

**Cyflwynwyd yr ymateb hwn i ymgynghoriad y [Pwyllgor Plant, Pobl Ifanc ac Addysg](#) ar [Flaenoriaethau'r Chweched Senedd](#)**

**This response was submitted to the [Children, Young People and Education Committee](#) consultation on [Sixth Senedd Priorities](#)**

**CYPE SP 86**

**Ymateb gan: Chris Haines, Rheolwr Materion Allanol, Cymdeithas Genedlaethol Awtistiaeth Cymru**

**Response from: Chris Haines, External Affairs Manager, National Autistic Society Cymru**

---

Beth yn eich barn chi yw'r prif flaenoriaethau neu'r materion y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd? Os oes modd, nodwch eich barn o ran sut y gallai'r Pwyllgor fynd i'r afael â hyn.

What do you consider to be the main priorities or issues that the Committee should consider during the Sixth Senedd? Where possible, please set out your view about how the Committee could address them.

**Thema 1: Addysg oedran ysgol | Theme 1: School-age education**

**Additional Learning Needs (ALN)**

Autistic children and young people may need additional help and support with education. Some will need highly specialised education while others will follow a more mainstream path. The most recent figures from the Pupil Level Annual School Census show that 5,265 autistic pupils have a statement of special educational needs. This means that more than one in five pupils with statements are autistic. A further 4,553 autistic pupils are receiving support through the graduated response system.

We know the current system is not working for autistic pupils, who have lodged more appeals than those with any other condition, according to the Special Educational Needs Tribunal for Wales' annual reports. The statistics show the number of Autism Spectrum Disorder-related appeals more than doubled between 2012 and 2018. One test of the Additional Learning Needs and Education Tribunal (Wales) Act, and its accompanying code, will be whether it leads to a reduction in the alarming number of appeals, with more autistic pupils receiving the education they deserve.

NAS Cymru is concerned about implementation of the ALN code, particularly reports of misleading messages being spread by the regional transformation leads for the past 18 months to two years. While the Welsh Government is expected to correct some of this misinterpretation in a technical guidance note, we are concerned that



dissemination of such messages has created ambiguity and confusion within the system.

## **Teacher training**

All teachers will work with autistic pupils throughout their career – yet many are not given training to understand their autistic pupils' needs, or what they can do to help. This has been particularly evident over the past year as pupils have alternated between home-learning and school, facing huge changes to usual rules and routines. The pandemic has laid bare the lack of understanding of autism within our education system.

We need to make sure the people teaching autistic children have a basic understanding of their needs. During the Fifth Senedd, the Health, Social Care and Sport Committee agreed. It recommended that the Welsh Government ensures all school staff – particularly teachers and teaching assistants – receive training in awareness and understanding of autism, during initial teacher training and continuing professional development.

The Welsh Government needs to deliver this. There is a new system of support in place for pupils with ALN, which places added responsibilities on schools and colleges to assess and meet pupils' needs. Similarly, the new curriculum will be implemented during the next Senedd term. With such seismic changes taking place, it is crucial that school staff are given the support they need to ensure autistic pupils succeed.

## **Careers advice**

Young learners with additional needs are at an increased risk of becoming not in education, employment or training. Consequently, careers advice can be particularly valuable for autistic learners and their parents. Careers advisers should be part of a multi-agency approach to IDP reviews.

## **Girls**

Research has found that many autistic girls are often overlooked, which can result in misdiagnosis, late diagnosis or girls not being diagnosed at all. In education settings, this can mean that girls miss out on support. NAS Cymru wants to see a focus on identifying autism in women and girls to ensure they receive the same opportunity to fulfil their potential.



## **Thema 2: Addysg bellach ac addysg uwch | Theme 2: Further and higher education**

### **Further education**

It is crucial that autistic pupils, their families and others in their circle of support are involved in transition planning early. Decisions made as we prepare to leave school can impact the rest of our lives. Transition from secondary school can be one of the most life-changing events an autistic young person and their family will face, and the process is often difficult.

An autistic person may decide to stay in sixth-form or move into further education and thought must be given to how they can be supported to reduce anxiety throughout the process. Early action and support strategies can help young people transition. Planning to leave school can be a long process, often taking more than two years. New support staff should work with the young person before the move and they should have the chance to visit their new educational environment in advance. It is vital to involve autistic young people and their families in discussions around transition.

### **Higher education**

Many students report frustration with accessing support in higher education. NAS Cymru believes the Additional Learning Needs and Tribunals (Wales) Act should also cover higher education to ensure a consistent approach. The key to autistic students' success will be a good transition, with staff getting to know students and how to meet their needs. There is a link between poor transitions and less successful outcomes, so it is important that autistic students do not face a 'cliff edge'. Removing support that a young person has previously received could hamper an autistic learner's chances of success in higher education.

