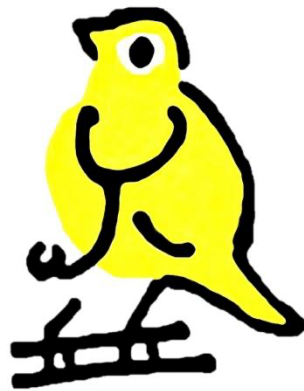


Autistic Doctors International (ADI)

**A response to the British Medical Association call
for evidence for the COVID-19 enquiry**



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Contributor List

The following individuals, in alphabetical order, contributed towards this short report and are happy to be identified as such:

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We would also like to acknowledge and thank some anonymous contributors and those who completed the informal member poll.

Introduction

Autistic Doctors International (ADI) is a peer support group representing the interests of autistic doctors around the globe. Autism is a lifelong state of being, which may present with differences in communication, social preferences and sensory processing (Shaw et al, in press). Most autistic adults do not have an associated learning disability (Brugha et al, 2016). Autistic people have higher mortality rates than non-autistic people (Hirvikoski et al, 2016), and there is some evidence to suggest that being autistic is linked with increased risk from Covid (Schott et al, 2021). Estimates of autism prevalence in the United Kingdom (UK) population currently sit at 1-2% (Brugha et al, 2016). The prevalence in doctors may yet be found to be higher, as we know that medicine “*selects for many autistic strengths*” (McCowan et al, 2021). This report has been developed primarily through the experiences of the contributors, supplemented by a small, informal poll of ADI members regarding their experiences of working in the UK National Health Service (NHS) during the COVID-19 pandemic.

Autistic doctors are first and foremost doctors as any others in the NHS, experiencing the pandemic and serving our patients alongside our colleagues. Whilst ADI advocates for the many positive roles and strengths that autistic doctors bring to medicine, we are also aware that autistic doctors may have differing needs, stemming from sociocultural and environmental factors, which can be addressed with reasonable adjustments. Some of the changes that have happened very rapidly since 2020 have made achieving such adjustments challenging in the context of the pandemic, with COVID-19 alone monopolising occupational physician health time. Autistic doctors may identify openly in the workplace, but as it is frequently a hidden disability, even where doctors identify, their need for reasonable adjustment may be deprioritised within the pressurised environment of an NHS trying to cope with COVID-19. This has caused considerable strain for many of our members, which may yet lead to moral injury and burnout.

Autistic doctors and medical students remain at ongoing disproportionate risk of being adversely affected by the pandemic in multiple ways. Increased recognition and action are needed to support and retain these valuable members of the workforce.

Our thoughts on the protection of UK healthcare workers from COVID-19

We have significant concerns over the lack of appropriate protection for healthcare workers in the UK and the impact that this has had on staff working to provide care for others.

For autistic doctors in particular, the following areas have been problematic:

- Risk assessments have not taken into account autism diagnoses, either from the perspective of added risk, or reasonable adjustments in the workplace.
- Some junior doctors reported that the use of Personal Protective Equipment (PPE) had been inconsistent between hospitals, with some using FFP3 and others insisting on simple surgical masks and related concerns around aerosol generating procedures (AGPs).
“In one [hospital], they would tell us off for wearing FFP3 masks around patients (even after AGPs) because it would ‘worry the patients that covid is more serious than it really is’.”
- Sensory issues have been challenging for some. Members of the group voiced that it is known that simple surgical masks do not provide appropriate levels of protection for frontline workers and can cause sensory issues for some autistic people, especially with elastic which is hooked behind ears.
“I really suffered with the sensation of the rubbing around the ears until some kind volunteers provided straps.”
- Some reported using FFP2/3 masks which they had sourced themselves and had then sometimes been told they were not allowed to wear at work, instead having to wear simple surgical masks.
- Some reported they had had problems wearing hoods due to the noise they generated. Others suggested that hoods with motors at the belt might have been an improvement, but neither type of hood has been available to the majority of NHS staff.
- Many of us have been asked to wear clear visors, which again carry significant sensory impact.
“It was the visor that made me feel the most claustrophobic (and impaired me when trying to do anything more difficult than talk to a patient).”
- Some autistic doctors felt a sense of being abandoned within the workplace.

