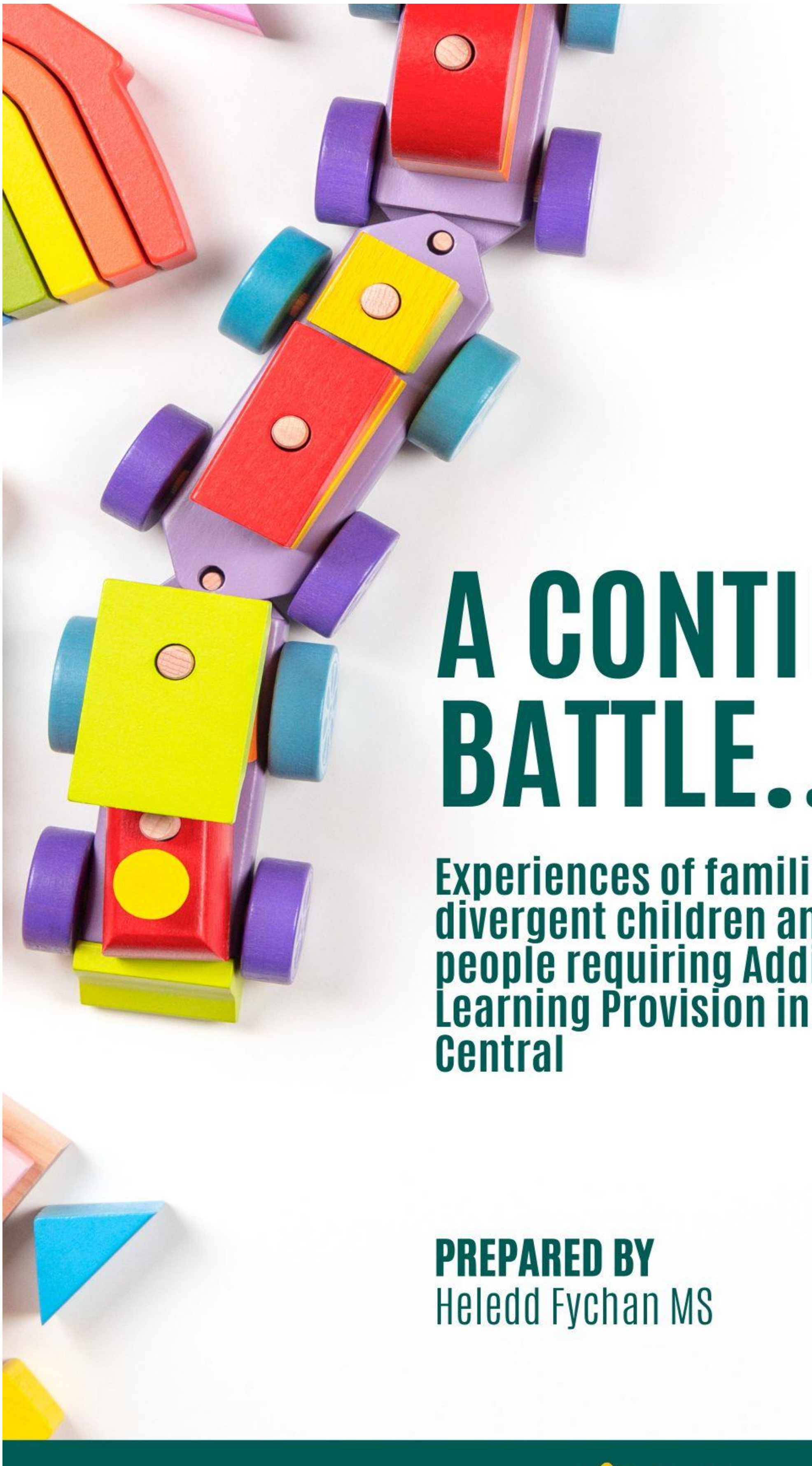
Cyflwynwyd yr ymateb hwn i'r Pwyllgor Plant, Pobl Ifanc ac Addysg ar gyfer yr ymchwiliad: A oes gan blant a phobl ifanc anabl fynediad cyfartal at addysg a gofal plant?

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 78
Ymateb gan: Heledd Fychan MS
Response from: Heledd Fychan MS



2023

A CONTINUOUS BATTLE...

