

## **Poor Lass x The Civic**

### **No Boundaries - Episode 1: Rachel**

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 the very excellent Rachel along. Rachel shares her experience of hearing loss and discusses what diagnosis looks like, disclosure and agency, being able to share her needs, societal and internalized shame, the politics behind identifying with the word Deaf and also disabled, barriers to work and communication, how covid-19 impacted on the Deaf and hard of hearing community and how we can all help to make their lives easier.

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

#### **Em Ledger**

Hello and welcome back to Poor Lass. This podcast episode is recorded in partnership with The Civic Barnsley, an Arts Center 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. Art and activism by disabled people has historically been the reason access rights and awareness has been improved. 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 Laverne Daye**

Welcome to Poor Lass, a podcast about real life experiences...

**Em**

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

**Seleena**

Hiya!

**Em**

Ayup!

**Seleena**

I'm Selena.

**Em**

And I'm Em.

**Seleena**

We're just a couple of poor lasses...

**Em**

...doing a podcast.

**Seleena**

Ay up!

**Em**

So let's get to the important question. Selena, what have you had for your tea?

**Seleena**

I've not had it yet. I'm having chippy obviously, because it's a Friday evening. What have you had for tea?

**Em**

I med this new... well, it's like gnocci with broccoli and peas and cheese in a pile and I just put it in the oven. It was very good to be honest. Just like mix it all together, put cheese on it, and then just put it in the oven. A pile of cheese!

But yeah, anyway... we've got a special guest today and she a'nt said owt yet, she been sat very quiet in the background. But we're going to invite her to the foreground - firstly by saying Hi Rachel. But also tell us about yourself and most importantly, what have you had for your tea?

**Rachel**

Hi, I was struggling to stay quiet then because I can't believe what you just had for your dinner and actually, we used to live together a long long time ago right and it's a sea change, yeah?

**Em**

It's not Super Noodles.

**Rachel**

Yeah, I've not had my tea yet. I'm gonna have a pizza later on. Maybe a glass of wine to celebrate, having made it through the podcast.

So yeah, I'm Rachel. It's like age sex location, like MSNs.

I'm Rachel, 39, Bradford, Saltaire, and I just qualified as a counsellor, psychotherapist. I was born in Rotherham. Then I lived in Huddersfield for a long time and then just kind of moved about a lot until settling back in in BFD [Bradford]. And yeah, anything else? I guess that part of the reason I'm here is to talk a little bit about like my experience with hearing loss. I was diagnosed when I was 30 to 33, so

it's not been long now since it's settled into my kind of normal. So, I'm going to chat with you about that.

**Em**

So, I guess Rachel, the first thing that I want to ask you is about use of words. Obviously, you used the phrase hearing loss there, and there's lots of different phrases that people use, I wanted to ask you what phrases do you prefer to use? So example like, 'hard of hearing', 'deaf', 'hearing loss' etc. But also, how would you feel about the term disability as well?

**Rachel**

These are quite interesting questions, because I used to use hearing impaired as my kind of description, but that's not like very PC at all. People in the hearing loss community don't like it because it's stigmatized, and it sounds like something is wrong with you. A lot of people use hard of hearing. I think this is very personal to me. There's also a bit of ageism coming into it. Something about it just makes me think of my Gran. I say I have hearing loss and sometimes I say hard of hearing.

And then there's a big thing about the Deaf identity. For people with hearing loss – it's like in the queer communities where like, nobody feels like they're queer enough to call themselves queer. It's like that for me. Am I deaf enough to call myself Deaf? I don't sign. I went to a mainstream school. And most of the time, when I'm wearing hearing aids and the conditions are right, a lot of people like wouldn't necessarily know that there was anything going on with me. So sometimes I feel like a bit of a fraud by saying I'm deaf. It's such a such a simple thing, like how you identify and describe yourself, but there's many layers to it.

I know that there are campaigns and Luke [Luke Christian] created his brand Deaf Identity. There are lots of different types of deaf people, it's a spectrum. You still get to call yourself Deaf and you don't have to prove it or have to be at a certain level to be able to use that term.