Our thoughts on the impact that the pandemic has had on healthcare workers in general and ourselves as autistic healthcare workers

Autistic people frequently have a strong sense of moral and social justice, following policies and rules that are in place for logical reasons. When combined with communication differences, this has made some clinical situations more challenging for some when asked to do things that caused moral distress.

“Navigating social encounters with different views on rules could be particularly difficult between autistic and neurotypical people due to the double empathy problem (not understanding each other’s views) and communication differences”

Concerns have been raised about the level of work doctors are being asked to cover. This may be fostering a reluctance to ask for reasonable adjustments due to a lack of other staff to cover workload. Many of us have struggled with the degree of rapid change that has been implemented during the last two years.

“The sheer level of flexibility and change that was involved was staggering, it wasn’t just autistic people struggling with that, although admittedly we are more susceptible to having a harder time with it. Room changes daily, lack of tech accommodations due to moving rooms, redeployment, complete change of the way in which we work, placements extended/shortened, significant changes back to back as the system tries to adapt and guidance alters hourly, huge numbers of emails all trying to make things clearer but too fast to keep up with. The lack of clear, consistent guidance from the government. There was very little certainty of anything public or private.”

Several General Practitioners reported how primary care, which has always been stressful, has become even more challenging during the pandemic.

“Also dealing with the anti-vaxxers, the anti-maskers, vaccinating the entire population thrice, the media fanning the flames of the GP bashers who think we’ve been closed throughout.”

Our thoughts on the impact of COVID-19 on the delivery of healthcare, both as autistic doctors and as autistic patients

There have been huge impacts from the changes in healthcare delivery; both positive and negative. Whilst this has been the case for all healthcare professionals, there were some specific areas which recur prominently as themes for autistic doctors. These have included;

- challenges navigating coping with ongoing uncertainty, including changes to established routines
- challenges surrounding communication changes
- some have found a shift to more home working very beneficial and would like this to continue
- some have also observed that they have specific skills sets which have allowed them to adjust to communication in PPE compared to their non-autistic colleagues
- again, the theme of loss of reasonable adjustments due to rapid service reconfiguration was reported

Many clinicians have suffered during the COVID-19 period due to difficulties tolerating uncertainty. Common stressors amongst hospital clinicians were constantly changing timetables, multiple deaths within a ward round, uncomfortable PPE communicating through masks to also masked patients and relatives, and communicating with patients' relatives via the telephone due to visiting limitations. To quote an Acute Medicine Consultant:

“Our rota changed four times in a fortnight and the number of forms I had to fill in as a consultant on the post-take ward round went up from two to five. It was stressful not having dedicated desk space/IT for my rounds. Donning and doffing uncomfortable PPE was also tiring and ward rounds took twice as long per patient.”

“Trying to discuss ceilings of care/treatment escalation plans was near impossible whilst wearing a mask as both doctors and patients rely on facial expressions to understand what the other party is saying. It was even trickier trying to palliate patients via telephone discussions with their next of kin and we have received numerous complaints from patient relatives over how deteriorating patient status/the need to palliate was conveyed in the context of restricted visiting hours. We were exhausted from covering for clinician sickness all the time. Service work was prioritised so few professional discussions/ audits/ projects/junior teaching took place. Meetings now take place via Microsoft teams, so waiting for technology to start is also irritating. I do, however, appreciate the fact that no one wears a mask on teams so it's easier to communicate that way.”

