

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 56

Ymateb gan: Ymddiriedolaeth Gofalwyr Cymru

Response from: Carers Trust Wales

Carers Trust is the UK charity working to transform the lives of unpaid carers across the UK. In Wales, it partners with its network of local carer organisations to provide funding and support, deliver innovative evidence-based programmes and raise awareness & influence policy.

Through its network of nine Network Partners across Wales, it has directly supported 28,729 unpaid carers in the last year, including 2,300 parent carers (8% of carers supported).

This response is based on insights Carers Trust has gained through its Network Partners and through feedback directly provided by parent carers to Carers Trust.

1. Are disabled and neurodivergent children and young people able to access everything their school or childcare offers?

It is clear from the evidence provided by parent carers that there are various aspects of school that some children and young people are not able to access because of their disability or neurodiversity. This varies from being unable to participate in extra-curricular activities run by the school to inability to access or be equally involved in classwork. The inequitable access is a source of concern and frustration for parents and opportunities to work constructively with schools to address this aren't always easily identified.

Some parents have shared with us that securing a place for their child in a specialist school helped their child get the support they need to engage fully with school life. This highlights the importance of ensuring that every child has access to an appropriate educational setting. Parent carers describe seeing significant positive behavioural change in their child as a result of being educated in a setting that properly recognises and meets their needs. For many this improves their ability to fully access the curriculum and thrive in a school-based setting.

Parent carers tell us that overall, children with severe and complex disabilities who are identified as in need of specialist support are more likely to be able to access education than children with invisible disabilities or unclear diagnoses. Those with low level needs, or challenges that present at home as a result of inadequate support at school, are less likely to have the support they need to access everything their school offers.

One parent carer described: “They don’t fit into the boxes that Welsh Government have, they become ‘grey’ children...just lost in a vast sea of nothingness”. And another emphasised: “There’s nowhere she fits into... [they] either stay home for the rest of your life, or be part of a day centre which doesn’t match [their] needs”

2. Are disabled and neurodivergent children and young people excluded from any part of their education because of their disability or because they are neurodivergent?

Many parent carers describe that their disabled and/or neurodivergent children are being excluded from parts of their education because of their disability or because they are neurodivergent. Parents reference the blanket treatment of all children, and how this can result in their child being excluded from parts of their education, often because their needs weren’t considered and so they couldn’t take part, or take part fully, in certain activities.

One parent explained shared with us that her child has not attended school for 2 years due to their disability/neurodiversity, but they remain on the school’s register. The school is yet to offer them any support and has not put in place any appropriate plans to support a return to the school setting, meaning that the child is currently being excluded from all parts of their education.

For some, the journey to gaining appropriate support is difficult and lengthy. For too many families this results in a pressure to home educate:

“He now has support in school – we had to fight for every minute of that support”.

One parent shared that whilst waiting for a diagnosis, specialist support wasn’t made available for their child. As a result, this parent felt like they had no choice but to home educate. Exclusion from parts of their education due to having to wait for a diagnosis in order for their child to have support in school is a common experience for parent carers. Several of our Network Partners run programmes to support parents of neurodiverse children and the children themselves during the school day, recognising that there is a demand for support amongst those who are not accessing support through the education system.

3. Have disabled and neurodivergent children and young people been discriminated against because of their disability or because they are neurodivergent?

Parents of children and young people with a disability or neurodiversity, consistently tell us that they perceive high levels of discrimination in school environments based on disability or neurodivergence. For most, they describe that this discrimination occurs due to a lack of understanding of their child's disability or neurodiversity and of statutory responsibilities to understand, plan for and meet their needs. A lack of training for teachers and school-based staff on identifying and supporting neurodiverse children is described by parents as a significant barrier to both inclusion and the creation of spaces that recognises and celebrates difference.

Many carers with children whose disability isn't visible or who are neurodiverse describe the behaviours exhibited, that are a direct result of unmet needs in the classroom, are often erroneously labelled as 'bad behaviour'. Many parents describe experiencing what they perceive as discrimination from school staff and find it difficult to get the school to take their concerns/grievances seriously. This in turn, is a barrier for them when they try to get support for their child in school.

4. What impact do these issues have on disabled and neurodivergent children and young people's mental health and wellbeing and how well do they do at school or nursery?

Many parent carers describe that their disabled and/or neurodivergent children's mental health and wellbeing is negatively impacted by the challenges they've faced or are facing at school. One of the main frustrations children feel is that they're not being listened to by teachers and school staff when they express a need or preference. One parent said that for her child, being ignored has "pushed her so far, that she internalises her issues, and the only way to go is crisis point".

Many parents shared stories that captured experiences that led to their child reaching crisis point before concerns were taken seriously. These experiences of disabled and neurodivergent children not being heard and valued is contrary to the aspirations within the new Curriculum for Wales, where schools should draw on learner voice and respond to learners' needs, experiences and input.

Not having the support they need at school, or not being at the correct type of school, can lead to school avoidance, which in turn leads to missing out on education and negatively impacts attainment. Parent carers report

that managing the challenges their child faces at school has a negative impact on their own health and wellbeing. The effects can be significant and enduring and often impacted the whole family.

