neurodiverse conditions. These include initiatives related to Down Syndrome, Foetal Alcohol Spectrum Disorder, Tics and Tourette's Syndrome, Epilepsy, Deaf Autism and ADHD Assessments, hearing checks, and Project SEARCH among others. These efforts reflect our commitment to supporting the diverse needs of our population and ensuring that individuals with a wide range of neurodiverse conditions receive the care and support they need.

### **Inaccuracies/Potentially Misleading Information**

Assessments for children under 5 take a year to ensure a thorough evaluation over a longer period of time to distinguish between developmental delays and autism.

The report says there is no support available pre and post assessment, however there is a variety of support available depending on the needs of the young person, individual and family. This includes NHS and York Council commissioned services, as well as support from our partners in the Voluntary Community Social Enterprise (VCSE) sector. Some examples

include Autism Central, SHOUT, MIND Cafes, Autism Plus, Neurodiverse Parents Group and Castaway Music Theatre. In addition, there are more specialised support services available, tailored to specific needs, such as help with managing finances or getting active. We are also strengthening our collaboration with local businesses within York to better support their neurodiverse customers, ensuring that our communities becomes more inclusive and an increased understanding of diverse needs.

TEWV (Tees Esk Wear And Valleys NHS Foundation Trust) currently use International Classification of Diseases (ICD)-10, and there are other organisations within our Integrated Care System that also use this tool. There is no mandatory implementation for organisations to use ICD-11, however our aim is for all organisations to use ICD-11 as we move forward with our programme of work to ensure consistency across our geography.

There is no blanket policy preventing GPs from entering shared care; decisions are made based on clinical judgment and the validity of the assessment and we are advising families to remain with the same provider for the entire episode of care to ensure continuity, as switching between independent and NHS providers often causes delays.

The section on auditory processing disorder (ADP) should note that there are services available for assessment and support, such as the Royal National Ear Nose and Throat Eastman Hospital and Great Ormond Street Hospital. These centres accept referrals from York families, with eligibility assessed case-by-case, typically requiring prior hearing checks. Support strategies, while not curative, are widely available and effective in helping individuals manage auditory processing disorder.

The Designated Clinical Officer (DCO) for Special Educational Needs has oversight of health's statutory duties and/or Disabilities (SEND) in York and Associated DCOs have reviewed the guidance for education setting regarding requesting health information for Annual Reviews with colleagues from the Local Authority. This guidance has been shared

across school networks and the DCO and ADCO have attended Special educational needs coordinators network meetings, both in person and virtually to deliver training regarding this guidance and the process for education settings to request health advice. Alongside the guidance we have also shared Single Point of Contact email directory for health providers, a timeline for the process and a digital health questionnaire that can be provided to parents/carers and young people to complete ahead of their annual review which informs which health services are currently involved with the child or young person. The timeliness of initial health advice provided for Education Health Care Plans is monitored by the DCO and ADCO and this information is shared with the SEND Partnership Board. In Quarter 2 (2024/25) 97% of health advice was returned within the statutory timeframe 6 weeks, 1 piece of advice was returned late by 1 day.

## **Engagement Opportunities**

It would be beneficial for Healthwatch York to engage with children's and young people's organisations that specialise in this area. Two key partners to consider are the Parent Carer Forum York and the Nothing About Us Without Us Group. We also link in closely with several local groups and national organisations, such as the National Autistic Society and ADHD360 and would be happy to connect these organisations with Healthwatch York, if they are not already linked in.

Nothing About Us Without Us is a Humber and North Yorkshire Wide lived experience advisory group which includes representation from Children and Young People aged 10-25 from across our diverse communities including those with autism and ADHD and learning disabilities. The group holds regular place based and system wide events to enable children and young people to share their lived experience and collaborate with senior leaders to coproduce solutions to recommendations from consultations, improve access and experience of services and to shape the mental health priorities for 2025 and beyond. For more information please contact [\*\*Be.Heard@nhs.net\*\*](mailto:Be.Heard@nhs.net).

**Sarah Coltman-Lovell**

York NHS Place Director

York Health and Care Partnership

# Conclusion

It is clear from the stories shared in this report that there are specific challenges being experienced by neurodivergent young people. Our current systems for supporting them and their families are over-stretched.

