

**A No Wrong Door
Approach to
Neurodiversity:**
a Book of
Experiences



Contents

- 4 Foreword by the Children’s Commissioner for Wales**
- 5 Background to this work**
- 8 Neurodiversity and Welsh Government policy**
- 9 An insight into families’ experiences**
- 14 Face to Face sessions**
- 22 Promising Practice**
- 23 A professional’s perspective**
by Dr Mair Edwards, Clinical Psychologist
- 24 Next steps and what families would like to see**

Terms we use

Throughout the Book of Experiences we will mention lots of different organisations and experiences. Some of the words may be tricky, so we've created a list of tricky words here for you to check your understanding.

Regional Partnership Boards (we might say RPBs)	The Boards work to find out what the needs of the people in their region are, and to bring health, social services, education and other services together to meet their needs.
Children's Commissioner for Wales	Rocio Cifuentes is the Children's Commissioner for Wales. Rocio's job is to make sure all children and young people in Wales get their children's rights.
United Nations Convention on the Rights of the Child (UNCRC). We will also say Children's Rights	The UNCRC is a list of rights all children and young people have. Children's rights are the things children and young people need to grow up feeling happy, healthy and safe.
No Wrong Door	The approach the Children's Commissioner has called for: for children and young people to get the help they need wherever they ask for it – so they aren't told they've knocked on the 'wrong door' and won't get the help they need.
NEST/NYTH Framework	NEST stands for Nurturing; Empowering; Safe; Trusted. NYTH = rhoi Nerth; Ymddiried; Tyfu'n ddiogel; Hybu. NEST / NYTH is the name of a plan for every region of Wales to create a wraparound support system for children and young people's mental health and wellbeing. It aims to make expertise and advice quicker to access, and to support adults supporting children to have the tools they need to help.
Neurodiversity and neurodivergence	When we talk about neurodiversity, we are recognising that we all have different ways of thinking and feeling, and that our brains work differently from each other. Neurodivergence means that the brain works in ways that are different from what are considered 'typical'. This could be because of what we might call a neurodevelopmental condition, a learning disability, or it could be because of the effects of physical differences, such as an acquired brain injury.
Neurodevelopmental conditions	Neurodevelopmental conditions are a group of conditions which can be described by the way in which the brain develops. This includes lots of different conditions, but some examples are Autism Spectrum Disorder, Dyslexia, Dyspraxia, Attention Deficit Hyperactivity Disorder, or Tourette's and tics.

Foreword by the Children's Commissioner for Wales

The lack of support for neurodivergent children and their families is something that has long been a concern for my office and my predecessor, and has been highlighted to me frequently by families and professionals alike since I started as Children's Commissioner for Wales.



The waiting times for assessment for a neurodevelopmental condition are extremely long, and too often children and young people are offered little or no meaningful support while waiting for a diagnosis. Even achieving a referral, as the below case studies demonstrate, can take months and even years of a child's life. This is not a needs-led approach. A child presenting in distress; refusing to go to school; displaying extreme and harmful behaviours; quite clearly needs more than a stern response from their school, or being told 'sorry, there is no one to help'. They need a No Wrong Door response – which pulls services together to meet a child's need, not expecting a child and their family to navigate a complex and lengthy system featuring various different agencies.

This book of experiences aims to bring to life the challenges faced by children and their families who are simply trying to reach out for help and access their rights. We must do better. I hope that these examples assist Welsh Government and service providers in modelling new approaches to neurodevelopmental services to bring about the transformation so desperately needed.

Background to this work

The *No Wrong Door* project first came about because of a notable pattern in casework coming to our Investigations and Advice team. We were seeing too many examples of children and families who were looking for support for a range of needs who found that they were having to navigate a very complex system.

Some may have ‘fallen through the gaps’ where there are no services to meet their needs, or were on a waiting list for a long time only to be told that they were waiting in the wrong queue, or had been knocking on the ‘wrong door’ all along.

Unfortunately, this is still the situation for far too many.

These conversations and concerns led us to undertake a major piece of work which culminated in a report, published in June 2020, about support for children with mental health, emotional wellbeing and behavioural needs, and how services could work better together to support these children. The report was called **No Wrong Door – bringing services together to meet children’s needs**.

To inform the report, the Commissioner and her team visited every Regional Partnership Board (whose job it is to bring services together) in Wales in 2019/20, to ask them what they were doing to meet children’s needs.

The report made a series of recommendations to Regional Partnership Boards (RPBs), and to Welsh Government.

Some of the key findings were that:

- Far too often, children who need support are on a waiting list for one service, only to be told when they get there that they were waiting in the wrong queue all along and are told to wait in another queue. All the while, they are not getting the help they need. For some children this process happens multiple times before they receive any support at all.
- Children with complex health and social care needs who need residential care are too often sent many miles away from home to placements, which don’t necessarily meet their needs.
- There was not enough focus on children’s issues generally, from most regions. They had tended to concentrate on services for adults.
- There were some good examples of work to try to address these issues, which we highlighted in our report, but every region still had lots of work to do.



We then attended virtual meetings of every Regional Partnership Boards in Wales during 2021, to find out how each were doing. A detailed report of our findings and recommendations can be found here.