Experiences of families of neuro divergent children and young people requiring Additional Learning Provision in South Wales Central

PREPARED BY
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Rights of disabled children include:

- The right to join in with activities, and their disability shouldn't stop them from taking part.
- The right to join in and feel included at school.
- The right to get special care if they need it.
- The right to choose what they do and have a say in choices about their lives.
- The right to be included in their local community and to do the kinds of things that non-disabled children do[1]

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[1] https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/morris-Disabled-children-the-Children-Act-and-human-rights.pdf Jenny Morris
(Talk at 'Young and Powerful' Conference, organised by Disability North: 26 May 1999)

In the words of one parent who wrote to me:

It is one, long draining, exhausting, soul destroying fight and battle just trying to get your child the educational provision they need and deserve. Some kids get that in the form of specialist SEN provision but most are just left to utterly struggle and suffer and are left, like me with emotional and mental trauma and damage from school and the complete lack of support….

Over the past two years I have witnessed a sharp increase in the number of constituents who have approached me, asking for support to advocate for a suitable education for their child. All of these calls for help came from parents or carers whose children have an Additional Learning Need. Their stories are often heart breaking, passionate and brave. I felt it was important their voices are heard. This report has been prepared in response to the Senedd's Children and Young People's Committee conducting an investigation to find out if disabled and neurodiverse children and young people have equal access to education and childcare. A survey was disseminated through social media in Rhondda Cynon Taf, Cardiff and The Vale of Glamorgan and we are grateful to the 117 people who took the time to respond and to the organisations who helped us reach out to parents and carers.

I have tried to stay true to the sentiments and information shared with me in a manner which is mindful of protecting personal details. For this reason occasionally a quote may have changed slightly in order that it cannot be attributable. An option for children and young people to answer was also made available although the numbers of returned questionnaires were very small. The testimony here is from parents and carers only.

Respondents

115 people responded in English and 2 parents responded in Welsh. 69% of them live in Rhondda Cynon Taf, 19.5% live in Cardiff and 11.5% live in the Vale of Glamorgan.

79% of the respondents had children who attended English medium schools, 17% had children in Welsh medium schools and just under 10% indicated their children were either receiving elective home education or home schooling. A small group of under 5 parents said their children had experience of both English and Welsh medium education.

School Life

I. Formal Curriculum Lessons

We asked

"To what extent is your child able to access formal curriculum lessons the moment"

Answers given:

1: Completely (20.5%) Some of the time (43.8 %) Not at all (35.7%)

Parents offered 80 different comments about this which are summarised below.

The long road

Many respondents made comments alluding to the slow process of getting their children's needs acknowledged, assessed and diagnosed. Seven people specifically mentioned the frustrations of being in situations where there they were waiting assessments to be made so that they could then access a suitable ALP. Timelines of 2 years up to 4 years were mentioned. The emotional impact of this has a clear impact on some families:

> *"I am now burnt out trying to fight the system.....Nobody listens to you........it is one long, draining, exhausting, soul destroying fight and battle just trying to get your child the educational provision they need and deserve"*

The child's experience – 'misunderstood' 'naughty' and 'overwhelmed'

Descriptions of children's experiences ranged from being "overwhelmed" (a term used 8 times by parents) to being "anxious" which 6 parents told us and children struggling with the demands made on them.

A few parents went on to share examples where their child's reaction to the overwhelming stimulus of the environment would result in a meltdown which was then punished by teachers or teaching assistants, with the child or young person becoming labelled as naughty.

School Environment

Aspects relating to the environmental stresses that a school environment can place on neuro-diverse children also featured clearly in responses. The most frequent mentions were of the noise, sounds and smells of schools being difficult for children and young people. Several people mentioned that there was no quiet area. Four parents mentioned that technical support for accessibility that should have been in place following a discussion and agreement with the school on transition or during IDP meetings, was not followed through as promised.

One to One support

Many parents were of the opinion that a key part of whether their child could access a full formal curriculum was them having 1 to 1 support. Six people mentioned that there were no Teaching Assistant support nor any extra help offered to their child. Five people mentioned that the support was part time or irregular and 13 children / young people were only able to access a reduced part time timetable. Four families have reached the point of opting out of the system altogether and were home educating with another two families having support from the EOTAS provision.