There has been a significant societal shift, with more people's neurodivergence being recognised. Change is essential for services to adapt their offer to better meet the needs of neurodivergent children and their families. A positive and successful future life for many neurodivergent children depends on this, the ability of these services to adapt and change. Such change is essential to preventing inflicting and reinforcing trauma and anxiety.

We need to see change in schools. They must have access to expert support and advice, to make sure they can provide an environment where more neurodivergent children can thrive. It is clear that many are already managing transitions well – but there is a need to improve the ongoing support after transition. We urge partners across York to work together to develop a neurodivergent schools charter. We acknowledge that funding will need to be found for this, and will reach out to local academic institutions to gauge appetite for working on this with us, neurodivergent families and local schools.

But beyond this, we need to see a change in approach – recognising these families as experts in their own child, and working together to wrap support around them. There are opportunities in the increased focus on integrated care, and multi-disciplinary team approaches, and serious consideration needs to be given to how some of this work addresses the challenges outlined throughout this report.

There are also inequalities across Humber and North Yorkshire in terms of access to services. We call for change in particular around support with sleep. In York, we have a more robust offer for under 5s than our neighbours in North Yorkshire, through the Healthy Child Service. But no



sleep service for over 5s. North Yorkshire has tier 1 and 2 nurse-led support. East Riding also has a sleep service. This must be addressed.

# Appendices

## Appendix 1: Glossary

<b>Term</b>	<b>Definition</b>
Accessible Information Standard	The Accessible Information Standard is a legal obligation introduced in 2016. It applies to all organisations that provide NHS care or publicly funded adult social care. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.
Alternative Provision (AP)	Alternative education options for children who cannot go to mainstream schools, for any reason. In York, this includes services like Danesgate School, Medical Tuition Service, Teach Me Happy, and Bilborough Country Classrooms.
Attention deficit hyperactivity disorder (ADHD)	ADHD is a condition that affects people's behaviour. People with ADHD can seem restless, may have trouble concentrating and may act on impulse. In this report, we include three different types of ADHD including inattentive, hyperactive and impulsive and combined when we talk about ADHD.
Auditory Processing Disorder (APD)	APD is where you have difficulty understanding sounds, including spoken words. It often starts in childhood, but some people develop it later. It cannot be cured, but there are things that can help. Testing for

Autism	<p>APD is not usually done on children under the age of 7.</p> <p>The NHS defines autism as a lifelong condition that affects how a person communicates with, and relates to, other people.</p>
AQ – Autism Spectrum Quotient	<p>The Autism Spectrum Quotient (AQ) is a 50 item self-report measure used to assess traits of autism in adults and adolescents aged 16 years and over.</p>
Dyscalculia	<p>Dyscalculia is a specific and persistent difficulty in understanding numbers which can lead to a diverse range of difficulties with mathematics.</p>
Dyslexia	<p>Dyslexia is a common learning difficulty that mainly causes problems with reading, writing and spelling.</p>
Dyspraxia	<p>Dyspraxia (also known as developmental coordination disorder) is a condition affecting movement and coordination in children and adults. Dyspraxia affects all areas of life, making it difficult for people to carry out activities that others can take for granted.</p>
EBSA	<p>Emotionally Based Schools Avoidance - a term used to describe children and young people who experience challenges in attending school due to negative feelings such as anxiety. It is thought to currently affect around 3 in 10 children of secondary school age.</p>
EHCP	<p>Education, Health and Care Plan - An EHCP can be put in place to support a young person with special educational needs (SEN) if their educational setting feels they don't have the resources required to support them. The EHCP</p>

EOTAS	<p>will identify the child’s particular needs, and what additional support should be put in place to meet those needs. An EHCP can stay in place until the young person reaches the age of 25 if they remain in education to that age.</p> <p>Education Otherwise Than At School – the legal mechanism whereby a child with an EHCP can receive educational provision despite being unable to attend school.</p>
EP	<p>Educational Psychologist – educational psychologists assess children’s learning and emotional needs; design, develop and support therapeutic and behaviour management programmes; support other professionals by advising on the best approaches to use. There is a national shortage of Educational Psychologists in the UK with many local authorities finding it hard to meet demand for their services.</p>
MASH	<p>Multi Agency Safeguarding Hub – York’s multi agency single point of contact for anyone with concerns about a child. Their role is to make sure children get the right support. MASH is also the home of the Early Help team – who provide extra support for families who need it.</p>
NICE	<p>National Institute for Health and Care Excellence</p>
OCD	<p>Obsessive compulsive disorder</p>
PDA	<p>Historically Pathological Demand Avoidance syndrome. However, many Autism professionals suggest it be renamed Pervasive Drive for Autonomy.</p>
QbTest	<p>A digital technology recommended by NICE for young people aged 6 to 17 that can help speed up the diagnosis of ADHD.</p>

