

Autistic UK (Cymru)

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20th April 2020

Dear Rt. Hon. Mark Drakeford,

As autistic community members, we are hearing many reports from autistic adults – as well as from parents of autistic children – who are confused and too scared to leave the house for health reasons. **We need clarity in the legal system as information is being communicated ambiguously, in particular we need firm, objective information as to how to use, and behave in, public places.**

Please note that we are writing to give a voice to all autistic people. This includes those who are referred to as 'high support needs', who often have a number of co-occurring conditions which include, but are not limited to: learning disabilities and the use of forms of communication other than speech. People in the high needs group typically need support workers or personal assistants in order to be able to access education, employment, and society more generally.

It also includes those who are referred to as 'low support needs', though this in itself is often a misnomer, as people in this category often 'mask' their difficulties, something which the current pandemic is making far more difficult. Although many report that the effort of masking causes them to develop additional mental health difficulties – commonly anxiety, depression, c-PTSD, and OCD – but as a result of their ability to mask they are often refused additional support; quite often they are perceived as 'not autistic enough', which is damaging at all times, but dangerous during the current pandemic. This second group also tend to have many co-occurring conditions like dyslexia, ADHD, dyspraxia, and other forms of neurodivergence as well as having other supposedly rare conditions like Ehlers Danlos Syndrome or Epilepsy. All these conditions are 'hidden' disabilities so regardless of which group they belong to they can experience massive distress when their different needs are not met; none of us can mask when situations are new or strange. In this context, most importantly, none of us can predict how 'neurotypical' (those who are not autistic or otherwise neurodivergent) people will respond to situations, and we cannot follow



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rules we do not understand. **As such, we request that Welsh Government adopt the same approach, and that communication pertaining to autistic people relates to all autistics. This needs to be made clear in your statements.**

Both groups have similar difficulties in understanding 'typical' behaviours because even those who can mask for short periods of time are only able to if they are able to pretend to be like others. Coronavirus, and subsequent lockdown, has changed everything so as the general population struggles to adapt their behaviours, we no longer have people to mimic. Our distress at not having clear rules to follow mean that our autistic behaviours are more apparent: stimming in in public to ease distress; slower processing of new rules leaving us confused, with the community increasingly reporting their experiencing periods where they are unable to communicate through speech; and heightened levels of distress mean that tone of voice and body language – things that autistic people struggle to adapt in typical situations – are unlikely to be interpreted as distress, rather being labelled rude, argumentative and aggressive. **We ask that Welsh Government ensure that police and park staff are provided with guidance as to how to communicate with autistic people, and that appropriate steps are taken to evaluate the situation.**

As a result, the autistic community is increasingly too scared to go out at all. As many of us have co-occurring conditions (as mentioned above), we need to work much harder than others to maintain physical health and mental wellbeing. Our inability to go out for appropriate exercise means we are increasingly becoming more physically and mentally unwell during a time in which the NHS cannot be expected to treat these issues. It is also concerning that disabled people have not been considered when access to benches and other rest places have been removed – many of us cannot exercise to maintain a reasonable physical condition without taking breaks, some of which may be deemed substantial.

For many autistic people, the ability to exercise in their immediate vicinity is impossible. Co-occurring conditions mean that many of us are deemed high-risk (regardless of our perceived support levels), so using local parks which are still quite busy is not safe. For others, sensory differences, learning disabilities, and impulsivity means that adhering to social distancing rules can be incredibly difficult. Therefore, when the 'guidelines' were relaxed in



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England many in our community felt that meant their needs were being understood and they were able to again access open spaces but we soon discovered that was not the case in Wales. We have had an increasing number of enquiries from autistic people who were confused about what they could and could not do. In order to get clarification, one member of our community contacted Bindmans, the solicitors who brought the case to challenge the English guidance and they confirmed the rules did not apply to Wales because Welsh Government wrote the 'only leave the house once a day for exercise' into their regulations. We are aware of at least four families who have contacted the solicitors in order to instruct a judicial review of the Welsh Regulations and guidance but this process will take time as legal aid applications need to be approved first. We are hoping Welsh government will bring Wales in line with the UK guidance for people with health conditions before this judicial review is necessary.

