

## **Poor Lass x The Civic**

### **No Boundaries - Episode 2: Sarah**

This is a super special episode in partnership with Barnsley Civic as part of their No Boundaries season. No Boundaries is a season of exhibitions, performances, community projects and workshops amplifying the voices and creativity of disabled artists as well as other communities under-represented in the arts and exploring the barriers that those communities face in society.

For this episode, we're exploring the intersections between class and disability and have invited special guest Sarah along. Sarah talks about what it's like to be autistic and looks back on her childhood, discusses the fact women are under-diagnosed, what it's actually like to get diagnosed, how becoming a parent shifted things for how she was able to cope and where she's at now. As ever, we finish on what people can do to be kinder and how the world can be more accommodating to those with autism

The following conversation took place in September 2021. This transcript is a has been slightly edited.

**EM**

Hi ya! Welcome back to Poor Lass. This podcast episode is recorded in partnership with The Civic, Barnsley, an Art Centre in South Yorkshire. It has been programmed as part of their No Boundaries season, which is running until spring 2022. No Boundaries is a season of exhibitions, performances, community projects and workshops, amplifying the voices and creativity of disabled artists as well as other communities underrepresented in the arts. It also explores the barriers that those communities face in society. You can find out more about The Civic and their No Boundaries program at [barnsleycivic.co.uk](http://barnsleycivic.co.uk). This episode will explore the experiences and the intersections of being working class and having a disability

**SELEENA**

Welcome to Poor Lass. A podcast about the real-life experiences...

**EM**

...from the mouths of legit working-class people.

**SELEENA**

Hi ya. I'm Seleena.

**EM**

And I'm Em.

**SELEENA**

Just a couple of poor lasses making a podcast.

**EM**

How are you doing?

**SELEENA**

I'm all right. A bit tired - as you know, that's my general state of being. How are you?

**EM**

Perma tired, you know. I'm obviously buzzing about this episode but at the same time, I'm halfway through the final episode of Manhunt, staring the man, the legend that is Martin Clunes and they've just got the guy and I'm like, oh my god, what happens now? So that's where my head's at. But let's get down to it. Have you had your tea yet or are you having it after this?

**SELEENA**

I'm going to have me tea after and watch Strictly. I had some chips at like 12 though. I know, I've made an error and I think.

**EM**

It's gonna be a struggle. Let's hope you don't get too hangry three quarters the way through this.

**SELEENA**

Yeah, I'm gonna be chucking my mic on the floor and storming out. I can't take these conditions. You've had yours. You're sensible.

**EM**

Of course. I always have early teas. I decided to do a Sunday dinner for Saturday night tea because I'm a rebel.

**SELEENA**

You know, I almost did that.

**EM**

Imagine!

**SELEENA**

I've roasted some potatoes.

**EM**

You can't beat moving when a traditional dinner should be, to rogue times. It's like when you have breakfast at tea.

And so, those who have listened to the first episode of this No Boundaries miniseries, will know we will have a special guest joining us. I always want to be like *special guest reveal yourself*, like a proper ITV gameshow.

**SELEENA**

Come through the curtain.

**EM**

To be fair, it is Saturday night, so it is quite the night for a game show vibe. So, let's welcome our guest for today. Hi Sarah, step from the darkness, into the light.

**SARAH**

Hello. I would quite like a Stars in Their Eyes type reveal. Maybe have some dry ice.

**EM**

Sarah, what have you had for your tea?

**SARAH**

I have had a spicy chili tomato pasta with two types of cheese. It was a BBC Good Food recipe because I never know what to make and so I just went on BBC Good Food and just looked at every single menu I could find on there. I was like, yes, I can make this so that's what we had.

**EM**

What were these two cheeses?

**SARAH**

Mozzarella and cheddar

**EM**

Ooh, the best two. Honestly, those two together is never a bad move.

Okay, what's your name? Where'd you come from and all that?

