The Doctor podcast | Episode 6

Dr Giles Armstrong: I was reading the *Metro* on the way to work, and it said ‘Manchester airport has been accredited by the National Autistic Society’, and there was this real light bulb moment of all the things that I'm stressing about in terms of emergency departments – chaos, busyness, unscheduled things happening, light, noise, a constantly changing rota of people – that’s an airport.

And so actually, if an airport can do it, I thought, well, we might be able to do as well.

Voiceover: Welcome to the sixth episode of The Doctor podcast, brought to you by the British Medical Association. Each month we bring you conversations inspired by stories featured in *The Doctor* magazine.

This episode builds on the feature article ‘Sensory overload – making the NHS more accessible for autistic patients’ by Tim Tonkin.

You don’t need to have read the article to enjoy this episode but if you’d like to do so you can find a link to it in the show notes and at thedoctor.bma.org.uk/podcast

Dr Sarah Davies: I’m Dr Sarah Davies, GP partner at Sedlescombe and Westfield Surgeries in East Sussex.

Giles: And I'm Dr Giles Armstrong. I'm a consultant paediatric emergency medicine at the Royal London Hospital, which is part of Barts Health.

All autistic patients are different. They're all individuals in their own right. They may have some common themes and commonalities around what they will struggle with, but actually you have to recognise that you can't build your system around one patient and then assume that that means that you fix the problem.

I'm now old enough to talk about how medicine has changed since in my day, because I'm 52 now and I've been a doctor since 1997.

If I go back to when I started in emergency medicine, which was around 2000, the numbers we had at the time was reasonably manageable. And if somebody came in and mum said, ‘actually, he'd be much better if we can get them into a room.’ We could do that; we could accommodate that.

That became harder in an organic sense, and we had a few difficult/challenging cases where things really didn't go as well as they could have done. And it just wasn't a good experience. It wasn't a good experience for the patient. It wasn't a good experience for the family.

And actually, it really wasn't a good experience for the staff. It was it was morally distressing to the staff to see the state some of our patients were getting into, not through any individual's fault, but through the fact that the system was busier and it was harder to manage things.

And then around about the same time in my personal life, my nephew received a diagnosis. He's autistic. And watching my sister manage him and managing myself when we would look after him and really getting more of an appreciation of the challenges that exists in the everyday world – it all kind of came together and I thought, we've got to do something better.

And then there was one of these random things. I was reading the *Metro* on the way to work, and it said ‘Manchester airport has been accredited by the National Autistic Society’, and there was this real light bulb moment of all the things that I'm stressing about in terms of emergency departments – chaos, busyness, unscheduled things happening, light, noise, a constantly changing rota of people – that’s an airport.

And so actually, if an airport can do it, I thought, well, we might be able to do as well. And that was the real point where I actively started investigating the process

Voiceover: The National Autistic Society – the NAS - is a UK charity dedicated to improving the lives of autistic individuals through offerings of support, education, and public awareness. The NAS provides services, and training to influence policy changes that benefit those with autism and educate companies on how they can provide adjusted services. Both Dr Armstrong and Dr Davies embarked on setting these changes in their workplaces through the NAS.

Giles: When I reached out to the National Autistic Society for the first time, there were a few conversations. They are a charity, but they do have to raise funds to do what they do and so they charge a fee for the accreditation. And we thankfully found the funds for that from the Barts Health charity. They agreed to do it for us for the whole emergency department. And so that's where we started.

Sarah: I think I would agree with Giles in that if you go back five to 10 years, especially in a small rural practice where I work, we would know those patients that were struggling, we would know those patients that got really stressed.

And for us again, probably about the same time, with experiences of autistic people within the family, it just became something that I was more aware of. So, we started with, just something simple on the, the, the booking screen that said, ‘this patient is autistic, so please be on time.’

So, it started there and then the introduction of the PCNs in the last few years meant we needed to look after the needs of vulnerable people within the catchment area. Just talking it through with my PCN colleagues, it became something that everyone wanted to be a part of. So, with their support and the practice’s support we decided to do something a bit more formally and realised that there was an accreditation.

For us in our PCN, the, the idea is that my practice is the guinea pig. So, we are going to get the accreditation and form the blueprint for the other six practices to follow. So that's the process that we are still working towards. And hopefully we will get there.

Giles: Putting autism aside for a second, I'm one of the named doctors for safeguarding. And, you know, how we recognise and respond to all sorts of children’s safeguarding concerns is so different from where it was when I started paediatrics in 1999.

