Graeae Podcast: Disability and Change

**Welcome to the Graeae and Disability Arts Online Podcast, bringing together thoughtful discussion and debate. This month Nickie Miles-Wildin, Graeae’s Associate Director talks to artist Jess Thom about Disability and Change.**

**This podcast contains strong language through out.**

Nikki: I'm Nickie Miles-Wildin. I'm the Associate Director at Graeae. And I am joined by the wonderful Jess Thom.

Jess: *Biscuit*, hi. *Biscuit*.

Nikki: And should we talk about what we look like?

Jess: Yes. *Biscuit*.

Nikki: Go on, you go first.

Jess: *Biscuit*. I am a white woman in my late 30's. *Fuck a goat. Biscuit*. I have Tourette syndrome which means I have a very wiggly body. You'll be able to hear some of my vocal ticks, *biscuit and hedgehog. Biscuit*. And you might also be able to hear one of my motor ticks which is banging my chest, fuck a goat. Biscuit. I am a wheelchair user and I love table tennis. I don't love table tennis. *Fuck. Sausage*.

Nikki: Yeah, I quite like table tennis, I wish I played it more.

Jess: *Biscuit*, it's not really my game. Any game that involves any sort of bat or sharp implement or heavy object are really not my friends. I'm likely to be doing Javalin or putt-putt. I mean, there's quite a lot.

Nikki: Paralympics, come on!

Jess: *Biscuit. Biscuit*, I'm often talking about wanting to like do a knife act when I probably would not survive for that long.

Nikki: Nor would the audience possibly.

Jess: It would be a very dramatic shot. I've got very wiggly arms, *Biscuit*, and poor impulse control. That means that if there's something that you can hit on your head or stab into your skin I will do that. So, *sausage*.

Nikki: Yeah, best not to do that. Well, I am- What am I? 4'10" white woman, short blonde hair. My dye is coming out now so you can see my roots.

Jess: Fuck.

Nikki: I'm a wobbly walker.

Jess: Wobbly walker.

Nikki: I use a wheelchair as well. So, yeah. I'm in my 40's even though I sound about 12. Okay. Jess has had ticks since she was a child.

Jess: *Fuck*.

Nikki: But wasn't diagnosed with Tourette's until she was in her 20's.

Jess: *Fuck a goat*.

Nikki: With some encouragement from her friends, Jess decided to turn her ticks into a source of imaginative creativity and the Touretteshero project was born.

Jess: *Sausage. Biscuit.*

Nikki: So, tell us more about Touretteshero then? What is that? Who is Touretteshero?

Jess: *Biscuit*. So, Tourette's Hero is a super hero persona and a creative multi-disciplinary organisation. *Fuck. Sausage*. And I started Touretteshero in 2010 with my sort of long-term friend and creative collaborator, Matthew Pountney. We'd work together in inclusive play, on adventure playgrounds for disabled/non-disabled children at that point for 10 years. And my ticks had increased over that time and he had been very supportive of that as I adjusted, but we'd also had some really significant conversations, one of which is that Touretteshero's origin story which was me basically sitting around his kitchen in South London.

Jess: And we'd be having a conversation about Tourette's and my ticks, which we would have had lots of times before at that point. And I used to find it very hard to talk about that aspect of myself without tears. But in this conversation he described Tourette's as a crazy language generating machine and told me that not doing something creative with my ticks was wasteful. And for some reason that the image of the machine and my ticks just sort of spontaneous sort of creativity engine and the idea, like I'd been raised to think being wasteful was really bad. So, somehow that sentence or that fragment of conversation embedded itself in my thinking in a new way and was the start of me being able to allow myself to even give space to Tourette's and to ticks and then see value in that. And that really is the start of Touretteshero. Within a few months we co-founded Touretteshero 2010. So, we're almost 10.

Nikki: Wow, yeah.

Jess: And it started off as a very small idea and we just went with it and it has grown. We'd put on creative events for children and young people with and without ticks. I'm a strong believer in providing sort of creative, positive opportunities for disabled children to be themselves exactly as they are and that those positive experiences, and positive memories are protective when they face barriers.