Funding was mentioned by three parents who felt this has been a barrier to getting one to one support

Skills and training of staff

There were 17 comments that mentioned there being no additional learning provision being in place or staff who were unskilled or uninformed about neuro-diversity. Three people shared the view that teachers and schools could not "cope" with their children and 5 thought that their children could not "cope" with the school.

> *"School had no knowledge of special needs although they did try their best but admitted they were not equipped"*

Support in Welsh

One parent stated they had moved their child out of Welsh medium school to an English medium school " *as the support is very limited*"

I. School Trips

We asked "To what extent is your child able to access school trips at the moment"

Completely (29.2%) Some of the time (31 %) Not at all (39.8%)

Parents offered 71 different comments about this which are summarised below.

Suitability of the Trip

25 parents said their child had not attended trips due the destinations and plans not being suitable for their child's needs. The reasons for this ranged from facilities not suitable, mode of transport not being suitable, destination being a noisy location or that the trip would likely cause anxiety for the child or young person and so they did not choose to attend.

"They are aimed at neurotypical children. Coaches are noisy and a sensory nightmare. The venue and toilet access is usually not suitable either"

Suitable and safe support

The lack of 1:1 support for children or young people was cited as a reason for them not being able to join school trips. For some, having a parent attend was a solution, but for others this did not seem an option.

Six parents mentioned this problem specifically.

"No additional Support when on trips"

"My relative[1] doesn't go on school trips because the school doesn't provide his one to one care longer than a few hours a day".

It was clear that the willingness and availability of parents to accompany their child on a school trip is the deciding factor on whether a child can experience a school trip. 14 parents mentioned that they were expected to attend in order for their child to be able to go on the trip with some reasons offered such as: the health and safety of the child, managing diets and personal care needs. Two families stated their child had not attended school trips due to them not being able to accompany their child for work reasons.

A few parents mentioned how this singled out their child for different treatment:

"I was the only parent to go"

Exclusions and punishment

The word “excluded” or “exclusion” was used five times by parents. There were also other indications by parents of this being a recurring theme such as the times parents mentioned their children were ‘not included’.

> *‘Our child wasn’t invited to the festive event and*
>
> *wasn’t given the opportunity to be there with their friends[1]”*

A few parents stated that their child:

> *“doesn’t go on school trips”*
>
> *“is not allowed to attend trips / breaks”*
>
> *“is not included in school trips”.*

One parent noted that the situation was imposed as a punishment by the school due to behaviours which in their opinion were poorly managed Autism traits.

Special School provision / home educated children

Two parents mentioned that since their child was placed in a special school their children were able to access trips for the first time. Home Educating parents also mentioned they had the freedom to plan trips according to their child’s needs.

Finances

Lack of financial means was cited a reason in one case for a child being unable to attend school trips.

II. Extra- curricular activities

We asked “To what extent is your child able to access extra- curricular activities at the moment”

Completely (14.4%)   Some of the time   (24.3 %)   Not at all (61.3%)

Parents offered 111 different comments about this which are summarised below. There were recurring themes.

The high level of responses for this question was noted and on considering comments the themes were so clear they can be categorised by the presence of certain words alone.

The experiences described were divided into two broad categories. There was a large group of parents who commented that mainstream clubs and activities were not suitable provision for their children. The reasons cited for this were many and included:

“needs not understood” “staff not trained” “sports clubs too competitive” “no time to give extra support” “too many children there” “too noisy” “too exhausted” “not safe enough” “my child gets ridiculed and bullied” “no adaptations made”

Other parents noted that provision that is and should be suitable for their children was almost non- existent. This included sports clubs, breakfast clubs and holiday clubs.

A few parents said their children had good experiences accessing provision run by different charities but that securing a place on such a provision was extremely hard as demand for places outstripped supply.

Lack of funding for 1:1 support staff to enable children to participate was mentioned by five parents.

It is clear that there are some good accessible and inclusive clubs and activities in the area but they are few and far between. The majority of children do not have access to suitable and accessible out of school activities.

In a word analysis of all the responses received, the word that appeared most often was

NEVER

ARE NEURODIVERSE OR DISABLED CHILDREN AND YOUNG PEOPLE BEING EXCLUDED FROM ASPECTS OF EDUCATION AND BEING TREATED UNFAIRLY?

