

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy'n aros am ddiagnosis neu driniaeth](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment](#)

WT 27

Ymateb gan: | Response from: Cymdeithas Genedlaethol Awtistiaeth |
National Autistic Society Cymru





Response to the Health and Social Care Committee's consultation on the impact of the waiting list backlog

January 2021



About National Autistic Society Cymru

The National Autistic Society (NAS) 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. Research shows that 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 The National Autistic Society welcomes the opportunity to respond to the Health and Social Care Committee's consultation about the impact of the waiting times backlog on people awaiting diagnosis.
- 1.2 Children and adults faced long waits for autism assessments even before the pandemic and waiting lists have increased significantly in the past few years. As Wales recovers from the coronavirus crisis, it is vital that services for autistic children and adults are placed on a more sustainable footing for the future.

Overview

- 2.1 More than 4,100 children and 2,300 adults in Wales were awaiting a neuro-developmental assessment in September, according to freedom of information requests. We know that people in Wales, and across the UK, are waiting unacceptably long for assessment and support. Tackling this backlog and reducing waiting times must be a priority for the Sixth Senedd.

- 2.2 In response to the pandemic, some health boards chose to stand down their children's neurodevelopmental (ND) services and/or Integrated Autism Service (IAS). With staff redeployed elsewhere, many services stood still, leading to longer waits for autistic children and adults at a critical time in their lives.

"I was really disappointed to learn that there was a 30-month waiting period to access the service. My son is just turning three and the next three years will be critical to his development. I believe I have no other option but to explore this privately, an option that won't be available to many."

—A father raises concerns about waiting times in south Wales

- 2.3 In the Cardiff and Vale University Health Board area, for example, children were waiting an average of 27 weeks from referral to assessment in 2018. Now, families tell us they are facing a wait of 130 weeks to access the service, an increase of more than 380% over the past four years.
- 2.4 Unfortunately, the picture is similar in other parts of Wales. According to latest data gathered under the Freedom of Information Act, no health board in Wales was hitting the 26-week target. In Hywel Dda, children waited an average of 64 weeks and as long as 160 weeks from referral to assessment. Similarly, in Betsi Cadwaladr, children waited an average of 76 weeks, with the longest recorded wait being 200 weeks. The average wait was 95 weeks in Swansea Bay, 53 in Powys, 34 in Cwm Taf and 33 in Aneurin Bevan.
- 2.5 Waiting times have also grown for the seven Integrated Autism Services. In Hywel Dda, for example, adults waited an average of 82 weeks and as long as 210 weeks from referral to assessment, while the average wait was about 95 weeks for adults in the Cwm Taf and Swansea Bay areas.
- 2.6 Demand for assessments is far outstripping capacity to deliver them and it shows little sign of subsiding. Over the past two years, for roughly every two children or adults referred for an assessment, only one was undertaken.

- 2.7 Improved awareness of autism among parents, carers and professionals has seen more children and adults referred for diagnosis. This increase should be welcomed and pathways should not be restricted through 'gatekeeping' strategies such as limiting referrals or enhanced screening.

Impact

- 3.1 The impact of unduly long waiting times can hardly be overstated. Long waits have pushed autistic people and their families to crisis point, with many experiencing avoidable mental health problems as a result. The waiting times backlog delays support for autistic adults and children, fuels the frustrations of families, and places staff under unsustainable pressure.

- 3.2 We are concerned that the waiting times backlog has seen many autistic people and their families struggle for years before they can make sense of themselves and access support. While we welcome moves to decouple diagnosis from access to services, which should be based on need, diagnosis often remains the key to unlocking support.

- 3.3 Delays in intervention cause problems to escalate, creating pressure on primary care, mental health, education, social care and other services.

We want to see a focus on early support for autistic people and their families.

- 3.4 Our research paints a worrying picture of the impact of the pandemic on autistic people's mental health. A survey 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.

- 3.5 NAS Cymru wants to see improved access to psychological therapies and emotional support for those experiencing distress as a result of long waiting times for diagnosis. We believe making adapted counselling available – alongside other community-based support, and clear autism-specific pathways – would help prevent unmet mental health needs from escalating.

- 3.6 The waiting time backlog also impacts on the well-being of the workforce. We are concerned that experienced staff could be lost due to stress and burnout caused by a lack of capacity within services to provide pre- and post-diagnostic support as well as assessments.

“Our daughter was referred for ND assessment aged 13. She was eventually assessed just before her 16th birthday, but only because we had involved our MP in desperation. Our daughter had an overnight stay in A&E, was at risk of child sexual exploitation, refused to attend school, and was abused by peers. We also had numerous police visits. The overall impact has been to estrange our children and impact our mental health. We believe there needs to be more funding for services, which must be more transparent and accountable.”

