

[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 70

Ymateb gan: Unigolyn

Response from: Individual

To the Senydd,

Please hear me when I say the system is failing. Change is needed. No more families should have to struggle and fight to get their child the support and provision they need, its not fair, and its not right.

■■■■■ is my beautiful ■■■■ year-old son. I knew very early on that he wasn't meeting his expected milestones. He was showing signs of many of the Autism "Red Flags" but as well as these failings of developmental guidelines, I knew as a mother, my instincts told me so early on that ■■■■■ had additional needs. And it's at this point, at 13months old the failings start. I felt unheard. That it was far too early, I was told to wait for his SOGGS test with the Health Visitor. The earliest test time would be 20months. 7 months later, surer than I'd ever been, ■■■■■ did the SOGGS test and failed Social & Communication. By this time, he had very few words but even these were starting to go. The health visitor had arranged for ■■■■■ to be seen by the community nursery nurse, talk and play and play therapist, all of which ran approx. 6-8week programmes. I found this time extremely hard as it felt almost humiliating to have to "prove" that my play and language with ■■■■■ was correct. It's almost as if you're proving you're not doing something wrong as opposed to looking at the child. As a mother with 2 other older children, ■■■■■ it's very difficult knowing you're not being heard when you are saying over and over, something isn't right, telling everyone, I want a referral, only to be told time and time again, that he might just be a bit slower to talk, a bit slower to point, a bit slower to understand. It's too early to tell. All whilst every month developing more 'quirks', losing the last of his words, becoming increasingly more apparent that he was different.

I knew by 13months. So how did it take till hewas 22months before I saw any real action? Almost a year of me desperately seeking a professional to see ■■■■■, of course he hasn't gotten to see a professional yet at 37months, but you know, were on the list so ...eventually.

I had to self-refer for speech and language and will be grateful to this day that I was heard by a lady there ■■■■■, who met ■■■■■, spent time to listen to

me & interacting with [REDACTED] and she agreed to do the referral I so desperately had been asking for. Who knows how many more workshops and clubs we would have had to attend before the Health Visitor would have finally given us a referral.

To understand the need for that referral as soon as possible from a parents point of view is, you feel acknowledged, that you know your child is on that waiting list (30-36months) that you're going to see a professional who have that better understanding, experience and knowledge to help your child, hearing and understanding the diagnosis, what support is needed. It's about getting early intervention that is specifically aimed at my child and what he needs. Having to fight for that referral, to beg and be rejected by people I knew could do it (GP & Health Visitor) was heartbreaking and incredibly frustrating.

[REDACTED] sadly lost all his words which was a heartbreaking time to grieve the loss of his last word muma which finally went sometime in August 2022 and has not spoken any words since.

Just before [REDACTED] turned 2years old we were recommended to go and see [REDACTED]. We met them and knew instantly that these were people who listened and cared. They heard me. They understood and they embraced [REDACTED] into their beautiful setting. [REDACTED] has been with [REDACTED] since September 2022 and to say they are amazing would not do them justice.

Since he has been at [REDACTED] we have tried on several occasions to go the Early Years Forum with the aim of looking at the best provision for [REDACTED] when he starts school.

Myself and [REDACTED] have both said that [REDACTED] would be best in a provision that is small and quiet, similar to [REDACTED]. [REDACTED] struggles with noise and does not enjoy other childrens' company. He can become very distressed and often will display behaviours such as scramming and pinching when he is put in these situations. He needs close supervision and lacks understanding of risk/danger. He communicates using PECs (picture cards) for basic wants such as snack or toys. I am aware that some mainstream schools are denying the use of PECs due to lack of resources. Can you imagine telling a blind person no braille would be available for that same reason?!

Unfortunately, even with my report and [REDACTED] report, Early years Forum still came to the decision that [REDACTED] should be offered transition into Mainstream school. The very place I said would cause him distress and harm. The place completely unsuited to his needs.

This is the point at which the biggest failings for [REDACTED] occur. Knowingly recommending that against the knowledge that myself and [REDACTED], (a specialist Autism Nursery) have provided, still trying to get [REDACTED] to go somewhere he is almost certainly going to fail in.

This is the point that a child's life, their well being, their chance to thrive or fail, their happiness or distress is decided by a room of people who have not met this child. This is when change needs to happen. It is desperately needed. Change the system for [REDACTED] and all the other families who are made to send their children to provisions knowing that it isn't right for their child. It's disgusting that I now have to fight to try to get a PCP meeting for my child. I must fight to get heard in a meeting with other professionals to discuss what's best for my child. I must fight to do this?! How is that right?

Shouldn't [REDACTED] be at the very centre of all decisions? Shouldn't his needs be guiding the support and direction of the provision? Shouldn't those who know [REDACTED] best, his mother, his nursery, his speech therapist...shouldn't these people have a massive input into the planning of this? The answer is yes of course. But that isn't what's happening. Instead I'm fighting, putting in complaints, speaking to MPS, stressing, crying, praying that Early Years change their decision. Knowing if they don't, that it will affect not only [REDACTED] but myself. I will have to give up work to home school him as there would be no way I'd send my child to a place that will quite frankly torture him.

Please hear me, please listen and make changes that bring the children and their individual needs to the very centre of decisions. Where the opinions of families and Nursery staff are vitally important if not more so, than their own experts who may only see that child 1 time, then make a decision based on paper not on the child, it's ridiculous.

My final thoughts are, if we are being told that early intervention is crucial to our children, then why are we not getting it? 30-36 months wait to see Neuro Development, that's bad yes, but don't forget that getting that referral is also long and hard, doing all the Soggs, nursery nurse, talk and play etc, that's at least 9-12 months, all the time knowing you are years away from that diagnosis, that takes its toll. It's like a heavy bag that you carry around all the time, and in that bag there's a whole weight of worry, that your child isn't getting that vital correct, child centred support and early intervention that they need and should be getting at that point you are highlighting concern, not 4 years later.

We need more nurseries such as [REDACTED], nurseries specifically that have trained ASD staff with a ton of experience who are able to offer support and trusted care for our children. How many nurseries are there specifically providing care for ASD children in the [REDACTED]. It's not enough. I can't tell you how much having [REDACTED] has helped myself and [REDACTED] where I know [REDACTED] needs are recognised and met with care and understanding, where I am supported and able to share the burden of worry and stress, and help me fight for what is going to be the right provision for [REDACTED] helping me stand up to the Early Years Forum.

I think about the families who aren't as lucky as me to have their child in a setting like [REDACTED], where they are unable to get a vital break without fear and concern, where they may feel unsupported, and burdened with worry, where Early Years could do the same to them, offer a place they know will fail their child but not know or feel they can battle against this decision. I can't imagine the pain of having to send a child somewhere knowing they will be in distress, it goes against everything you do as a mother, protecting your child from harm. Failing both that child and the family. It's too sad and awful to comprehend that this is the reality for lots of families in my position. And it's wrong. Change it please!

I give permission for this letter to be used/ shown to whoever needs to see it, I want to be heard, change needs to happen, give my name, give my number, ill tell whoever will listen, my child deserves better. All children deserve a system that is there to support, recognise and meet their individual needs.

Thankyou [REDACTED]

[REDACTED]