**SARAH**

I'm Sarah and I'm originally from Doncaster. I now live in Sheffield, which I much prefer. I moved here at the end of uni, and just stayed basically and it became home. I think it had this dream that I would move to Sheffield and just live in a Pulp video. And I think I did for a few years. But now I don't live in a Pulp video anymore.

**EM**

Well, I would say that your outfits could definitely still be in the Disco 2000 video for sure.

**SARAH**

Yeah, I think I still dress like it. And I live in a terraced house, there is wood chip in our spare room that's never getting pulled off. No one wants to deal with that in their DIY life, so we've just piled all our record racks in there and pretended it doesn't exist.

**EM**

You're joining us today as part of No Boundaries. Do you want to explain to us about yourself, Sarah? What brings you here today?

**SARAH**

So, I'm going to be talking about my late-in-life diagnosis of Autism, which was diagnosed in 2019. I'm quite proud of myself self-advocating my way through the entire process.

**EM**

Let's start with, what does it mean to you, to use the word Autism, or Autistic? For instance, how do you describe yourself? Do you use those words? Obviously, there are lots of different ways to talk about this stuff and everybody has their own way of identifying with certain phrases – how do you feel about those phrases? And also, while we are here, how do you feel about the word disability? Do you consider yourself disabled? Do you feel okay using that phrase?

**SARAH**

I personally prefer *Autistic* and I refer to myself as an autistic person. I use *Autism* when I am talking about it in terms of... talking about it on the whole. But it's not just one thing, obviously everybody that is autistic is different. Sometimes you use words so that the people you're talking to, can appreciate it on a level that they understand because they've probably not going down the wormholes that you have while researching it.

If you talk to them on a less personal level, you sort of separate yourself from it so that you can have discussions with people without putting yourself out there and feeling responsible. But I do prefer Autistic.

**EM**

How do you introduce yourself?

**SARAH**

It's hard. I feel like I'm in some sort of secret club where there's only certain people that I outright talk to about it, which then I guess leads me to that point about the word disability, because it is a disability. It affects you every single day, in so many instances. There's such a stigma around it. You don't look disabled, therefore people just think you're not. You don't want to use things that might help you, like I use the sunflower lanyard in particularly stressful situations. Or, if I need to use an accessible toilet because I don't fancy going in a big toilet with 30 people, all shouting and using hand dryers and banging doors and stuff. But I do feel when I come out of the accessible loo, people are really like 'really?' and you just want to say 'I am' but you can't just tell strangers. And you shouldn't have to.

**EM**

I guess on that one then, do you kind of have the feeling that of imposter syndrome, especially when a disability is invisible. How do you feel about that?

**SARAH**

With an invisible disability, you do play around with the idea of, am I severe enough? How do I exist with these difficulties that nobody else can see, but want people to understand that they exist? How do those people that might just need a bit of kindness or buffering around them get the help? But you can't outright reach out and ask people for help because you feel like they might not believe you, even though you know it of yourself.

I was brought up thinking that there's always someone who's got it worse, and you know, I think that's designed to just shut everybody up, isn't it? There is always someone who's got it worse, so it just makes you go, *oh well, things aren't so bad. I'll just get on with what I'm doing.* But I think it's a really dangerous thing to fall into. Just because someone's got it worse or different, doesn't mean what you're experiencing isn't hard or difficult for yourself.

**EM**

Definitely. If we go into the murky waters of class, you said you were brought up with this idea of, there's people out there that have got it worse. Absolutely. One of those put up and shup up working-class things.

**SARAH**

Yeah, you've not got it that bad, but you know, it's still really hard. Or my mum's favourite saying when I was little – 'I'll give you something you cry about'.

I used to think I have to cry more than I am. I think that was just one of those working-class mumisms. It's a big deciding factor in learning not to speak up, because you think you're not allowed.

**SELEENA**

I never thought about it in the sense of, it's to shut you up. I guess, I don't have to worry about it if someone's worse off than us. Let's just deal with it.

