

# Senedd 2021

Priorities for the next Welsh Government

# Throughout the last Senedd term, autism services in Wales have been a significant feature of debate, both inside and outside of the Welsh Parliament.

From the proposed Autism Bill, to the Code of Practice on the Delivery of Autism Services, the issues that autistic people and their families in Wales continue to face have been regularly discussed through consultations, plenary sessions and committee inquiries.

But now, the sixth Senedd, must be the time for action.

Not least because of the coronavirus pandemic, which has left many autistic people completely stranded. The inequalities that autistic people and their families face aren't new - we've been highlighting them for years, but over the last year, they have been laid bare and deepened further.

Autistic people are six times more likely to have low life satisfaction compared to the general population. We know that autistic children and young people struggle to get the right help in school and autistic adults face huge challenges in getting the support they need too, especially for their mental health. We must also improve public understanding of autism so that autistic people and families can feel included and accepted in their communities.

Underpinning all the improvements we need to see is the need to strengthen the rights of autistic people and their families in Wales, so they can get the services and support they need, when they need them.

Those elected to the Senedd this year, including the next Welsh Government, must act to deliver the changes and improvements that autistic people and their families in Wales need and deserve.

### What is autism?

Autism is a lifelong disability which affects how people communicate and interact with the world. There are approximately 34,000 autistic adults and children in Wales.

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 behaviours, such as hand flapping, rocking or repeating sounds. They can experience intense anxiety and extreme unease around unexpected change. Many autistic people have sensory issues with noise, smells and bright lights, which can be very painful and distressing.

Without the right support or understanding, autistic people can miss out on an education, struggle to find work and become extremely isolated.

## What the next Welsh Government needs to do:

- strengthen the rights of autistic people
- improve the mental health support available to autistic people in Wales
- ensure every teacher receives autism training
- develop and deliver a public autism understanding campaign.

# 1. Strengthen the rights of autistic people

The Welsh autism strategy has been in place since 2008, and has many admirable aims. The challenge has been, and continues to be, delivering on these ambitions and making real improvements to people's lives.

This is why ahead of the 2016 election, our charity called on the next Welsh Government to introduce an Autism Act for Wales, to go further in protecting and promoting the rights of autistic people and their families, and to ensure that they can access the services and support they need.

In response, the Welsh Government has developed a Code of Practice on the Delivery of Autism Services. The Code aims to set out what is legally required of services provided by local authorities, health boards and other public bodies in relation to the support they offer autistic people and their families in Wales.

While our charity has helped to develop the Code and suggested ways it should be improved, we do still have concerns that, by itself, the Code won't address the full scale of the challenges that autistic people and their families are facing every day.

#### We are calling on the next Welsh Government to:

- appoint an independent person or body to oversee the implementation of the Code, educate public bodies on their role and responsibilities, and advise the Welsh Government when enforcement action is required
- review the Autism Code within two years, and if it is not making the improvements we need to see, commit to introducing an Autism Act by the end of this Senedd term.

# 2. Improve the mental health support available to autistic people in Wales

Autism is not a mental health condition, but many autistic people develop mental health problems. This is often avoidable, but the lack of support can mean preventable issues worsen. Mental health problems start young and need addressing early. Research shows that more than 80% of autistic young people have experienced mental health problems.

The coronavirus pandemic has made this far worse. Our charity found that nine out of ten autistic people have worried about their mental health during the pandemic and subsequent lockdown. Compared to the general public, autistic people were seven times more likely to be chronically lonely during June and July 2020 and six times more likely to have low life satisfaction.

Without access to personalised, evidenced, community-based mental health services, such as autism adapted counselling, autistic people's mental health issues can deteriorate quickly. Too many autistic people end up in hospital because they fall into a preventable mental health crisis.

#### We are calling on the next Welsh Government to:

- ensure all mental health professionals receive training in autism, and that assessment and support services are available to autistic people who have a co-occurring mental health condition
- make available timely, adapted counselling, as well as other communitybased support services, to prevent unmet mental health needs escalating into crisis
- require data to be collected on the numbers of autistic people receiving mental health services and require health boards and NHS trusts to reduce the number of autistic people admitted to inpatient facilities
- ensure casework services are available, such as the National Autistic Society's Autism Inpatient Mental Health Service, which is currently funded in England, and provides advice and support to autistic people and the families of autistic people who have been detained in a mental health hospital, or are at imminent risk of detention or re-detention.

# 3. Ensure every teacher receives autism training

All teachers will work with autistic pupils throughout their career, yet many aren't given training to understand their autistic pupils' needs, or what they can do to help. This has been particularly evident over the last 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 systems. We need to make sure that the people teaching autistic children have a basic understanding of their needs.

In 2018, a cross-party committee of Senedd Members agreed with us. It recommended that the Welsh Government ensure 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 next Welsh Government need to deliver this.

There will be a new system of support in place for pupils with additional learning needs from September 2021, 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 significant changes taking place, it's crucial that school staff, including teachers, are given the support they need to ensure their autistic pupils succeed.

#### We are calling on the next Welsh Government to:

- ensure that teachers receive training in autism as part of their initial teacher education (ITE)
- develop an autism education programme to deliver regular, up-to-date professional development opportunities and information, share best practice across Wales and support better educational outcomes for autistic pupils
- ensure that data is collected on exclusions, additional learning provision and educational outcomes of autistic pupils so that areas of concern can be easily identified and remedied.

# 4. Develop and deliver a public autism understanding campaign

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 has shown 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 had been asked to leave a public place as a result of autism-associated behaviour.

This means that things many people take for granted, like going to the shop, 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.

Governments can help to improve public understanding. They have invested in the past in campaigns to improve awareness of dementia and of mental health. But autistic people so far have not seen a full-scale government campaign to educate the public about their needs.

#### We are calling on the next Welsh Government to:

 develop and deliver a Wales-wide public autism awareness campaign, to improve public understanding of autism and inform the public about the key things they can do to support autistic people.

### **About the National Autistic Society Cymru**

The National Autistic Society Cymru 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 34,000 autistic adults and children in Wales, as well as their family members and carers. Autistic people turn to us at key moments or challenging times 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.

### **About our local branches and groups**

Our 14 volunteer-led branches and groups are the first line of local support for parents, carers and autistic people. This can include sharing vital information and advice, organising social groups and leisure activities, as well as campaigning and fundraising activities.

You can find your local branch at <a href="https://www.autism.org.uk/branches">www.autism.org.uk/branches</a>

### **Helpline services**

Our Autism Helpline provides impartial, confidential information and advice for autistic people and their families and carers. We also offer specialist Education Rights and Transition services. Find out more about our information and advice services:

www.autism.org.uk/what-we-do/help-and-support

### **Autism Services Directory**

The Autism Services Directory is an online UK-wide database designed to help autistic people, their families and the people who work with them professionally to find out more about local and national services and events. Search the directory at <a href="https://www.autism.org.uk/directory">www.autism.org.uk/directory</a>

We are also on Facebook and Twitter



The National Autistic Society is a charity registered in England and Wales (269425) and in Scotland (SC039427) and a company limited by guarantee registered in England (No.1205298), registered office 393 City Road, London EC1V 1NG.