Jess: If you have something to draw on and if you have some experience that it doesn't have to be this way that the exclusion of disabled people is not the natural order, then I feel that that's powerful. So, creative events that are fun and playful are an important part of what we do. As is making artwork, and often artwork that draws attention to the sort of invisible barriers to our cultural spaces. You know, things like rules about how you behave or who has access to what sort of work.

Jess: And advocacy and training and basically speaking out about sort of some of the issues, and policies, and politics that impact some disability culture of disabled people's lives. I also have a really great Lycra onesie.

Nikki: Do you wear one quite a lot?

Jess: I think at the beginning actually the question and the mask in particular were really significant for me because it meant that I was able to speak as Touretteshero and not as Jess. And at that point it was still very new for me to like identify really positively as a disabled person and understand and talk about my experiences. And so, doing that behind a mask gave me a sense of freedom that I didn't have otherwise, and confidence I didn't have otherwise.

Nikki: It's that super hero thing anyway, isn't? That you wear, people wear that mask so they're not known, are they? They can go off and be this other person.

Jess: And we quite like we were drawn to the idea of a super hero because of that sort of legacy, political legacy of masks. Also, because of this playfulness and wanting to have something that was able to sort of transcend age and that would appeal to both children, and people, and adults. I think we really cared about walking that line when we talk about heroes and power.

Jess: And there's an element where I wanted to reclaim the idea of what super powers were what. Like this sort of super crypt idea. So, the idea that disabled people are all exceptional just because they're disabled is weird and inspirational is really damaging to many disabled people and setups really unrealistic expectations. But playing that idea of finding strength in things that can be difficult.

Jess: And I do a lot of performance work at festivals with an amazing comedy songwriter with bi-polar disorder called Captain Hot Knives. And he has a brilliant act rant he does around how he doesn't want super heroes whose powers make their lives easier. That's not heroic. If you can fly or be invisible then just stop bragging about it.

Nikki: Exactly, yeah.

Jess: He wants super heroes whose powers make them more layed rich, potentially flawed but also relatable. *Biscuit. Fuck a goat*.

Nikki: And I think that's like saying about Touretteshero what's really stumping me there you're saying about you being a like this word generator. And I think that's being taken that what you said you thought you could never talk about to then turning that into that positive thing.

Jess: Yeah. *Biscuit*. And I had never been told I couldn't talk about it. I grew up in a sort of family that was very accepting of my unusual behaviour and sort of understood in a context of neuro diversity. But I still internalised most of those messages from the world around me so that.

Nikki: We do, don't we? As young disabled people, yeah.

Jess: *Biscuit*. And so that and it's such an undoing that internalised ableism is such an active process and takes decades with many people. I'm interested in how art can catalyse conversations and help that happen quicker. And so, because I think that often we lose a lot of time and use a lot of energy trying to change ourselves when actually we can expect the world to adjust to us.

Jess: I had experienced a couple of years ago quite an intense hate crime on a London bus. And at that point I had been doing lots of public speaking and had been talking a lot about the role adjustment had played in my life and how transformative it was, and how positive it was to transform your environment to meet your requirements.

Jess: And then I had this experience where this woman sort of shouted really very targeted and horrible abuse at me because I was a wheelchair user actually rather actually than because of my ticks, which was also a total unusual- Oh, you're picking on this?

Nikki: You're picking on that. Yeah.

Jess: And you know, so it was horrible. And then what was even more distressing for me, actually, was this sort of silence that followed. It was like nobody really acknowledged that. But also I realised that my instincts was to minimise it, was to explain it away, was to try to ignore it. I didn't actually make any adjustments in that moment to change that situation.

Jess: I didn't ask my support worker to go and tell the bus driver to stop. Or I didn't, you know, get my phone out, and there were reasons for that. But when I was thinking about it afterwards and particularly when I had an opportunity to speak at a creative sort of conference called No Boundaries which I'd been invited to speak at beforehand have a plan for what I was going to talk about a change because of that experience.

