

Autistic Flappy Hour Podcast

Transcript of [Episode 5: Identity](#)

Introduction:

Nat: Welcome to Autistic Flappy Hour, a podcast with an autistic angle. I am Nat at Autscape.

Megan: I'm Megan at Autscape.

John-James: I'm John-James at Autscape.

Laurine: And I'm Laurine at Autscape.

Nat: Yes, we're at Autscape again, much like in episode three. And this is the exciting return of Megan, who was first heard on our Steve Silberman interview special, and the podcast debut of John-James. It's exciting to have you both here.

Megan: [chuckles]

John-James: It's exciting to be here.

Laurine: [chuckles]

Nat: Yay. So Autistic Flappy Hour remains a podcast about autism made by autistic adults, but now we have even more of us involved. We're expanding the number of people working on this podcast, both increasing the pool of hosts who can appear on episodes and the number of people working behind the scenes to get them edited, transcribed and released (hopefully!).

And since four of us were going to be at Autscape anyway, we thought we would take the opportunity to record another episode while we were here.

This year's Autscape is themed on identity, so we've seen several talks and discussions on the subject by this point, which is the evening of the second to last day. So we thought: 'What better topic for recording at Autscape than an episode on Autscape's theme of identity?'

Flappy Things:

Nat: But before we talk about identity, it's time for our Flappy Things.

This is where we discuss autism-relevant things that have been making us happy or *flappy* since we last recorded.

So, John-James, what has been making you flappy recently?

John-James: Well, I'm going first so I'm probably stealing someone else's idea, but Autescape is making me happy flappy at the moment. Hum, it's my first time here and it's a little bit how I imagined it, but also completely different. It's like a whole other world, an autistic-friendly world, mostly. And, yeah, it's just... been really cool, I'm really happy to be here.

Nat: Yay!

Everyone: [chuckles]

Nat: Are we allowed to react to things?

Laurine: Yeah, we always have this.

Laurine: Yeah, I'm especially happy that John-James is here because I followed him on the train and everything and will follow him back down on the train, so if he wasn't there I wouldn't have been able to take the train. So... thanks... [chuckles].

Everyone: [chuckles]

John-James: It's alright. It makes the journey really fun, so...

Nat: Yeah, I like it when you travel with people and Autescape kind of starts at whatever station you meet the person and...

John-James & Laurine: Yeah!

Nat: ...keep bringing autistic space into public transport. Well...

Laurine: [chuckles]

Nat: Laurine, what's your flappy thing?

Laurine: Well, my flappy thing is sort of *vaguely* autism-related. It's that, hum, because I've started cross-stitching again, uh, a while ago, Par La Fenêtre, who makes a webcomic that we talked about before, let me take one of her drawings and turn it into a cross-stitch pattern.

It's one of her drawings from the *ABC of Stimming*, which is an ABC of different stims that autistic people have. So, I've been cross-stitching 'B is for Blinking', and I started before Autscope but I've got loads more done at Autscope so I've been quite excited about that, and I'm excited to... I'm looking forward to finishing it.

Nat: It's so cool I've... we have, like, discussions, and I'm just like 'Oh, there's our friend who can't be here, she's here in spirit and in cross-stitch!'

Megan: Yeah, it's a very nice [chuckles] little thing!

Laurine: Yeah, that's what I've been telling people. Like, I'm cross-stitching and pretending she's there in the room and, uh, it's been nice.

Nat: And, hm, Megan, what's been making you flappy-happy since you recorded the Steve Silberman interview?

Megan: Mine is something that might instill fear in the hearts of many autistic people, but I went to Disneyland Paris in June and I'm a huge Disney fan, but I haven't been to a Disney theme park since I was a child and I went to Disney World a couple of times when I was very young, and I haven't been to *any* sort of theme park since I was a teenager.

So I was very anxious about it, but Disney is actually very good for disabled access. It's fairly straight-forward to get a pass, a disabled access pass, that you can use at any of the rides to go in a special queue that's shorter than the main queue and sometimes there's no one else in that queue, so you don't have to worry about waiting in line, lots of people in the crowds. And they have a good guide to all of the rides, showing what accessibility issues there are for a range of disabilities, and almost every ride is wheelchair accessible and they have details of how to access them, whether you have to transfer from the wheelchair, whether you can take the wheelchair onto the ride and I was just really impressed with how they handled it all, and how easy it made my visit, and how nice it made my visit.

I think that, if I hadn't had that, I wouldn't have been able to do a quarter of the things I did there and I would have been a crying mess in the middle of Disneyland, which would have been really embarrassing, but I just had a great time and I think another autistic aspect to it is the sort of acceptance there is there of adults liking things that are normally intended for children.

I met a lot of the characters and there were lots of other adults who were meeting the characters and getting autographs of Winnie the Pooh or Mickey and Minnie and getting

photos with them and it's a totally normal thing to do there and you can be an adult walking around wearing mouse ears, and no one looks at you askance or wonders what's wrong with you and so, that was, that was really nice 'cause I would do that in my day-to-day life if people wouldn't give me strange looks.

So, yeah, that's my flappy thing.

Nat: That is so awesome!

Laurine: Yeah! [laughs]

Nat: I want to go to Disneyland Paris now!

Megan: It's really good!

Laurine: And Nat, what is your flappy thing?

Nat: My flappy thing was actually really recent at the time of the recording, which is like mid-August, it was just at the weekend.

It was going to a science-fiction convention I really like, called Nine Worlds GeekFest which has moved now and it's in Hammersmith, in London.

And it's... I absolutely love conferences and conventions, I think I've talked about this before, it's socialising, where there's a discussion topic that everybody is interested in and it's something I really like so I can just go off on one about things I like and everyone seems appreciative instead of staring at me and being like, 'what's wrong with you?'

So that's awesome! And everyone wears name badges and there's a timetable, it's just, it's all my favorite things. So that would be awesome, hum, anyway but there's a really good autism connection though, because Nine Worlds has multiple streams about various different topics whether it's a fandom or a genre or like writing, or whatever. There is a neurodiversity stream, so I was able to go to multiple autistic or neurodivergent-focussed discussion topics about science-fiction and fantasy stuff, like characters or writing.

The very first thing I attended at the con was a panel about making video games accessible to neurodivergent people and one of the panelists was dyspraxic and had the same sort of issues as me and that was just so affirming and cool.

