

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 12

Ymateb gan: Unigolyn

Response from: Individual

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In a simple answer - no they don't far from it.

[REDACTED]  
[REDACTED]

Dear

My name is [REDACTED] and I am a resident of [REDACTED] Borough. My [REDACTED] year old son was diagnosed with a brain tumour on 22 April 2018 he was [REDACTED] years old. He was extremely poorly, in intensive care on life support for a while and on multiple occasions we almost lost him. [REDACTED] Children's Hospital saved his life and continue to provide excellent care for his needs. [REDACTED] tumour was partially removed what remains can't be taken away because of where it is so it is monitored for regrowth. Thankfully his tumour was benign. It was discovered that as well as an 8 cm tumour my son had had prolonged hydrocephalus for approximately 8 months prior to his collapse and emergency diagnosis.

This trauma understandably has left [REDACTED] with brain damage. He has complex processing issues amongst other things which has made attending main stream school extremely difficult. He is in year [REDACTED] of primary has one to one support for 7.5 hours a week!!!! There have been horrendous behavioural issues in school to the point [REDACTED] stays in school 20-30 mins unsupervised then has to be collected. The only way [REDACTED] remains in school currently is if myself or my [REDACTED] son go in with him, stay with him, supervise him, try to teach him and ultimately take responsibility for him.

As it is he is segregated from his peers (literally isolated) not allowed to socialise, communicate or interact in the slightest. His educational progression in the last four years has been minimal the gap educationally between [REDACTED] and his peers is ever widening. The school have had multiple contact with [REDACTED] doctors who have explained the issues [REDACTED] has. Processing issues, visual rather than verbal

teaching small groups no more than 4 because he can't follow multiple conversations and ultimately becomes frustrated which results in violent outbursts. He responds EXTREMELY well to one-to-one teaching. My son is due to go to Comprehensive school in September.

Following a meeting with the school, a disability social worker, [REDACTED] doctors, myself and the special needs coordinator for [REDACTED] Comprehensive (which would be his feeder school) it has been universally agreed that [REDACTED] can't meet [REDACTED] needs. I've asked repeatedly what I have to do next where do I apply, what are [REDACTED] options and have been told I need to wait on the school, although it currently appears there isn't ANYWHERE that can meet [REDACTED] needs). Upon investigation it appears there is very little (if any) educational provision for children with the complex brain damage my son (and other children) have. It's even harder to find out about any provision let alone access it!

My son has been let down by the education system. He is entitled to an education his current teachers think when he says "I don't understand" he is misbehaving, he isn't he genuinely doesn't understand and we have medical evidence to prove this is the case.

This extremely poor understanding of teaching children with brain injury has created an extremely agitated, frustrated, unhappy, isolated young man who has lost all faith in the educational system and who is being penalised because his brain doesn't work the way other children's do! His Consultant has explained it as essentially it's the equivalent of her standing in front of a group of people, explaining in Russian what they need to do and expecting them to get on with it, and getting angry and assuming they are misbehaving to try and avoid the work when, In all honesty, they don't speak Russian! It isn't his fault and the education system has a duty of care to provide education to suit his needs.

As it currently stands, I won't be starting him in [REDACTED] comp the provision isn't there, medical recommendations have been made and until they are followed, I believe it would be detrimental to [REDACTED] well-being, mental health and self-belief, I WILL. NOT set my son up to fail.

Teaching children with brain damage is a specialised field that is severely overlooked, our children are being let down.

With the greatest of respect I'm at a loss as to where I go from here, how best do I help my son and the inevitable children requiring support that come after

him?? My sons doctors are willing to provide the training to all interested parties. Are you able to advise or provide any assistance in this matter?

I was working but had to give up my job as what employer will let you leave after 20 minutes on a repeated basis. Childcare options for children with [REDACTED] needs are very limited, I'm a single parent with no local family support and am ex husband who is very intermittent in his commitment to my son. I firmly believe (and have experienced) that there is a massive gap in the educational system for children with hidden disabilities. The detriment on my sons mental health has been immense and not fair, he doesn't deserve to feel like this no child should.

I'm glad this review is taking place it's very badly needed so I watch in anticipation of things changing for the better.

Many thanks

Kind regards

[REDACTED]