

TO SUPPORT THE CYPE COMMITTEE
WITH THEIR LATEST INQUIRY
2023

ALN RHONDDA REPORT



A message from Buffy

Having worked in classrooms across Rhondda supporting children with Additional Learning Needs for 15 years, and from discussions I have with NASRCT who are based at my local Charity “Canolfan Pentre”, I know only too well that the current system isn’t sustainable. Through no fault of their own, parents and guardians don’t feel supported, teachers don’t feel supported, and children are being let down. Of course there are examples of families and schools that don’t recognise that picture, but this is the very clear reality for far too many. This has to change, and I’m determined to do everything in my power to change this.

I’ve always believed that to bring about change, meaningful change that is, change that inspires and makes progress, it has to be from the bottom up. It needs to come from the voices of those experiencing the system day in, day out. It needs to start in our communities, not from Government Officials with insights and stats and figures.

It’s why I decided to compile this report. I’m a member of the Children, Young People, and Education Committee in the Senedd. We’re currently in the process of gathering evidence for our inquiry titled “Do disabled children and young people have equal access to education and childcare?”. From my experience as a teacher, and as a mother, I know that the answer to this question is a resounding no. I also know from conversations with parents and teachers since becoming the Senedd member that the answer is a resounding no.

We need change across all aspects of the journey. Changes to the way needs are communicated between health visitors and schools before pupils even attend school, changes to the care received at school and the communication between schools and mental health services, changes for teachers to make it far easier to create and implement the package of care required, changes to the process of being “statemended” so families receive the support they need. Changes to make sure our children can be the best they possibly can be.

The responses received within this report will be used as evidence to help shape the recommendations produced by the Committee, I can’t thank you all enough for sharing your experiences. Your voices will be heard.

Buffy Williams

Responses from Rhondda

"The whole system has been abhorrent regarding my daughter. I am not new to Autism. My son was diagnosed.

She has been failed by speech and language and especially by school and the education system.

When covid hit, our family we're shielding (we still are). At first, the school sent work online. My daughter was the only child in the class that completed the work. A year later, they stopped all work. I started educating myself. Due to my daughter refusing to wear clothing and she was non verbal, we decided to home educate.

Before we started that journey , my daughter was offered a 'virtual' place at a special school. This was the worst mistake that we agreed to. Over the course of 10 months, the school sent out 13 pieces of work (from a possibly 40 weeks).

My daughter has a statement. The school and local authority failed her. I requested to officially home educate several times but every time it went to panel, I was told give the school another chance. I had had enough of the excuses. I wrote to the school governors (the letter was intercepted by the head).

I formally requested that my daughter be home educated. Panel came back with wanting more information. I have it. We were finally free of the incompetence of the school.

We officially began home educating. I have had one email from the EHE team who said that they would be in touch in 8 weeks time. Still waiting for that email. I'd rather not hear from them to be frank as I am fed up of the failures. My daughter deserves better.

My daughter has thrived with home education. She can now talk, wears clothing, is exceptional at maths (she knows her square numbers beyond 20x20), can spell, can read, loves baking and has a love for crafts. She is a happy, thriving little girl with no thanks to the educational system at all!"

"My son is....with autism (not diagnosed as of yet). He goes to school and only goes for 2.5hrs a day as he can't cope any longer and they don't have enough specialised staff to provide him with the help he needs. I am currently fighting to get him a place in another school with an asd unit."

"My eldest daughter 15 is only now going through diagnosis after pushing since age 3 and my youngest 10 no one will listen as she's fine in school exactly the same as I had with her sister"

"I have 3 diagnosed children took untill they were 7.8 and 9 to get theyr diagnosis. Two of my children have been on long term reductive tables for over a year while battling to get support in place and then into a unit . Taking untill my oldest son with asd was in year 9. I have not found any childcare specifically for aln . Also no support to access the community provisions such as play scheme there for excluding them. The new idp system has made the threshold of obtaining support higher and therefore more difficult for my daughter with adhd and delayed development . There is no units for adhd therefore while planning g for comprehensive it looks like she will havto struggle before any help is in place in mainstream "

"My grandson is 4 the school has said they cannot cater for his needs. My daughter had a meeting to be told there's no money available. The outcome is if there's nowhere for him to go he has to stay where he is which I find outrageous why shouldn't he have the right to education to get on in life?? (He's autistic and still in nappies)."

"I started to find out if my daughter has ASD when she was around 5yrs old (noticed it when she was about 3 and she had a small amount of speech therapy) but because the school didn't see any behavior associated with ASD ectthey didn't really help, then COVID hit and they were out of school for a while and during this time I just tried to find help from outside places myself (internet and also resources from Resilient Families). When she returned back to school in yr2 she had two seperate outburst that she's never done in school before and the class teacher finally allowed me to fill in the form needed for the neurological test needed and they would then send it, only as I was persistent. That was/will be 2yrs this September and we are still being told we have to wait for a further 3yrs for an answer.

Her school still don't think she has any problems at all because of her 'normal behavior' whilst at school, even though they have recently notice her 'ticks' that she sometimes has. She gets extra help with reading and maths but they say this is due to falling behind during COVID. Personally our journey has been a lot of her having outburst at home and sometimes in public and I've done most of the work myself, coming up with ways to deal with these outburst alone in ways that help her cope. I think it would be helpful to have more opportunities to get diagnosed other than schools having to agree with parents because some children can hide their ASD ect when they need to and then it gets easily over looked, mostly as bad behavior or just that they are upset or tired which is usually the reason for my daughters 'issues' in school."

"My experience with trying to even get my daughter through the diagnosis has been difficult it's taken 2 and half years to get her referred to Neuro. At home the melt downs are hard work draining and effecting home life yet her school says she's fine there's nothing wrong with her. She masks everyday in school so she can fit in and be like the rest of the children in her class but the moment we leave school she meltdowns. If it wasn't for speech and language picking up on traits we would of never been referred back to neuro. As as parents shouldn't have to fight for a diagnosis for our children and a massive waiting time to be seen. Schools also need more education ALN too."