There were two questions that elicited information about parents experiences and views on whether they believed their children and young people were being excluded or treated unfairly:

1. *Do you feel that your child is excluded from certain aspects of their education (or childcare) because of their disability or neuro divergence?*

Completely (64.6%) Some of the time (21.2 %) Not at all (14.2%)

2. *To what extent do you believed your child is treated unfairly due to their disability of neuro divergence?*

Completely (54%) Some of the time (34.2 %) Not at all (11.7%)

Respondents had an opportunity to elaborate about their experiences. 78 people and 71 people chose to share comments in response to these two questions and there were recurring themes. We have tried to summarise the main messages below.

"They are slipping through the cracks neglected and ignored. Their rights are not being met, which pains me as I have a very articulate child who I know with the right help will thrive"

The following examples were cited as evidence of exclusion and / or unfair treatment:

- Lack of 1:1 support
- Lack of professional understanding of neuro-diversity
- Environmental factors
- Pace of the school day
- Sensory demands on pupils
- Lack of technology being used effectively
- Reliance on reading and writing in curriculum excluding children with dyslexia

Parents consistently shared the sentiments that their children could not access

- Breakfast clubs
- After School clubs
- School Holiday clubs
- Sports clubs
- School trips

A new theme of significance emerged in the comments which showed considerable concern about the psychological damage being caused to children and young people and the bullying that they suffer.

Bullying

Several parents mentioned that their children had been bullied in school. In the words of one parent:

> *"Not enough attention is given to the social integration within groups in the school. (My child) has repeatedly been the victim of bullying from neurotypical pupils who regard her as an easy target. Often the solutions to problems advocated by the school involve her having to make changes to her routines and behaviours rather than the bullies themselves."*

Another parent reported:

> *"My child has no friends and was horrendously bullied for a long time. School did not deal with it. She hated school and frequently refused to go"*

Psychological damage

Parents told me that many children and young people who are neurodiverse are experiencing psychological damage due to their experience of being excluded and not understood.

Examples of children being punished and labelled as "naughty" was described by 4 parents.

> *"My son has been good for 4 months with no bad behaviour but if there is an incident they escalate it and threaten exclusion"*

12 parents described their children having psychologically damaging experiences. It is not possible to gauge whether these were short term or prolonged and repeated experiences. These comments give a flavour of what appears in the responses:

"We had to watch our 4 year old in floods of tears because of how she was treated. We spent 10 weeks at home to build her confidence back up"

"He is neglected, left outside for his 'hour' of school, has no children with him and is stuck with two adults with no activities"

"My child does not learn the same as neurotypical child and the ADHD is a barrier to learning in a mainstream environment. Due to not being able to sit still and concentrate….XX has struggled to the point of being physically ill for years. This has resulted in developing a severe negative attitude towards school and learning"

"My child is autistic and has other conditions. She has trauma from a failed school placement too"

"School was causing more anxiety for my child. The system fails so many ALN children"

" my child will get told off, shouted at, called ridiculous, letters sent home about attendance because she get physically ill with sickness / headaches because of anxiety about school"

‘Unwanted’

The inclusion of this term as a theme in the responses may seem emotive. Reading the comments shared was difficult as several parents described feeling that their children were unwanted by others, based on their experiences. It is not clear whether they believe their children or young people also felt unwanted.

“xxxx wasn’t invited to take part in the Christmas Concert”

“No invitations to trips. No mention of clubs to attend. Feel unwanted”

“My child was not allowed to attend her school residential or school trips as the school do not have staff to supervise”

“His non- attendance has been actively encouraged by the school”

“My child has never been included”

“My child has not had any school photo, as she could not cope with echoes and space of the school hall, and no preparations were made for her”

