

Cyflwynwyd yr ymateb hwn i'r [Pwyllgor Plant, Pobl Ifanc ac Addysg](#) ar gyfer yr ymchwiliad: [A oes gan blant a phobl ifanc anabl fynediad cyfartal at addysg a gofal plant?](#)

This response was submitted to the [Children, Young People and Education Committee](#) for the inquiry: [Do disabled children and young people have equal access to education and childcare?](#)

AEC 33

Ymateb gan: Unigolyn

Response from: Individual

I have three children [REDACTED]

[REDACTED] was diagnosed as autistic in March 2021. Whilst at [REDACTED] Primary school, we tried to raise concerns with the headteacher - [REDACTED], and the ALNCo at the time [REDACTED] about [REDACTED] social and emotional challenges. She is a really bright girl, very academic, and I was just brushed off due to her being so academic. She had experienced a number of friendship issues in school, and it was glaringly obvious that she was autistic, but school would not even consider supporting her, because, as I was told 'there are other pupils in this school who are in a worse position than [REDACTED] who deserve our time and input.'

[REDACTED] had ELSA support and school counselling (she had already been in external mental health support due to bullying issues, where she had tried to end her life.) When I advised the head of school of this with [REDACTED], she said 'don't children do the funniest things!'

I had only been successful of getting [REDACTED] in front of external mental health support because of support that we had from an amazing Family Support Worker at Families First called [REDACTED], who supported me with enough evidence from working with [REDACTED] and observing her in school.

Based on school evidence - where they barely filled in the form, we were rejected at the first panel meeting. I asked for a copy of [REDACTED] school file, where there was a lengthy report in there about another boy in the school, and there was also a copy of a Thrive assessment that they had completed for [REDACTED] in school without our knowledge, and they had completely fabricated the whole thing.

[REDACTED] is also hypermobile 9/9 on the Beighton score, and is query Ehlers Danlos. I had to get occupational therapy into school to assess [REDACTED] for safety purposes, as school would not even provide reasonable adjustment without an OT report. [REDACTED] ended up with grippers to help her to write, and a slope, it was advised that she had a quiet space to work in, that she had support on the stairs, due to amount of steps and that she could leave at the front of the class so that she wouldn't be pushed/knocked by other class members and the teacher would be there to support her.

We asked if she could come out of an exit where there would be an external handrail, to be advised 'no' and that we would have to transport her down the steps on our own, as it's not school responsibility, despite it being in school grounds.

Due to bullying that [REDACTED] encountered in [REDACTED] and the lack of support around her additional needs, we moved her to [REDACTED] Primary. She seemed to be a bit more settled initially when she joined in year 3, and so we put some of it down to

environmental issues of the previous school and the bullying. We soon hit lockdown. On return, [REDACTED] could not cope with being in the classroom, the noise disruption was too much, again she struggled with making friends and maintaining those relationships and was very much guided by her peers. We had expressed all of our concerns when joining the school, and I had provided a copy of all evidence for her file. Again, [REDACTED] needs were ignored until she was in year 6, and she started to refuse to go to school. We had experienced some of this in year 5 too.

I had to fight and fight for reasonable adjustment for her with [REDACTED] the Headteacher and [REDACTED] the ALN Co.

Both [REDACTED] and [REDACTED] along with the class teachers would highlight some of the emotional and social challenges that she was having, but refused to acknowledge that there was anything else going on.

[REDACTED] could not tolerate being in the school hall - too loud/echo, so this meant that she often missed PE, assembly, school productions (she would bolt from the room in floods of tears), and she had to sit outside the hall in the library to eat her lunch. School tried to push me to collect her at lunchtime, but I refused as I know that they just wanted her off site so that she wasn't their issue. [REDACTED] was given an opportunity to work on a table in the corridor outside her class as a quieter space, but she had to take it in turns as 'otherwise it wouldn't be fair on the other children.' I also had to fight for her to be able to come in through the main reception rather than the main school entrance with all of the other children as she just found the crowds too overwhelming.

I managed to get [REDACTED] diagnosis in March 2021 after 7.5 years and with absolutely no supporting evidence from either of the primary schools. In the meantime, her self esteem and mental health has taken an absolute battering and she has tried to take her own life twice.