"My son is 12 years old. He was diagnosed when he was 3. The pathway through the UHB Neuro team was ok back then...not easy but by comparison to what parents are facing now, with waiting times and lack of capacity, it seemed easier. Services are still diagnosis, not needs led. Education is by far the worst. We have had to fight every step of the way to get what my son needs to give him the best provision. The new ALN legislation has only made matters worse. RCTCBC had made it more laborious, bureaucratic, with too many stages and layers to jump through. The graduated response approach means that children with ALN or neuro conditions must sink or swim in mainstream provision for up to 2 years before the appropriate support is put in place. By then, the child is often traumatised and the opportunity for early intervention is lost. I have continued to experience barriers, delays and inaction at every step of my son's transitions through his education to date. There is not enough ASD specific provision in education, health services or social support services. Everything is still siloed and a parent had to tell their story over and over and over to different professionals often with no recourse for action or support. Where is all the funding from Social Services and Well-being Regional Partnership going? Neurodivergent people are a priority group but we see absolutely no benefit of this for families living with these conditions."

"Treated very unfairly by a teacher with little insight or training. School response was to ask us to agree to an exclusion."

"It took me 12 years to get a diagnosis of autism and dyspraxia for my son the school and doctors never listened to me I kept on and on they kept saying he's fine meeting all targets more help is definitely needed as now he's in the comprehensive he has no help as they say it wasn't needed in junior school the only help he has is a door to door bus as he has no road sense if he had had an earlier diagnosis things could have been better for him"

"What I've learned with all 3 is how a diagnosis allows you to access support and that without it, it is almost impossible. With such long waiting lists for diagnosis it means that children are left with unsuitable schooling and become anxious and often non attenders. I heard Julie Morgan AM saying how a diagnosis isn't necessary and it made me angry as it really is. It doesn't matter what the ALN code states, schools do not want to support without one!

Autism is such a massive spectrum and many school staff only have a limited understanding. And unless a child meets their definition of autism, they will often ignore the child's sensory needs telling parents that the child is 'fine' or that it must be something upsetting them at home.

Schools are heavily targeted on academic achievement and attendance. Achieving either of these targets is impossible for some children, so they feel a failure and excluded from awards. Schools are rarely inclusive. It's much easier to focus on the high achieving children. If the child with ALN is not of any danger to themselves or others then they are ignored.

Teachers fail to understand that children with autism especially girls mask. This means that to a teacher they are 'fine' in school: that child then explodes at home like a fizzy bottle of pop. When the parent approaches the teacher, the teacher judges this as home based issue.

Schools have limited budget. If they pretend that a child doesn't need help then they don't have to pay to support it. So this becomes the favourable option.

Our son who is now diagnosed with autism could not access an autism specialist school as his diagnosis came late. Through a tribunal at age 15 he eventually joined a wonderful autism unit but I'm so sad he didn't get that opportunity sooner. To meet the criteria to join, you had to be diagnosed.

To get my children the support and schools they needed I have had to pay for private reports and go through two tribunal processes - the LA eventually conceded on both.....

...We had a head teacher turn so against us as we challenged how they were dismissing our daughters ALN, that they probed her (age 4) with leading questions and instigated a child protection investigation against us. We were cleared of any wrongdoing but it was upsetting and scary. School staff are seen as the pinnacles of society and the processes in place to complain about them mean there is zero accountability!

Two out of three of my children are now in independent schools after awful experiences in maintained schools. They are doing amazing as class sizes are small and they don't get overwhelmed. Staff are also caring, kind and supportive. I've met the odd decent teacher in mainstream schools but many seem to be in it for the perks and not for the child.

When I challenged the training of my child's teacher in mainstream school I was told that 'education under the act states that there is no requirement under the Act to have specific training. My daughter's teacher had been in the school for over 20 years and had no training in autism! The governors have found this acceptable as the Act states there is no requirement for it.

I could go on and on! Please help with this.

Thanks"

"Child diagnosed with autism November 22. Has been sent to mainstream school. No extra support put in place. Local authority rejected to take her IDP on in January have spent months gaining enough evidence to show why she shouldn't be in mainstream and finally got her a placement from September in an ASD unit. Very stressful few months."

"My son is 4 not yet diagnosed

Takes 3 years for diagnosis here in RCT.. he has just been told that the mainstream school cant cater for him (we knew this before he started there) he been there a year and is going to panel this month.

Diagnosis times is ridiculous there is other places who have their kids diagnosed before they are 2.

We couldn't apply straight to the ALN School as you need mainstream to say they are Cannot handle them and jump through loads of hoops.. we have known hes autistic for a long time paper dont change anything.

The only reason I have support in place is because a family member has complex medical needs and have used the services."

"Pretty poor. In short. Kicked out of his nursery at age 3. They cited he needed 121 which they didn't have funding for. Put him in a school nursery.They can only cope with him for 1 hour a day at the end of which I have to collect him. Half the time he's behaving well and doesn't want to leave so I have to drag him out screaming. I work full time luckily mostly from home however it's pretty challenging doing this on 1 hour childcare a day. School say they just don't have the money for the 121 support he needs. I'm trying to get him an afternoon private nursery placement under the 30 hours scheme however all enquiries prove fruitless when I say he has additional needs. They don't have the funding to accommodate. Im a qualified social worker and worked with victims of domestic abuse for 14 years.I often have to take phone calls of a confidential and sensitive nature.

Sadly I'm resorting to plying my son with screens and treats to keep him quiet so I can take these calls and work on my laptop.

He's not getting the early years education experience he deserves.

Meanwhile I feel I'm screaming into a void trying to get him the support he needs and the childcare I need to keep a roof over our heads."

