**Poor Lass x The Civic**

**No Boundaries - Episode 3: Drawn Poorly – Rose, Bhav and Peg**

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 teaming up with the incredible Drawn Poorly zine to talk about the intersections of class with disability & illness. Drawn Poorly collates stories from people of all backgrounds and experiences and creates a safe space to tell them. We chat to Rose who is behind the zine and two contributors: Bhav & Peg. Bhav shares her experience of PCOS & endometriosis and Peg shares their experience of fibromyalgia & mental health. We talk about access to diagnosis and support, what it's like to work while in pain, benefits and the UK system (including PIP assessments) and as always, how we can all be kinder and have more empathy for those around us.

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

**EM**

Ayup and welcome back to Poor Lass. This podcast episode is recorded in partnership with The Civic in Barnsley, an Arts 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. 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.

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 real life experiences...

**EM**

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

**SELEENA**

Hiya.

**EM**

Hiya.

**SELEENA**

I'm Selena.

**EM**

And I'm Em.

**SELEENA**

Just a couple of Poor Lasses...

**EM**

...doing a podcast.

It's Friday. How's your week been?

**SELEENA**

It's been busy. I can't believe it's October

**EM**

Is it Christmas at work yet?

**SELEENA**

We did Christmas [retail] training aBout a month ago. I think people have started shopping earlier as well. You know, because every day there's a new crisis. It's put people in panic mode. So yeah, just been busy. How's your how's your week been?

**EM**

Yeah,it's been proper mad at work for a while. Lliving the dream. Continuing to work from home. Love it. But yeah, so main thing is, it's Friday, which means it's Gogglebox in a bit. So I get to do this episode, then I get to watch Gogglebox. I had pizza for me tea.

**SELEENA**

Oh, I had pizza as well.

**EM**

Yes, on a wavelength as per usual.

**SELEENA**

Magic.

**EM**

We have got some very special guests in this virtual room tonight. We're going to introduce each person one at a time, just so we can make sure that everybody gets a little platform and a segment just to themselves. We can make sure everyone has the opportunity to tell their story and have a bit of space there.

So the first person who's going to set the tone for to this collaboration is Rose. So Rose, step out from the shadows of this virtual room and say hello.

**ROSE**

Hi, everyone.

**EM**

Hi, Rose. How are you doing?

**ROSE**

Good. Thanks. How are you?

**EM**

Very good. Thank you. What did you have for your tea?

**ROSE**

I was just getting a little bit jealous, as I actually didn't have pizza. I had a pretend fish finger sandwich. It was good.

**SELEENA**

A faux fish finger buttie. That's still a Friday night tea. Yeah.

**EM**

That's quite a mouthful that - a faux fish finger buttie. So Rose, I was gonna say you are famous for Drawn Poorly, amongst other things. We're going to talk to you about Drawn Poorly, which is an awesome zine. And what's really nice for us is that we're doing this podcast in this futuristic world of technology, using tech like Skype, and we like you are very much zine people, and you know Poor Lass was also originally a zine. So that's nice for us. So tell us more about Drawn Poorly.

**ROSE**

Thanks. And yeah, there is definitely space in this futuristic techno world for zine making. I think it's always quite a nice contrast to do a bit zine making.

So, I've run a project called Drawn Poorly, which I started back in 2017. The main focus of this was to bring together ill and disabled creatives from all over the UK and beyond. And there are seven zines all together, and they focus on different topics. Some, for example, are nature, diagnosis, identity - really broad themes covering a lot of different subjects. You'll know this as zine makers; the actual like format, and the choice for Drawn Poorly to be a zine was really important to the project.

Quite often, when ill and disabled people share their stories to news outlets or other organizations, they can be framed in a way that is less about the stories we want to tell us more about how they want it to fit their criteria. So we often seen that they're framed for inspiration or shock, and they don't actually feel like they're stories for ill and disabled people, but more about how other people feel comfortable perceiving us.

