



Your Voice Neurodiverse Meeting Minutes

Thursday 5th February 2026

Topic: Autism 101; what would you like professionals to know?



Attending

Self-advocates from Gloucestershire
South-Advocates from Devon
Self-Advocates from North Somerset

Organisations Represented: Inclusion
Gloucestershire

Opening Question

What are you looking forward to about Spring?

Planting things in the garden, feeling part of the natural cycle, being dryer than recently! Not freezing to death, cherry blossoms on our tree.

Tonight we'd like to focus on: Stimming, spiky profiles, language (the use of the word disorder vs condition and low vs high functioning). Autistic people are sometimes described as 'seeing the world differently' – what does this mean to you? What does neurodiversity mean to you?

D: When I used to rock and stim in hospital they did not know I was doing it to self-regulate and calm myself down. It is not me being mentally unstable/distressed

S – Often professionals don't understand about stimming, it's important we talk about it

K – High vs low functioning winds me up as it underestimates those who are non-speaking or have high support needs and overestimates what those who are able to speak or who mask difficulties say. When I'm having a meltdown in a work situation, I then feel shame and feel like my manager will think less of me and think I'm less capable. Functioning labels are harmful for everyone. The phrase 'selective mutism' is a misnomer as 'selective' implies that the person chooses. "Situation mutism" far better explains it, due to the stress and anxiety you feel in the situation. I feel frustrated that there are people in my life who are autistic who still use the word Aspergers when there's the link to the Nazis.

S – Autistic children may sometimes select but that could also come under situational, the situation could be too stressful for them. I honestly forget how to speak sometimes! Something came up the other day (about the term Aspergers) and someone online said, 'Stop saying everyone is autistic when you just have Aspergers. Time to bring back the Aspergers diagnosis' and, 'that's because people can't speak'. No, it's not, it was used by Aspergers to select who went to the concentration camps. There is a massive divide between who are verbal or not verbal.

Everyone communicates in some way. The Aspergers debate winds a lot of people up as it doesn't actually mean about not speaking.

H – On the topic of mutism, I used to run activities for kids, one family was full of autistic children and they had difficulties getting diagnosed. I helped them to feel uncomfortable when I was working with them. They had good engagement with the activities. The youngest was 'selectively mute'. We learned that talking with her whilst not making eye contact and coming up beside her and not in her eyeline helped her. It's important to always give choices. She would indicate what she wanted. She felt safe and secure and after a year and a half she began to communicate with words. Communicating is about feeling safe. It's about needing to know someone understands your needs; it's triggering if they don't. Having the conversation is too hard if they don't understand. It's about feeling safe – if you feel safe then communication isn't such a barrier. Communication is when both parties communicate, it's circular. It's not communication unless it's effective.

M - High vs low functioning, it seems to be an example of how neurotypicals have a sense of black and white thinking. It's a bit like a projection of diagnostic criteria. If we started classifying them (neurotypicals) as high vs low functioning, they would probably be very insulted.

S – People keep on saying, 'Why do autistic people put people in boxes?', but they're the ones putting us in the box. A lot of neurotypical people use it as a reason not to get a diagnosis.

D - In my opinion there is no high or low functioning as everyone has things they are good at and other things they struggle with. If you are high functioning people might assume you cope well with everything. If you are low functioning people might underestimate your abilities and strengths. Could we explore the Aspergers label later because I was not aware it was linked with Nazis?

S – That also leads onto spiky profiles.

M – Looking at spiky profiles from the inside may mean someone is good at a combination of things that are expected, so if you can do Y you should be able to do X, or Y and Z. You can't just do one. Autistic people might not understand a topic in the way expected or things may seem arbitrary or sometimes boxed together.

Chat - I have a real problem internally with the Aspergers label ... it feels more descriptive of me so creates better understanding if I refer to myself this way, but I'm also appalled by the history. It's a problem, mostly boys ... he called them his 'little professors'

S – It was anybody who didn't conform to the social norms of the master race who were taken to the concentration camps. The Nazi party believed that some autistic people have skills that may benefit them and Asperger did research to prove that some autistic people had high IQs and could communicate well and may be easily manipulated. They could have skills that were useful to the Nazi administration. They were labelled with Aspergers syndrome instead and not sent to the camps. Therefore, there is a backlash about it in the autistic community. Much of autistic research is based on boys.

