



Your Voice Network Neurodiverse group

Thursday 6th July 2023

Ice breaker question

Favourite thing about summer or Christmas tradition

People said: Having a quiet, low key Christmas,
Going away on holiday to get away from
everyone, Listening to carols and carol singing ,
Like that its hot in the summer, Carols by the sea
front, Christmas swim on the beach

Main Discussion

mental health services

Feedback given by the group

We were talking about people's experience of mental health services. In these minutes the acronym IAPT is used. IAPT = Improving access to Psychological Therapies. This service is called Let's Talk in Gloucestershire, Talkworks in Devon, Vitamins in Bristol, North Somerset and South Gloucestershire and Wiltshire Talking Therapies in Wiltshire and Swindon.

- One person said they had to seek out private services. Once used Let's Talk about 10 years ago and was given a CBT workbook.
- Someone did a taught CBT course and referred for high intensity CBT. There were some useful things for getting out of anxious or depressive thought spirals. It seems you have to be neurotypical for it to work for you.
- Someone said they disliked that CBT works on fixing the way your faulty mind works. (autism isn't disordered thinking or faulty thinking)
- Someone else said that CBT isn't reasonably adjusted for autistic people. Mental health practitioners may bar autistic people as they don't know how to work with them.
- The IAPT services usually only offer 6 weeks of support and it's barely enough for an autistic person to build a relationship with the therapist.
- Autism services aren't very joined up, there is a lot of chasing to do and following up the forms to send back to them. There is a lot of work to do to keep track of who you need to follow up and to keep on top of contact with services.
- Someone said that when they got their autism diagnosis they thought that they would get support with crises that they experience. They accessed the Devon IAPT services but the practitioner was very young and didn't seem very experienced
- Someone hadn't had a previous diagnosis removed from their records so the MH practitioner couldn't work with them and they had to go to the MH service. The MH service said that they couldn't offer them therapies, even though they believed they would help because they didn't have a mental illness and they discharged them.
- Someone said their IAPT said they were too complex but there is no alternative service. They referred to CMHT in July 2020, given a care coordinator in 2021 put forward for psychology in March 2022 and allocated a psychologist in Jan 23. The generic offer of 20 sessions is not enough and they seem incapable of offering reasonable adjustments for autistic people.

Feedback given by the group

They have asked if the MH team could consider more sessions as they felt they weren't where they needed to be. After the end of 20 sessions of psychological therapy how long do you have to wait until if you are felt to need more support, the person questioned do you go to the back of the queue? Feels that there should be a single point of access for all services for autistic people including assessment, health and social care etc.

- Autistic adults need access to continual support and care before and after diagnosis. There should be an Autism nurse to support people, along the lines of a mental health nurse. So many services are fragmented and it's hard to know where to go when you struggle. We are left to chase services and it is exhausting.
- Someone said that autistic people need long term support. 20 sessions of therapy was not long enough. It takes a long time for us to get used to a therapist and also to get used to it stopping. They were able to access MH support through BASS in Bristol the past.
- Autisms hold monthly support groups for women and girls whether they have a formal diagnosis or not. They see a lot of women who don't have a diagnosis and who need MH support. There is a huge gap in service provision for autistic people.
- Someone said It is so exhausting and draining trying to navigate the system to get support and it feels like banging your head against the wall. A key worker would help with this if you don't have family support.
- Someone said The children's services are also in a terrible shape and are not at all joined up. A family member has suffered significantly whilst waiting a number of years for a diagnosis as she doesn't get support because she doesn't have a learning disability. A young family member had a breakdown because of the stress of the situation. An older family member approached their doctor for a diagnosis and the GP said "realistically what would the benefits of a diagnosis be?".

- Someone said they feel that CAT therapy could be suitable for autistic people but some people have not had good experiences with it. Conflating the issue of neurodiversity with mental health is a long standing problem

Recommendations

- IAPT and CBT should be reasonably adjusted to work with autistic people. More sessions than the normally offered 6, longer sessions etc
- Mental health services can be gatekept and fragmented, there needs to be more support given to autistic people to navigate the system. A key worker or advocate would help. This would help with referrals and forms too
- There is a reliance on CBT it would be good if other therapies such as CAT could be considered for Autistic people
- There should be a way to extend the number of sessions an autistic person has with a psychologist or/and a way to skip the waiting queue if rereferred after the 20 sessions if needed
- There needs to be a lot more support pre and post diagnosis especially for women to prevent people getting in to crisis
- There needs to be a lot more support for those that are awaiting a reassessment of their diagnosis, or don't get a diagnosis or those that self identify as neurodiverse

Neurodiverse online Conference

- We have been given the green light to hold a co designed co produced online conference. The rough idea for the meeting is “what's it like to be Neurodiverse in the South west today?”
- We started talking about it at the meeting.
- We talked about some of us giving presentations about things like women and autism, or the services your group provides
- We also heard from one of the Torbay ambassadors about their event recently that had been for both professionals and people with lived experience.

I have put together an initial questionnaire to gather some early ideas if there is something that you'd like to say and haven't got space too please email me [What is it like to be neurodiverse in the South west today Survey \(surveymonkey.co.uk\)](mailto:What is it like to be neurodiverse in the South west today Survey (surveymonkey.co.uk))
<https://www.surveymonkey.co.uk/r/FY53CZK>

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 issues with housing for autistic people weather to rent or buy rent and suitable assessable housing

Next meeting is Thursday 3rd August 2023