An Anaesthetic Consultant reported that she found telephone consulting difficult as visual clues and lip reading aren't available to help her interpret what the caller is saying. She has let her colleagues know this and has asked them to communicate via text message if possible. She would like them to acknowledge the discomfort of wearing PPE and has found that wearing custom-made scrubs and taking hot showers after work has been beneficial. Stringent infection control guidance means that she cannot keep her usual fidget toys, so she is stimming more without masking (stimming is repetitive use of an object or activity, often used to gain or reduce sensory input, deal with stress or anxiety and to block out uncertainty. Some autistics use small fidget toys to provide this input in a less socially stigmatising way). The stressful days mean that she has minimal verbal interaction once out of the hospital and prioritises getting sufficient restorative solitude whilst also balancing family needs. Clinical routines and predictability have been chaotic

during this pandemic and deliberately creating new routines has helped her provide a degree of predictability in her life. She advises that clinicians should be vigilant regarding signs of overload; taking breaks as soon as possible and using the time to recharge, either alone or with colleagues according to what the autistic clinician prefers.

Other autistic clinicians have benefitted from COVID-19 ways of working and would like this to remain their default mode of practice. Some have experienced reduced cognitive load in not having to decide what to wear in the morning, with hospital uniform policies simplifying the decision to scrubs with PPE. Others are thriving with telemedicine/telephone consulting and relish the lack of hard start and finish times. Previously they would have to pause and reset their thinking to run their surgery to time, instead of completing notes and referrals as they go along. They appreciate the use of triaging so as to see the most unwell face to face and having time to help patients who previously found it difficult to obtain appointments. There were also comments regarding the home environment with dim lighting being much easier to work in, rather than the sensory overload in the workplace of fluorescent lights and almost exclusively white/hard bright surfaces. A common theme experienced by those working from home/teleconsulting is explained by this doctor about the non-autistic, or commonly referred to as neurotypical (NT), workplace set up -

“I feel like the pandemic has made me realise how much I’ve had to wedge myself uncomfortably into an NT world when it doesn’t fit. And instead of accommodating me, I have to work around them. All. The. Time.”

A psychiatry colleague has a similarly positive experience:

‘I was very fortunate in that I needed to be removed from patient-facing activities at the beginning for health reasons so I have mainly been working from home but going to work once a week to sign off on paperwork. This is the longest time in my life that I have not been in the thick of it whilst working and have learnt a lot about myself in the last nine weeks. The most striking thing has been a new appreciation of just how affected I have been by constant sensory overload, senseless interruptions, feeling trapped and unable to escape and that all these overwhelming stimuli have led to hypertension and poor blood sugar control. At home I am happy to work longer hours, produce better work and reflect on the challenges facing our unit and come up with constructive solutions. Having dedicated relaxing time because household chores have been worked into the long work day means that weekends are now spent doing things that nourish my spirit. My blood sugars are normalising as is my blood pressure. The thought of going back to “normality” at the end of all of this fills my heart with dread.’

Several autistic clinicians have noted that it has been interesting to observe some non-autistic colleagues trying to communicate whilst using PPE. They have struggled extensively whilst being unable to rely on their usual non-verbal communication; this is an area where autistic clinicians can have an advantage in some ways, given our often extensive reliance on verbal communication and communicating very directly and clearly when items or actions are required.

Our group noted that increasing service capacity to treat COVID-19 meant that other “elective” areas were inevitably affected. Also that patient assumptions regarding healthcare availability were an issue and seemingly linked to media commentary. We experienced patients with valid concerns about hospital safety and there is a view that nosocomial transmission seems under-investigated. GP members experienced primary care being overwhelmed and unsupported,

despite working at maximum efficiency, and with unhelpful media rhetoric, which was felt to have compromised the use of phone triage, despite it being well established prior to the pandemic. Concerns about training have also been raised, which will have an impact on delivering healthcare. This includes factors affecting the Annual Review of Competence Progression (ARCP) which is central to whether doctors progress to the next stage of training.

Delays in the waiting lists for autism assessments have been very long in most areas pre pandemic and anecdotally seem to be longer since.

“1) I found training opportunities decreased substantially for my specialty which depends on elective work, especially in the first wave and couldn’t get my numbers of cases. This resulted in a COVID-19 type ARCP outcome but there is a gap in my specialty training experience with no extensions to training or real extra help to bridge it.

2) Waiting lists for autistic assessments are beyond unacceptable; hard to say how much pandemic has affected this. But even private assessment ended up with a delay, probably due to staff illness.”