It is common for parent carers to describe that the issues faced by their disabled and neurodivergent children also has an impact on the other children in the family. One parent said: "I'm the only one that can support my son...that also means my other children bear the brunt of that".

Despite a number of ways for carers to access respite in Wales, including ' (part of Welsh Government's Short Breaks Scheme) which is facilitated by Carers Trust, the majority of parent carers we spoke with hadn't accessed respite / a short break and weren't hopeful about the prospect of having a break from their caring role. For many, the inconsistency of access to education and concern about needing to always be available for their child made making and keeping plans for themselves impossible.

It is worth noting also that recipients of the Carers Support Fund Wales, a Welsh Government fund distributed by Carers Trust to help reduce financial vulnerability, is in significant demand amongst the parent carer community. Therefore, it is important to note that many children with a disability or neurodiversity live in families who are experiencing poverty or are financially vulnerable. The relationship between inequitable access to education for disabled and neurodiverse children and access to employment for their parents is an area that requires further exploration. There is clear evidence that living in poverty has a negative impact on a child's mental health and wellbeing and it is important to fully understand the important role education plays in creating a context within which parent carers can seek and sustain employment.

5. What are the barriers for schools and childcare providers in providing inclusive and accessible education?

The evidence from parent carers suggests that there are two key barriers to schools and childcare providers providing inclusive and accessible education: lack of funding/ resource and adequate understanding of the needs of disabled and neurodiverse children.

The lack of funding and resources to be able to cater to different educational needs is something the parents carers describe having high levels of empathy with school staff about. It is clear that there is significant good will amongst teachers and school based staff. Parent carers often describe circumstances where the class teacher wants to be able to do more to support their child but is limited by school budget, access to support staff or access to specialist referrals. In particular, one parent

described a key barrier to accessing a pathway to diagnosis for their child was an assessment by an educational psychologist. The class teacher supported the need for this assessment, agreeing that a diagnosis would be helpful along with expert recommendations as to how to better meet the child's needs in the classroom. However, the school had used up its total number of "slots" with the educational psychologist that year based on the service level agreement in place. Other children with more significant or obvious needs had been prioritised. No budget was available for an additional number of consultations for the school with an educational psychologist.

Many parent carers describe having experienced schools and providers identifying cost as a barrier. This includes costs associated with important diagnostic pathways as described above, especially for children showing traits that may suggest and autism spectrum disorder. Parents highlight that teachers haven't had sufficient specialist training to enable them to create a supportive and inclusive environment for their child. This is particularly prevalent amongst parent carers of neurodivergent learners.

In an engagement session funded by Welsh Government to support the work of the Ministerial Advisory Group for Unpaid Carers one parent described that their child's school "held their hands up" and said that they wanted to help, but are unable to because they didn't know how to or have the time due to the pressure to focus on attendance and attainment.

6. How well do schools or childcare providers talk to disabled and neurodivergent children and young people, and their families and keep them informed or include them in decisions and choices?

Perhaps the strongest message from parents of disabled and neurodivergent children and young people, is that they are the experts on their children and they should be consulted on any decision regarding their child's education. Many parents are aware of their right to be included but feel that in reality it was a challenging and sometimes frustrating process to navigate

Many parent carers described that getting schools and local authorities to listen to them is "almost impossible". One parent, whose story is similar to many, said that the school wouldn't take his concerns seriously because the child is "fine" in school. However, there is clear evidence that for many neurodiverse children the negative impacts of coping throughout the school day without appropriate support can result in behaviours and feelings that are only expressed at home.

One parent described the importance of working with parents as partners in ensuring access to and achievement within education: “Please actively listen...we are not the enemy, we’re here because we know our children the best”

Instead of keeping the family informed or including them in decisions and choices, some parents we’ve engaged with express that they have a negative relationship with their child’s teacher. Some describe a “bullying” or blame culture which left them feeling responsible for the behaviours exhibited by their child as a result of inadequate recognition and support in the classroom. Again, this potentially highlights gaps in teachers and school staff’s understanding of the presentation of some disabilities and neurodiversities when needs have not been properly met.

7. Do disabled and neurodivergent children and young people and their families feel they get the same choices as other children, young people and their families?

As described above, a lack of adaptation to tasks or classroom management can result in disabled or neurodiverse children being unable to fully participate in all aspects of school life. This might mean not being able to complete tasks or group work in the classroom, accessing opportunities for play and time outdoors or ability to participate in school trips and activities.

For some, adaptations to support their needs only go so far as ensuring that they can participate – not that the way they participate is optimal, or equal to that of children without a disability or neurodiversity. Many of the choices that would better meet these children’s needs are not available either because of understanding, time or resources.

Some parents report a pressure to go on school trips with their child to manage their behaviour or because their child is seen as more of a risk. This inevitably places pressure on parents and may be impossible for parents who are in work or have other caring responsibilities. This is more likely to be a barrier in mainstream settings.