Jess: And I think it changed because I realised that particularly as disabled people we're used to adjusting. We're constantly adjusting both our environments and to meet our changing bodily requirements and our changing environments. But I think there then is a risk that is very easy because we're so good at adjusting to adjust to inequality rather than to make the necessary adjustments to equalise opportunity.

Jess: So, that was a good lesson for me about making the right adjustment. But not just like understanding that adjusting isn't always positive. It can be really amazing and transformative, but it's important that we… It's really easy to adjust to rubbish. And at a time when disabled people are sort of under so much pressure, external pressure because of political policies and the removal of services and the rhetoric around austerity it's easy to feel like we have to adjust to that pressure rather than resist it. So, yeah.

Nikki: And there are some days as a disabled person you just go I don't know if I can do this today. Do you know what I mean?

Jess: Yeah, of course.

Nikki: Like sometimes even leaving the house it's like, okay, you know someone is going to look at you as soon as you leave the house using your wheelchair, or whatever. And you're like do I feel strong enough to fight the fight? I don't mean that in the kind of a poor me kind of way, I just think it gets you have those days where it just feels really hard.

Jess: Yeah, and it's relentless. And I think often that the relentlessness of it. And I think that's one of the issues with systemic oppression is that if you say the things that most bother me out loud then they sound so petty, they sound so small, but because they're happening many, many times a day, that the key to the fact is huge. And so, it's really, and I now recognise that as someone who has been able to have the opportunity to engage with the politics, and art, and activism of disability.

Jess: But it's so embedded that it's really easy, first of all, to not really even realise that that's happening to you. And to feel then to take on that responsibility and feel like, oh, I'm bad tempered, or I'm grouchy, or I'm not patient enough. Or to be like oh, somehow, I'm a disabled person, but also I have all these character flaws in terms of how impatient I am with the world rather than see that actually that there's this sort of relentless wearing down on disabled lives.

Musical interlude.

What's been your history with Graeae? And has Graeae been any part of that journey of yours?

Jess: Oh yeah, absolutely. *Biscuit.* Several years ago after we started Touretteshero, but before we even touched performance and the theatre world, or even thought about that. Like I'm not a trained performer. I'm a play worker by profession, which arguably does have quite a big element of performance with it.

Nikki: Yeah, definitely.

Jess: If you can hold 60 children and at circle time we don't have to be there then, you know, that is quite a performance. But I wouldn't have identified as a performer in any way. But I went to a show by the comedian Mark Thomas and we'd done a lot of prep beforehand. At that point I hadn't been to the theatre much because of my ticks and because of assumptions that meant that I wouldn't be welcome in their spaces.

Jess: But I was really wanting to see the set show and so was felt motivated to try and find a way. And so, I talked to Mark beforehand and to the theatre, made all of these plans, and he introduced me to the audience at the start of the show. But despite all of that planning, the one bit of thinking we hadn't done was what if? What if someone complains?

Jess: And because we hadn't done that thinking, that meant at the front of house manager at the interval asked me to move and sit in a sound booth at the side of the stage, which was sort of a show about segregation. And then I was sat behind glass. And it really upset me and I sort of sobbed in that sound booth and it was a really humiliating experience.

Jess: And in that moment I was like I am never setting foot in another theatre again. This is not a space that I can occupy, it's too damaging for me. It's not worth it. Never again. And I was actually supported to instead of keeping that promise to understand that there were other ways that I could respond and one of those was to make a show of my own which was about called Backstage in Biscuit Land which was the first time I'd really made a stage show and been involved with theatre.

Jess: And I made it with Matthew, the co-founder of Touretteshero and with Jess Mable Jones who is an amazing performer and puppeteer. And we made Backstage in Biscuit Land in a sort of community room in Stockwell. And the first person we ever showed it to who wasn't one of us three was Jenny Sealey. And her response, support, mentorship in that time was really crucial for me to feel like that was something that we could do.

Jess: Because I hadn't seen loads of theatre so I didn't know what a show should look or feel like. And I think partly that was great because that meant that we made something that may be in on our own terms rather than was emulating anything else.