So, the Drawn Poorly zine and project are focused on creating spaces for ourselves, and telling our stories, how we want to tell them and how we want to share them with others. And each issue contains about 20 to 30 responses through written pieces, artwork, photography, and more. These respond to those things, but also how these topics intersect with our illness, and other aspects of our identity. These respond to the core themes of the zines, but also how these topics intersect with our illness and other aspects of our identities. So who we are, our environments, the care we have access to, our support networks, and how they all impact the experiences we have of illness and disability.

So I hope that with each issue, those reading it might recognise their own experiences in the work or gain a better understanding of alternative experiences and perspectives. In prep for this podcast, I reread the Poor Lass 'Health' zine, which everyone should go and read because it's brilliant. It's just filled with so many important pieces of writing, exploring health and class. What stayed with me particularly is the topic, that featured in so many of them, was access to provisions, waiting lists, perceptions of illness, and these experiences can be so isolating. So having space to collectively explore these are so important.

I'm really glad we're doing this today and that we're joined by Bhav & Peg, who have both been part of different Drawn Poorly zines and projects

**EM**

Excellent. Well, we are very happy to have you and we're super excited to talk to everybody on the call today. I think what you're trying to do with Drawn Poorly is very much what we tried to do with with Poor Lass - just give people an opportunity to tell their stories in a space where it wasn't going to be, you know, turned into something for like you know, I don't know, some kind of intent, by someone else. That's going to try and structure it into a-feel-sorry-for-someone angle or like a vilify someone angle. So yeah, I think it's nice that we're all gonna get to talk together about this.

I think in particular, if we think about illness and we think about disability, we think about how actually that has a massive I guess impact on the ability to work or the ability to have access to certain things or you know, if you're growing up working class or if in later life, you know, something happens with your health and then it means that you have these extra barriers to work and education. Financial circumstances are a massive part of that world as well. I think talking about the two together is a pretty big thing that really impacts lots of people.

So with that, let's introduce another guest Seleena.

**SELEENA**

Yes, I can't wait. I'm excited.

**EM**

Hope everybody else is as buzzing as we are. I've not even at any pop. So, our second person to come and speak is Bhav.

**BHAV**

Hello.

**EM**

Come on down. Welcome to Poor Lass. The first thing we're going to ask you is A - have you had your tea? And B - What did you have?

**BHAV**

I had a lasagna I made like two days ago, but I always seem to make enough for the street.

**EM**

Oh reheated lasagne. So good. Extra crisp. So tell us about yourself. I know that's super awkward, so we don't want to make it into a big scary thing. But you know, you're on the podcast today, what do you want to tell our listeners and what you want to share about yourself?

**BHAV**

Well, I'd say I'm quite creative. I think that's a big thing about me. But I'm also I think the conditions that I've had have really, really shaped me and the kind of the work that I do, my passions, like how I take life, just sort of everything. So, I suffer from endometriosis and PCOS, polycystic ovaries. And so yeah, I think they have quite a big effect on me as a person.

**EM**

So in particular, with these two things, what is the impact on your life on a day to day basis? And how does that, in practical terms, shape the way that you have to live your life?

BHAV

On a day to day basis, for years, I've had pains, like every day. I remember being in school, uni, work, and just literally struggling day to day to be able to do simple things, like socialise, go out for dinner, wherever it is. It also just kind of there affects you mentally and physically. The conditions obviously affect your hormones, and so can trigger anxiety or low mood and things like that. But it's also the pain, and the fact that you know, you've got this, and all the kinds of symptoms that come with it, that can kind of get you down a bit as well. So that's kind of like a double whammy mentally, I guess,

**SELEENA**

What drew you to contribute to Drawn Poorly zine? Was it because you wanted to kind of share your story, or you didn't see somebody with similar things to you telling your story or anyone that you can relate it to?

**BHAV**

It's kind of both ways. So first of all, I think I don't see much about the conditions that I have. I think it's only sort of very recently, in the last year or so that I've seen more on social media, magazines, podcasts, especially on PCOS. But also at the same time, I think in the last year, more women sharing their stories and things, it feels like more of a collective. I don't feel so alone in my pain and what I've been through. So I think the idea of a podcast, and I've been listening to podcasts a lot more recently as well, it's just nice to hear that you're not the only one.

