

**Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#)
ar y [gweithlu Iechyd a Gofal Cymdeithasol](#)**

**This response was submitted to the [Health and Social Care](#)
[Committee](#) consultation on [Health and Social Care Workforce](#)**

HSC 34

Ymateb gan: | Response from: NAS Cymru



About National Autistic Society Cymru

The National Autistic Society is Wales' leading charity for autistic people. Since 1962, we've been transforming lives, changing attitudes and helping to create a society that works for autistic adults and children.

We transform lives by providing support, guidance and practical advice for the 700,000 autistic adults and children in the UK, as well as their three million family members and carers. Since 1962, autistic people have turned to us at key moments in their lives, be it getting a diagnosis, going to school or finding work.

We change attitudes by improving public understanding of autism and the difficulties many autistic people face. We also work closely with businesses, local authorities and government to help them provide more autism-friendly spaces, deliver better services and improve laws.

We have come a long way but it is not good enough. There is still so much to do to increase opportunities, reduce social isolation and build a brighter future for people on the spectrum. With your help, we can make it happen.

About Autism

Autism is a lifelong disability which affects how people communicate and interact with the world. All autistic people have difficulties with communication and social interaction. These can include not being able to speak, delays in processing information or difficulty holding conversations and making friends.

Autistic people also engage in repetitive (sometimes restrictive) behaviours, such as hand flapping, rocking or repeating sounds. They can experience intense anxiety and unease around unexpected change. Many autistic people have sensory issues with noise, smells and bright lights, which can be distressing. These challenges can make the world feel scary and hard to understand. They can also send an autistic person into debilitating physical and emotional 'meltdowns' or 'shutdowns'.

Like all people, autistic people have their own individual strengths but life can become a huge struggle if the right support or understanding isn't provided. It is very important that autistic people get help from an early age and learn strategies to cope with the world. Attitudes in society also need to change.

Autism is a spectrum condition. This means autistic people have varying and complex needs, from 24-hour care to simply needing clearer communication and a little longer to do things at work and school. In addition, around a third of autistic people have learning disabilities. An important thing to remember is that the autism spectrum is not a simple line that goes from one end to the other. Therefore, an autistic person may be able to do highly complicated tasks but struggle with things that others find easy such as crossing the road, tying shoelaces or cooking a meal.

Many autistic people go undiagnosed or are unable to get support. They can also become isolated and miss out on education, employment and social activities. Currently, only 16% of autistic people in the UK have a full-time job, 79% of autistic people report feeling isolated and autistic children are four times more likely to be excluded from mainstream school.

Introduction

- 1.1 Our charity welcomes the opportunity to respond to the committee's consultation about the health and social care workforce in Wales.
- 1.2 NAS Cymru wants to place on record our thanks to the workforce. We recognise the dedication of all health and social care staff delivering neurodevelopmental services across Wales amid the pandemic and in the face of rising demand. We believe a focus on recruitment, retention and training is required to alleviate the pressure on staff, and ensure autism services recover and emerge stronger from the crisis.

Health

- 2.1 Even before coronavirus, demand for neurodevelopmental services was outstripping capacity in many parts of Wales. This mismatch has led to long waiting lists for diagnostic assessments for children and adults, limited support, and a postcode lottery. With many staff redeployed, the crisis has exacerbated existing workforce issues, meaning that neurodevelopmental services have, in some cases, 'stood still' for the past two years.
- 2.2 In the Hywel Dda University Health Board area alone, as an example, there are more than 1,400 children and nearly 800 adults on waiting lists for autism assessments. In August, the average wait from referral to assessment was 64 weeks for children and 82 weeks for adults. However, in some cases, children are facing a wait of more than three years while adults could be waiting as long as four. In Cardiff and the Vale, the wait for adult assessments has risen to 18 months and the Integrated Autism Service (IAS) warns that this may continue to increase.
- 2.3 Staffing issues are often cited as the main reason behind long waits and the health and social care workforce strategy must address such long-standing challenges. Hywel Dda's IAS, for example, reports that staffing issues have worsened with a high-level of long-term sickness. We are also told that the service does not employ a psychologist and has struggled to fill the vacancy despite advertising three times. Many health boards also lack staff able to deliver services in Welsh and there is a shortfall in the number of speech and language therapists in north Wales.
- 2.4 NAS Cymru wants to see urgent action to address such shortages. We need to see increased funding to recruit more staff as well as a long-term focus on training to tackle a shortage of specialists. We are calling for autism-specific actions in the workforce strategy. It is critical that the strategy starts at university and ensures sufficient numbers of people are studying subjects such as psychology. We would also like to see a similar scheme to the Initial Teacher Education priority subject incentives, which offer grants of up to £20,000. This would encourage students to undertake specific courses and provide a pipeline of specialists for NHS Wales.
- 2.5 Under the autism code, which was introduced on 1 September, services must comply with waiting time standards. Ministers have set a target of 26 weeks from referral to assessment for children and are expected to

introduce the same timeframe for adults. However, according to the responses to a freedom of information request received to date, not one health board is currently hitting this target for adults or children. NAS Cymru believes more ambitious targets should be set, especially given that NICE recommends no child should wait more than 13 weeks.

