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ar [anhydraddoldebau iechyd meddwl](#)

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

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## **Response to the Health and Social Care Committee consultation on mental health inequalities in Wales**

February 2022



## 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 as part of its inquiry about mental health inequalities in Wales.
- 1.2 Autism is not a mental health condition, but many autistic adults and children develop mental health problems and too many reach crisis point. This is often avoidable, but the lack of support can mean preventable issues worsen. Autistic people and their families are disproportionately affected by poor mental health, and tackling inequalities must be a priority for the Senedd.

## Covid-19

- 2.1 Coronavirus has made the situation considerably worse. Our *Left Stranded* report highlighted the devastating impact of the pandemic on autistic people and their families<sup>1</sup>. Many went months without seeing their friends and families. For others, support from public services disappeared, leading to impossible pressures on families and leaving many feeling abandoned.
- 2.2 Overall, autistic people's mental health has suffered, leaving too many at serious risk of falling into crisis. Our findings show that nine out of ten autistic people worried about their mental health during lockdown. 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.
- 2.3 Lockdown upended everyone's lives, but it undermined the essential ways many autistic people cope with daily life – through routine, structure, exercise, and time with friends or family. Without additional support, autistic people can find it more challenging to adjust. Periods of crisis are all too common among autistic people who cannot get the necessary support.
- 2.4 The withdrawal of mental health and social care services left many without the support they needed to adapt to the pandemic. The impact on mental health and loneliness was felt most strongly by those with higher support needs, who also reported significantly lower life satisfaction. This was also true of autistic women and non-binary people.

## Children and Young People

- 3.1 Mental health problems start young and need addressing early. Research shows more than 71% of autistic young people have experienced mental health problems<sup>2</sup>. A survey carried out by Ambitious about Autism found that two thirds of respondents were 'not at all' or only 'a little' confident they would receive appropriate support if they contacted mental health services. Only 14% felt comfortable disclosing mental health problems to healthcare professionals, which fell to 10% in education.
- 3.2 Young people say they have faced many barriers including a lack of tailored support, poor transitions to adult services and long waiting lists. Autistic

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<sup>1</sup> National Autistic Society (2020), [Left stranded: the impact of coronavirus on autistic people and their families in the UK](#)

<sup>2</sup> Simonoff E, et al. (2008), [Psychiatric disorders in children with autism spectrum disorders](#)

children also raise stigma as a barrier so it is important to challenge and change negative attitudes and behaviours towards mental ill health. Families regularly tell us that some mental health problems are often dismissed as untreatable after being confused with features of autism.

- 3.3 According to recent research by Swansea University, more than three quarters of autistic pupils in Wales say they have been a victim of bullying and one in four feels unsafe in school<sup>3</sup>. Nearly 80% feel heightened anxiety and worries when attending school. The study also showed gender differences with autistic girls feeling less understood than male peers. Half of autistic girls said they were unhappy in school, compared to 38% of boys. And, in one academic year alone, 7% of autistic children faced a fixed-term exclusion. We must ensure teachers receive training in autism as part of initial teacher education and take a whole-school approach to understanding autism.
- 3.4 Under the Together for Children and Young People (T4CYP) programme, neurodevelopmental services are one of the three key work streams. We are concerned by the uncertainty surrounding the programme's future beyond 2022. We must build on the work of T4CYP, and autistic children and young people's needs must be prioritised within revised plans.
- 3.5 We believe it's vital that the Health and Social Care Committee engages with the Children, Young People and Education Committee to ensure this inquiry covers the full breadth of mental health provision in Wales.

## Suicide

- 4.1 Research shows that autistic adults are at heightened risk of suicide<sup>4</sup>. 66% had contemplated suicide, significantly higher than the general population (17%), and 35% had planned or attempted suicide. A study on the reasons for this found unique risk factors associated with autism such as 'camouflaging' and unmet support needs<sup>5</sup>. Many autistic children and adults feel pressure to 'camouflage' features of autistic and conform to non-autistic social behaviour, which can cause extreme exhaustion and anxiety.

## Hospitals

- 5.1 Too many autistic people end up in hospital because they fall into a preventable mental health crisis. Hundreds are in inpatient mental health hospitals instead of living full lives in the community, near family and friends.
- 5.2 In some harrowing cases, autistic people are subject to seclusion and unnecessary restraint. We believe Care Inspectorate Wales should conduct a national thematic review, similar to the Care Quality Commission's report about restraint, seclusion and segregation<sup>6</sup>. This invaluable research tells the story of restrictive practices from the perspective of autistic people, those with a learning disability and/or mental health condition.

