Your Voice Neurodiverse

Meeting Minutes

Thursday 4th December 2025

Topic: What is your experience of Masking? How does affect your mental health. Also, what are the affects of having a late diagnosis?

Attending

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

Organisations Represented: Inclusion Gloucestershire

Opening Question

What's are your favourite Christmas treats?

Christmas dinner meal deals, Christmas cake with marzipan, mince pies, GF mince pies and Christmas cake, lighting the Christmas pudding

Introductions from everyone in the Network and Your Voice facilitators.

Topic today: What is your experience of Masking? How does affect your mental health and also what are the affects of having a late diagnosis.

S - Thank you for your recording [K]. The webinar is next week and we're preparing for that. Today we'd like to talk about masking and its effect on mental health, and late diagnosis.

K – I was not identified as autistic until age 30-31, so the mask is my face now. It's rare to completely unmask, usually when at breaking point and cognitively and emotionally exhausted. As I was socialized as a girl growing up in USA, the expectations were very rigid and any deviation could lead to punishment or social ostracization by peers. The older I get, the harder I find it to maintain the mask. I've got so used to it as a means of survival to get to adulthood. I work from home which makes it easier to manage as there's not the sensory overload of working in an office.

S – I don't even know when I'm masking as I've done it so often

H – there's a CAT-Q masking test on embrace-autism.com website. It's an assessment tool which has a cut off about 110, so if you score above that you're masking. I've done lots of unmasking over time by employing strategies, but I still recently came out as 130. The penny didn't drop until I was about 45. The effect of long-term masking is debilitating physical illness, so my body has absorbed the difficulty of outward presentation; burnout; mental health issues which have affected my relationships.

There are some people I feel safe enough to unmask around and drop the mask. Long term masking divides you from yourself. The longer it goes on the more you learn you can't be authentic in order to function in society.

M – you don't know what you don't know until you know you've been masking. One big thing from being assessed or self-identifying is that you learn to recognize the idea of masking but it can take years to recognize what the masking is and how you're doing it. It's another evolution to learn what it's done over time, it can leave an imprint on you as a form of trauma which we may not be aware of. We've been acting a part for most of our lives, which distinguishes us as people who have been assessed and recognized; we're performing a different script from a lot of other people. One first realisation I had post assessment was that my normal was my normal. How it differs from others is impossible to observe. Our values are built on perceptions and senses which are unique to us as individuals. A big challenge of masking and unmasking is recognizing what we're doing, how and why we do it. It's a long process as these things are learned in early development. We relearn in a safe environment and work towards being valid, ok and normalized in safe communities.

S – I don't know when I'm masking as it's my normal. I don't know how to unmask as I've been doing it since I was 2, watching other females (another question of how I relate to being female). Some neurotypicals overestimate how much they understand, they may say 'I understand disabilities' and expect us to be able to unmask around them. Especially females are expected to be pretty and quiet so we mimic others to fit in; I had to copy my friend to fit in.

D - Masking can be exhausting and draining if I have to do it over a long time to try and fit in and I need to recharge as it takes a lot of energy

S – it comes back to energy accounting

M – it's the wrong word to use, 'narcissistic' streak but the social expectations on females are on another level from which males experience, amplified more with females with greater social expectations. Males perhaps learn to mask later than females to some degree. You may not recognise you're doing it or that you don't fit in, it's a different level of intuition. It's deeply embedded in females and leads to addition difficulties with identification of neurodiversity, like putting on a proverbial show. It needs questions to penetrate the mask. Learning to drop the mask is a process which takes time and learning and reflection. We're focussed on the outward stuff more than the inward stuff; another dimension in the female sex arena and not one to be underestimated.

M – I was gender questioning from the age of 7 which complicates things. An aspect of masking is the colouration of stuff, toleration of social norms, stuff you'd rather not have to put up with. The idea of a role model, it's something I struggled with a lot, even the idea of there being such a thing. I've struggled with a few social norms.

S – me too, there was the person I copied and learned to mask from. How to meet expectations, my role model was acting in the way that somebody expected them to.

M – role models singular versus the plural/ambiguous role models, in marketing terms it's like what your ideal customer is. It's interesting about social role models and idols that people look at amongst school and social groups; looking in the wider context about societal role models, these are changing as time evolves. There's a contrast to how we look at ourselves and how we compare ourselves; a desire to imitate, comparing and contrasting how to relate to others and vice versa

K – masking can be seen as a trauma response, though not exclusively. I have distinct memories of things going wrong at school when I was young and the threat of being socially ostracised when you're 6 or 7 is horrifying. You can't help but go into yourself and observe others around you to try and pick up what acceptable behaviour is. It starts from there and progresses. I found myself drinking a lot and smoking weed because my peers were, I wanted to feel like I belonged. I look back now and think 'what was I thinking?', but I was trying to figure it out. I can't help but think how different my experience may have been if I'd known.

H – I had similar experiences. Thinking of the point in life when the social exchanges, dynamics, coded messages and the complexity level of what's going on, neurotypicals may be oblivious to it. Autistic people may not get it if they try and do the same thing, it's too complex and the context may have been missing. It's like a science experiment in real life which we're trying to figure out.

M – thinking about trauma, there is some confusion and shame which gets woven in and leads to trauma when you're trying to amalgamate what someone else has done, or repeating something someone else said but you get a different response and don't understand why, it doesn't make sense. It defies analysis when you get a different response as it doesn't stack up and may end up in a spiral of trial and error; it can feel a mess.

