

## Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)

HSC PSS 99

Ymateb gan: | Response from: **NAS Cymru**

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### **Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor** **Initial priorities identified by the Committee**

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrysgerbydol.

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

#### **C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?**

**Q1. Which of the issues listed above do you think should be a priority, and why?**

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#### **Mental health**

Autism is not a mental health condition, but many autistic 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 that are adjusted and adapted to support autistic 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 out of ten autistic people worried about their mental health during lockdown.



NAS Cymru urges the committee to examine the support services available to autistic people who have a co-occurring mental health condition. We believe making adapted counselling available – alongside other community-based support, and clear autism specific pathways – would help prevent unmet mental health needs escalating. To further evidence-led policymaking, data on the number of autistic 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.

## **Workforce**

NAS Cymru is deeply concerned about the sufficiency of staffing levels in children's neurodevelopmental services. We believe more must be done to recruit and retain NHS staff amid rising demand for services and growing waiting lists due to the pandemic. A lack of staff is often cited as the number one barrier to tackling long waiting times and improving services. NAS Cymru welcomes the Welsh Government's demand and capacity review of neurodevelopmental services, which is due to be published in March 2022. We urge committee members to take evidence following the review to help ensure services are put on a more sustainable footing for the future.

We are also concerned by a lack of available Welsh-speaking NHS staff, such as speech and language therapists. Receiving services in their first language could be a clinical necessity for autistic people and their families, who should be able to access services in their language of choice.

Training has a pivotal part to play in improving outcomes for autistic people. We recently published a [good practice guide](#) for professionals delivering talking therapies for autistic adults and children, which details some of the additional support they may need. As well as ensuring that all mental health professionals receive autism training, it is important to improve understanding for the wider workforce in primary, secondary and tertiary health care. Receptionists and call handlers, for example, need to be trained to handle queries from autistic people. This would help ensure that services in Wales are autism-friendly.

## **Blaenoriaethau allweddol ar gyfer y Chweched Senedd**

### **Key priorities for the Sixth Senedd**

**C2. Yn eich barn chi, pa flaenoriaethau allweddol eraill y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd mewn perthynas â:**

- a) gwasanaethau iechyd;**
- b) gofal cymdeithasol a gofalwyr;**
- c) adfer yn dilyn COVID?**

**Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:**

- a) health services;**
  - b) social care and carers;**
  - c) COVID recovery?**
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### **Gwasanaethau iechyd**

#### **Health services**

##### **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 understanding and acceptance 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 that 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. As a result of 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 awareness campaign to inform the public about the key things they can do to support autistic people.

We are also concerned the code may not be strongly enforced by the Welsh Government. That is why we are calling on the 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 neuro-developmental conditions, which could unintentionally dilute the rights of autistic 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. We believe a waiting list target should also be introduced for adults.

We urge the committee to hold an inquiry in September 2022 to scrutinise progress on services, implementation of the code and other issues outlined in this response. As well as taking evidence from councils, health boards, RPBs, central government and the third sector, any inquiry should also include the voice of autistic people, their families and carers. NAS Cymru firmly believes that such an inquiry would significantly strengthen the code, helping to create a society that works for autistic people.

### **Additional Learning Needs (ALN)**

NAS Cymru is concerned that NHS bodies may not be fully aware of their duties under the ALN code to identify children who may have ALN to local authorities when it is in the best interests of a child. Paediatricians and health visitors are often able to identify potential ALN before professionals in education, so it is vital that awareness is raised of the new duties. Also, if a health body believes that a particular voluntary organisation – such as NAS Cymru – is likely to be able to advise or assist in connection with ALN, the parents must be informed.

## **Gofal Cymdeithasol a gofalwyr**

### **Social care and carers**

#### **Social care**

For many autistic people, social care is the difference between being able to leave the house or not; wash, dress, eat or not; and work or not. It is the difference between high and low life satisfaction. Even before the coronavirus outbreak, the provision of basic care for autistic people was dangerously low but the virus has reduced care provision further, leaving many feeling abandoned.

As support needs increase, so do their worries and those of their families. According to the responses to our survey, those with relatives who require more support were almost twice as likely in every case to worry about friends or family members contracting coronavirus. They also raised concerns about not getting the support they or their family need, what would happen when lockdown ended, their mental health, and social distancing. This has had a profound effect on the well-being of autistic people. According to our survey, more than half of those who require

support all of the time reported higher levels of anxiety, as well as changes in mood and behaviour.