So, it's like, going to a little bit of autistic space, it's not exactly like Autscope but it does now have communication-level badges, very like Autscope's but they are acetate coloured overlays that just go over your badge, so you can just go, okay, I'm going to go on yellow now, and just slip one out and put it over the top. And they have the green badge as well but it's blue because of the colorblindness issues. They've got like a symbol for each one and a colour.

And basically I usually struggle to talk to people who I haven't already talked to in one of the sessions where I've put my hand up and said stuff and then someone's come to talk to me - but with different people wearing the blue badges and with me wearing the blue badge, people were talking to me a lot more, it just felt a lot easier. And it just really really made a difference.

And I struggle with really really busy conventions, and that is really busy on the Saturdays and there's lots of issues but their access team is so fantastic and so committed to getting, er, autism access and all sorts of other types of disability access, invisible disabilities.

Like, the major thing they've done this year: last year I had a really difficult time because I would go to the rooms and they'd be full. And I couldn't get myself together earlier because anxiety issues delaying me, with IBS, and with just executive function issues making me late. I was just really struggling to be on time. And I'd show up, and it would say 'room closed' so I gave them feedback on this and now it says 'room closed, but some access seats available' or 'room closed, all access seats full'.

So I can show up and be like 'oh, I can come in' and they explicitly told me that, like, being late for disability reasons is the reason to use a priority seat so that has transformed my ability to access this convention and have a really good time there. So, yay!

Laurine: Yeah, I'm glad it really went well for you like that and, also it's nice to see more events adopting badges and trying to improve their accessibility.

Nat: Yeah. Absolutely. Oh, and I should also say 'thank you' to everybody at Nine Worlds and at BiCon that I was at the week before, and at this Autscope who has come up and they said 'thank you' for the podcast and that they loved the podcast. That's just so awesome to meet people who listen to the podcast who aren't people I know and aren't people I gave a piece of card to saying 'here is my podcast'. That's so cool. So, yay!

Laurine: Yeah, that is really cool!

Discussion - Identity:

Claiming an autistic identity (co-hosts' backstory):

Nat: Okay, let's get on to our main discussion. This isn't as pre-prepared as usual because we were waiting to hear the Autscope presentations on identity before we recorded our own thoughts on identity. So this is more of the type of informal talk that you might have at an Autscope anyway, but with a microphone in the room.

And you've probably noticed the sound quality isn't quite as good as usual because we've only got one microphone. It's a really really shiny and exciting-looking microphone and I kind of want one like this, but we've only got one, so there's going to be I guess some echoey-ness and it's going to be harder to edit if we accidentally talk over each other. But if

you have any problems, there's going to be a transcript as always linked from flappyhourcast dot wordpress dot com. So if you are having any problems following anything, you can read along on there.

So, identity. I think the first thing to discuss about identity is how we each came to claim or recognise the identity of autistic as applying to us. Now Laurine and I have already talked at length about this in episode 1 that was about Our Autism Stories. But this would seem like an ideal place for our new co-hosts to introduce themselves and talk about their own backstory.

Megan, this is your second episode. So your introduction actually seems kind of overdue. So would you like to tell us a little bit about yourself, when you first came to recognise that you identified with autistic experiences, and how you came to claim this identity for yourself.

Megan: Sure. Well, I'm Megan, as we've said already. I'm from Norwich, but I've only lived in Britain since 2003 and prior to that I lived in the US, mostly in Kentucky. I don't really remember hearing much about autism, growing up. I wasn't diagnosed until my 30s, a few years ago. The only thing I remember about, hearing about autism, growing up, were cases of non-verbal autism, so it was never something that I thought could ever apply to me.

I think I was quite lucky in a lot of ways because I was pretty successful academically, and I really liked school. And although I wasn't great at the social aspects, I think it took me a very long time to realise that. So I was in a little bit of blissful ignorance until my teenage years, when I started having more problems socially.

Then, I think my biggest moment was when I moved to Britain (as I said in 2003) and I came here as a postgraduate student and it was a totally different experience to my undergraduate experience, and again I think I was very lucky in that because I went to a really small university, so there was a lot of, hum, we had really good relationships with the lecturers, and there was that sort of level of pastoral support that I didn't have at the university I went to in Britain, and it was just such a different experience.

And I felt really isolated and unsupported, and I had a lot of mental health difficulties at the time, um, as a result of that. And I thought it was all just cultural problems, cultural shift, so I ended up leaving my course before I wrote my dissertation, and yeah. I just gave up on it and started working full-time. That experience always kind of stuck with me, and was a really negative introduction to Britain. [chuckles]

And then, around 2010 I think it was, I heard an interview on NPR with Temple Grandin and I think I'd heard of her before because I'm interested in animals, but I'd never really heard her story. When I heard that, I identified a lot with the way that she thought and the way she described things. I think that was to promote the film with Claire Danes playing her, telling her life story, and I watched that as well and I thought 'yeah, that - that is a lot like the way I think. It may not be the way I appear on the outside, but it's the way my brain works in a lot of ways.' And that led me to look more at autism, and start to identify with that, but I didn't

seek a diagnosis because I wasn't really sure about the process and I wasn't sure what I would get out of it.

Then a couple of years later, my husband and I tried to adopt and we were refused after a long home study process, and the social workers were really critical of me and said that I was like a wounded child, and I'd clearly had some childhood trauma that I hadn't processed. And I just didn't relate to that at all, and to anything they said, and I thought 'that's completely wrong'. And a lot of the things they brought up were clearly autism-linked, so after that I sought a diagnosis to sort of redeem myself I think, and sort of claim back some self-esteem that I'd lost in the process.

So I was diagnosed, then, in 2013 at the age of 32, finally! So yeah, so it's still something that's sort of new to me in some ways but I think probably this year is the first year that I've felt like it's not something I'm thinking about *all the time*. It's taken a while to settle in to my identity, but I think that it finally has!

Nat: I'm really sorry that you went through that bad experience with social services.

Megan: Thank you. So am I! [laughs] It does make me sad for other people, as well, because obviously there's no reason that someone who's autistic shouldn't be allowed to adopt. I do wonder - if I'd been diagnosed, I don't know that it would have been any different, and I've heard of other people who are autistic who've had problems with social services in those ways. I think that's something that really I hope is addressed at some point, that people realise that autistic people might have special skills in dealing with children who've been through trauma, and that their autism would be an asset in that rather than a hindrance to dealing with those emotional difficulties a child might experience.

