



# Your Voice Network Neurodiverse group

Thursday 4<sup>th</sup> April 2024

## **Attended by**

Self-advocates from Gloucestershire  
Self-advocates from Wiltshire  
Self-advocates From Devon  
Self-Advocates from Cornwall

## **Represented groups**

Dimensions for Autism  
Your Voice

## **Main Discussion**

**Planning for our conversation  
with Graham Carr  
Meeting the needs of  
Neurodiverse people**

# Feedback given by the group

We discussed what to bring up with Graham Carr from NHS England South West at the next meeting:

Sammy shared that he will do a short presentation about what the NHS is going to do in the next year for Autistic people.

We need a specialist autistic service that is holistic. Our needs are quite specific and specialist. Services are not keyed into the nuances or needs of our community. I question whether it is appropriate for generalized services to have to meet our needs. Disordered eating, executive functioning, how we perceive things are all issues.

We need specialist services where all health services are provided. Every medical clinician we come across is a chance to check in on how we are doing with our health. It is a lot to ask generalized services to understand and meet our needs. There is an article that says there is a x5 increase in referrals for diagnosis since 2019.

There are starting to be some more specialist teams.

- There is an autism and ADHD specialist social care team in Devon
- Plymouth Hospitals trust have an autism liaison nurse and it appears that Bristol does too
- Gloucestershire were advertising for an Autism Liaison nurse. Devon are a bit of anomaly in having a specialist social care team.

If there are specialist services they would do well to recruit from our community. The Devon community MH social care team opened a new role for a support worker who is an ex psychiatric nurse and has experience of MH issues

# Feedback given by the group

The community MH team have said they have a lot of people who are still very affected by COVID, who are isolated and still struggling.

Very often professionals will thank us for our input and take our ideas away. There needs to be more coproduction, there is still too much of a 'them and us' where professionals think they know best.

- The specialist services that understand the needs and nuances of our community. Some one had heard about a non speaking autistic person who was refused a service because they couldn't articulate their needs. Where are the easy wins here that will get progress? We are the experts in our conditions and we may come up with different ideas and ways to solve the issue.
- There is culture of applying a person centred approach to service users but not applying the same principles to employees. The majority of us are constantly in burn out, particularly those in work. If they are not getting services right, how can we move from thriving to surviving and not hitting burn out every other week.
- Somebody said that they didn't like the title of either Autism awareness or Autism Acceptance and it was felt that something like Autism Pride or Neurodiversity celebration was better terminology

## Next meeting

- Next meeting is Thursday 2<sup>nd</sup> May 2024 – 6.00-7.30
- We will be joined by Graham Carr who is lead on the NHS England South West Learning disabilities and Autism Program