

Jess Thom

J:

I love beans.

Hello cat.

*Trigonometry killed the radio star
but it didn't kill mother's kitten.*

Beans. Fuck it. I love cats.

Fuck it. I hate cats.

A: Tell me the story of your life. What's your first memory?

J: *Biscuit.* Um My first memory that is a dateable memory was my third birthday and I have a very vivid memory *biscuit* of a cake with a three candle (..) on it, which I thought was magic and it was in the garden of a house where I was staying, in Norfolk I think, there was a big tree over it. *Biscuit. Fuck.* So that's one of my, that's one of my first memories. I also wanted to get into the tree. *Biscuit.*

Er, I was born in London in 1980, feel very lucky to be born in 1980, because it has always made it easy to work out how old I am. I feel that getting harder as I get older. *Fuck it.*

A: I have the same thing, being born in 1950.

J: (*Sausage*) *I love cats.* Um I er *biscuit*, I, *biscuit*, I grew up with, I lived in Blackpool on and off with my grandparents as well. Er and so moved a bit between Blackpool and er Islington, King's Cross. And I started having lots of difficulties in school. *Biscuit.*

I struggled in my first primary school because of *biscuit*, because I moved around a lot, fell over a lot, relatively, I was relatively disruptive in lots of ways but not intentionally. *Biscuit.* Obviously, as a neuro-diverse child in the '80s, it was *biscuit. Hedgehog. Biscuit It.* There wasn't a, inclusive processes were less talked about. And so I've got some very early memories

of failing as well, teachers talking about me. So I think certainly my school life er up until the age of er nine or ten was mainly characterised by a feeling of failure. But what I, one of the other very strong memories I have is being taken by school to the Tate Gallery, er, when I was about six or seven, going up a spiral staircase and sitting in a studio In a big circle with my classmates and a man in the middle introducing himself as an artist. And it blew me away, because I didn't, didn't know that artists were alive people, I didn't know that they were, I didn't know it was an actual job you could do. And I think from that point on I knew that that was gonna be the job that I did, and that's what everybody else told me was the job I was gonna do. Although there were definitely points where I felt differently or wanted to do other

things or er, but yeah, that sense of creativity, creativity has always been an integral part of my life, partly because I was encouraged to draw instead of doing anything more substantial at school, for the first years of my primary education. *Biscuit*. But um but also because it gave me, sort of a freedom and a , *biscuit*, that I couldn't find in, *biscuit* in other places. And I had tics since I was a child but they were much less noticeable to other people then. My parents were very accepting of me and my range of very unusual sort of chaotic behaviour, um and I felt very accepted exactly as I am, but I did feel that lots of their aspects of how, there were aspects of my being I didn't understand and didn't feel like I had space to talk about.

Er and I think that that is something that I say to parents is just because a child looks like they're managing or their tics aren't that noticeable, they will know, and, to a certain extent and not talking about it can make people feel that they're embarrassing or that there's shame and that process of shame as a, you know, disabled child, young person adult, that process of shame starts really early. *Biscuit*.

And so I think that has lots of influence in terms of the importance of play work and playfulness in my practice and working with children and young people has always been an absolutely integral part of what I want to be doing as a creative person. Some of that is because playing is fun and it's exciting to make things happen and kids are really full of imagination and joy and go with the process in a, an exciting way, part of that is because I believe that those positive experiences are protective um and that they give children and young people stuff to draw on and feel proud of when things are inevitably tough when they hit barriers. *Sausage* so um inclusive play and working on adventure playgrounds for disabled and non-disabled children is what, like where I *biscuit*, where I think I learned to be a performer for sure. I certainly didn't go to drama school *fuuck* (..) *I love pitta bread*. *Snoopy fucked the radio star*. *Again*. There is no evidence of that. *Fuck it*.

What else do you wanna know?

A: Keep going, keep telling me.

J: Um *I love cats*.

A: Childhood.

J: *Biscuit*.

A: Any other..

J: So, I have one sister, who I am really, really close to and she's a doctor and has, we have a very close relationship, she's five years younger than me, um and was on the receiving end of a lot of unusual behaviour as a child. I think I am very, I realised a few years ago that I think one of the things that was important to me is that she's the only other person in the whole world

biscuit who, for whom my tics have always been part of their life. Whereas other people have to get to know them, or get to know my body or get to know how my mind works, *biscuit*, my sister being a very present part of my sister's life and so she has an acceptance and a response to that that is so deep and supportive that it almost defies description. And I think that's, er, that sort of unconditional acceptance of the reality of the situation and that being a fact, the fact about me and my body, amongst many other facts and is interesting, because in lots of other areas of my life it's something that people have to learn to be with, to cope with, whatever language you wanna use. And certainly, you know, my parents are very supportive of me, I think they really struggled at various times to know how to help me grow into a sort of independent and er happy person, who I am. They've done it but I don't think that's been a straightforward journey for anybody raising a child who er is neuro-diverse and likely to encounter barriers that are often invisible to other people. I think some of the physical barriers I encounter are really easy to explain to people um and I think people can understand some of the *biscuit*, the attitudinal barriers, but the experience of constantly being problematised um is, is hard and I think that that's er.

A: Do you want to give me some examples of that?

J: There's er, I think particularly on public transport I have, I have had loads of sort of amazing conversations but also really difficult experiences, my right to be in public space as someone who behaves in an unusual way is often something people have opinions on. So, you know people have, when I was a child people had opinions on er whether I should be in the classroom or whether I should be in mainstream setting or not. As a young adult, travelling by public transport, people had opinions on whether I should be on the bus or not, as I wanted to go to art galleries or um theatres or people had opinions on that and I think I had been inadvertently taught by the system of how we like to educate and raise young people as a community, I had been taught that other people's rights trumped my own. *Biscuit*. And that there were certain places where I, weren't for me because I couldn't behave in a way that was appropriate for those contexts and therefore, and that was always me, and it didn't occur to me, *biscuit*, as a child to question that or as a young person to question those contexts but that's why it's important to do that now. We held an event at Battersea Arts Centre called Brewing in Battersea, the end of this summer, the last few days of the summer holiday. And we did, so we did daytime activities for children and young people, then sort of cabaret on one of the evenings celebrating disability culture, with a sort of older young people and adult audience. I remember one of the things, I was sort of watching children come in to the beautiful auditorium, the beautiful dome at Battersea, I don't know quite what you call it, but there's an amazing stained glass dome with light coming through and we'd created this amazing, my designer'd created this amazing installation full of potions and mixtures in the middle and it was covered in fragile stickers. But then there were play workers encouraging children to touch it and get involved and move the liquid away. And I watched children, families come into that space and I was very aware that there were children coming into that space who in every other environment in their lives, I could instantly see from how their behaviour and character and energy was presenting itself that it's like you are going to have, you are going to be made to

feel like a problem in lots of different areas of your life. There's very few places where you will be accepted in this amazing way that you are with this amazing imagination and sort of force behind your being. And I felt really proud to be part of creating spaces where people and specifically children get to be themselves exactly as they are. But the flip side of that and then feels very sad that, I was very aware that the majority of these children's experiences would not be like that. And it was so simple to create that.

And also I enjoyed watching parents um sort of , I loved the, I loved the, the mix of a very sort of comprehensive, like intricate fragile-looking sculpture with their absolute permission to reshape it. And that had been given instantly in terms of how, how, the sort of behavioural cues. And then that just sort of set up, set children after diving into a load of amazing activities. But I did feel really connected at that point to those young people in relation to my own experience but also in thinking about how we create a future where um different minds and bodies are considered and more people are gonna feel free and safe to be themselves exactly as they are, because what that then added to that event, in terms of the amazing directions, playful directions that we went in because those children were in the room and that they didn't work, their brains don't work in sort of you know conventional normative ways, it just made for humour and joy and um *biscuit* creative routes that I don't think anybody would have got to otherwise. *Fuck biscuit.* And I suppose that for me *biscuit*, you know I was taught publicly over and over again about this sort of moment *biscuit* where I felt a real change in my own attitude to my body. And it was in a conversation with the co-founder of TourettesHero, Matthew, about me. And we were sitting in his kitchen. We've worked in playgrounds together since 2000. So for a long time we've worked together. And we'd had lots of conversations in that time about my changing tics and the sort of impact of that on my work *biscuit* and I'd always up until that point got upset, and I couldn't talk about Tourette's or any of my experiences relating to them without tears.