Laurine: I know when you told me about that last year I was so outraged that I couldn't cope with it!

Nat: John-James, what's your abridged autism story?

John-James: Okay, so, I was diagnosed at 29, which is just over a year ago. But as we know, professional diagnosis isn't the beginning or the end, or maybe even a feature of someone's autism story. Mine started quite a bit before then. I had a much younger sibling who was diagnosed at a young age, so I've always known what autism looked like even in a very subjective sense - and my family sort of lightly joked that we were very similar, and that perhaps I was autistic too. So I'd considered I was perhaps autistic since my mid-teens, but unfortunately I didn't know that self-diagnosis was even a thing until I was professionally diagnosed and then looked more into autistic culture, and just stuff around autism really online.

I wish I had known back then, because I could have come to the identity much sooner. So post-university it was, when all the routines seemed to fall away that come with formal education. I had a bit of a breakdown. Following that I was under the care of the Mental Health Team, and in my notes (which I later obtained) it says that I likely 'suffered from'

Asperger's Syndrome, but they didn't think to tell me at the time because they didn't think it was necessary or relevant.

Nat: ugh [groans].

John-James: So I recovered from that breakdown thankfully. It took a few years, but I got back on my feet. I had a full-time job, I had a flat and a partner. Everything seemed to be going okay, but the stress of all those things, just normal life, and also not knowing I was autistic, so trying to pretend I was neurotypical all the time - sort of built up, and my mental health did take a dip a bit, and I was re-admitted under the care of the Mental Health Team.

The psychiatrist this time looked over my notes (which I had already obtained by then) and we both decided together that a diagnosis might be a good thing for me. It might explain a lot, and help me deal with my issues.

So I was referred to their colleague, and over two appointments I got my diagnosis. Like I say it was only thirteen months ago so, Megan talked about sort of settling into the identity and I'm still at that stage.

It's still quite new to me, but online resources have been really helpful with that, like blogs and Twitter. I've got involved with a local charity, because I'm based in Brighton & Hove there's a really great charity called Assert. They run social groups and support groups. I've made some autistic friends, I think that's the most important thing - spending time with other autistic adults.

And that's my story really.

Megan: Yeah, I think that meeting other autistic adults has been really important to me as well. And especially as a part of accepting myself as autistic, because even though I identified with it and was pretty sure it fit me before my diagnosis, I still kind of questioned it and thought 'well, maybe they're wrong and maybe I'm wrong and maybe I've got something else and there's something wrong with me'. So I think it's been really reassuring to meet other autistic adults, and realise 'Oh! These people are really cool, so maybe I'm not as awful as I thought!' [laughs]

John-James: Yeah, definitely, I can relate to that.

Nat: I would agree with that. The other thing that really helped with meeting large numbers of autistic adults was that a lot of my niggling fears and doubts that I didn't perfectly fit this thing, autism, that had such, like, strong connotations or was described in all these very specific ways. Going to, like, Autscape and meeting, you know like, 90 other autistic people you very quickly realise that we're all very different. We're alike in lots of ways, but we're also very different, and there's no one here that perfectly fits every aspect. And that, just, that was just so affirming to me to just be like, no, I'm an individual and we're all different, and I am definitely like these people. Even if it's a subset of the things, there's someone here who can

relate to everything that I'm saying. It's just, like, a group of people have to get together to be like the full match.

John-James: Yeah.

Autism and other identities:

Nat: One of the discussions that I was in this week, run by Kalen, looked at all the different aspects of a person's identity and how autism relates to them, and whether autism is inherently different or similar to them. And that really got me thinking about how being autistic affects the way that I relate to the rest of my identity. Have you got any thoughts on how autism affects your other identity aspects, Laurine?

Laurine: Um, yeah. So I think sort of one of the main things is that ever since I was about 14 I was interested in Deaf Studies, and started learning French Sign Language. And so I think already knowing of a framework of a strong community of people, um, with disability history and everything kind of influenced me from the start. There's a book called 'Deaf Gain', as opposed to 'hearing loss', edited by Bauman and Murray and it actually references neurodiversity because there are lots of links to be made. And I think that part of my particular interests really had an impact, once I had my diagnosis, on how I started perceiving myself. And also how I started perceiving my position as someone who's doing a PhD in Deaf Studies, and who's hearing, and all of those things, and that's been really interesting for me to explore.

Nat: Yeah, I kind of relate to – um, obviously not every aspect of that, but from quite an early age I would tend to watch anything related to disability on television, especially, like, actually about disabled people's experiences and identities, and I guess that I always felt that I was different from people, and I was always interested in people that were different. It wasn't just like I was obsessed with disability, it was just any TV show that was about something that didn't fit and was different or was finding identity in that was something that (even like, we're talking really young) was a thing that I really related to.

Laurine: Yeah. I think like sort of always being for the underdog, from a really early age, because I knew I was different but I didn't know why, that kind of was an important thing.

Nat: So a big thing that's happened in my life since we last put out an episode (and actually it's only in the last five weeks at the time of recording) is that I've now also been diagnosed with ADHD, in addition to Asperger's Syndrome, dyspraxia and Sensory Modulation Disorder. It's becoming quite a list! I don't have dyslexia – I've been tested! And I don't have dyslexia.

The assessment process for that, and the post-diagnostic write up for that, has been really thought-provoking for me, and had like a definite effect on how I think about identity and autistic identity. In many ways this Autscope themed on identity has been incredibly well-timed, because it's kind of come while I've been exploring these issues and really thinking about everything, because in light of having this additional diagnosis that could be

just as significant, pervasive effects on someone's life as autism. And what was really interesting in the write up is that it says that I have multiple neurodivergence – actually, 'multiple neurodevelopmental disorders' is what it says. Maybe not how I'd word it. But it says I have these, and it's counterproductive and unhelpful to try to think about them separately – to try to say that this thing that Nat does is because of their Asperger's syndrome, and this thing that Nat does is because of their ADHD. It's far more useful to say that together, they have a profound effect on me, and instead of thinking of me as any of those one things, to instead look at like my unique profile of strengths, challenges and also, like, my cognitive profile. And that was kind of thought-provoking and I was very much like 'Should I be calling myself multiply neurodivergent, rather than autistic?' and really, I have been really thinking a lot about that.