In England, the UK government [relaxed its rules¹](#) for autistic people and those with other health related conditions:

1. To allow families to travel in their cars just to enjoy a car ride
2. To travel to locations outside their local areas. The only requirement is that if they stop somewhere it must be to exercise for longer than the car journey was.
3. To leave the house as often as is necessary to maintain routines and to manage our co-occurring health conditions as well as maintain our mental health as many of us are distressed when we cannot access open spaces.
4. To be able to take breaks and even picnics with the household whilst out so long as the break/picnic takes less time than the exercise did.

The autistic community have seen this as fantastic news for the UK, but for those of us in Wales it has simply brought further confusion. As we are now hearing reports that 'some' police forces are accepting the English guidance whereas others are insisting on following the Welsh regulations to the letter. **We would advise that Welsh Government adopts the same standards for autistic, and otherwise disabled, constituents in line with English guidance.** [This article by Mind²](#) explains the benefits of being in nature on mental health, and for some with reduced mobility, the only way to access this is by car. We are getting reports from people who have been told their cars will be clamped if they drive to a local park, meaning people with mobility issues can only walk on their main roads. Autistic people are more likely to be living in poverty than the general population. As a result, we often live in

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substandard housing, and many do not have access to any outside space. Therefore, it is unreasonable to render these people housebound as exercising in the streets which surround their property is unsafe and unattainable.

Because of the added confusion, we have had many enquiries from autistic people seeking clarification, and as no 'official' sources seem to be able to clarify these issues, we are having to try to decipher them ourselves which is proving to be next to impossible. The more we look at the Welsh guidance the more confused we become. We have included screenshots at the end of this letter of Tweets and Welsh Gov website which have added to the confusion.

We ask that Welsh Government move to rectify this as a matter of urgency so they can bring clarity and consistency to those who need it.

For those who are too scared to leave the house, the inability to access home delivered groceries is a huge source of stress and anxiety. As many supermarkets are reserving delivery slots to those who received shielding letters, autistic people who relied on this method of food shopping prior to the pandemic are having their deliveries cancelled.

Many autistic people struggle with food shopping anyway, and the new rules (many of which are not being followed in actuality) mean that many autistics are reducing their food consumption to avoid going to the supermarket.

Autistic experiences have been spoken about [here](#)³ in full. The removal of 'autism hour' highlights that its purpose was to cater to parents of autistic children, as autistic adults have not been considered. We would class many in our community to be vulnerable, but as the guidance as to who is deemed 'vulnerable' is not clear, we are unsure whether we are allowed to access the dedicated hour for vulnerable and/or elderly customers. It has not been stated how one proves they are in a vulnerable group, which (as our disabilities are invisible) is another source of contention – how do we communicate that we need to be included in this group? Autistic people have also expressed concerns that if they have been out to exercise, this means they cannot also go to the shop due to the once a day rule. **Government expectations in this area needs to be clarified.**

As autistic people, including autistic parents of autistic children, struggle to communicate their difficulties and needs, even outside the pandemic, it is impossible for most people who have contacted us to access the social care services, who could assist in this matter, and as many services have been reduced as per the [Care Act easements](#)⁴, it would be difficult for us to access support, even if our communication styles were accounted for. It seems that consideration



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hasn't been given to the number of 'hidden carers' who exist because the social care budget is too low, and some people who require full time (or near full time) care don't meet the social care remit. Who is responsible for ensuring these people are safeguarded if their carer becomes unwell? As many of us could not get full Carer/Support Assessments before the pandemic, we are not confident that we would be able to access these now, despite guidance stating that "Local Authorities will still be expected to take all reasonable steps to continue to meet needs as now." **We need confirmation that we will not be left behind by social care, and that our needs will be met.**