**SARAH**

So then you grow up thinking I shouldn't talk about it. I shouldn't complain about these things and just get on with it. And you know, I'll do my 50 hour a week job that's really hard and make me feel like I'm just going to break down constantly, but you've got a job, so thank you.

**SELEENA**

You shouldn't have to prove it either.

**SARAH**

Yeah, that's it. You feel like you're having to justify why you feel bad without allowing yourself to just feel bad because you are actually allowed to not feel great about things sometimes.

**SELEENA**

And with a hidden disability, you shouldn't have to be walking around telling everybody – am I allowed to use the accessible toilet and I'm going to prove to you why.

**SARAH**

Yeah, here's my letter of diagnosis, as it's the only evidence I actually have.

**SELEENA**

Laminate it and carry it around with you to show you every time you scowl at me.

**EM**

Grim. So Sarah, in terms of how we've covered the use of the term Autism and Autistic, what does it mean to you. Obviously, everybody can Google is right, and look at Instagram memes and figure it out for themselves as to what Autism mean but what does it mean for you? What is your experience?

**SARAH**

The experience of realizing that I could possibly be autistic came about when I started finding things much harder than my peers, and I was wondering why. I was diagnosed with severe depression and anxiety in my late teens, but there was absolutely no low mood, I felt pretty good. I felt like I couldn't function on a day-to-day basis, when everybody else seemed to be doing fine. I was thinking, why am I not able to do it? It was only through a friend of a friend who was also diagnosed later in life, who is quite good at advocacy work – she would send interesting articles on social media and I'd have a read. And slowly I was thinking, this all applies to me, but surely it isn't me. Like I've said before, you think it's not visible, so can it be true? And bit by bit, I'd start to piece it together. I had not spoken to anybody about it, it was just in my head, spinning round and round and thinking, why am I finding basic things more difficult now.

After I had a baby, everybody else seemed to have just had babies and still had their life together in one piece and doing things. Whereas in order to focus my attention on my baby, I had to remove my attention from any other thing that could possibly derail my focus. It was really hard getting out to exercise or staying in touch with friends, or thinking what to cook for my tea. It was like everything was just really, really hard. And eventually, I messaged this friend of a friend and just said, I don't want to be offensive by saying this, but I really think there is a chance I am Autistic, and have you got any articles that you could forward me. And the best thing she ever said was, 'I always thought you were'. It was really validating that another person that has seemingly gone through similar steps to me say that. I just felt this sort of kinship. It was just quite a relief to sort of hear another actually autistic person say, yes, I've always related to you on those similar tangents of our lives. She did give me lots of articles to read, particularly ones focusing on the female or atypical presentation, and particularly those who have gone onto later life before being shaken off their tracks.

I was just constantly exhausted, and worried about the smallest things and it was nice to be able to channel that energy of fear and feeling stressed out all the time and the more you research it, the more you sort of go, yeah, my history with anxiety and depression and eating disorders, things like that they all tie together. Without that, I felt like I was spinning loose and I didn't know what was gonna happen. With this it gave me a sort of rational feeling that allowed me to go, okay, this is why things feel hard, but now what can I do to make myself feel better? And I'm finding ways now to do things that I probably would have never, never dared do before, like stimming. Or like forcefully taking time out of difficult situations to say, I'm done with this, I need to just go off for half an hour on my own, and not feeling guilty. Whereas before you just keep going and going, because you didn't say I can't do this anymore.

## **EM**

You touched on the fact that autism in women is underdiagnosed. It's a contentious thing, right? I was reading something - a study being done in Leeds about a month ago - trying to disprove that women can actually be autistic

## **SARAH**

Yes, it feels like there is this community of autistic people, and then there's subsections within it and some of them crossover. Some of them have just got the worst deal because some say women can't be autistic because of the classic male brain approach to it [diagnostic criteria], and I think that's why the younger generation of girls are still at risk of not being diagnosed, because they're still using criteria that doesn't encapsulate a lot of what is atypical female presentation and masking and actually wanting to be social; wanting to have friends. But sometimes my brain just tells me *No, you can't do that*, so you don't do it or you shy away from things. But you do still want to sort of have

meaningful friendships and relationships, but you just do it differently and the people that get you still allow you to be within a friendship circle, and just accept that you are Autistic.