Some of the things we found were that:

- Every RPB has a plan for children’s provision, and has begun to make changes towards a No Wrong Door approach.
- Every RPB now has a group dedicated to children’s issues, which reports to the main Board.
- There are some really encouraging examples of taking a No Wrong Door approach which include:
 - Several Boards have improved how children’s mental health professionals support and train up other professionals in places like schools and social care.
 - Most Boards have plans to create new places to stay overnight or for a few days if they need it, for children and young people with complex needs, or who are experiencing a mental health crisis. These will help to avoid children being admitted to hospital, or being placed many miles away from home, when this is not necessary or in their best interests. Some of these plans are advanced and the new provision was due to start in 2022.
 - In several regions, children’s mental health crisis teams have extended their operations. In some areas this means they will operate 24/7, which is very welcome, especially given the current difficulties around recruitment of NHS staff.
- Most Boards have, or will soon have, new systems for supporting children with Learning Disabilities who are making the transition from children’s to adult services.
- Most Boards have plans for new therapeutic accommodation for young people with complex mental health and social care needs who often have to move a long way from home to be looked after currently. Their start-up costs receive direct funding from Welsh Government and some will open in 2022. At the time of writing, many of these plans have unfortunately been delayed. We recommend in our 2021/22 Annual Report that Welsh Government ensures that the new accommodation across Wales is operational by the end of 2022/23.
- Some Boards could tell us how they themselves have worked directly with children and young people, and how they have made information about services more accessible. One Board has a shadow RPB made up of young people, for example.
- We are pleased with the development of the new NEST / NYTH framework, designed to support RPBs to deliver a ‘whole system approach’ meaning that children and young people get the right support from the right people, first time. The NEST/NYTH framework includes No Wrong Door as one of its key principles. Boards have engaged positively with the new NEST / NYTH framework and all have a plan to work within this framework.



However, one of our conclusions was that while some had made progress, no region had yet done enough for the needs of neurodivergent children and young people. We were still hearing stories regularly of children who could access little or no support at all; or who were on waiting lists for an assessment for a neurodevelopmental disorder for years with little meaningful support being offered to them while they wait.

Some of the key barriers we identified were that:

- Waiting times for an assessment for a neurodevelopmental condition (for children with suspected Autism, ADHD and other similar conditions) are extremely long, and in the meantime children and their families can receive very little if any support. There are some good plans being developed at a national level on this, but in the meantime plans for improving support within the regions are patchy.
- When children may have both a neurodevelopmental condition and poor mental health they often receive a very disjointed service, despite this co-diagnosis being very common.

We made the following recommendation to Welsh Government:

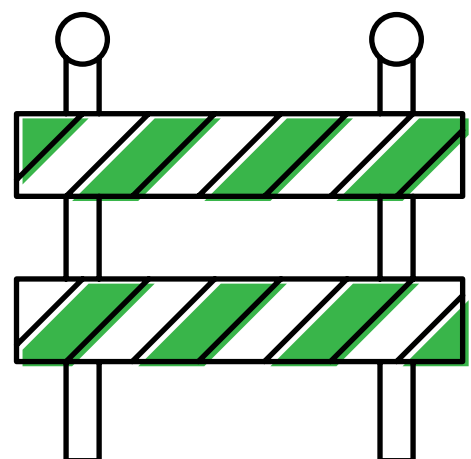
- Support and deliver the joined up approach to neurodevelopmental services which recognises the full spectrum of neurodiversity, as developed by the Together for Children and Young People Programme.

This means creating a system of support for neurodivergent children and young people which is based on need, not just whether they have a diagnosis of a neurodevelopmental condition. This is the vision set out by the NEST / NYTH Framework.

Welsh Government responded to our recommendation by saying:

To support joined up working across government, in 2021 the Welsh Government established an integrated team across health and social care, with close links to other departments such as education. We are expanding policy development to reflect the span of neurodiversity, building on the progress we have made in autism services. A demand and capacity review of all neurodevelopmental services has been undertaken and we are currently considering the recommendations made to improve support. We want to ensure that services are collaborative, person centred and support the NEST/NYTH model and the No Wrong Door approach. The review report will be published this summer.

We decided that, to inform the work of Welsh Government and Regional Partnership Boards and highlight the urgency for change, we would compile this Book of Experiences to demonstrate real life stories for children and their families struggling while seeking support and/ or awaiting an assessment.



Neurodiversity and Welsh Government policy

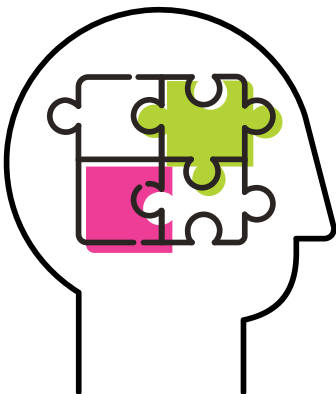
The Together for Children and Young People Programme was set up in 2015 as an NHS Improvement Programme designed to try to address children's mental wellbeing and mental health services. In 2019, work to improve neurodevelopmental services was included as a key work stream for the final two years of the Programme. The Programme called for a 'culture shift' in how neurodevelopmental services are delivered.

As the work of the Together for Children and Young People Programme came to an end in summer 2022, Welsh Government Deputy Minister for Social Services Julie Morgan announced additional funding to create a 'national improvement programme for neurodevelopmental conditions to 2025'. As well as Autism, the improvement programme aims to include further support for people with 'other neurodevelopmental conditions, such as ADHD and Tourette's syndrome'.

The reform programme will have three main work streams – the first taking immediate action to provide additional support to reduce some of the here-and-now pressures on assessment services, and to quickly put in place much needed support for parents and families.

The second workstream will co-produce and test models to reform neurodevelopmental condition services so they meet identified needs and are sustainable in the long term. The third workstream will develop important cross-cutting priorities, including developing a workforce strategy, improved data collection and monitoring and making the best use of digital opportunities to support services in the future.¹

This work is welcome, and we hope that this book of experiences will provide a useful source of information to Welsh Government. However, while we welcome developments, we will be scrutinising Welsh Government to ensure that the broad definition of neurodiversity is taken properly into account and that need rather than diagnosis truly is the key consideration.