Autistic people often struggle to access appropriate healthcare. The pandemic has made this increasingly more difficult. Some people are reporting that there is a large waiting time for prescriptions – some as long as two weeks – and there is a lack of stability and continuity, even in the same health board. Despite the increased waiting times, they were told they were not allowed to order early, despite lack of medication causing physical and mental ill health. This goes against the [guidance⁵](#) published by Welsh Government whereby medics need to use a "rights based approach and the social model of disability to fair and effective decision making in healthcare." It is not unreasonable for a portion of society who struggle with executive dysfunction, where medication is difficult to access, to be allowed to order repeat prescriptions early.

It is more concerning that we will not be listened to in a hospital setting, and we as a community are still anxious that [despite the NICE retraction⁶](#), staff will use our being autistic against us if we require ICU treatment for COVID-19. **We need assurance from Welsh Government that our disabilities will not prohibit us from accessing critical care.**

To add confusion, the law throughout the UK not only seems to be inconsistent, but the Welsh Regulations themselves have been written in a way that further confuses autistic people. E.g. voluntary work is permitted, but when you look at the Welsh Regulations it states the only voluntary work which is acceptable is helping vulnerable people. Many autistic people do voluntary work as only 16% of us are in full time employment, yet out of the unemployed 70% want to, and NEED to work. Many of us are, as mentioned above, also in the vulnerable group so we cannot volunteer to help the vulnerable, but we could be accessing private farms where social distancing is strictly adhered to in order for our children and the adults to work the land, plant seeds, and gain gentle exercise.



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We do not all have access to one of these places so it is essential we be allowed to travel out of town to volunteer in these settings.

For autistic employers, the [provided guidance](#)⁷ on the regulations is unclear:

In order to act reasonably you must ask yourself what other prudent (or careful) people would do if they were in your shoes.

This is not a measure to perform an “objective test” – relying on your interpretation of what someone may, or may not, be thinking can never be objective. Autistic people struggle to conceptualise what other people “would do in their shoes”. Part of the reason we end up needing a diagnosis is due to not knowing how others react to things, and what ‘normal’ expected behaviours are, because we do not experience the world the same way most neurotypical people do. Therefore, saying that in order to abide by the law we need to know what ‘prudent (or careful) people would do in our shoes’ is outright discriminatory⁷, especially as we are often more prudent and careful than others because of our mixed abilities and experience of co-occurring conditions.

Our children are out of school; however, this is not typical home-schooling. Schools are either expecting their pupils to follow a set curriculum, despite support needs, or parents are having to write and deliver their own curriculum. In England, pupils with EHCPs are being supported by their education authorities, with many being permitted to use school facilities with the children of keyworkers. While many of the families whose children have either a statement of special educational needs, or a funded healthcare plan, who have contacted us do not necessarily want their children to go to school, many feel abandoned as their children are being completely unsupported. Some have advised they have received one, maybe two, welfare calls, but none have reported being in receipt of a differentiated curriculum. No consideration has been made for families in which the adult carer is also disabled, and the lack of support and clarity about the amount of schoolwork families are expected to complete. **We require Welsh Government to make it clear that families who are struggling will not be penalised for forgoing mainstream curriculum to prioritise mental wellbeing for the family.**

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Autistic people need constancy and clarity of rules. **We therefore ask that Welsh Government tackle this as a matter of urgency because those of us with medical needs – including autism – are suffering disproportionately and, as England has shown, this does not have to be the case.** All guidance needs to be written in straightforward, unambiguous language. Kat Williams, one of the signatories on this letter, has written for Welsh Government funded projects. Part of the remit was to ensure plain English was used, and to not include idioms, to ensure that anyone wishing to access the information was able, regardless of age, disability, or literacy level.