Salvere	A not for profit community interest company who support people to employ their own health and care support workers.
Section 19	Section 19 of the Education Act places a duty on local authorities to make suitable alternative education available for children of compulsory school age who cannot attend school because of illness, exclusion, or for any other reason.
TAF	Team Around the Family – used to get everyone together who is or could be working with your family. They work together to identify family needs and strengths, and the best way to put in place any extra support needed. TAFs are voluntary.

## Appendix 2 – Services and support

### Local Services

#### The Land

The Land's aim is to support families of children with high anxiety who find it difficult to leave home. They are currently creating a tranquil nature reserve offering small group sessions, parent carer meet ups, and workshops.

Email [info@theland.org.uk](mailto:info@theland.org.uk)

<https://theland.org.uk>

#### York Disability Rights Forum

York Disability Right Forum (YDRF) is led by disabled people and works to promote equal access to human rights for all disabled people who live, work, or study in York. ND Parent Uprising is a project started in recognition of the fact that parents of ND kids often feel isolated and alone in their experiences.

Email: [hello@ydrf.org.uk](mailto:hello@ydrf.org.uk)

<https://ydrf.org.uk>

#### Parent Carer Forum York

The Parent Carer Forum York is an independent charity who is commissioned to represent the voice of parent carer lived experience in York. We represent parent carer views to Education, Health and Social Care to inform development of services for young people with additional needs aged 0-25.

Email: [connect@pcf york.co.uk](mailto:connect@pcf york.co.uk)

<https://www.parentcarerforumyork.org>

Their website includes a useful resources section with information about York's Local Offer, SENDIASS service, Raise York and CAMHS amongst other useful links.

<https://www.parentcarerforumyork.org/useful-resources>

## **York Carers Centre**

York Carers Centre is an independent charity and a network member of the national Carers Trust. We work in partnership with carers, statutory and voluntary organisations to ensure unpaid carers throughout York have access to confidential information, advice and support. We work with carers to influence positive change in service delivery with local government, employers, schools and health providers.

York Carers Centre supports carers of all ages:

- Adults
- Young adults (18 to 25)
- Young carers (5 to 18)

Tel: 01904 715490

Email [enquiries@yorkcarerscentre.co.uk](mailto:enquiries@yorkcarerscentre.co.uk)

<https://yorkcarerscentre.co.uk/>

## **York Inspirational Kids (YIP)**

Have a number of Facebook groups including York Inspirational Kids main page, with 16 channels, York Hemi Kids for parents and carers of children with hemiplegia, York Inspirational Adopters for families who have adopted a child with additional needs, and York Ausome Kids for parents and carers of children with autism. Details are on their website or find them on Facebook

<https://www.keyworking.co.uk/what-we-do.html>.

## **YDANN – Your Dyslexia and Neurodiversity Network**

A support group for adults impacted by Dyslexia, Dyspraxia, Irlens and ADHD. They meet to talk, share.

Contact via Facebook:

<https://www.facebook.com/YorkshireAdultNeurodiversityNetwork/>

## **York Neurodiverse Adults Meetup**

An opportunity to meet with other autistic, neurodiverse adults in York for informal chat, board games, and cards etc.

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**Venue:** De Grey Building, Room 019 at St John's University

**Date:** The second Monday of every month

**Time:** 7.00pm to 9.00pm

<https://www.facebook.com/groups/422784726311376>

**The Mind Garden** – York support group for neurodivergent families

Offer support for children, young people and their families whether you have received a diagnosis, are on the waiting list or displaying signs of neurodivergence. Website has details of the support they offer:

Email: [hello@mindgardenyork.co.uk](mailto:hello@mindgardenyork.co.uk)

<https://mindgardenyork.co.uk/neurodivergent-families/>

**The Island**

Local mentoring service for young people:

<https://www.theislandyork.org/how-to-support-neurodiverse-children>

**TEWV Single Point of Access (SPA)**

01904 615345 – to self refer for assessment

**Gender Identity Services**

Tel: 0113 855 6346

Email [gid.lypft@nhs.net](mailto:gid.lypft@nhs.net)

<https://www.leedsandyorkpft.nhs.uk/our-services/gender-identity-service/>

or contact the Gender Outreach Workers on 0800 183 1486

**York SENDIASS (Special Educational Needs and Disability Information, Advice and Support Service)**

York SENDIASS can help you understand support in educational settings and advise on a range of issues, your rights and the law, writing and seeking an EHCP or solving disagreements and helping when things go wrong.