Another autistic doctor felt that they were slightly less able to deliver healthcare, due to struggling with the sensory effects of visor and mask. However they incorporated recovery periods to ensure that patients were seen, working outside their hours daily to do so.

Overall, difficulties have increased but with some specific benefits for our autistic doctors. Many may now have clearer comparisons of beneficial and detrimental effects, providing personal and group feedback from the coal face on the need for long term reasonable accommodations in these areas.

Being an autistic patient/doctor

Experience as an autistic patient has been varied. Here are the accounts of three doctors.

“I moved areas and registered with a local GP. Couldn’t get seen by my local GP despite calling at 8am ...despite needing them to prescribe medication and leaving messages and trying different things. Therefore I had to switch to babylon/GP at hand which is not ideal since London is a commute for me that I do for work, but I’m lucky that it is even an option... I have both physical and mental health needs and access to primary care locally was far too difficult.”

“As an autistic patient I have benefitted hugely from the new system of econsults at my very good GP surgery. Much easier for me than telephone, I can list all the info and feel more confident it’s been ‘heard’, I often get an email or text message reply which I can refer to and not forget anything and me appearing a bit anxious about a face to face interaction (because of autism, but amplified because of past assumptions and mis-diagnoses) isn’t confused for anxiety being the cause of the health problem I’m presenting with. This has been difficult despite having been a GP myself and until my diagnosis I had no idea this was what was happening. I can now explain in one sentence! If only they and I’d known this in the first 48 years of my life!

I needed a hospital admission for several weeks in summer 2020. Covid precautions were very lacking re toilet and bathroom areas, drip stands not being cleaned etc Gloves, aprons and masks all used well. My management wasn’t good in general but I don’t think any worse re Covid...They were not aware I’m autistic - I think this would have worsened it all, presuming anxiety...I’m aware that others may find it much harder to get good healthcare

because their GP surgery is so busy or needing A&E who have little understanding and don't provide accommodations at all, even when an autism passport is presented and backed up by their GP."

"Access to my GP has been incredibly difficult since March 2020. They were always a bit difficult, with routine appointments booking up 3-6 weeks in advance, but it got so much worse. They have changed how appointments are triaged every couple of months, which means I keep having to relearn the system, and it's often completely incomprehensible. Their latest system gets rid of routine appointments all together, and involves having a history taken by a member of reception staff, who document the history, which is reviewed by a triage GP. I asked how this works and was told that the triage GP categorises as 'see today', 'see in 2 weeks', or 'does not require an appointment'. Having to give a mental health history to a receptionist who, despite being perfectly polite, was blatantly out of her depth, and asked clumsy, inappropriate questions was horrible. No safety netting questions were asked, and based on this alone the GP decided I didn't need an appointment any time soon. It took a 30 minute phone call and a lot of energy before they would acknowledge that this was not an appropriate decision, and was based on inadequate information. It feels so horribly cruel and unsafe as a system."

Our thoughts on the public response to the pandemic as individuals, autistic doctors and autistic people

Mask exemptions and autistics

Throughout the pandemic response in the UK, autistic people have been considered to be one of the groups who might be allowed exemption from mask wearing. Some autistics find it impossible to wear a mask, but we also note that despite many finding sensory aspects of mask wearing difficult, they still choose to wear them. Possibly the most difficult aspect of this for autistic doctors has been the adoption of the 'sunflower' lanyard by people who don't want to wear a mask. The lanyard was intended to be worn to indicate a hidden disability, but has now become a symbol for some of defiance against mask wearing, which can be very hard to navigate. Members of ADI reported having strangers approach them to ask why they were wearing a mask when they were also wearing a 'sunflower' lanyard.

General public response

There was feedback that we have watched the public response unfold and observed that the public often responded in line with their previous personalities and beliefs, ranging from extreme caution, using masks diligently and going above and beyond rules to reduce risk of infection to prioritising and sharing various internet memes and theories.