¹ Welsh Government (2022) Written Statement: Improvements in Neurodevelopmental Conditions Services. Available at: gov.wales/written-statement-improvements-neurodevelopmental-conditions-services

An insight into families' experiences

The experiences set out in this book are all cases handled via our independent Investigations and Advice service within the last two years. This service is free and confidential and is there as a source of advice and support to children, their families and professionals who feel they have nowhere else to go with their issues.

The issue of difficulties in obtaining a referral for an assessment to identify need and get a diagnosis of a neurodevelopmental condition have repeatedly been brought to the attention of this office.

Families complain to us about schools apparently refusing to refer their child into the neurodevelopmental team (henceforth NDT) pathway as the school do not feel that the presenting needs in schools warrant such a referral, or they suggest the need simply isn't severe enough to use their allocated budget to start the referral by calling in the Educational Psychologist.

For those children who are referred to the neurodevelopmental team, the waiting times for assessment for a neurodevelopmental condition are eye-watering. A Freedom of Information request published by Welsh Government covering Autism assessment waiting times as at end of February 2022 showed that there were a total of 9,014 children waiting for assessments at that point across Wales. Of these 3,331 were patients waiting over one year. We have been told of waits for several years.

We believe that support for any child and their family should be needs led rather than diagnosis led, allowing support to be tailored specifically to the individual. However, with the statutory agencies having a limited amount of resources available, the diagnosis often can be viewed as the key to accessing provision. One local authority, after agreeing that the presenting needs suggested a specialist provision was necessary stated 'we simply do not have enough resources, so we have to prioritise those children who have the diagnosis'.

Below are some case examples of real families with real issues that unfortunately are not a rare occurrences across Wales:

A School refusing to refer a child to the Neurodevelopmental Team (NDT)

The original contact:

A third sector organisation contacted us as they felt that a family they were supporting were not receiving the help that they needed with their child who was displaying challenging behaviour.

The children in the family are child A aged 3, and child B aged 10. Concerns related to child A aged 3.

An officer from the third sector organisation had visited the family home and were concerned at what they were seeing and hearing from the parent. Child A had smashed a window in the home and the family said that they felt they had become prisoners within their home, afraid to go out as they were worried about what child A might do. Child A displayed some challenging behaviour, including physical violence towards the parent and Child B. All requests to refer for an assessment had been refused by the school.

We had been told that Child A had attempted to hit the parent with a brick and had injured the parent with a sharp pencil. We were also told that Child A would kick and punch Child B regularly resulting in Child B spending all their

free time in the bedroom to keep themselves safe. An early intervention service had already been involved with the family on more than one occasion, these interventions were limited to 6 week interventions.

Our advice and actions:

Child A attended a school based nursery class. With the family's consent, we spoke with Child A's school head teacher who told us that, in their opinion, it was a parenting issue and that they were not witnessing the behaviours that the parents was stating were happening outside of school within the school setting. The headteacher did however acknowledge there were issues when the parent was dropping the child off in the morning. The headteacher believed this was happening at the start of the school day because the child was experiencing separation anxiety. As a result of the headteacher not seeing evidence of the home behaviour in nursery, they were not prepared to call in the educational psychologist or make a referral into the authority's neurodevelopmental team (NDT team).

We called the relevant NDT team and established that the parent could self-refer their child for an initial appointment and assessment, but would need supporting evidence for the referral to be triaged appropriately.

The parent did make a self-referral and, as a result, Child A's needs have been assessed as meeting the criteria to be on the NDT pathway waiting list for an assessment. This is just the first rung on the ladder; this does not in itself lead to the offer of any particular support or advice. Child A's parent has been referred to a Local Authority project for support and Child B's school are supporting them as a young carer and providing them with the relevant support.

What this experience is telling us:

This appears to be an example of a school gatekeeping and making decisions on who does and doesn't get supported for a referral onto the NDT pathway. Without advice and intervention from our office, this family would not have known that they could make a self-referral; this is notable as the referral they went on to make was accepted.

B Unable to access specialist educational placements without a diagnosis

The original contact:

A parent called us as their child, aged 14, was on the NDT assessment pathway, but they were being told that their assessment could not be completed due to staff shortages. We were told that the child was on a significantly reduced timetable in school as they were not coping with the surroundings. The school told us they were doing all they could to try and support the child, spending sometimes 45 minutes coaxing the child out of the car and into the school, trying different entrances, which were quieter, and having the parent drive around the school a few times before trying to persuade the child to go in. It was becoming increasingly difficult with the child refusing to speak. We were told that the child's anxiety levels had increased but the

school continued to work at a pace the child could manage. This however meant that this child was falling further and further behind his peer group academically as he was accessing less and less education. The parent had asked us about the possibility of their child accessing a specialist provision.

Our advice and actions:

We contacted the Local Health Board and established that there had been a delay completing this child's assessment for Autism Spectrum Disorder (ASD) as there had been a shortage of staff but that they were expecting a new member of staff to begin in post imminently. We raised the importance of clear consistent information to families to reduce added anxieties and pressures.

We also contacted the local authority as this child was clearly missing out on a large amount of their schooling and asked about the possibility of identifying a specialist provision. The Education Department within the authority confirmed that they were aware of this child and their presenting needs. They did however confirm that in order to access a specialist education provision children must have a diagnosis, irrespective of their presenting needs.

What this experience is telling us:

This is a scenario that we have noted throughout Wales, where professionals within one department acknowledge a child's needs but are unable to put specialist provision in place without an official assessment of the child by another department/health board culminating in a diagnosis of a condition. This means that the process continues to be diagnosis-led and not needs-led.