To conclude, Autistic UK-Cymru are asking that Welsh Government clarify their guidance in a number of areas pertaining to the Coronavirus lockdown, and re-assess some current guidelines in line with English changes:

1. Right to exercise to be brought in line with the UK guidance on accommodations for autistic and otherwise disabled people so there is no confusion and to ensure that we are granted the right to travel (safely) out of our local area.
2. Access to grocery shopping
3. Access to Social Care assessments and provision
4. Access to healthcare – including critical care if required
5. Right to volunteer
6. Access/right to work – both as an employer and an employee
7. Right to access a differentiated curriculum, particularly that set out in a Statement of Special Educational Needs or a Funded Healthcare Plan

We request that this information be clear, concise, and free of idioms to ensure it is accessible to all, including the provision of an 'Easy Read' version of all communication. We trust that you will respond to this letter in a timely manner to enable us to update the autistic community in Wales.

Yours sincerely,

Willow Holloway

Willow Holloway

Monique Craine

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Kat Williams

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Representative

North Wales

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Representative

South-West Wales

Autistic UK

Representative

South-East Wales

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Screenshots

The Welsh regulations specifically do not allow many of these changes so here are some examples that we are still being asked to only leave the house for one exercise a day:

Stay at home. Save lives. Protect the NHS.

You can:

- Go out once a day for exercise.
 - You can go out with the people you live with (but you should observe Welsh Government guidelines and stay at least 2 metres away from anyone you don't live with).

Although people in England are allowed to leave their local area here is evidence to show that is not permitted in Wales, even though we hear reports that some police forces are fine with this. However, people can travel to their allotments as long as they adhere to social distancing rules:



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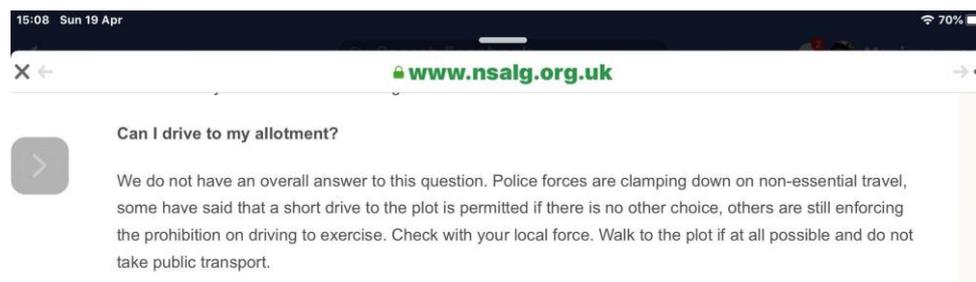
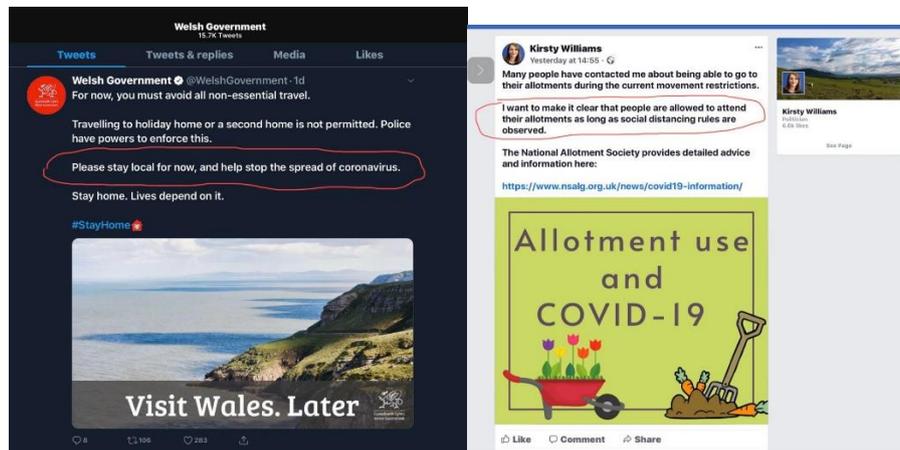
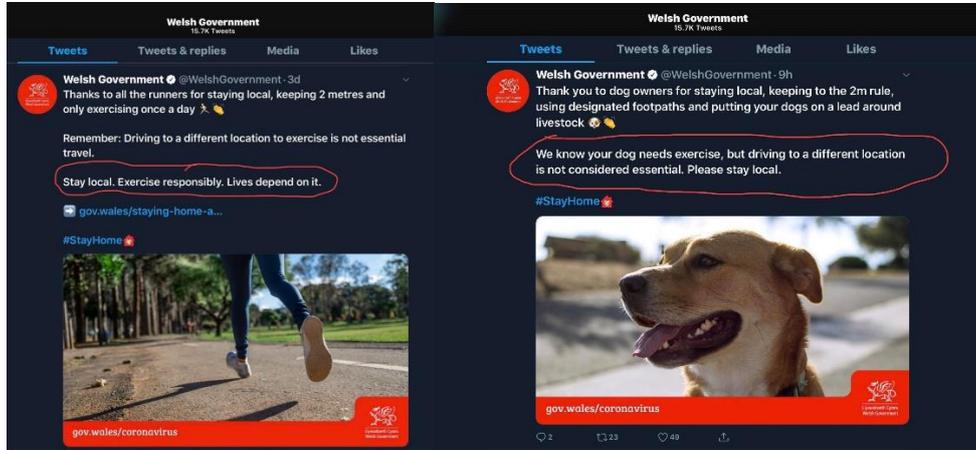
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Screenshot regarding "all reasonable measures":



