



TSANA is facilitated by
Hwylusir TSANA gan

Cynghrair Anghenion
Ychwanegol y Trydydd Sector
Third Sector Additional
Needs Alliance



PLANT YNG NGHYMRU
CHILDREN IN WALES

Evidence to the Children, Young People and Education Committee:

Education access for disabled children and young people inquiry

About TSANA

The Third Sector Additional Needs Alliance (TSANA) is a coalition of third sector organisations working with, supporting and representing a broad range of children and young people who have additional learning needs and disabilities. The Alliance is chaired and facilitated by Children in Wales.

TSANA works to improve the educational and training outcomes and opportunities for children and young people with additional learning needs and disabilities in Wales, ensuring they are valued, empowered, respected and represented.

- To promote the United Nations Convention on the Rights of the Child, particularly in regard to children and young people with additional learning needs and disabilities.
- To promote the United Nations Convention on the Rights of Persons of Disabilities
- To increase public and professional understanding of additional learning needs and disabilities in Wales
- To ensure local and national Government respect, reflect and address the needs of children and young people with additional learning needs and disabilities
- To provide a forum to support policy development in Wales
- To provide a united voice on key issues regarding statutory systems in Wales
- To promote partnership working across third sector organisations who work to support and represent children and young people with additional learning needs and disabilities

The evidence below has been provided by the following TSANA member organisations:

[All Wales Forum](#)

[Guide Dogs Cymru](#) in collaboration with [RNIB](#)

[National Autistic Society](#)

[National Deaf Children's Society](#)

[Natspec](#)

[Snap Cymru](#)

All Wales Forum of Parents & Carers of People with Learning Disabilities (AWF)

Quotes from parent carers of children and young adults with learning disabilities

"I've fought for two schools to be fully adapted here, one primary school and one high school and now they are finally going to do the field out a path going down and a classroom on the field so children can take part in activities like nature walks. Also planning just emailed me and looking like they've agreed with doing a race track that disabled children can use ready for sports day as last year it was so upsetting seeing my child struggle and also another little boy who uses a wheelchair and one with a frame (one child got stuck in the mud)...when my oldest was in school, sports days was often cancelled because of this....planning have said they'll give me information on the racetrack situation asap....proves it can be done"

Bridgend

"The pandemic created a situation where my child went from being in a mainstream school to being isolated in a mainstream school. The staff were encouraging my child to have lunch and break times on their own in a 'special area' rather than being included with other students. I could appreciate the caution, but it's ended up isolating them and also it's difficult to explain to a child why it would be better for them to interact with other children when they have the option to be in a room and access games etc."

Swansea

"I've always had to homeschool my child. The schools around where we live wouldn't take them and the nearest school was so far away logistically it wouldn't make sense, we would have spent all day travelling back and forth and with my child's disabilities, that wouldn't be possible."

Ceredigion

"Because of the pandemic, the school transport was suspended, which means we had to take our child to school, which we could do whilst we were working from home, but the transport service didn't start again, even after lockdown was lifted and schools had reopened and were back to normal, until we threatened judicial review. It shouldn't be like this; my child has a right to access school."

West Wales

Case study

Mother carer to an autistic young person living with cerebral palsy. Mom tells us that when the young adult was in high school, at times when staff could not cope with the young person's needs, they would leave them without support, even to physically move around the school, or would ask other pupils to support the young adult travel from one place to another. Mom also reported that the school would leave the young autistic adult alone when they were having an intense response to an overwhelming situation, also commonly known as a 'meltdown'.

Approximately a year later (2020), the young adult was diagnosed with cancer which started a two-year journey to fight, and thankfully overcome the cancer. This fight has unfortunately aggravated the cerebral palsy symptoms and the developed anxiety has caused further complications with their autism.

Upon returning to education, the school could not cope with the young adult's needs and again they were left alone without support, especially with the excuse of it be a Covid-19 prevention measure. Mom asked the Local Authority for a statutory assessment of the young adult's educational needs so they could move to a school that could better support their needs. The statutory assessment was refused.