Sometimes you might just remove yourself from the group chat, because you can't deal with all the notifications. But it's not like you don't ever want to talk to them again or you've fallen out, it's just you being able to finally set boundaries and say, I can't do this anymore. But they say that because you are able to be social, that you are not able to also be an autistic person

## **EM**

It must drive you mad hearing stuff like that in big 2021; still seeing these comments is just totally ridiculous. I think whatever this new study is, I read the first paragraph and then I was like, I'm not gonna carry on reading this, because they're just total hacks.

Where did all this sort of start for you then? Obviously, you've said it was later in life, in terms of diagnosis, and then becoming a parent. I know it's a bit of an ignorant question to ask, but knowing what you know now, are there any things that you did as a kid, in school for example, or relationships with your parents or friends as a young person - is there anything now that you look back and see and think, okay, that makes more sense now?

## **SARAH**

Loads of it. Right down to memories from a very, very young age. When I did all of my assessments, the occupational therapist said my memory is just so intense. She said I remember stuff in a sensory manner. So, if I've got a memory, I can smell it and feel it and taste it, and see how the light is in that memory. It can also be hard because you actually feel like you're immersed back in that memory. She said that's connected to any traumatic incidences in particular. She said it plays a big factor in my mental health, going right back to childhood. She talked about how I used to use sleep as a coping mechanism.

So if we went to a noisy family party, I wouldn't be the typical Autistic child putting their hands over their ears and you know, getting stressed out. I'd get a pile of coats and make a nest and I'd sleep through the entire party. I remember waking up and my granddad having a stripper-gram, which is just a classic Doncaster 1970s pub party. I just slept through it with my Roger Rabbit teddy, oblivious. I don't know how long we were there, and in the end, my Dad just sort of pulled these coats off and scooped me up and took me home. Even now, my family joke about my ability to just sleep at the drop of a hat. And it has always been a coping mechanism and I can remember it right through from toddlerhood and into my teen years. You know, everyone else was open about doing stuff and socializing, while I was reading through my mom's Danielle Steel collection at the speed no one knows, and then just napping.

I probably only attended about 20% of lectures and seminars across the whole three years of uni because I just couldn't attend, but never knew why I couldn't attend. Obviously, I do now. I'd just stay home and sleep because it just felt like a really good way to just pass time because I didn't really know what else to do.

There are loads of instances at school. I managed to remain in the circle of the popular girls but I was not popular. I think people knew I was odd, but I think I managed to pull it off by masking enough of what they were doing and just be a bit different and quirky and silly. I fitted in with the boys a lot because, I was a class clown. I think I managed to avoid being singled out, but they also knew I was not quite one of them.

I think as soon as GCSEs we're done, I just stopped talking to all of them. It was like, the contract was terminated. We don't need to speak again after this. I think it felt really hard at the time, trying to keep up with everybody. I wasn't fashionable, but I dressed like you said, I was in a Pulp video. I think I always have dressed a little bit like a music video, and I probably transgressed from Spice Girls to Pulp somehow along the way. I think I just did enough, that people just accepted that it was me. But I was never fully embraced by anyone in school. I don't think I had like singular friends that I'd get attached to. We'd sort of go together for a year, and then the friendship would just end and I never really knew why.

I still don't – I just sort of float about till somebody else says, pick me up and hang out with me. It's one of those things, I kind of look back and go yeah, that makes sense now. I now know that I just didn't understand all of the social rules and the passing trends and fashions to get involved with. But I could watch it and copy enough of it to sort of fit in. By sixth form, I did the opposite and flipped and just said, I'm going to be the opposite of all the popular people and now I'm going to be the weird kid. So that's what I did. I made a new identity. That makes sense?

**EM**

Yeah, definitely. Now I know you IRL and Seleena, I don't know if you guys are connected on social media or anything, but the way Sarah dresses is amazing. I always thought you looked cool. Always really colourful. Were you working in Freshman's or somewhere like that?