C Local Authority not accepting a private diagnosis of Autism Spectrum Disorder (ASD)

The original contact:

A foster carer contacted us as there was a significant risk of the placement for a child, aged 11, breaking down. We were told that the child, who already had a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD), was showing what they believed to be signs of Autism Spectrum Disorder (ASD). We were told that the child appeared to be high functioning in primary school. The child was moved from one primary school to another in the hope of better support. However even though there was a suggestion from the new primary school that this child may have ASD no referral to the Neurodevelopmental Team (NDT) nor the Special Needs Educational team within the local authority was made. The child was given access to the existing classroom teaching assistant for support.

On entering secondary school, the school made an immediate referral to the relevant Neurodevelopmental Team (NDT). At the time of contacting us, the child had been on the waiting list for an assessment for 10 months, with the expectation that they would remain on the waiting list for at least another 18 months.

The foster carer told us that they had offered to pay for the child to be seen and assessed privately, so that it could be clarified sooner rather than later whether or not this child would be diagnosed with ASD and may have benefitted from specific support or a specific type of educational placement. The education

department told the foster carer that they do not accept or recognise a private assessment and diagnosis.

Whilst waiting for the assessment to take place, the school continued to support this child with the resources they had, while avoiding exclusionary practices for the behaviour on display.

What this experience is telling us:

Delays in referral to and completion of the assessment process have led to a vulnerable child being left, potentially, in an even more vulnerable position with unmet needs and a foster placement breakdown.

There appears to be a focus on assessment for one potential diagnosis (in this case ADHD), when there is a need for assessment for another condition (in this case ASD). Unless a dual assessment is requested, one assessment will go ahead while assessment for another condition will not be considered until that original process has completed.

Until recent changes in legislation (ALNET Act), agencies have refused to accept private assessments.

While the foster carer was calling for specific support, this would have to be taken forward by the child's social worker as local authority have corporat parent responsibility.

D No-one accepting responsibility for referral to NDT

The original contact:

The parent of a 16 year old child made contact seeking advice on accessing a referral to the NDT.

Advice was given to the parent by a Child and Adolescent Mental Health Service (CAMHS) practitioner to make a formal complaint to the school as they felt the school should have referred the child to the relevant Neurodevelopmental Team (NDT) a 'long time ago'. CAMHS told the parent it was evident the child has ASD and it was for the school not CAMHS to make the referral.

The parent had been told by the school that in order to make a referral to the NDT, the child would need to be seen by the Educational Psychologist first and they did not have the money to buy in any Educational Psychology time for this child.

The parent asked the GP to make a referral to the NDT pathway for assessment, but the GP told the parent that they couldn't make the referral, the school had to make it.

Our advice and actions:

We spoke to the local authority's Education department who advised that this child had gone to their inclusion panel for support in school but the school had been tasked with getting an Educational Psychologist assessment first. We understand that in fact this never happened. The local authority inclusion team did not pursue this.

We spoke to the relevant NDT service and it was confirmed that the parent could self-refer their child, however they would need supporting evidence for the referral to be accepted.

We also spoke to social services as this child's name was on the child protection register, to ensure that the parent and young person would be supported to access relevant assessments/support.

NDT confirmed that they had received the referral from the parent and the young person was now on the triage waiting list to see if they were to be placed on the assessment waiting list.

What this experience is telling us:

Families tell us how frustrating they find it when a CAMHS consultant informs them that in their professional opinion the child has a Neuro Developmental condition. Rather than make a diagnosis or make a referral to the relevant NDT themselves, families are told to go back to their school or GP and seek a referral for an assessment through the NDT. Our casework tells us that GP's may not know enough about the child to make a full referral, resulting in further delays, and schools often tell us that they have used up their educational psychologist allotted time for the academic year. Due to shortage of resource, schools are notifying us that they are referring those children that are having the most 'disruptive' effect on their peers to the Educational Psychologist. In some cases this results in some children never getting a referral to the Educational Psychologist until they change schools.

E Lack of access to support for Welsh speakers

A parent contacted us, whose child is a pupil in a Welsh medium school. The family uses Welsh as their first language. They explained that they had asked the school to make a referral into the NDT assessment process. The parent told us that the school responded to the parent stating that as their child was from a Welsh speaking background they were not seen as the priority for this type of referral. The parent told us that the children from English speaking homes were being given priority. The school informed the parent that the school has limited access to Educational Psychology time and unfortunately were having to prioritise which children were being put forward.

Our advice and actions:

We advised the parent on how to make a formal complaint. This parent felt able to take forward the complaint themselves.

What this experience is telling us:

Children have a human right under article 30 of the UNCRC to use their language of choice. Welsh public bodies are under a duty to provide services through the medium of Welsh under the Welsh Language (Wales) Measure 2011. This experience tells us that children may have an additional barrier to accessing support if their first language is Welsh.

Face to Face sessions

We felt that it was important to meet with young people and their families to hear directly from them. Families were able to share their experiences and the impact these experiences had on them. They also shared what they thought would be helpful for families in the same situation as them. Here are their stories:

C's story

C is 4 years old. He's still not toilet trained. School refuse to change him and will phone mum to come in to change him. Mum works 40 minutes away and so by the time mum would arrive at school, C would still be sitting in class soiled. This was a daily occurrence. Mum was told by the school that if C had a diagnosis for a neurodevelopmental condition, then school would change him. Mum has given up work. Mum is now a full time carer for C.

Mum said: *"I'm not doing this to label him. I just want to know how to make him happy. One piece of paper will change it all; people will see him from a different view. He won't just be the naughty child, they will think this is happening because of something else."*

This is C's story >

6 mths

6 months old: C would violently head-butt the floor and cot. Mum said: *"He would freak out if I wasn't in the room and was clingy and didn't like visitors to the house."* Mum went to their Health Visitor for advice and help and was told C would only do the things he did for attention.

> No support offered.