Um *biscuit.* And then *biscuit*, we'd have lots of conversations about creativity in relation to that, but I heard, I heard, I heard this conversation differently. And the key part of that was that he described Tourette's as a crazy language-generating machine, and told me that not doing something creative with it would be wasteful. And it was the combination of those two things, it's the combination of imagining it as, as a , as a machine, as a sort of fascinating producer of new ideas and language and churning out words that I was really drawn to. And I was also really drawn to the idea. Like I'd been brought up not knowing that not knowing, feeling what being wasteful was like or worse. So I didn't wanna be wasteful. But more than that, I was able to understand that maybe that access to that spontaneous creativity that Tourette's gives me has value, and didn't just have value for me within my own practice, but potentially I could record the things that I said and gift them to other people to be used as sort of springboards for their own creativity. And that was the, the birth of TourettesHero but also, as an idea, but also the first time where I was able to er really connect Tourette's to my professional understanding around disability and play, actually bring it into my own life and live it, rather than just feel on the side of it, does that make sense? *Sausage! Fuck it. Pitta bread. Biscuit.*

So I trained, I trained *biscuit* in, I went to Camberwell College of Art.

A: Coming back a little

J: Yeah!

A: To. We were at infant school and suddenly we were at Camberwell College of Art. What comes in between? Did you go to a mainstream school?

J: Yeah, I did two years, I left my first primary school when I was eight, eight or nine and did two years in a specialist setting for young people with sort of specific learning disabilities and you know other, it was a setting that was designed to take er young people who were struggling at school and work with them intensively to a point where they would be able to go back into a mainstream um system *biscuit*. And so I had lots of input there but the most important thing I think that they did was rebuild my confidence and while that was also the first time that I'd ever been, we'd ever done, I'd never done school plays, they did, they did, they had lots of drama and stuff and so I did, I was, that was really, I got involved in that and I was chosen to be involved in that and I think *biscuit* that's the other thing that I don't think it would have ever occurred to me in lots of ways to, to go in a sort of performance direction, but it was always sort of teachers recognising certain characteristics or abilities or, there were definitely those were key moments when teachers recognised that and er, er nurtured it and I think that's an amazing opportunity that educators have in terms of recognising talent and nurturing it and helping people feel confident about aspects of themselves particularly if you are used to being talked about in terms of deficit and in terms of like problems, people, I'd definitely started to feel like a problem and had been made to feel like a problem in school lots of the time. I *biscuit* I was *biscuit* saying that some of my, there were sort of different classes they sort of did, they experimented quite a lot at that school and it was in the very early nineties and some of, one, couple of classes were given computers, they were taught how to touch type using a sort of specialist programme and like taught, were able to use computing and computers in their lessons. I was not part of that group, I was part of a group of children that got to walk around the hall with a hula hoop round their middle trying not to bump into each other. So I got a hula hoop and the other guys got laptops which didn't feel quite (..) at the time *biscuit*. But I left that school and went um and we were living in London and then I went, we moved to Milton Keynes, which is where my grandparents were at that point and I didn't balance..

I had a very close relationship with my maternal grandparents because they'd um, I lived on and off with them at various points in my, um in my life. And it was my gran that er er *biscuit*, persevered in terms of my education, I think she was probably the only one, only person who ever managed to properly teach me anything as in a sort of one person teaching another person directly something um and she did that by a combination of bribery and repetition. Er *biscuit*. But I'm also, it's funny how you know the other thing, my granddad was quite an obsessive, I'm sure that there's an element of Tourette's that links to sort of that obsessive compulsive

behaviour and there's definitely, you can trace that back in the family and one of the things that me and my grandad used to do together in an evening was walk around locally and identify broken lampposts and take down their serial numbers, and then once a week he'd go and report them all to the council and we'd have to stand in line while he did his weekly report, and he'd get very frustrated if the same lamp-post you know continued to be out of action. But that's funny now to me in, that was a very, a lovely like I really enjoyed those walks (*Doorbell*) *biscuit*, I'm now *biscuit* reflecting back on that, that's not a natural activity, there aren't rambling associations that do that as part of their routes. When I moved into this place, there's a lamppost that I can see from my bedroom window that my tics have a very strange relationship with *biscuit*, so I brush my teeth, get into my pyjamas, get into bed and then go to the lamppost about the brightness of the moon and you know, talk to a TV aerial, I think one of the things *biscuit* that I've really come to appreciate and actually writing every day as part of the blog um, the TourettesHero blog I think helped me get to this point was really valuing the relationship that Tourette's gives me to the world around me. I notice details, or my tics notice details that the conscious part of me would never, wouldn't, and then draws my attention to them and everybody else's attention to them, in often very funny ways. And there's a geranium my friend, my friend Matthew got given a geranium. And the moment it appeared in his house I started swearing at it and sticking my finger up at it, essentially bullying the geranium. *Biscuit*. But I'm sure that plant would not have survived and would not have been kept alive had it not had that impact on my tics. So I feel like I might have been being quite mean to the geranium, but I feel like it owes me its life, because there's no way Matthew would have looked after that plant and kept it alive if I hadn't been regularly shouting at it and he found that funny. So it is, you know, and that's every place I'd be new home, I'd sort of build up these different relationships with the things around me and that it, that's funny. And I notice the themes, like Tourettes will often notice the seasons before I do and will start chatting to the tree or to the sky. *Sausage! Biscuit! Fuck a goat! Lamppost! We're not talking about you. Lamppost. You don't have a say in this, lamppost, biscuit, lamppost, stop loitering. A sausage. Lampposts live off the state. Sausage.*

So I didn't have a diagnosis of Tourette's in secondary school, I had a diagnosis of other conditions, but *biscuit*, but I was lucky in that I was er, my behaviour was I think always understood in the context of neuro-diversity, I went through a phase at secondary school of running uncontrollably into closed doors, which, you know, retrospectively was probably quite a large thing for teachers to manage. But they did and I was never told off for that, which was, I feel very lucky about that and I often, talk to, I talk to teachers, I often talk about an experience where I was, you know, just started secondary school in year seven and we were, sort of my whole year group was in the, the gymnasium and we'd all got basketballs in front of us and we were all told to put the basketballs in front of us and not to touch them. And the PE teacher was standing at the front and, he wasn't my PE teacher, a male PE teacher was standing at the front and told us not to touch the balls, the basket balls. And I just picked one up, picked the one up in front of me and hurled it at him and it hit him square in the face. And he ordered me out of the gym in a rage, and the humiliation that was written over him and the fear and the terror that was in me of having done something I definitely didn't feel like I had chosen to do.

It had totally shocked me in terms of what had happened, and so he ordered me out of the gym and he came to speak to me and he asked me why I'd done it. And I said I didn't know, and said, I didn't, I hadn't chosen to do it and it had just happened. And he believed me, and he understood me and he did not punish me, and he did not go on about it and he, and I now retrospectively feel that that would have taken an incredible amount of strength. If you're humiliated by a child it's very easy for teachers to react on a very impersonal level, but he didn't. And I don't think you need to know the diagnosis of children and young people to provide them with support. And I, some of that was sort of spoken by the way that I was responded to in school. And I'm, you know I was sent on errands all the time. It had not occurred to me that I was being given carefully structured movement breaks (ATS laughter drowns out tics)...*biscuit, cats*. So there's certain things now that I know that are there. I was being looked out for. But um er there was an idea that, I was in all the bottom sets and I didn't find school easy from an academic point of view *biscuit*. But then about six weeks before my GCSEs, I don't know where or when but I suddenly realised that the teachers basically knew what was gonna be in the exam papers, or had a fairly good idea, that they, we just needed to remember it and I was, I was furious, why did nobody tell me that all I needed to do was remember it, like remember stuff, because I knew that I could make myself remember it, just couldn't do it in a way that they were trying to teach me, I was trying to know this stuff. I don't need to know it, I just need to remember it. *Biscuit*. (ATS laughs.) *Biscuit*. So I created myself loads of big posters, colourful posters but with lots of, all the key information on them, and I put them around the house, and every time I walked past them or used the toilet I would make myself read them from start to finish. And it was like, that was utilising that obsessive part of my brain to acquire information. It's exactly the same strategy that I use now when I'm learning lines. The reason that I can do Samuel Beckett's 'Not I' is because of that exact same process that I realised, worked out when I was fifteen. I then did much better in my *biscuit*, in my GCSE exams than anyone was expecting. So I didn't go to agricultural college as planned at sixteen and do a land-based industries course. Instead I stayed on and suddenly got art in a way that like suddenly got that, that I could make art in a way that I wanted. And I think that that's, there was like a, that it wasn't about being good at doing a specific thing, it was just about that I just needed to let myself be creative and that would work. And so that was exciting and then I er applied for art college. I went and did a foundation course at Camberwell College of Art and then stayed on did a, a BA in drawing.