When my husband and I attended the IDP meeting with [REDACTED] she had already made her decision and took great pleasure in telling us so. She couldn't justify why, aside from there are other children with a greater need in this school than [REDACTED]. We appealed it with the local authority and they stood by the decision of the school.

In year 6, [REDACTED] didn't attend the residential trip as they thought it wouldn't be her thing, as opposed to saying that they couldn't accommodate her needs. She didn't attend her prom either. [REDACTED] was on a reduced timetable for a considerable part of the year, as we stood by caring for her mental health and wellbeing, as if that isn't in place and cared for, there was no way she would be ready for learning. The headteacher threatened me with a referral to families First, but I had already self referred, and she also threatened me with a report to social services, as I was neglecting [REDACTED] education. When all I was doing was fighting for her to have relevant support, and being met with a brick wall. We couldn't wait for her to be out of there and i wasn't reported to social services.

I took transition to high school into my own hands, as I felt I couldn't rely on the primary school, and I have to say the ALNCo at [REDACTED] was amazing. [REDACTED] has lots of reasonable adjustments put into place to support her, simple things like, leaving class five minutes towards the end of each lesson to avoid crowds, having a lunch pass so she doesn't have to stand in queues so she can eat, she can access the hub at anytime of the day, she is in a smaller group for PE so there isn't so much noise in the hall, and she can register in the hub for assembly if she chooses. It has put her in control,

her voice is heard and she is having a couple of wobbles but has settled and has a group of friends in the year above.

Unfortunately, from a review point of view and communication perspective with the ALNCo - [REDACTED] it is now impossible to communicate with her, the school haven't responded to an email that I have sent at the end of term last year, and it's like [REDACTED] doesn't exist. She is quiet, compliant and just gets totally overlooked as a result, and because she is a bright kid with no behavioural issues.

[REDACTED] is [REDACTED] - he too was in [REDACTED] Primary and at the age of 5 was under community speech and language as he had a bad stammer. The SALT provided relevant resources to the school, for them to continue to do with [REDACTED] on a daily basis when he was doing his group guided reading. The TA doing reading with them at the time was [REDACTED]. She admitted to me that they didn't use them and kept them in the cupboard in case they needed them.

[REDACTED] was removed from [REDACTED] due to physical bullying and he also moved to [REDACTED]

[REDACTED] stammer came under control and we when then went into Covid. [REDACTED] has always really struggled with social and emotional elements, very similar to his sister, and he cannot articulate his thoughts, feelings and worries. Instead it results in tears and when we try and ask, he says 'I don't know.' He loves routine, hates unexpected change, has to know the ins and outs of everything and his specialist subject is football. He knows the ins and outs of every club, every player - it is his special interest.

I have raised concerns that I think [REDACTED] is on the spectrum for years. Again, I have been totally ignored. [REDACTED] also really struggles with his reading, writing and literacy, so I have also raised the question that [REDACTED] may be dyslexic (his Dad is also dyslexic). Again - ignored as 'it will come in time.' It hasn't.

[REDACTED] left [REDACTED] following the diabolical meeting with the ALNCo about his sister, as I refused to leave him in a school where they clearly did not care about his wellbeing to even consider monitoring [REDACTED] literally had only a few months to go, hence she stayed, whilst [REDACTED] transitioned to [REDACTED] primary. It would have had to happen anyway, as it is impossible for me to do a school run of a morning to three different schools, when two is challenging enough.

[REDACTED] was in school at [REDACTED] n for 3 weeks, [REDACTED] He was in a wheelchair as a result, and school refused to have him in due to it being a health and safety risk. He was in a cast and a wheelchair for 18 weeks, and he was out of school until 2 weeks before the end of the school year. I asked for school to send home school work for [REDACTED], we received none. I asked for log ons to things like Bug Club, Ed Shed....anything at all that he could do from home - we received nothing and the school didn't even check in to see how he was doing, unless I updated them on appointments and consultant advise that we had received. So if during the consultation - you could also please consider temporary disability within it, it would be much appreciated.

[REDACTED] is purpose built for wheelchair access, and it has wheelchair users within the school.

I gave a file of all evidence to [REDACTED] for [REDACTED] the same as I did for [REDACTED] and again raised my concerns, nothing has been done to date.