Nikki: Yeah, and it was raw, it was authentic. It didn't have all of this, it wasn't made into something it wasn’t going to be.

Jess: I don't know whether Jenny knows how significant sharing that with her and her response and her support in that moment was, but I think that's one of the things that I'm really keen to do as a disabled artist is support other artist to challenge themselves to do things that are maybe feel slightly outside of their comfort zone.

Jess: If I can use any of the skills or knowledge I have gained to support other people to make work what they want to make with it, they think they might want to make, then I'm really up for that because that's what Jenny did. It was that active generosity with her time and her expertise that enabled us to make something that we could go into Edinburgh with for the first time and feel solid about.

Nikki: Wasn't part of it on the BBC?

Jess: *Fuck. Biscuit.* Yeah, we then the following year we then had this incredible opportunity to make a half-hour version for BCC 4 as part of a night of live theatre in the old television centre building which was being turned into luxury flats.

Nikki: Sweet.

Jess: So, we were the last sort of creative thing to happen in that space and that broadcast to happen. And we were in the old, we used the old props store. And it was such an amazing chance to think about how you take a piece of theatre and make it work for telly. But to also have live performance present.

Jess: And for me the ultimate sort of moment of going full circle from there was this incredible moment just before we went live where I was like they are letting me, a woman, a disabled wheelchair using woman with Tourette's go live on their channel. Whereas, just a few years ago I was pulled from an audience and made to be sit back.

Jess: And it just was like, it's like it showed me what art can do. And that art had helped me go on that journey myself, and repair, and heal, and find a positive way to talk about the experience. But it had also enabled me to claim space for other people and to promote the idea of relaxed performances, which I feel like which are a big step in helping to get people to think about the diversity of bodies and minds that are part of our community.

Musical interlude.

Nikki: So, we're here to talk about disability and change. And I think what you're saying now about relaxed performances you are starting to make a big change in the industry with that. You've become kind of the spokesperson.

Jess: Frustratingly slow.

Nikki: I feel like every sense of change is regarding disability in theatre, film, TV, whatever. It is tremendously slow.

Jess: And I feel a bit impatient with that now. For ages, I thought, oh, you know, it's like change takes time. And then they banned straws in six months and I was like wow, if we can ban straws, which are an incredibly important access tool for many disabled people, with such speed, and with such effectiveness, like the landscape and how you can expect to drink as a disabled person in a public space has radically changed.

Jess: And in an invisible way to many people. If we can do that, why have Mencap been had to campaign for changing place toilets for decades?

Nikki: Yeah, exactly.

Jess: Why are we having to- Why, you know? Almost like eight or nine years after Biscuit Land, why am I still not able to see a broad range of work without having to do those for extra labour? You know? I recently looked at the sort of statistics around the relaxed performances across 10 major London venues, and it was 14 in the next year. The most ridiculously small number. And if you take out the children shows and the pantos, there's nothing.

Nikki: Yeah.

Jess: And I feel frustrated by that because it's about people accessing our shared culture. And about who has the right and who is expected in those spaces. Relaxed performances are described performances that take a relaxed approach to noise and movement coming from the audience. They allow people to come and go as they need to and they will acknowledge that at the start of the show.

Jess: So, that freedom and that invitation is given to everyone. They're not anarchy, they're like a very simple, relaxing of the rules. And actually to do them properly it takes a small amount of thought, but not a lot of extra money or effort.

Nikki: And I've worked at the Royal Exchange in Manchester the last two years and we do relaxed performances on every show that we have in the main house. And I have to be honest, they don't take a lot organisation, they're really on it. We have easy read synopsis, house lights stay on a low level and the round module at the Royal Exchange it’s in the round. All of the doors are kept open, we might have two shut for like Entrance and exits of like for bits of set, but everything else is kept open, people come and go, whatever. And it's explained at the beginning of the show. Actors introduce themselves as well. And just going in and watching those performances, they are some of the best performances the actors do as well.

Jess: Because you have to concentrate. You have to focus in a different way.

Nikki: Yeah.