H – internalised blame and shame, thinking it must be about me. They pay actors to be good at masking, but they have to train a lot and very few make it to the top. It seems that it should be obvious how much harm this can bring us as bad amateur actors. You wouldn't expect an inexperienced actor to perform on the west end without training night after night after night.

S – we've been different people all our lives because we have to be. Stress and cortisol from constantly having to mask has an effect on physical health. Is there a correlation between autistic people and physical chronic ill health? I'm sure there is.

M – long term effects of not just masking but stress and mental health have a marked effect on physical health. It might not be primary but a secondary impact. If we're gaslighted into believing we don't have the problems that we do, denying problems that are there and could be serious (mental health or trauma) can extend in physical things. They may be camouflaged in a different way.

S - Autistic people have different thresholds to pain and different expressions of pain. Also, introspection and identifying pain in the first place and where it is in your body is also a difficulty

K – There's a Buzzfeed representation of a doctor who didn't believe my pain e.g. women with severe endometriosis or PCOS; the medical person in the ER said 'are you sure you're not just sad about your relationship?', etc. One woman has PCOS and didn't know, collapsed in high school during basketball. An ovarian cyst has burst and the doctor initially said, 'she's sad because her friend passed away'. When you add neurodivergence and presenting, it took me years to get fibromyalgia diagnosed. I still don't have diagnosis of chronic fatigue even though I know it's there, it's a decade's journey. Medical misogyny exists even with female doctors as textbooks are generally written by men.

S – identifying introspection and pain; when I tell people I have PCOS people say, 'oh I had one cyst and it was painful as hell', but it's my existence.

D – I've also seen statements as "it is all in your head" or "it is just wear and tear" or they will associate with a recent event

S – the longer you mask and follow those social roles the longer you go without diagnosis. The SR in the room is different from the SR elsewhere e.g. with Gareth or at work. People say, 'oh I didn't know you were autistic. Or you can't be autistic as you're masking too well.'

H – it circles back to what do medical professionals need to know, we don't all look like what you've read in the textbook. I was told I couldn't have PCOS when I already had a diagnosis from the USA. It took a lot to get the diagnosis here. We don't all look like the stereotype; it varies across all human beings.

S – what used to be Aspergers syndrome was based on 10-year-old boys, or the perception of not being disabled enough. Judging everyone by that especially when we've learned to mask, the textbooks won't show that. Meeting one autistic person doesn't represent all autistic people.

K – effects of late diagnosis, I'm glad I have the ones I have if only a means to be believed by people at work and by medical professionals. I had to write an assertive message for my ADHD review, to assert myself on a pre-review form saying that I don't want to discuss my weight. They have raised the weight loss drug (Mounjaro, the scientific name) so I put I only want to discuss my medication and not weight loss drugs. I'll have to assert that every time I have a review which sucks. My chronic conditions may have arose maybe due to masking so heavily during adolescence and early adulthood.

S – I had a diabetic review due to weight and I still can't eat properly, I felt blamed for being overweight. I was forced onto the programme due to the nurses' judgement about my BMI.

H – I had a late diagnosis and can generalise a little that the chances are good that you've been seen and missed by mental health professionals or services. I lived knowing something is wrong but not knowing what it was, reinforcing the thought that something is not right with me by being gaslit by people. The gauntlets of being told 'that's not you'. As a woman, chances are they're not looking for you and the trauma can be significant. If mental health primary services had picked up on presenting depression and exhaustion or the anxiety; if early interventions had done a deeper dive and if I'd got help at that point, I might still be married and working. It's deep, multiple and across the board. The thing that gets me through is knowing I can do something better for my children and for people who come later. Late diagnosis means lost time. It can be the hallelujah moment of 'that makes sense' but there's also that feeling of lost time.

K – on the regret side of it, I try to look at it as yes things could've been different but also would I be where I am right now without that. I may not have gone to university, which was the vehicle to moving to the UK, the friends that I have, my fellow neuro-spicy husband. If you pull on one thread it changes ones' story.

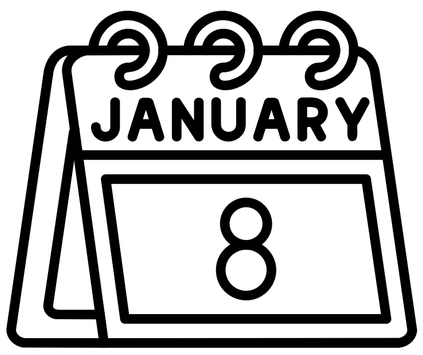
S – I wanted to be a sports journalist; had I not had autistic burnout and realised there were other people like me, I wouldn't be doing what I'm doing now. Is it lost time or is it what's got us to where we are?

The next meeting is scheduled for New Years Day so we'll move it to the 8th of January.

Self Care

What are we doing to look after ourselves tonight and over Christmas?

Watching Star Trek original series which I'm enjoying immensely, having the kids for Christmas, might treat myself to a Paramount subscription. Midnight mass service at church, decluttering and admin support 'Destination Organised' in Devon and life admin, finding things to hold onto over the dark and miserable season, winter solstice and s'mores, working unfortunately, seeing family, looking forward to January when things go back to normal, visiting family for a month, eating cheese and being distracted with work, looking forward to January, watching Torchwood.



Next meeting is Thursday 8th January 6pm 2026

Subject: TBC