When I've been talking to medical professionals and things like that, you obviously get a doctor saying completely different things. It's not very supportive, it's more helpful in a medical sense. So it's nice to literally just to have some comfort, whether it's through a conversation with a friend through a podcast, something like this. Yeah, it just it's just kind of a bit comforting. Feel like I waffled there. Sorry about that.

**EM**

Not at all close. We'll have a good chat. So, I think with you know, the general topic of especially PCOS, and increasingly Endo as well, is it's one of those things that's quite hard to get a diagnosis, right. It's often misdiagnosed. There's lots of different things in terms of like, almost an ignorance for some healthcare staff that want to kind of put it in another bucket or that type of thing. Like what's your experience in terms of access to a diagnosis, but also access to you know, pain relief, or options to choose how to manage that pain, etc.

**BHAV**

It is really, really difficult to get a diagnosis. It took me about six or seven years from when I first went to the doctors and started getting pains and suffering. And then I kind looked it up and it turns out that seven years is the average it takes to get diagnosed with endometriosis. When you hear that, it's shocking. Seven years. It is difficult because obviously NHS is free for everyone. You know, free healthcare is fantastic. It's brilliant. The only thing is obviously when they're stretched, it can be really difficult to even get an appointment, you know, for months. I was lucky enough to be able to get a diagnosis and get surgery privately through workplace private healthcare. But it just kind of quite upsetting because it's the fact that you know for years like couldn't get a diagnosis. And I just kind of think so many people won't have really the opportunity, or to be able to kind of chase a diagnosis or go private.

And so I think it can be really difficult because you can spend years thinking like Jesus what's wrong with my body. I was struggling to get a diagnosis, and especially with the condition, it's difficult to pinpoint exactly what it is because it kind of affects your, your stomach, your pains, your hormones, your mental state, you know, your menstrual period. So it's really difficult to pinpoint exactly that.

**SELEENA**

Seven years is actually wild, isn't it? They say, like, that's, that's the average. And I think you were saying as well that, obviously the NHS is free, but the fact that, you know people have to wait so long to get diagnosis and the treatment, unless you have got this opportunity or ways and means of paying for it, you know, you could still just be waiting for a very long time. And it's just yeah, the whole thing is just wild.

**BHAV**

100%. While I was, you know, being supported by medical professionals on the NHS, I saw loads of different experts on kind of different areas of the body to try and pinpoint what it was. And it took that long, it took six or seven years where as soon as I went private, within a couple of months, I got a diagnosis. And about three months later, I had my surgery. So it's just wild the way the way it moved so quickly. And it was just kind of I've managed to get a diagnosis straightaway. Which doesn't sound you know, the best. And I wouldn't say that I know what's wrong with you, but kind of know what and why your body suffering the way it is. But it's just it's just crazy. But it, it works out that way.

**EM**

Is there a barrier to accessing care for this? Like hidden behind the diagnosis? So for example, do you have to have it written on paper to have access to like, therapists or medication of some sort? Like, what does that look like?

**BHAV**

So the thing is, once you have a diagnosis, the standard prescription, or way to deal with it, is to go on the pill, which is quite frustrating. There's a lot of side effects to the pill. And it's not, it's not the most helpful. So that's just kind of universally, through my research and what I've been told, that's kind of what medical professionals will come out with. And then you know, the standard look after your diet, exercise, etc, keep a healthy lifestyle. It can be quite difficult to get any sort of support on that.

And again, it's only when I really, really pushed, even privately, when I really pushed to try and get some additional help. But yeah, it is increasingly difficult to be able to get proper pain relief, therapy or support groups, things like that. I just don't think there's enough of that available. And if there is it's not broadcasted enough. It's not encouraged enough.

**EM**

So probably, Bahv, are you working or are you in school or anything?

**BHAV**

Yeah, I work full time.

**EM**

How do the two worlds work together? You know, is it something that, if any people are listening to this episode, or are line managers or work with people, you know, is there anything that you could share that would be really helpful for people to know and understand? How to support colleagues, you know, for people that are there around in a work capacity, also in a life capacity, and the overlap with class and access and financial positions, having any kind of like long term illness, disability condition, etc, can be a real barrier to work, right? So, are there any things that you would like to share about that?

