

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 31

Ymateb gan: Unigolyn

Response from: Individual

To whom it may concern,

I would like to submit my contributions to the Senedd. I have a [REDACTED] year old son with ASD. He is non verbal (with no understanding of language), has round the clock care needs and cannot be left unsupervised day or night as he has behaviours that could injure himself or is unaware of dangers. This makes life more challenging. I have a two year old daughter who is presenting neurotypically at present and the difference in access to childcare and education is stark.

[REDACTED] was not able to access all parts of childcare and education provision. Until he was nearly 4, the only provision I could find for him was 2 hours a couple of times a week in a toddler childcare group which is the only place he could be safely as there is no childcare available for children like [REDACTED]. Because of his needs I was not able to find any childcare for him at all. This meant his father had to give up work to care for him and this eventually helped contribute to the breakdown of our nuclear family as financial pressures were building. The rate of divorce in families with a child with disabilities is far higher than the average population because of the isolation from society and lack of support that other parents can access. [REDACTED] was not able to access any childcare provision as nowhere could meet his needs. When he was nearly 4, he got a specialist Nursery communication unit place in [REDACTED]. There are only 16 places available in the entire of [REDACTED]. We were very fortunate. Despite this, he still only had access to 2.5 hours per day and no access to private childcare and the foundation phase as his sister currently enjoys. Whilst we have had some success taking [REDACTED] to extra curricular activities run by the [REDACTED] centre, we have not yet found any differentiated extra curricular activities this side of the border. This means that the summer holidays and half terms are especially long and challenging because there simply are no extra curricular activities set up by the council for children with ASD (as far as I can find). I tried to enrol my son for swimming lessons with the local council. Because he is completely non verbal with no understanding, he would need a swimming session set up for his needs. I kept applying on the waiting list for the younger swim groups as they allow parents in the water to assist the children but when I finally was offered a space they rejected [REDACTED] because they said he was too old and that they had nothing to offer

him. His sister, in contrast, has a wide choice of extracurricular activities including swimming lessons, gymnastics, ballet and goes to childcare five mornings a week. If it wasn't for the [REDACTED] centre offering the sessions they do once they turn 5 (all run through a charity with limited funding), then the nearest provision is in Bristol.

In regards to the extent that children with disabilities are excluded from childcare – the first nursery school I applied for (a Welsh school with the logic being that pictures might help him develop language), they flat out told me it wasn't the right school for him when I was offered a place and spoke to the headteacher to explain [REDACTED] needs. Thankfully, he did get the communication unit and later he was accepted into the ASD school in [REDACTED] – of which there are only 8 places but hundreds of children that would have been eligible. In short – even the best childcare facilities are unable to meet the needs of children with disabilities and this pushed our family into poverty.

Indirectly, we have been adversely impacted because of the financial strain of losing one income. This was a factor in causing our family to split and [REDACTED] father and I are now divorced. The lack of external help caused us to seek out private speech and language appointments as the wait was nearly 2 years to be seen despite [REDACTED] not talking. He also had extreme pain every night due to compacted ears and because of his ALN he would need to be put under a general anaesthetic to have this treated. We ended up taking out loans to pay for this privately to ease his pain. Neurotypical children could have been treated with microsuction while awake. He also had bi lateral grommets inserted as he was found to have glue ear (being non verbal he cannot explain the pain he has) and it was not until 3 years after he started screaming in pain every night that he finally saw an ENT on the NHS. I don't know how we would have survived had we not sought private surgery on his 3rd birthday.

[REDACTED] is a very anxious child. His limited interactions with other children because of a lack of childcare/ education means he struggles around them more than if he had been able to access education earlier. This is particularly damaging as these are children who already struggle with social communication and this seclusion exacerbates the problems. Indirectly, my daughter is shy around other children because she expects them to react to her as her brother does, and so having had them together in close proximity without [REDACTED] having time away from me has impacted her negatively also.

In terms of choice for education or childcare settings there is no choices. There is no childcare in [REDACTED] for disabled children like [REDACTED]. There is only 8 places in the only ASD school in [REDACTED] so although there is the choice of mainstreaming them, there is no choice for specialist provision (LRBs do not contain ASD specialists as they cater for a wide range of disabilities and emotional problems. The tacking on of these units to mainstream schools means that children who really need a differentiated curriculum are instead funnelled

into units that are not designed to meet their individual needs but rather the needs of general ALN children. Additionally, most schools have LRB staff who move around the different classes/ years – they are not people who have set out to work with ALN and often find themselves ‘dumped there’ as described by a teaching assistant I know) In fact, because you don’t apply to the schools, you may not find out if your child has gotten a place anywhere until well after neurotypical children are informed. We found out in March of this year that [REDACTED] had been offered a place at his school. I can only imagine stress of the 30 or so other parents who didn’t get a place finding out in the last term of school before they are due to start that their child has not secured a place.

I don’t think there is a obvious path for parents to follow when they realise their child is not neurotypical. In order to access specialist education you have to contact the council and go through a 6 month process to get an IDP. Parents unaware (I work in education but even I struggled to identify what I needed to do), will likely not get specialist provision and will not be signposted correctly to applying through the council. It is assumed, wrongly, that when the health visitor identifies these missed timescales the referral will ensure everything goes from there. People are not aware that the medical diagnosis of delayed development etc is very different to the needs assessments completed by the council and that there are in fact processes they should start immediately with the council. Otherwise, parents waiting the 3 years for a paediatrician to assess their child will then (if they are lucky) find out they need to apply to the council for a statement of needs. Other parents do not find this out at all until the child is of school age. It is very unclear and these parents who do not find this out themselves in a timely manner will miss the opportunity to have specialist provision.

In conclusion – it is obvious that there is not childcare provision available in SE wales for children with disabilities such as ASD. This has a knock on effect on the mental well being and careers of everyone around the child including the child. There is limited access to extra curricular – the only available is through the [REDACTED] centre and given that [REDACTED] is charity funded – that can’t be considered to be government money spent to support SEN children to access summer/ extra curriculums. There simply is no provision for the vast majority and any parent with a child with SEN will tell you the same – if they get 5 minutes to do so because they have no access to childcare either.

[REDACTED]