"I approached my sons primary school with concerns that he may be neurodivergent when he was 6 years old, I was told that without a diagnosis they could not offer him additional support and there was no funding available. Over the next 4 years he received a dx of DCD, ADD and eventually Autism when he was 10. Throughout these years they showed a complete lack of understanding and offered little to no extra support always saying they didn't have resources. By the time he left primary school he was more than 3/4 years below his age for reading, writing etc. They utterly failed him and because he was a very well behaved child he went completely under the radar, not a 'problem child'. He is 12 now and thankfully year 7 of secondary school has been a turning point with him receiving a decent amount of support, extra lessons in the subjects he fell behind on and constant access to a special ASD unit. I always felt alone and not listened to throughout his time at primary and that he didn't receive a fair education based on his needs. He is much happier now at school than he ever has been. He attends Welsh medium".

"My experience have been so difficult 3 year wait for nuro it isn't fair our poor children are suffering 🙄 these children don't understand anything"

"My daughter has an ASD diagnosis, diagnosed dyspraxia, shortening of the limbs, hyper mobility, a genetic disease and several other health issues. School has always been very hard as even at the age 6, she is identified amongst her peers as different and picked on for it. The school have kept her back with a younger year since starting school (despite several requests for her to access work for her own age). She has always been put down and I've told she won't cope.

However, clubs seem to be the worst. I have been unable to find a club for her to develop in as there is nothing near us. She has been kicked out of several clubs because of her disability. One even kicked her out and told her it's because she's too slow.

I am gob smacked by the lack of availability for children with additional needs in the Rhondda. I have a max card which helps us save money taking her out and there is no places near to us that accept it. Really not inclusive in our area."

"I have 2 children one with a diagnosis of adhd & asd and one still on the waiting list to be assessed. She has been on the list over a year and still has probably another year or more left to be seen. There should never be this long of a wait. The poor kid is struggling there's no help while we wait. She's struggling with food sensory issues around clothes not to mention her school work and social side of school. I don't find school are very helpful with her at all with her especially as she's very good at masking while at school. I have been querying adhd/asd since she was 4 it took till she was 11 to get a referral excepted. She's now nearly 13 and still not seen by ND. If she was seen and assessed when the first referral went in she would of had so many more years of help than she's had. As a result her anxiety may not of been as bad as it is now. Her reading may have been better her maths may have been. She may of actually wanted to go to school rather than have arguments everyday about not wanting to be in school. There needs to be a much better system put in place. Because right now it's not fit for purpose."

"For us it has been the most stressful time of our lives. My son regressed at 2 years old and this was a very scary time for our family. To then hear how long the waits were to find out why were terrifying. His needs were too high for private day nursery, there was no extra funding for him to have 1:1 support and so this resulted in me taking an 18 month career break so I could drive 30 mins away 4 days a week to take my son to asd rainbows who were a lifeline for us. I sat outside in the car for the 2.5hrs he was there a day and would then drive home. Accessing services was extremely difficult, very limited support until school age. In RCT it feels like you must throw your child in the deep end with school and try them in mainstream when you know there is no way it's the right provision for your child. We did the statement process with the help of a private legal advocate to ensure our son got the support he needed and so that I could get back to work which cost us thousands at a time I was already out of work and without pay. He therefore went straight into a specialist setting. Now he is in a specialist setting he is thriving, us as a family are happy, his teachers are incredible working with him. It's just such a shame it was so stressful to get him to this point. We also had to pay for private assessments to identify his needs, these should be carried out as part of the statement process but they were not"

""My child masks in school and comes across as fine. He tells me schools loud, to many people, its bright, hes anxious doesnt like people looking at him or being put on the spot, p.e causes anxiety. He would shut down after school stimming or hqve meltdowns from supressing regulation techniques and stims. He started burning out and was struggling to go with that and the big change of school coming up (juniour building knocked down) his sensory issues got worse and he wasnt coping. It was a fight to get him to school. School said hes choosing to behave this way to stay home and told me be firm mum, show him that no matter his behaviour he will still be coming to school so i pulled my distressed screaming son up the road and the staff members dragged and carried man handled my screaming distressed child through them gates and told me hes fine once in which shows hes choosing to behave this way. My sons coming out of school crying mumma why did u make me go i didnt want to go and broke down when i got him home. Be tough mum they made me think i had to do this to do all i can to show them im doing all i can to get him into school. They dragged and manhandled my son into staff members car in year 3 to the temporary building while he was screaming my name and trying to fight himself away. They caused trauma to my son where he could no longer go to school at all. His mental health has suffered he has hallicinations now and hes more anxious. Hes had an ND referal sent of i should hear from soon and is on the OT waiting list, i got him on the OT waiting list myself as school dont listen to parents concerns about there child and it was a fight to get the ND referal. I went private for my sons irlens syndrome dignosis (visual stress) as school again wasnt listening. There threatening fines and prosecution and hwve given me 3 options to choose from. 1 elective home educate. 2 change schools (wont fix the issues) and option 3 another transition plan (didnt work last 2 times) ive tried all the advice given to me and its caused trauma and mental health issues. If they listened 2 years ago and put support in my child wouldnt have got to this point. Hes frightened and scared of school, these figures he sees he says there after him. It shouldnt get to this point. Change needs to happen. Fines and sending parents to prison arent going to get child into school. If you would like to speak to me further please let me no. I have the minutes pdf from the meeting stating 3 options given to me and i no that school should not be pushing parents to electivily home educate"

"My child is reaching 19 years of age, he suffered a stroke prior to his birth leading to several medical & learning needs. Diagnosis at aged 2 and aged 8 and went to school with a support plan with the support of the educational psychologist. He attended a Welsh medium primary school (mainstream) where for the latter part of his school years (and a change of headteacher) life was pure hell. Staff had no understanding of his medical or learning needs and were not interested in learning, they made not only my child's life hell but also mine. They kept refusing support until it took steps with me reaching out to politicians, within a year AND backing from the education department as they revealed the headteachers "lies" my son was granted a statement and a place at an SEN school, all this after the school claimed that there was nothing wrong with my child. After receiving his statement he finished his last year in mainstream and with things in place from the education dept the school had a different attitude towards my child. We as parents should not have to fight for the right for our children to have an education. Mainstream schools, in particular my findings, welsh medium schools don't want SEN children at their schools where it will cause them further work. Once everything was in place for my son he has spent the past 8 years having an amazing education experience and is now in a position to transfer to a mainstream college with an SEN course. Primary schools are a child's first experience of school life, it is supposed to be a great experience but whilst staff don't have understanding or training in SEN they are failing children.