**BHAV**

I think that's a great question. I think, obviously, I'm working now. But during when I was studying and in school and education, things like that, it was really, really difficult. I missed school quite a lot, because the pain I just couldn't take. I also wasn't in the mood to, even when I did go into school, I remember I was, I would be sitting in my math class on the floor with a hot water bottle, so everyone would know. And I remember in school, it would be things like - as a result of the pandemic, obviously, the world has learned how to work from home to the point where it's completely possible now to work from home all the time, whereas it wasn't before it wasn't an option then.

So I think that's really, really helped and I think that's something that should be kept on. The option to have flexible working is a lot more helpful. I live in London, and you know, not having to do the commute into work is just a lot easier for me because it takes less energy out of me, I'm able to work comfortably in my home and comfortable clothes, have a hot water bottle, and, you know, make food myself, it just made life a lot easier.

I think the flexible working is definitely something that could be helpful to people suffering from various conditions and illnesses, not just this one. Also, I just think support, I guess, so that kind of across life, isn't it? I just think support, especially if even if employees don't make the disclosures of suffering with the condition or anything, I think once managers and line-manager do know, it's important to just kind of stay in contact, just check on them - it's as simple as 'how you doing today? How's your pain?' Just something that shows that they have some sort of interest in it, or some sort of care. And even if they can't think of anything, how to help, even just asking can I help? But I think that should be done across the workplace in general?

**EM**

Oh, absolutely. And we talk a lot about empathy as well. This idea that sometimes you don't know what is going on with the person that is in front of you, right? It could be someone close to you, it could be a stranger, or the boss, it could be anyone and the main thing is really to be empathetic, right, and not make any snap judgments. You know, someone has decided oh, that person's doing something that I don't agree with, or I don't like the look of or whatever, and then feeling the need to be rude about it or get involved with what someone's doing. And I think, you know, that's something we've talked about quite a lot recently. And like you say, if it is something that impacts you, it's not something that you can just keep to your own house. Is it something that will impact you in the workplace, or on public transport, as you said, you know, this is something that is your life, you can't switch it on and off. And it's not entirely visible to people outside.

So, I guess, is there anything you wanted to add with that as well, you know, outside of a workplace situation? Is there anything that you would like people to know about this condition that you think maybe people a don't know about or maybe just have a bit of a wrong idea about this is

**BHAV**

A bit of a random add on, but I think it would be PCOS and Endometriosis both have an effect on kind of fertility, and that sort of side of things. And I think what I've experienced quite a lot is I'm, you know, in my early to mid 20s and people don't really register the fact that you're young, you may not be wanting kids or anything at this time. But it's still upsetting. Like, that was a huge part of getting my diagnosis, realising you know that it's a very low fertility rate. Even things like miscarriages, and things are quite common with PCOS. And that was kind of a big thing for me to have to register. Considering I wasn't really close to thinking about kids and things yet. So I think that would be a big thing. Just kind of be aware of all the symptoms and I think, literally just to be more empathetic, and mindful of that side of things.

**SELEENA**

Yeah. And I think that ties into, which will probably happen as you get older, when they're asking questions about fertility and children and not to make assumptions and the way people discuss that, I guess. You don't know what somebody is going through, or somebody's reasons. So I think, in the broader sense, I think that'd be it, like you say, knowing all the side effects of this condition, but also not talking to people in a way that could make them I feel upset or you know, have to talk about it when they don't want to.

**EM**

I guess to finish off now, is there anything that you'd like to recommend, any books, zines or podcasts or really anything that that has made you feel seen, and a bit less alone in the world? As a person who has both of these conditions, is there anything that you'd recommend that other people read or access, etc.