—Parents describe their experiences while on a waiting list in north Wales

- 3.7 We are also concerned by the impact of waiting times on those transitioning between ND services and the IASs. Depending on when a child moves to adult services, they could have to wait twice: on the ND list then the IAS list. While it is unfair to make young people wait again, expediting cases would disadvantage those already on the IAS list. Children's and adults' services could be better aligned to improve collaboration and transition planning.

Targets and data

- 4.1 The NHS Delivery Framework includes a target of 80% of children and young people waiting less than 26 weeks to start an assessment. NICE recommends an assessment should begin within 13 weeks of referral, which is the target elsewhere in the UK. We believe children in Wales should not be expected to wait twice as long, so we want to see a similarly ambitious target set in line with NICE clinical guidelines. We would also welcome increased transparency, with data published routinely.

"We've been pressing for an autism assessment for my seven-year-old granddaughter for over four years. We were getting nowhere until May 2021 when a locum GP referred her to the ND team, and she was finally accepted onto the waiting list in September 2021. We have been told we will have to wait a minimum of a further three years. Her school has been no help and she cannot read or write. My daughter is a single parent of three and we don't know how to get help which is sorely needed."

—A grandmother on her family facing a seven-year wait in west Wales

- 4.2 NAS Cymru also urges Welsh Government to consider establishing and reporting on new standards, involving autistic people and their families to identify an appropriate benchmark wait. Waiting times can be measured in different ways; for example, from referral or first contact with services to assessment, diagnosis or intervention. Parents and carers tell us that they can wait many years even when the referral-to-assessment target is met, so a new measure could better reflect the reality of how long families are waiting.
- 4.3 We would oppose suspending or abolishing targets because services should be person-centred and waiting times are high among the concerns of autistic people and their families. Waiting time standards provide accountability as well as a key measure of patient experiences and the quality of children's ND services, so shelving the target would be a backward step. It would send the wrong message and could be seen as giving up or moving the goalposts.
- 4.4 Wales' health boards gather and record data in seven different ways, so there is a need to improve data collection. Some start the clock when a referral is received, for example, while others wait until they have received all the information they need to accept a referral. In response to freedom of information requests, one health board was unable to tell us the average referral-to-assessment wait for children or adults and another said it could not say how many children were on its waiting list. We believe there is a need to develop more robust and meaningful data on neurodevelopmental services.

Resources

- 5.1 We welcome Welsh Government's 2022-23 draft budget, particularly the additional £893m for the NHS to tackle the record high waiting times caused by coronavirus. It is critical that this 7.8% increase results in more investment in neurodevelopmental services for children and adults.
- 5.2 Funding for ND services has remained flat since 2015, which equates to a substantial reduction in real terms. Just to keep pace with inflation, the £2m-a-year allocation to ND services would need to increase by more than 13%. Similarly, core funding for the IASs has been flat at £2.97m since 2018. NAS Cymru believes a significant funding increase will be required to address both the waiting times backlog and the need for long-term service redesign.

Workforce

- 6.1 NAS Cymru is concerned about the sufficiency of staffing levels in children's and adults' autism services. A lack of staff is often cited as the number one barrier to tackling long waiting lists and improving services. The small size of teams leaves services vulnerable to recruitment and retention problems or staff absence due to sickness. A focus on recruitment, retention and training is required to alleviate the pressure on staff.

"I've been waiting two years for a referral for an autism assessment. Having made several phone calls today it's been made apparent my referral has been lost. I've been advised to send another application for a referral, but I'm worried I'll be left waiting another two years for a mistake that wasn't my fault. I'm very anxious and just need answers.

—A woman struggles to access adult services in north Wales

- 6.2 Funding alone will not solve workforce issues. There is a shortage of suitable staff available to be recruited in many parts of Wales, which leaves ND services and the IASs competing against each other. A workforce strategy must be at the heart of Welsh Government's integrated, all-age neurodevelopmental conditions action plan. It is critical that this strategy starts at university, ensuring enough people are studying subjects such as psychology and sufficient training places are available. We would welcome incentives to encourage students to take certain priority subjects and stay in Wales. This would provide a pipeline of specialists for the health service.

Demand and capacity review

- 7.1 NAS Cymru welcomes Welsh Government's ongoing review of the demand, capacity and design of neurodevelopmental services, which is due to report in March 2022. We hope that the recommendations of the review – led by Dr Duncan Holtham – will address many of the issues outlined in this response.
- 7.2 We would urge the committee to hold a short inquiry following the review's publication to examine the short- and long-term options for reforming neurodevelopmental services in Wales.