"Primary life was horrific for my disabled child lack of help lack of everything ... Everyday was a battle primary teachers need more support in understanding in the wide range of problems mentality and physically that children today have had to deal with ... A lot of primary children know have mental health by time they hit comp age !!! My oldest had cerebral palsy and my middle child has severe anxiety did primary help big massive no !!!"

"My son didn't get his diagnosis until year 5 in primary before this he slipped between the gaps. He was a non reader and hated schools. It was not a place he could access an education.

He was a non reader and his writing was not legible what little he could manage. His needs were not met and I had to fight to get his diagnosis even paying privately for his dyslexia diagnosis which then enabled the council to implement a statement of educational needs. They had refused to assess before this even though his needs were apparent.

I fought harder and got him diagnosed with ADHD and dyspraxia.

His adhd has also been so apparent since nursery. School didn't spot this and have not supported him until recently. This has been traumatic for my son being made to be neurotypical when that's impossible for him.

The welsh government need to enforce proper training for schools to spot and support children who are neurodivergent. They need to support them properly before it is diagnosed."

"we knew when he was about 2 years old he was autistic as I am a qualified nursery nurse I knew the signs. He was nearly 6 when he had his diagnosis, by this time he was in mainstream school, struggling and very often excluded for his disruptive and aggressive behaviour when he has meltdowns. Now they are looking to changing his school as they can not deal with him which means another upset in his routine. They need to listen to parents when they are telling you something is not right with their child and it should be done before school age to lessen more trauma than needed, life is hard enough for them as it is"

"It took me twenty one years for my son to have a diagnosis of ASD. We were told that he had learning difficulties within the first two weeks of him starting school. I had to seek help myself in his adult years as his behaviour was evident that he had ASD. Unfortunately it was overlooked all of his school years."

My daughter who is non verbal, 4 and attends ASD observation class we have been waiting on the neuro development list for just over 2 years now, originally when I started seeing something different every health visitor who came out basically told me she was too young and what would a piece of paper actually do? when in reality if they were trained correctly would know that piece of paper means everything for us parents/carers

We have been stuck in limbo from 13 months old and when asked for help by professionals (resilient families) was told basically couldn't help with what I needed as my daughter didn't have an official diagnosis

Turned to Snap Cymru was told my daughter too young she needs to be 4 to access help from them she was 2 at the time (turned 4 2023)

I was told of a local ASD group and attended once a week and this was lovely and really helped us as a family and to communicate with our daughter

Then I turned to another community group, the organiser rang me and had a lovely conversation and offered me to attend a soft play session with my daughter we attended, it was lovely to see children like my daughter running around But these children were all 8+ years old, there was no young children like my daughter and the older children were very boisterous and my daughter didn't feel comfortable

We were then told of another community group and spoke with them and my daughter was offered a place but within this week was also offered a place at her current observation class, in hindsight I couldn't afford the expense to take my daughter to the community group and feel there should be more places like the community group closer to home.

Speech and language have and still are no help last conversation I had basically was told she will get more help when she starts SEN School leaving us again to feel left in limbo"

"I am an autistic/ADHD mother. The last few years have been horrendous. I had to leave my job of 20 years because my children don't have education.

Child 1 now 16. Missed most of her high school education due to undiagnosed adhd/autism leading to suicide attempts. She's been failed by both camhs and her school. School pressured me to home educate her and in the end I deregistered her as they were incapable of sticking to what we agreed.

Child 2 now age 15. Diagnosed autistic age 8. After covid she could no longer cope with the large school setting. She was left doing the odd hour a week in school for around 2 years. I asked and asked for assessments and I was told no they don't do that. She had a complete physical and mental break down in Jan 2022. She hasn't had any education since then. Camhs refused her because she's autistic. I've been asking for a tutor as she doesn't leave the house. The LA keep saying they need evidence for this but all referrals get refused so how can I get evidence.

This school has broken my children. As an autistic mother the complaints process is too confusing and when relations are bad with the school I don't feel safe to complain to them. I feel the complaints system should be independent and not through the school.

Child 3

Trying to get her on the ADHD pathway having to chase up forms etc been 6 months since request and still hasn't even gone to panel. She starts that night school in September and again I don't have the evidence for them to meet her needs. Adhd/autism follows in families, this needs to be taken into account when trying to get a child referred.

I'm financially broken and severely traumatised from the endless school meetings and having to fight for my children. They deserve a future. They are discriminated against over and over again and there is not accountability.

I also volunteer with a local charity supporting parents of children experiencing EBSA. We have the same issues over and over. Lack of understanding. Lack of alternative provision. Parents blamed/bullied and threatened with fines, years waiting for and help and even then the mh services don't understand and"

"My son had full one to one in flying start placement then moved to Main School and lost all one to one he has struggled from age 4 he is currently age 7 and only now they are putting in assignments

I tried to get him help myself and professional kept dismissing me and saying and I quote "he don't have needs its just something you've read about " "or mum looking for issues "

Even though his Health visitor noticed this at age 2 he's currently now had a appointment with occupational therapy in Trealaw but I would not have got no where if finally school stated pushing but it's taken me until his last few months of year 2 in school for this where I have been asking for help since nursery"

"My Son had his diagnosis at the age of 8, nothing changes I literally got a letter confirming he met the criteria for ASD and given a parent information book. I'm lucky that I have no behavioural issues in school with him but because he sticks to the rules and doesn't get in trouble he always goes under the radar and forgotten about. My Son is 16 and had massively changed since his diagnosis but not once had anyone check in with us to see if we are getting the right support at home or at school. Lucky he goes to a local school and has an amazing head of year who goes above and beyond but if it wasn't for them he would not of survived school. As a parent you constantly have to ask to make sure there are procedures in place to make school comfortable. I also feel that if your child does not cause an issue they go unnoticed. I work in a primary school myself and I'm so passionate about getting support for the children and parents and have held coffee morning with different organisations to help support the parents but also to try and raise awareness so these children will get invited to parties and over other children's houses for food. All children should be included in all activities. I feel that school's are so understaffed and this has an impact on all the children."