█████ had some friendship issues online over the holidays, and as a result he has missed two days off of school this term due to those, as he was in floods of tears and again not able to articulate what has happened or how he is feeling. After speaking to the ALNCo - ██████ I have again spoken to her about my concerns for ██████ and she has spoken to REACH, who advised the same as me, that he is quiet and compliant instead of well regulated, and they will now be completing a Thrive assessment over the coming weeks, with a PCP meeting to be scheduled at the end of that time, so that we can formulate the One Page Person profile with targets for ██████ and agree on reasonable adjustments. The headteacher at ██████ has told me that I will never receive a diagnosis of autism for ██████, as his needs aren't great enough, so it's not worth their while pursuing. I have backed off a little for the moment and said that it should not stop them from meeting his needs though - and this is what I am currently fighting for. So far it's taken me all of his school life.

█████ is ██████ I noticed that something wasn't quite right and raised my concerns with my health visitor from around 9-12 months old when he wasn't babbling/cooing, trying to make sounds or pointing at things of interest. We hadn't had any first words. He went to Flying Start nursery in ██████ community centre, and thankfully, I knew the staff there as ██████ had also attended the same playgroup. They made a note of my concerns, provided ██████ with a very small group setting within the larger group and ██████ (his playworker) did 1:1 with ██████ every day to try and encourage his speech. ██████ also hated loud noise, would cry and cover his ears, wore his ██████ coat and woolly hat, with his backpack on the whole time that he was there, with his hood up. Even in the summer they couldn't get it off of him. His diet is incredibly limited, and he has toileting issues to this day, which he is on medication for. We had his first word at aged 5.

I applied for him to attend ██████ nursery, and when ██████ and ██████ started at ██████ I had a meeting with the head to see if they could accommodate ██████ needs. She made it sound like she was doing me a favour by allocating him for one hour a day. This was on the provision that I brought him in 30 minutes after everyone else had started and that I take him to the toilet, ██████ would then join in with activities, except he didn't as he needed that trusted adult to guide him into it and to support him throughout. They ignored him as he sat in the corner crying. They made him feel like a total burden on their time and resources. When I tried to raise the issue of discrimination, I was met with 'not our problem, he isn't of compulsory school age.' Rather than helping to write a report to support to say that they were unable to meet his needs.

The nursery also refused to change him, or support him in pulling up his trousers, so I ended up dropping him off and sitting in the car outside nursery the whole time, because the school is out of catchment for us.

█████ was always really upset when I picked him up as he couldn't understand why he was not able to stay with the other children. All of the other children were being sent home with reading books - ██████ wasn't as 'what's the point.' They didn't even try to make him feel welcome.

I took him out after 2/3 weeks, and I paid privately for him to go a private provision so that he could socialise with children of his own age. None of them were trained in working with children with additional needs, but in all fairness, they did their utmost to support ██████ and to make him feel included and welcome. He took a little while to settle in, but once he did, he was ok and able to do a full day once a week. He loved seeing the nursery children come back on the wrap around care and he made a little friend.

We tried again with reception with the same school, again they would only offer him one hour a day. I didn't even let him start, as it wholly wasn't fair on him. I again tried to raise a formal complaint, again to be met with 'he isn't of compulsory school age.' It was challenging because even though the private nursery and Flying Start provided written reports, the local authority would not accept them because they would not recognise them as an education provider!!! I was trying desperately to get [REDACTED] into a place where his needs would be met, and the paediatrician would not diagnose him because he was not in an educational setting!!

Thankfully [REDACTED] had been under speech and language since he was 2 years old, in the community at first, and then over to the [REDACTED] Centre with the wonderful [REDACTED] who was also able to provide copies of [REDACTED] care plans, her concerns about his speech (he was non-verbal until he was five). He now has a severe speech delay, and has been through sign, PECS and now an AAC. He has a SALT visit once a week in school, and intervention daily from staff in the LRB at [REDACTED]. [REDACTED] was amazing in that her reports significantly contributed to Dr [REDACTED] to diagnose [REDACTED]. It was only due to Dr [REDACTED] writing a strongly worded letter to the local authority reminding them that placements were to be needs met as opposed to diagnosis. I then had a call just before his 5th birthday advising that [REDACTED] would finally be discussed at panel.

