

Your Voice Network Neurodiverse group

Thursday 1st June 2023

Ice breaker question

What is one thing on your bucket list?

People said: Visiting where Twin Peaks was filmed, Going on an epic journey via train, looking after their cat for all her life, cuddling a baby orangutan.

Main Discussion

Free for all and catch up

Feedback given by the group

We had a few new members to the group Sammy gave an overview of the history of the network for new attendees.

She also explained how the meetings work and how the topics are decided

- One person explained their experience with attempting to get an assessment and re-assessment for autism and ADHD. They struggled with the executive function required to complete the form they were asked to, but following a phone call the clinic told them that the form was just to see if they still wanted the service. They felt that they did not want to engage with BASS any more due to how obstructive they have been. It was suggested by someone else that there was help to fill in the form
- One person said that the NHS can be okay with private neurodiverse diagnoses, but they don't accept the post diagnostic report.
- It isn't clear whether BASS in Bristol accept private diagnoses as people have heard different things.
- Someone felt their assessment was very infantilising, for example being asked to take 4 trinkets and make up a story. The idea that this task evaluates your imagination and that all autistic people have no imagination is not accurate. They also suggested that this person talked too much and too articulately to be autistic, but when you're in an assessment and need to get across your struggles it's imperative that you do talk a lot.

The recent Panorama programme about private diagnoses was awful and has negatively impacted on people who have been seeking private diagnoses for ADHD.

- The waiting NHS list in Devon for autism and ADHD assessments is 4-5 years and now it may be longer due to people not pursuing private diagnoses due to the Panorama programme
- In Devon the Mental Health services are lacking and some people from Dimensions for Autism have put themselves into groups looking at reform of the services. They are campaigning for a single point of access and to have neurodivergent services provided all in within one service.
- One person has an idea for having a conference for all ages of neurodiverse people and all services in the South West to look at the service provision for neurodiverse people. Sammy suggested meeting with them outside the network meeting to explore this idea.

- People discussed their experience of different stimulant and non-stimulant medications such as Ritalin and Atomoxetine. You cannot have caffeine on stimulants.

Recommendations

- We were concerned about the feedback given around Bass - We have agreed to discuss the issues around BASS with the head of program of the NHS England South West learning disabilities and Autism program – we hope to give an update in the next couple of weeks

- Private diagnosis should be accepted by autism support services and should not be a barrier to accessing post diagnostic support

- Waiting lists for diagnostic services should be reduced so that people don't feel forced in to going private in the first place

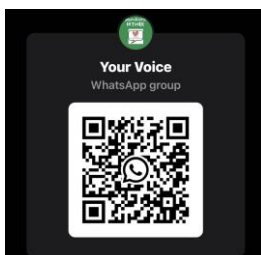
- It may be helpful to have a pharmacist to come to the group to talk about the different medications

- Look in to how to arrange a conference looking at the provision of neurodiverse services across the South West

WHATSAPP

- We have a private Whatsapp group which you can add by following this link <https://chat.whatsapp.com/Gb8XKGGEns42ANgpxUaTtd>

- OR scanning this QR code



Next meeting

- We will be talking about Mental health and mental health services

- Next meeting is Thursday 6th July 2023 6-7.30pm