As of the end of 2022, the young adult was at home because the catchment school is not suitable for their needs and the local council will not pay for them to travel to the new school until they have been through the statementing process which is being refused by the Local Authority. Mom is appealing the statement, but this will take time which means that in the meantime, the young adult is stuck at home and not getting their education, one of their human rights and hasn't been receiving a standard education ever since they joined high school in 2019 due to lack of support towards their needs.

Powys

Guide Dogs Cymru in collaboration with RNIB

In Wales there are 1,663 children and young people (CYP) with vision impairment (VI) known to local authorities in Wales. They have the same rights to thrive in education and beyond, as their sighted peers. Many schools lack the specialist skills needed to support a child with a visual impairment so provide universal support only. 80% of learning is through vision, and the lack of specialist support means that there is a significant attainment gap between CYP with VI and their sighted peers.

At Key Stage 4, GCSE results show a gap of greater than 26% for pupils achieving Level 2 (equivalent to 5 A* to C) including English/Welsh and maths, which needs to be addressed. If CYP with a VI are supported by a specially trained teaching assistant (TA) who is overseen by a Qualified teacher of the Visually Impaired (QTVI), a child can achieve their full potential. This specialist provision must be noted in the child's Individual Development Plan. Guide Dogs are concerned that research from RNIB's FOI request in 2023, shows that 12 local authorities in Wales have no QTVI and the ratio of QTVI to child ranges from 1:13 to 1:85.

Acquiring digital skills is particularly important for a child with VI. They must be taught by a specialist teacher who understands how to engage with the technology. This requires a good understanding of the different types of access technology (as children with VI may not be able to use a mouse, and others will require screen magnifying software). A parent of a child with VI told us she wanted her son to use technology which mirrored the classroom whiteboard. Initially the local authority didn't allow this, citing security. An alternative method was found which gave him the same classroom experience as his peers – but this is not always the case.

CYP with VI have lower wellbeing and poorer mental health than their fully sighted peers. Secondary analysis of the Millennium Cohort by RNIB found that at age 17, CYP with VI were five times more likely to 'feel depressed all or most of the time'.

The ALN and Education Tribunal (Wales) Act includes early years. Intervention from qualified habilitation specialists is vital for the child to thrive in education and beyond. We are concerned that the FOI report found the percentage of children and young people on VI service active caseloads who are accessing habilitation support from within education, ranges from below 9% to 48% while waiting times for habilitation support vary from 1 week to 12 months. This inconsistency must stop.

The Curriculum Framework for Children and Young People with Vision Impairment (CFVI) accessible via this [link](#), has been developed to support children and young people with vision impairment access an appropriate and equitable education. Stakeholders from Wales contributed to its development and Guide Dogs and RNIB believe it presents an approach for addressing many of the issues we have highlighted. We ask that the CFVI is:-

- Endorsed by the Welsh Government and recognised and referenced in Additional Learning Needs policies.
- Embedded in local authority service commissioning and delivery frameworks.
- Followed by all educational settings supporting children and young people with vision impairment and their families, in partnership with VI specialists.
- Embedded within quality standards and professional training for teachers of children with vision impairment and habilitation specialists in Wales
- Resourced via adequate centralised funding for local authorities so they can support their local VI populations.

The CFVI shares the ambition of the ALN system to support all learners to reach their potential and provides the evidence base on how this can be achieved for CYP with VI. One child who has a positive experience of education is Nell Sutton, who features in the Guide Dog TV advertisements. Further details of her story can be accessed via this [link](#). Nell's experience contrasts to Ryder who is 8. His mother Kirsty said "There is no specialist support at all for Ryder in school. He was being taught braille but that stopped a while ago. He got a magnifier from the local Optician, and that's all, he just has to manage. We do what we can to help but we have no experience of visual impairment. He is well behind in his school work and my husband and I are very concerned. Ryder has had mobility support from Guide Dogs out of school and that's gone very well, if we lived two miles away in Caerphilly, he would get support from the SENCOM service – that's so unfair, why should he suffer because he is vision impaired and just doesn't live in the right local authority"

These inequities in education provision and support available for CYP with VI must not continue.