And I was lucky that that the course I did was a very *biscuit cat flap*, took a very broad, broad view of what drawing was and understood it as a process of creative thinking *biscuit*. And I think that that sort of thinking creatively and the sort of process of like trying, testing stuff out and solving problems, definitely I think had been enhanced by my experiences as a disabled person. And I think sometimes it means that, you know as disabled people we are very good at adapting, it means that we can find amazing solutions to problems and barriers. Um *biscuit*. But most recently I was, I started to understand that we have to make the right adjustments. And it can be very easy to adapt to inequality rather than make some of the adjustments necessary to equalise opportunity. And weirdly, the place I realised that, and the place I really deeply felt the choice of positive memories as protection was at the start of um last year, 2017,

when I had, I'm used to having all sorts of weird experiences on buses and public transport. Had so many, whether that's laughing, whether that's nice conversations, curious conversations, aggressive responses, I've had all of that in response to my tics. But what happened at the start of last year in terms of what was so different, and it was based on me being a wheelchair user rather than my tics. And, straightforwardly, and it was ten minutes of the most like personal abuse that I've ever experienced, targeted abuse, and abuse that, they were really wanting to make sure that I knew that the horrible things that they were saying were directed at me and were directed at me because I used a wheelchair. Um and *biscuit*. Nobody else on the bus did anything and actually what was very, the most upsetting part of that was the silence afterwards rather than the horrible things that were said to me. Um *biscuit*, well my instinct was to minimise it, was to like, to feel like, to not say anything, to rationalise why that happened, to feel like I couldn't, I you know, texted my, I didn't stop the bus, didn't tell the bus driver, didn't ask my PA to ask the bus driver, didn't do anything to take action about it other than make some notes about what was being said to me and where *biscuit*. But that, that's sort of the natural instinct, to just explain things away um was so present, and it was only with the sort of support of em friends, it was like this does need to, I do need to talk to the police about this, I do need to go through all these steps, but I also wrote about it um and had a, had a creative network to draw on, had a way of making that experience visible to other people and processing it.

And I know that my response five or six years ago would have been totally different, and I wouldn't have felt that I had any sort of resilience to that. That would have probably limited, had a big impact, limiting impact on my life. So the idea that those creative tools and networks are powerful was very tangible to me at that point, as was the idea that you have to make sure that we're not just adjusting to shit *Biscuit*. And that we are making the right adjustments. *Sausage*. And as individuals and as a community. And I think the other thing that I feel very lucky about recently is because I have had an opportunity to travel internationally, I understand, I've got the chance to understand and see how disabled, the expectations of disabled people are so very much shaped by the politics of where they live, the politics of the place or systems with which it's very ha.., you know, listening to our, criptime was talked about in Canada, for example, the assumptions that were learnt, they made about the control people had over their lives um or going to, hearing people talk about the way that they crowd source their care and manage that (and it was like) I listened to a woman speaker at a disability arts festival in er in Germany where she was an American woman and she had taken an approach to basically using the sort of crowd funding approach to fund her care, not in terms of generating money to pay people, but generating people. She had a sort of, she had a pool of people that she gave time to support her and she was sort of managing this system. And when she described the system it was very similar to mine, we felt like, we are, we have similar support requirements, we are managing our, we have come to the same solution in terms of how we are managing our care, it looks very similar in terms of the intimacy of that, but I have an expectation that my carers are a professional job that is funded by the state that I am not having, that I am paying people to do, to enable me to live, and that I am in control of, and that I am not having to negotiate and beg people for access to the world. But that was like, that was

totally shaped by having, there being a system, it's not an ongoing food system all the time, and to a system that works for everybody, certainly to an equal system, but there is a system, so I'm really keen *biscuit* thinking, I'm really keen to keep trying to have a sort of global and international perspective on our conversations, because otherwise we can't see the barriers that are just part of the system that we're living in. It's really easy to miss the barriers when you're being restricted by them, but often on our side I will be like, you don't need different time, you just need accessible public transport um *sausage*. *Fuck it*. And obviously, some of that is simplistic um but er, but I do think the politics of place and continuing to find way to have conversations across borders feels essential, crucial, now more than ever. *Fuck it*. *Biscuit*. *A sausage*. *A pitta bread*.

So where we got to(...) Camberwell.

A: Yeah, I was just gonna.. Have we finished Camberwell?

J: I reckon so. All the time of my creative education I was also working as a play worker, in an adventure playground for disabled and non-disabled children in Camberwell.

A: How did that start?

J: I needed a, I needed to earn some money, I needed a sum, like a summer or weekend job. I'd grown up on adventure playgrounds as a child and was going past one that looked good and actually saw an advert for jobs there in the Big Issue. And so applied and started working there.

A: Was that Oasis?

J: That was actually a place called Charlie Chaplin Adventure Playground.

A: I was on the management committee.

J: Were you?

A: I helped set it up.

J: Amazing! Amazing! Yeah um, Matthew and I have a big relationship with that and it's where we met. It's where we started putting on participatory events for the children there and the first event that we really coped with together was in 2006 and was a screening of two films made by children at the Ritzy in Brixton. And then we also did an event couple of years later called Something out of Nothing, at the South London Gallery, where we decanted the whole of Charlie Chaplin, like eighty kids to um to the South London Gallery, they'd given us the space, the main space when they had a gap in their programme, sometimes they'd, we've got a nice relationship with them where sometimes they'll ring up and be like well, like a week, we haven't got an exhibition in, d'you wanna do something? And so we did something, the idea was to do

an event without outcomes um, where we had no expectation of what the outcome would be, we had no funders, we made it, we funded it between the SLG and Chaplin. And um children arrived and were given a sort of white boiler suit (..) to change into and then there were loads of artists in there, musicians, er people, digital artists who had computers and projectors set up, allowed people to paint on the walls and put them, make murals on the walls, people to costume stuff, there was a load of different resources. And artists and play workers, but there was no expectation of what the children would do with that. And then they created these incredible questions and games and stories which ended in a parade um.

And that was definitely one of the first events that Matthew and I had really like created and designed in a cultural space rather than in a playground. And it, it did some good stuff in terms of both within that institution and in terms of the opportunities for young people we were working with. So we got, we just started doing that more and more. And doing that through to (...) meant that it felt like, there were, you were, there were lots of challenges with Charlie Chaplin in terms of it would be, it changed management, it was taken over by an organisation who hadn't got experience in running playgrounds and I think there were lots of issues in terms of the resources around, um, around that. And they wanted to introduce charging for the services and as a staff team we were very against that and did a lot of work campaigning and they're like, you know, sometimes a sort of naughty campaign, in terms of, you know, challenging our employers in a way that we, but eventually we won and Chaplin became independent, their organisation didn't want to run it any more, so we formed a management committee and um er carried it on but um *biscuit* that's a bit, *biscuit*, then I had to, yeah I worked for Lambeth council for a little bit because I um, because I had been made redundant but they, we were job sharing at Chaplin for a little bit, I became, I was the deputy senior play worker at Chaplin. There were two of us but for a while they said they only had resource for one post, so we shared it. But that didn't work for me money-wise, so I went and started working for a.. *Biscuit*. At the very end of the last Labour government where they were still some resources for disabled children I worked for Lambeth Children with Disabilities team, but in with CAMS, the Child and Adolescent Mental Health Service, a sort of home-school, family support and behavioural support service for children with autism and er, so, and, severe learning disabilities, *biscuit*, working at home and thinking about that, I basically, I'm challenging behaviour and understanding behaviour is communicating and supporting children to em develop new skills or have different, try and resolve some of the challenges for those families and children that were resulting in behaviour that was potentially restricting their lives in different ways and to try and find, understand that behaviour as communication, so that was a team that I think no longer exists any more that was a bit of an experiment but I missed, I loved doing that, I loved the families that I worked with but I did, I'm a play worker and wanted to, and an artist and um I did a residency at that point at the um for the South London Gallery um called, which was the, where I was in residence on, in a barber's shop on the Sceaux Gardens Estate, just behind the South London Gallery.

I worked with the children and young people on the estate to um er map and research and investigate their play through like (partic..) like through a load of creative things and we turned

the *biscuit* the barber's shop into the er a sort of three dimensional map of their, of their play on their estate and er also like it was a centre for playful responses to the world around them. Um *biscuit*. And then that was also a challenging time because as you know shortly after that residency there was a big fire on that estate and several, some of the children, like not all of the children, lots of the children witnessed that and it was quite a difficult, traumatic time for the whole community and two of the children who'd been involved with that project died in that fire, which was the Lakanal House fire, but and then I sort of worked in some of the West centres after that because I knew, you know I had that relationship with lots of the families and was a play worker and recognised that in those traumatic, in those traumatic spaces children's, the needs of children are often missed and so in, not deliberately missed but not given the, not given attention where people are trying to cope with losing their homes and their possessions and finding housing and um the sort of distress of that, the trauma of that, the trauma of that, then doing play work in the middle of that was, felt important.