<https://www.yorksendiass.org.uk/>

## National Resources

**Autistic Girls Network** – a small registered charity working to support, educate, and bring change. The website contains lots of resources for individuals, families and professionals about autistic girls and gender diversity among autistic people

<https://autisticgirlsnetwork.org/>

**Spectrum** – is a multi-award-winning, parent-led children’s charity. They provide events, sessions, and support for families of children with Autism, additional needs, learning difficulties, and disabilities. Membership is free.

Tel: 01223 955404 M-F 10-4

Email: [hello@spectrum.org.uk](mailto:hello@spectrum.org.uk)

<https://spectrum.org.uk/>

## The Sleep Charity

Tel: 01302 751416

Email: [info@thesleepcharity.org.uk](mailto:info@thesleepcharity.org.uk)

<https://bit.ly/SleepandADHD>

**Cerebra** – provide a range of information guides for parents, run an expert sleep service and a legal rights service, have a bespoke equipment and modification team, and a toy and book library.

Email: [sleep@cerebra.org.uk](mailto:sleep@cerebra.org.uk)

<https://cerebra.org.uk/>

## PDA Society

<https://pdasociety.org.uk>

Introduction to PDA youtube video – the PDA Society

<https://www.youtube.com/watch?v=diHUmhPWXUY>

## ADDitude

Website with guidance and support for living better with ADHD and its related mental health conditions.

<https://www.additudemag.com/>

## **ADHD Foundation**

General contact details:

Phone: 0151 541 9020

Email: [info@adhdfoundation.org.uk](mailto:info@adhdfoundation.org.uk)

They also have a parenting team, who run courses and who might be able to provide more specific support and advice, this is their email address:

[parenting@adhdfoundation.org.uk](mailto:parenting@adhdfoundation.org.uk)

<https://www.adhdfoundation.org.uk/services-for-families/>

## **ADHD and you**

Large range of resources including guide for parents, templates and checklists of questions to ask school about adjustments they could make and support they could offer.

[www.adhdandyou.co.uk](http://www.adhdandyou.co.uk)

Specific questions to ask school which might be helpful in requesting reasonable adjustments at school:

<https://www.adhdandyou.co.uk/child-with-adhd/helping-your-childs-educational-development/>

## **Ambitious about Autism**

A national charity for children and young people with autism, has a lot of resources, including information about education at different stages and for parents on assessment processes.

Email: [info@ambitiousaboutautism.org.uk](mailto:info@ambitiousaboutautism.org.uk)

<https://www.ambitiousaboutautism.org.uk>

## **Autistic Minds**

Run HelpHub, a national helpline providing support, information and guidance to autistic adults, parents of autistic children and professionals working with the autistic community.

<https://autisticminds.org.uk/how-we-can-help/the-helphub/>

## **The National Autistic Society**

A website with various resources and a number of specialist helplines, including a parent-to-parent emotional support helpline, website:

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<https://www.autism.org.uk/>

<https://www.autism.org.uk/advice-and-guidance/topics/education> - information about rights in education

## **Neuroclastic**

A collective of Autistic people responsive to the evolving needs and trajectory of the Autistic community. Publishing autistic voices, to catalogue the intersectional experiences, insights, knowledge, talents, and creative pursuits of Autistics. They follow a unique model of interdependence, leveraging the passions, skills, and specialisations of contributors to create a living repository of information cataloguing the autistic experience.

<https://neuroclastic.com/>

## **IPSEA: Independent Panel for Special Education Advice**

Registered charity providing advice on LEA's legal duties towards children with special educational needs.

Advice line: 0800 018 4016 or 01394 382814

General enquiries: 01394 380518

## **Specialist Autism Services**

Works exclusively for and with adults (18+) on the autism spectrum and their families since 1999. A non-profit organisation that works with the charity Sacar to provide autism specific services across the Yorkshire region.