When I started, it was predominately physical abuse we talked about. Now we've got a whole spectrum of things we think about, and I think the same thing is probably happening when we look at neurodivergence.

We’re dealing with actually not just with patients who are autistic. We're dealing with staff members and colleagues who are autistic, and we've got nurses and doctors who have that lived experience themselves.

And I think there's a recognition – that's the thing that's probably changed and will continue to change – it's more acceptable to talk about it. And if it's more acceptable to talk about it, that makes it easy to talk about with patients and their families.

It certainly seems to be more common in terms of awareness within medical students. Now, whether I don't know what their exact curriculum is. But certainly, if you have a discussion around neurodivergence and accommodations, people are able to engage with that meaningfully as a medical student. I doubt I would have been able to because it just wasn't part of our curriculum.

Sarah: I think within society, there really is. That's why the diagnostic rates are going up. People are aware of it. More children are getting a diagnosis. And I think patients are also getting better at understanding this concept of reasonable adjustments and starting to ask for that, which is a good thing.

Voiceover: Under the Equality Act 2010, ‘Reasonable adjustments’ are changes that must be made to how things are done to ensure that disabled people, including autistic people, are not disadvantaged and can access things like healthcare on an equal basis with others.

Adjustments should be tailored to an individual's needs. Their aim is to remove barriers that might prevent someone from receiving safe and compassionate care. Dr Davies and Dr Armstrong discuss how adjustments can vary and ways to implement them in their practices.

Sarah: We've we reached out to all of our autistic patients to try and get their reasonable adjustments. And that was actually much harder than we thought. We actually only got about maybe 20 to 30% to actually respond for all sorts of reasons.

But for those that have responded, I know now that they have a preferred clinician, that will get a double appointment that we try and arrange appointments for the end of the day when it's quieter – they think that’s brilliant.

Giles: Certainly, our work with the NAS was very clear that when you look at the phrase ‘reasonable accommodations’, the most important word in that is ‘reasonable’ – it's not about making thousands of modifications. It's about supporting people in getting the care in a way that still works for the department as a whole.

In an emergency department setting the problem is it's all unscheduled. It's all unplanned. We don't know how long it will be, so we just have to kind of live with to a certain extent. I can't alter that. What I can do is try to make the waiting as least uncomfortable as possible in the context of, you know, where you are in an emergency department.

But if I was doing that for our outpatient clinics, I'd be doing something very different, because then it would be more around consistency and trying to keep it to a routine that people are expecting. So, it varies where you are in healthcare.

Sarah: I agree. It's difficult to accept that sometimes we can't always meet those. And with the best will in the world, we're never going to be perfect. And that's the tricky bit really, having this gold standard that we want to achieve – in reality we’re never going to quite get there. You’re in a work in environment where the unexpected happens.

But we can, like you say, have a systematic approach so that people don't slip through the net.

Giles: Yeah, I think if you look at the direction of travel, there's some encouraging signs. So, I think from next year, there's going to be a flag on the spine which will say if you need reasonable adjustments. And that's meant to then display on everybody's record system a digital red flag. So that will at least be a standardised national recognition that you need additional support.

Sarah: I think reasonable adjustments should be open to everybody with or without a diagnosis, which it is technically. But at the moment we still only really pursue it with those people with the diagnosis.

The offer of reasonable accommodations which are really easy for any primary care setting – the preferred clinician that double appointment, certain time of day, and waiting in the car or outside are really easy things. And the Oliver McGovern training I think is a straightforward step that every primary care setting could do.

Voiceover: Oliver McGowan, an autistic 18-year-old from Bristol, tragically died after being given anti-psychotic medication, despite medical staff being told by both Oliver and his parents that he had reacted badly to it in the past. His unfortunate passing highlighted a greater need for healthcare staff to have better training and understanding of autism and its varying impact on patients.

Giles: For those who aren't familiar with the story, Oliver McGowan was a young man who tragically died, primarily due to a lack of knowledge of him having a medical issue apart from his autism. He wasn't listened to, and his family weren't listened to. The training is very good at bringing the patient and their family's story through into how we care for people who are autistic.

Sarah: The Oliver McGowan training is online training. It's free and takes maybe half an hour or 40 minutes. Lots of videos on there with people with the lived experience and the experience of Oliver McGowan and his family.

Giles: The national Oliver McGowan programme has been rolled out to help support healthcare providers in looking after people who are autistic and have additional needs and reasonable adjustments.

The training is very good at bringing the patient and his family's story through into how we care for people who are autistic.

