Editorial

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Levelling up, with autism in mind

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In 2022, the Health and Care Act in England made appropriate training in Autism and learning disabilitys statutory for regulated health and social care providers. Oliver McGowan was not the only autistic person whose care has been adversely impacted by a workforce and systems ill equipped to provide reasonable adaptation to engrained ways of working. But owing to what can only be described as the bravery and courage of his mother Paula McGowan, and those who knew and loved him, Oliver has become *the* name synonymous with a need to 'do better'. Oliver's tragic death was, as they say, a 'catalyst' for change. He remains in the memory of his loved ones that multi-faceted, vibrant young man to whom avoidable harm occurred. That he has become this catalyst, cannot be absolution for systemic issues that harmed him and those like him. That sort of redemption will only come from a workforce ready and committed to make every single care episode better.

Many of those working in intensive care in England, will have recently carried out part one of the Oliver McGowan mandatory training package. Many will also be aware that the reception of this training has not been immune to the general growing dissatisfaction healthcare professionals have with the Sisyphean nature of 'mandatory' training. It is something I have witnessed. I say this as someone who has so far failed to secure one of the limited places on the, also mandatory, part two (face to face) training and who has just grumbled over my morning coffee, having received another email notifying me that the information governance training which I have already completed, at least 10 times, is once again 'out of date'. So, I can understand that quelling the frustration that comes from yet *another* element of training, which many will struggle to fit into their working hours, is a challenge. It has been a challenge for me too.

Perhaps it is also the case though that as people committed to a profession built on 'caring', it is somewhat jarring to our sense of self to be schooled on the fundamentals of humanised interaction. Irrespective, the accumulation of health inequalities amongst autistic people is clear. Adults with autism are consistnatly recognised to accumulate more chronic physical and mental health conditions, more premature mortality and report more barriers in accessing healthcare as frequently as they would like.[1–3] It has further been reported that physicians are not necessarily aware that they have any adult autistic patients in their population[4] and the quality of healthcare experiences reported by autistic adults are 'overwhlemingingly' worse than their non-autistic peers.[3] It follows that as a medical profession, we do need to respond appropriately.

The burdens and benefits of treatment in intensive care are often balanced on a knife edge. We work in an arena where the true implications of the long-term burdens from treatments we provide are still being elucidated and where access to appropriate post intensive care rehabilaition is not uniform. Decision making with complex ethics at its core is therefore part of our everyday practice. In this sphere, our ability to 'see' the individual before we define our goals of treatment is paramount to how we function and we cannot 'see' autistic patients if we do not allow them appropriate space to reveal themselves. Baruah references the three underpinning domains of the SPACE framework: physical space, emotional space and processing space.[5]

In 2023, I was pleased to handle an article for *Intensive Care Medicine*, which gave our community a window into the concerns a consultant intensivist and father of an autistic child had about ableism in intensive care.[6] Those who understand what is at stake when ableism is allowed to go unchecked, see the dangers. As Tacconne's article demonstrates, shining a light on this particular form of discrimination is often left to those whose lives are intimately connected with someone at risk of that discrimination, or indeed to the people who are at risk themselves. But everyone else must engage with the responsibility listen. This insight should be seen in context of the evidence demonstrating variations in clinician's ability to appropriately asses the 'quality of life' and wider healthcare status of individual patients[7,8] and a lack of explicit weighing up of intensive care treatments for individual patients.[9] Although autism is not a learning disability, the co-prevalence of autism and learning disability is well recognised[10] and perhaps the most striking representation of the dangers we are navigating comes from work by Baksh et al., which demonstrated that during the Covid-19 pandemic, adjusted for age, sex, severity of illness, comorbidities and Down syndrome, patients with intellectual disability were 37% less likely to receive non-invasive ventilation, 40% less likely to receive invasive ventilation and 50% less likely to be admitted to intensive care.[11]

Baruah has provided us with clear framework to level-up our skills in adapting to the needs of autistic persons.[5] Her article is particularly welcome because, in contrast to

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the much broader and arguably therefore less immediately useful, scope of the mandatory training I have been provided to date, it uses the SPACE framework to tailor advice to the intensive care environment. Her article demonstrates that the idea that intensive care is somehow too complex to be impacted by a tool not specifically designed for our environment, just isn't true.

The inclusion of advice centred around working together with autistic colleagues is also welcome. A recent publication by the *Intensive Care Society* highlighted some of the experience of autistic persons and those with disabilities in our teams.[12] Moreover though, it highlighted a mismatch between the reporting of neurodivergence and disability in our teams, compared to the prevalence of people living with neurodivergence and disability in our community. This is a finding echoed by a recent General Medical Council report into tackling disadvantage in medical education.[13]

Diversity amongst healthcare can improve both the quality of care we give to patients and financial results for the system.[14,15] Cultivating a literacy into the needs of our *whole* team is the key to true inclusivity and that, I am convinced, is the key to performance. Patients come to us often with odds stacked against them, they arrive vulnerable and with little or no choice about who they place their trust in - the very least we owe them is a team made strong by individuals who are *allowed* to be at their best.

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