

Autistic adults and carers' views

Autistic adult's view

Richie

When I was working with the team it was awesome. I am 100% in support of everything the team are doing. Positive and negative feedback is meaningful as it demonstrates that people are listening.

The mental health component of the work is particularly relevant to my own personal experience of accessing mental health services in the past which was not good. Through the work that the team are doing I am hopeful that if my children for example were to access mental health services in the future their experience would be much improved as a result of the training.

The work needs to continue so that more autism awareness training is given that helps staff see autistic people as individuals and make reasonable adjustments to meet the needs of the individual.

I have learnt such a lot about myself through working as an expert in the team and I am using new skills to establish my own business. Working with the team gave me the confidence to be the "real Richie".

Carers' views

Hazel

I am a carer for my son who has a diagnosis of autism and catatonia. I first met Jacqui, my local Mental Health Trust Autism Strategy Manager, when she came to present at a council of governors development day. It was clear early on that she understood how important it was to improve the experiences of autistic people accessing mainstream mental health services, and that she wanted autistic people and their carers to be working together on this project right from the beginning and learn together to bring meaningful changes. Carers get a gut feeling when a professional is genuine about co-producing and co-delivering and not just making a tokenistic gesture.

So, I joined the steering group and we consulted with autistic people and their families, and the professionals working with them. We all worked together on producing and delivering the elements of the project, including the autism framework document, the training videos, the face to face training, and the autism CLiP.

I am finding the whole experience of working together on this project meaningful. I feel valued and actively involved: in fact, I think the team got more than they

bargained for, as I am not known for going with the crowd and can be very vocal on what should be happening!

In particular, nationally there needs to be some clarity around what is meant by “abnormally aggressive and seriously irresponsible behaviour” in autistic people. I would like to see a change in language - the current terminology locates the problem within the individual/their behaviour, rather than seeing distressed behaviour as a means of communication about what is distressing them.

The team recognise we have still a long way to go locally and nationally, and welcome the NHS ten year plan making autism a priority and the Autism Act refresh next year, not forgetting the current independent Mental Health Act review. All are opportunities to change hearts and minds and bring real change and make genuine improvements for autistic people accessing mainstream mental health services.

David

Prior to 2016 there was no evidence that the staff of Tees Esk and Wear Valleys NHS Foundation Trust were receiving the autism awareness training required by the Autism Act statutory guidance. The Trust was also clearly failing to make the most basic of reasonable adjustments for autistic people.

Over a number of years I had been complaining to the Trust about an absence of any real leadership on autism. That situation changed when, in 2016, the senior team at the Trust realised that delivering on its duties and responsibilities under both the Autism Act and Equality Act was ‘The right thing to do’.

I was initially surprised and then delighted to be asked to be a ‘critical friend’ to the Trust as it developed its Autism Strategy. I’ve also appreciated being a member of the team that has shaped and developed the training programme and reasonably adjusted pathways and documentation. My comments, feedback and ideas have all been treated with respect and properly considered. To be part of a wider team that has genuinely involved service users, carers, managers and members of staff has been a breath of fresh air!

NHS staff are often not confident in their ability to make reasonable adjustments for autistic people – it is seen as being all too difficult. The training programme and support materials developed by the Trust have, I believe, demonstrated that making adjustments for autistic people is not as complex as many staff think.

I look forward to the Trust being recognised as the most autism-friendly NHS organisation in the North of England.