They provide a range of services including group social skills workshops (through an autism-specific learning programme), information and guidance, autism-specific counselling, employment support, autism awareness training and community outreach support. Under the name Autism First they also provide bespoke support for adults with autism and additional needs.

<https://www.specialistautismservices.org/>

## **Appendix 3 – PMG statement on Right to Choose and Shared Care**

Priory Medical Group statement reflecting their position regarding Right to Choose and Shared Care arrangements:

<https://www.priorymedical.com/latest-news/updated-private-shared-care-policy/>

### **Private shared care agreements**

#### **ADHD in adults**

We have been reviewing PMG's guidance around adult ADHD and shared care with the multiple providers that we get these requests from. Having discussed with other local practices and the local LMC over the last few months we have published an updated policy that will go live on 1st June 2024.

We will only agree to shared care guidance with the Retreat – the locally NHS commissioned service. To ensure safe, well-monitored and evidence based prescribing, we will not be accepting any new or requests for ongoing prescribing from any other clinics.

Any patients with shared care agreements we have already accepted will be offered a referral to the NHS medication review service via the Retreat. We will continue prescribing under shared care guidance with the Retreat or these patients can remain under their Right to choose or private provider but we won't be taking over responsibility for prescribing medication going forward.

See policy here (<https://www.priorymedical.com/seecmsfile/?id=78>) - this will be reviewed regularly.

#### **ADHD in children**

Similarly, we will not be taking on any shared care agreements from Right to Choose or private providers for children with ADHD. We will take over

shared care agreements with the locally commissioned NHS service via TEWV (Orca House is their community base for children and young people's services. It is also known as York CAMHS).

## **Gender Identity Disorder**

PMG will not take on any new requests for shared care agreements (SCA) for GID medications. As a local system, we have raised concerns about patient safety in the absence of a funded, formal shared care agreement process with NHSE, as unmonitored hormone prescribing can cause serious complications to a patient's health.

Patients already prescribed hormone therapy by PMG will continue to be reviewed, but should complications or concerns arise- the medication may need to be stopped or reduced and re-referral back to the Leeds Specialist Clinic- as there is no current SCA support for prescribers.

Unfortunately we are unable to continue prescribing for patients that newly register with us, even if stable and prescribed by your previous practice. We ask that you approach your private provider or NHS GID clinic for ongoing prescriptions.

## **Appendix 4 – Views from an independent social worker supporting parents with EHCPs**

LAs rarely deliver anything in timescales – this leaves parents frustrated and children without the support they are entitled to.

Despite being the responsibility of the authority, LAs do not have oversight of the 'contracted out' EHCP review – they rely on schools who 'convene' reviews to do **everything** accurately and in time (schools do not). Where reviews are convened by schools, there is no LA oversight regarding whether they are in timescales. Schools delay and delay because of workload and availability of invitees.

Example – the school will convene the meeting later than the review date. They may fail to consult with health and care, so an incomplete review is conducted. They complete the review paperwork late and the LA compounds this by accepting poor evidence or a poorly constructed plan on the basis that 'if the school didn't consult, it must not have been relevant' and 'if it's a bad plan, it's the school's responsibility'. The LAs show no professional curiosity. The system relies on parents and/or a good advocate to say what's missing and what's going wrong.

### **Parents often do not know they can use an advocate.**

Transfers in and out from neighbouring areas continue to be a problem (e.g. York to wider North Yorkshire or vice versa) in respect of timescales; these do not appear to happen automatically – the systems rely on parents chasing both LA teams.

### **Issues with the quality of plans**

**The plans do not clearly articulate needs.** Often there are some (perhaps six) learning goals clearly articulated by schools, but they fail to encapsulate the wider support needed – an example might be a wheelchair using young person has support for writing using a tablet/writing aid, but no consideration for how the young person is going



to get from one classroom to another, access the toilet, change themselves etc.

**There appears to be little oversight** in terms of how realistic the aims of the plan are, or how appropriate. Example - I have seen a plan where the main aim was for 'correctly formed cursive script'.

**Needs are generally identified in relation to 'education provision'** - which schools see narrowly as the learning targets, not broader support required.

**There is a consistent failure to address the isolating nature of SEND** and plans do not routinely reflect the support needs around this. Support for forming friendships, interacting with peers, or taking any part in social exchanges is limited or missing.

**Child's needs not being met.** There is an inconsistency around how it is appropriate to support/respond to a young person where their behaviour is 'unwelcome' - stimming etc.

