



Your Voice Network Neurodiverse group

Thursday 2nd March 2023

Ice breaker question

Favorite book or thing to read

People talked about books they enjoyed reading and
a few people liked reading on an kindle or tablet

Main Discussion

Barriers to Health Care

Feedback given by the group

Mark Tucker, came to see how the group works and listen to the issues that were brought up

- Mark tucker is from the NHS England South West Learning Disability and Autism programme, and one of the people that commission the Your voice project

- Some one talked about difficulties with The E consult form and it not being flexible enough to add more details so now the reasonable adjustment of being able to use a paper form is in use (North Somerset surgery) .Questions sometimes require a more nuanced answer which is difficult to respond to.

- People say that they don't feel listened too or understood. Some one added that "If I have to see someone different to the normal doctor, it has been difficult to get my messages across or to be understood" they do normally have a named doctor though

- People said that when there is a change of GP there is an important part of needing to build a new relationship with someone else in the practice and this can make things difficult

- People have experienced things like bullying, difficult relationships, a world that hasn't been set up for us and which has given us a different life experience. This can be particularly difficult if you have grown up in a world that is different, and you are seen as different. Therefore, there is a need to have a Trauma informed approach to care otherwise it makes it difficult to engage with health care

- Someone said that for those chronic ongoing conditions it can be difficult to contact the doctors as they don't know where it sits within the system. People don't feel its urgent or takes precedence over more acute conditions of others – it can be a timely issue rather than an urgent issue but doesn't really sit into the service.

- There is a lot of issues in the diagnostic services at the moment with lots of unknowns, long waiting lists and some people going private or considering going private. But private diagnosis are still seen as what someone had heard referred to as 'mickey mouse' diagnosis or simply paying for the diagnosis people want. GP's seem to have little understanding of onward pathways

- It would be good if there was a way of screening for things like social communication difficulties and executive dysfunction as these might indicate some one is neurodiverse

- Our thinking behaviours do not relate to the standard therapy. Constant and repeated referrals to therapies like CBT don't always help

- People have different experiences of the diagnostic process. Some one said:
"I was told not to be autistic and that I should be happy that I wasn't. It was just 'anxiety' which is treatable. Spending time with other people who are autistic. I struggle getting the healthcare professionals to see this in me. I can't go to adult autism service and don't have a diagnosis".

They are struggling to get a referral for a second opinion.

Some one else had no issues with getting referral. They said, "I had a very good employer and they supported the referral". They were offered the opportunity to go to the NHS. They had a letter for appointment by August and a diagnosis by September

- A number of people said that the current diagnostic model is infantilising and very child focused – ability to tell a story from a picture book, make up a story using objects familiar to children, especially male children
- Some one said they had an issue with getting the post-diagnosis information and support – it was mainly directed to young people and not really relevant for them. Having a diagnosis doesn't open a lot of doors for support
- The current diagnosis process follows the medical model. It would be good if it was more based on the social model and assessed functional needs

Mark Said

- Mark thought that it was good that there were positives throughout the feed back that people were experiencing some reasonable adjustments like having a named Dr. The feed back wasn't all negative. There should be reasonable adjustments and a different way to book appointments especially for example being able to call, or do so in person. A one size fits all e-form isn't going to cut it.

- There is a change happening and we are trying to change behaviours, but with doctors, it can be very difficult
- There is beginning to be sea-change in how neurodiversity is seen. We are moving away from that traditional diagnosis model with long waiting lists to a more needs based pathway. He said Devon are doing it and Bristol. North Somerset were trying but they are not there yet. They are currently changing their diagnostic criteria and trying to move slowly towards early identification, having a screening process and working diagnoses. The diagnostic process can help with ownership of the lived experience.

- It was suggested it might be a good idea to have a few bullet points to talk around such as self-identification, preferring text based communication

- There is still an autism pathway in use but Mark would rather use a neurodiverse pathway. The medical model is dominant. We need reasonable adjustments for the social model. He said there was a lot going on moving towards this model for under 25s but little else where there needed to be

- Mark said that private diagnosis shouldn't be seen as a "mickey mouse" diagnosis and is concerned that people are still hearing it be referred to like that

- Mark said there was a need to take onboard the trauma informed work

Recommendations

- Move away from using diagnostic models and criteria that infantilise and aren't suitable for women towards a broader social and functional model of neurodiversity using people with lived experience,

- It would be good if the holistic, whole person work that is being done with the under 25s was extended in to the adult services

- There needs to be more post diagnostic support, rather than people having to find the support for themselves

- There needs to be a more trauma informed approach to diagnosis services and support

- Health services should offer a broad range of reasonable adjustments – named doctors, differing ways to book appointments and such like.

Next meeting

- This is your group we want to make sure we discuss things that are important to the Neurodiverse community in the South West, so what topics are important to you that we focus on, would you like us to invite guests or experts in specific areas?

- **Next meeting Thursday 4th May 2023**
- **6:00 pm – 7:30pm**