But I still sometimes feel a bit queasy using it. It represents a community that I'm not really part of. Does that make any sense?

**Seleena**

It's like you fear you're taking up space? It's like when you said in the Queer community, am I queer enough; am I taking up space that was meant for someone else? Is there someone that needs this space more than me? If that makes sense?

**Rachel**

It's like trying to be authentic as a person. It's like you don't fit into this narrow category of what I think a deaf person is.

It's interesting. How you describe disability is another one as well. I think maybe having an invisible disability kind of ties into that. It's not something someone would know by looking at me. It's a can of worms.

**Em**

That's the beauty of the podcast. We're just gonna be like, right Rachel, you're in the hot seat now. We've got you.

I guess then this should be a bit easier. What was your experience hearing loss in mainstream school? When did you start seeing the signs of this? What did that look like to you?

**Rachel**

I just stopped being able to hear people. I was misunderstanding people a lot and it just became more and more evident - like asking people to repeat themselves. It just starting to have an impact on relationships.

In term of Poor Lass and class, in my family there is a lot of genetic hearing loss. My granddad, my uncle, my dad, and some other family members down my maternal line. It's strong - they all had hearing loss, but it was kind of disguised because they worked in industry, in factories. My dad worked in steel works, and they all just assumed it was industrial hearing loss, so I didn't get that kind of heads up that I might get it too. So there's a family connection and but I wasn't expecting it, is basically what I'm saying.

**Seleena**

Yeah, I guess all your family's hearing loss was explained away because of where they worked. And you weren't working somewhere where you would get industrial hearing loss, yeah?

**Rachel**

I remember my Great Uncle Jim. He was an accountant, and he wore an hearing aid.

But I've done it to myself a bit. I just kind of assumed it was from going to gigs, listening to my Walkman really loudly. And so in some way, I felt a sense of shame around it, because I left like I had caused this myself and it stopped me going to the doctors for a long time. I delayed going to see anybody about my hearing for ages, which I think is very common. I think I read that it's something like seven years that some wait, between developing hearing loss symptoms and going to get a hearing test. I think seven years is an average. That's wild

**Em**

That's a crazy amount of time. I guess, to go back to the class thing as well, and the industrial circumstances in your working class family, do you think being working class also means that you maybe don't seek help as soon as other people would?

**Rachel**

I think there is a definite thing about it. Before I left my previous job, I saved up and spent quite a bit of money on my hearing aids. And I know that was something that raised eyebrows in my family, because the ones on the NHS we were fine and free. That was something that I definitely noticed.. It's like an experience that maybe I wouldn't have had if... you know wasting all your money, it's considered a bit of an indulgence.

**Em**

That's mad, calling a hearing aid an indulgence.

**Seleena**

You think other families would have just been like, oh you're getting hearing aids right? Well we're gonna to seek this out and then we're going to pay for the best. But this is free. Why would you spend money on it?

**Rachel**

I was about to retrain in a career while the number one job specification was listening. You know, if I'd not been going into that career, then maybe I wouldn't have done that.

But yeah, I don't know about help seeking generally, I think there's definitely something about the relationship with the consultants. It was quite interesting to talk to them. I've had a range of different consultants and different experiences. Unfortunately, the first one that I had wasn't a great experience and he was quite like the cliched middle class white guy who was just so arrogant. And just not the experience that I really wanted at that point because I was in a really quite vulnerable place. I think he told me that I had collapsed ear drums, which to me sounded really severe and he was like, yeah, well I've seen three of those today already.

**Seleena**

Three? Sorry, I'm not a medical professional, but if someone said to me collapsed ear drums, I'm like, oh my, it's broken, it's all gone wrong yeah?

**Rachel**

Yes. Sounds like something that I should be panicking about. Like are you going to do anything about it? I actually asked him, is there going to be any treatment here? So that was just an experience where I didn't like the kind of power dynamic - somebody who has a lot of knowledge and a vocabulary that you don't understand, but you need their help, and so it kind of makes you feel quite small. Yeah. That

**Seleena**

And his job was to help you.