I still recall the call from the head - [REDACTED] at [REDACTED] who said that she had heard all about [REDACTED], he sounds like a wonderful character and she would love to welcome him to [REDACTED]. It was the kindest call I had ever received about [REDACTED]. I cried my eyes out. He did his transition and started in year one with them in September 2021 in the LRB. His teacher [REDACTED] supported us all the way with his diagnosis and he was then finally diagnosed not long after starting school.

[REDACTED] hasn't been without his challenges in school, down to unkind behaviour from other children within his class, who have behavioural challenges. [REDACTED] had come home on several occasions with scrams down his back, he had been kicked, punched, a chunk missing from underneath his eye where a child had [REDACTED] at him, he has been pushed off of climbing frames, had balls kicked at him and been scrambled down his face where the scars are still visible several months on. I met with the head and his teacher, and they suggested that [REDACTED] start to access mainstream for some social time with the mainstream children, and also to give him some breathing space from the [REDACTED] who were causing his misery. I said I was willing to try it, as I was just desperate for [REDACTED] to be away from this behaviour and it was agreed on a temporary basis when he was in year 2.

[REDACTED] started to access mainstream year 2 for playtimes and he did quite well, but staff were aware of his needs, and he was provided with a card that he could show if he wanted to return to the LRB at any point.

This year [REDACTED] has returned to school, and whilst he is in the LRB (he has gone from LRB1 to LRB2), he has been placed into mainstream frequently. He has no support in transition after 6 weeks out of school, and the staff in mainstream and supporting at lunchtime are not aware of [REDACTED] needs.

None of the mainstream staff have any neurodiversity training, they are also not trained in the total communication techniques that [REDACTED] needs access to and for a trusted adult to understand when he is trying to communicate with them.

He was given his AAC device at the end of last term, but the school have said that it can go in the cupboard when he is not using it, so that the other children don't get to it. It is pointless as he needs access to it at all times and all staff that interact with [REDACTED] needs to be able to know how to support him in using it. Only one staff member attended the AAC training, and it was over within 30 minutes. There is no plan if she is off sick or gets moved to another area in the school.

During [REDACTED] statement review last term, the head has made it clear that the local authority target is that [REDACTED] will be in mainstream year 6. How can that even be possible, when he doesn't have any 1:1 support, he still hasn't got to grips with using the toilet, he has sensory needs, needs a smaller group working environment, and has such challenging communication needs. Again, he is being overlooked because he is quiet, compliant and he is a bright child. He needs to be in a specialist provision for his speech alone, where all staff are trained in signalong, PECS and AAC. [REDACTED] is not able to dress himself, he has an extremely limited diet and cannot tolerate certain textures/sounds/lights. He will not be able to cope with the demands of full time mainstream learning.

There was an incident in school last week, where [REDACTED] (it was an accident) but it wasn't dealt with as staff on duty were not aware of [REDACTED] needs. This is a safeguarding risk in this instance.

I have had to demand with school that under no circumstances is [REDACTED] to be accessing mainstream until he has managed to settle back in to the LRB provision (today is his first full day back in since children returned), and until we meet again to discuss what access to mainstream will look like and the support that he will have, along with evidence of training for the relevant staff across the school who [REDACTED] will encounter within a mainstream provision. In the interim, I am going to start looking at specialist provisions, that can accommodate [REDACTED] needs all the way through to 19, and then put up the fight of my life to get him into one.

I have had the blame put on me on numerous occasions, I am sick of hearing 'they are fine when they are in school.' I am fed up of feeling like I am going crazy and to be made to feel that it is all in my head. I am fed up of having my childrens needs ignored, of being on constant hyper alert for the next thing, and then to have to fight like hell to get what they need. I do not have the financial means for legal support if needed, and I do not have a home that I can re-mortgage to provide private support for my children.

Schools and local authority are not an all inclusive environment. They focus on budgets, targets and outcomes of examination results, which is outdated in itself and certainly not being pupil led with needs met.

I can only speak truly for myself, but I have been blamed as a parent for the situation with my children, I have been ignored, threatened and bullied by schools and the Local Authority. My children have been severely let down. I take anti-depressants, have complex PTSD and I too am autistic as well as having other health issues. I dare not disclose any of this to the school though, as I know we will not move forward in getting the support that my children need and it will totally be used against me.

Schools say that they want positive relationships with families, but that goes both ways, and I truly do not feel that parents/carers are heard, pupil voice is usually a tick box exercise for most places, as they cannot demonstrate how they have included the voice

of children with additional learning needs as many of them are unable to communicate or articulate.

