

Autism and healthcare: an interview with Dr Carole Buckley

1. Can you tell us how you first became interested in autism?

I've been a GP for more than 30 years and my son who is 29 was diagnosed on the autistic spectrum when he was two years old. So I had early life experience of it, and then in 2010 a colleague asked me if I'd be interested in getting involved in the NICE, the National Institute for Health and Clinical Excellence guidelines for autism in adults, and I said yes, and it escalated from there. I've got invited to do an awful lot of things around autism since then.

2. Can you tell us about your current work?

I retired from clinical work, that's the work of seeing patients in 2017. And now I remain the Royal College of Practitioners representative for autism. So I work with a whole variety of other bodies around the health service and Department of Health encouraging autism awareness in primary care.

And I'm very excited to be working with Autistica as a member of their Discover strategy, they've got a Discover autism research network, I'm on the steering group for that, and working with their physical health and ageing topic group because I think if we are going to improve the health and wellbeing of people on the autistic spectrum from a physical point of view that general practise has going to be pivotal in that, it's going to need to step up to the mark and offer the right support. With autism as a clinical priority, what changes did this bring for GPs and autistic people.

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The clinical priority was aimed at delivering accessible resources, so resources suitable for general practise along with raising an awareness about autism within the primary care team. So it's not just about GPs, this is about the whole primary care team, 'cause we work as a team, we don't work individually. And so the college accepted that autism needed a bigger place in it, it also produced a position statement committing it to ongoing support for autism both for clinical work and around generating research in primary care.

And as such we produced an autism pack which went out to over 7000 practices in the UK, and we produced an autism toolkit which I'm very proud of, which is on the Royal College of General Practitioners website, it's a free resource, it's open to anybody. You don't have to be a member, it's not password protected, it's got

resources for professionals, it's got resources for patients, it's got resources for carers, it's got resources for commissioners. It's got links to other resources, it's kept up to date, it's really quite exciting.

They also committed to increasing the presence of autism in the GP registrar training curriculum. So those are people who are training to become future GPs, and we managed to get three articles about autism in the training journal that is produced regularly, which is brilliant, absolutely brilliant.

4. How can we make healthcare more accessible for autistic people.

The difficulty with the barriers are they're multifactorial, it's not one single thing. So there's not one single thing that we can do that will actually make this better. So there are the barriers because staff have not had sufficient training, they don't have sufficient awareness, they don't understand autism.

There are also other barriers because they don't flag the reasonable adjustments that are needed to get somebody into the practice, to allow them to visit us, to have equity of access.

There's also the problem of not sharing that, but I have to say that's not unique to autism. Most patients would complain that they have to tell their story again and again and again. So that's not unique, but on top of that, I think particularly for autism, there's the problem within the individual. So each individual is different but there is the problem of the individual not recognising the significance of their symptoms.

So they may not recognise the significance of the pain that they are experiencing. They don't seek advice in a timely fashion, they don't come and see us because of a problem with their health, and that's why there's a lot of work happening at the moment around developing a health check that is suitable for people on the autistic spectrum that would mean that we were proactively offer them an appointment.

So they would be invited into the health service by the health service and then they would go and see somebody at the general practise who had extra training, who was particularly autism aware, was able to deal with them in the right sort of fashion. And I think that's gonna hopefully make quite big strides getting NHS England to make autism one of the top priorities for the next 10 years, has I think focused attention, I think that will help hugely.

5. Can you briefly summarise the key points of the Autism Act, what impact it has made and what still needs to be done?

I think for me the key thing about the act was the statutory requirement to produce the guidelines, the strategy, and that that had to be reviewed every five years because if there's one thing that is very obvious is that the state of play within autism is changing very rapidly.

And I think the other thing it did which is again very unique is that it brought together all the agencies. So we had really, real multi agency working. So we had health, we had social care, we had education, we had the Department of Works and Pensions, we had the prison service. Everybody came together in one room to work on a strategy, and that really is special 'cause when we were doing the children's guidelines for NICE, education weren't there, they weren't in the room and that's bizarre when you think about it really.

And I think what it's done, it's raised the profile, it's significantly raised the profile of autism. I don't think we would have persuaded my college to have autism as a clinical priority if the act hadn't happened. I think there are lots of examples of things that the act has enabled.

I think what it hasn't done is probably be hard enough on the statutory agencies. So I think we haven't got universality of support across all the agencies. So there are beacons of excellence, I mean for instance in Bristol we have a stunningly good adult autism service, stunningly good, but it's not replicated, it's not everywhere, and in some parts of the country education services are really good, but not everywhere. And I think what we need is we need just a little bit more of a stick behind the statutory services to make them all step up to the mark.

6. How can we improve pathways to autism diagnosis and suitable post-diagnostic support?

I would probably like to stop focusing on diagnosis, I actually think we should be starting to look at specialist autism teams. I think the teams should go beyond the idea that diagnosis is what you need to do.

So the team should be there for diagnosis and post-diagnostic support, and I also think we need to start recognising that autism is very like dementia services were for a long while, the dementia specialists thought that dementia was a specialist subject, and actually do you know, it isn't, it can't be because dementia's out there in the community and what we need to start doing is looking at getting community services to embrace autism rather than there being a specialist team that deals with autism.

And I think we've got a really good opportunity with both the 10 year plan from NHS England which has put autism there in the plan, but also I don't know if you've seen the recent five year GP contract that's come out. But the GP contract is requiring all practises to clump together to form primary care networks with a 30 to 50,000 patient population.

And I think once we've got that population and the GPs working together within that group that we should actually have an autism lead. There should be a clinician, doesn't matter if it's a GP or a nurse, or a psychologist, a clinician who is the autism lead for that population of patients. And that person would be there to enable services, to enable inclusion, to ensure that training was happening.

To ensure that training was followed up because there's no point training everybody and not doing it again you have to keep on doing training. You have to offer it for all the new recruits, all the new receptionists that are starting and things like that, and I think that this is a really good opportunity, I think we're actually at the peak of a wave, and I think we can really make a difference.

7. How can autistic people influence social change and professional best practise?

That's a very interesting question. I have to say that I think the autistic community are amazingly good at doing that. The phrase, nothing about us without us has been really fully embraced, and I don't think there is any other area in medicine where that has not been so true, and I think you should just carry on doing more of the same.

8. What changes would you like to see for autistic people in the years to come?

I think that we need a bit more of the stick. I think the carrot is fine, but I think we need a bit more of the stick so I think we need mandatory level one training across the whole of health and social care, and I think the regulatory bodies, the general medical council, the general nursing council I think they need to start, and CQC, they need to start asking the questions about whether or not this has happened.

So in my appraisal and my revalidation which I have to do every, appraisal every year, revalidation every five years. I have to have done cardiopulmonary resuscitation training and I have to have done children safe guarding and I have to have done adult safe guarding while I need to have done autism awareness training as well. And that's not being asked, and I'm quite interested in the idea, moving this out into the community that we should be looking at schools, and I don't mean about just doing autism awareness training for teachers, I mean autism



awareness for the pupils. Because if I think we actually get a groundswell of informed young people then actually that will make a big difference.

And last year I had the pleasure of introducing Dame Christine Lenehan at the conference and she was talking about getting more things out there, more help, more support and helping the more complex people and I asked her after the event what would make the biggest difference? And she said the media, so actually I think what we need is more autism in the media. I know it's happening, I know there is more than there used to be, but she says it's got to be out there mainstream in the media, and that will make the biggest difference.