H – When we talk about high and low support needs, etc. People are pointing to what skills they have and if they're 'normal'. Some feel they're not good at maths and struggle to balance a cheque book and figures. There's guidance on what's strong and not so strong and something like maths might even give you social capital if you're not good at it. I manage money through spreadsheets to help me make decisions about money. Of the skills available, why is my OCD level money management somehow looked down upon because I struggle to make decisions, but for the average run of the mill person it seems normal? Why are some skill deficits socially unacceptable when lots of people have deficits? My skill deficits are just not the usual ones. If people had the right support in place they could do wonderful things. I have an advanced degree, but I can't manage my time or belongings effectively; I need support in those areas. It's the lack of social support in the structure that hasn't got it right.

S – That's completely right and comes back to spiky profiles. I cannot keep my house tidy, but I can plan a trip at short notice to see John Barriman. I don't have a deficit, I just don't see it the same as my mother does. Skills vary. The social model of disability says it's society not disability that disables us. If society was accessible to everyone then disability wouldn't exist.

M – An issue with support particularly within a majority group, often support you need is included as standard. I don't like the 'additional needs' term, I prefer 'alternative needs'. Autistic people may need support whereas others don't and vice versa. Minority vs majority groups, the needs of minority are often seen as additional or 'on top of', which feeds into the idea of support levels which people misunderstand. Support levels turn into a high, middle and low functioning metaphor. The DSM5 doesn't have a support level for autistic levels, which gets overlooked

Chat - we usually have the same needs, just our needs are often so invisible because NTs have never experienced life without those needs met so can't believe it's possible to exist that way... maybe?

S – What does neurodiversity mean to you?

H – Neurodiversity to me and my children is that everyone's brains work differently and gets us into murky waters. Then people say, 'everyone's a little autistic'. Human brains are organic, messy, crazy, marvellous, amazing things that have some things in common and a lot of differences, some radically different. Neurodiversity means something different to how I use it in the world. Everyone's brains are different and play out differently by their social experiences in life. I use it to point out how my needs are different to what you may expect. It's important to have some imagination about how my life is and my struggles. If you don't have that, we don't have a basis for communication, then communication breaks down.

M – I've learned over the years in the community that communication is different, our language about how we work has evolved to an extent that doesn't sit the same in different circles of people. We talk about regulation and know what it means but we have to explain what it means in our lives. Neurodiversity is similar in sorts, but our experience and life challenges have shaped us. I'm intrigued by what's familiar to us may be foreign to neurotypicals; it's difficult to translate to how other people can relate to us. For lots of people it's removed from their normal, but our normal is our normal; it's difficult to articulate without the experience of it.

Chat - I truly wish I was as confident about what 'regulation' means to me ... still trying to access the 'how' part of that equation, having spent so many decades pushing any signals in my body to regulate down as far as possible until they were invisible. Learning to regulate at 51 is hard.

S – Like we've said before, when you meet one autistic people you've met one autistic person. Neurotypicals may think that they know what autism is and think that everyone with autism is the same. Like not making eye contact, but we teach ourselves to do it in different ways. Or that we're all non-verbal, but I sometimes I just forget how to speak. Not everyone's the same. What's normal anyway?

D - Neurodiverse is the collective term for everyone in that community and all the different ways our brains function. Society has then split this into neurodivergent and neurotypical. This was my basic understanding. They are all just labels

K – There's a link in the chat about Aspergers. History has taught us to focus on the Jewish population, but there were a lot of queer, disabled, people of colour and travellers; the Nazis were equal opportunity murderers. If you were not a strict Arian profile you were subject to being eliminated. Only the 'useful' were spared the concentration camps.

There's another link to someone in Germany, the video is about Aspie supremacy, a schism in the neurodiverse community where people who, despite knowing the atrocities, still view themselves as superior to other autistic adults. I do not say Aspie anymore.

D - Not being 'typical' is a way to dehumanise that cohort

S – I was one of the last diagnosed as Aspergers. By the time the letter was sent following my diagnosis, it was ASD not Aspergers. It was my first interaction with the autistic community was Aspie, like 'I'm not autistic, I'm Aspie'. I cringe at the word now

M – The Aspie argument is interesting, and some relate to the Aspie term better. This may be an incident of who you're talking to and their experience and knowledge.

