

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 65

Ymateb gan: Unigolyn

Response from: Individual

Our son hit all his early milestones and developed typically until around the age he could walk (15 months old). He was a very content, happy and social baby. He would imitate sounds, he would make eye contact, socially smile, copy actions and had started to say a few words. At 20 months old he had a regression whereby he stopped responding to name, became emotionless, didn't respond or appear to recognise his family anymore and lost many skills he had developed. Over the following few months, he lost the few words he had, stopped waving, stopped clapping and stopped imitating. He could no longer wave Hi and Bye, didn't bring us items to share interest and lost his joint attention. I raised concerns with my health visitor who reassured me that there was nothing to worry about and who said 'there was no way our son was autistic.' At this point we felt totally lost as a family.

We were extremely fortunate as a family that we found [REDACTED] and from February 2021 to April 2022 my son was able to attend 4 mornings a week. We will be forever grateful to them as straight away they said come up for a chat and could immediately see the concerns I had for my son. For the first time I felt like I wasn't going mad and was being taken seriously. [REDACTED] is a 40-minute drive away from my home and is a 2.5hr session. This meant the only way I could get my son to this provision was to take a career break as there were no other suitable provisions closer to home that could meet his needs. Financially this was very difficult for us as a family as I had to take 18 months off work unpaid, it also meant sitting outside the center in the car everyday as the distance to drive home was too far. However, seeing the progress our son made there and how happy he was there made it all worthwhile. The ladies that work there are incredible, I only wish there was an [REDACTED] in every community.

The hardest part of this journey without doubt has been the fight to get our son seen by professionals and the support he needs in school. We knew it was very likely our son would need a specialist provision and we applied for a statement which was rejected by the local authority. We then hired a legal advocate to help guide us through the statement process and our son was awarded a statement a few months later after a long and stressful process. We had to pay

for independent professional reports to identify our sons needs as detailed speech and occupational therapy assessments were not carried out by the local authority as part of the statement process. It is without a doubt the most stressful experience I have been through and I ended up being very poorly as a result from it.

These are just some of the struggles we faced:

Our sons first referral to neurodevelopmental for a diagnosis was rejected and we were given the reason that our son was too young to be added to the waiting list. Our Health Visitor then submitted another referral once our son turned 2 which was accepted. When we were finally accepted onto the waiting list in March 2021 we were informed that the wait was around 2 years for this service. Our son is now diagnosed autistic.

Our son had a significant speech delay and disordered speech and it took months to be seen by NHS Speech and Language. Knowing how critical early intervention is for children this was a really stressful wait and we were fortunate to have [REDACTED] teaching our son how to use PECS. Disappointingly once accepted under NHS speech our son was only seen face to face by a speech therapist for 5.5hrs in 1 year and 5 month. Whilst his speech therapist was brilliant the service is so stretched they were unable to allocate anymore time to him. For our son to benefit from this service he required more face to face appointments. As a result of this we sought private support but sadly many families are not able to access this.

It was extremely difficult to get our son seen by a NHS OT. Therefore we paid privately for a detailed assessment of his sensory needs. During the statement process I explained that our son had sensory processing difficulties and these needs should be written into his statement. I was informed that as my son wasn't under NHS OT they wouldn't contribute to his statement, they also said I had to submit a new form to be under them which meant we wouldn't be seen for a few months (after the statement deadline). Again, once under OT the ladies working there have been fantastic, but the service is so stretched, they weren't able to help us at the point we really needed their support.

Our son was referred to the Educational Psychology Service back in January 2021, after an initial call in March 2021 I was advised that it would be best to delay involvement until September 2021 when I thought the Educational Psychologist would be coming out in person to carry out a full assessment of our son. However, on discovering that this wasn't the case I asked for that involvement to start as soon as possible. Due to miscommunication, I was then informed that our son would be allocated an Educational Psychologist when he started school

in September 2021 (he starts in 2022) and once I corrected this mistake, I was then told our son needed to be referred by my Health Visitor or his setting to the Early Years Forum in September and they would decide if an Educational Psychologists involvement was required. After explaining I have already been on the list since January 2021 and am not happy to go back through the referral process again, I was informed that someone will be in touch in September 2021. Therefore, it would have taken 8 months to have had any Educational Psychologist involvement with our son. Our legal advocate supported us in having an educational assessment as part of our sons statement process.

Our son attended a mainstream day nursery 3 days a week whilst I worked. When he regressed, I sought support for our son to help him progress. I first raised concerns with the Health Visitor back in October 2020 and felt there was very little support available to help our son. From a google search I came across the specialist setting [REDACTED] who were able to offer the more specialised support our son needs. I took a career break so he could attend this setting and in the meantime looked for suitable options closer to home that would enable me to go back to work. I self referred to resilient families in the hope that I was missing something and that they could find a specialist provision closer to home or a minimum of 1:1 support in his current setting. They advised they couldn't offer a 1:1 in his current setting but if I paid for our son to attend a different local setting, they would fund 1:1 support there. After only 5 weeks in his new setting, I was informed that the funding would end on the 16th July 2021 and that his new setting would look at other possible funding avenues for our son as they agreed he needs additional support. Our son attended his fifth and what we believed would be his last session here on the 12th July while we waited to hear if he had additional funding. He was then granted an additional 5 weeks of funding between the 26th July to 23rd August 2021. We were then informed he had an additional 2 weeks funding for the 6th September and the 13th September 2021. However at midday on the 6th September I had a call from the setting to inform me that there was no funding for our son and I either had to pay for the 1:1 myself (£11 an hour on top of the £50 day fee, £138 a day in total) or collect him immediately so I collected our son. This was really upsetting for us as a family and it also meant I was unable to return to work.

Our son has happily been in his specialist setting since not long after his 3rd birthday. He is now almost [REDACTED] and is thriving. The support he has had in his first few years of life has been life changing for him but accessing that support took a huge toll on us all as a family. There is also the worry that if he is seen as doing too well that support will be pulled and he could potentially regress again. If all children were able to access support early it could be lifechanging for them and their families.