"My child, now 18 was diagnosed with bipolar when she was 16. We have endured 8 years of struggle trying to keep her safe, get help and give her a meaningful life. It has been a battle all the way. We finally got support from the community intensive therapy team I call them who were amazing."

"Waited 3 years for initial appointment with neurodevelopment service and been waiting 4 months since that for feedback. Was told during the appointment they feel he meets criteria of ASD but has to be taken to panel and if all members don't agree he will need further testing/consultation. No timescale available. I sensed frustration from the very kind and capable dr we seen too.

School are difficult to work with won't implement changes without diagnosis, very judgmental of seeking diagnosis. Also seen by Camhs who told us he has ASD traits if he has diagnosis and support it will improve mental health therefore nothing can do. He's 10 in July, started the process of seeing GP, seeking support from school just before he turned 6. If I could afford to I could have a diagnosis in weeks."

"My daughter has suffered with her mental health for nearly 7 years now. She was diagnosed with autism last October. We waited a long long time just to be seen and feel that we have been passed from pillar to post.

Our experiences with Camhs has been unbelievably shocking as we fell through the cracks initially of having secondary camhs not escalating us to primary camhs despite my daughter expressing she wanted to die.

Behaviours have escalated and she now also self harms.

I honestly believe if we had had support sooner we would not be where we are today.

Every service blames each other, getting passed around and no one taking accountability.

Resilient families we are currently using for the 4th time but behaviour escalates after the short term support stops.

I have asked to be appointed a social worker on so many occasions over the past year - to no avail.

Respite we were initially told no too and then told we could have it but there's a 5 year waiting list.

I truly believe my daughter has been failed by a broken system"

"Senior teachers/head teachers are not aware of how the new ALN system works.

As parents we feel like they "passify" us and saying they will offer some support and tell us our child is coping and progressing. However the daily chats with the class teacher show a different picture. We keep being told that there is no additional support/funding available yet they are able to fund extra curricular activities where by the children who excel in school life are fully supported.

When demonstrating documentation from medical and health professionals we are continually told that there is no support available or our child can't be supported until they receive a "label", which as a senior health care professional I know isn't true.

I feel like the school is failing my child and there is nothing I can do about it apart from move him away from his friends and routine to a different school. we have asked on numerous occasions for the school to explain to us how they apply for funding or if there is someone we can email for further support/escalation but they refuse to discuss the topic any further."

"My 7 year old son has Autism, glue ear and global development delay is now in SEN School where he is progressing well and has come on amazingly well and can't speak highly enough of them, however the process to get to this point was mind boggling. The amount of forms to fill in and the information required is extensive and stressful. Having a child with disabilities is hard enough without feeling like you have to beg for help."

"Waiting times to be seen are to long. You get a diagnosis and no follow up help or support unless it's for a health check for medication.

The school it's self have been amazing but the local authority's approach and support is shocking I have tried for the past 7 years to get additional support for my son and it is turned down by the local authority everytime."

"My children received diagnosis aged 8 and aged 9. Even after ASD diagnosis neither of them received any support, I begged for help but the school made me feel that it was my issue and my fault. They had no training on ASD and didn't believe that my daughter was masking. Secondary school was better for my son as they were able to offer a hub as support. Any strategies offered to my daughter did not work. She had school based anxiety and trauma and went from a happy child to one that was always in fight mode and couldn't leave the house. She missed a year and a half of school and still no support. After numerous phone calls to the local authority I had access to an educational psychologist. The school didn't help me until I got SNAP cymru involved and had someone from the local authority on board. The school still said they couldn't do anything more or different to support. The headteacher told me that my daughter was one of many and there was nothing that she could do. I eventually got EOTAS for my daughter after a lot of fighting.

I had to give up my job to be able to support my daughter and the constant fight left me exhausted. Parents have to fight so hard to get what their child needs.

When someone is diagnosed as neuro diverse they should be allowed to live like that, not be forced to live as a neuro typical person. They are being treated as square pegs going into a round hole. Being mentally damaged daily. If someone was physically disabled they would have appropriate support to be included as they are. Neuro diverse people are disabled because their needs are not being met.

There must be training given to everyone that comes into contact with a neuro diverse child or young person. Parents and the child/young persons voice must be heard."

"I have 13 year old that is struggling massively with education we have had to go private for diagnosis to try support her getting help in school and with her being 13 we couldn't wait for nhs as she would be leaving school by the time of diagnosis"

My son waited 2 years for a Neurodevelopment appointment he has finally now had that and been told we will be getting a ASD diagnosis but need to now wait for forum to discuss him. Schooling has been a constant battle. I was told to try mainstream schooling by local authority even though they knew he had additional learning needs and put a IDP in place. We started mainstream schooling in treorchy primary. The school was completely awful and not fit to take additional needs children. Completely over crowded with 50 children in nursery split over 2 classrooms over seen by one qualified teacher. I had to fight for basic needs such as having a nappy disposal bin for him they sent soiled nappies home everyday often tied to his back pack on display for everyone to see as we walk home. They was offered training to use his communication cards which his use deteriorated after starting there but didnt take s.a.l.t up on the offer for the training that would have helped him. They kept everything from me and i had to beg for feedback on what he was doing everyday. He was coming home from school soaking wet every sinlge day. I have a full diary on his time spent there . I used resileant familes . Snap cymru . I reported the school to estyn . I had several meetings with the head an teachers an nothing was improving. I then went to the local authority about his need for specialist placement. At last after getting the school to fill in the relevant forms the local authority even after showing evidence of needing specialist schooling offered me a observation unit which is in Ferndale so a fair distance from our home at treorchy. So my 4 Yr old has to travel in taxis to get to school as part of school transport. I am now fighting for a place at specialist school for him to have a permanent place for September as the observation unit he is in is only til July as its for children of nursery age. where he will be in reception class we are hoping and praying for a SEN School. He has and Individual learning plan an mainstream school has proven to not to be able to uphold this. Everything is a constant battle. Endless appointments. Meetings. And refferals. And fighting for my son to have the same opportunities as his peers. They tell you early intervention is key yet they stick you in situations that are more wait an see approached . They lead you to believe that if mainstream doesn't work out your child will get additional help but the help doesn't really come. It's often who shouts the loudest gets their child's needs met. Countless emails and phonecalls and months of it just to get a little further along. There is not enough spaces in schools for our children. No funding for 1:1 in mainstream so you have to fight an plead your case to get into the appropriate schools. Most schools are often way out of catchment so our children have to travel far. My child's story for the 4 years of his life can only be described as a battle. Please contact me if you would like a more detailed encounter."