And then on the train to BiCon last week, or a little while ago, I lost my train ticket after changing trains, and had an anxiety attack and went non-verbal, and couldn't communicate and had to use my communication cards... and then I was like, no, I feel quite autistic actually, I think that's fine to identify with this! [laughs]

Yeah... but that has been something that I've been really thinking strongly about, and there's been some really thought-provoking discussions in this last few days about identity and about different neurodivergences overlapping and different other identities intersecting with autism, so yeah I've got quite a lot of things percolating through my mind. But Autscope has helped me be like no, I'm really comfortable identifying as autistic here, and a lot of the discussions have shown me that there are a lot of other people here who identify as 'autistic and...' you know, like 'autistic and mentally ill' or 'autistic and an immigrant' and you know, people have like, their own perspective that makes their experience unique, and it's kind of like a constellation of identities really, but autism is definitely an important part.

Laurine: Megan, what about you? What intersections would you want to talk about in those terms?

Megan: Well, I think it is kind of hard to unpick. I think it sort of goes back to what Nat was saying, it's hard to separate what is autism from what is this other aspect of my identity. What's my depression or my anxiety, or what are OCD tendencies and what's being a different culture, what's the result of the way I grew up...

The two that came to mind immediately, the first one was similar to Laurine (I guess I'm just copying everyone now!) but similar to what Laurine said about having an interest in another culture. And mine, growing up in Kentucky I was always – I always felt like I didn't belong, I felt like an outsider and I was a huge Anglophile growing up, and I read Charles Dickens and things when I was about ten when everyone else was reading 'Sweet Valley High' and 'Babysitters' Club' and things, I was reading 'David Copperfield' and I learned a lot of my social skills from 19th-century British novels – which isn't really the way to behave in Kentucky, and led to lots of very embarrassing incidents, especially as a teenager!

But yeah, I was always an Anglophile, and more broadly sort of a xenophile, always interested in other cultures and other places, and I remember at university, the end of the

first semester I was sitting at a table at dinner with a group of international students and we were all talking about what we were going to do over the Christmas break, and I said 'Oh, well, I'm going home tomorrow' and they said 'Oh – how long is your journey?' and I said 'Oh, it's only about a two and a half hour drive' and everyone at the table was like 'What?! Where are you from?' because they all thought that I was from somewhere else – they thought I wasn't American! I was like, 'No, I'm from Kentucky', so... and this isn't my accent I had then. For anyone who's listening and thinking 'She doesn't sound like she's from Kentucky', I did have an accent! But I guess I just gave off this vibe of otherness, and so now I can look back and say 'Oh, that's probably because I'm autistic'... because when I moved to Britain I had the same sort of experiences, but people said 'Oh, you're not like other Americans! You're not loud like other Americans, you're not friendly like other Americans...'

So yeah, I think autism has sort of made me less critical about those aspects of my identity, and less questioning about them. The other major aspect that I thought of was religion: I grew up in the Bible Belt, a place where religion is very important to most people's lives, and I always felt... I changed denominations, I was always a Christian but I changed denominations a few times – several times, growing up, and I always felt like nothing suited me and I never felt like part of this thing that everyone else seemed to be feeling and experiencing around me. I sort of stepped back from religion for a few years as an adult – for almost ten years, I think – and now I identify as a Christian again, but I think because now I know I'm autistic I'm much less self-critical about when I don't feel like a part of that group, or a part of any other group I identify with. I think like Nat said, seeing the diversity in autistic people has made me feel less critical of my difference to people in other groups that I identify with.

Nat: I relate quite strongly to your saying that you would go from – I mean, you were specifically talking about going from one denomination to another and not feeling that you quite fit each one – but my kind of experience was of going from one identity to another and kind of immersing myself in it and feeling that this must explain everything... and then gradually I'd meet more and more people who were, I don't know, asexual or whatever it was each time, and then be like, okay, well, I am like these people but I also feel completely different from them and I don't feel like I fit in. This hasn't answered all my questions. And realising, I guess what autism is, is the thing that makes you not feel like you fit in in lots of places – it's also why Autscape's so awesome!

Megan: Yeah, I think it's that thing of being a misfit among misfits, is really reassuring and reaffirming. I had the same thing with being asexual, and yeah, like you said, with any sort of identity and now I feel okay with not feeling 100% like I fit this narrow definition of what this specific term is.

Laurine: That's really interesting.

Nat: So, John-James, how do you feel that autism interacts or intersects with other aspects of your identity?

John-James: Well, it's interesting... we were actually talking earlier, myself and Nat, about how because I've experienced psychosis in the past and previously they've been exclusionary categories, like you can't, in the DSM you couldn't be psychotic and autistic, but I'm both – not all the time, but sometimes I am. I was comfortable with the psychosis label, and it seemed to explain most things but not everything, but then the autistic label sort of explains everything as well, so they intersect and they overlap each other, and it's like Megan said, and Nat said: it's difficult to pull them apart and find out which part is which. Also, special interests have played quite a lot in forming my character as well. So my first special interests were the colour pink, and My Little Ponies, and dresses – which were quite unusual for a little boy coming from a small town, so I felt quite confused about my gender for a while when I was younger, and into my teens. And that was directly influenced by my autism, I think.

Nat: Yeah! And I won't go on about gender again because I've done it on so many episodes now, but obviously it's a major thing. I don't think I related to being transgender, and I don't think I related to having gender dysphoria in the same way as a lot of other people who maybe have the same sorts of feelings, because gender just didn't make sense to me, and still doesn't really make sense to me! So...

Laurine: Yeah, what John-James said about mental health issues, yeah I feel like my mental health issues – and I guess Megan also kind of mentioned that – that influences me a lot, because when I don't know which is which, and having professionals blame things on autism... and that impacts how I see myself, because I'm like well I don't think that's the autism part, I think that's really the anxiety part, and I feel like I can know when my anxiety's linked to my autism, and when my anxiety's linked to having generalised anxiety disorder, kind of thing.

And also, about culture, I don't know if Megan feels the same way about that, but being non-British, it's been interesting to me because the reputation of British people being a bit awkward, and you know, all these things that you see about British culture, I feel like almost to me Britain is more friendly to the way I am because people are like 'Haw haw haw, this is how British people are!' And sometimes I also use the fact that I'm foreign to hide that I am autistic. I just say, like 'Oh! Sorry I didn't understand this social rule, that's because I'm not British!' When actually, that is not the reason at all, but it kind of gives you excuses.