**SARAH**

Yeah. You worked in The Forum [Sheffield] and I worked on the edge of The Forum in Freshman's [vintage clothes shop].

**EM**

Whenever I saw you, you would look like you just existed in a different decade or so.

**SARAH**

That's why I always felt like I didn't really know how to be like everybody else. I eventually just found the things I liked, which again, linking it into Autism, I now realise that these things are Special Interests, Focused Interests, or whatever people want to call them. So I was obsessed with Pulp. I decided I wanted to dress like I was in a Pulp video. Once Exposed Magazine in Sheffield took a photograph of me in the street – *one of those what are people wearing today* things. My friend still laughs about it now. Weirdly enough, she was also diagnosed Autistic in adulthood, just not long after me. We'd been friends prior to this, and we sort of existed in this little bubble where we were weird with each other, like we were destined to be together. She laughs about it now because everyone else was dead cool and I was wearing a blue pinafore with pink tights and purple leg warmers and little silver high heels.

They [Exposed Magazine] said, what's your fashion inspiration. I was like, My Little Pony. It still collect them. I still clean them up and do their hair. And just looking at the colours makes my eyeballs feel really happy. So, I'd just pick clothes that look like My Little Ponies, and still do. That's something I sort of normalized or made it look less intense than it probably was. But the fact that I'm a 39-year-old woman that loves My Little Pony and has tubs of them lying around the house. It's just something I do.

But a lot of people my age probably don't do things like that and probably think why is she doing that? Like, does she make money from it? No, it has no financial gain. It's just something I enjoy

doing. I think that's another thing that people think - that everything you do has got to be making you money somehow.

I think that was a big step after my diagnosis, asking what are the things that I can do to make myself feel better and a lot of them didn't revolve around making money. I've never had an interest in having a career. That was always something that I thought - everybody going into uni and coming out saying they're gonna do this, or they're gonna do that. And I was just kind of like, well, I went to university because I was doing well at A-Levels and the head of Sixth Form forced me to apply. I didn't really know what I was doing. I just got railroaded into a lot of things. I think growing up, I looked around and just copied what everybody else was doing, or did what somebody in authority told me to do. I've never utilized my degree. I went through clearing in the end, because I just panicked and cancelled all my offers. I didn't know what else to do.

When I look back, all these are things and because of your autistic thought patterns and you didn't quite understand what was going on around you. You just picked the person that looked like they were coping the best and tried to copy what they would do.

**EM**

In terms of class, do you feel that there's any kind of correlation with neurodiversity and the ability to study or start a career? Do you feel that being an autistic person may actually hinder you in being able to make money? Or if we talk about class, specifically this idea of transcending class, or having more money, do you see it being a thing that may actually prevent people from kind of getting out of poverty?

**SARAH**

Some people can utilise their special interests and find a great way of living and supporting themselves by doing something that's not draining their social battery. They can find ways to incorporate their interests and navigate a way through it. But if you're starting off with not much money, it's hard to start up something like that. You probably take a pay cut from what you could be doing, getting paid by somebody else instead of paying yourself.

Let's say, if you wanted to go self-employed, that's probably one of the best routes that you could go down in terms of limiting people pressuring you, intentionally or unintentionally. You're in control of your own time and then you work quite hard. But again, it's very hard to make the megabucks. I think a lot of Autistic people that I've spoken to, since being diagnosed, and while I was waiting to be, we're all just happy making enough to survive, because if you push yourself further, you just hit that barrier, where you burn-out, you just go, I can't do this anymore. You've got a further drop to fall, because you've created this bigger step for yourself.

I was the first family member to go to university. But because I just did what everyone in my year group was doing and didn't really have a concept of what you're meant to do at university and where it's meant to take you, what job I should have got as a result, and because I didn't know how to transfer the skills that I supposedly had, or how to apply for a job – I just don't understand how you do that. I only ever really worked in retail jobs, because that was the safest thing I could do by just getting immersed in the actual job and doing it.