Um, I think one of the things to say about the South, the mapping event at the South London Gallery, it was like, it was that idea of events without outcomes and the fact that you, that you trusted in children's imagination and you set up a load of stuff and then trusted it was gonna work, that something was gonna happen but you didn't know what that was. And *biscuit* it's definitely something that's carried on for us. Matthew often talks about a beautiful moment at that event when one of the technicians was just, accidentally was repositioning a spotlight and the children noticed that and started following it and trying to reach for it and jump for it and then this game emerged between the technician and the children where he was moving the light around and they were jumping around and reaching for it and it was like a sort of amazing, trying, you know trying to catch the moon. That had just, nobody had planned that, nobody had defined that, designed that, it's about understanding that you just go with the flow *biscuit* and then within TourettesHero, going with the, going with tics, and they were some of the first creative experiments we did where, rather than have a conversation like this where we *biscuit* largely ignore the tics, instead we went with them and let them tell their unusual stories unfold. *Fuck*. *Sausage*. Some of the, within our practice now, some of the, some of what we do that I feel most excited by is where we use tics like my neurology to generate involuntary text. And the poetry of that, it's really hard because it's like I er that coming from my brain is important and a big moment for me and partly why I think I relate to the 'Not I' text is, part of my progress as an artist and as a human being was understanding that Tourette's was part of me and was coming from my brain and my tics. Before that I would always talk about them as the tics, the Tourette's and lots of like accepting how you live with a voice that you don't have control of *biscuit* is a really, and words that aren't communicative straightforwardly is a really challenging place to negotiate, particularly as an adult, because you sort of, because of the variety of um responses and judgements that, that then comes with, *Fuck*. *Biscuit*. And sort of the lack of anonymity and the sort of standing out in public space and, you know I don't feel like, I'd often feel like talking about Tourette's and talking about my impairment and talking about disability isn't always a choice, it's a tool for living. And in a way being a performer and doing that on stage or doing that in, in, in sort of public speaking, it's just you hit more people at the same time. And there's an element where it's you know that, I value conversation

deeply but I also recognise that talking about Tourette's has changed my life in terms of having the confidence to do that and explain what I need and ask for help when I need it and understand that that independence isn't about doing everything for yourself, but about being in control of the decisions. *Biscuit. Sausage. And fuck it.*

And lots of my learning around that, and how I came to feel confident with, you know before TourettesHero, where that process started was through things like BBC Ouch! and I feel a great sadness that we've lost Ouch! as a disabled-led platform, the way that it used to exist, because it allowed me from the safety of my home to engage with disability culture in a playful, funny, really accessible way. And to be introduced to disabled artists who then shaped my, my expectations of myself, seeing, you know, Mat Fraser and Liz Carr um at Liberty Festival, watching Katherine Araniello, the Disabled Avant-Garde videos um Amazing Art is one of my favourite videos of all time, they just, that I found it very hard to find experiences of Tourette's and disability reflected. Part of the reason we started TourettesHero because I just, there wasn't anything that reflected the humour and surrealness.

A: *(Lots of tics in background)* You were talking before about how you had that conversation with Matthew where he said you should make yourself creative. Did it then go right we'll start TourettesHero tomorrow? Or.

J: I don't think there was loads of gap. *Biscuit.* There was obviously a little bit of gap. I think that was part of a conversation for Matthew encouraging me to starting to see, we experienced a gap, we experienced going to events that sort of have a more traditionally supportive model, like conferences for people with Tourette's where neurologists give detailed presentations to a room full of people shouting, a kind of acknowledgement of the humour of that and the weirdness of that, like why are we doing *this*? Who's getting what out of this? So, and both of those things definitely have their place. But I did feel like the humour and weirdness of my experiences weren't being reflected. And, so I started writing, so Matthew, we tried TourettesHero, we started talking about it as a website and there's a, the main goal was to share tics for other people to make art in response to and we had a go with hundreds of images and poems and you know these lists of musicians who've responded and film makers, so that was the sort of intent and so Matthew's saying to me you should start practicing writing. And I was what d'you mean, what for and he'd been talking about a blog for ages, but I didn't really know what one was at that point. It wasn't a common part of the language that everybody would know about in the same way that it is now. And I just thought it was like a news area on the website, and he's no you should start writing a blog about, that's gonna be important to give the, to give the context of lots of the stuff that we're doing, to give the wry humour and to make sure that people understand about sitting in the right place.

So I started writing and, and I hadn't written since school and had obviously had a relationship with writing that was not always good. But it became an incredibly important part of my life. And particularly important because it helped, I think before that I would have always drawn from the negative experiences. I'd be able to talk about the times people had hurt me and

discriminated against me and the challenges of that would have been, they were all instantly available to me. What writing every day helped me realise was all the spontaneous support in conversations, beautiful moments and as well as the challenging bits, and that, and I was able to see them in a new way. And also, and difficult experiences I would be thinking in my mind well I'm going to be able to write about this and how am I going to do that? And again, it gave me opportunities to reframe those and feel strong at points where things were hard. Um and then *biscuit* one of the other things that happened was my tics had really started to, had already been intensifying for several years which isn't sort of a natural progression. It does go up and down in the course of someone's life, but my tics, I started working at Oasis in 2010, went back into play work and worked there as the, full-time as the project co-ordinator, so I was responsible for running three play sites, an adventure playground, a nature garden and a go-kart track, but were mainstream services at the point where I got involved. And then being informally supporting disabled children and their families for years and years, but I recognised that disabled children weren't having equal access to them and so er I fund raised for er the inclusion projects and then Matthew came and ran that as the inclusion project manager and we, Oasis is now operating as a sort of amazing, fully-inclusive play space.

But in the process of that my, in 2011 I started experiencing increasing episodes, tics that affected my mobility, tics that affected , that meant I would suddenly lose complete control of my body and speech. I had some support from Access to Work but not a support like I had a support worker two days a week and I had no social care *biscuit* and I, at home until I, and I was increasingly, and I was living in a flat up, you know six flights of stairs with no lift and with deteriorating ability I felt very trapped and then I er *biscuit* I was supported to apply for access to work, my employer was brilliant and I got to experience being managed by a quiet, strong female manager who managed in a way that was very supportive and gentle and I learnt a lot from her, (from what I'm experiencing now?). And access to work and the inclusive environment at Oasis allowed me to keep working and doing the job that I loved at a point where that felt impossible and would, like I didn't think that was possible at the beginning, but I was supported to see that that could happen, that very, you know, adapted to that um *biscuit* But for a long time I had, was much more independent at work than I was at home, couldn't take any leave because I had access to work supporting me at work, but at home I was put upstairs by a support worker on the Friday night and then had to stay there until somebody came to take me down on a Monday unless I had, you know friends or family came and got involved. So I think then *biscuit* suddenly realising that it was time to um you know think about accessing support. It's really hard to know at what point to make those decisions, and how to do that. I was very lucky in that I'd worked in those professional settings, but still doing that for myself was a very, I didn't know how to do that.

And I think that that's , lots of those systems are really invisible to people and invisible to people who need them. And you know, I don't see that that's going to change um from a structural level so I think as a disabled, with disabled people as communities we need to make, we need to share the knowledge about those systems and to keep doing that and challenging that and doing that in like as broad a way as possible to try and catch some of those people

who you know I feel very clear that there is a large amount of institutional discrimination that is not acknowledged about who accesses what and how. And *biscuit* the hierarchy brains and you know the role of *biscuit* fluent, fluency in terms of your language, in terms of getting what you deserve and I certainly think that there are some local authorities *biscuit* who you know, certainly in recent years *biscuit* basically you know divide up support not on, not on needs but on the risk of people taking legal action, how able someone is to assert their rights to certain services. And that's you know, that's not on um. *Fuck. Sausage.* Um but I think, I'm certainly living through an era, the era of the first two years of the cuts as a disabled person was very unsettling, watching equalities being rolled backwards.

A: Can we come back to that

J: I haven't got, probably only got another five or ten minutes in me in terms of energy.

A: That's what I was thinking, so can we go back and fill in some little bits. At school how did other kids react?

J: I was largely supported by my peers, some difficult bits in transitioning, particularly moving out of London was hard for me, I was very part of a community in London and part of a playing out community. And um Milton Keynes is a city and built on those amazing ideals, but it means that people are more spread about. Um but, I feel like my peers were really respectful of lots of, and supported lots of difference, as I've seen lots of young people subsequently being often discomfort around disability and the horrible bullying and reaction and reactions that some children experience from it often stem from the, *biscuit*, the approach of adults. Adults have a huge impact on that and, and creating environments where children see difference understood and supported within the adults who are involved in providing their care, education, support, wellbeing is important, like I felt being a disabled play worker was a really, and being able to have those conversations was important because I wanted children, particularly disabled children to see difference being understood and supported. *Biscuit. Hedgehog.*

There was definitely some experiences that were less positive, but I do remember going on a trip to the Old Vic theatre with school, one of the only times I'd sort of been to the theatre at that point. And er sitting and realising that I couldn't sit still and that I shook all the way through and suddenly my peers noticed that in a way that they hadn't noticed that within a classroom, probably because my teachers kept letting me get up. Suddenly I, I really struggled and I left that performance of, I think it was Henry V or something at the Old Vic feeling that I wouldn't, theatre wasn't for me(..) Fifteen, it was like that's done. *Biscuit.*

A: You referred, I think to crip time. Is that the name of a..?