In a nutshell:

- * Mandatory neurodiversity training for ALL school staff including the caretakers and lunchtime supervisors, which is updated annually at a minimum.
- * Mandatory total communication training for all staff to support children with all needs, including anxiety, selective mutism etc
- * Teacher and teaching assistant qualifications to be reviewed. Neurodiversity and disability needs to be a module within the learning curriculum on degree programmes for teachers, and they should access to placements within mainstream and special needs education before they can complete their degree to get a balanced view on challenges pupils face. TAs are not even taught about ALN in level 2 qualification, which is what the majority of TAs have.
- * ALNCo to be specialists within their field - so many staff are placed into that role and do not want that role, this is the same for LRB teachers. We are lucky with [REDACTED] teacher where she has come across to [REDACTED] having been a higher level teaching assistant at [REDACTED], received excellent training and knowledge there, and brought that to the LRB as a newly qualified teacher. She is now [REDACTED] teacher for the third consecutive year.
- * ALNCo decide if a child will receive an IDP or not. In our experience for [REDACTED] the ALNCo also taught full time and had no opportunity to assess [REDACTED] over a period of time, and she is not a specialist in additional learning needs. This should go back to the previous panel meeting, where a board of professionals are involved for a multi-disciplinary approach, and not for it to be one person's opinion.
- * Total transparency from the local authority and the schools. It is a minefield - and the most information that I have found out is from other parents going through similar situations or from the Family Liaison Offices at [REDACTED] [REDACTED] has really held me on in there at times when I have felt like ending it all, because I have been made like a total failure to my children and I feel like I cannot fight anymore.
- * More funding for schools - it cannot be needs met in mainstream education when schools do not have the funding and resourcing to provide it for pupils who need it.
- * Wider access and support for parents/carers of children with ALN
- * Transport - escorts and drivers to also receive ALN/disability training, along with escorts to be trained in total communication techniques.
- * Mandatory placements for children in nursery/reception especially query additional needs so that support needs can be identified earlier.
- * Mandatory training also for all childcare providers - be that private nurseries or childminders.

[REDACTED] - the ELSA assessment was completed but he has not met the threshold for ELSA support. I have now been given a copy of his One Page profile with targets, which states that it has been put in place at mum's request. I have had to source alternative support for [REDACTED] by referring him to Young Carers at Banardos where there is a 20 week waiting list for provision. I have also self-referred to Families First, both of which school could have done, but chose not to. This also demonstrates that the Welsh Government policy of 'No Wrong Door' is also not working effectively. I have also spoken to my GP for further help and support in respect of suspected ASD and dyslexia. I have been told that school can arrange dyslexia assessments - again they have chosen not to despite my concerns, and also again shows that the ALNCo is not a specialist in their role as the ALN reform suggests they should be.

As for [REDACTED] - my husband and I met with school on Tuesday. they gave us a 30 minute minute to discuss [REDACTED], which include safeguarding concerns for [REDACTED] under peer-on-peer abuse, and also appropriate support for him in school. I have had to fight for a copy of his Annual review which was completed in June 2023, and have not had the opportunity to see any draft before it was submitted to the LEA. Needless to say that there are parts in there that are not factual and I disagree with. He has also been given an outcome of P1, which means that he is working at the age of a 3-5 year old. How can this be justified that my son is to access mainstream provision without 1:1 support to meet his needs, never mind be academically able to cope with the work when he is essentially 2- 3 years difference???

The school seem to think that having one trained member of staff is sufficient in regards to his AAC, yet there are no contingency plans. They say that they occasionally have to use supply and when they do, they request someone with experience in ALN, but this is not always guaranteed. This is not ok on the staff or the children.

The ALNCo has stated that lunchtimes have two options in that my son joins mainstream, where lunchtime supervisors are not aware of his needs or appropriately trained to support his communication, or the foundation LRB where he is physically attacked everytime he comes into contact with another pupil in that class. The ALNCo advised that she would need to discuss this further with the headteacher. This was three days ago and I am yet to have a response, or to receive a copy of the minutes from the meeting that I requested.

In the meantime, for his own safeguarding and wellbeing, my son is out of school.

I appreciate that we are one family with issues, sadly there are thousands more out there.

[REDACTED]