**EM**

So Seleena, you will love to hear that Sarah is also a retail friend. Yes?

**SELEENA**

The more I hear about you Sarah, the more I'm like, how have we not met?

I did have a question. It's kind of similar to what Em's just asked, relating to class. Obviously we were talking about that study where they were saying women can't be autistic, and we know it's a lot harder for women to get diagnosed. But do you think that because women can mask well, and you were saying you were just mimicking people because you didn't know how to get along, do you think being told to put up and shut up played a part in kind of like bumbling along?

#### **SARAH**

Yeah, it's a case of know your place and stay in line, just keep going. And that's what it felt like, just treading water, just to keep going. And then that's what working was like. I was going to work and just begging to get to the end of the day without a mystery shopper, without an audit coming, you know, all these horrible things that just put pressure on everybody. And then being undiagnosed Autistic and thinking, how can I survive this? Basically, I was just fraught with stress, but brought up to just not talk about it.

You know, other people have got it worse. I think that sort of upbringing probably did affect why I lived with diagnosed mental illnesses, why I was mentally ill with depression and anxiety. It wasn't a misdiagnosis – just wasn't a complete diagnosis. But that was what was expected of me, rather than, hang on, let's have a look into this a little bit. Maybe she's Autistic? I think the more people that start to get diagnosed in later, that should affect diagnosis and assessment processes for the younger generation, so they're not getting missed. But they're still saying, oh, women aren't autistic, or if you play with your children, they won't become Autistic. It's like, you don't become Autistic – they are Autistic because it's a neurotype. Different behaviours can delay the point at which you get diagnosed, so me being told to just get on with my life and stop complaining is what led me to being a grown up that didn't get diagnosed until later on; until something shook their life up to the point that they couldn't coast by, which is pretty much what I was doing.

So I just do the bare minimum that I have to do without making stuff too hard for myself. Then having a baby, it was like, I can't coast anymore. I've actually got to try and do a good job. I can't just pretend that I know what I'm doing. That has been something that a lot of people have said is a familiar concept – that the actual obviousness of their Autism doesn't show until some sort of trigger in their life happens. You get flipped over and you go, oh I can't go on anymore because it's inauthentic, because you've constructed a way of living that's not natural or sustainable. Then eventually, you have to kind of deal with everything now, or just basically burn out basically. That was pre diagnosis, because I just couldn't keep turning up to work in a cafe and getting shouted out and things like that. Another key part of my experience of autism is I've got a strong sense of justice. And I don't understand people being mean to each other for no reason. So, if you're a retail person, you know that people can just come in and just be mean to you for no reason. And it can completely throw you off your tracks for the day, the week. One bad event at work can just undo all the good that you've felt for weeks. It was really hard, turning up and doing that every day and then trying to come home and be a good mom; which is the person I wanted to be but was struggling because all these other influences in my life were just completely burning me out.

#### **EM**

Right at the beginning, you said you were proud for advocating for yourself in terms of getting a diagnosis. What happened there? What were the steps that you took to get that diagnosis? What did it look like for you? Obviously, as you said, there weren't people going *let's just have a little check*

on Sarah. It was like, *No, I'm gonna do this myself*. So, I'm keen to hear a bit more about what you had to do and what it looked like?

## **SARAH**

So the friend that I messaged, that kickstarted it all by showing me some concrete information about Autism when I asked for help – In read it all and saw that it applied to me.

I basically made a list of the DSM-5 criteria, and how specific examples of how my life applied to each thing. I didn't tell my husband, because you do just think, someone's going to say, why are you doing this? But it's hard to try to explain to somebody else that you just want to feel better.

So, I thought I'd do the appointment first, and I thought if that person of authority doesn't laugh at me, then I can tell my husband and tell him that the process has started. So I went to the appointment and cried the entire list out at him. I sweated and was really uncomfortable. He said, 'yes, that does all indicate to you being Autistic. Fill in this AQ10 questionnaire and come back in two weeks'.

