

Senedd Cymru
Y Pwyllgor Plant, Pobl Ifanc ac Addysg

Ymchwiliad i effaith argyfwng Covid-19
ar blant a phobl ifanc yng Nghymru

COV 41

Ymateb gan: Cymdeithas
Genedlaethol Awtistiaeth Cymru

Welsh Parliament
Children, Young People and Education
Committee

Inquiry into the impact of the Covid-19 outbreak
on children and young people in Wales

COV 41

Response from: National Autistic Society Cymru

We welcome the opportunity to contribute to the Children, Young People and Education committee inquiry into impact of the COVID19 outbreak on children and young people 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.¹

Autistic children and young people may need additional help and support with education. Some will need highly-specialised education, others will follow a more mainstream path.

Recent figures available from the Pupil Level Annual School Census shows 7655 autistic pupils in Wales currently receiving support through the existing graduated response system. Of these, 4258 have a statement of special educational needs. This means that one third of all pupils with statements are autistic².

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

¹ 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.

² The Pupil Level Annual School Census (PLASC) 2018, Welsh Government

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 social care or special educational support. 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.

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

Provision for children with special educational needs

The impact of lockdown and school closures on children on the autism spectrum – and their families – cannot be under-estimated. While the law is clear that local authorities still have a duty to secure and deliver the special educational provision set out in a child or young person’s statement, we know that there is a gap emerging between guidance from Welsh Government and people’s experiences in their local areas.

For many families of autistic children, their experience of lockdown and school closures is that their child has been left without the educational support or therapies they need, and families are increasingly struggling as the lockdown continues. Where good support for families is in place, this is dependent on the school or individual teachers, and subject to extreme variability, even across individual local authorities.

The current Welsh Government guidance³ for families is that if your child can stay at home, they should do so, and we know of many families who have taken the decision not to use available provision and to keep their

³ Welsh Government, Guidance for hubs and schools: provision for children of critical workers and vulnerable children: <https://gov.wales/sites/default/files/publications/2020-04/guidance-hubs-schools-coronavirus-provision.pdf>

children at home. This might be because they have health concerns or because they worry their child may not cope attending a new setting with different teachers and pupils. However, we also know of many families for whom staying at home isn't possible.

Pupils who are considered 'vulnerable' and therefore able to access school or an area hub, include those with a statement of special educational needs or a care and support plan. We welcome a focus on children who have particularly high needs, however we are concerned that this doesn't capture all of the children and families who need additional support

We hear from parents of children who do not currently have a statement or care and support plan, but who do receive SEN support at school. These children are mostly at home (unless they are particularly vulnerable, or have a parent who is a key worker), and many parents are unable to provide the specialist support a child may receive at school to enable them to learn.

One family told us that 'home [education] did not get off to a great start, and there were meltdowns... aplenty.' They said that their child is 'bright and often articulate, but very demand avoidant and some days it is a struggle to get him to do anything'

The guidance suggesting that only those with a statement or care and support plan are eligible for education provision therefore risks setting an arbitrary threshold that isn't reflective of individual needs.

We are similarly aware of instances where support is requested from those with complex needs, but local authorities aren't providing it⁴. This can put a huge strain on families, particularly those with more than one child.

There are also concerns that autistic children will fall behind during this period and their mental health will be affected. The transition back to school – when it comes – will also be a significant issue for many autistic children and young people. **The Welsh Government and local authorities need to start planning now for how they will support this.**

The Coronavirus Act 2020 gives the Welsh Government the power to modify the duty on local authorities to secure and deliver special educational provision contained within a child's SEN Statement, so that a 'duty' is downgraded to 'reasonable endeavours'. However, the definition of 'reasonable endeavours' in this context is far from clear, and no guidance has yet been issued to local authorities on what it will mean. The duty remains unchanged at present.

⁴ BBC Wales, (1st May 2020), Coronavirus: Missing school 'ever so difficult' for girl with autism: <https://www.bbc.co.uk/news/uk-wales-52488631>

We would urge the Welsh Government not to issue a notice to disapply or modify the existing statutory provisions, as we believe this would have a further detrimental impact in the well-being and outcomes of autistic pupils. No autistic child should fall behind as a result of the pandemic.

The Coronavirus Act 2020 also gives the Welsh Government power to modify the Learning and Skills Act 2000, affecting the duties on Welsh Ministers to arrange assessments and provision for learners with SEN, including autistic young people. We know of families who currently have no learning and skills plan in place to set out their provision for the next academic year. We also know of families who have children in their final year of education, who have missed out on meaningful transition into adult services. This is the subject of a current Senedd petition⁵ with over 300 signatures at the time of writing.

The Welsh Government must provide clear guidance and support to autistic learners in further education (FE), or transitioning into FE so that they don't miss out on crucial planning and transition support.

Children's social care

We note that children's social care services hasn't been subject to the same modifications as is the case for adult social care under the Coronavirus Act 2020. However, the Welsh Government has published additional guidance as to how social care providers and local authorities might operate differently during the coronavirus outbreak.

We would like to see information published which sets out changes local authorities make to care and support children receive, including the effect on availability of preventative services in each area. We also need clearer information on what happens to children and young people transitioning into adult services, where duties may be modified.

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 home are set out in the Health Protection (Coronavirus Restrictions) (Wales) Regulations 2020, and subsequent guidance.

⁵ Senedd Petitions Committee: An emergency amendment to extend age of entitlement to additional educational support from 25 to 26 and to define within Government guidance the Covid 19 pandemic as an exceptional circumstance: <https://petitions.senedd.wales/petitions/1801>

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 8th April to make 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.⁶

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 regulations⁷ which came into force on 25th April. A further letter from the Chief Nursing Officer⁸ 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 time⁹.

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.

⁶ Cabinet Office (March 2020 – updated April 2020), *Coronavirus outbreak FAQs: what you can and can't do* (paragraph 15).

⁷ Welsh Government, April 2020, Leaving home to exercise: guidance, <https://gov.wales/leaving-home-exercise-guidance>

⁸ Chief Nursing Officer, (1st May 2020): Welsh Government ref: JW/KE/280420: <https://bit.ly/2A7B4Tb>

⁹ Wales Online (17th 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>

Police officers need to be fully aware of what the current guidance says on when autistic people can leave their homes.

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 children and young people's health and wellbeing, and access to education provision and other support 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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