D - There were some cases of people being denied autism diagnoses because they made eye contact with the "professional"

K – I very nearly wasn't diagnosed because I engaged well with the psychologist and I was very creative. I read so many books as a kid, I was in the drama club, plays and musical. Don't tell me autistic people can't be creative. I had waited over a year, what did they expect me to do, not engage and be quiet? I put together a 27-page word document explaining my difficulties to put with my assessment request – after my 2-3 hours assessment, they said the Kate in the room is very different to the Kate in the paperwork. No shit! What you're seeing is a lifetime of masking.

Chat - I intentionally took performing and acting classes in order to better understand human behaviour better and therefore mask better at least that is what I now understand in hindsight.

S – My gender fluidity and presentation actually helped me as I match in male ways to what they expected. So many females say the autism diagnosis is really hard, but I didn't find that as I present in a male way.

M – Pigeonholes and stereotypes; it's frustrating that the 'beauty is skin deep' sort of thing; look a bit deeper and under the edges. The more I see neurodiversity assessments, the process is interesting but I think a good clinician knows what they're looking for and where to poke. That's important and shouldn't be underestimated. The difficult things will be out of sight and mind. It's not an easy thing to go there. Having talking therapy you get to a point where you're genuinely yourself; we put up fences to survive. Looking at autism as a condition, it's not simply a case of impairment, it's more nuanced than that. Criteria could be subjective. It's putting jigsaw together in a useful way

Chat - Stimming... as I child I hit my stimming very well, e.g. twiddling my hair or a pen or folding bits of paper, rearranging markers or pencils into specific order (I still do this) ... I 'spun' repeatedly over and over on the monkey bars or went on the swings for as long as possible rather than find other children to play with at recess. Looking at me, you would never know ... only someone trained in female presentation would spot it. Of course my parents and I had no idea. I now take my knitting with me to all meetings and explain that I can't listen if my hands aren't busy, and so far I haven't been to a meeting where it's so awkward that there's an issue, but then again I've never tried this in a professional setting.

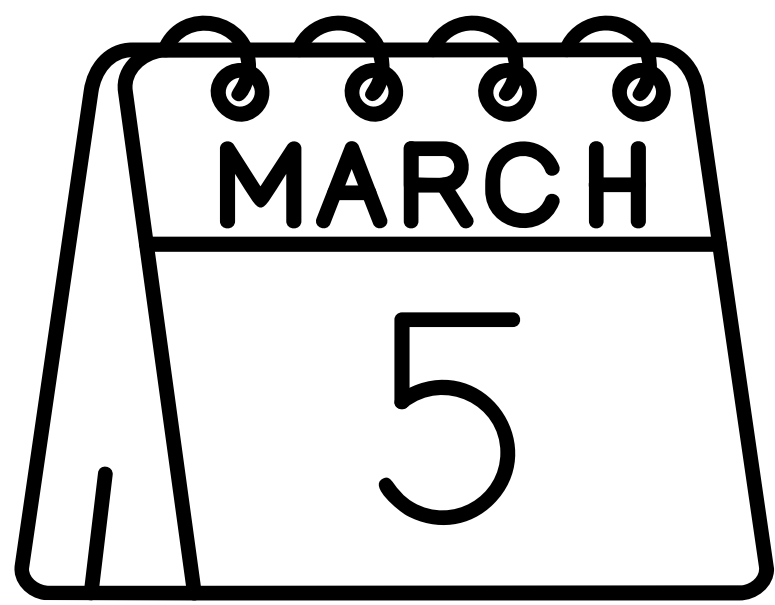
S – Our last meeting is in March. E and R will be joining. There are a couple of things we want to do to wrap up. Think about how you want to link up with Inclusion Gloucestershire, as after March I will delete emails due to GDPR. We'd need membership forms if you want to stay in touch. Staying in touch with Inclusion is one way to stay in touch with our communities.

M - Could we brainstorm ways to keep some influence going, e.g. partnering with existing movements or organisations? To effect some change in policy and practice, it's figuring out how we can do that. Chat with Disability Together, there may be opportunities for neurodiversity. Keeping in contact is key and partnerships boards are a way to hear about opportunities.

Self Care



Nail polish arrived today, magnetic polish tonight or tomorrow. Veggie burgers and chips. Games night at the pub and breakfast trip to the café on Friday. Colouring, watching Star Wars series Acolyte, reading The Help, watching a new Star Trek episode. Can't wait for Olympics tomorrow. Have tea and hopefully get more than 3 hours sleep! Biscuits and bed.



Next meeting is Thursday 5th March 6pm 2026

Subject: Final meeting, a round up of Your Voice