



Your Voice Network Neurodiverse group

Thursday 1st February 2024

Attended by

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

Represented groups

Dimensions for Autism
Your Voice
Auti – Ms

Ice breaker question

What do you like about spring? People said warmer days, lighter days, not going to work and coming home from work in the dark, gardening and being outside more.

Main Discussion

Meeting the needs of Neurodiverse people

Feedback given by the group

- The discussion started with Many of us struggle with executive function or self-regulation and this is not understood by services. Getting practical help and to live better with this issue would be really helpful. It was felt that OT support with MH and neurodiversity would be the most useful. It is not helpful to have to jump through so many hoops and tick many diagnostic boxes in order to access a service..

- :Someone said that they were able to advocate for themselves but some one who wasn't as far down the path might not be able to.

- MH services would work for a neurotypical person would benefit a person with short term depression or anxiety. It would make sense to be signed a case worker once you are diagnosed as neurodiverse later in life. The talking therapies service has limited options and they can't work with you as they call you too complex and MH services can't work with you because you don't have a MH condition. The only option is to go privately which many do. There are co-occurring conditions like hypermobility and disordered eating and if you had a central person to support you wouldn't have to keep going back to your GP, it would save time and stress and exhaustion. I know they have that sort of thing for other conditions and it would make things a lot easier.

- It's important to switch to a needs based system not a diagnosis based system and it would be good if the case worker was was an OT who could look at the person was an OT or social prescriber so they could look at people holistically

Someone mentioned that in Holland they allocate people an autism advocate for life once being diagnosed. The benefits are all the things mentioned above and more.

It was thought that it would help a great deal if it should be a centralized and umbrella service to cover, social care, MH, social prescribers, enablers etc. Everything we have to go to separately who then deem us as problematic and too complex

A few people said that they had found accessing some services difficult because they came against services saying working with one known member of staff would cause dependency and one person said enablement dint work for them because of this. And someone who had worked in support services said that they had been discouraged from going working closely people and told that they were going to burn out

Feedback given by the group

- Some one was accessing a vocational mental Health programme after being referred by the social care autism team who gave full instructions about the reasonable adjustments that were needed.. The service normally work with people who are looking to move into employment or volunteer work. It was explained that this wouldn't be needed but they agreed to work with the them They agreed that I wouldn't have to move around and work with different people every 6 weeks as they normally do. They had been working with a technical instructor who was really god at working with them which took away some of their mental load. But now the service are saying that they must rotate to work with someone else as as they'd been at the programme 6 weeks. Because they say this is how they enabled socializing but this was contrary to what the social care worker said they needed. they asked the OT for support with another issue and they said they wanted to move away from co-dependency, but they feel how does asking for help doesn't equate to co-dependency The coordinator at the vocational service has ignored everything that the OT has told her..

- it feels like We are deemed as a problem and services are stopped or we are discharged.

- :Some one said you are trying to help someone to improve their life you need consistency, predictability, seeing the same people. Needing the same person is seen as co-dependency and that is miles off course. Its in order to flourish we need predictability and consistency. For Someone at the beginning of their journey as that means trust can be obliterated. If someone build s a trusting relationship with someone they don't have to worry about working with other people, they can build a rapport, it takes away a lot of mental load and it allows their brain not to be in a state of alert and it has a ripple effect in my personal life and home. Changing to a new person takes you back to the start. It feels like a it's a waste of time and that their falling short of making progress. If they stay with someone for 18 weeks I make 18 weeks of progress and if they change they don't get that chance.

- somebody uses have coloured wrist bands that show my anxiety states but the coordinator of the service said it wasn't going to work and they needed big flash cards. The OT introduced them so they are discreet and I can maintain some dignity. The coordinator they I needed to come up with another system but they have been using the system for 8 months and it works for them. You can't ask an autistic adult to completely change a system that work for them we have to do things multiple times before it becomes a system. It makes the service a less safe place for the autistic person using the service.

Feedback given by the group

- it was discussed how having a limited number of weeks service could limit the effectiveness for an autistic person a certain number of weeks in a service it falls around the idea of recovery. If you get a service for a certain time you will then be recovered. Social care isn't structured in a way to provide long term, flexible support when you need it and it needs to be specialized for us. Mainstream services just don't accommodate us.
- Some one said lot of services are geared up to recovery but that risks going towards curing autism.
- For our community recovery is different and a lot of us are in survival mode, recovery isn't the right word its better to have guidance on strategies and coping mechanisms, how to adapt your environment to set you up to achieve, taking note of your sensory issues and recognizing what you need to accommodate them. If we had services that met our needs our mental health would naturally improve.
- Some one mentioned that they had found Devon's social care service since they got the Ots useful . The OT did a sensory report, an interoception and proprioception assessment, they did an anxiety report, looked at funding for computer equipment. They are lacking support workers in their team.
- ⊖ We would like to see NHS and local authorities to complete a review of services from our perspective. Professionals and paid staff talk to us is infantilised and we are looked as rude because we get frustrated. The professionals always seem to think that they know better but they don't. Many people in this community have so much to offer but they think we have a deficit of understanding and knowledge.

Recommendations

- We'd like to see the introduction of a key worker/advocate for later diagnosed adults . It would good if the case worker was was an OT who could look at the person was an OT or social prescriber so they could look at people holistically
- A centralized specialist service like made up of practitioners from different disaplines Mental health, Speech and Language, social care, enablement and Social prescribers rather than have to access services separately and be have to refer to multiple services repeatedly
- we would want services who say they can provide reasonable adjustments tfulfil those reasonable adjustments and not change the goal posts once an autistic person was using the service

Feedback given by the group

- we would like to see services move away from time limited programmes and not allowing people to work with one key person so that people can make progress and build trust and rapport.
- We would like to see a userled review quality check of services, to make that peoples with lived experience voices are heard through out the system

Next few meetings

Our march meeting will be our final chance to finalise the plan for the conference.

We have invited Graham Carr from NHEngland South West to come to our meeting in May to hear directly from the group. We thought it would be good to carry on the discussion we were having about making sure services met the needs of Autistic people as a topic.

With this in mind the April meeting will be planning what we want to say to graham .

Next meeting

- Next meeting is Thursday 7th March 2024 – 6☺0-7.30