National Autistic Society

The [National Autistic Society](#) is the UK's leading charity for autistic people. We aim to transform lives, change attitudes and create a society that works for autistic people.

We welcome the opportunity to contribute to this important inquiry. Unfortunately, anecdotal evidence and qualitative data indicate that autistic children and young people often do not have equal access to education nor childcare. Our charity is deeply concerned about the findings of research conducted Swansea University's School of Education into the education experiences of autistic pupils.

The study found that:

- 76% of autistic pupils said they have been a victim of bullying in school
- 28% of pupils said they do not feel safe in school
- 43% of autistic pupils said they were unhappy in school
- 77% told the study that school makes them feel anxious or worried
- 59% of pupils said they feel excluded at school

Pressures

Autistic children and young people can often face additional pressures. They may:

- struggle with the environment due to loud noises, strong smells or bright lights
- experience anxiety in social situations or find it hard to make friends
- get in trouble for unintentionally being rude or inappropriate
- find unstructured times such as lunch breaks hard
- struggle to cope with the demands of the school timetable or curriculum
- find transitions such as moving classrooms or school difficult
- take things literally or misunderstand a teacher's instructions
- find crowded assemblies or school transport too much
- become so overwhelmed they experience a 'meltdown' or 'shut down'

Understanding

Autistic children and young people tell us school would be better if staff understood autism. However, research shows only 28% feel their teachers understand autism.

Better understanding of autism would improve learning experiences, lower incidents of bullying at school and boost employment prospects.

All teachers will work with autistic pupils during their career – yet many aren't given training to understand their autistic pupils' needs, or what they can do to help.

Attendance

Some autistic children find the demands of the environment unbearable, leading to absence or 'school refusal'. It's a term some feel unfairly implies the child or young person has a choice, when they may be willing but unable to tolerate school.

Autistic children and young people are vulnerable to being excluded. Nearly a quarter of parents say their child has faced exclusion through isolation or externally through fixed-term or permanent exclusions.

Home education

Parents often tell us that they feel like they've been left with no choice but to home school due to a lack of support when they would rather their child was educated alongside their peers to develop the skills they will need to navigate the world. We are concerned by anecdotal evidence of parents feeling pressured into 'off-rolling' in the interests of the school rather than the child's best interests.

Childcare

Our charity is concerned about the lack of suitable childcare provision. Even where specialist private provision exists, the financial cost can be a significant barrier. Families tell us they feel discriminated against in accessing free childcare because mainstream public-run nurseries often do not cater to their child.

Learner travel

Autistic learners and their families tell us transport can be a significant barrier to accessing education. We are concerned that older autistic pupils, who often attend further education beyond age 19, are not currently being served by legislation.

The availability of transport varies widely – some local authorities include colleges and sixth forms in post-16 provision on a discretionary basis while others don't. We believe post-16 travel should be brought into the scope of the Learner Travel Measure to ensure it better aligns with the Additional Learning Needs Act.

National Deaf Children's Society

- Deaf children face inequitable service offers across local services in Wales. Deaf children and their families in different parts of Wales can receive different levels of provision, and an unequal access to education services compared to their hearing peers.
- A Rights based approach to British Sign Language in Wales is needed, with specific reference to Articles 2, 18 (2), 23, 30 and 31 of the United Nation Convention on the Rights of the Child (UNCRC).

Deaf children do not have an equal access to education and childcare compared to their hearing peers. Deaf children and their families have a right to access sufficient provision of services and British Sign Language (BSL) in the early years.

For example, deaf children need access to communication, language, services, health provision, audiology services, hearing aids, cochlear implants and Teachers of the Deaf.