I think they thought I'd go home and change my mind, but I filled it in and went back. He then filled it all in on his computer and he said 'yes, this does indicate that you're on the spectrum. I'll forward you onto the adult Autism service here'.

That's when I told my husband. By text. Because even though I've been with him years, I still find it hard to initiate a verbal conversation with anybody that might make me feel uncomfortable. I text him from work and said I'm doing this. He said, that makes sense. I instantly had his support and was able to talk about how things fitted and how they affected me.

I had problems with crossing the road. I never had it until I had a baby. Because I was now responsible for this small person, I felt that everything was a threat, including crossing the road. And so I can't cross the road unless I find a pedestrian crossing. I can't see clearly, and I panic. My husband would get really annoyed with me, but when I explained that Autism causes this high sensory, high alert vigilance, he was like, this all makes sense now. It was hard to explain this to him, without the doctor giving me the greenlight that I might be Autistic. That was imposter syndrome. I didn't want to say this is why I struggle to cross the road, in case someone laughed at me.

I was working part-time in a café and I was gradually getting more and more burned out, being in charge of a group of people that I didn't want to be in charge of. I only wanted to be in charge of my child and my family. I didn't want to go into work, count money and use safes and those scary things. It was too much pressure. I just cracked one day. My boss asked if I was okay. I hid in a fridge. There's nowhere for me to hide apart from this fridge. My boss was great. She offered to cut my shifts down to one a week until I was feeling better. She tried to make my time at work easier and keep me in a job.

My husband has his own business. He said, 'just quit and come and work for me. We can then organise what works for you as a workload'. While I was awaiting my diagnosis, which is a long time, they sent me a letter saying *you're on a list*, which was exciting, because the waiting lists are so long.

I started working with my husband and it was a weight lifted. No stranger danger. Having a laugh with friends is one thing, but you don't always feel 100% safe with them. It made my ability to selfcare increase because I wasn't stretching myself too far. After about 18 months, to two years, I got my appointment. I saw an assistant psychologist on my first appointment. We spoke for two hours, about my entire childhood up to my recent employment. I cried a lot. It was like going to

therapy but being told you'd only got one appointment and you had to get everything out in one go. So I did that appointment and dropped it all out. She basically totted up everything that she thought applied [to the diagnostic criteria] and they gave me a score, and they yes, you've scored high enough to move to the next level.

On the morning of the second appointment, I got a voicemail – and I don't do well with voicemails – and all it said was 'we've got to cancel your appointment today, we'll be in touch'. Queue big meltdown. It was just too much unknown, and change to my routine. I had so much pinned on that meeting, finding out a bit more of myself and using that to me feel better and making my life a bit easier and manageable.

I rang them up. I don't really express emotions to strangers, but I did this time. I just howled down the phone and this poor woman. I said 'how can you just cancel four hours before with an Autistic person? We don't deal with change. And now my whole week is broken'.

She was really kind. They rang me back that afternoon and said they'd got me an appointment in two days. That was with the Occupational Therapist. She compiled all of the information from the first appointment with the psychologist, and then she did an interview based upon what your life is like now – your sensory processing areas. She adds it all up and delivers the diagnosis in the appointment, which is nice. It wasn't as hard as talking about your childhood for two hours, but it was still hard work. This is the woman who then untangles it. She said, 'yes you are Autistic'. She said that under the old criteria, I would have been diagnosed with Asperger's, but they don't use that anymore, and I'm glad, as there's all sorts of connotations, and it's [not very nice](#). I prefer that it is just Autistic, but they do write on your forms things like High Functioning, which is only really about how the world see's you and not how you see yourself.

I don't really like functioning labels, as it doesn't really describe how you see yourself, it's about how you fit into their society. Functioning levels can change throughout, as certain stresses can stop you doing certain things, and so you have to remove them.