**Rachel**

I was quite excited about going to see him because the GP's are obviously great, but they're not specialists in hearing, and I really wanted an answer. At that point, I was like, what the heck is going on? And I was thinking great, I'm gonna go to the specialists and they're gonna give me all this information, and unfortunately it wasn't a great experience. So, that thing of dealing with consultants and medical professionals, it can be quite an intimidating thing, I guess.

**Em**

When you said about the vocabulary, I think it is a really intimidating thing when there's a vulnerability about going to someone for help. If they're using words and phrases I don't know, or even just their attitude, if you feel like they're being condescending, or looking down on you, then your walls do go up, don't they? It is pretty common I think, when you go into those types of arenas, whether it's jobs or healthcare, and someone speaks to you in a way that you're like, I don't know what you're talking about, and rather than say I don't know what you're talking about - which not everybody feels they can do that - you sometimes just end up going, alright, well, I'm just not coming back here again. And then it's at your detriment.

**Rachel**

I guess. Thankfully, my next consultant was just lovely. So they're not all bad.

It's like some people in different situations, they're really good at the job, the technical bit and they know a lot of stuff, but they don't have any people skills. And I feel from my perspective, there's such a big psychological impact. Somebody saying to you got hearing loss, it hits you on a profound level. You're going to have to wear hearing aids for the rest of the life. There's nothing you can do about it, see you later.

Psychologically, that was a massive thing for me to take in. For me, or anybody getting that kind of news about a disability diagnosis, health diagnosis, you know it's gonna throw you for six. And something that I feel really quite angry about, actually now. I do kind of wish that, they could have offered some sort of counselling or psychological support around disability diagnosis, because I think it threw me off for a long time.

Looking back, I kind of see it almost like going through a process of grief, and going through the different stages of grief. You know, a long time I was in denial. And then I was just really sad a lot because it felt like this loss, like I'd just lost this part of myself and I was never going to get it back. I think sometimes those experiences that overlap with other stuff you've got going on in your life at the same time. And then the next stage that I went into was thinking about assimilation. I thought, right, I've got to wear hearing aid. I was worried, but the doctor said hearing aids aren't what they were in the 80s and it did make me feel better. It was the right thing to say at that point, which was good.

I have memories of my Nan with this hearing aid which constantly fed back and whistled all the time. And she had a bit of a Catherine Tate vibe. She was a cockney and she'd be all 'that effing dog, shut that dog up, it's right in my hearing aid!' I was thinking, that's going to be me. I don't want to be like that. Just like, no!

But the technology has come on immensely. Another thing the doctor said was that as a young lady, you can hide them behind your ears and nobody would know, and that did make me feel better because at that point, I thinking I'm gonna get some really good hearing aids and some really good tech and no one's ever going to know that this is going on. That's my goal. Just be normal and don't tell anybody about it. Don't talk about it and kind of hide it.

With an invisible disability, that's very easy to do. The downside is that if you never tell anybody about what's going on, you can never ask for any accommodations and they don't have the opportunity to make stuff easy for you. You're going to miss out on lots of stuff, because you're hiding the fact that you need accommodations.

The assertiveness and the disclosure were big steps, and knowing that stuff's better when you talk about what you need and let people know how they can help you. But psychologically, me, I was kind of tired. Around the same time, I started my own long-term therapy. It wasn't specifically about hearing loss, but those kind of themes of like, you know you can show up in the world and ask people for what you need and be visible, and it's okay.

**Em**

It's interesting what you said about this idea of almost hiding away, hiding the hearing aids behind your hair and stuff like that. Do you think society and culture makes you feel like you have to hide a bit - if you have hearing aids? Did you feel that it was this thing that was bad? I mean, the reason I ask is that my dad had a similar thing where the doctors said to him that he should wear hearing aids, and he had an appointment booked. He said, 'I'm not wearing earplugs' and never went back. He can't hear a certain frequency, so when I talk to my dad, I have to do it in a really low voice. He

just simply can't hear it. But his reaction to it is like, you know, a working class bloke saying I'm not wearing an hearing aid. It just never went back. There's almost like a stigma in there and I think it links back to that vulnerability and asking for help too. Maybe it's like a working class pride thing. I don't know.