	Deaf children face inequitable provision across local services in Wales	A Rights based approach to British/Family Sign Language in Wales
Education access for deaf children and young people	<p>Increase the number of Teachers of the Deaf in Wales to reverse the decline – Teachers of the Deaf are expected to cover for gaps in the workforce.</p> <p>Implementation of ALN reforms is inconsistent – we need to move away from a deficit model and towards an enabling model.</p> <p>Workforce differences across the Deaf education services in Wales.</p> <p>Training and upskilling the workforce around deaf awareness and reasonable adjustments, under the Equality Act 2010.</p> <p>Deaf children and young people can be more vulnerable to experiencing difficulties with emotional wellbeing and mental health.</p> <p>Deaf children face limited access to childcare, pre-/post school activities and holiday care often because the provision is not deaf friendly, staff are not aware of how to use equipment or the right communication adjustments have not been put into place. For example, are Flying Start Leads engaged with and</p>	<p>Deaf children should have a right under the UNCRC to access BSL education (Articles 18 (2), 23, 30 and 31). Deaf children do not currently receive this right particularly in the early years. Refer to Family Sign Language stats.</p> <p>80% of services neither provide, fund or commission any courses in sign language to families. Deaf children are not receiving this right.</p> <p>We want to see an awareness by commissioners of the rights of deaf children under the UNCRC (in line with Article 2).</p> <p>Pressure from Government and other bodies for services to meet this right.</p> <p>The number of qualified BSL tutors in a local authority area.</p>

	<p>meeting the needs of deaf children and their families?</p> <p>Service offer to deaf children should be needs led not service led. For example, for settings to meet the needs of deaf children it is essential families, settings and schools have clear diagnosis and an Individual Development Plan in order to drive the supply chain on what is needed locally.</p>	
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Natspec

We are concerned that equal access to post-16 education and training for young people with complex ALN is threatened by ALN reform.

This is because Chapter 17 of the ALN Code is unclear about what further education means for a young person with complex ALN leaving special school and also because funding arrangements for learners whose additional learning provision is a specialist FE college will move away from the Welsh Government support for learners division to local authority control.

We believe that the changes in funding arrangements will result in some young people not having the FE opportunities they would previously have done. This scenario is made more problematic for learners requiring joint funding from education, social care and/or health budgets at the time they may be moving from Childrens' to Adult services and seeking placements at specialist colleges.

Most young people with complex ALN stay in school until they are 19 years old and to date under the SEND system, Welsh Government have used what they have called discretionary powers, to ensure these school leavers can access further education and training whether that is at a mainstream FEI or a specialist FE college.

In the new system, the Additional Learning Needs (ALN) code states a two-year entitlement to education and training, but it is unclear if this is a post-16 or a post-school entitlement. Furthermore, for learners with complex ALN, local authority officials will be required to assess a 'reasonable need' for education and training and there is no expectation that the discretionary powers are maintained to ensure all learners regardless of the challenges they face can continue to have equitable access to post school further education and training.

We are concerned that parity of opportunity for young people with complex ALN to access further education is being put at risk and that this is of particular concern for young people with low incidence and complex ALN whose needs cannot be met by a FEI.

We are further concerned that uncertainty over how or if local authorities work with Careers Wales will jeopardise timely transition planning and access to sufficient and timely impartial information and guidance on post-16 options.

We are already aware that the ambiguous criteria in the Code (17.75) is being interpreted differently by stakeholders and have called for Welsh Government to provide clarifications and guidance. We don't believe it is acceptable for learners with complex ALN to face barriers to FE compared to their less disabled peers and it is not acceptable to wait for the code to be tested by Tribunals and their associated costs, and stress on young people and their families.

Snap Cymru

Family, Children and Young Peoples Charity SNAP Cymru, comes with a unique perspective, and is Wales' leading ally for Parents and carers who have CYP with ALN, Neurodivergence and disabilities. Working throughout Wales from SNAP Cymru offices, drop in centres, surgeries and by providing families with home visits when needed, we work

holistically with families in an empowerment model, providing accurate information, objective advice and direct independent professional specialist casework, Avoidance of Disagreement, Disagreement Resolution, Disability discrimination in education, formal mediation, advocacy, support and training for a range of issues.