"My son is currently in Year 9 in the SEN provision of a mainstream comprehensive school. He has quadriplegic cerebral palsy and is a full time wheelchair user who relies on his 1-2-1 support assistant for everything, from scribing his work, to taking him to classes, helping him with physio, to feeding him his lunch, and even helping him with personal care tasks. He is cognitively able and gets a great deal of enjoyment from learning and participating in class.

The school have been absolutely fabulous, as undoubtedly it has been a learning curve for them in having such a physically disabled child join them. Even though there have been other wheelchair users before my son, none of them have had the level of physical disability that he has.

However the one major issue that we've come across which is having a negative effect on my son and his well-being is the extremely high turnover of support staff. The council inclusion service are relying in agency staff at present as they are struggling to recruit. And the agency staff move in to other better paid jobs as soon as they are able as it's only a temporary stop gap for them.

My son started to query last year if it was his fault that his 1-2-1's kept leaving. And despite reassurance that it wasn't he still partly holds that opinion.

This is happening to lots of the children that I know have 1-2-1 support. So it's not an isolated incident."

"2 years for a diagnosis is shocking and they won't diagnosis a child until age 5. Things need to change waiting so long isn't fair on the children who need a diagnosis to have support in school. It is really frustrating for the children and parents. Trying to get support they desperately need is also frustrating aswell."

"My son is 7 and he has a diagnosis of both adhd and asd. Our experience is probably the same as many other, the wait is too long and there is too little support, blame being pushed back on parents and passed from pillar to post when seeking help! At 3 years old my son started nursery on Porth community school, I had met with the school before to raise my concerns surrounding my son's behaviour he was currently presenting with and was assured it wouldn't be an issue! 2 weeks in there was a severe incident and I was told by the then head 1 or 5 in 2 years to find someone else for my son to be educated! None the while we began looking for somewhere else for him to go, absent from education for 2 weeks, nothing from the school or the local authority as the school hadn't informed them, I contacted access and inclusion and a meeting was arranged and a reduced time table put in place, which continued on larger for 2 years. With little support from school or the council, nothing in place to meet his needs until Snap Cymru were involved by myself! Multiple exclusions at 5 years old! Being in school for 45 minutes what an experience for a child as he was so disruptive they were unable to manage him. The system isn't in place to support children with additional needs it's there to make them suffer because they're unable to manage in a setting where they should be able to! Our first experience with an educational psychologist wasn't pleasant either! Telling me that all my child needed was to be loved, whilst she witnessed him hitting me and being unable to manage his emotions! Love my child what a thought if I didn't love him she wouldn't have been there! The never ending wait for diagnosis within the health service is agonising for parents who just want support for their child after receiving an autism diagnosis waiting nearly 3 years, you are given a book and a leaflet signposting you to services and sent on your way! If you require ADHD medication you are lucky enough to be able to access the service, however trying to contact the service to request medication or speak to someone with an issue is probably on par with getting an audience with the king near on impossible! Services are over stretched and the need for them is greater than ever! Parents are in crisis with nowhere to turn no support and are made to feel useless when they need extra support with their children who have additional needs! There needs to be more support pre diagnosis for parents to access and the council need to increase the number of specialist placements available as despite the new ALN code a mainstream placement is not best suited to meet everyone's needs, there are children which require specialist environments with highly trained staff who are able to meet individual needs of these extraordinary pupils and not left to one side as a teacher hasn't got the time nor skills to be able to best support them!"

"The waiting times for neuro development appointments are over two years long . We were referred to them in 2018 seen 2020

Now diagnosed non verbal autism, GDD, PVL .

The school system is an uphill battle . The local authorities place a child in mainstream to "see " how they cope , even tho they have never met the child . Child placed on a Limited time table , mainstream staff have no clue with additional needs , class sizes far to big (35:2) . Waiting times for an educational psychologist is far to long . No parent should have to fight for the right education in this day & age . Waiting times for assessments are crazy . The worry & stress this puts on a family is incredible. Paperwork is passed from one department to another , children have to be discussed again at a panel who have never met the child, they then decide what is best for that child . How can someone who's never met a child truly understand their educational needs . We were told when our child started school (chronological age 3 mental age 12/14 months) to show them their uniform and that they need to understand that school is for big boys & he needs to be a big boy . They simply don't understand and from experience mainstream schools don't want to understand.

Specialist school provisions are needed so much more , the empathy , compassion, understanding from staff there is absolutely incredible. The children to them are children not a number , not a child who can bring in additional funding for school but they are loved & they develop in this environment so quickly it's unbelievable. But it shouldn't be so hard to get placement"

"Communication from my sons teacher and the school as a whole very poor. The school has three ASD units, however aren't particularly inclusive when it comes to extra curricular activities. Accepting a placement for my son to attend a small autism unit should have been the best option, but I'm doubting myself if I've made the right choice. Ideally, more asd units should be in other schools, so you aren't limited of where your child can go! As he needs extra support, however if you are unhappy with his school placement, there should be more options!"

""2.5 years on waiting list before given a diagnosis. No support pre diagnosis. Had to seek out support myself.