Another thing that I've written in my notes was I feel like the history of my sexual orientation feels really linked to my autism, because I felt like I was going with what was expected – so, straightness – just because, at least, people around me kept showing me how to be straight. You know, everything in movies was like 'This is how straight people behave', and all that sort of thing. So it was just like, oh, I can follow this script. And imagining going off that script that I was able to learn, I was like 'How do I learn the other scripts?!' and because I came from a place that was like a small, conservative kind of place, I just had no idea and I think that was really influenced by my autism, because I just couldn't figure out how to go out of that model and how to learn other things.

Nat: That's actually reminded me of, I guess a really strong aspect of my identity growing up and still in adulthood is how alienated I feel from Britishness and British culture.

I, you know, I like British humour fine, that's fine, I'm okay with that aspect of it, but just about everything else, whenever there's like... there's a Twitter thing called 'Very British Problems' and every time someone retweets stuff from that, I get really like... I don't know why it upsets me so much but I just end up reading through them and just being like 'I don't know why I live in this country, because I just don't do any of these things'.

It's all about people being indirect, and not being explicable, and not... and not explaining things, or keeping things to themselves and I'm just like 'Aah, everything I do is wrong! I can't...' so I guess, nationality is not a big part of my identity, in fact in previous censuses I've put like European for my nationality and now I feel really upset because of Brexit.

Laurine: [stifled sad laughter from the one with no British citizenship]

Megan: Yeah, I think in response to what Laurine said, I feel a bit like Nat I think, I think I feel sort of in-between.

When I came here, it wasn't 19th century Dickens novels! [laughs] And it wasn't Monty Python, and yeah, it wasn't the sort of things I thought it would be and I have had a lot of problems with people not being direct... yeah, understanding all the nuances and yeah, being frustrated by people not admitting to what they actually mean! I find it really hard.

I do feel like this sort of quiriness and things that people see in British culture that's exported isn't... because people have said to me 'Oh well, you know, there are characters like Sherlock Holmes so you must feel really at home there!' and I'm like... if he were here now, he wouldn't be accepted by people! They would be talking about him behind his back, or they'd be making fun of him and he wouldn't realise they were making fun of him.

So yeah, I found those aspects of Britain really difficult and in some ways I miss the directness of America and I miss understanding how social things work there, even though it took me until my twenties to get it, I eventually got it! And maybe when I'm in my 40s or 50s I will get Britain more... and I do like it here, but yeah, I'm definitely disillusioned. [laughs]

Laurine: Yeah, I think yeah, just to clarify what I meant, it's like... I like the idea of, you know, how people expect British people to be a bit awkward, but that's not necessarily in the same way as autistic people. It's just that I feel like not being British really gives me allowances to not understand, because when I'm in my home country and I don't understand a rule, people are like 'Well, you grew up here, how come you don't know this specific social rule?' whereas here people are friendly enough, I can just be like 'Oh! I do not understand what it is!'

Nat: I love the body language! You don't really get this on podcast recordings, all this stuff...

[general laughter throughout]

How important is our autistic identity to us?

Nat: So the obvious follow-up question now would be, we've talked about how we feel that autism overlaps with all of our different identities, but how important do we feel that being autistic feels to us to be, within our identity-constellations? I really like that term! Did I hear that here at Autscope? I can't remember, but I really like it. I'm claiming it, it's mine now!

Like... I'm guessing that because all of us are attending an autistic conference and retreat, and co-hosting a podcast with 'autistic' in the title, that it's probably pretty significant to all of us... but I guess, where would you specifically or generally say 'autistic' falls within the, I guess, hierarchy of your identity, if you feel that you have a hierarchical identity? Would it be like one of the first things you'd say when summarising your identity to somebody, or like, writing it in a bio or whatever? Or would it be further down the list, or something that you would only mention if it came up or was relevant? Or does it, like, depend on who you're with or what you're doing?

John-James: Nat, you mentioned describing yourself in a bio, so I thought 'How do I describe myself?' and I looked on my twitter and I went to see how I describe myself, and the third word is 'autistic' so it's pretty important to my identity I feel, and also it's helped me claim the identity (rightly so, I feel) of 'disabled' because that was sort of forced on me while I was mentally unwell, that I was told, you know, 'Oh, you should apply for this disabled railcard, you should get Disability Living Allowance because you're not working' and I didn't feel disabled at the time... or I didn't feel like I was rightly disabled.

I don't know if that makes sense, but... being autistic, it makes me feel like I am part of the disability community, and that affects me more than that I am part of the LGBT community, which is kind of weird because... I don't know, people would expect it to be the other way round, I think, and there's a lot exclusion from the LGBT community when you are disabled. There are lots of accessibility issues. For example, I don't like going to loud gay clubs because they're loud! And Pride is just... *sigh* horrible...

Nat: Whistles, whistles! What's with the whistles?

John-James: Whistles everywhere! [laughs]

Megan: I think that... um, if I were... I don't know if I can think of it in terms of a constellation, although I do like that analogy, but if I had – if it were a solar system, then I think autism might not be the Sun, but it would be a fairly massive body in that solar system, or at least a fairly important body to me, so maybe it would be my Jupiter in my personal solar system.

I think as John-James said, it's something that in, I think, most of my bios on social media, I mention somewhere, and I think as I said earlier it's helped me accept myself in other ways, and accept other aspects of my identity, and that's why I feel that it has a gravitational pull of its own!

I think that when I said in my introduction that it's been now three years since my diagnosis, that it may not be the first thing I think of in terms of my identity anymore, it's still important and it's something that feels more ingrained in me now, and... sort of part of me at an atomic level (I've just gone from solar system to atoms, sorry!).

Nat: They have orbits! They have orbits!

Megan: That's true, yes! [laughs]

I think though that it is somewhat context-dependent now and I did have some issues when I first was diagnosed, and I was um... I disclosed it, because I was like 'This is a great thing that I've found out, and it's amazing! Everyone look, it's really good!' and I think I sort of only saw it from my perspective, that if I knew someone and they said 'Oh, I was diagnosed with this and it explains all these things in my life' I would think 'Oh wow, that's amazing! I want to know more about it'. And I didn't really account for the negative reactions that some people would have to that, and so now I try to disclose it when I think people will react positively to it, or when I think it'll be helpful to someone understanding me, but I do find that difficult to judge, which is why I probably have a tendency to disclose more than some people would.