J: Crip time is the sort of academic or, it's a way that some activists and academics talk about disabled people's experience of time. *Biscuit.*

A: I got that correct. The estate you were talking about.

J: The Sceaux Gardens estate.

A: Say that again?

J: Sceaux Gardens I can give you. I think it's saux, I can give you a thing from it. I'll give you the thing and it was...

A: And the house fire

J: Yeah the Lakanal House in Camberwell in 2009.

A: I remember that.

J: Obviously, it's just across the road from here, you can see it from ..

A: Amazing Art - is that a thing?

J: Yes, it's Katharine Araniello's Disabled Avant-Garde, there's one of her videos which I think is called 'Amazing Art'. I'm pretty sure that's what it is, that was a really significant reference for both Matthew and I. And we both love that video. Basically it's Katherine and her collaborator, whose name I can't remember *biscuit* right now, they're using all the disability language that is like cliched, they throw everything in there. And then Aaron has a big pencil,, you know it's like Aaron's profoundly deaf and then he's got this massive pencil strapped to his head and he's doing this, it's so funny and so confusing for non-disabled people (..) And I can see some of what we do, we are really drawn to those.

A: Did you go to that exhibition at the Gasworks Gallery at the Oval? They did a series of videos, like sort of parodies of other things. One of whom was er what they call those two brothers, the bad boys of Young British Artists

J: Yeah, oh yeah yeah, the Chapman Brothers.

A: The Chapman brothers. They did that thing with children with penis noses. Katherine and Aaron did this thing where they took like it was something where they were actors, and set up this sort of backstage chat with the two of them with these strapped-on penis noses.

J: It was just, I love that, lots of their things made me feel less isolated because you know so much of what you see presented about disability and the experience of being a disabled person on telly and the press is so flat and dead and tragic and it's really hard to position yourself within that. Seeing content that didn't. And that's why the internet was brilliant, felt particularly powerful for me at that time because while lots of my physical world was shutting

down because of support or because of my own worries about people's reactions to my tics, actually my networking connection with the disabled art world was rapidly growing, and was able to do that rather than you know chat to my house when I got bored with watching Columbo. Um *biscuit*. I suppose, I was going to say something about. So TourettesHero as an organisation, I feel like we work across art forms, we work with museums and galleries , we work with, you know I haven't got much time left.

A: I'm saying let's stop now and do another session sometime.

J: Okay. Alright. *Biscuit*

A: Because I think there's quite a lot to talk about. Tourette's Hero and 'Not I' .

J: Yeah, yeah, yeah, you want to get it all then let's do another day cause I'm, I'm completely done for now.

A: One thing I'll ask you then which you might want to think about is I've found it quite interesting what people say about when they first call themselves disabled.

J: Mm-hm

A: Which is often a lot later than you might think. Mat Fraser is really interesting about how he went from being a punk and a crusty to being a disabled person and consciously made a decision.

J: And I would describe myself as politically disabled.

A: I'm gonna ask you about that as well when we get to the politics. Let's stop.

J: Thank you.

Ends

Jess Thom: Transcription 2

Part One

J: *Hedgehog*

A: It's recording.

J: *Lovely. I love cats. Sausage. Good afternoon welcome to Legoland Windsor please insert your sheepdog after the tone. Beep. Biscuit. Biscuit.*

A: (Indistinct.)

Bringing

J: *The moon, the moon ran off with a springer spaniel called Dave. I love cats innit?*

A: Right we got to..

J: (..) *Indifferent to cats*

A: As far as Sceaux Gardens.

J: Yes.

A: Where do we go from there?

J Um, so er, so that was probably, that was the, that was at the brink of me bringing my self-identity as a play worker and my identity as an artist together. So I think that happened first, understanding that *biscuit*. My practice as a playworker and my creative practice were equally important to me and as an inclusive playworker. But that they sat well together and that it was also around that time that Matthew and I first started working together on creative events for um for children that we were working with. And that came out of our, of us working together at Charlie Chaplin and increasingly we put on events that gave children creative opportunities outside of the playground environment. So we did a, one of the first things we did was a, set up a sort of annual film-making screening at the Ritzy cinema, where children from Charlie Chaplin would make films and throughout the year and that we'd also get, screen films made by other disabled young people, and that we would take over a cinema, one of the cinema spaces at the Ritzy, it was sort of red carpet event for the children so that they could come and watch their films in that environment.

That was one of the first things that Matthew and I did together and then shortly after that we did something called 'Something out of Nothing', which I think would have been in 2009, nine? it would have been earlier it was 2008, so 2008 around the same time as I did the residency on

Sceaux Gardens Estate. Matthew and I put on our first big creative event in a art gallery, which was in the South London Gallery. They had a space, they had a gap in their main exhibition space and so we basically decamped the playground so that about seventy children, disabled and non-disabled children from Charlie Chaplin arrived at South London Gallery and it was an event, *biscuit*, it was an event without outcome, so it was not directly funded by anyone, so it meant that we weren't worrying about it having to do anything. *Biscuit*. It was an experiment. We created a space where there were costume-making practitioners, musicians, live musicians, digital artists and DJs and painters and collage artists and there was an accessible ramp that went down the middle of the like catwalk style platform ramp that went down the middle of the gallery that was fully accessible. And then every child when they arrived was given, and every adult, everybody in fact all the staff were working in the gallery that day, every single person was given a white paper sort of dust suit and the invitation is that this is your starting point, you can use any of the resources or any of the things here to create whatever, like to make something out of this nothing. And our hunch was that the imaginations and energy of the children, we could trust in that, we didn't need to do anything else. And it was absolutely, it was an absolutely brilliant event, there's a lovely video of it and it ended in a sort of parade along this ramp of all of these costumes. But there were also all of these amazing spontaneous unplanned moments. Matthew has written a chapter in a book called *The Cat Came as a Tomato*, which is a publication about play and art. And he wrote a chapter on events without outcomes. *Biscuit*. Because that's something that we were interested in..

A: Right. Right.

J: Working within the voluntary sector, I think increasingly getting frustrated by how restrictive some, there's a danger of um fulfilling funders' requirements rather than the needs of a particular community. And so we wanted to find ways that do that, that respond differently. But he talks about this brilliant spontaneous moment where one of the technicians was moving a spotlight around. Just because he needed to move it. But then the children started chasing it. And so this game emerged between the technician and the children where they were trying to reach for it like they were trying to catch the moon. And it's those, it's that, it's using that beautiful spontaneity of play and the theory associated to it around play cues and like responding to people when they, when they reach out to you creatively in whatever way, And that, that can look a million different ways. But that idea of responsiveness, spontaneity and being person being focused on the people in the room rather than feeling restricted by the sort of constant need to demonstrate outcomes.

Of course that all, that all has a place. But I think that that is really interesting in terms of, it was us starting to recognise the power of creative events and actually how one day events has, could have a legacy beyond just them having nice memories. Because one of the ideas *biscuit* that underpins Tourette's Hero is the idea that positive memories are protective, that if we give disabled people, particularly disabled children, positive experiences in public space then they have something to draw on when they inevitably hit barriers. Words like resilience have been politicised and used by other, by the current government and the polit.. You know some of those

things are about putting it back on communities to manage without the right support. But actually there is also I think a really important role of *biscuit* making sure people have the tools to withstand the barriers and keep going, because that is hard. And having positive experiences are key for me, feels like the key part of that I know that from experiences I've had that being able to feel connected to um to a network of other disabled artists having the tools skills resources to communicate my experiences has meant that I've been able to process and manage changes or challenges that would have at other points in my life really floored me.