**BHAV**

Oh, you've got me on the spot here. I think there's quite a lot of Instagram pages with support and advice tips, and literally just logging daily diaries on PCOS and endometriosis. I found quite a lot of them. And they range from literally some of them are quotes about having the strength to cope with each day how each one feels, knowing that you're not alone, kind of empowering women that way. And they range from that side of things to literally dietary advice, what certain foods that may trigger pain, things like that. So there's a lot of that out there on Instagram. I've come across a lot more podcasts on both conditions as well. That's definitely something to look into. And I think reading articles helps me quite a lot - informative articles, and blogs too, but it just kind of helps that it's actually in the news. These are the facts, you know, so and more people are becoming aware of them. That's kind of what's helped me the most

**EM**

Great, thank you for sharing.

**BHAV**

Thanks, guys for having me.

**EM**

No, thanks so much. So, now let's welcome our next guest. And I was going to do reveal yourself - like on Take Me Out. Our next guest is Peg. Hi, Peg.

**PEG**

Hiya

**EM**

Hiya.

**PEG**

I'm just thinking of Paddy McGuinness now.

**EM**

What have you had for your tea Peg?

**PEG**

I haven't had my tea yet today. But yesterday, I did make the best baked potato of my life. So I'm still thinking about that.

**EM**

Oh, the best of your like! I mean, that is a bold claim.

**PEG**

Yeah, when you just get everything that's in the weird little jars in your fridge that you got from the nice aisle in Aldi and you just put it all on the potato at once. And it's just a really good time.

**SELEENA**

Mate. You'll never be able to recreate that potato again, like no matter how hard you try.

**EM**

I love it. So, Peg, what brings you here today? Tell us about yourself, please?

**PEG**

Well, I'm a zine maker. I've submitted to Drawn Poorly before. I was in their nature issue talking about going for walks during lockdown and finding my sanity that way. So I'm here today as a disabled, quote unquote, working class person. I struggle with the word working class when I don't feel like I'm working very much, if you know what I mean? But yeah, I'm definitely very skint, so I think that's my conclusion.

**EM**

Do you know, I learned recently that in the US they've started using the phrase underserved? Seleena, have you seen this as well?

**SELEENA**

No, I've not heard that.

**EM**

So, it's about taking the 'work' out of 'working class', because you know, sometimes that word in particular can sometimes not be relevant in the conversation. But also, I think it's a nice angle to actually show, that it's not often a choice thing. 'Underserved' kind of opens it up to being about all the people that are literally underserved in the world that we live in. I think it's a really great phrase. I don't know how you guys think about that. So, let's run with that one Peg. We'll take the word 'work' out, it's probably a good place to start then if we talk about this idea of work or not working. What is it in your world that impacts on your life, from illness, disability perspective? What's your identity? How do we know a little bit more about you?

**PEG**

So, I currently do what I've done for a good handful of years now, which is a strange mishmash of freelance jobs that I picked up somehow. Basically, I make my income from doing these freelance jobs, all of which are, you know, from home, sat in bed on my laptop, so that I can manage what's going on with my disabilities.

I've got Fibro, so widespread chronic pain. I'm also realising that I'm autistic, which explains why I've never understood how to operate in an office environment, or they've never really got on with me. And just a lot of, you know, mental health stuff going on - that kind of thing. So, I do these little jobs, like I transcribe a podcast and I do a lot of meetings about redesigning mental health services, and just the things that are sort of shorter interactions, like these little zoom calls, and then we lie back down for a bit. And that's kind of how I manage my time.

**EM**

So I guess then, similar to when we were talking to Rachel as part of the No Boundaries series in episode one. She was sharing her story about sometimes going into a world of self-employment can be a real necessity for people who have the need to kind of regulate or have timeout or take breaks. As you said, it's just a case of, you know, needing to lay down and kind of coming back to it. So, is that something that happened with your experience as well, or is it something that is like, these are projects that you really want to work on? In fact, we should first probably check with you what words do you like to use? Do you use the word condition, for example? Or do you prefer illness? Or what do you like to use?

**PEG**

I don't know that I use condition or illness. It's definitely just the Fibro. My fibro has she her pronouns for some reason. So, I refer to what she needs quite often, which is a strange concept, but I don't know that I talk about it enough to use words like condition or anything. It took me a long time to be okay with the word disabled. And now I'm very okay with the word disabled. So, I'm okay with that. I don't know what the Fibro is, I don't know if it's an illness or a condition or what.

