

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 34

Ymateb gan: Unigolyn

Response from: Individual

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In response to your current consultation: 'Do disabled children and young people have equal access to education and childcare?' The answer is simply NO.

When examining all the points you wish to explore during your consultation, I cannot respond favourably to any point raised. I am a mother of two girls aged ■ & ■ who are both neurodivergent and have learning difficulties. They are both diagnosed with ASD and ■ year old also has a Chromosome Micro duplication. They are both non/limited verbally, have no sense of danger, doubly incontinent and have complex learning needs. They now both attend a SEN school, however ■ year old has attended 5 different provisions over the years, with 4 of them not being parental choice and were the wrong decision by the LEA. As a result she was pushed from pillar to post and this lack of continuity significantly impaired her early learning and development.

Although a SEN setting is the appropriate provision for my girls, they have in the past, been discriminated against due to their disability. For example, in ■ year olds previous school we were asked to keep her home during sports days as they weren't prepared to make safe provisions for her. I am pleased to say her current school has not done this and she has fully embraced and enjoyed sports days, although this has been somewhat different for my elder daughter. In previous settings, no changes or adaptations were made on school trips/Santa visits to cater for her needs including sensory and safety and as a result was asked to stay home from school, therefore not having the same opportunities as other children. Both my girls do not access extra-curricular activities within the school as there is no provision or adult supervision for them to attend anything. Any social activities are arranged by us as their parents. However, this is extremely difficult as both girls officially need 2:1 when out and about in the community and when it's just myself and their father, that's only 1:1.

The most challenging aspect is during the school holidays, in particular the 6 weeks holidays. I work full time as a teacher so although I have the same time off as my children, unfortunately my husband does not as he works ■. Therefore, during the weeks he has to work, my daughters cannot access any activities in the community due to the lack of carer's needed for safety. It is important to point out that although my girls have the same diagnosis, and sub diagnosis such as echolalia, sensory processing disorder, etc, they both present differently to each other. Therefore, some activities would only suit one and not the other. Having said this, there are very few activities and venues that are designed specifically for ALN children. Even when these few are advertised, they are oversubscribed and packed out due to high demand within the autistic

community, and for some children with SPD, defeats the point of accessing somewhere calm so they don't have a sensory overload and meltdown. Even when they are advertised, they are often at inconvenient and unrealistic times such as extremely early in the morning or late in the evening when they should be calming and settling. This is because neurotypical families and the general public always take priority over our children and are naturally given more appropriate, convenient times to them. It makes neurodivergent families feel we are offered the scraps that society doesn't want, so venues can tick their disability friendly box and we are expected to be grateful. This isn't equality. Even when these rare activities and venues are on, they are not always staffed by people with an understanding of children with ALN. Venues aren't always flexible in their procedures and can often use discriminatory language, which then can make ASD families not want to return. If there were supportive staff members, trained in ASD & ALN to support families on arrival that would help somewhat.

During the summer holidays, various programmes are held in schools, however not all schools have them, my daughters' school is a prime example. When contacting the LEA to ask why one special needs school in the authority offered this but the other didn't, they said it was based on the socio-economic area. Although I would understand this reason for mainstream settings, this should not be the deciding factor when it comes to SEN schools. The issue isn't money, that parents in one school could afford to take their children out but not the other. The issue is provision and finding somewhere safe, suitable, ALN friendly and with support staff who know the children and how to interact and support them. Yet again, my girls were not offered anything over the six weeks break and it is unfair to them to stay home whilst other children in the other SEN school got the same recreational opportunities again and again. If there had been this provision, even if it was for 1 of my girls, it would have given the opportunity for me and their father to take out our other daughter for an activity or break from the house. As time during the 6 weeks progresses, frustrations can build if there's a lack of differentiation in activity and although ASD children like routine and structure, they also need interests and activity. This is just one example how my girls do not get the same opportunities as others of their age.

Access to speech and language provision and therapists is incredibly poor in Wales where some children in need are denied them. [REDACTED] year old was removed from the Speech & Language register many years ago without my consent and I have been asked if [REDACTED] year old can be removed in which my answer is No! This in my view is appalling, both my girls need Speech & Language and communication support, and I will never ever give up on my girls like the education authority appear to have.

Considering the [REDACTED] age gap between them, both girls are now in or moving into the teen phase of their lives. A time where soft plays and younger activities are no longer suitable or age appropriate. I would like to ask, what social or recreational activities does Wales offer teenagers with complex learning needs? Where can they go other than school? Anywhere people suggest, the same old answers appear, places are full, there's a waiting list, etc. But do these places actually exist? My two girls have only recently been approved for PA's, but finding four suitable candidates which is needed for both is a challenge. We have never, ever received any respite for our girls and have been told the waiting list is incredibly long.

We are loving parents who work full time despite our obvious sleep deprivation to provide the best life we possibly can for our beautiful girls, but a far wider understanding and empathy is needed at government level for Autism acceptance, which clearly isn't the case as the Autism Bill was not passed in the Assembly in 2019. Wales needs to do better to irradiate neurodivergent exclusion from society and should strive to give equal opportunities for children, teenagers, and adults like my girls to ensure they are valued and have a happy, fulfilling life.

Yours sincerely,

A solid black rectangular redaction box covering the signature.