MENTAL HEALTH AND WELL-BEING

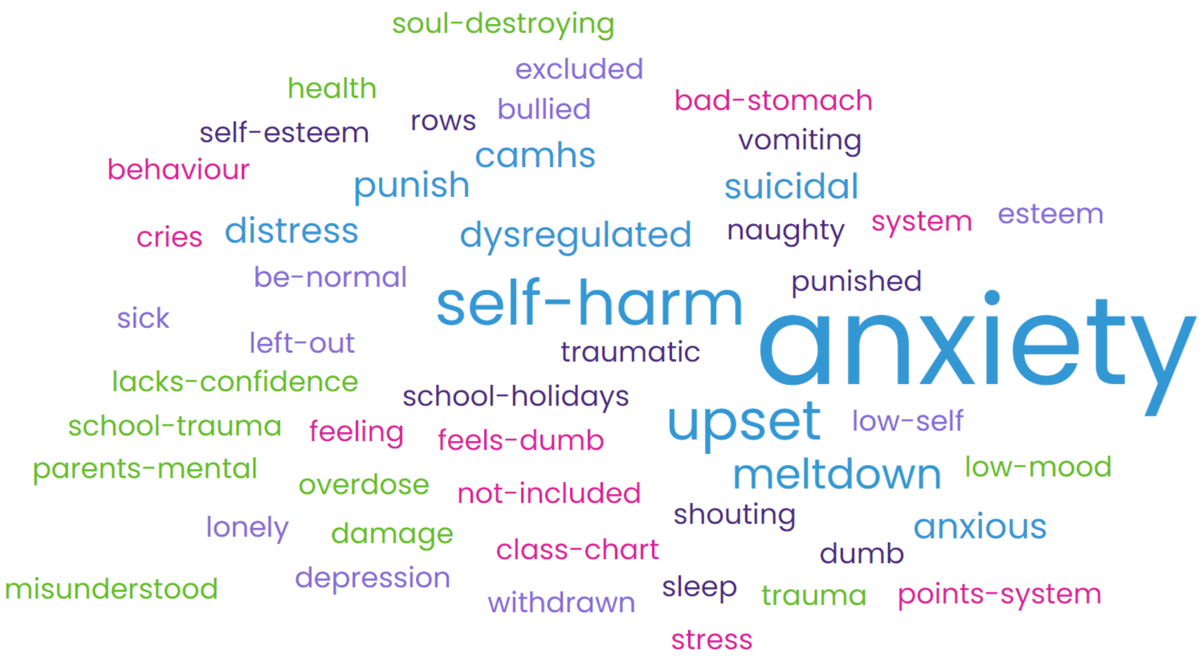
71 people chose to share their views with us about how their children's mental health and wellbeing are impacted. 113 answered the question:

Do these issues affect your child's mental health and well-being?

Answers given:

1: Completely (76.1%) 2: Some of the time (15.9 %) 3: Not at all (8%)

There was a notable repetition of the same words in the responses received to this question. Entering the top 60 words into a word cloud tool revealed the following picture



Impact on parental mental health

Several parents noted that their own mental health had suffered significantly due to trying to support their children and be advocates for them. The comments shared made upsetting reading and left no doubt that the overwhelming majority of those who replied were of the opinion that their child's mental health had been negatively impacted by the experiences of being neuro-diverse within the education system in Wales.

Communication and Consultation

We asked:

Does the school consult with your child about their choices and education options?

Completely 16.2%   Some of the time 42.3%   Not at all 41.4%

50 people submitted comments

Does your child receive clear information about their options and about any additional provision for them?

Completely (8%)   Some of the time (32.7 %)   Not at all (59.3%)

47 people submitted comments

Do you as parents of a disabled or neuro-divergent child, get effective information and support from Local Authorities and schools?

Completely (2.7%)   Some of the time (23 %)   Not at all (74.3%)

70 people submitted comments

Challenges of Communication within schools and Multi Agency

"There is no information and no pathway – we've been bounced between services"

"Once statemented nothing ever seemed to change and the dyslexia diagnosis doesn't seem to filter from year to year / teacher to teacher"

"The ALN and IDP process is a minefield and there is no clear route of support for children with additional needs. More transparency about the options and routes to access specialist provision would be helpful."

" The LEA are dire – they make you jump through hoops to get anything out of them…..Why do I have to be passed from pillar to post with family support services just to see a social worker"

There were divided opinions on the questions of whether or meaningful consultation was taking place, and it was a mixed picture.

Many parents did stress that they had positive experiences of communication from schools and 25 parents gave examples of schools trying hard to respect their wishes and their children's wishes.