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<sup>3</sup> Davies, S. (2021), [The Education of Autistic Pupils in Wales: Preliminary Report](#)

<sup>4</sup> Cassidy, S. et al. (2014), [Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study](#)

<sup>5</sup> Cassidy, S. et al. (2018), [Risk markers for suicidality in autistic adults](#)

<sup>6</sup> Care Quality Commission (2020) [Out of sight – who cares?: Restraint, segregation and seclusion review](#)

- 5.3 We need better social care and community mental health services, so autistic people don't reach crisis point and end up in mental health hospitals in the first place. If someone is admitted to hospital, it's essential that this is for as short a time as possible and they're supported by people who understand autism, in an environment that reflects their needs.
- 5.4 We are concerned about the lack of any data on the number of autistic people in mental health hospitals in Wales. By comparison, in England, NHS Digital publishes detailed statistics every month as part of the Assuring Transformation data collection project<sup>7</sup>. We want to see a similar dataset in Wales and a commitment to reducing the number of autistic people in inpatient mental health hospitals.
- 5.5 Our [Autism Inpatient Mental Health Casework Service](#) helps autistic people and families who are detained or at risk of detention or re-detention in England. The new service, which is funded by NHS England and the UK Government, provides confidential information, advice and support. We would welcome financial support to expand this invaluable casework service to autistic people and their families in Wales.

### Overmedication

- 5.6 Families in Wales have raised concerns with the National Autistic Society about overmedication. We want to see Welsh Government 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.

### Accessing Services

- 6.1 Autistic people face serious health inequalities including an increased risk of suicide and reduced life expectancy<sup>8</sup> – yet many face obstacles accessing services. Our research suggests that mental health inequalities are driven by a lack of community services that are adjusted and adapted to support autistic people's needs. Without access to personalised, evidenced, community-based mental health services, such as low-level psychological therapy, autistic people's mental health issues can deteriorate quickly.
- 6.2 While some support has been available online or on the phone during the pandemic, for some autistic people it simply isn't accessible and doesn't work<sup>9</sup>. It's vital that research is conducted to understand what digital or online support works for autistic people and how to overcome barriers.
- 6.3 We need to see timely, adapted counselling, as well as other community-based support services made available to prevent unmet mental health needs escalating into crisis. We think Annual Health Checks could play an increased role in terms of closely monitoring the mental and physical health needs of the autistic population.

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<sup>7</sup> NHS Digital (2022), [Learning disability services monthly statistics from Assuring Transformation dataset](#)

<sup>8</sup> Hirvikoski, T. (2015), [Premature mortality in autism spectrum disorder](#)

<sup>9</sup> Autistica (2020), [Impact of Covid-19 on autistic people, Action Briefing](#)

- 6.4 Autistic people report being pushed between services. Often, mental health services are not confident in 'dealing with autism' and refer autistic patients to disability services that are ill-equipped to provide mental health care. Wales needs to invest in training to ensure all staff are knowledgeable about autism and mental health, so they can make adaptations and adjustments to suit autistic people's needs.
- 6.5 In partnership with Mind, the National Autistic Society has produced a guide which aims to establish how to make mental health talking therapies better for autistic people<sup>10</sup>. The good practice guide identifies the biggest barriers to accessing therapy and details how services can be made more accessible.
- 6.6 NAS Cymru welcomes Welsh Government plans to introduce a neuro-developmental (ND) flag on GPs' patient records, which would work in a similar way to the existing learning disability marker. This could aid doctors in making changes to meet the needs of their autistic patients. It will be important that there is clear guidance about what information should be recorded under this flag, so that autistic people's access needs are met.
- 6.7 We also want to see greater involvement of autistic people in the design and delivery of services. This would result in the most effective support, tailored to individual needs, and increase confidence in services.

## Public Understanding

- 7.1 Getting out and about can be hugely challenging for some autistic people and their families due to a lack of understanding or reasonable adjustments in public places. Our research shows that while 99% of people have heard of autism, only 16% of autistic people feel that the public understands them<sup>11</sup>. One in eight autistic people and one in six family members said they had been asked to leave a public place due to autism-associated behaviour.
- 7.2 Things people take for granted, like going to the shops, using public transport or visiting a restaurant or pub are extremely difficult for some autistic people, due to anxiety, bad past experiences or a lack of confidence. As a result, many autistic people and their families avoid going out, which can lead to increasing social isolation and loneliness, and have a significant impact on someone's mental health.
- 7.3 We are calling for Welsh Government to develop a Wales-wide autism understanding campaign to improve public acceptance of autism and inform the public about the key things they can do to support autistic people.

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<sup>10</sup> NAS (2021), [Good practice guide: for professionals delivering talking therapies for autistic adults and children](#)

<sup>11</sup> NAS (2016), [Too much information](#)