Jess: And you can't, you know, drift off and think about your-

Nikki: What you’re having for dinner.

Jess: Yeah, or you know, what your to-do list for tomorrow looks like. Which if you're doing a show often, like maintaining attention and maintaining focus is an issue. I think one of the things, so relaxed performances I think send a really clear invitation for people that they've been thought about. I think the reason that I like relaxed performance as a term rather than using condition specific stuff like dementia friendly performances or autism friendly performances is that they throw the invitation as wide as possible.

Nikki: Yeah, we have mothers with babies in arms and whatever, and it's great. And not just for the actors, but it's a good atmosphere in the theatre.

Jess: Yeah. My frustration is that they can be an element of being like we've done our one relaxed performance for this one, so we're not going to do any.

Nikki: Anymore, yeah.

Jess: Lots of theatres don't even have a consistent offer. They will do a relaxed performance almost like when it occurs to them, but that could not occur to them for months or years.

Nikki: Yeah.

Jess: I have been working with Battersea Arts Centre to experiment with and develop the methodology for what relaxed venue would look like. So, what happens of while we've been thinking about relaxed venues as the exception, and so the sort of special shows. What happens if we flip that assumption and say that everything will take a relaxed approach unless there was a clear creative or other rational, why not?

Jess: And also understanding relaxed performance in its broadest term. So, for me, I think rather than being sort of paternalistic about that show can be a relaxed performance because there are some at it's purest form you can rule out a lot of shows. For me, I want to see a broad range of work. I'm sensitive to noise, but that doesn't mean that I don't want to see a loud show.

Nikki: Yeah.

Jess: I just need to know about it so I can prepare and make a decision. So, for me what I really encourage companies to do is to do what works for the show first, but to really think about your audience and what information they need to know and communicate that clearly in accessible ways using pre-show information and opportunities. Think about whether you can make small adjustments often to then make mean that every show is accessible in a different way.

Jess: It frustrates me incredibly that we have a sort of creative centre that is always ready to experiment and excited by that sort of process. And yet, doesn't really seem to embrace access provisions as creative tools. They are opportunities to enrich your work. You are already using sound, and light, and bodies. They can be used to give freedoms, and permissions, and information in multisensory ways.

Nikki: It can make it more exciting. And I think, yeah, for the more creative possibility.

Jess: Yes.

Nikki: And that's what I think, you know, I think some of that comes from who's creating the work at the moment, people get very set that it has to be a certain way because that's how theatre has been for the last hundreds of years. And you know, I don't care. I don't care how many classics I see that have got X, Y, and Z in them. I'm interested in new stories and the new way of doing things to accommodate the society in which we live in.

Jess: *Biscuit*. But even like, you know, even when we think about like new writing is exciting, it's a real opportunity to diversify the voices. And to make sure that people, particularly people who have been underrepresented within disability culture, black and brown people, and learning disabled people, often people of those intersections are less present within our disability arts sector, and that is damaging across all.

Jess: And there are some incredible artist making work. And I really like the work of Matilda Ibini and… Downton Abbey, like those things are exciting. Blink Dance Theatre are doing some incredible work as a learning disabled/non-learning disabled led company. So, I feel really excited of some that work that that work is happening, but I feel frustrated with the pace of change within the rest of the sector because it's not a niche issue.

Nikki: That's the thing is when are we ever trendy? Do you know what I mean? We have peeks of going oh, disability is trendy now, it will be our focus. Then we get overtaken by something, it's like we're never consistently talked about.

Jess: Well, it's not a gimmick, it's not a trend. It is people's lives.

Nikki: No, it is.

Jess: And I often get frustrated when, you know, you have sort of, I've definitely had some sort of media type saying to me, "Oh, we're going to do this project." And it was going to normalise disability. It's like disabled people are- Disability is very normal.

Nikki: Yeah, normal. Yeah, we're all right actually. But I think that's the thing, isn't? Is that at the moment the disabled narrative is not there.

Jess: No. It's not there and it's diversity.

Nikki: Yeah.

Jess: There are, you know, you have tragic narratives and you have inspirational narratives, and then you have the evil villains, and there's very little in between.

