



Where Autism
Professionals Connect

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An interview with Carol Povey

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

The first autistic person I met was a teenager, Nevada, in the late 70s, and she was the daughter of a wardrobe mistress, because I was working in the theatre at the time, and I was absolutely fascinated by her; she was so interesting, I lost all interest in making clothes for the shows, which was what I was employed to do, and just was really fascinated by this young lady, so, didn't think much more about it, was working again in the theatre, a time when I had no work, I saw an advert for classroom assistant in the City of Westminster, and it was in an autistic unit, what was then really, really unusual; it was an autistic unit for young adults and I took that job thinking I'd be there about four weeks, and that was 1980, so that's a long time ago! And I never looked back, it's the most fascinating field to work in, work with, just the most amazing people all that time, and constantly curious to understand more about it.

Can you tell us about your current work?

So, my role is Director of the Centre for Autism, at the National Autistic Society, and in that I'm really...everything that I do is really about raising standards, developing knowledge, trying to improve things not only within the National Autistic Society but across the autism field, so things like conferences, training, accreditation, many of our own quality monitoring, quality assessments come under my remit, so yet again, it's a great job and a fascinating job, and a very, very wide job.

Within the National Autistic Society, how do you ensure staff are given the right skills and training?

That's a really important question, because the National Autistic Society employs around 3,500 staff; we're a big organisation, and, you know, we want to make sure that in every area of what we do, staff have a really good understanding of autism, that it's current, they understand what evidence-based practice is about, and person-centred approaches.

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So, we've developed the Autism Academy, which is our internal training program, specifically around autism, and there's a number of different elements to that, part is a taught program, a modular program, and part is around reflective practice, so it's very much around not just knowing things but really understanding how to put that into practice every day in working with students in our schools, and the people who use our services.

What are the challenges when it comes to diagnosis for autistic people?

It's interesting because the Lorna Wing Centre, which is our diagnostics centre, was established by Lorna Wing and Judy Gould in the early 90s with a view to being a sort of exemplar service so that other services in the community could replicate that and services would be, diagnostic services would be offered in local communities, and to some extent that started to happen, but now I'm very aware that, and we've shown this through our diagnostic, diagnosis campaign...people are waiting years to get a diagnosis, and it's so important because without that diagnosis, it's really difficult to get services, and I know many people will say even with a diagnosis it's difficult to get services, but certainly without it it's enormously difficult.

So we recognise there is still a need for specialist diagnostic services such as we're on at the Lorna Wing Centre, and that specialises in perhaps what we would call some of the more complex presentations; we do a lot of work with women and girls, who often find it more difficult to get proper diagnosis, with older people and with people perhaps with some complex mental health presentations, and they're often the people that get left out of local diagnostic services, so there remains a need for specialist diagnostic services, and in fact we are intending, developing a second Lorna Wing Centre in Essex as part of our new NAS Enterprise Campus, which will have Lorna Wing Centre Essex as part of it, it will have the Anderson School, which will be a large secondary school, and it will have an Enterprise Centre, focusing on social enterprise and vocational activity for young people, autistic people with a view to making sure that they can get into the world of employment.

Can you tell us what challenges autistic women and girls may face in diagnosis and support?

As I mentioned at the beginning, I've been involved in autism for a long, long time, and in those early days, we always thought that autism was a particularly male condition, that there just weren't the women and girls around, and what we've recognised since then is, it's not that they are not there, but that they present differently, and therefore diagnosticians, perhaps teachers, may not recognise that the difficulties that the girls, that they are working with, are experiencing, maybe because they are autistic and that hasn't been recognised, and therefore the right strategies, the right approaches can't be put in place.

Because girls and women aren't getting the diagnosis, they may display secondary difficulties, so they may display, or they may have and display depression, very high anxiety, other behaviours such as eating disorders, but that may not be the core difficulty; often, it's because the autism hasn't been recognised.

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So I think we really have to understand better how women and girls both present, and how they experience the world, so that we can really understand their needs and change our approaches, our teaching strategies and the support that we give them to be much more responsive to their individual needs.

What difficulties do autistic people face as they get older?

We know from the work that Autistica recently did, and some Swedish studies, that there is...autistic people die earlier than non-autistic people, and there is no real reason why that should be. The key causes are epilepsy and suicide, and we really need to, we need to change that.

We're doing some work with Newcastle University and Northumberland, Tyne and Wear Foundation Trust which has been very kindly funded by the Inge Wakehurst Trust, which is going to look at the health issues of older adults.

We think if we can make sure that GPs and other primary care professions can understand and adapt their practices to the needs of older autistic people, then we can respond better to their health needs. We know a lot of older people don't go to the doctor, they often avoid dentists, they find those environments very...not welcoming at all, and just really unhelpful as far as getting their health needs understood. So we're putting, doing this research and practice project where we work with GPs to adapt their practice, to adapt their practices, to be able to respond better to the health needs, and we'll follow some individuals through that process, and hopefully if we can find a way to respond to those health needs, we can then scale that up and replicate it, be talking to NHS England and the government about how they can improve older people's lives.

What would be your key advice to other professionals?

I think that is really easy, and that is just listen to autistic people, you know, not only through their words, but through their actions and behaviours. In the old days, we really didn't understand about things like sensory differences, we only really learnt that, that wasn't through research being done to autistic people, that was through listening to them, through people's first-hand accounts, through people like Temple Grandin and others telling us that they were experiencing the world differently, so it's really, really important to put aside your own professional judgement, and actually listen to people when they are telling you about their lives.