**EM**

I suppose this is the thing, right? For each person, it will be a different, a different way of approaching it right? And we've also spoke quite a lot in this series about this. And you absolutely just touched on it there about the almost imposter syndrome, and sometimes the use of some words, and especially the word disabled in particular. So, you've got lots of different freelance roles as well. Do you also claim disability benefits?

**PEG**

Yes, I do. That's basically what holds everything together financially. It's interesting, some I'm on Universal Credit with the limited capability for work thing, which makes it very interesting that I need to tell them how much I've earned. But it doesn't quite line up with their thinking, because they feel as a group that I can't do any work. And then I have to go once a month and tell them how much I've earned. And they don't really understand how I've earned it. And for quite a long time, they weren't willing to accept that I was receiving that money. And it's just a very strange system. That doesn't make too much sense when you look at it for too long.

**EM**

And does that overlap as well with things like PIP assessment?

**PEG**

It's interesting. The PIP assessment and the Universal Credit disability assessment are so completely different. One of them has been updated a lot recently. So the Universal Credit one, they stop assessing you when they think they have enough evidence. So you can go in with your massive folder and be ready to talk for hours. And you'll talk for 20 minutes, and they'll say that's definitely enough. I'm going to send that off now. And then they send you home.

That PIP one, they absolutely destroy you for hours and hours and hours. And they're asking completely different questions. And so I've seen a friend of mine recently, they're being reassessed for Universal Credit, because they like to often look at whether you're still disabled or not, which is always ridiculous. And they've commented and said, ‘Can you just take the information from my PIP assessment and apply it to this?’ And they've said, ‘no, it's completely different information, completely different questions’. And I quite often see people get given one benefit, but not the other. It's just a very backwards system, that you feel like you need a lot of luck and skill and knowledge to get anywhere near making it work for you.

**SELEENA**

It sounds like the most inaccessible thing ever, which is ridiculous.

**PEG**

Being disabled is a huge amount of life admin. It takes absolutely hours of work. I was thinking about that when Bhav was talking about getting a doctor's appointment, because quite often I need a doctor's appointment quite urgently. So, I'm going to need to take hours of phoning around, advocating for myself to try and get that appointment. And that's going to be my work for the day. And that's going to be exhausting. But yeah, applying for benefits is a week's worth of work that you need to be well enough to do or have someone to do for you. And that's exhausting.

**SELEENA**

They're telling you that you can't work or don't work. But in order to even get to that point is a lot of work. It does make zero sense.

**PEG**

It's a very strange, it's a very old way of looking at disability that you need to be completely incapacitated to deserve any money from this government. And it obviously gets harder, the longer we're in our current government setup. Yeah, it's just very strange. It makes me feel like I'm a Victorian on a fainting couch being painted in some kind of dramatic way. That's all I do all day, is lie around feeling dramatic and getting given money for it. Very often, I've got some kind of chaise lounge, and I've got my hand over my forehead. That's exactly what I think I look like

**EM**

I think the thing with the PIP assessment stuff as well, from close friends and their experiences, is it's just like a performance, right? You've kind of got to go and be like, I am to the level that you expect of this particular illness condition, disability. You almost have to be, on that day and in that moment, performing to a level that they are expecting to view. And then on top of all that sort of stuff that that you've just been saying, as well the exhaustion, life admin. It is wild, the whole system is so crazy.

**PEG**

It's a very upsetting process, the PIP assessment. It's never gotten easier for me and I've been through hundreds of them now. The PIP assessment that they sent me to, there's a coffee shop around the corner, and that's the reward. You've done the PIP assessment, it's been really hard, I'm going to take myself to this coffee shop at the end. And it's really not a very good coffee shop. Every time I go, anything I order is kind of quite disappointing. And it just feels like I've taken myself out for this hot chocolate because I've been through this traumatic process of feeling really disabled. And now I'm just going to have this really naff hot chocolate afterwards. And that's just the whole experience. Really.