**Support around a young person's coping strategies is a need, but mostly not articulated** as such as it does not sit anywhere obvious in the plan paperwork.

**Language used** - parents who have fought very hard for a plan may prefer diagnostic labels to be used - e.g. autistic - there seems to have been a shift toward phrases like "neurodivergent traits" - parents should be asked how their child's condition/diagnosis/issue should be described (the young person should be asked where possible).

Phrases like 'what am I going to do or learn to meet my outcomes' is a weird shift of responsibility to the young person. How about 'what is the school hoping to teach this young person, how does the school hope to do that' and 'how will success be measured'? There should be some sense of why these things are the most important (who decided them and why - parent involvement in this part is usually entirely absent - I go back to my

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earlier example of a school thinking the most important goal for a young person was to write in cursive script!). The young person has no accountability here – how can they have? The school is accountable (as is the LA) – so why is it all "what am I going to...."

**Layout** – LAs have their own interpretations of the layout of an EHCP plan – these are confusing and make transfer difficult. The logic of the layout is unclear – EHCPs often have a need, an aim and then support. Such a formulaic approach is oddly constructed and excludes the broader picture.

**The rules around updating the plan are bizarre – outdated data is struck through rather than deleting.** It makes people involved reluctant to make changes because 'it looks messy' – it dissuades change and **the idea of the plan should be that it is responsive, a living document.**

I would love to see big changes every year – young people do change a lot in a year, but I often see tiny variations on a theme, so no forward progress. In fact, EHCPs fail to be forward looking – they read as what's happening now, rather than what do we want to happen in the coming year.

**Schools are acting as gatekeeper to an EHCP** – parents are frequently given the impression that educational psychologist input is required prior to requesting an assessment. This is not the case. An advice leaflet for parents would be helpful – setting out their rights and each agency's responsibilities.

**Nobody is on top of health** – health input is rarely received and the NHS does not follow the agreement (they do not have a list of young people with review dates, they routinely fail to contribute anything and the reason for this is unclear). Health advice is often missing from plans.

**Rushed reviews** – reviewing a plan is a big job, it should take time, it should not be rushed, it should not be seen as a paperwork exercise. This is the

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document that steers a young person's year ahead and it should have sufficient detail for all to have insight into that young person's journey through education, health and care.

## **Appendix 5 – Healthwatch York issues log entries**

### **Issues logged between July and September 2024**

Person's son (8) has been on the autism assessment list for four years. They have been told it will be another 12 months before their son gets an assessment. The person has just been diagnosed with ADHD themselves and they have been waiting for 18 years for that diagnosis.

Person has been waiting for years for an ADHD assessment and diagnosis. She is also worried about her son but has been told he is too young to have an assessment despite signs and behaviour issues.

Man has a number of mental health conditions and ADHD (and their sons, age 13 and 9 also have ADHD). He was assessed and diagnosed privately and has been paying for medication. He was told he wasn't eligible for support via the NHS for either himself or his children. He is having problems affording the medication so has stopped taking his medication but it has left him suicidal to the extent that he has attempted suicide twice in the past few months. When he approached the hospital in crisis, they turned him away, but the crisis team helped. He has tried his GP practice but he has been told there is a ban on GPs talking to people about condition controlled medication and that there is a two year wait for a medication review via The Retreat. The crisis team told him that York is a bad area regarding ADHD medication and doctors can't talk to you about it – you need to go to the Tuke Centre but there is a five year waiting list for an assessment. He is finding it all very scary and doesn't know where to turn. He is thinking of registering with a GP in Harrogate as he has a friend there who is getting medication.

Person's great niece is autistic. They are struggling at school and their father (single parent) isn't sure where to turn for help.

Person is struggling with a child who can't sleep. She said that her daughter aged 13 had struggled to sleep. Her daughter is autistic and has help from CAMHS. She had been on a waiting list since March and has now been told there is no sleep service in York. She also said that the transition to adulthood with mental health services and sleep support is a nightmare. She has three children who are all autistic and who all have issues with sleep. Her eldest child was prescribed melatonin which really helped. But when he reached 18, he was told that they don't prescribe melatonin for adults, was given a three day supply and that was it. It took him 2 - 3 hours to relax and so he started self-medicating with alcohol. This later led to him having to seek help for addiction. The person's second child was also prescribed melatonin and is still receiving it even though she is 18. But when the person asked about melatonin for her 13 year old, she was told no. The child's lack of sleep is significantly affecting her, her schooling and the rest of the family. "It is absolutely awful and there is no help."