### **Rachel**

Yeah, we should get our dads together Em. He has hearing aids now and he does wear them, but I can see him masking. I know he can't often hear me. I'm tuned into what people can't hear and I'm like 'put them on Dad'.

I do have sympathy though, because it's not like glasses where you put them on and you can see. You have this stage where the brain has to do a lot of work, like recalibrating the noise level. So, when you first wear hearing aids, there is really a lot of like background noise, and you're like, if this is what it's like, I'm going to throw these in the bin!

Now I can't live without them. I don't get to work without them. So the question about hiding stuff... I think for me, with this particular disability, there was a thing about it being linked to age. And it being like an old person thing. I kind of felt embarrassed about it. That was really hard for me and I feel now I'm in a really different position.

### **Seleena**

At the time, were you working in the Arts? Did that play into it at all, or... ?

### **Rachel**

No. I think in some ways, actually having a place where I worked at, which was quite right on and they wanted to be inclusive, meant I wasn't going to work and worrying about them booting me out. My job is more about training as a therapist, so I read a lot about that and about disclosing around that. But actually, rightly or wrongly, it did feel like a bit of a more secure place. Actually, don't want to say it was this secure place to work, because I think actually sometimes people say one thing and do another. But at least if they ever did anything that wasn't cool, then I'd have proof. I felt like I was on sort of solid ground.

### **Em**

So I guess related to that, we were looking at stats and you know, around 65% of working age adults in the UK, who are deaf or hard of hearing are in jobs, which is not a lot. It's obviously an impact. I just wanted to ask you, when you were talking about disclosing, do you feel like there's a barrier to work? And if so, what did that look like to you? Disclosing is part of this, but generally speaking, when you have a job and being able to do the job right, what is the impact for you? What's your experience of that?

### **Rachel**

I'm not gonna lie. I think it's part of why I decided I wanted to go self-employed. I get to control how much I work and don't work, without dealing with anybody else's prejudice or anything like that. I think in terms of controlling the amount of client work that I do, and I get a lot out of it, because auditory fatigue is kind of a real thing, and I have to be a bit more mindful and make sure that I have breaks and I don't kind of over schedule on my working day. I don't have to explain that to anybody else. I can kind of control my own workload. Whereas I think in an organization they'd be more of a

push to a certain number of clients and all that kind of thing. I was really worried about it and I don't know how much of it was in my head and how much of it was like a genuine.

You know, you tick the Deaf or Hard of Hearing box and you never hear from people. You get literally sorry, and never hear from people again.

Part of the reason I went to the University and did my qualification was because they had a disability office and I went to meet them before I applied for the course. Psychologically, it felt like an important thing to me, just to feel like I could do this. And if I do this, someone's kind of got my back a bit. So, I went to see them, they helped me apply for DSA, which is disabled students allowance, and then I got that and I got my tech.

They had a little disability resource room. It was really quiet. When I didn't want to socialize with anybody - which is hard, because partly you just want to socialize, but are so tired from listening to people, my brain had to work a bit harder, because there are gaps in what I can hear - and when I needed a break, I'd just go and sit in the quiet room and stare at a wall and not having anybody go 'you wierdo!'

**Em**

I guess one of the other statistics as well is that 20% of people who are deaf or have hearing loss, live in poverty. So, I guess this kind of prompts the question about DSA. What does that access and support look like? When you said before about hearing aids and stuff, and getting the right tech, what does that look like in your experience? And are you aware of what it looks like outside of your experience as well? For example, does the NHS provide certain things? Do you know what that is? With quite a big chunk of people living in poverty, is there something there that you think is because of not having access to things that would make life a little bit more achievable, in a job space context? Or like you said, sometimes you don't want to ask, or you don't want to disclose and that could mean, you know, not applying for stuff or not feeling like you can belong in certain spaces. Or being limited by it.

**Rachel**

Yeah, I think that's a big thing and thinking back to class, if you've always been kind of struggling with imposter syndrome, or you're working up to having a seat at table in one of these spaces that is really intimidating, and you feel like don't belong there; to then go and say 'can we make sure the lighting is okay in here' and make sure I have this seat here so I can hear, or 'can you wear this mic' – all these other things I need as well like... I guess if you have that sense of entitlement, that you were welcome in this space and your voice was important here, then maybe asking for those things wouldn't be as big a deal. Does that makes sense?