We also help with complaints to School, Further Education Institutes FEI or LA. PSOW, Health and Social Care, Welsh Language Commissioner, Children's Commissioner for Wales, Administrative Court for judicial review. Working with families and partner statutory and voluntary sector agencies in partnership, we develop and provide services designed to meet the needs of the 'whole family' with an emphasis on prevention and protection to reduce the need for formal action. We have been doing this for nearly 40 years and bring a wealth of experience, along with the Legal Aid Agency's Specialist Quality Mark for Education Advice.

Exclusion and Discrimination

Last year from April 1st, 2022, to March 31st, 2023, we worked with nearly 6,000 cases, supporting families to resolve over 8,000 matters. From these matters:

- Over 600 children and young people have been excluded (or were at risk of exclusion) from aspects of education due to their ALN, disability or neurodivergence (SNAP Cymru data 2022/2023 – all cases where the main matter was exclusion).
- Nearly 1,200 families and children feel that they have been affected by direct, indirect or discrimination arising from ALN, disability or neurodivergence (SNAP Cymru data 2022/2023 – all cases).

Families come with a range of issues, and many have barriers to accessing education due to their ALN or disability. The case study described below is indicative of the issues families face. It should be noted that many families do not realise that their child is being discriminated against, and in many instances inadvertently support school or setting, often to the detriment of the family who may not be able to pursue employment, education, or training as they are 'on call' as in this case where the children were both excluded and discriminated against:

Case Study

Client background: Twins from Asian background where English was not preferred first language. Both children were under assessment looking at possible diagnosis of autism. Delays in diagnosis and pending delays in being seen by Consultants within the Health board delayed further information awaited from health confirming needs/diagnosis so school could offer support.

The twins remained on role of a mainstream nursery, but only allowed to attend for up to 1 – 1.5 hours a day. Unfortunately, this varied and often they could be in the setting for just 30 minutes before school were ringing parents to pick them up as setting said they could not manage their needs. This was not unusual and was happening on a regular basis.

The twins were not experiencing any educational opportunities and were not supported to socially engage with peers of the same age who were all attending setting full time. Parents felt they were treated less favourably, not only because of their difficulties but also because of language and cultural barriers. Parents explored returning to India to enable diagnosis as to them, the system seemed quicker in India and family were also aware of how it worked there. They had no idea about the process and understanding of how additional learning needs are met in Wales. It served to confuse and overwhelm them and they voiced they felt isolated, alone, and unable to understand how to move forward.

What we did and how it made a difference: Presenting issues and rights explored: SNAP Cymru caseworker supported parents in the first instance with Equality Act and reasonable adjustments. They considered language barriers and asked if an interpreter would be supportive and talked to family how we could overcome language barrier in the first instance to enable their understanding about how the ALN process works, and work with them to explore options to move forward.

Father identified that if communication was presented in emails in English, rather than verbal, this was something they could respond to as they could be supported by family members to compile responses and questions to promote their understanding. We also identified any face-to-face meetings could be supported by requesting an interpreter be available and family felt this would be good, however, communication via emails worked well enabling caseworkers to inform and empower family around Rights in line with meetings their children's needs.

Permission was gained from family to advocate their concerns and work closely with school to gather all information around twins needs. Caseworkers worked with Local Authority on behalf of family to explore avenues of support available to aid school to increase time in school and provide inclusive opportunities. Caseworkers requested professional reports to look at suitability of placement as parents felt the mainstream setting was not specialist enough to meet the twins' complex needs. Family asked if Local Authority would consider specialist placement whilst ongoing assessments via Health looking at possible diagnosis for autism continues.

Parents were included through adjustments made to support communication and felt they had a voice and being empowered and informed around process and ALN system. They were supported by SNAP Cymru to navigate and ask questions and have choices relayed to relieve their anxieties that their children's needs would be met, and they could finally attend a setting full time.

SNAP caseworkers advocated for family, gathering further evidence, presenting to Local authority, working closely with school to ensure evidence was gathered and shared, enabling Local Authority to take to panel to agree and explore specialist placement along with consideration for transport to and from provision.

