



## **Senedd Health, Social Care and Sport Committee inquiry into the impact of the coronavirus outbreak on health and social care in Wales.**

We welcome the opportunity to contribute to the Health, Social Care and Sport Committees inquiry into the impact of the coronavirus outbreak on health and social care in Wales.

Autism is a lifelong disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while there are certain difficulties that everyone on the autism spectrum shares, the condition affects them in different ways. Some autistic people are able to live relatively independent lives, while others will need a lifetime of specialist support. It affects more than one in 100 people in the UK.<sup>1</sup>

### **Autism and the coronavirus outbreak**

The coronavirus outbreak and ensuing lockdown has 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 extreme unease around unexpected change. They may also need more time to process information and instructions.

Many autistic people have contacted us to describe their experiences. Adjusting to the sudden change in their lives and routines is a huge challenge, alongside concerns about the availability of health or social care. In addition, families are often unable to visit relatives who live in residential care settings, and this causes anxiety both for them and their family members.

People say they are struggling with isolation from their families and friends, and with 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 the 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 began.

Before the coronavirus outbreak, this committee looked at existing autism support and services as part of their inquiry into the proposed Autism (Wales) Bill. The committee's report stated:

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<sup>1</sup> The NHS Information Centre, Community and Mental Health Team, Brugha T et al (2012), *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*, Leeds: NHS Information Centre for Health and Social Care.

"We are... in agreement that there is a pressing need to improve support services for people with ASD and their families across Wales, and believe this must be addressed as a matter of priority."<sup>2</sup>

**Autistic people are now struggling more than ever, when many of the services they rely on have been removed or reduced.**

### **Delay to the consultation on the Code of Practice on the Delivery of Autism services.**

To address the concerns raised by autistic people and families in Wales, as well as those highlighted by this committee in its report on the Autism (Wales) Bill, the Welsh Government committed to develop a Code of Practice on the Delivery of Autism Services. Following an initial consultation, the Code was due to undergo a further 12-week consultation from the 6<sup>th</sup> April 2020. The Welsh Government has planned to lay the final Code before the Senedd in March 2021.

This consultation has subsequently been postponed due to the coronavirus outbreak. Whilst this delay is understandable in the circumstances, this committee published its report on the Autism (Wales) Bill in December 2018, which called for urgent improvement to autism services and support. Our charity had existing concerns that the suggested timetable didn't meet the urgency demanded of the committee, or autistic people and families in Wales.

Given the delay to the consultation, we are deeply worried that the Code of Practice of the Delivery of Autism Services will not be in force within the planned time-frame.

**We would seek assurances from the Welsh Government that this work will be a priority and will be expedited to ensure it the Code is developed in line with the existing commitments.**

### **Rule on when people can leave their homes during lockdown – and public perceptions**

The rules about the circumstances under which people in Wales can leave their homes are set out in the Health Protection (Coronavirus Restrictions) (Wales) Regulations 2020, and subsequent guidance.

Autistic children and adults are disproportionately impacted by the general lockdown policy that people should leave their home for exercise only once a day. This is because some people need to go out more than once a day to maintain their physical or mental health – such as by taking specific exercise in an open space that may not be in the immediate vicinity of their home – and they may need to be accompanied by carers who are not people they live with.

Many people expressed their concerns to us about the guidance on leaving home, and the impact this was having on their health and wellbeing. The Department for Health and Social Care amended the guidance in England on the 8<sup>th</sup> April to make

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<sup>2</sup> National Assembly for Wales, Health, Social Care and Sport Committee (December 2018), Autism (Wales) Bill Committee Stage 1 Report <http://senedd.assembly.wales/documents/s82008/Report%20-%20Autism%20Wales%20Bill%20Committee%20Stage%201%20Report%20-%207%20December%202018.pdf>

it clear that autistic people are permitted to leave their homes more than once a day, to travel beyond their immediate local area if their condition requires it, and to be accompanied by carers.<sup>3</sup>

We asked the Welsh Government to consider implementing guidance in Wales that similarly took the needs of autistic people into account, and welcomed the amendment to the regulations<sup>4</sup> which came into force on 25<sup>th</sup> April. A further letter from the Chief Nursing Officer<sup>5</sup> set out the rules around taking therapeutic drives. However, it's worth stating that autistic people and families faced an unnecessary period of confusion and uncertainty during this time<sup>6</sup>.

As noted above, autism is often a hidden disability. People on the autism spectrum who are following guidance that allows them to leave their homes more frequently than once a day, or to go further afield, find that they are sometimes judged by members of the public for doing so. This is a source of great anxiety for autistic people and their families.