18 mths

18 months old: C was still clingy and now physically hurting mum. He would refuse to get in and out of the car so they couldn't go anywhere. C would refuse to eat and throw food. Mum self-referred to a Team Around the Family support service, who supported with a play specialist, nursery support and parent support. Mum thought: *"[Team Around the Family] were good but the help I wanted was to focus on C not me. I wanted to know how I could help him but I also wanted to know why he was doing the things he was doing."*

> No additional support or alternative provision offered.

2 years

2 years old: C walked for the first time and started nursery. It took 5 members of staff to change his nappy; he would bite and kick others but mum was told that C was just a 'hard child; it's just him, he's young and he'll grow out of it'.

> No additional support or alternative provision offered.

2.5 years

2.5 years old: C was pulling mum's hair and gave her a black eye. Team Around the Family visited the family and identified an attachment issue. Mum thought: *"I think they thought it was me. All along I've thought that."*

> No referral for further support

3 years

3 years old: C started school where he displayed same behaviour as he did at nursery. School told mum that 'he's volatile and you have to be harder on him'; 'he's headstrong and stubborn'.

Our office was told by the head teacher that the issue was mum's parenting and ability to deal with C's behaviour they stated they thought he had separation anxiety. Head teacher didn't believe his behaviour warranted a referral.

Mum self-referred to social services because she felt this was her only option because she was on the edge of a breakdown. Mum waited for contact from social services. No contact was made until mum phoned. They had closed the case without speaking to mum. Mum asked for the case to be re-opened, which resulted in an assessment of need being undertaken by Social Services. A care and support package was suggested.

Meeting took place with everyone involved in C's life. Mum felt the school deflected the situation and C's behaviours back onto mum. Health visitor offered the school help on how to work with C. Social services closed the case.

4 years

4 years old: C was still getting up 4 to 5 times a night. Mum made a self-referral to the NDT (2021). Mum asked school for an Additional Learning Needs (ALN) assessment.

Now

Now: As a result of the evidence provided by mum, the NDT triage team placed C on the waiting list for an assessment.

Mum has been told an assessment won't take place until November '22 – March '23 at the earliest.

No ALN assessment has been undertaken by the school.

We are told C has attacked other pupils and school staff.



E's story

E's mum is an early years professional. E's mum has compiled two lever arch files of evidence of how E has been 'bounced from service to service'.

"What about parents who aren't quite sure. I'm lucky because I've worked in education and know some of the systems. What about those who don't understand it?"

Some of the elements to E and his mum's story involve, as they see it, fighting for a diagnosis for an additional condition, we have included it in the story as it highlights the additional barriers children are facing. A health board has told us that children need to see the community paediatrician to rule out other conditions before being considered for the neurodevelopmental pathway.

Here is E and his mum's story >

10 mths

10 months old (2015): Mum asked their health visitor for a referral to a physiotherapist because E's legs and feet didn't quite look right. Mum said: **"We saw the physio who said that there was nothing wrong; they made me feel like I was mad!"**

> No support or alternative provision provided.

16 months old (2016): E was referred back to the physiotherapist because he was a tip-toe walker and didn't start walking until he was 16 months old. Physiotherapist witnessed some Autism Spectrum Disorder (ASD)-typical behaviour and suggested a referral to the community paediatrician.

Mum insisted E saw someone for his tip-toe walking, so E was referred to a trauma and orthopaedic consultant.

> No additional support or alternative provision offered.

3 years

3 years old (2017): E started nursery school.

Additional condition: E was seen by a trauma and orthopaedic consultant, and paediatric neurologist. Mum thought: **"I was spoke down to so bad; was told it was me and there was nothing wrong with him. It was all in my head apparently and all children do these things. They were so rude to me and said it was a waste of time and there was nothing wrong with E."**

Shortly after this consultation, E was observed by the ASD advisory teacher. Within their report, they stated E's different behaviours that they'd observed, including clear indications of ASD and potentially Attention Deficit Hyperactivity Disorder (ADHD). This report, which also highlighted E's strengths, was sent to the community paediatric team.

4 years

4 years old (2018): May: E's mum engaged with the paediatrician who suggested E should be placed on the waiting list and should have an Autism Diagnostic Observation Schedule (ADOS) assessment.

September: E had his ADOS assessment. E did not meet the criteria for an ASD diagnosis. There was no method for E's mum to challenge the outcome. E's mum had explained prior to assessment that because E is high functioning, he may not score on ADOS. There were no observations of E during assessment. E's mum asked whether the case could be kept open and reviewed in a year's time. E's family was told: **"No, and if you want to do that you'll need to collect the evidence and re-submit and restart the process again."**

5 years

5 years old (2019): E's mum went to discuss the situation with the family's GP. Mum felt the GP's hands were tied – they sent a lot of referrals but they kept bouncing back. GP decided to refer E to the Child and Adult Mental Health Service (CAHMS) because of E's tics. Mum said: **"It's quite scary to see tics when it's the face and eye rolls. It's quite frightening to see your child like this and you don't know what it is."**

E was seen by a primary mental health professional who observed "...irregular tics and inappropriate environmental noises, abnormal body movements amongst other things which would indicate ASD" and advised E's school to put him back on the neurodevelopmental pathway.

Mum referred E back to physiotherapist because of feet and extreme leg pain, coordination difficulties and behaviour challenges. Physiotherapist recommended a Developmental Coordination Disorder (DCD) assessment. E was referred back to trauma and orthopaedic team for further investigation.

October 2019: Additional condition: E had a DCD assessment.

At the same time E's school was supportive and gathered information for a neurodevelopmental pathway assessment.

December 2019: Additional condition: E was seen for a DCD assessment. E was discharged and offered podiatry support for insoles. They didn't want to see E again until he was a teenager.