Sarah: I think for a lot of people that that really opened their eyes. The best fit we could do is get everyone to do the Oliver McGowan training. And then anything that we come across, we share with all staff – any five-minute YouTube videos. But actually, that takes a whole system change to make sure that everyone gets that training at some point in their medical career, which they don't.

Voiceover: Some patients may also need additional support, especially if they do not want to go into hospital or a GP practice. Dr Davies and Dr Armstrong talk about their experiences with patients outside clinical environments and how reasonable adjustment training helped them ensure patients got seen.

Giles: As part of our emergency service, we have something called a physician response unit – a team of doctors and nurses that go out to the patient's home, after they've been assessed by a healthcare provider.

And the advantage of that is a lot of autistic patients struggle with the changed environment of coming to hospital. No matter how nice you make it, the whole transition itself is quite distressing.

And these were often patients who'd had really negative experiences where on some occasions, police had had to be called to support the ambulance service to physically transfer the patient to hospital.

They clearly had a medical need, they clearly had to receive care, but the act of getting them out the house was so distressing that the police had to be called to get that young adult to hospital.

By bringing that SOP in with the physician response unit, we were able in some scenarios to manage that person at home without needing to transfer them. And obviously that was massively better. And actually, if they had to come into hospital, that could be supported by helping to give them medication to make them a bit calmer.

So instead of relying on physical force to get them into hospital, you helped make them a bit calmer by giving them some medication to make them feel a bit happier about that move.

Now, admittedly, not everyone has a PRU, but thinking outside the box and going from physically carrying a patient into hospital to going out and meeting them in their home, was a huge benefit.

Sarah: We know our patients. There is that cynicism with some people, that ‘well why should they get priority?’ As opposed to, you know, every day is difficult for some people. So why not give them a break?

I think the story I would describe is a young man who, who didn't engage well with services, who didn't come for his learning disability reviews, his lifestyle was rather chaotic. He needed to see our nurse, so we opportunistically went him and gained rapport and, but he needed to go to A&E.

Previously he would always walk out before being seen because it was too much for him. So, I rang ahead, spoke to the on-call team. I said actually what you need to do is liaise with your learning disability team.

And so, when he comes to hospital, somebody meets him in the A&E department and takes him straight through. And that happened. He was seen to within an hour.

And consequently, the family was so grateful. He'd had his emergency care – which I think otherwise he wouldn't have and he hadn’t done previously – because we'd been able to liaise with the hospital and get that sorted for him.

Voiceover: Change in the NHS is never easy. Dr Davies and Dr Armstrong talk about the steps in getting their NAS accreditation and share the best advice on making their workplaces more accommodating for autistic patients.

Giles: Ours was a little complicated because, the pandemic happened in the middle of it, and everything paused for about 18 months.

The NAS were fantastic. We contacted them and went ‘I genuinely don't think we’re going to be able to get this where needs it. Literally every time I walk into the department, it's physically, structurally different to how it was last week.’

In the interim they had actually realised they needed a more health-specific accreditation, and so they designed a health-care specific accreditation programme which covers all primary and secondary care.

We got amazing support from our NAS person, Hannelore Bout, who has been brilliant throughout. She came to the site, she went through our first round of self-accreditation, and then she supported us in giving us directions in terms of where we were going.

She said, ‘You know, even if you buy 15 different types of air defenders, some will walk in and go, I don't like those, I need that one.’ So, you can't base your systems on somehow magically having the right case. It was far more about preparing as well as we can how to meet people's accommodations by working with them.

The other piece of work we did, apart from signage when you arrive at the hospital –actually in healthcare, we're really poor at recognising that people tend to Google things.

And our externally facing website was slightly, embarrassingly sparse. Hannelore was very good at saying, ‘Well, what would be helpful for families is understanding, you know, what sort of things do you have? How long is the wait likely to be? What are your options if you need to wait? If your child needs electronic device, please bring the charger with you.’

So, we did a lot of work on the external facing website with the support of our trusted comms team.

Sarah: I would echo you on the IT. One of our receptionists is our autism champion, Hayley, she’s fabulous.

Although we get people's reasonable adjustments and we document them, we have a little pop-up box on the right-hand side, which in there, along with all their QOF reminders would say ‘has reasonable adjustments’.

So, you have to search for that but also you have to have taken the patient's name. So, when they ring up and we have no appointments, we wouldn't necessarily take their name. So, we don't know that they have reasonable adjustments. You have to really search for it.

We were only talking the other day about if there was a way on the system for the tab to come up a different colour so that if someone has reasonable adjustments so that it's obvious.