After she delivers the diagnosis, you have a half hour chat afterwards where she asks how you feel about your diagnosis and a bit of a wrap up on her findings. If you remember how I said earlier, my memories have a sensory aspect to them. It's like I don't just remember that day as nice. My whole body remembers it, to remember it, feels physical and exhausting.

When I came out of that appointment, I felt like I'd ran a marathon. I felt so hungry. I couldn't think about what I needed to do next. I just walked to town, text my husband and told him. I just bought a bag of nuts and some fizzy pop, trying to put some energy back in my body. It was so hard, talking to a stranger for two hours. But they said some people have different reactions. Some people feel grief. I never got any sad feelings. I was buzzing. It was a like a full stop to all of that not knowing. And now I can learn a way to make everything feel better and now I can be a stronger version of myself for my family. Now I can commit to the strategies. It was nice to get that validation.

#### **SELEENA**

You've kind of answered my next question about how did it feel, getting your diagnosis, but you've said, it made you feel validated?

#### **SARAH**

Yeah, for me, part of my Autism is a rule driven way of thinking, and even though I know self-diagnosis is valid and I know self-diagnosed people that haven't chased diagnosis for reasons that

suit their families, but for me I felt like I needed that little tick for me to go on. I needed that to make piece with myself. It would have taken a lot longer for me to make things comfortable for myself, without that stamp of officiality from a doctor. I didn't want people to think I was making it up. And maybe this is a class thing, but people thinking, you're a girl, you're a drama queen. The whole shutting up and getting on with your life.

It'll be two years in December. Life is much better now because I can say straight away that I have isolated a problem and I can work straight away to make it better.

### **SELEENA**

What would you suggest that people - work, friends - do, who want to make the world more inclusive? What adjustments have you found that work? Things to do and not do?

### **SARAH**

One of my things is, if you can't see it, it doesn't mean it's not there.

In my late teens, early 20s, I drank a lot and partied a lot. And I think that was a way of making my problems more visible for people. A lot of people in the Autistic community, say their younger days were party days and now I'm older, I understand myself more and don't do that. It's way of making yourself more visible to your friendship groups and highlighting when you're more sensitive to stuff.

Now, because you can't see my struggling, it doesn't mean I'm not. Friends check up on me and it means that I don't have to go out for meals or parties. And they understand why I'm not doing it, and not questioning and not judging. You don't want to do it because it's rubbish. I don't want to do it because it's stressful as an Autistic person.

For example, this week, me and my husband went to see Nick Cave at Sheffield City Hall and it was the first time I've been outside of my house after 5pm for two years. Obviously, my husband has the inside knowledge of how to look after me. He did everything he could. He got me and aisle seat, so that I didn't have to lap dance thirty strangers if I wanted to get out. I have to weigh up the worst possible scenario and put my adjustments in place. It's the same at the cinema. We'll make sure we're sat near the stairs and toilets and plan routes in advance, so that I'm not panicked.

Things like that make the world a better place. Just because I don't look disabled, it doesn't mean I automatically know how to do things. I'll go hungry instead of going in a café because that social interaction with the person at the counter, is too much unknown for me to deal with. I'd rather not eat for three hours and I'll wait til I get home, rather than deal with small talk with a stranger. I try and avoid things like that. Everybody should just be kinder and not judge them if they use an accessible toilet. Or judging people if they use a plastic straw instead of a paper one, even though it's bad for the environment because for some people, from a sensory perspective, they have to. They can't bear the feeling of the glass on their teeth.

### **EM**

Those people are the worst. Full stop. People just need to mind their own business.

### **SARAH**

I need to conserve my energy for the stuff that really counts.

### **EM**

It's been so interesting Sarah. Thank you for sharing your story. There's a lot to be said about people's intent, when they feel the need to call people out for something in public.

It's so much more about them and their wanting to be morally superior and just basically being a total meanie, rather than being about anyone else. People need to mind their own business.

Thank you for coming onto the show and baring your soul on a Saturday night.

**SELEENA**

Thank you

**SARAH**

I hope I haven't rambled too much. I do go off on a tangent.

**EM**

Mate, you've been brill.

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