6 years

6 years old (2020): Another test to check for an additional condition: E had an MRI scan.

March 2020: Additional condition: E's MRI scan results showed a small bleed on the brain. The neurology team didn't want to see E but referred him to a genetics team.

E was also referred to a speech and language service (SALT) to rule out a developmental language disorder before being placed back onto the neurodevelopmental pathway.

No diagnosis.

December 2020: Additional test: E had a genetics team appointment (outcome unknown). Mum was concerned about E's growing physical difficulties. E was seen by an occupational therapist at a children's centre who recommended E should have another DCD assessment.

October 2020: E was seen via a virtual platform by the SALT. The therapist who saw E then left the service. E's mum chased for an update and found out that E had been on the wrong waiting list for **62 weeks** for a follow-up appointment. E was going to be put on the correct waiting list but at the bottom of that waiting list. Mum challenged this as the results of this appointment would impact E's acceptance onto the ND Pathway.

7 years

7 years old (2021): Additional condition: E had an assessment for DCD. E was assessed as being on the 0.5 centile, meaning a very high level of need.

Mum said: **"They'd originally tried to tell me there was nothing wrong and we don't want to see him until he's a teenager (December 2019) – most parents would listen to this. They would take it as it is. Even if there was no diagnosis the first time around, why didn't they support me and the school?"**

No ND diagnosis.

DCD diagnosis – Mum felt this helped E understand his difference to peers and accept that he's good at some things and his friends are good at others. **"The diagnosis helped and opened the gates for conversations about it."**

July 2021: E's mum had a meeting with the educational psychologist for the psychologist to authorise referral to the neurodevelopmental pathway. Mum raised concerns about E's tics getting worse. Educational Psychologist felt the ND pathway was a lengthy process and E shouldn't wait that long for support with tics. They suggested E should be referred back to the GP to refer to the community paediatricians.

School submitted the referral for a joint ASD and ADHD assessment.

Referral returned due to minor errors.

August 2021: E's mum went back to the same GP to be referred to community paediatricians regarding E's tics. E's mum made contact with CAMHS about E's tics who said: **"if you get the GP to refer to us, we will accept it."** GP referred E to CAMHS. CAMHS would only see E about the tics and nothing else.

September 2021: School returned the referral to the Neurodevelopmental Team. Delayed return due to the summer holidays.

Mid-September mum rung the ND Team to see if the referral had been accepted. She had a phone call the next day for more information even though it wasn't originally requested and had been triaged. The missing information was from health professionals not mum/ education. Mum photocopied all the medical information they needed and hand delivered it to the ND Team.

Mum was informed at this point that E wouldn't be seen for a dual assessment as it wasn't clear that he had ADHD traits, even though the educational psychologist highlighted some traits. Mum was told it would be an assessment for ASD or nothing at all.

Mum accepted this as she felt it was the quickest way to get him accepted onto the ND Pathway.

E was accepted onto the pathway. Mum received a letter saying the wait time is 22 months.

8 years

8 years old (2022): E finally seen for follow up SALT appointment (from October 2020). This delayed the neurodevelopmental referral.

E had a virtual appointment with a clinical nurse from CAHMS. The nurse witnessed E's tics.

E's was no longer able to suppress his tics at school, staff found them upsetting (seeing E in pain) as they hadn't noticed them before.

E is very aware of them.

CAHMS nurse agreed E needed to be seen by the ND team urgently. She said she would try her best to support with expediting the referral.

November 2021: Additional condition: E was placed on the list to see a new neurologist. Family received a letter to say there would be a 12 month waiting list.

Now: E is still awaiting an assessment with the ND Team. Mum has concerns that it may not happen before he transitions to secondary school.

"He'll be off to comp, the diagnosis carries so much weight. I really wanted him to have it before he went to comp. His school now is great. Will a new school have the same provision? It's a massive thing going to comp and he deserves a break before he goes there. It makes me feel anxious about going through it all again. Are they going to listen to me?"

She met with the education psychologist and the school and wrote a report. School brought E forward again for discussion as **"his sense of difference is impacting on E's self-esteem and self-confidence"**.

They had concerns about the long term impact on his mental health as his 'differences' are now noticed by his peers.

They wanted to expedite the referral to the ND Team – ND Team refused.

Mum followed up with ND Team asking about their policy for expediting appointments. Mum was told that they don't have one. Mum said **"Basically they just make decisions. Basically they told me unless I was dying they wouldn't see me. They'd only see me if I was dying to get the information they needed."**



N's story

In this story you will hear thoughts from N and his mum.

2 years old: Attending Cylch Meithrin (pre-school), N started to worry about the buttons on his shirt and the texture on his shirt. He didn't sleep very well and there was some non-attendance. No issues picked up by professionals.

4/5 years old: Referral to paediatrician for his tummy issues (mum told us that, looking back, this is one common sign of a neurodevelopmental condition).

N felt the intensity of the classroom: *"It's like a lack of focus - not easy to describe, it's like losing control. My brain can't focus, can feel yourself like you are going to snap and you want to leave the classroom. I wanted to (leave) many times but I never did - this has been since the start (of school)."*

11 years old (Year 7): Started secondary school.

N thought: *"I liked the structure of moving to different classes. It's methodical and it works with my method of thinking. The lessons weren't jumbled up."* But a change happened when peers started to be disruptive: more loud noise, more shouting.

Mum thought: *"Noticed a change; after school he started melting down, flapping hands, ripping shirt off and crying and stared at the ceiling for hours. N didn't know why he felt this way - it was everything, from the noise to the texture of his uniform. There was no support to get help for ASD but instead a feeling from the school that N needed 'a good talking to'."*

7 years old: Moved primary school due to the class environment in his previous school. *"Maybe as kids get older teachers feel you can handle more (of a telling off), when you are ND [neurodiverse] that's not the case"*

10/11 years old: School was nurturing and supportive. Diagnosed with HSP (mobility issues) but not any neurodevelopmental condition. N missed the last 6 weeks of year 6 resulting in no transitional support for year 7.