Hedgehog. So that was um. And it was probably *biscuit*, that was also at a time when my tics had been intensifying from my early twenties which was around, say from around 2000, 2001, they had begun intensifying. *Biscuit.* By 2006 they were enough of an issue for me to have sought diagnosis. I knew I had Tourette's long before that and that is probably the point where I was, they were having significant impact on my life and my visibility in public space *biscuit* and I'd come across things like BBC Ouch. And that was another. For me, finding BBC Ouch and being able to read and access the voices of disabled people with a range of different experience and impairments in funny, really accessible, really engaging ways but being able to do that from home without anyone else, without having to make that step that felt more, felt more public, it meant that I could build my identity as a disabled person quietly and then *biscuit* get to a point where I was able to articulate and express that with the language of the sort of disability, rooted in the sort of language of disability activism. So I think BBC Ouch was a key player actually in, in its old form, a key part of me. And it is, and there's some.. And that's also why I think online space is really crucial, I don't think it's the only way, cause I think also for example, it was through BBC Ouch that I found Liberty Festival. It was through Liberty Festival that I um came, you know saw people on stage and saw the depth and richness of the *biscuit* disability arts scene and started to at that point I had been increasingly restricting my life. And that's from, that's from my early, from my late teens not staying very long in places, constantly having to manage the impact of my impairment without feeling like I could share that with anyone. Well you know I did share it with, I did share, I did talk about it, I certainly found it very difficult to talk about, it was an a, it was an upsetting part of my life rather than now it feels like a very positive part of my identity. *Sausage! Biscuit.*

And I'm *biscuit*, I'm really interested in how, in how that process can ch.. (..) And I've now, like I was a disabled child and definitely I received you know specialist, specialist education, I had a number of different, you know different diagnoses that didn't lead to Tourette's definitely understood in the context of neurodiversity. And I remember when I was at my first primary school, which means that I would have been under eight, looking for information around the things that I was experiencing in the children's library. And the closest that I remember bringing home a book called 'Mentally Handicaped', it was such and such is mentally handicapped, it was a book for children. And using that language and talking to my mum, is this me. So I was looking for that as a child. What I didn't get was any good answers or good representation, that's not necessarily the fault of my family, because I think there was a lot of openness and discussion around you know I had lots of things explained to me really well, but I, but it was around what was wrong with me rather than anything about the sort of barriers that I

would encounter in the world. It was just interesting because lots of parents when they, you know when they first receive diagnoses what they worry about is the future and for me, I think lots of that is about worrying about when parents say they're worrying about the future they're worrying about their children living full active lives and being able to participate within their communities. They're not necessarily worrying about the future in terms of you know. Obviously it's different for different conditions but I think that there's an element where if I'm curious if we change *biscuit*, if we change those first moments, if we change the way children and families receive diagnosis we can tweak some of those early encounters including making sure parents understand the social model, potentially including parents understanding their role as advocates, and being given skills and resources to do that and being honest about the challenges which they face, I wonder if there is a, if there is a welcome rather than a sorrow around diagnosis or a sort of here you go, go and get on with it. I wonder if, I feel like we could drastically change the outcomes for the children who will then go on to be disabled adults and then become *biscuit*, become the next generation of disabled makers and creators.
Sausage!

Um so yeah 2008 was 'Something out of Nothing'. Matthew and I continued to do a number of sort of, like to develop creative programmes for the children that um we were sort of directly working with on a day to day basis. But, increasingly we felt frustrated in that we wanted, frustrated by the constraints of a sort of the larger organisations and wanted to make something *biscuit* that fitted our ethos and that succeeded or failed based on our energy. And so we created Tourette's Hero in 2010, with the support of UnLtd the social enterprise organisation, so that's U.N.L.T.D. rather than the disability arts commissioning Unlimited. And, and er I remember that we got, we got five thousand pounds grant from them for Tourette's Hero and it enabled us to create a new website for the first Tourette's Hero costume to be made, for us to have a logo and basically connected us into lots of amazing pro bono support and advice and then mentorship and legal support. But the very first sort of partnership agreement between Matthew and I was written on a napkin in a pub, in a café next to the UnLtd offices which I don't think were very accessible, which is why we met in this café. But um that's I think and right from the outset of Tourette's Hero I very much saw that as part of my creative practice as a project that embodied my life as an artist.

And that what I don't think I would ever have anticipated *biscuit* was how, was how that's enabled me to grow and develop my practice. At heart I would describe myself as a participatory artist. But then performance definitely became an increasing part of what we were doing. And I think lots of that is around being drawn to the, drawn to barriers and drawn to the sort of invisible barriers and trying to draw attention to them but also to offer *biscuit* offer ways to bring them down or get round them or. The, oh fuck all gone the memory. Yeah, so that's, so that's the start of TourettesHero. *Sausage!* And I've talked a lot about the sort of the very first, the conversation that was a very sort of transformative moment for me when Matthew describes Tourette's as a crazy language generating machine and told me that not doing something creative with it would be wasteful. And that, that sentence really got in my head in a particular way. But it got in my head in a particular way on top of all the reading that

I'd been doing on all of that, you know, stuff that had been brewing and the right sentence helped me understand my body and understand Tourette's as a potential collaborator with me rather than just as something, as a problem that I ignored *biscuit*. And I think that's one of the things that we're very overt about when we were *biscuit*, recently discussing our sort of aims as an organisation and absolutely everything we do goes beyond Tourette's as a specific impairment. And I totally subscribe to the view that we don't necessarily, that disabled people don't need to talk about their impairments and people don't have a right to know about my impairment. However *biscuit* one of the interesting things about Tourette's and how we've chosen to work with it is it feels so intrinsic to my, to my practice and that collaborating with that part of my neurology and makeup um and using the things that are the product, that essentially could be, would be described in a medical context as symptoms of a condition as springboards for creativity and catalysts for making art means that I feel like I'm acknowledging my impairment in a particular way that isn't about, isn't about educating others and is much more about using the creative force that's within me. *Sausage! Pitta. Fuck a goat. I'm good at talking for a long time without a question, hey? Sausage.*

A: It's fine. I mean

J: *Pitta bread!*

A: I'm, I'm, I'm happy to

(Break?)

A: We got Tourette's Hero setup. Did 'Backstage in Biscuit Land', did that come too. Or is there more to tell before we get to that?

J: No, well there's about, there's, so we created TourettesHero in 2010 and actually we made 'Biscuit Land' in 2014. And we had already put on several large scale events including...

A: Tell me about those.

J: Our first event as TourettesHero was in December 2010 and was on the snowiest day of the year. And we had 300 children invited from all over the UK with and without Tourette's to a secret superhero lair where they came and we'd made a sort of emergency video that was about Tourette's Hero doing a sort of emergency broadcast which was about this impending dull wave and the character called Bureaucrat who was threatening to overwhelm the country with dullness and make us all conform, he was obsessed with checking best before dates and making sure people's shoelaces were tied. So we did this callout that was calling children to come and saying that we needed the energy and creativity of children to come and create their own (superior) identities and come and save the world from the dull wave. You'll be pleased to know that they were successful. But that's an example of what was emerging for us is that we use narrative within lots of our events so that children have a way of buying in. There's often

an under, like an underpinning ethic that is, so for example we did a big event in 2014 called 'We Forgot the Lot' which was a collaboration with Tate schools and teachers team and was at Tate Britain and and um was access.. Again it was a national event and we worked with eleven artists who made work in response to the idea of, created activities and installations and things that the children could engage with on the, based on the idea of changing your environment to meet your individual requirements.

So the idea of changing space to meet your needs was the underpinning theme of the event. That wasn't spelled out to the children but there was this narrative of Tate needs, Tate has revamped all of its gallery spaces but it's forgotten how people would look at art and how people would move in galleries, so we need you to come and help us. We invent the way we look at art, so it was get involved with the artist and make sure that nothing gets forgotten. So increasingly I suppose the way that performance crept into our practice was through the role of narrative in communicating ideas, in getting children excited and feel like they have power within the particular space. And *hedgehog* so we in 2014 we went straight, so my book 'Welcome to Biscuit Land' came out in 2012, which was based on, which used quite a lot of writing I'd been doing on the blog. I was writing daily up until around 2015, when it became increasingly hard to maintain that level of daily writing activity. But writing was something that I had never excelled, I had never found my way with, throughout education and when Matthew first started telling me I should practice writing I had for the blog I had no idea what a blog was, I thought it was a news area. So I'd been listening to him chat about the sort of blog and then he was eventually you should start writing and I was like Writing? What? And yeah, but writing every day about my experiences with Tourettes was a phenomenally important um part of me becoming an artist who feels confident and has the language and confidence to talk about their experiences. And again I think was key to me both identifying as disabled person but really connecting with the social model. I actually had been taught about the social model in school. And I had been taught about it in training but I think it wasn't until I actually started writing and then reading that really meant that I connected it to my day to day life. Before writing the blog I would easily identify all the really negative difficult or upsetting experiences that I'd had in public. But writing every day also made me notice the spontaneous support, the huge quantities of laughter, the surreal experience of disabling, that disabling barriers can sometimes bring in people's, the brilliant and unusual and upsetting interactions about *biscuit* standing out in a particular way and *hedgehog*. So I wrote a book, don't know what we were doing in 2013 but I think we felt busy. And then in 2014 yeah we, Matthew had been to the Edinburgh Fringe with a totally unconnected project, performance project in 2013, we were both working full time at Oasis Play in Stockwell which is a children's organisation and we had been, I started there in 2010 and in 2011 we'd formed the inclusion project that I'd fund-raised for and basically we took a mainstream service that was an adventure playground, a nature garden and a go-kart track and worked to make it inclusive at every level for both the children and the staff and to make sure that, to formalise, to formalise and equalise the offer to disabled children. Oasis had been informally supporting disabled children for years but they weren't able to access in an equal way to their non-disabled peers and the inclusion project was a key part in changing that.