SNAP Cymru caseworkers supported family to visit specialist settings once Local Authority suggested possible placements and supported family to ask questions to settings to ensure they were happy and felt included that they were making the right choice before accepting any placement offers (during visits SNAP arranged for an interpreter to come along to ensure possible language barriers were addressed). Family offered support to work closely with school and involvement of local community group to support language barriers with GEMS also able to provide direct support to school whilst working with twins.

Options presented to family - A specialist placement in Newport to support autism identified for twins who could start the following term with a supported enhanced transition plan, which involved existing mainstream setting providing one to one support to attend new specialist setting to build up familiarity and support the development of plans such as 1 page profile identifying twins needs and Additional Learning Provision (ALP) to meet their needs. Local Authority Individual Development Plan's (IDP) in process of being drafted with parents fully included in the process. Caseworkers identified local services to offer ongoing support to family which included Barnardo's family support, GEMS interpretation service and local parent groups and facilities within Serennau Centre, Newport led by health professionals to support family with further interventions and links to other families.

Outcomes

- Twins accessing full time placements in specialist unit provisions in Newport local authority.
- Individual Development Plans identifying additional learning provision in place – these are legal documents ensuring needs met as twins move through educational process.
- Legal Documents and information translated into families first language if requested which empowered them to be fully involved and include.
- Language barriers overcome with support of both interpreter, preferred communication via email agreed and used, adjustments for family members to offer support.
- Involvement of other community services to support language barriers moving forward.
- Parents less anxious, feel happier their children included and access educational opportunities and making friends.
- Family empowered and informed around ALN process and Rights in line with access to education and know who to ask for help and support in the future if any further concerns arise via SNAP Cymru and they have links to all information around how best to support your child with ALN via SNAP resources, websites where documents can be translated into their preferred language if required.
- Health diagnosis of Autism given and confirmed and family accessing support from other agencies to support understanding of autism, parent groups.
- Referrals made by SNAP Cymru and supported by school to Barnardo's to provide ongoing family-based support.
- Communication, relationships, and trust has enhanced for family working with all professionals offering support for the twins.

Information and support

Whether parents of disabled and neurodivergent children and the children themselves receive effective information and support from local authorities and schools. It is a challenging area. Information is available from a variety of sources. For example, SNAP Cymru provides a comprehensive range of accessible information which is independent, accurate and impartial. However, we are concerned that some information may not be accurate, or may be biased towards local practice rather than legislation and regulations.

We are pleased that most Local Authorities have continued to commission SNAP Cymru to provide Information, Advice and Support as per 6.10 of the ALN Code. However, Cardiff, Swansea and Pembrokeshire have their own arrangements. Where SNAP Cymru provides it, families have the full access to information, advice, and support, including specialist casework, disagreement resolution, support for discrimination, and advocacy. Working with 6,000 families and at capacity, we understand that this is a small proportion of families who have children with ALN and disabilities in Wales, so there is still an unmet need.

Local Authorities have a duty to provide information, and although the ALN Code sets out this duty in Chapter 6 SNAP Cymru believes that its instructions are not strong enough. For example, 6.8 says 'There are lots of ways in which local authorities can provide information and advice about its ALN services, including leaflets, posters, websites, face-to-face contact centres, and telephone helplines'.

It is fair to say that the availability of good quality information from some Local Authorities and schools is patchy, and without this availability some families will be at a disadvantage, and possibly Childrens Rights will be eroded.

At the recent from SEN to ALN events commissioned by Welsh Government and delivered by SNAP Cymru, families told us that they 'need much more clear information and support than in Independent'. In the final report, we found from feedback given to us by families, that access to information for parents and carers of children and young people with ALN is highly variable across Wales. However, some families reported feeling well informed and up to date about ALN processes in their area, which is very positive.

There is a huge concern from SNAP Cymru that unless families can access free quality assured independent information and advice, this will not support the aspiration of the new ALN Act that it will help to resolve disagreements at the earliest opportunity and enable parents/carers and young people to fully participate in the decisions being made about their children. Lack of information promotes a '*done too*' culture rather than a '*done with*'.