**SELEENA**

I feel like that sums it up. It's like, my treat is this thing that I know is going to be a bit naff.

**PEG**

At my last assessment, they put all of the assessments on pause, so anybody that was meant to be reassessed for PIP, they put them on pause for COVID. And everybody sort of just got automatically renewed. And then for some reason, I got sent a letter saying that I needed to go in, and they need to reassess me right now. And I thought that sounded quite unnecessary. So, what they actually did is they cut all of my benefits before telling me that they decided to reassess me. And then I sent in the reassessment form, and they have now automatically renewed it until 2024. So, I don't have to go in for an assessment for another three years. But as part of that, on the letter back to me, they wrote a bunch of stuff that they don't believe is wrong with me. And it's all stuff that my medical professionals also struggled to understand.

I have a swallowing disorder now, which I didn't used to have. And on the PIP form, they ask if you've got anything new. And I said that I've got this new thing where I can't swallow food. And quite often I have to drink fuel, which is this disgusting protein shake thing because I can't get any other food in. And they've written back on this form saying we don't believe you. And I've just got to sit with that. And I'm so irritated about that, I really want to write to them and just be like, why would I make that up? I'm very angry about that specific thing.

**EM**

I mean, having anybody question your actual lived experience and your reality is so infuriating, so to then be reliant on an organisation or whatever it's called, for them to turn around and say actually, no, and then not allow you to have the things that you need to survive is just abhorrent.

**PEG**

Yeah, completely. I was trying to do a master's degree until sometime last year. I had to give up on that due to the university not being accessible. But um, I went in there, sort of all guns blazing, armed with all of my files of paperwork I've always got, telling them exactly what I need and how they were going to give me it, and the whole university experience was just them, thinking that all of it was me making a fast one, that I didn't need any of these requirements. And it's just completely exasperating. And I just… it's really taken me some time to come back to feeling like I'm allowed to advocate for what I need, and that I'm not just making a fuss. And it's because of all these institutions around me acting like I'm being making a fuss all the time.

**EM**

Yeah, we talked about this idea of if you have like more than one thing, if we think about like, underrepresented groups as a whole, right, there's all these different things. And sometimes it's just, you feel almost like you tick too many boxes, right? Or, people see you as a person that ticks too many boxes, right? And we talk a lot on Poor Lass about taking up space and feeling that you have the ability or the agency to be able to ask for what you need, or just to be you in a space. And so, yeah, I mean it sounds like a lot. You know, I'm sorry that you have to deal with this.

**PEG**

It's a very pertinent day for it. I’ve been house hunting all day. I’ve got to find somewhere to live within the next three and a half weeks. I need somewhere to take benefits and somewhere that is accessible enough for me and it’s just exhausting. Too many diversity criteria at one.

I commented on something the other day, that I didn’t realise was a public post on Facebook, referring to myself as a disabled and autistic, queer and trans, and a bunch of random men with opinions commented and told me that I was winning the oppression Olympics.

**EM**

Ugh, grim.

**SELEENA**

It’s like, oh you can’t play all your cards at once, and it’s just like, go away!

I’ve got no words that are suitable.

**EM**

To nick your question from earlier Seleena - Peg, what was it that brought you to share your story, for Drawn Poorly and to share your story today. What drives you to share your experiences?

**PEG**

I used to always share my story to make sure people like me were represented. But with Drawn Poorly and Poor Lass, I don’t think that’s what it is. I feel like I belong here and that it’s okay to talk about things and that people will understand.

My submission to Drawn Poorly wasn’t explicitly about being disabled, but it’s about me feeling connected and being in nature, and there’s nobody reading that zine and thinking I don’t fit in there. They’re reading it and thinking I’m part of this group of people and that really does something to me. Especially with what I’m talking about, navigating this world where I’m made to feel like I’m strange, like in don’t fit in, and that I’m not doing the right thing. And to come to these spaces where I do fit in, where other people have similar experiences, I just find that incredibly powerful.

**EM**

Well, we are very lucky to have you here. Thank you for sharing your story today.

**PEG**

You’re welcome.

