



Your Voice Network Neurodiverse group

Thursday 2nd May 2024

Attended by

Self-advocates from Gloucestershire
Self-advocates from Wiltshire
Self-advocates From Devon
Self-Advocates from North Somerset
Lead of the LDAP for NHS England
South West

Represented groups

Dimensions for Autism
Your Voice
NHS England

Ice breaker question

What is your favourite plant or flower. People said: hyacinths or lilacs, pea plant, blue hydrangea, Hosta, primrose, bluebells, roses, peace lily.

Main Discussion

**Conversation with Graham Carr
from NHS England South West**

Feedback given by the group

NHS England South West is the regional arm of the national NHS programme. NHS England funds the local ICBs (Integrated Care Boards) and work with them around our expectations.

They have performance expectations of the ICBs which are that they want to see a reduction of adults and children with Learning Disabilities and autism in mental health hospitals, 75% of people with a learning disability have an annual health check. The programme started in 2017 and the focus was initially people with a learning disability due to the abuse of people in Winterbourne view. They recognise that they haven't been looking at the needs of autistic people without a learning disability in the same way. Over the past 2-3 years there has been more of a push to focus on this. There will be more of a focus autism over the next 8 years.

There are different subgroups/aspects of their work – LEDER and SEND. They work with IG to address their thinking and approach. Graham is aware that he has a neurotypical perspective.

Graham Carr's role is the Lead of the Learning Disabilities and Autism programme for the South West. He is a nurse and worked in adult and childhood mental health, before moving into neurodiversity.

It was asked if there was every going to be a focus on autism separate from Learning Disabilities

Graham answered "We are at a crucial juncture at the moment. The NHS is going to focus on ADHD. In the next 24-36 months there will be clarity around autism being its own thing under the umbrella of neurodiversity".

Someone thought having neurodiversity as an overarching approach would be great as there are so many co-occurring conditions including things like Fibromyalgia and Ehlers Danlos syndrome. And it was mentioned that it could be a problem having separate ADHD and autism task forces as there are so many people with both.

Graham said "Its important that we consider neurodivergence as a population need rather that a diagnosis need".

And it was clarified that Graham was saying that there will be a move away from autism being part of the Learning Disabilities provision. The overlapping demographic is a minority of both the autistic and learning disability communities.

Feedback given by the group

It was mentioned autistic people without a Learning disability face more health inequalities. People with Learning Disabilities are often already in the system and receiving support. Feels that we are still waiting for things that have been promised for 15 years. When Learning Disabilities and autism are grouped together you have 3 demographics Learning Disabilities, Learning Disabilities and autism, and autistic people. A lot of co-production has involved parents bullying and shouting down autistic adults.

Graham said “At a national level NHS England is working with ‘Autistica’ to make a focus on autism. From a commissioning perspective it takes years of funding and focus to make changes. There is a request that has gone to the treasury for a significant amount of money for 8 years this will initially be focused on the diagnostic pathway. Then it will be on the broader focus on community support”.

It was said we would like to know what co-production opportunities there are.

Graham said that he is happy to think about how he can work together with the network on co-production. There will be more performance metrics on pre and post diagnostic support, supporting people in and out of hospital. He wants to work together and to communicate well.

Someone said they understand the fact that things will take time. They are concerned that her daughters who they is supporting now will burn out later in life. Will there ever be support based on functional deficits rather than diagnosis? This may address the long waiting lists.

Graham responded Our focus has been on a diagnostic approach and it has got us in a lot of bother. If we closed the waiting lists now it would cost us £850 million pounds to diagnose people. The damage that can be done to people on waiting lists is immense as their lives are on hold. Needs led is the way we have to go. This requires more than a health led focus, to make the difference we need social care, charity sector etc involved. They are having conversations with the Department of Education around taking a needs led approach. You can be involved through this group and utilising co-production.

Feedback given by the group

Somebody in the group said There might need to be some focus on what the needs are because their needs aren't reflected in what Graham said. Their needs are about getting things done in the house.

Somebody talked about how they and other people they know mask and this can have a severe effect on mental health . A lot of autistic people who mask say that is has significant costs to them. After going through diagnostic assessments for autism and ADHD and being refused a diagnosis it is hard to believe that the professionals have got it right. A lot of people in my life do feel that I am on the spectrum. There is a human cost as it lead me to a dark place and questioning my identity.

Graham: we are going to look at shame and acceptance in order to address masking. We are looking at partnerships for education to create neuro acceptance within primary schools so people can grow up in a more accepting society. Masking creates burnout and so many risks for people. There does need to be some element of gatekeeping as services would get swamped. When GPs for example aren't sure what to do they refer people on and then services get overwhelmed so some gatekeeping is needed.

Someone asked Who is responsible for implementing the Autism strategy in Devon? We are never informed of any opportunities for co-production through the autism partnership board. In children's services there is no support if you have autism with no learning disability. Children who cannot go to school due to sensory issues are considered school refusal and parents are being taken to court.

Next meeting

- Next meeting is Thursday 6th June 2024 – 6.00-7.30
- We will having a chat about autistic joy and wellbeing