We both, so we made 'Backstage in Biscuit Land'. In 2011 Matthew and I had gone to the theatre to see a Mark Thomas show called um 'Extreme Rambling', which was about Mark Thomas walking the Palestinian separation barrier. And I had not been going to the theatre. I mean, I wasn't a big theatre-goer.

(DOORBELL)

In 2011, yeah, I went to a show at the Tricycle Theatre which was a Mark Thomas show called 'Extreme Rambling' which was around him walking the Palestinian separation barrier. I hadn't been to the theatre in a long time and considered it something that I couldn't really do any more, it hadn't felt like a space that I could be in safely. I'd had several tricky experiences in comedy clubs predating, around that time, including, my friend Ruth who also has Tourette's, we'd gone to a comedy club together and then several weeks later I remember, I was at work and somebody was oh we read about you going to the comedy, you were in Time Out, Time Out London and I was well I don't know what you mean and it was basically a comedian who had been performing had been asked about difficult gigs and had talked about a gig that Ruth and I were at and quoted our tics in a way that without, I don't think without really thinking or realising how identifiable that made us and how instantly by somebody shouting Leg on Penis, not only did I know that you were talking about me but so did all the people I worked with, all my friends and family, it was, that was actually before Tourette'sHero, it was before I'd made a decision to be, to talk publicly about my experiences. So that lack of invisibility and the sort of constant need to explain to people around me about my tics in order to have access to basic parts of life, I think made Tourette'sHero feel like an essential um way of combatting lots of the negative stuff around Tourette's.

There's huge amounts online of people pretending to have tics and so much of that is just not funny. And rather than complain about what was there we wanted to create, we wanted to do it better, create a real cultural alternative but also claim the market and have that, make sure that the humour was being firmly held by us and used as a tool. And I think when we started Tourette'sHero we had no idea how other people with Tourette's would respond. But we've had incredible support. There's been very little difficulty and misunderstanding of our position. I think that that is because of where the laughter sits and how clearly that is (...) and how careful we are about how we then communicate that externally and you know that doesn't always work, we talk a lot to journalists about language and you get brilliant articles with the headlines written by someone else. Can then be pretty bleak. But the thing about lots of stuff being online now is that you can sometimes get them to change where it expressly goes against something that we've been specific about. One of the great things about being part of a collab., Tourette'sHero being an organisation rather than me as an individual artist and being part of a team is that some of that work, some of the real emotional labour of that can be held and taken on by people who care about it and understand it on a really deep level but who it doesn't have to be me all the time. Which is what's made the way that Tourette'sHero works sustainable. And it's very much a sort of equal collaborative project. People often,

Matthew's contribution is often not understood as easily because he's not a public face in the same way. But it is, there's definitely this synergy between our creative, between our sort of individual practices that means that together I feel that we can both be better artists if that makes sense. Some of that is around how we divide and share labour. So the, I wrote about the experience, I had this difficult experience at the Tricycle Theatre where despite having done loads of prep beforehand and Mark introducing me to the audience at the start of the show I was still asked to move at the interval and sit in the sound booth because people were threatening to not come back unless I left or was moved. And it was obvious that Mark wasn't comfortable with that happening at the time and by the time that had been asked of me I felt I had no choice but to move. And it was a deeply humiliating and upsetting experience and I sat and watched the rest of the show in floods of tears in this sound booth behind glass and I made a promise to myself I would never set foot in another theatre again, I was like well that's it, this doesn't work, it's not for me. Um but actually through conversations with Matthew and through him going to the Edinburgh Fringe in 2013 and thinking he was gonna lose a,...) He thought he was going to lose loads of money so he had a pleasant (...) At least I'm gonna watch, get watching a load of theatre out of this, so that I can get my money's worth. So he focused on trying to look for work that was disabled-led or that was by disabled artists and found very little but did find a show by Robert Softly-Gale called um 'If These Spasms Could Talk' or 'If These Spasms Could Speak', which was sort of um and Matthew came back (..) 'We should make a show and take it to Edinburgh'. *Hedgehog*. It was something, we'd been, you know we'd at various points been approached by different TV production companies and sometimes had worked ideas and presented them to different people and making a show and taking it to Edinburgh was initially part of the sort of TV idea. But it got more and more sort of warped from our original focus to becoming something that, by the time it got to the commissioners we were very relieved that it wasn't commissioned. You know I needed a celebrity mentor and all sorts of, you know it just didn't feel right that actually in the end we were relieved that it didn't get commissioned, we were like oh well we should still make the show anyway.

And so we basically did the big project with Tate in March or April 2014. And then immediately afterwards, the weekend afterwards we launched the kickstarter for Wellcome, 'Backstage in Biscuit Land', which was made with Jess Mabel-Jones, me and Matthew co-devised it and we also got funding, a research and development award from UnLtd,. I think our background in play meant that we and our lack of knowledge of how you made theatre and of arts, more formal arts funding meant that we um we made the whole show, we didn't, we missed out the research and development bit, made the show and took it to Edinburgh and it was a, made a finished thing on five grand. We were then supported to sort of develop it more and be able to tour it which was phenomen.. Brilliant, I can't say the word phenomenal. *Biscuit*. I'd never, I saw more theatre in my first week at Edinburgh than I'd seen in my life to that point. And we knew, we knew in making Biscuit Land that we wanted to take a show that talked about Tourette's, my experience more broadly, but also particularly talked about theatre and our belief that making art inclusive makes it better, makes it stronger, richer, deeper art and makes the experience of it more interesting for everyone.

Um. *Biscuit*. And then it, I think we'd, taking it to Edinburgh was our end goal. We hadn't thought about that, we hadn't thought about what that would mean beyond that. And I'd never, I'd never performed in that way er before but I think there's a strong element of play work that is about performance, if you can hold a circle time of 60 children that don't have to be there, you can probably hold a room of paying adults who've chosen to be there. So yeah, so we did that. And then, what I think surprised us was firstly how warmly enthusiastically it was received by other creative people and other people's interest in making their work accessible as a result, Daniel Clipson had a relaxed performance of 'Tree' at the Old Vic, Nina Conteh and various other people who saw it then started holding relaxed performances. Which is something that I don't think we'd thought about. Mark Thomas is also committed, he, ever since the experience at the Tricycle, he has always had relaxed performances and broader access as part of his runs. And, so that was one surprise and then the other surprise was you know the ability to, was the interest in touring it and taking it to other places. I think within Tourette's Hero the idea of art as a catalyst for change and the idea that you can use creativity to present stuff in a way that then changes people's thinking (...) was something that we very much believed in but 'Biscuit Land' is a really, 'Backstage in Biscuit Land' is a really great example of what that means in practice and how wide that reach can be.

A: How so?

J: In terms of like getting, like drawing people's attention to those barriers and getting people, and people wanting to make work, other artists making work in different ways. Being able to take it to venues and you know them having to hold all of the performances of 'Backstage in Biscuit Land' were relaxed, which meant that wherever we toured would do a load of work with those venues about what that meant. So it was a great way of, Matthew will often describe our work as a Trojan horse and I think that's quite a good way of thinking about it, whether it's events, whether it's performance, everything that we do really is about it sort of presents itself as you know, a piece of art in a particular way but alongside it will often go a load of training, thinking, action, activity that is aimed at sort of changing the systems that it's existing within. *Hedgehog!*

We then did a load of touring in 2015, or we did a little bit of touring in 2015 and then had the sort of national, and international, tour of that show in 2016. And we just at that point, like our boss at Oasis was incredibly flexible, incredibly supportive and I feel very connected still, very connected to that organisation. But it had just become untenable, us essentially doing two full-time jobs and it was putting pressure on both of us. And the opportunities that TourettesHero offered meant that it would, it felt for that to really grow and for us to really see where that could take us we had to leave Oasis. Which was a very sad, very sad er thing for me because not, having that connection to play had always been really important. That's still very present within TourettesHero, we still support Oasis in various ways and still feel connected to those places and those teams of people. But it was a big change. And I think for me it was a big, a big challenge around identity and I think I found it harder to make that decision than Matthew. Because there was definitely part of me that liked challenges,

challenging people's assumption that I, there's so many people assume I can't work or don't work or, and I liked having a job that was a sort of project management job that didn't straightforwardly relate to my impairment, that people could, that challenged those assumptions really easily. I just didn't, you know it took me a long time after leaving Oasis to really be able to confidently answer the question, you know what do you do, like I didn't know what to say like do I say in terms of Tourette's Hero, I felt I think, I worried about what that meant for my identity, particularly something that related so closely to my impairment.

