



Your Voice Neurodiverse Meeting Minutes



Thursday 5th December 2024

Topic – Language



Attending

Self-advocates from Gloucestershire
South-Advocates from Devon
Self-Advocates from North Somerset
Self Advocates from Wiltshire
Self Advocates from South Gloucestershire
Organisations Represented Inclusion
Gloucestershire, Dimensions For Autism



Opening Question

Favourite Christmas traditions

food, hand made ornaments made by grandparents, make a Christmas cake, avoiding Christmas, Christmas Eve get together with family, spending Boxing day with family, supermarket Christmas sandwiches, racing down to open presents with family, Dr Who Christmas special, spending Christmas away from family.



Language

We continued our discussion about the commonly used misunderstood phrases about autistic people. These have been used by health care professionals in the past. The autistic community views these phrases as harmful as they diminish the journey and struggles autistic people face daily. There were also some positive phrases sprinkled into the crib sheet.



Use of the Aspergers and Autism as separate terms.

Some one talked about how uncomfortable they were with the use of “Aspergers” (this is generally shared by the Autistic community) this is often because of the Hans Aspergers links to the Nazi party. They said that one friend refers to themselves as having Aspergers even though they shared information with them about the Nazi associations with the term. The person struggles with people using this term as it can seem like the friend is saying ‘I’m not Autistic’. The person did identify as an Aspie for a while themselves but once they learnt about the history they stopped and they now refer themselves as Autistic. At the same time the person feels they “don’t want to police the language of friends.”

Someone who was one of the last people to be diagnosed as Aspergers in 2013 said that “Aspie” was the word of the moment in the community but it felt excluding. Out of that came the word Autie to describe just being autistic . Within the non-autistic community everybody believes if you are Aspergers you are high functioning and you’re not really autistic and you struggle a little. People like to tell you how mild it is. During a pre-op assessment someone was asked if they had any medical conditions and the nurse asked whether they had Aspergers, and I think this leads to being medicalized.

Someone who also had an original diagnosis was for Aspergers, said that Engaging with the community on You Tube has led me to use the term Autism. If someone uses the term AS it reflects on them rather than the whole community.

Somebody said that they use the term Asperger's-y or Aspie because although their getting more comfortable with the Autism label they feel that aspie is the closest label that exists to my experience but I don't agree with DSM criteria. I might say I am neurodiverse and I need some accommodations. One of the best people they know resisted all labels. Their definition of being aspergers comes with a little "TED" Talk about the links to to Nazism and the diagnosis criteria.

Someone said they regard them selves as autistic, they also have other labels and who they choose to share that with and in what context is up to them. They said "this is who I am take it or leave it" If anyone doesn't appreciate it that's the other person's problem, if they want to listen about it that's fine but if they don't that's fine too. The autistic person has had enough of boxes.

Levels of Autism and Neurospicy



We talked a little about the phases that are creeping in about levels of autism and how they are used.

Levels of Autism, The levels come from the US and they are meant to represent the support level needed.

Someone said some people don't understand that high needs and high functioning are not the same thing and reverse them.

Someone said that during a post diagnosis meeting they were talking about whether might qualify for support from social services they was put off from applying because the professional said that they were too 'high functioning'. They had just spent hours explaining all the way in which they struggle to function. They almost put in a complaint about it, especially as it was used by someone in the diagnostic service.

Someone said The term spicy came about in relation to being 'mild'.

Someone said that they had heard a description of the term Neurospicy it's the equivalent of saying you are bicurious because you are not committing to a label (bisexual). For me it comes across as meaning a 'sprinkling of autism'.

Someone said I dislike the 'quirky and edgy' portrayal of autistic people because I am not like this for effect or to be different. If a neurotypical person says you are 'neurospicy' I will tell them to shut up, but if an autistic person says it I won't mind as much.

Neurospicy is often used on social media especially TikTok Because of the nature of TikTok, people you have to do something that grabs attention in a short amount of time. Its also an industry so they are making money out of not entirely being truthful, appealing to people who don't really understand ADHD and Autism. Its like they are cartoonifying it or playing it down.

Someone said it's the trivialisation of autism. Now they are careful about who they tell because they don't want it to be trivialised. We are complex people with strengths and weaknesses.

Someone commented There is no term that is specific to discrimination against autistic people like there is for disabled people (ableism).

Next Meeting

We are hoping that Caroline Longman will be available to join us in January . Because the scheduled meeting was very close to the holidays, we chose to delay the meeting by a week the new date is:

Thursday 9th January 2024



As we are relying on a guest this might change.

Merry
Christmas
and Happy
New Year
2025

