



# Your Voice Network Neurodiverse group

Thursday 5<sup>th</sup> January 2022

## Ice breaker question

Favorite holiday tradition

## Main Discussion

Co production – are the neurodiverse community being engaged with and how to make it better

# Feedback given by the group

## Is co-production happening in your area? Are neurodiverse people being involved in making decisions with the NHS?

- Only one member of the group had been involved in something labeled as co production. They were part of a discussion with Cornwall Council deciding what the future vision would be for services. They were there as a lived experience member, and will be doing that on a regular basis over the next couple of months. It was mainly carers there. They are going to have more discussions and events so some more autistic people may come forward. The council want to design services with autistic people and people with learning disabilities. They want to get views from people and act on them. It will be online and in person. It's in the setting up stages so far. It looks like most of the people involved are carers.

- Anti- Ms said : There is not much co-production going on. Being an autism group in Bristol you would think they would use us, but we get no contact

- One person had some experience of co production saying "I'm not aware of specific co-production projects that specifically involve autistic people local to me. That doesn't mean they are not happening. I'm doing co-production in an informal way, they don't call it co-production. It is a community project linked with the GP surgery to do community outreach. I bring my perspective of underrepresented groups. I'm not sure how much influence that has. The nurse manager wanted to put something together so that people could connect with their community and for the surgery to pick up on issues e.g. to recognise if someone is isolated, they also run a diabetes awareness session so they can pick up on people who are at risk. It is an in-person event. The need it meets is for people to meet and to have a chat, but it doesn't really meet the need of the surgery where they want people to get their health needs met. It's doing good but it could be better with more support."

- Some one said that carers being involved may be a way of getting the views of other people

- Someone said that there is a big emphasis on the needs of children and young people. While some one else agreed and said that the needs of autistic adults diagnosed later in life should also be recognised

- It is important that experts by experience get recognised and paid, but it should not be in such a way that there is a risk of losing benefits

- Sometimes we are involved in co-production, but we don't know what happens next and what the outcome is. there needs to be follow up to maintain trust with the community.

- Some one said that “Some time ago I did some co-production with a mental health provider in North Somerset. It seemed like a good opportunity and I was going to be paid. Nowhere in the information about how they were going to pay me did they say they were going to put me on PAYE and it would have appeared to the job centre that I was an employee. I couldn’t contribute once that lack of transparency had become clear. I would never have accepted that payment if they had made it clear I was on PAYE”.

- One person had met with their MP Dr Liam Fox last spring to talk about the needs of the autistic community and how we could work with the government. While he seemed to listen, his solution was to say “what worked for you?” “Why don’t you go and do that for everyone else?” His main solution was that the autistic community should support itself. This doesn’t feel like co production. We need to work with allies

## **We talked about how to make co production better? Changing the question from “is co production happening?” to “how can services engage the community better?”**

- One person suggested people doing co-production should start by asking “what questions should we be asking you?” They often come into these situations expecting to have their ideas rubber stamped and to prove that they were on the right track. They should start by saying “You are the experts, tell us what we should know”. They should ask “what are the barriers to your participation?”.

- Someone said that one of the barriers to good co production is how stretched the NHS staff are when. For them to carve out co-production activities for autistic people would take a lot of time, it would need baby steps to build trust but you would get fantastic stuff out of it. You need to be realistic about how you go about engaging with autistic people. It’s important for people to understand the barriers for autistic people, they need to have training and to meet autistic people. They need to come to people, rather than asking us to come to them.

- Someone said they had seen people use prerecorded video messages to take part in co production if they couldn’t be in the room. Some one suggested that perhaps people could learn from techniques used when interviewing children for TV shows, doing the interview in the persons own environment, putting them at ease etc.

- We shared a resource pack from the NHS about good sensory environments. Autims said that they had been involved in co producing it in the past. It was suggested that it might be helpful to share with doctors work places etc.

# Future meetings

- We talked about whether we'd like to invite a member of the NHS England South West Learning disability and Autism programme team to join us
- It was felt that it would be good to get someone from the NHS to come to our meeting as our discussions could be a demonstration of how to engage the autistic community
- If someone from the NHS was to come to a meeting it would be good to know a few weeks before hand the topic that we are discussing is and when they were coming
- Sammy and Debbie are going to invite someone to come and clarify Graham Carr's role so we understand the structure a bit better .
- Someone suggested that some good topics to talk about would be the barriers to health care or having support based on needs rather than diagnosis.
- At the February meeting it was suggested that we discussed transport provision, the effect it has on accessing health and social care and our well being

- **Next meeting Thursday 2<sup>nd</sup> February 2023**
- **6:00 pm – 7:30pm**