- 2.6 We want to see a renewed focus on reducing waiting times to achieve tangible results for families, but it must not be at the expense of other much-needed support. We must ensure that clinicians also have the capacity to provide support services. Children, young people and adults with a diagnosis of autism, for example, must be offered a follow-up appointment within six weeks to discuss post-diagnosis support.
- 2.7 The new statutory code also includes a duty on health boards to ensure professionals have the knowledge and training in autism they need to undertake their roles. Training needs assessments must be carried out and a plan developed to ensure all health care staff have appropriate training. Training plans should also include provision for ongoing learning and development. Autistic people and their families/carers must be involved in the development and delivery of autism training.
- 2.8 It is vital that the workforce feels valued. IAS staff have raised concerns about feeling isolated and unsupported. They cite a lack of consultation on where the IAS would sit and warn that the service faces an identity crisis. Service managers report feeling like 'glorified team leaders', with little involvement at a senior level and no access to budget holders. We're also told some staff have not had an appraisal in three years or more.
- 2.9 Duncan Holtham's review of the demand, capacity and design of children's neurodevelopmental services, the Integrated Autism Service and wider support – which is due to be published in March 2022 – will be key to making the improvements we need to see. It is crucial that Dr Holtham's evidence-based review feeds into planning more sustainable services and any identified gaps in provision are addressed quickly.
- 2.10 As a 2019 study recommended, the Welsh Government, health boards and councils should review funding for children's and adults' services to ensure it aligns with demand. We are concerned that some services continue to receive fixed funding, which equates to a real-terms cut, at a time when services are already over-stretched. If you factor in annual pay rises as well as inflation, the funding diminishes significantly each year.
- 2.11 NAS Cymru is also concerned that proposed moves to widen services to other conditions such as ADHD could result in support for autistic people being harder to access. Any increase in the scope of services must be met by adequate resource, otherwise waiting times and workforce issues will persist. We would also express caution about introducing prescribers and psychiatrists into services and believe government should set out clear plans for reducing reliance on medication. Psychotropic medication should never be used to treat the core features of autism. In England, the NHS' STOMP/STAMP programme has helped address this issue.

Social care

- 3.1 NAS Cymru provides day, residential, supported living and outreach services in Cardiff, Newport and Neath. We employ around 400 people in Wales, the majority of whom are front-line social care staff, supporting hundreds of autistic people and their families/carers.
- 3.2 Our services report persistent problems with recruitment and retention, which have significantly worsened during the pandemic, with high turn-over and vacancy rates. At the time of writing, our charity has dozens of vacancies and finding the right quality of staff presents a major challenge.
- 3.3 While outcomes for the autistic people and families we support have not worsened, that is only due to the hard work and dedication of our staff who have gone above and beyond throughout the crisis. Many have worked additional hours, pulling out all the stops to ensure the people we support continue to receive a first-rate service. However, this is not sustainable in the long term with many staff reporting feeling tired – a picture that is replicated across the wider social care sector.
- 3.4 There are a growing number of vacancies in sectors such as hospitality and retail, which can pay a higher rate for roles with less responsibility.
- 3.5 In terms of demographics, women in their 40s and 50s make up a majority of our workforce. From speaking to the managers in our services we heard that people with a background in industry can make great care workers after retraining. As such, we would welcome better engagement with the ReAct scheme, which supports people whose jobs are made redundant. On the other hand, we have heard that younger members of the workforce can bring recruitment challenges, in particular because they may move in and out of areas more frequently.
- 3.6 Care work needs to become a long-term career choice and Wales must raise the status of social care. Too often, social care is viewed as a low pay, low status profession, with limited opportunity for progression. Key to achieving this will be parity of esteem between health and social care.
- 3.7 NAS Cymru has found some recent success through Care Friends, an employee referral app, which offers financial rewards. The app helps maximise the number of referrals from our existing workforce and their recommendations are often a high-quality source of new care staff.
- 3.8 Concerns have been raised about eligibility for the Welsh Government bonus for carers. While NAS Cymru's staff in residential settings were eligible, workers in our day centres and administrators – who are often the backbone of our services – were not. This created a sense of unfairness and we were pleased to see eligibility widened for the second bonus. However, there were issues with the way the scheme was delivered, including payments taking six months or more.

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