**EM**

To wrap up Peg, it would be really nice to give you the opportunity to share, if there is anything that you would like to ask of people, or to let people know how they can be more accommodating and kinder. To go back to the point of empathy – people don’t always know what is going on with the person sat next to them, a friend, a stranger on a bus, a family member, a work colleague. Is there anything you’d like to share with folks, based on your lived experience, to give them a realistic experience to learn from?

**PEG**

I think the fact that disabilities fluctuate is an important one. In my past, I’ve had people think, because I could do something yesterday, that it means I can do the exact same thing today, without taking into consideration that my energy levels might be different, or I might still be tired from what I did yesterday. And there’s something about learning what a person needs, but also continuingly asking and being able to adapt to it. That’s what makes it easier for me to do things like work with people or socialise with people. And that idea that my capacity might be different on different days and I find that really pertinent, really useful to have people around me know.

It's sort of the opposite to this Paralympic model of disability, where we see people with this static, unchanging disability on television, and we think that is how everybody with a disability works. There is more fluctuation in myself and most of the disabled people I know.

And if I can have one more point, I work because I have something valuable to give. I’m still a person who should be contributing and should be at the table when we have these discussions. Just because I have to do the Zoom meeting and then lay down afterwards, doesn’t mean that I didn’t have something important to say. I really find, especially now we are used to working from home, giving disabled people a voice and a seat at the table, I find it really important to have that diversity and to listen to people.

**EM**

Absolutely. Peg, thank you so much for joining us today. Especially on a Friday night. I say that like I’m off out to the club or something.

**PEG**

You never know – I might be.

**EM**

You might be. I definitely won’t be.

**SELEENA**

We’re definitely not.

**EM**

I’m absolutely gearing up for a bit of Gogglebox now. I don’t know about you guys?

**PEG**

I do love Gogglebox.

**EM**

It is the best. It is the best.

So yeah, thanks a lot Peg. Thanks for coming along. Thanks for sharing. And I wish you lots of good luck with securing housing in the next few weeks.

**PEG**

Thank you for having me. And I’m going to look a whole bunch of Right Move links as we speak.

**Em**

Fingers crossed mate.

At this point, Rose mate, you’ve been sat in the shadows this whole time. Welcome back into the fold. Do you have anything you’d like to share on the back of Bhav and Peg sharing their stories?

**ROSE**

Hi. I’ve just really enjoyed listening to conversations you’ve been having and the things that you’ve shared. I think when you live with illness and disability, you feel like you’re on your own with a lot of this. You carry a lot of it. When I was listening to Bhav for example, talk about the commute and how difficult that might be, I was going yeah, it’s tough. You feel it all over when you’ve got an illness.

And the same with Peg, just the difficulties in securing what you need and people not believing you, and that added element, when you feel ill and not well, that’s the last thing you need – someone going ‘is this thing actually happening?’

I feel appreciation for the stories that have been shared and all of the awesome zines you make, and also to you Em and Seleena for having us and giving us space to talk about these things.

**SELEENA**

Oh, it’s been brilliant. This whole series, I’ve really enjoyed. I know I’m always going on about that I’m grateful that people want to share their stories, it means a lot.

**EM**

Definitely. I think, to go back to the beginning of this episode, how we both have our independent project and similar needs, that we are often talked about in ways that don’t… I guess our voices aren’t represented in the best way. Or people can use our voices to put agendas against us. So, I think having an ability to hold your own voice and our own space, and where people are kind, is super important.

So, thank you for trusting with your stories and experience and feeling like you can come on share. It does mean a lot.

**SELEENA**

Yeah, it does mean a lot. And if anyone is listening and related to any of the stories or wants to reach out and know more about Drawn Poorly, the zines and the projects, how can people do that Rose.

**ROSE**

The best way is through Instagram, which is [www.instagram.com/drawnpoorlyzine](http://www.instagram.com/drawnpoorlyzine)

There is also a website that I am very bad at updating, which is [drawnpoorly.wordpress.com](http://drawnpoorly.wordpress.com)

But there’s some cool stuff on there.