"There was a sense of support from the public with banners and claps and so on through the first wave that seems to have faded. This doesn't seem to have materialised into real support for the health service or any benefits that are even close to what someone in the military might expect even though words like 'frontline' 'heroes' etc have been used, people have fallen in the battle against covid and leave has been cancelled and redeployments made. Healthcare workers expected to do a job where they were kept safe; the public seem to see them as

soldiers getting on with a duty, when that's never what healthcare workers signed up for and they certainly haven't been given compensation, comfort and benefits that would match that understanding."

The group felt that many of the public were tiring regarding restrictions and less motivated to follow guidance, likely not being fully aware of the impact on hospitalisations and healthcare workers. At the same time some resolve seemed to become firmer, for example those feeling vaccination was unnecessary or harmful and those choosing and advising only natural approaches to immunity and health.

There was a strong feeling that public guidance should also be followed by the government, and that media reports questioning whether this was the case left the public feeling their efforts were not worth their often very considerable sacrifices, for example regarding not being physically present for loved ones in desperate need.

Doctors commented -

"I was surprised at how many members of the public fully believed Facebook memes without fact checking or speaking to health care professional friends like us. Some did. But without the years of understanding of how viruses, healthcare and the system works they weren't really swayed."

"...many think it's a conspiracy that GPs are being paid to give the vaccinations even when I explain that's just how GP surgeries have been paid long term now and that GPs didn't even want that system originally."

Some in the group voiced that they have witnessed the public being confused, receiving mixed messages by the media and government. Reconciling anxieties about COVID-19 and wanting to protect oneself with adequate precautions can also be hard for autistics when others around them have less or no concerns so do not follow guidance. Autistic people may often undertake what are unnatural and effortful approaches for them out of consideration for others and it can be difficult to understand why others may not act accordingly. Some autistics see masks on a par with basic hygiene for instance.

Alarm has been voiced over the seeming normalisation of morbidity and mortality levels from COVID-19 and the sense of low public awareness or impact of comparison data regarding countries with similar healthcare systems and general characteristics.

Our thoughts on the impact of the pandemic on population health

Some felt that this area was not for our group to comment on as firm data needs to be collected. As clinicians however, we share many of the same concerns as our colleagues over population health as a consequence of the handling of the COVID-19 pandemic in the UK.

Amongst many issues, anecdotal feedback was that

- physical activity has reduced, healthcare seeking reduced and substance misuse and domestic violence increased.

- Loneliness has seemed to increase, with high concerns amongst our group for children, and is seen to be contributing to difficulties with mental health and pressure on mental health services. The group felt that older adults and those living alone are also particularly vulnerable.
- The group have seen pandemic demands highlighting the lack of spare capacity in the National Health Service, with concerns about future resilience and feel there will be a link with further lockdowns. Resources from mental health, cardiology, cancer treatment and more have been witnessed to be diverted to the COVID-19 response. There is strong feeling in the group that a fully funded and staffed NHS would have performed better and experience on the ground of the public starting to blame individual NHS and social care staff for delays, rather than defunding.
- In most specialities, the group are anecdotally seeing more advanced cancers with some delays in the pathway for a variety of reasons such as delays in initial patient presentation due to staying away, and being unwell with COVID-19 whilst already under investigation and management.
- For many clinicians, we have witnessed personal health and wellbeing deteriorating during the pandemic, with COVID-19 infection and subsequent Long COVID. The impact of both on healthcare workers and the healthcare system should not be underestimated.
- The population morbidity from COVID-19 will have likely long-term effects which are emerging and seemingly less focussed on so far.

We also note that there have been changes which may bring benefits. For instance we have seen that changes in the UK implemented during the pandemic have meant

- more working from home, with some benefit in wellbeing and also considerable environmental benefit
- for some neurodivergent children, being taught in bubbles, with reduced class sizes, staggered break times and stricter expectations on social interaction has been beneficial
- other neurodivergent children have benefitted from periods of home learning and some parents made the decision with them not to return to school given their improved wellbeing out of that environment
- Some have noted that mask wearing, social distancing, personal hygiene, hand-washing have seemingly resulted in fewer winter flu/COPD admissions

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