But yeah, I find it hard to know – I think some people view it as a liability, or I get paranoid maybe, and I don't know whether justifiably so, that they'll use it as a justification to dismiss me, or my capabilities or my judgement and think 'Oh well, that's not really how it is, you just think that because you're autistic and you don't understand.' But despite that, I do feel that it's a very important part of my identity.

Nat: So, for me it's kind of a contradiction because like, I also looked at my profiles in various places and mine are – it's very interestingly all about things that I do and like.

It starts off saying I'm a science fiction fan, which is like, it means that I watch and consume a lot of science fiction, and it also talks about being an IT professional, and it also talks about being trans and neurodivergent but only in terms of blogging about those things, which is interesting. And it says that I sing and draw stuff, which is also true.

And I think that partly there was a very limited character limit on that, because it's Twitter, and then I just used it everywhere else, and I think partly that I said 'neurodiversity blogger' or 'neurodivergent' or whatever it actually says because I find, in practicality terms, and I'm always interested in like practicalities, that it's important to, whatever the context is where I'm telling somebody about my various labels or impairments or disabilities or whatever, that I choose the one that makes the most sense and requires the least explanation for the situation I'm actually in.

So if I'm in a scenario where someone needs me to like, carry drinks, hot drinks down the stairs on a tray, I'm going to say dyspraxia; and then if I'm in a situation where I'm gonna be horrendously sensorily overloaded, I will talk about either sensory modulation and maybe I'll say I'm also autistic, because people can kind of relate to both of those things.

I guess I haven't disclosed ADHD for those sorts of reasons yet, but I'm sure that if it was a scenario where they want me to sit in front of a glass window where people do distracting things all the time and expect me to do anything other than be distracted by the people, then I would need to tell them that I have ADHD...

But the kind of contradiction from the fact that I don't, like, put it front and centre in my bios is that I really strongly believe in disclosing and being open and explicable, and I really think that it's quite difficult to get on with me and understand me without knowing this stuff. I really rely on other people being aware that I'm trying really hard, and that me being what looks like socially carelessness to other people, and like, you know, sometimes apparently I seem quite callous or all sorts of other stuff that like, I put so much effort into, and I get so anxious about being good to other people and I care a lot about being thoughtful about other people, and put huge amounts of effort in, to the point where it's quite exhausting and upsetting and causes all sorts of problems – and the idea that other people are just being like, 'Oh, that Nat just doesn't give a toss, and just, you know, if they just put in a little bit more effort it would all be fine, but they just can't be bothered' – that just upsets me so much!

And I also, like, kind of just... it feels really important to me that other people who are like... Everything I do, like when I podcast or when I write FAQs or when I do talks in places, that they're always aimed at like, somebody who's like where I was before I knew anything and someone who could avoid going through, like, ten years of struggles and not understanding and feeling bad about themselves. So I'm just, like, reaching out to people like me who are a few years behind, you know of whatever age, and just like helping them find the things that they need, and I guess I can do that.

So that's my rambling way of [laughs] talking about how it doesn't feel like it defines me but it also affects everything and I feel like although it doesn't define who I am, I don't think that I necessarily am a sci fi fan because of being autistic, but also when I think about it, probably that's why I first got into sci-fi. It's really hard to pick these things apart. It's pervasive, let's say that. But, yeah, it's something that I kind of want everybody to know who knows me more than just on a very casual basis. I don't meet people in the street and say 'Hello, I'm autistic! Do you have the time? Thanks, bye!' but otherwise... yeah.

Laurine: Yeah, well... as I've said probably a few times on the podcast, like, the kind of stuff that Nat does is what allowed me to, like... 'Oh! There are autistic adults, and they exist' and I loved, like, their twitter feed where they would self-narrate and everything, so that's been so helpful to me.

And I guess in terms of identity, well, it depends on the situation like Megan said. Like at first I was very very cautious, and then I got overexcited and told, like, you know, whoever would listen and now I'm trying to get back in between.

Overall it is pretty high on my list, and I do often try to disclose quite quickly if it's gonna be relevant in future. You know, like, if it's someone that I'm gonna have to interact with again, because like Nat said, I don't want people to think that I'm this really not-very-nice person, who doesn't want to interact with others, because I'm like, 'I'm trying really hard here!'

But I think in general, my identity kind of feels in flux because by discovering this really big thing, that I'm autistic and I hadn't known for so long, I've only known for a couple years and was officially diagnosed about a year and a half ago now... It's like it's allowed me to get more room to explore other aspects of my identity, because I was so stuck on the thing where I was like 'I'm different! Why am I different? Why don't I feel like belong anywhere?' kind of thing. So now I kinda have a label and an explanation for that, so I can start thinking about all the other stuff, because I think there's only so much that you can do cognitively and with several of my friends we have spoken about the same thing, where suddenly after I knew I was autistic my mental health issues kind of suddenly exploded more. It was almost like my brain was like, 'Okay, we've figured that out! Now let's move on to that *other* thing...'

Because before there just was so much going on, but I couldn't explore my identity so. Yeah, I'd say it's pretty high on the list, and it's probably one of the first things I would write in a bio – certainly so much more important than my nationality. I really hate it when people are like 'Where are you from?' I'm like '...I'm just autistic. I come from Autismland.' Yeah, and lots of other aspects, you know, that other people might be interested in knowing about me, I just feel like for now, because it's still so new and I still think about it a lot, like Megan said, now she's started to think about it a bit less and it's not as much front and centre. For me it's still very much front and centre.

John-James: I think it's even newer for me, so it's all I think about pretty much a lot of the time, so I'm still trying to figure it out.

Laurine: Yeah! It's like, it's all I've been thinking about for two years it's like, 'Hmm, I wonder why I can't make food!' and things like that – my brain is too busy! [laughs]

Reflecting on Autscope's presentations on the theme:

Nat: So, we've talked about our own kind of, our own identities and where autism fits into those identities, but we're having this particular discussion at Autscope – at an Autscope that's themed on identity. And we've all... I assume – I don't know, I did meet someone at my Home Group today who'd been to literally no talks and just been socialising the whole time, I'm like 'Wow, you can do that!? I didn't know!'... But I assume that most of us have gone to at least a few discussions.