We have heard from many people through our helplines, volunteer network and other means, that they lost their support as soon as social distancing policies were introduced. Carer visits, clubs and events were cancelled, leaving many people without support. This is true both of people with eligible needs with a care and support plan, but also those trying to access preventative services, including things like the Integrated Autism Services.

During the pandemic, it was not straightforward to determine which local authorities were operating under modified duties. And what we heard from autistic people and their families was not reflected in what was understood to be happening – people were telling us that they were losing their support, even when local authorities had not ‘turned off’ duties. We are concerned that these changes have had a disproportionate impact on autistic people, leaving many without the care they need during an unprecedentedly challenging time. NAS Cymru urges the committee to review the impact of the loss of support.

NAS Cymru is concerned that the Welsh Government’s social care recovery framework makes little reference to autism, especially given that autistic people with eligible social care needs are often among the people with the highest level of needs. We are also worried that the framework says little about widening eligibility, including to many working age disabled people. Many autistic people are able to live independent lives in their own home but would benefit from community services, such as respite or support groups.

It is vital that social care services across Wales have the resources they need to ensure autistic people and their families get support. We have been campaigning to end the social care funding crisis for years. We are concerned that, under the UK Government’s plan for social care, full funding will not be in place for three years. NAS Cymru believes the consequential funding should be ringfenced and we urge the Welsh Government to bring forward its own proposals as a matter of urgency. While we welcome the reconvening of the inter-ministerial group on paying for social care, the sector is in crisis now – so Wales must grab the once-in-a-generation opportunity to fix the system.

## **Adfer yn dilyn COVID COVID recovery**

### **Coronavirus**

The coronavirus crisis and ensuing lockdowns have changed the lives and daily routines of most people in the country. While this has been hard for everyone, it is particularly challenging for autistic people, who typically experience intense anxiety and unease around unexpected change. They may also need more time to process information. Many have gone months without seeing their friends and families. For others, support from public services disappeared overnight, leading to impossible pressures on families.

Many autistic people have contacted us to describe their experiences. Adjusting to the sudden change in their lives and routines is a huge challenge. In addition, families were often unable to visit relatives who live in residential care settings, causing anxiety for both parties. People say they are struggling with isolation from families and friends, and the rules around social distancing. This is intensified by anxiety about their health or that of family members, and fear of what might happen in future. Alongside these new challenges, we know that too many people on the autism spectrum, both children and adults, were not getting the support they needed before the coronavirus outbreak, which has had a disproportionate impact on autistic people.

Many people have contacted us to express concern that they or their autistic family member will not get the treatment they need if they become seriously ill with Covid-19. Based on their own experiences of using health services, or what they see reported in the media, they are worried that health professionals will decide on the basis of their autism diagnosis that they should not receive the same treatment that would be otherwise offered. This is causing extra stress at a difficult and uncertain time. It is vital that clinicians avoid any kind of blanket policy on which groups of people are entitled to particular types of treatment. While we recognise that guidance is clear that each person should be considered and assessed with for their individual needs and circumstances – rather than their diagnosis or disability – we would like to see autism explicitly included in guidance to provide additional reassurance.

Some families have contacted us concerned about what would happen if they, or a loved one was hospitalised. We welcome updated guidance which says autistic people who are admitted for non-coronavirus-related reasons could receive visitors if needed. However, this visitation will be at the discretion of the person in charge of the ward. Similarly, if someone is admitted for Covid 19-related reasons, there is little guidance as to what level of contact would be allowed. We would like to see clear guidance on visitation for autistic people to ensure that the full scope of an individual's needs are considered.

## Unrhyw faterion eraill

### Any other issues

#### **C3. A oes unrhyw faterion eraill yr hoffech dynnu sylw'r Pwyllgor atynt?**

#### **Q3. Are there any other issues you wish to draw to the Committee's attention?**

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##### 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 that the people teaching autistic children have at least a basic understanding of their needs. During the Fifth Senedd, the predecessor 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 their initial teacher training and as part of their continuing professional development.

The Welsh Government needs to deliver this. It is crucial that school staff, including teachers, are given the support they need to ensure autistic pupils succeed.