My son has ASD and is in mainstream. Teachers lack knowledge of autism and how it affects my son. Made to feel like a nuisance parent when advocating my child's needs with some of the teachers (not all). I feel like my sons emotional needs are not being met in school. My son is doing fine academically and feel due to this his additional needs are being ignored in school. He is also very well behaved in school and masks. He comes home often very overwhelmed and we have to deal with the challenging behaviour because school haven't met his needs during the day. There is no quiet/ nurture area in the school for him to access. My son has severe sensory difficulties and needs quiet time to regulate. I worry about the long term affect all of this is having on my sons mental health and what the future holds when he moves to a mainstream comprehensive.

The biggest support I have received is from Halcyon training foundation, they are commissioned by the neuro developmental service and due to them we are successfully managing Finns behaviour at home and helping him over come his anxiety to leave home and experience different things. They have helped me with my emotional well being too and don't know where we would be without them!

Raising a child with additional needs is a very lonely path, no support offered, little understanding from the outside world and a constant fight to get your child what they need."

"Waiting lists for diagnosis way to long, referred Jan 2018, oct 2022 got adhd diagnosis still waiting for autism panel. My son also has a lot of medical needs and cerebral palsy. He has 32.5 hr statement, his primary school have been brilliant with him- I'm very lucky. However a shortage of educational psychologists- again waiting years."

"My daughter age 15 has been waiting to go to panel for an official ASD diagnoses since 2019-2020 . Her problems started when attending school where she struggled with not only change, but noises, crowds, people touching her etc etc which would result in extreme anxiety and panic attacks. Many occasions we would be called to go and get her because she was so bad, that is of course on the days that we would actually get her into school. It was during this time at the age of 12 that we discovered that she was also self harming, which led us to the unofficial diagnoses from CAMHS of ASD . The schools "support" was to put her on a reduced timetable (finish at 11) and to make the wellbeing office available to her when I gets to much.

On a routine appointment with CAMHS it was advised that based on what our daughter had told her in a session, was that we were to remove her from.that school for her safety and wellbeing . That there had been a couple of occasions when it appears that our daughter had passed out through a panic attack and we weren't even informed, that instead she was just allowed to sleep it off. And because of severe bullying which was never dealt with.

We enrolled her at a different school.

Again we've had the same struggles where hallie has suffered with her asd, anxiety and diagnosed depression and her attendance was quite poor, however she DOES want to be in school she loves to learn and is a bright, intelligent,articulate girl.

Again the school came up with a reduced timetable and to make the hive available to her when she needs support, however she has been turned away in tears from.this several times.

It was agreed that the school (being her GCSE year) would regularly send work home with her so that she doesn't fall behind, however this has never EVER happened. Being aware of her poor attendance hallie has tried her best to attend full days of late, minus the days when she had CAMHS appointments or having a bad day, despite these she really wants to catch up and do her best.

This week has been awfully distressing for Hallie, Being that her GCSE exams started...exams that she had absolutly no idea were happening, has never recieved a timetable for, and has had no prep work for. I found out via the school app on Tuesday eve that there was an English exam Wednesday. My daughter had absolutely no idea which in turn concluded in an meltdown. She did not sit that exam 😞

This is not the first time that I feel she's been forgotten about by the school. During Xmas holidays she was told that come Jan there was going to be a English exam, of mice and men was the topic. She had never been given a book to read, worksheets ro complete, revision material.....nothing. had it not been for us going out sourcing these items there's no way she could've sat that exam, an a exam that she found out via facebook.....

.....We feel collectively as a family that she has not been given the support, the care, the time that she deserves. Almost as though as long as she gets her mark then that's enough. I feel like school has failed her. She is not going to be sitting her exams, she can't, she's never been given the chance to have the same education that others have had.

Had she been given the official diagnoses at panel and had it on paper in black and white, maybe she would've had a chance. But we feel that she hasn't been given the education that she deserves"

"My son has been let down by the school and Neurodevelopment process I've fought for years to get my son into an appropriate school which he does 4 days a week now he is moving to key stage 2 I'm having to fight for a full time placement as he's a danger to himself and others in a mainstream setting, it's been such a hard fight and has made me so stressed for my son and I continue to feel like he's being let down by a system that is there to help him, Neurodevelopment take so long for appointments in the first place and has took years to get part diagnosis and night time medicine for my son to sleep I could go on and on this is a quick over view I also as a parent feel let down any more info please contact me thanks"

"My son was born with a cleft palate and hyperthyroidism. Other learning needs then appeared as he grew up, finally getting a chromosome deletion diagnosis aged 7. This then gave us the reasoning behind why he couldn't learn in school. My son was moved to a school which is an absolutely amazing school. Now attends Comprehensive school as they can cater for his needs."

"My son is now in year 9. His current school has been quite supportive but we are being given the runaround with applying for extra time for tests etc and I'm having to chase. He has social anxiety and we are still waiting for school to organise counselling as CAMHS aren't fit for purpose. His first infants/primary school was appalling. We moved him in year 1 to a much better school. His first school actively made getting his diagnosis harder and obstructed us at every turn."

"My son had a terrible experience in primary school since nursery class. He was classed as the 'pocket rocket' then in juniors 'naughty child' where teachers and pupils knew him for not listening and being very energetic. I knew my son had ADHD and some sort of delay development in learning. Through the years of primary he was 6 years behind his age where my concerns were brought up constantly. School didn't provide support and pushed him aside with basic support. My son's confidence was knocked severely as he knew he was different and wasn't able to do the things as the other children. It felt the school wasn't interested in children with ALN and classed them as naughty. I had an ongoing battle to get my son a statement even with a diagnosis. I fought so that my son could have the best possible support to help him thrive. Now that he has been statemented, and is placed in a smaller class in Comprehensive School he has improved in 7 months that he has ever done in primary school. It shows that with little support from primary where he made tiny improvements, if teachers had the knowledge about different aspects of ALN and the correct support children can improve. I often tell my son that everyone is different in different ways and treat others how you like to be treated with respect."

The eldest one we have been told by a psychologist to get tested as they are certain FASD/ASD is present
GP & school won't refer her as there isn't enough signs
Why isn't there more help to these children & parents?
Why can't teachers be trained on how to test children?