**Em**

Yeah, definitely. Entitlement is a big word, and that says a lot. To just go in anywhere and be like, Hey, I'm a person with needs and I deserve my needs to be met. Imagine that world

**Rachel**

It's really important that I contribute and have a voice. It's weird, because I'm saying it I like I believe those things about myself, but I think that because of different cognitive layers, I don't think those things on some kind of emotional level. It's like not I'm not quite caught up with my beliefs.

**Seleena**

Yeah, it takes a lot to just to say it, but asking for it is a completely different thing. It's like you have to talk yourself into that first.

**Em**

Totally and I guess if you think about it in terms of any person from any marginalized community – to use that phrase again - feeling like you can take up space, and to be the person that says I have needs and I need to be respected, but in this instance to be also, well actually, I can't enjoy the show that I've paid for, or I can't enjoy this thing that I was really looking forward to, because that person didn't help me, or you felt you couldn't ask the person. It's like this extra layer on top of the other identity issues that that people can have.

What I wanted to talk to you about next is the world we live in now. Boris & friends' new normal - a world where people are distant, wearing masks, and there's the whole hybrid working thing. And the feeling of the future could happen more on zoom - you can either choose to pay money and go to a gig, or you can pay a fraction of the cost and sit on your chair at home and watch the gig. We seem to be moving into this new world of doing things like that, and I wondered how has that impacted on you? And how do you think it will impact going forward? I'm thinking about especially things to do with having the right access to the right tech, and other things that are really integral to your own needs – especially in regard to your job, that would typically have been quite a face to face. What does this look like in the new normal?

**Rachel**

It's this kind of, almost sense of trepidation. I just want to be a bit careful, because there has been real communication challenges for hard of hearing people. And basically, all the kind things that I do to make my life easier, Corona has kind of taken that away a little bit, like not being too far away from people, lip reading. The physical distance really. I can't do any more, because it's really important that people don't spread Coronavirus.

Other disabled people have been impacted on such a disproportionate level. I don't want to get the tiny violin out now or whatever, because I just want to be respectful of the fact that other people have had great challenges basically.

**Em**

Listen - everybody has their own challenges. It's all your own experience, so don't worry about that. Put that tiny violin away.

**Rachel**

You know, masks are really challenging, but I don't want somebody who's shielding to get Corona, I don't want them to have to stay in forever, because they can't go out. Do you what I mean? It's challenging, but this whole mess is challenging as well, and there are people that are worse off. And I know that doesn't mean that I can't talk about my communication challenges, but at the same time, I did kind of want to tip my hat at that, because I feel like it's important.

**Seleena**

Are you hopeful that things will be more accessible, as they have been in other ways during the pandemic? Or do you think that people being told that we can't remote work, or we can't have a meeting this way, or we can't make these adjustments, but we could when everybody needed

adjustments. That suddenly everybody will just forget and be like, right, we have to go back to how it was before because that's how it was for many years, and that's how it has to be.

**Rachel**

Definitely. I agree with you about the being told for years that we can't do X, Y and Z, just suddenly be like, you can now because everybody's affected. But I'm affected now, so we can do it?

I feel like, I go out into the world and it'll just feel like it never happened but in other ways – I'll give you a concrete example. I remember when it all first happened and obviously my placement was suspended, uni was suspended, and there was this big thing that BSEP (British Association for Counselling and Psychotherapy) would never count online or video call counselling towards your placement hours or towards your qualification. You know, they had a bit of a bit of a wobble, trying to figure out what they were going to do, but then given the circumstances, they got the green light to actually count video calls and telephone counselling towards your placement. So that was a big thing and I feel like in that world, where a lot of people are using online methods, I feel like it will be a hybrid model going forward, some people want to go back face to face, and some people want to do it alone. I was actually really surprised, and I think this is very representative of other hard of hearing people, but I love Zoom for one-to-one things. I find the group calls much more challenging. But I can control that environment and get my hearing level set, and I've got all my tech and it's always easier for me than face to face. But I know other people with hearing loss who really hate working online. So, it's quite personal. I think it depends on the degree of hearing loss and I guess what sort of tech you've got.