Nikki: There's nothing in between about anything.

Jess: And it's just does not serve anyone to reduce any group of people to a stereotype and to not show the sort of loud richness of our community. And the fact that, you know, being a disabled person is not about what our bodies do, it's about that lived experience of barriers, and that relentless experience of barriers. And the opportunity to give and receive solidarity is one of the things that makes me feel hopeful at a time where there's lots of reasons to feel, you know, the other way.

Nikki: Yeah, the other way.

Jess: *Biscuit.* But I think, you know, there's so much fear around disabled bodies and minds. And that some of that fear is our internal fear. Like it's understandable, totally understandable that if you face barriers it feels frightening to put make yourself exposed. But there is also a fear of disabled people because it's not visible, because the diversity of those narratives is not present.

Jess: And because often stories around disability are not written by disabled people. And it's like it's not good enough just to have difference visible on stage. And that's even no where close, it's got to happen at every layer. And we have to be supporting disabled people as writers, and directors, and producers, and programmers. And I am desperate to get one of us running a major building.

Nikki: Also, just picking up on about relaxed performances, we're seeing a change throughout and on stage as well. What is it about sort of audience protocol? Because there's been lots in the news at the moment about people going, I think, you know, so and so they've cheapened tickets, they've made the bar cheap, that's attracting the wrong people. I wish people would stop rustling their sweet wrappers.

Jess: *Fuck. Biscuit*, for an art form that is so about lifeness and about humanity and about presenting stories, it confuses me that we expect audiences not to have bodies. Not to need a wee, not to need sugar levels to be at a good point. Not to need to cough, and sigh, and wiggle because they are bodies in a space. To deny that is a very privileged position.

Jess: I think like that fear around if like my experience might be damaged if I set next to someone with down syndrome. And it's like it probably won't, it might be different, but to always understand that this is the right way and anyone coming into this space has to do it our way. That doesn't work because that's just about dominant power.

Jess: And it hasn't been that way for very long. It's like just because you've claimed that for the last hundred years that we've sat in silence, you know?

Nikki: Yeah, because if you look at it before like Shakespeare's time people would go and throw tomatoes-

Jess: Unrecognisable

Nikki: Exactly.

Jess: And I think one of the things, so, Edinburgh one year I went to see a comedian. And I hadn't, like, they had known that I was coming beforehand, but maybe with not enough time. And I hadn't done that introduction personally. Not like I had necessarily should have to. But what was interesting is that they then were quite thrown by my presence and sort of talked to me for about 15 minutes and asked a lot of questions that were like difficult for me, and invasive, and unnecessary.

Jess: And but one of the things that they said that really stuck with me was that, oh, you know, as a comedian you prepare for hecklers, and you prepare for drunk people, and you prepare for Hen do’s, but I've never prepared for someone with Tourette's. And it's like, why not? Because it's not just about Tourette's as a specific condition, why do we go to the theatre and expect not to be sitting not to be sitting next to a learning disabled person? Or someone with dementia or a neurological condition?

Jess: Why are we expecting those people not to be present in that space? That is the issue. And one of the things that I say to artist a lot who are worried and fearful about relaxed performance, or like what that might mean for their work, is that you get to be in creative control. You get to control the work you make, but you don't get to say who gets to see it.

Jess: And relaxed performance is just one way of ensuring that a broad range of people get to see it the same as captioning and audio description. Like having access is about audience development, but it is also about meeting basic responsibilities to not be discriminating in your practise. So, for companies who aren't considering the diversity of bodies and minds, not only is there a sort of creative risk, and a social and ethical risk, and a business and financial risk, there is a legal risk.

Jess: Like just because, you know, the legislations doesn't quite have the teeth that it needs to have, and that we shouldn't, you know, we shouldn't be threatening people into, you know, we're going to sue you if you don't do it. But there is a point where it's like this is not an extra piece of work that we're asking you to do, this is your existing work. You're just not doing it well enough for lots of people. There are obviously lots of companies who are doing it brilliantly and work is really exciting and pushing the boundaries of what access can look like.