Mum thought: *"Is this me; are we over-reacting?"* N said of his prolonged period away from school: *"...it nailed in the idea of staying home. Change in routine made me feel like that."*

12 years old (Year 8): N was given support in school - the best he says he'd had. N started attending the school's Pupil Referral Unit for some hours a day. N said: *"I like being with Mrs S as I believe she had my best interest in mind."*

Family self-referred to CAHMS. Mum thought: *"There was an expectation we would receive more help. But we received more blame than help."*

13 years old: Started having days off school which N said always started with feeling physically poorly and then getting used to the change and the relief of not worrying about teachers snapping at him.

Mum said: *"We saw more deterioration; the school used to phone me in work, threatening to take further action if N didn't return, Education Welfare Officer (EWO) phoning N's doctor to say 'there was nothing wrong with him', negativity with senior leads and the authority. N wasn't a school refuser, he just needed empathy and sympathy and support. I started doubting myself with no-one listening. It was hell."*

14 years old: N was referred by his GP to CAMHS. The CAMHS team lost N's medical notes. N was told to 'sit on them' if he had fidgety hands. Therapy assessments then took place and they were all brilliant.

Mum thought: *"I was worried they would take N away. Because no alternatives were offered to us, I feared the only way of helping N was to give up work."*

Pandemic: No more school; N didn't attend any online lessons and no check-ins from school.

14 years old (Year 9 & 10): Returned to school after lockdown for just 1 day.

N thought: *"I don't want to go in; I'm not going to learn anything. I had to spend the entire day in one class with teachers moving in and out. This didn't work for me as there was no break and no break meant it riled up and up and I felt I couldn't cope. This is when we decided on home education."*

15 years old: N tried online learning systems but realised that being in a school/space which was designated for learning helped him focus.

N thought: *"I was referred to the PRU who deal with school refusers. I wasn't a refuser, I was an 'unsettler' - I wasn't able to settle."*

Mum thought: *"Deregistration from school in pure desperation - since deregistration, no one wants to know."*

Now: N has been on the ND Pathway awaiting assessment. In September 2022, N received a diagnosis of Autism. N now attends college.



Promising Practice

Throughout our work with families we were also able to identify some promising practice. The practice highlighted below is designed to support children, young people and their families, some of whom are awaiting assessments.

ASD Rainbows - Mountain Ash

ASD Rainbows is a non-profit charity. They aim to provide early intervention therapies tailored to children's needs, enabling them to lead a happy inclusive life. They recognised there was a lack of suitable provision for preschool children on the autistic spectrum and aimed to fill the gap in provision.

They currently have 26 children aged 2 to 5 years attending half day sessions at their setting in Rhondda Cynon Taff.

Children attending the setting come from Rhondda Cynon Taff, Cardiff, Swansea, Neath, Port Talbot and the Vale of Glamorgan, and we were told families will often work in their cars outside the setting for 2.5 hours while their children attend the session, such is the value they place on this support.

The staff at ASD Rainbows share their knowledge and expertise with families ensuring that the support they put in place in the nursery setting can be continued at home. Staff at ASD Rainbows also support children as they transition to school, and take time to advise schools about the support they are currently providing to children and what they would suggest during the transition period.

The team at ASD Rainbows are passionate about improving the lives of children and their families and are currently using grant funding to enable them to provide this service including the specialist equipment they need.

“This is the ONLY provision specifically for ASD that my son can attend at his age”
(Parent)

Sparkle – Gwent

Sparkle's Family Liaison Service supports families who have a child/young person with a disability and/or developmental difficulty. They are a point of contact whilst waiting for an assessment and are also available to support and inform after a diagnosis. Families can access the Family Liaison Officer instantly with any query or request without having to wait, therefore families always have someone to help navigate them through.

The service offers a variety of different support, resources and signposting which is tailored to the individual family's needs. They inform on the leisure services Sparkle offer such as a youth club, family swim sessions, on site cinema and a playgroup for pre-school children. They can signpost to the Helping Hands Psychology team for parent counselling and workshops, and will assist with benefit forms and grant applications.

They co-ordinate parent/carer support groups and coffee mornings, to enable families to meet other families in a similar situation. They arrange drop-in sessions for external organisations to deliver support on a range of topics, including education and employment issues. They offer an opportunity for families to seek information from Health, Local Authority, Education, Sport and Voluntary sectors.

They research events in the local area that would be suitable for families who have a child/young person with a disability and/or developmental difficulty and form relationships with local organisations passing on information via weekly bulletins. If communication is challenging between parents and professionals, they can liaise to assist with this too.

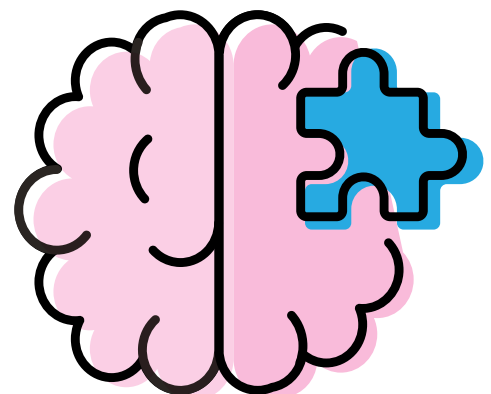
A professional's perspective

by Dr Mair Edwards, Clinical Psychologist

As a Clinical Psychologist who has worked with children and young people for over 20 years, it's very sad to note that the assessment provision for neurodiverse conditions is unacceptably poor in Wales.