"My child's school is fantastic at keeping us informed of their decision"

"There's no pressure. Our children's voices and rights matter at his current school, it's been amazing to see him progress"

"School are amazing, council not so much. I applied for a statement 4 times before my child had any support…. By then 2 years of education had been missed"

The subject of the Local Authority’s role was mentioned many times, all in a negative context:

> *“They make you jump through hoops to get anything…”*

The theme of the ‘**Long road to support’** was evident and one respondent chose to share here that they had waited from when their child was in Year 1 to when they were in Year 6 for an appropriate referral to a neurodevelopmental services.

Two other clear themes to emerge were:

1. Communication and having information was often parent led and parent initiated. Many parents had turned to charities to find support and one family even sought legal advice. Many parents had become experts by their own research

2. The other word that described many people’s experiences and which featured heavily in responses in this section was “**fight”,** due to parents feeling like they had to ‘fight’ for their child’s learning provision and their children’s rights.

Challenges according to parents

We asked: **What do you think are the reasons that prevent schools (or childcare providers) from offering a suitable provision for you child?**

106 Respondents provided written responses to this question. There were no prompts provided.

There was a clear consensus about what the challenges were, categorised as followed:

Funding:	Mentioned 56 times
Training / Qualification / Lack of understanding:	Mentioned 52 times
Resources and Staff	Mentioned 34 times
Out dated teaching / assessment	Mentioned 4 times
Lack of Multi Agency working	Mentioned 2 times
Bureaucracy / Long waiting times	Mentioned 5 times
Ethos, Culture. Environment	Mentioned 5 times

There was a myriad of comments offered, many reflecting the same issues that had already been shared. Some areas that were highlighted for the first time:

“The demands on teachers”

“More parental and pupil choice, involving pupils and parents in decisions making. New ALN code talks about a person centred approach and involving pupils and parents but this isn’t happening”

“The need for provision for outdoor schools / child led learning and therapeutic provisions need to be available for children who cannot access ALN units or mainstream”

“TIME”

“UNDERSTANDING, caring, equal and fair responses to situations, not prejudice and negative attitudes”

“Access to education. Access to healthcare professionals. My child looks like everyone else and therefore he is expected to be the same as everyone else. XXX has detention at school for not completing work like the rest of the class. Society is cruel”

“More varied teaching methods”

“Specialist provision in Welsh from nursery for children with attachment and trauma issues”

“Timescales, all the panels, professionals not listening”

“Bureaucracy! Also liaison between stakeholders, dated medicalised model of understanding in some areas”

“School funding and a Welsh medium ASD unit”

“A change in attitude for children with allergies. Allergy is the most common chronic condition amongst children yet the education system in Wales continues to do the bare minimum to help children feel included and safe”

Solutions according to parents

We asked: If you could change the situation for the better what would be your priority?

92 people answered this question and there were some recurring themes. We have tried to summarise the main messages and emerging themes below. These are ranked in the order of how many parents placed them on the top of their list. The top answer far surpassed any of the other solutions with a third of respondents saying the same.

- Training for all teachers and school staff
- Reduce waiting lists
- Less focus on curriculum targets to allow more time for individual needs, make examinations more inclusive, fewer compulsory subjects and more flexibility in alternative curriculum (outdoor subjects, bushcraft skills, lego therapy, art therapy equine therapy)
- More staff
- Mental health covered by IDP's and more emotional support and respite for families
- Accessible after schools clubs and holiday clubs
- Better pay for staff to improve retention
- Training for the Local Authority staff on equality
- More Educational Psychologist support
- Establish child diagnostic centres – early intervention
- Establish Welsh Language units for Autistic children
- Fund charities that parents are referred to by NHS
- Sensory rooms in mainstream schools
- Establish Autistic Pride in the Summer
- Appoint an Allergy Lead for Wales

"These children are wonderfully gifted and have so many beautiful ways of looking at life and it needs to be encouraged and explored"

Conclusion

The words and sentiments of the parents and carers who took a long time to share their views with us, speak volumes. From analysis of all the comments and responses the clear conclusion is that:

- Provision for the inclusion of neuro-divergent and disabled pupils in mainstream education in Wales is inadequate.
- Provision is understaffed and underfunded.
- The teaching profession has not been equipped to provide for the needs of neuro-diverse pupils, neither in terms of training or resources.
- The consequences of this lack of provision are costly, both in terms of resultant pressures on medical services and educational outcomes.
- The costs resulting from the pressures placed on neuro-diverse pupils, their families and other Support Services is incalculable.

◆