Nickie: And as we touched on earlier about plastic straws, there's a big change here. Plastic straws being banned

Jess: I was actually talking about it quite a lot on the journey here. I think that in the beginning when it became clear that sort of the campaign to ban plastic straws was gaining momentum and which happened very quickly, initially I felt frustrated that disabled people were being overlooked. Of the fact this was an example of us not being considered.

Jess: And because the majority of people don't depend on them on the day to day it's been assumed that they are a frivolous luxury, and therefore we can ban them without any issue. Once numerous disabled people spoke up sharing their experiences, explaining the nuances of that educating in a way that we shouldn't necessarily have to, but being really generous with time, and energy, and lived to perspective.

Jess: And that's been happening solidly. There are tables that show like why lots of the alternatives don't work. I mean, give me a metal or a glass straw and you're getting pretty close to the knife act because it's about to start. And then, so this far down the line having that, and obviously in the U.K. there has been the exception, this sort of medical exception, but it does medicalised and aspect of my life that wasn't medicalised before.

Jess: It does mean that really to reliably drink away from home I have to carry my own straws with me when I didn't have to before. I am choosing to buy biodegradable straws, but they have quadrupled in price in the last year. And that most upsettingly I am frequently shamed for using a straw.

Nikki: Really?

Jess: If I have to ask for straws and being told off. And, you know, it's illegal for me to give you a straw, it's not. Actually, it's a reasonable adjustment to give me a straw. But I think that many places have just, because of the ban, have just got rid of them without then thinking we should at least have some.

Nikki: At least have some, yeah.

Jess: And I think that that's the most upset like, you know, learning that a disabled woman had died from an injury caused by a metal straw was really distressing because the shaming and the judgement is what is forcing disabled people to try things that they know probably aren't safe for them.

Nikki: Yeah.

Jess: And I am, I get frustrated and more angry when it feels like it moves beyond a lack of thought, an oversight to being a deliberate point. And I also, biscuit, I just don't think that that's the solution. It feels like a very, you know, it's frustrating to go into a restaurant and see lines of plastic cutlery, and then paper straws. It's like really guys? And I think my frustration is that people, that the disabled people are listened to and it's like and learning about that death was just like I felt so upset that it's like this is exactly what we are saying is going to happen. But we're not allowed to be experts on our own experience.

Jess: And just for example like the number of people who will if you talk about that issue will just come back to you with all the alternatives. It's like I have given this some thought.

Nikki: Like I've not been completely ignorant. Yeah, I'm trying.

Jess: It's like I've tried things, I've worked out actually what I need, I'm saying that and we're choosing not to respond to that, we're choosing to overlook that, that is adding another layer of challenge to my day. And it's about hydration, it's about water, it's not a trivial issue to disabled people. Like being on a plane and needing a drink and not having, you know, not realising that you've run out of straws is like oh, gosh.

Nikki: Yeah, it's not about making your cocktail look pretty.

Jess: No. And the answer to that is about everyone else saying no rather than disabled people doing extra labour. So, that was the option. The option was that as a society we take responsibility and we make it illegal to put straws in drinks as a mandatory a bit like without thinking and make it something that you request. Or make it something that, it's just what? Like disabled people are doing the work.

Nikki: Yeah, again.

Jess: Again.

Nikki: And so another change because this podcast has been about change.

Jess: Change.

Nikki: Change. One final thing is that your lamp post.

Jess: Yeah.

Nikki: It's all been changed.

Jess: Fuck. A big change.

Nikki: The lamp post in your bedroom window.

Jess: Yeah, the new lamp post is a terrible, gives off a terrible light. And he's like a little white angle, he's got no substance to his body.

Nikki: Shame.

Jess: I'm not body shaming a lamp. I mean, I am body shaming a lamp post. The lamp post, so I moved into my current flat about eight years ago and that was because where I had been living before, which I thought of as my home was no longer accessible to me, it was up six flights of stairs. It was very precarious and so I moved.