### **Issues logged between April and June 2024**

Person's daughter is 15 and has complex issues including mental health issues and she is autistic. The problems have been building for a long time and they are in touch with CAMHS. It was clear she was going to need a hospital admission for the past four months, but nothing was put in place. Now she has been sectioned. She is in York Hospital on a children's ward with young children as there is no appropriate mental health bed available. "All the healthcare professionals say there is nothing they can do to help as my daughter is not in the right place and she isn't." Mother said: 'I am

astonished that TEWV only started looking for a bed for her when she was sectioned even they knew this was going to happen for months'.

Very poor support from TEWV and school

Person's son is now out of school. He is neurodiverse and has severe anxiety. The school has not been helpful and neither has TEWV. The person is trying to find other support to help their son and them.

### **Issues logged between January and March 2024**

Assessment has taken a year

Person shared their experience of trying to access help through Orca House "They have not helped, they haven't contacted the school, absolutely shocking service."

Still waiting for a CAMHS assessment

My child has been waiting for a CAMHS assessment since 2021. In April 2023 we were told his file had been lost. Three weeks later I was told it had been found, but we are still waiting to be seen as my child's mental health spirals and no one will confirm we're at the appropriate place in the queue (i.e. joined 2021, not when the file was rediscovered) or how much longer we will have to wait.

Lack of mental health care for child

My child (13) has had EBSA (Emotionally Based Schools Avoidance) for more than five years now. We eventually got them autism and ADHD diagnoses at ages nine and 11 (I had been trying to get these since kindergarten). They were prescribed ADHD meds but couldn't take them as they can't take pills. They began showing trauma symptoms after a toxic friendship, but we were unable to get help from CAMHS and paid for private therapy, without a diagnosis because we could not afford both. They have been displaying escalating anxiety symptoms for more than six years, in the last two years including panic attacks and dissociation. They are further damaged by the

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evidence that nobody outside the family cares. We finally got some support last year, but the Face Your Fears intervention did not give them any tools that I had not already taught them. Now they are displaying symptoms of depression as well. They have desperately low self-esteem and despite a move to a specialist school which does not pressure them, and which they cope with if we can get them in, we are still failing to get them there three days out of four. This isn't surprising as they struggle to get to their hobbies too, often failing or arriving for the last five minutes. Their sleep has been severely disrupted for five years. We feel very alone. My spouse and I are struggling to care for them and work. We feel they desperately need to see a child psychiatrist, but this is not on offer and I don't even know how to find one. Does Right to Choose exist for CAMHS? Are there even any private ones? We can't find out. I am extremely worried about the things they are saying about themselves, their self-esteem is nothing. But they are not - that we know of - self harming, so there's no support. I can't bear to see how bad they are and it's not enough?! The GP is currently monitoring their weight but wouldn't refer them back to CAMHS "because nothing would happen".

How do I access autism support for daughter?

I hope you might be able to advise on a route for diagnosing autism in the case of a child. It's my daughter, she is 13 years old. Few weeks ago I read a post on a Facebook - a lady shared her experience with her autistic daughter and I've realised that it looks very much like us. (I've remembered several people mentioning before that it might be the case with my daughter, including our GP. But then I didn't want to accept this possibility. Also I was so busy with survival, no room for dealing with that.) But now, as I realised that it can lead to some serious issues, I've decided to learn what it is about and learn how to better support, organise and live our lives so that it is safe and bearable for my daughter. At times it is not, unfortunately, for her.



Would you please be able to direct me? Perhaps there are some communities, some organisations, etc. providing some special advice and support with such cases?

### **Issues logged between October and December 2023**

Short breaks and need for a diagnosis

Early help short breaks. I applied for short breaks for my daughter in the summer. At that time it allowed you to apply without the child needing to have a diagnosis. We never got anywhere as a couple of months later they announced they were closing the scheme, and would then relaunch and everyone would have to reapply. The new form was launched this week. However, the first page says we need to provide the diagnosis, date of diagnosis and by who. My daughter does not have a diagnosis. Interestingly I have been told this year by TEWV for myself that they don't find diagnosis helpful, it's about meeting the need, and by CAMHS 'What do I think a diagnosis will do for her anyway!' She has a My Support Plan and receives Disability Living Allowance (DLA), but according to Short Breaks she isn't eligible for support. This really feels like we are not being believed!