**Em**

If you think about going back into the real world, where it's likely that you and the client will be wearing a mask, in an enclosed space, is that something that is going to be challenging for you?

**Rachel**

Yes. That's my worst nightmare. If they're going to say, right you're all coming back in, but you've got to wear a mask and clients have got to wear a mask. I literally could not do it. I'd find a way, because you know you always adapt, but it would be pretty, pretty difficult. That's one of those things that has kept me up at night a little bit. Thankfully, that hasn't happened, I can control what I do a little bit more right now. I'm able to do that and not everybody can.

**Em**

When you talk about the tech that you have, can you help us and the audience understand what that tech actually is it?

**Rachel**

I have a Roger Direct and Roger Select. I think Roger Direct is the bit that communicates and the Roger Select is the actual microphone. And they communicate directly through blue tooth hearing aids. I can move that around and put it next to my laptop speaker, or if I'm face-to-face, it will pick up what they're saying a lot better than just a hearing aid because hearing aids are quite limit and difficult in situations with lots of background noise or if someone's far away.

Even if you don't have the blue tooth enabled hearing aids, you can get what you call a shoe, to put on the bottom of them, and that allows the hearing aid to communicate with a devise. They're really great.

You can also get these pens, the Roger Pen. I didn't get that because I ended up getting this one because that's what my audiologist recommended because it's a better speaker and better for my needs, but if you feel like you don't want to disclose, or have a conversation about what's going on with you, it just looks like a pen and you point it in the direction of people who are talking to you. It's a bit James Bond.

It's massively changed my life. It's one of those things; with tech, you're like, but what if it breaks? You become completely reliant.

**Em**

Are there things that other people can do to make like easier, or to make situations more accessible? Hearing loops, accessible events? What can people do to be more accommodating or more mindful?

**Rachel**

That thing of people constantly thinking I'm rude or stupid, because I'm not acknowledging them, because I can't hear them. That's quite upsetting. But I have a part to play in that as well. I can disclose. I've got hearing loss, I don't hear you. For it to even be a possibility that someone isn't communicating with you because they can't hear you and not because they're ignorant, is one of the big things.

The other ones are having spaces with no background noise. Background noise makes things really hard. Some spaces acoustically are much better than others. High ceilings with lots of reverberation are pretty horrible. For hearing aid users, soft furnishings make a big difference to how much people can hear. With hearing loops, a lot of people don't use them. They're often switched off or broken. I feel it's a vicious cycle. I feel like if you're not going to use the loops, then the event organisers will stop switching them on. Lighting is important, as a lot of people do lip reading. That can be really helpful.

The other thing is common sense. Just asking somebody what they need. People are on a spectrum of hearing loss and have different levels or patterns of hearing loss. When you said your Dad couldn't hear high frequencies; that's like the one I've got. It's called Ski Slope Hearing Loss. The audiogram looks like a ski slope.

There are people with Cookie Cutter Hearing Loss, where the audiogram looks like the Cookie Monster has taken a bite out of it, like you've lost random frequencies. That's very different to my experience. You might not be able to hear the low frequencies as well. Everyone's different. So find out about their experience and their individual needs.

**Em**

The other thing I find that is an interesting overlap, is when people do a story on Instagram and you can put automatic captioning on the screen, the technology does not get regional accents. I feel there is a cross over there with the class issue and working class people. If you're relying on that to understand what people are saying, bloody hell, hopefully the technology will get a bit better.

**Rachel**

Sometimes it's funny because it's so wrong, it's funny. It does annoy me, because accents are harder to understand from a hearing loss perspective. Also, I hear women less well than men. As a feminist, that gets me fuming.

I should go now and let you get on with your tea.

**Em**

I think that's it then. Thank you joining us and putting off having your pizza while you speak to us.

**Rachel**

Thanks for having me and thank you for letting me ramble on. Hope it all makes sense.

**Em**

See you IRL real soon.

**The Civic, Barnsley**

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