So that is something that we could maybe try and address. And I think every practice across the land would enjoy that. I'm in a small organisation, I'm a partner, I can make the changes.

Giles: A lot of hospital medicine is actually still heavily predicated on a 20th century model of care, which in itself was predicated on 19th century model of care. And we're not great at moving with the times.

One of the simplest things that we did in trying to make the service more friendly for autistic people is just having that conversation with people when they first come to the department saying, ‘Are you happy waiting here? Or would you rather wait somewhere else, leave your mobile phone number and we'll call you when it's your turn?’

Voiceover: Clear communication and dialogue between healthcare staff and patients is of paramount importance, especially if either party falls on the autism spectrum. Dr Armstrong and Dr Davies discuss how it is crucial that patients feel heard, and how offering different choices in healthcare can make a difference.

Giles: It's such a 20th century model of care concept that you have to sit in a physical place, in a queue, in your turn, and if you move, if you go to the back of the queue, we will get very annoyed with you. And actually, who are you helping by doing that?

It's so much better to have that conversation with autistic adults with parents of autistic children go. And some of them are really happy to say, ‘It's fine I've got my headphones. Just come and tap me on the shoulder when it's my turn so I don't get missed.’

Others say, ‘I'd much rather go and sit in the coffee shop across the road’ or others just prefer to walk around on side.’ We've got a few kids who just like traveling, their preference is to just to walk around the courtyard and that's fine, they're happy.

I think giving people that choice and recognising that a one size fits all model doesn't work for everyone. And actually, really unfairly sets some people back. This, you know, this concept of everyone is treated the same. It's an equality argument not an equity argument.

And I think we've got much better recognising that in healthcare. And one of the simplest things we did sign up saying ‘Tell the receptionist, if you are autistic, or if your child is autistic. And if they'd rather wait outside, put their mobile number on the screen and say call that mobile.’

Clearly there are some people where that's not appropriate because they're too sick. And that obviously takes precedence, they have to wait because we need to do observations. But there's a surprisingly large number of people who come to emergency care who are quite capable of ambulating around the place for a couple of hours until it's their turn. It's so much better for that person and for that family to be given that choice. And it's all down to communication.

Voiceover: After applying these changes, both Dr Davies and Dr Armstrong have seen vast improvements in patient experience and detail their advice on how other healthcare professionals can start implementing similar adjustments.

Sarah: The response we've had to the changes has been really positive.

Find some like-minded people, create a team, because you can't do it as one person. You got to have people that are, you know, willing to put the extra bit of work in initially. I like projects where you do a bit of legwork to start with and then it's done. It's always evolving, but you need that little bit of investment of time.

I think finding some people that are enthusiastic, and some with lived experience. So again, they see both sides of the coin. That would be my best advice.

Giles: Once you've found your team, I think in terms of advice, I would say the first one is your comms is your biggest bang for buck. Having a clear message to the people you serve that if they tell you that they are autistic and they need reasonable adjustments, you will work with them to meet that. That is probably the single fastest thing you can do in terms of getting an improvement in their experience.

You have to have the training to back that up. You have to do your Oliver McGowan. But just making it clear to people, if you say to people, ‘tell us’ they will, if you wait for them without telling them to tell you, they may not .

Sarah: See that’s really interesting. I've been having a circular debate about this. So, with people with a lived experience of a learning disability, leads in the hospital and the National Autistic Society. Our trouble is when they call for an appointment, we don't know they have reasonable adjustments. My proposal is we ask people to tell us, and actually, there's a 50-50 split on that advice.

But in an imperfect system, to me, it's the only way because they will be doing it to benefit. So, I agree, that’s the way we’re going to go too rather than just hope we see a little screen reminder.

Giles: And in an emergency setting where we don't necessarily know them, we have to ask. And often we also work on the basis that people may be more distressed.

The other thing I would say is don't be afraid of thinking outside the box. And I think if you look at what we've been talking about in terms of not being wedded to 20th century model of waiting in the waiting room until it's your turn.

I'm really pleased to say that I've been doing a huge work within Barts Health to try and raise the profile of this. They've invested in some of the, the food court pagers that vibrate and buzz.

And so now when you book in, if you say you can't wait in that small area, you're given one of those and you can walk anywhere within the building, you can't leave the building, but you can go to the cafe, you can go to canteen. And then it will buzz and say, please come out now, it's your turn next.

Working with people to make their reasonable adjustments just makes life so much nicer for them. And then it also makes it nice for you because you're then having a consultation where somebody isn't distressed, they’re ready to have the care they need.

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