Shortage of ADHD medication is having a significant impact on mental health and ability to act as a young carer.

M cares for mum whose wellbeing and capacity fluctuates, impacting her ability to consistently advocate for M's needs. M has a diagnosis for ADHD which requires medication in order to help him regulate his emotions and sleeping patterns. It is essential that M is prescribed a specific ADHD medication due to a known health condition. Due to the challenges around the supply of ADHD medication currently, M's mum is having to contact different pharmacies and travel across York in taxis to try and source this – this is a challenge due to her own support needs and also a financial challenge. M is also currently trying to access a diagnosis for autism with CAMHS – M's mum is

struggling with this process, made worse as CAMHS seem to have lost the paperwork on two different occasions. M is struggling to stay in school due to his ADHD not being managed and the impact this has on his sleep and wellbeing. Although it's been highlighted that M has other possible diagnoses, these are not currently being addressed. M is also navigating the challenges of growing up and supporting his mum. As a result M feels very isolated from his peers; he feels different to other people his age and finds it hard to maintain friendships. M has been missing from home on occasions, finds it impossible to engage with mainstream school and has been in mental health crisis resulting in police interventions. When asked, M states that his top priority is getting help with his sleep and regulation. He feels this will be made possible by securing a consistent supply of ADHD medication. He's been referred to Early Help for Targeted Intervention and a crisis meeting has been held with CAMHS.

## **Appendix 6 – Supporting statement from a family carer**

My name is Pauline Rogers, 85 years of age and the mother of Alison, who has moderate learning disabilities and who was diagnosed in her 40's with autism. Alison is now 60 years old. I am delighted to have been asked to support Vanessa and her whole family in their inspired quest to provide meaningful services for those unable to access existing provision as a consequence of their individual difficulties.

In around 2010 after having been involved with various groups in York, actively working towards improving the lives of people with learning disabilities and their families, I had become frustrated and demoralised by the bureaucratic process which involved meeting after meeting with much being said, but with little real improvements in families lives. I set up a group of 7 mothers of children of various ages who had different learning disabilities. I wanted to find a new approach to getting the voice of family carers heard.

We started writing about our lives and eventually self-published our book, in 2015 which we called "Uncut Cords", a reference to our feelings of always being connected to our child. I still believe that sharing our lived experiences with the general public and all those working in the learning disability field is vital to get carers issues and rights at the top of the governments agenda to achieve a better quality of life for all carers and their families.

In the final chapter of the book entitled "Hopes and fears for the future" I say "Alison's life now is better than I could have dreamed it could be, but that is in spite of the social care system in this country, not because of it. It has been the culmination of a great deal of determination and effort by the people who care about her and is testament to their commitment to ensure that Alison is as happy, secure and independent as it is possible for her to be. Many of the obstacles we had to overcome were products of the social care system – the fact that she had to live in so many different places, often with people she didn't get on with, the fact that her autism wasn't diagnosed until she was in her 40's, the fact that family carers get

so little support that many of us crack under the strain, unable to cope any longer with the stress of trying to do our best for our son's or daughters. This has to change. At the age of 85, despite my best efforts to let go, I am still very involved in my daughters life, as current support agencies are limited by the budgets that the Council provides and are unable to provide the level of care and support she needs. She has been deemed to have 'capacity' in most areas of her life. This is plainly not the case. In terms of 'capacity' to manage her financial affairs, she does not understand very much about money, consequently she pays for purchases with notes as she is unable to count out the required coins. Cheques she sees as bits of paper. I have only recently discovered that no-one has an overall view of her finances, including things like checking what her utility and insurance companies are charging.

My wider vision is for a completely different approach, a kinder, more compassionate system, which actually supports the whole family, instead of constantly creating barriers and difficulties.

I have been greatly saddened after talking to current family carers of young people to find that little has changed in their lives. Getting the right sort of support for their children is still fraught with difficulties. I cannot understand why the social care system fails to care and support our families.

The huge amount of thought, planning and physical work already carried out by Vanessa and her family at The Land project is truly awe-inspiring and could result in many young people who cannot access the provision available to them, receiving the sort of input that will change their lives. It is the most exciting and innovative project with new views of the future for these children, which is so badly needed in York and I fervently hope the City of York will support it wholeheartedly.



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