We have also heard (alongside positive stories of the police responding appropriately) from a number of autistic individuals, and families with autistic children, that they have been told to go home by police officers, or threatened with fines. Autistic people, or their family carers, are sometimes asked for 'proof' of their disability. This cannot easily be provided, and even when a document like an Autism Alert Card or care plan is produced, it is not always respected.

**Police officers and others enforcing the lockdown in Wales need to be fully aware of what the current guidance says on when autistic people can leave their homes.**

### **Reduction in social care provision**

The Coronavirus Act 2020 contains emergency powers, which could lead to changes in how the social care system works for autistic adults in Wales. Under the new law, existing Social Services and Well-being (Wales) Act duties on local authorities to assess adults needs for care and support (and adult carers needs for support), and to meet eligible needs, are temporarily relaxed.

We recognise the pressures on local authorities, but believe that the Welsh Government must go further to protect autistic people by providing specific guidance on how local authorities are expected to implement these changes, with specific requirements to ensure that autistic people aren't disproportionately affected. This should include clear guidance on how the integrated autism service should operate during this period.

We have heard from many people to our Helpline and through other routes that they lost their support as soon as social distancing policies were introduced. Carer

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<sup>3</sup> Cabinet Office (March 2020 – updated April 2020), *Coronavirus outbreak FAQs: what you can and can't do* (paragraph 15).

<sup>4</sup> Welsh Government, April 2020, Leaving home to exercise: guidance, <https://gov.wales/leaving-home-exercise-guidance>

<sup>5</sup> Chief Nursing Officer, (1<sup>st</sup> May 2020): Welsh Government ref: JW/KE/280420: <https://bit.ly/2A7B4Tb>

<sup>6</sup> Wales Online (17<sup>th</sup> April 2020), *How confusion about government lockdown rules is affecting the lives of people with autism* <https://www.walesonline.co.uk/news/wales-news/how-confusion-government-lockdown-rules-18100775>

visits were cancelled, clubs and events were cancelled, leaving many people without support.

We are very concerned that this will leave many autistic people without the care they need during this unprecedentedly challenging time. Autistic people with eligible social care needs are often people with the very highest level of needs. There is no way of reducing the care and support these individuals receive without causing severe hardship to this very vulnerable group of adults. There is also no clear way to determine which local authorities are operating under modified duties.

The Welsh Government have announced £40million in additional funding for social care services. This is welcome, along with the commitment to further review this allocation in the future. It's important that social care services across Wales have the resources they need to ensure autistic people and families get support. This funding, along with any additional funding, should be monitored to ensure it is used appropriately and to help local authorities avoid any departure from existing social care duties, as set out in the Social Services and Well-being (Wales) Act 2014 to provide timely assessment and support.

**The Welsh Government should urgently clarify social care guidance in respect of autistic people, report on the local authorities operating under modified duties and continue to increase funding to make sure that thousands of autistic adults and other disabled people do not go without essential support during this crisis.**

### **Availability of medical treatment**

Many people have contacted our charity 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. On the basis of their own experiences of using health services, or what they see reported in the media,<sup>7,8</sup> 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 offered to non-autistic people. This is causing extra stress at a very 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. Whilst we recognise that guidance<sup>9</sup> is clear that each person should be considered and assessed as an individual, with their individual needs and circumstances – rather than their diagnosis or disability – **we would like to see autism explicitly included in this guidance to provide additional reassurance.**

### **Hospital visitation**

Some families have contacted us concerned about what would happen in they, or a loved one was admitted to hospital. Currently, in-patient visitation is not permitted,

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<sup>7</sup> Financial Times (13 April 2020), *NHS 'score' tool to decide which patients receive critical care.*

<sup>8</sup> ITV Wales (1<sup>st</sup> April 2020), *Apology after patients with life-limiting illnesses asked to sign 'do not resuscitate' form if they get coronavirus:* <https://www.itv.com/news/wales/2020-04-01/surgery-asks-patients-with-significant-life-limiting-illnesses-to-sign-form-waiving-cpr-if-they-get-covid-19/>

<sup>9</sup> Welsh Government, *Coronavirus: Ethical values and principles for healthcare delivery framework:* <https://gov.wales/coronavirus-ethical-values-and-principles-healthcare-delivery-framework.html>

however we welcome updated guidance that says autistic people who are admitted for non-Covid-19 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 aid decision making and ensure that the full scope of an individuals' needs are considered.**

We are grateful for the opportunity to contribute to this inquiry. This submission seeks to address how the coronavirus outbreak, and the measures taken to combat it, have affected people on the autism spectrum in relation to autistic people's health and wellbeing, and access to services. The National Autistic Society Cymru is happy to provide any further information that the Committee would find useful, or to provide oral evidence if required.

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