



Your Voice Neurodiverse Meeting Minutes



Thursday 7th November 2024

Topic – Language and Identity



Attending

Self-advocates from Gloucestershire
South-Advocates from Devon

Self-Advocates from North Somerset
Self Advocates from Wiltshire

Organisations Represented Inclusion
Gloucestershire, Dimensions For Autism



Opening Question

Favourite Place to chill out and be cosy: people said in bed with the cats watching a film, bed with a video or a podcast, curled up on the sofa watching a youtube video about one of my special interests, Sofa with an electric blanket, (maybe one day with a dog.),



Identity

We ended up discussing the language used when we're talking about Autism/Neurodiversity and Identity.

Person First Language – Is language that puts a person before their diagnosis such as being a person without a disability, which they cannot. Uses terms such as 'person with autism' or 'somebody has autism.'

Identity first language – Way of referring to people that emphasises that being autistic is an inherent part of a person's identity. It uses terms like 'autistic person' or 'autistic.' People feel that autism is a different way of seeing and interacting with the world, rather than a negative thing.



Talk about the language of identity.

We want to make a statement about how we refer to ourselves and talk about autism and Neurodiversity on the Your Voice website. However much of the group were surprised we needed to have a discussion as it was thought that the Autistic community had chosen to use identity first language.

- Someone finds person first language strange as we normally use identity first language in society.
- Some people would find someone using person first language towards them as harassing. However Someone prefers person first language due to feeling labelled by society. Sometimes talking about language can be difficult due to person by person or societal levels.

Someone feels that using someone using person first language can mean they don't understand the autistic community and not having the language accepted feels like an injustice.

- It is safe in the community to say you are 'autistic.' But misunderstood in wider society.
- There is a difference between how you describe yourself and how you describe the autistic community.
- Some people prefer neurodivergent instead of autistic as it is not a medical diagnosis. They feel the word 'autism' is from outside the community.
- For some people who Self Identify without a diagnosis they prefer to say they are neurodiverse, this covers a lot without medicalising it. Sometimes they said they are autistic when self advocating. They are able to trust more often that identifying themselves as autistic will promote a better response that will help them.



Phases use about Autism.

We only had time for a brief discussion about the phases people use about Autism. And we will return to the topic of language in the new year. But we were told :

- When someone comes back with one of those phrases after you tell them you are autistic it is a means of saying the words that you use to describe yourself is incorrect. It gives the other person the power to correct you. Instead of helping you they are arguing with you over the words you use to describe yourself instead of meeting your needs.
- Phrases like “We are all on the spectrum.” are difficult, this feels like you have to argue. That experience is devaluing, it takes time and effort to be diagnosed. It is disheartening.
- Some people refer to neurodivergence as the 'latest thing' in casual conversations this is very difficult to hear.
- A lot of people learn about autism online – that means different types of phrases are creeping in.
- It is a nightmare for autism to be trivialised. The process of understanding your diagnosis is hard.



Feedback for the NHS

- NHS have a hard job on this issue, they have to describe a community who all have different views on this. It helps when NHS use what language you prefer. It seems the NHS are improving on this.
- It would help if people who write pamphlets for autistic people have the language agreed by neurodiverse people.



Closing moment for a bit of self care

It was a hard and potentially triggering topic. As many of our topics can be quite intense we're going to have a moment of being able to think of something we're doing to look after ourselves and well being some of the things the group were doing were

- Seeing John Barrowman in Cheltenham.
- Spending time trying to chill out
- Booking Pierre Novelli tickets.
- Cutting the grass and went to autism woodland
- Went to a Once Upon A Time convention
- Looking after yourself by looking after their children
- Going to Thorpe Park.
- Climbing on the climbing wall

Next Meeting



Our next meet Thursday 5th December 2024

We have been asked by the NHS to talk about Talking Therapies. We have the director for NHS Talking Therapies South -West Caroline Longman coming to the next meeting to hear this feedback.

As we are relying on a guest this might change. As a back up we may continue to discuss the language used when talking about Autism.