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What do you mean by “all reasonable measures”?

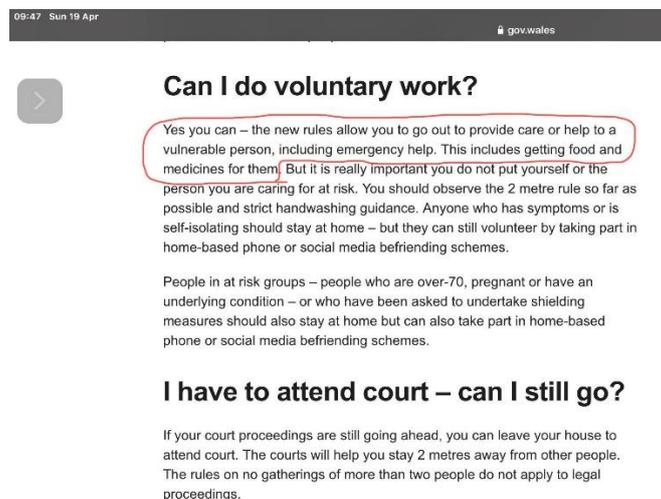
There is no hard and fast rule about what a reasonable measure is. It will depend on where people are working and the nature of the work being done. But in essence it means taking proportionate actions the person responsible for the work will be able to justify.

It is important to remember that deciding whether a measure is or isn't a reasonable one is not a subjective test, based solely on what you think, but rather an objective test, based on what other ordinary people in the same position as you would think. In order to act reasonably you must ask yourself what other prudent (or careful) people would do if they were in your shoes.

In practice various issues need to be considered when deciding what measures should be put in place. These include questions such as:

- Are the measures practical to put in place, bearing in mind the aspect of the business in which they are to be implemented?
- Are they rational and proportionate measures, bearing in mind the public health emergency which has given rise to this requirement and the need to reduce the transmission of the virus?
- Can they be put in place without compromising the health and safety of others, whether they are other employees, members of the public or anyone else?

Screenshot regarding voluntary work:



Bibliography

1. <https://www.bindmans.com/news/government-guidance-changed-to-permit-people-with-specific-health-needs-to-exercise-outside-more-than-once-a-day-and-to-travel-to-do-so-where-necessary>



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2. <https://www.mind.org.uk/information-support/tips-for-everyday-living/nature-and-mental-health/how-nature-benefits-mental-health/>
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7. <https://gov.wales/coronavirus-regulations-guidance#section-39249>