We were alarmed by proposed changes to Disabled Students' Allowance (DSA), which were consulted on last year. The consultation proposes putting in place more generalised 'off-the-shelf' support for disabled students. The proposals place the burden on the student to request a study needs assessment, only if they feel they need one. It is our view that the default position of all students being offered an assessment must continue. Moving away from study needs assessments will have a detrimental impact on autistic students' academic outcomes. NAS Cymru believes support should be person-centred, with the emphasis on individuals' needs rather than their condition. This proposed approach appears to be out of kilter with ALN reforms and other Welsh Government policies.

Reflecting the 'average needs of students depending on their disability' is not appropriate for a spectrum condition such as autism, which affects each person differently. No two autistic people are the same, yet Student Finance Wales suggests



that it can often 'predict' what support will be required. It is also unclear how a pre-determined package of support would respond to an autistic person's needs as they vary over time.

The consultation's description of assessment recommendations as a 'copy and paste exercise' clearly shows that the DSA system is not fit for purpose. We would welcome well thought out, uniquely Welsh reforms but we believe this change in particular would make the system worse.

### **Thema 3: Iechyd a lles, gan gynnwys gofal cymdeithasol (i'r graddau y maent yn ymwneud â phlant a phobl ifanc) | Theme 3: Health and well-being, including social care (as they relate to children and young people)**

#### **Mental health**

Autism is not a mental health condition, but many autistic young people develop mental health problems. This is often avoidable, but a lack of support can mean preventable issues worsen. Our research suggests that this situation is driven by a lack of community mental health services which are adjusted to support autistic young people's needs.

Our report, [Left Stranded](#), painted a worrying picture of the impact of the pandemic on autistic people's mental health. The survey – which received more than 4,000 responses – found that compared to the general public, autistic people were seven times more likely to be chronically lonely and six times more likely to have low life satisfaction. We also found that nine in ten autistic people worried about their mental health during lockdown.

NAS Cymru believes making adapted counselling available – alongside other community-based support, and clear autism-specific pathways – would help prevent unmet mental health needs from escalating. To further evidence-led policymaking, we think data on the number of autistic young people receiving mental health services must be collected.

We believe health boards should also be required to reduce the number of autistic people admitted to inpatient facilities. Wales also needs to ensure casework services are available, such as our [Autism Inpatient Mental Health Service](#), which is currently funded in England. The service provides advice to autistic people and the families of autistic people who have been detained in a mental health hospital or are at risk of detention.



## **Autism code**

As you will be aware, the Code of Practice on the Delivery of Autism Services came into force on September 1. The new legal duties include mandatory timeframes for accessing a diagnostic assessment and post-diagnostic support, training for specific staff, and better planning of services. The code has the potential to transform services for autistic people and their families but implementation will be key to making the improvements we need to see. While the code makes some welcome changes, we remain concerned that it does not address some significant challenges faced by autistic people and their families – many of which have been exacerbated by the pandemic.

NAS Cymru is disappointed that the code does not include duties to improve public awareness and understanding of autism, unlike the autism strategy in England. Our research shows that while 99% of people have heard of autism, only 16% of autistic people feel the public understands them. One in eight autistic people and one in six family members said they have been asked to leave public places as a result of autism-associated behaviour. Due to anxiety, bad experiences and a lack of confidence, many autistic people and their families avoid going out, which leads to increased social isolation. We call on the committee to urge the Welsh Government to help improve public understanding by launching a Wales-wide autism awareness campaign to inform people about the key things they can do to support autistic people.

We are also concerned the code may not be strongly enforced. That is why we are calling on the Welsh Government to appoint an independent person or body to oversee implementation, educate public bodies on their responsibilities, and advise ministers on enforcement action. It is crucial that autistic people and their families can enforce their rights if they are not receiving the support they are entitled to. Furthermore, we are concerned by suggestions the code could be expanded to other neurodevelopmental conditions, which may dilute the rights of autistic young people.

We would also like to see more ambitious waiting time targets set by ministers. Under clinical guidelines, NICE recommends that no child should have to wait more than three months from referral to autism diagnostic assessment – yet the target set by the Welsh Government is twice as long.



## **Thema 4: Plant a phobl Ifanc | Theme 4: Children and young people**

### **Covid-19**

The coronavirus outbreak and ensuing lockdown has changed the lives of most people in the country. While the crisis has been hard for everyone, it is particularly challenging for autistic young people, who typically experience intense anxiety and extreme unease around unexpected change. They may also need more time to process information and instructions.

Many autistic people have contacted us to describe their experiences. Adjusting to the sudden change in their lives and routines is a huge challenge, alongside concerns about the availability of social care or special educational support. In addition, families are often unable to visit relatives who live in residential care settings, and this causes anxiety both for them and their family members. As well as these new challenges, we know that too many children on the autism spectrum were not getting the support they needed before the coronavirus outbreak began.

Autistic children are struggling now more than ever, with many of the services they rely on having been removed or reduced. The impact of lockdown and school closures on children on the autism spectrum cannot be under-estimated. While the law is clear that local authorities still have a duty to secure and deliver the special educational provision set out in a child or young person's statement, we know that there is a gap emerging between guidance and young people's experiences.