Despite all the working groups, the statements about prioritising services, and the additional finance to target waiting lists (including substantial funding for private sector providers who were unable to provide a service through the medium of Welsh) it's hard to see any substantial continuing improvement. Even when a child's future is being considered in a Family Court case – where our most vulnerable and needy children have their welfare and care considered – it's impossible to secure a prompt assessment. Without complete information about the child's needs, there is no guarantee that the Care Plan and the final decisions of the Family Court will be appropriate as regards where and with whom the child should live, and what kind of care and educational, emotional and developmental provision is required. This causes me concern.

Without doubt, based on my direct experience of working with vulnerable and needy families, children and young people have suffered long term harm because of the unreasonable delay before their needs are officially recognised. How can it be acceptable for a child to wait years for an assessment of their needs when research shows clearly that appropriate support and intervention in the early years is so important? Even after diagnosis there is a shortage of suitable services to support and assist children and their families – particularly at times of transition, so that there is no further delay. It would surely be far more effective and efficient – and certainly more morally sound – to assess a child's needs as quickly as possible, so that children and their families can be supported and provided for in an appropriate manner, reducing the trauma of waiting and waiting and waiting.



Next steps and what families would like to see

In a statement by the Deputy Minister for Social Services in July 2022, it was announced there would be a new Neurodevelopmental Conditions Ministerial Advisory Group “to assist Ministers and Deputy Ministers with the direction, implementation and evaluation of neurodevelopmental conditions services”².

This Ministerial Advisory Group should aim for a truly needs-led not diagnosis-led approach for neurodivergent children. While the improvement work is likely to focus on expanding support beyond Autism to ADHD and Tourette’s, we want this to go further, to recognise that a child in distress and struggling because they are neurodivergent should have their needs met, despite not having a formal diagnosis. We will be closely scrutinising the work of the Group, and Welsh Government’s work in this area generally.

The No Wrong Door approach is still far from reality for many children and young people across Wales. We have highlighted the range of challenges families from across Wales have faced while trying to get the right support for their children and young people. These challenges stop children from enjoying their rights under the United Nations Convention on the Rights of the Child (UNCRC).

The points below were co-produced with families from across Wales. They highlight good practice that has supported families during their journey and also things families would like to see done differently. They also include our reflections of the challenges facing families.



1. No Wrong Door

Through sharing their experiences families have made it clear that the experience of being told you have come to the wrong place when looking for support, or being told there is no support available to you, is still very much the reality for lots of children and young people in Wales. Families have told us that they would like services to be able to meet the needs of their child, and if they are unable to do that to be able to refer them across to services that can help rather than sending them to the back of another queue. Families told us that having to wait at every point of access means their children are growing older without getting the appropriate support.

Links to:

Article 6 of the UNCRC – I should be supported to live and grow

2. Respectful communication

Children and young people told us that professionals should also be aware of the needs of the children and young people they are speaking to and ensure that their tone is appropriate.

Families told us they thought professionals supporting and working with children and young people should be mindful of them being in the room while they ask parents/ carers difficult questions.

They felt that when appropriate they should give children and parents the opportunity to speak separately.

² www.gov.wales/neurodivergence-ministerial-advisory-group

Links to:

Article 12 – I have the right to be listened to and taken seriously.

Article 16 – I have the right to keep some things private.

3. Welsh language

Families told us that it was important to them for their children to have access to the critical services they needed in their first language. Families also told us they would like to see this happen in a timely manner. We urge Welsh Government to ensure they include the needs of neurodivergent children and their families as part of the 5 year action plan to deliver More Than Just Words. We will also share these observations with the Welsh Language Commissioner.

Links to:

Article 30 - I have a right to speak my own language and to follow my family's way of life.

4. Transitions to secondary school

Families told us that they want better support for transitions to secondary school for children and young people without an Individual Development Plan (IDP - previously known as a Statement of Special Educational needs). The ALN Code places heavy emphasis on differentiated teaching so a child should receive the support they need without an IDP. Local authorities should work with ALNCos to ensure the duty is met under the ALN Code to support transitions to secondary school, and this should include information sharing and learning being taken from support given in primary settings where this has worked well for the family.

5. Supportive school environments

Families told us that they want the school environment to better support neurodivergent children as far as possible.

Families felt that in some instances schools can be quick to see families as 'non-attenders' or to employ disciplinary or exclusionary practices against children who would have benefited from a more understanding school environment. Plans from Welsh Government

to revise attendance and exclusions guidance are welcome. These revisions must include clear guidance for schools on supporting neurodivergent children and young people.

Links to:

Article 23 – If I have a disability, I have the right to special care and education

Article 28 – I have the right to an education

Article 29 – I have the right to an education which develops my personality, talents and mental and physical abilities to their fullest potential

6. Agencies working together

Families would like services to work together and ensure that everyone understands their role in the process and what is needed to get a child/ young person the appropriate assessment and support they need. This should be available to children and young people identified as having a need, whether they meet the criteria for an IDP or not.

7. Peer support

Families told us that they would like Local Authorities and Health Boards to review current support available locally and fund more and better advertise existing peer-to-peer support groups for families where possible.

Families told us that they would appreciate safe spaces to be able to talk about their situation without being judged on their parenting style. Families told us that services were quick to offer parenting courses to families when often they just wanted someone to listen and understand how they are feeling. Every family should have access to local support groups where they can share with and get support and advice from other families.

Links to:

Article 5 – The Government should respect the right of my family to help me know about my rights.

www.childrenscommissioner.wales

T: 01792 765600

E: post@childcomwales.org.uk



**Comisiynydd
Plant Cymru**

Children's
Commissioner
for Wales