So, has Autscope – has any of the interesting talks and discussions and workshops and conversations that you've had at Autscope, maybe about identity – kind of influenced, changed or inspired your thoughts around identity? Have you crystallised an opinion you already had? Or has everything just been like 'Yeah! This is all obvious, I didn't need to go to this'? So – anyone have any burning insights from this Autscope they'd like to share?

Megan: The one that I found – the talk that I found most interesting I think, and the most inspiring, I think I don't usually – well, actually I do get inspired really easily so I won't

pretend I don't – but the one I found most interesting was the, um, there was one called 'Training You, from a Dog's Point of View', which sounds... might sound offensive to some people, but the speaker was very careful to point out at the beginning that it wasn't about ABA-type therapies and training autistic people to behave certain ways.

They are autistic themselves, and they run a social enterprise called 'Canine Perspective CIC' that is, um... that uses dogs in a non-therapeutic way, with autistic people, with people with mental health difficulties, survivors of trauma, and they also, they work with rescue dogs and it's a mutually beneficial sort of relationship-building between the human and the dog. And it's about how the two species relate to one another.

And I mentioned in my introduction I think that I really love animals, and my brain tends to think of everything in terms of animals and I have a real problem with telling people, like, 'Oh! You look like a hedgehog!' and people taking offence at that when I mean it as a compliment, so if anyone who listens to this ever hears me refer to them as an animal, I mean it as a compliment so please don't be offended! It's not intentionally offensive.

Although I do that, I've always thought of dogs as neurotypical, because they're so... they're such social animals, they're very eager to please and you know, they want to be around people, they're kind of laid back in a lot of ways and I feel like I'm much more of a cat, and cats are a bit more cautious, they do things their own way, a lot of people don't understand them, people think cats are really mysterious whereas I find cats really easy to understand and relate to. I always, like, people are saying 'Oh I don't know why my cat does this' and I can always tell them why it does that! Because I think, 'I would do that!' If I could do whatever I want, I would just be a cat. I would just walk away while someone was talking me, if they were bothering me or I wasn't interested. I would, you know, I... cats don't look at you, because the words aren't visual, they just turn their ears to you – they're still listening.

But the workshop, or the presentation, made me see how autistic people are also like dogs. And again, please don't be offended by the animal comparison. In my mind that's a positive thing and that's just understanding how people work. The presentation helped me to understand a lot more about dog behaviour but also about human behaviour and it was about sort of what we can learn from dogs because dogs have all of these sensory capabilities that humans don't have. Obviously you know they have much better hearing and smell. So they have all of this input coming in that they have to deal with and they have to be able to go into noisy places with humans. So dogs have to adapt to that in their own way. And so in that way they're like autistic people with our sensory sensitivities. So some of the things they mentioned that we can learn from dogs are resilience, how to reduce anxiety,

positive self-talk. Because obviously if you're very like, negative with your dog, they're not going to like you, you're not going to build a good relationship and they aren't going to be happy well-adjusted dogs. And so it's the same thing with ourselves, that the more we talk down to ourselves, the more difficulties we'll have. And I found it really helpful to think in terms of that and think of how... not how I can reduce my cat-like tendencies and my cat-like behaviours, but I think there are some situations where it would be beneficial for me to be more dog-like, when I have to do things that I don't want to do. Yeah I found it really interesting and really helpful and it made me want to quit my job and live with cats. [laughs]

Nat: I quite enjoyed aspects of that talk as well. I missed the start and I'm kind of sad that I did because it was really interesting and... I mean I don't relate to everything in terms of animals, I relate to everything in terms of TV and film and fiction. So I'm all like thinking about things in terms of character arcs and editing, anyway.

What really struck me during that talk was how much a discussion of getting into sensory overload and relating that to the signs that the dog has, and it was like, a stairway, that was for some reason called a ladder, I don't understand.

Megan: No I don't understand either.

Nat: I don't understand, it was a stairway! [laughter] What really struck me on that and the diagram with the lines of getting overloaded and different points. It was exactly, I mean almost literally exactly like my occupational therapist's materials to explain Sensory Modulation Disorder and why I need to do my sensory diet. So I'm like, I'm gonna be like, I'm gonna take the Nat for a walk now, something like that, when I go bouncing and stuff. I'm like yeah, give myself exercise time.

Have you seen 'All Cats Have Asperger's Syndrome' and 'All Dogs Have ADHD'?

Megan: Yes, I read those books and like, yeah, that's exactly how I feel about the situation!

Yeah, I thought the steps - the stairway of dogs getting agitated - was really useful and like you, they pointed out the importance of if you are a dog owner, or if you're in any sort of situation with a dog, the importance of noticing those early behaviours, that if not noticed and if you don't address what's bothering the dog then, then you get an escalation of that, that leads to aggression in dogs and I think that's very important to relate to (as Nat said) our own sensory overload, and recognising those early behaviours in ourselves and not just dismissing them and going 'Oh, I'm just being ridiculous, it's fine, it's fine' because it will escalate and you'll just be exhausted and miserable!

Nat: Yeah, I think it's really important to have a kind of model that makes sense to whatever you're really passionate about, whatever your interest is, and a lot of people in the audience were clearly really getting things that maybe if it had just been a talk about, like, reward-based motivation (which was one of the things that I also recognised in myself)... If it

had just been about those things, and not related to something someone was really into, it wouldn't have made so much sense.

And for the people who weren't interested in that, it was actually just really interesting to learn about this awesome way of doing dog training that isn't, like, really negative and based on saying 'no' and stuff. So, yeah, I thought that was cool.

Like, I should stress that if anyone's listening to this and being like, 'Well that's rubbish' or whatever, it wasn't for everybody - like, it didn't really answer people that have inertia problems or executive function problems, but it was very good for lots of different things, as we've already discussed.

Anyone else?

Laurine: Yeah, well basically to me what was really good about some of the talks and discussions that I went to, they sort of re-highlighted the importance of *us* because I always kind of, in my advocacy that I do locally and things like that, I always worry about being, you know, *that* autistic who's trying to rock the boat.

