



# Your Voice Network Neurodiverse group

Thursday 7th September 2023

## **Attended by**

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

## **Represented groups**

Anti-ms  
Dimensions for Autism  
Your Voice

## **Ice breaker question**

### **favourite wild animal:**

People said:

Bottle nose dolphin, owl, sea otters, giraffe, something that runs away from you, grizzly bear, dolphin, meerkat, sloths, Asian elephant, orangutan

## **Main Discussion**

## **Planning the Online Conference**

# Feedback given by the group

We are organising an online conference. It will be a South West event delivered by Your Voice as part of Inclusion Gloucestershire. We want it to be co-produced and co-delivered.

- We decided that it would be good to aim it at the autistic community – especially those who are not linked up to the community and people who are undiagnosed or going through the process. We thought that it would be good to gather more voices and involvement from the community this time to give them the chance to have their voice heard and gather information. If we do an in person event in a year then it would be better to have the health care professionals involved.
- Someone made a good point that we need to make sure we don't scare the community and it would be important that we share our experiences in a way that wouldn't trigger people.
- Someone suggested that we have break out rooms so people self select into break out rooms that are on a specific topic it will tell us what their interest are.
- It was suggested that the title should be Life as a neurodiverse person in the South West: You Are Not Alone.
- Some of the topics for suggested break out rooms were:
  - The Diagnostic process (including not getting a diagnosis and misdiagnosis and covering the pros and cons of private diagnosis)
  - a day in the life of an autistic person – barriers to every day life
  - accessing higher education
  - Self advocacy and empowering families
  - Employment and reasonable adjustments in work
  - Asking for reasonable adjustment in health care
  - dispelling the myths about autism
  - Friends family and relationships
- Someone mentioned that there are gaps regards to autism in the Oliver McGowan training such as executive function and misdiagnosis.
- The current waiting list in Devon is at least 5 years and 2-3 years in Gloucestershire so you have people who are questioning if they are autistic or neurodivergent.

# Feedback given by the group

- Some one said that a doctor said to someone local 'is it really worth getting a diagnosis at your age?'.
- A lot of people are thinking about or finding that they have to go private there is a lot of NHS that don't accept private diagnoses. Maybe we could cover this and the pros and cons.
- Someone said there is a lot more in the media with personalities and actresses. I think its brilliant but there is a bit of a narrative along the lines of 'I was a bit odd and then I got this autism diagnosis'. I spent 10 years in and out of mental health services and it can alienate those of us who have experienced trauma.
- We felt that some of the media and social media representation of autism as a bit geeky or odd diminishes the experience of autistic people.
- If you are autistic you might not be the first autistic person in your family. A lot of parents discover this when their child is diagnosed. .

There is a video on our channel of a colleague who is autistic and discovered this when their child was being diagnosed. <https://www.youtube.com/watch?v=T1w-4Kq89A4>

- While we've decided that this conference this year should be aimed at the community we were decided that I would be good to concentrate on the NHS and other organisation like education
- Someone said its always good to keep reminding the NHS of the issues that we talk about.
- We can revisit the conference in December's meeting.

# Next meeting

- We talked about what we would like to talk about next time someone said they would like to talk about DWP and PIP benefits as they are waiting their appeal. The DWP are saying that as they can drive they have no mobility needs and that as they can make a sandwich they can feed themselves. It is extremely traumatizing and scrutinizing to expose all of your needs.
- Someone said PIP has been around for 10 years and it has fundamentally failed to help the people it is designed to support. It would be good to get behind any campaigns that are in place.

- Next meeting is Thursday 2<sup>nd</sup> of November 2023 – 6☺0-7.30
- We will be talking about PIP and Disability benefits