"Son still waiting for ASD assessment after 2 years of waiting. I've had to fight and push the school to get my son extra time for GCSEs after numerous meetings , emails, phone calls.

Everything is a battle for parents and while waiting for the ASD assessment you are left to fend for yourself without no advice.

My daughter was tested at age 10 for Asd came back inconclusive, shes been at Cahms since that age , when they said they thinknits Asd but were chopping and changing their minds about whether to test her again. At very last appointment/discharge at Cahms they said I think you should go for Asd testing, so she had to apply to go through adult Asd testing she turns 19 next month and after 9 years of mixed communications etc she has to wait probably another 2 years to be assessed.

As a parent it's a constant fight, battle pushing school, colleges, cahms to get something done. It's not a very good system currently, lots if waiting , no multi agency approach and we've had lots of information not being passed on from school to school, from school to neuro, it's a battle."

"They had a speech & language delay but after working with a private therapist for 15 months he's now able to communicate clearly and we've seen an improvement in their confidence. We've been asked on a number of occasions by the school to have their hearing checked and we arranged this ourselves with the health visitor but every time there was no issue with their hearing and there was no further action from the school once this was confirmed.

Since they started in the infants we've had the same discussions at every parents evening, in the November Meetings we're told they are quiet child and takes time to settle in and talk, then in March parents evening we're always told they really struggle but they'll give them interventions. Having looked at their work books and having discussions with his teacher in the latest parents evening we raised a request for an ALN as we were told that in January he had regressed back to a nursery level with his language assessment, key stage 1 with their maths and they struggles to complete tasks without support. I feel frustrated that these assessments were done in January and even though they had regressed and was struggling we did not know about this until 2 months later at the parents' evening.....

....We do a lot of reading with them and up until February this year they were on stage 3 Oxford Owl reading books which is a reception level, they have now advanced in the last 3 months to stage 5 but still really struggles.

After raising the request (A copy of the letter attached below) we were invited into school with the Head Teacher and the ALNCO to discuss them and at this point we confirmed we wanted to proceed with the ALN request and were advised they will book the meeting for the last day they legally could which was 5 weeks from the request to give everybody the chance to attend. We requested their teacher be present for that meeting as we felt it was important to have her there as it was following a parents evening with her that we raised the request and were told they would try to arrange cover.

When we attended the meeting we were told that over the 5 weeks they'd been unable to arrange cover and that she had sent her comments. They told us that when they re-done the assessments after parents evening they were fine and must have been having a bad day. We have yet been shown any physical evidence of their progression but instead provided with the Assessment Data table below. While the school is not disputing they may have ALN they feel these could be managed in house via interventions and other agreed measures however we were told they would start everyday reading last week and again this is yet to happen.

The council took the case to panel on the 17th May and I had a decline letter Monday via email but have had no further contact so I chased the council to understand what data had been taken to the meeting and was told my email with the ALN letter and PCP tool that I had attached. Following escalation with the council I was then told no the school had sent further information that they had also taken but I have an email off the school at 14:01 on the 17th May asking if I had referred it to the council yet, so I'm struggling to understand how they could have taken the information from the school if the school weren't even aware that I had escalated it yet.

The council then said they could take it back to panel in two weeks time and speak with the school if I wanted them to but again i feel frustrated that I'm having to push this and there no standardised process of information that is used when making their decision it seems as though it's easy to say no send an email and be done with it.

....After questioning how they could make a decision on if a child is ALN or not based on such little data Lucy the council then agreed to contact the ALNCO at The school yesterday and following her chat with the teacher she said she was happy with the measures they put in place and she's happy my child has made progress. I then asked could she show me the progress she seen and she said it was the Assessment Data document that showed he was an Outcome 1.4 and is now an Outcome 2.2 so I asked what a child needed to achieve to be an outcome 1.4 or 2.2 but she didn't know, I then asked what evidence she had seen to show he had progressed and met metrics for 2.2 and was told none but that teacher is a competent ALNCO.

I'm not querying anyone's competency but we were shown my child's work in parents evening which give us concerns which were also felt by the teacher however since we have not seen anything to suggest he's now made progress and I was under the impression that the council would ask for the data so they could review it themselves to make an informed impartial decision on what support my child needs. I also asked if she had queried when the extra measures they had put in place were starting but again she couldn't answer the question.

I was told by the school that measures had already been put in place and my child would be starting everyday readers from last week however this has not happened and we've had no contact to why this has not begun. I feel like our concerns are being acknowledged but then brushed under the carpet and told my child will be behind because of covid & my child's speech delay and that my child is still young and will probably benefit from an official IDP when in Juniors in the future. If this is the case how can they predict my child now and yet they think he will need ALN support at a time in the future?

I feel we're being fed measures that they are doing to help my child but this is only lip service as we've seen no evidence that these are in place or that my child has suddenly caught up and they no longer have any concerns.

I just want to see evidence of my child's progression now and not a table that tells me my child's an outcome 2.2 without the data that shows me what he's achieved to now be a 2.2.

I want the council to do an impartial review based on data so they can make an informed decision.....

....my child is a quiet child that tries their hardest but will admit my child really struggles with Literacy, Reading & Maths, all we want is for my child to have the help so they can catch up with their peers and have opportunities in the future and we're happy to support any way that we can at home to get them up to speed to but we need the school to keep us informed and not sit on concerns till parents evening.

After raising a request for my child to be considered as ALN on the Monday then on the Tuesday they were given a pencil grip to help them hold his pencil, my child is in year 2 now why has it taken us to request my child be considered ALN before anyone has given them the tools they had available to help my child with their pencil grip?

How long can we keep using covid, speech delays and the fact children are young as an excuse to why we're letting them fall behind, surely as a community there must be more we can do to ensure all children receive the same education regardless of if they're happy to sit there quietly or what school/borough they attend/live in. I know other schools do read with the children and write comments in their reading record book yet I can show you my child's reading record book that throughout the whole time they have been in school I can count on one hand the amount of comments off teacher or the amount of times they have actually listened to my child read and not just given my child another book."