So it's been pretty reaffirming to remind myself that yes, we are the ones that matter the most! Not in the world, but I mean in terms of versus professionals and like, our opinion is the one that matters the most versus some other people's opinion about autism.

And especially, for example, thinking about research, because I do a PhD, not about autism, but obviously that means I have access to autism research and things like that, it's really reaffirmed my opinions about research and how it should be carried in terms of involving autistic people, because sometimes I think when I'm on my own and I don't talk to anyone about it, I just tell myself, 'You're exaggerating, things aren't that bad'. And then seeing people raise the same issues and be frustrated about the same things, that's really reaffirmed it's okay to say that I'm unhappy about something, about a professional. It's okay to have needs, and it's okay to do all that work and have opinions - and to have *strong* opinions. Because I do really struggle when I try to share my strong opinions because I worry about then people not inviting me again or disliking me for them, and things like that, so... yeah. That's kind of, that's reaffirmed how I feel.

John-James: Well I was part of a discussion earlier called 'The Neurodiversity Manifesto' which I thought was really interesting, just because I liked the strong opposing viewpoints and it was a really lively discussion. Everyone was coming out with really good stuff, especially the thing about not necessarily needing a label as in a diagnosis, for something such as a workplace to be accommodating. So if for example you struggle to carry a tray of hot drinks down the stairs, you shouldn't need a diagnosis -

Nat: [overlaps] of dyspraxia -

John-James: for that to be accommodated, you should just be able to say 'I struggle with this' and you shouldn't be expected to do it. And I thought that was really helpful to me,

because I struggle a little bit at work at the moment about getting accommodations and stuff, and it was just something that I could bear in mind, so thanks for that.

Nat: Yeah, that's just the sort of thing that needs to be in a Neurodiversity Manifesto. That we don't... we shouldn't have to jump through the medical hoops, and go through the quite difficult process (and sometimes not accessible process).

Like a dyspraxia diagnosis, if you haven't already got an autism diagnosis, and in some areas just at all, you can't get that on the NHS. You have to pay. And I paid for one in 2007, and it was quite expensive - I wouldn't have done it if it wasn't really, really important to keeping my job. So that's important.

The thing where I related to what you were saying about hearing what other people were talking about and recognising that it's not just you that has these issues - the one that made me feel the most about that was today.

There was a discussion about our experiences of inertia, and it was really affirming to listen to a big group of people. It was a very, very well turned out discussion, and it was really well facilitated as well which helped. Taking down names and making sure everyone got a chance to talk. I really really appreciated that.

And it was just really good to hear people that have very similar issues to me, about starting and stopping things and other executive function issues; and other people who had much more major issues, and I could see how inertia could go as far as catatonia, and how some of the things I have, actually the strategies they were talking about, of... you just have to do one thing. So if you're struggling to get out of bed you can be like 'I just have to move my finger. I just have to move my arm. I just have to sit up' and just do each thing as a small step. That was really helpful.

But the thing that I found most thought-provoking and most challenging I guess was in Martijn, who guested in our last Autscope episode. Martijn had a fantastic talk earlier today which was about autistic identity and - I've got the slides open here so I don't misquote anything - the concept that stereotyping is a big part of autistic identity, which is quite a challenging concept.

That we all have a social pressure to conform to the autistic role, including the idea that we're immune from social pressure. And it's not just from outside society, but from other autistic people, and the example that sometimes it's necessary for us to play up to autism, to act like is expected. For example to get accommodations needed or when being assessed for benefits or services. If you don't seem autistic to the person, you won't get the services. And I was like 'hmmm...' and the final one was - this is a quote from Mel Baggs's Tumblr - 'all autistic people fake autism'. Which is quite a challenging statement!

And the idea is that we're in a stranglehold of self-fulfilling autism stereotypes, whereby we are all acting against what we are expected to do, and so on. And I was like, I don't think that I relate to that at all! But Martijn's description of why community norms in the autistic

community and certain expectations lead us there made me go away and think at length about that.

I'll put a link to Mel Baggs's blog post in our show notes, and everyone can read that and decide if they think it's complete rubbish or if there's something to it, or whether you kind of think maybe the reasons why I don't, like, the thoughts I was getting was, "maybe the reasons why I've felt alienated at certain autistic community things is because I didn't absorb certain stereotypes, or because I wasn't overlapping in certain ways". It's a weird and challenging end to my thoughts that, as I said, I don't know if I even agree with any of it, but it was one of the most thought-provoking parts of Autscope.

Final thoughts:

Nat: So does anyone have any final, final thoughts to finish us off on a less down and strange note than that one?

Laurine: My final, final thought is that I'm looking forward to going to the entertainment evening, to which we are late now! But I'm very excited to go, because it was really fun last year.

Nat: It's so great!

Megan: Yeah, it was a really good bonding experience, me and Laurine last year laughing at similar things - not laughing at people, I hasten to add, but yeah, being entertained I think, in very similar ways.

Nat: Did you find the standup comedy from last year funny? Because it was all, like, really punning and I just found it so funny that I could barely sit on my seat it was so hilarious!

[laughs]

John-James: Now I'm really excited to go to the entertainment as well, because I haven't experienced it yet!

Nat: I'm so sorry to all our listeners, you're just going to have to come to Autscope. That's the only way you can experience the amazement of the Autscope entertainment evening!

Closing:

Laurine: So that's it for another episode, and I hope you've enjoyed our thoughts about identity.

Cisco is still working on the episode about autistic professionals working in the field of autism, and we've also recorded another interview special with Jon Adams who is an autistic artist. So expect one or other one of these next.

As always we'd really love to hear your feedback, and you can contact us via social media where we are flappyhourcast, all one word, on Twitter, Facebook and Tumblr. You can also e-mail us at flappyhourcast at gmail dot com, or visit our website for show notes, and more information at flappyhourcast.wordpress.com.

Keep sending us feedback, and also rate us and view us on iTunes, because that apparently helps other people find us - and keep listening!

So, until next time, I've been Laurine at Autscape.

John-James: I've been John-James at Autscape.

Megan: I've been Megan at Autscape.

Nat: And I've been Nat at Autscape. Thanks for listening! Have fun, and be flappy!

Laurine: I like it when you do that bit.

[laughs]

Note:

This transcript was put together by [Fergus](#) and Maxens. Thanks for your hard work! Laurine did one round of proofreading, and Jay Avery did a second round.