Jess: And I was quite reluctant to move. But one of the things that happened very quickly was that my bedtime routine would like put on my pyjamas, brush my teeth, get into bed, goad the lamp post to about how bright the moon was or how cold it was. So, shouting at the lamp post my ticks involuntary checking the lamp post has been a feature of my life ever since.

Jess: And one of the things that I think I've come to really value about Tourette's is the fact that my ticks draw my attention to the details and the world around that I would otherwise miss. And those sort of strange totally random relationships that I develop with things like pieces of street furniture are some of the joys of living with a brain that works slightly unusually.

Jess: So recently, I had written a post about two years ago about my fear of what would happen if the lamp post got taken down and like I was thinking how does it need to be listed? Like I'd organise a crowdfunding campaign it's like- And then I was like don't worry, in my mind, don't worry about it local authorities have no money, they're not going to touch that lamp post. We went for lunch the other day and came back and the lamp post had been decapitated and they were replacing it with a new, you know, energy efficient I'm sure lamp post.

Jess: But this was one of these, so one of the places where my colleague Will who was with me at the time basically said, asked them if I could have it. And I just sort of sat still and looked disabled. They let me keep the lamp post, which is probably quite an unusual request.

Nikki: Yeah.

Jess: *Biscuit* I would like to, but so I like feel he's come in from being outside of my home and is now present in my home.

Nikki: And how is that going sharing your space with a lamp post?

Jess: It's going all right. I'm keen to get him working again as a lamp post and I've had lots of brilliant generous offers to help me get him up and running. So, I'm quite keen to have him as a- We've even written, we have a short rely play called Light Of My Life which is about the lamp post. So, I would really have ambitions for him being able to, you know, to talk.

Nikki: To be part of that.

Jess: Yeah.

Nikki: And he has forgiving you for all the goading?

Jess: Yeah, seems to be. He's pretty resilient.

Nikki: Fantastic.

Jess: And I have totally gendered him.

Nikki: Yeah. Love it.

Jess: Yeah, but I definitely do that.

Nikki: Yeah, cool. And so what have you got coming up next?

Jess: So, our most recent piece of work is a neuro diverse presentation of a sort of classic canon piece of canon theatre that is Samuel Beckett's short play Not I, which is one of the reasons that I was really drawn to Not I was because it is a very intense piece of theatre and a very established piece of theatre.

Jess: And when were touring Biscuit Land lots of places said to us, “Oh, we're really interested in relaxed performance we just haven't had the right type of show yet.” And I got really interested in that cultural curation which was happening around disabled people's access to work. And so, it's like all right we're going to take the most intense piece of theatre and make it accessible in every level to audience and performer.

Jess: But also what's interesting about that play is sort of particularly reading it was being like this is a disabled character. It's great to have new writing, but also disabled characters already exist they're just not being recognised as such and played by disabled people who can give them their authenticity-

Nikki: That they need.

Jess: That they need. So, I feel very proud to be in a position to take on that role then as a neuro diverse performing playing a neuro diverse character, the role of Mouth. And we'll be touring that show a little bit in the U.K. and internationally, hopefully, at the start of next year. So, that's a big thing.

Nikki: Yeah.

Jess: We're also working on a piece of work, more of an installation than a piece of theatre around the concept of the language generating machine and what that might look like. And particularly using that as a way of exploring non-intentional language, but also exploring the power and potential of words to bring us together and pull us apart.

Jess: And for that piece also I'm really interested in compiling my sort of expertise and knowledge as an inclusive play worker with my practise as a visual artist, which is what my training is in, and with our sort of interest in performance and live work. Because I think that those things together play, and performance, and making feel like they fit so tightly together, but you often don't see them brought together.

Jess: And I'm particularly interested in making work for children and young people that also works for adults and that maybe tackles like weighty themes, but in accessible, playful, joyful ways.

Nikki: Well, thank you very much Jess for joining me here at Graeae today.

Jess: Thank you for having me.

Nikki: And good luck with all of your projects.

Jess: Amazing. Thank you for inviting me to be part of what is such a wicked podcast.

Nikki: And here's to disability and change.

Jess: Here's to disability and change. Sausage dog!