But I also realised that loads of that was my, about my concerns about other people's perceptions rather than rather than (know) what I was actually doing as a job. So yeah, I think that was a, that was a, you know, even feeling very, you know, identifying as a sort of politically disabled person, it's interesting how, how sometimes the language of you know, other people's language and ideas can really easily be internalised and sort of get into your thinking, it can take a, it takes a lot of energy and attention sometimes to unpick that and work out I feel this way not because that's inherent in what I feel but because I'm, I've got all these concerns about, that relate to other people and not, and not to me. So that's, it's hard sometimes to get to know, to separate the sort of rubbish from the real feelings or perspective.

But leaving Oasis was a hugely important decision for TourettesHero in terms of the scale and scope of what we were able to do. The ambition with which we were able to work. We got offered, you know, we made, we um,. So what we did in 2015 we me and we made Broadcast in Biscuit Land, which was live from Television Centre, which was, went out on BBC Four. And to go from being asked to leave a theatre to being live on TV with a you know a choir of um people in car t-shirts, giant inflatable cats and dogs and biscuits, I mean that was quite a, that was a really just mind-blowing moment for me. And just before, just as Kirsty Wark sort of introduced us and just before we went live I led the sort of audience in a chorus of Don't fuck it up, fuck it up, fuck it up, don't fuck it up. And then we did it!

So we did that, we toured. We then were thinking a lot about what we wanted to be next and lots of people were sort of interested in our next show in relation to the performance. And there was no, no intention for us, we didn't, we still don't consider ourselves a theatre company. We are, we work across art forms and I feel very lucky with how easily we can jump, you know, from Tate to Battersea to Barbican and it's like we've, I feel very lucky in terms of the, and it's important to us to maintain that flexibility, that responsiveness and that ability to move across art forms and to do, to make the work, to do what's right for the work rather than trying to fit into any particular discipline. But we had a long, Matthew had introduced me to 'Not I' years before Tourette's Hero when my tics had first been intensifying and so it had been a reference for us for a while and had repeatedly sort of come up at various times and it came up within a, in a you know discussion with another theatre company who were asking me to get involved with a project that they were doing which was around a classic text um that didn't, that we didn't do in the end but within that conversation we mentioned 'Not I' and someone around the table said oh you'd never get, the Beckett Estate would never let Jess perform that. And I think that was the point that my fate was sealed. 'Cause Matthew came out of that meeting and

was like so "'Not I", I wonder how that works with the equality act' and it was like, we were really, he became fascinated by you know that side of things and as to sort of whether we would get, who gets a say in performance work and in what roles. And for a long time we thought well if they don't let us perform that I would put a ques.. Make a show that would put a question mark on the end and be 'Why Not I?'. Um but actually the more I read it and the more I looked at it, the more interested we became in demonstrating, modelling how you would make a really intense piece of theatre um accessible at every level without reducing its intensity, and to really challenge the cultural curation that was happening round relaxed performance *biscuit*. The idea that, you know, relaxed performance, it was alright for the Lion King to be relaxed, but nobody would do a Beckett play as a relaxed performance. So it's like alright, we'll do that. Um and actually the Beckett estate were very supportive of us and I think understood.

A: Was that right from the beginning or did you have to..

J: I think by the time, we were very careful in how we made the approach, we were lucky in being really well supported by the Beckett community, the academic and scholar community around um around Beckett's work were incredibly supportive of us and we did a lot of talking and thinking about the approach to air to Edward Beckett and the Beckett estate. And I wrote an email and so I think that by the time he, it was a very simple response. He said his sole interest was in Samuel Beckett's work being performed as it was intended, if we felt we could honour that then he was happy for us to proceed. And then we met him personally, had more detailed discussions. I think one of the things was, one of the interesting things was that actually was not the text being performed by someone with Tourette's that was the bit that was the most, that needed the most discussion, it was actually the integration of the British Sign Language, because I just don't think that they had been asked that before. Um and I think we felt a real responsibility because it's like if we get this (...) wrong, then that could potentially be a barrier, a more fixed barrier for loads of people in the future, if we get it right it's potentially opening that up. But we very clearly identified Mouth as a disabled character and neuro-diverse character and felt that it was right that she was performed by someone, by a performer who identified in that way. *Biscuit*. I was very relieved, because Beckett's famous quote was for god's sake don't act, which was a relief because I can't act. One of the things that laugh when people call me as an actor is that actually Tourette's makes me really rubbish at acting because I'm very bad at pretending *Hello!* I will call it out straightaway. But it's working with those, sort of, that's how, that's Tourette's becomes our collaborator, because it's those creative constraints that I think become really interesting. And that's definitely what we had with 'Not I', the challenge of the stage directions was it was like okay, well how do we, rather than worrying about how this has been done previously in other productions, because it feels like it was increasingly taking on alike, the, how it had been presented historically became the guide rather than Samuel Beckett's initial directions. So we went back to those and we thought how are we going to make this work for my body. And I liked that because that also fits with the social model idea that we don't, that people, to achieve amazing things, people that would look different for different types of body in mind and that we don't, it's not right to expect us all to do things in the same way because that's gonna mean that some people don't achieve

stuff, not because they can't but because they need to do it in a different way. Um and so by modelling, we hoped by modelling that we were sort of embodying those ideas. And challenging the sector to, and, there's an element where it's very hard I think now, well I hope it's very hard for a performer or director to turn round to me and say it's all very well doing relaxed performances for light comedy shows, but you could never do it do it for serious work. And it's like well, I performed that monologue while six or seven other people shout very, very brilliant things in the air. And it's been, and it has made me concentrate harder. It's meant my performance was better. All the things that I sort of said it was like oh that's actually true. I do believe that sort of, that that, particularly within theatre that live environment, the great thing about relaxed performance is that it, it really makes theatre live, or can do, in a way that um, it's interesting that I haven't been to the cinema in over a decade, because it's a much harder space to navigate than a space where you have real people, human beings who are able to respond in a more natural way. It's then supporting people to feel confident and it's that expectation, I remember a comedian saying um in a set, he'd been totally thrown by me being there, I had, he had been told but he hadn't met me in person which I wouldn't do now, he'd been told by someone else. And so he did this sort of fifteen minutes where he went, was totally thrown, asked me loads of questions about Tourettes including why are you in a wheelchair but all sorts of things that were very public in front of hundreds of people in an audience. But one of the things that he said that really struck me and has always stayed with me is, he said as a comedian you perform, you prepare for everything, you perform for hecklers and you prepare for people who are drunk but like you know you never expect someone with Tourette's in your audience. Why not? Why do we go to theatre and expect not to sit next to a learning disabled person, why do we expect, why are some, why are people with conditions like Tourette's having to make shows to occupy space or to have to actively advocate for their inclusion in these spaces. Because it's, audiences, one of the things that frustrates me is that companies say that not all directors are into doing relaxed performance. It's like well you don't get to, you get to make the work you do but you don't get to say who gets to see it. In my view. It's like you can't, you shouldn't be choosing your audience because it's like, if, okay if you are not prepared to do relaxed performance then list who you don't want in your audience, tell me who you don't want, because that's, that is the, and I think that that is the difficult thing about the exclusion of disabled people is that because there's this perception that, for so long the idea was that you gave access as a charitable act, as a gift, it was a nice bonus that you did for people rather than the right of everybody to be able to access our shared cultural space.

And that really, we're chipping away at that but it definitely hasn't been smashed to pieces yet. Which it needs to be. *Sausage!* I've done quite a lot today

A: D'you wanna have break?

J: Yes.

Part Two

J: Um what would you like to know next? Or what would you like me to focus on? I feel like..

A: How do you see the future? Where..?

J: Yup I can talk about the future. Yeah. Are we recording?

A: Yeah.

J: Great. *Biscuit*. So in terms of, in terms of future I think what's, certainly in the last couple of years what has been, what's been a challenge for me personally and sort of creatively is the sort of changing in my physicality, in my body and in my energy levels and in my pain. Um and so that means that having to sort of manage and adjust to new types of impairment and incorporate that, find ways that that is then incorporated into my practice and I that can still make the work I wanna make but maybe doing that in different ways, I think one of the things that that does, when you have reduced energy, is help focus your mind. So Tourette's Hero was built on just going relentlessly. And the idea that you get tired but then you can just, you recover and then you keep going. That doesn't work any more and there's a lot more, I think it means that we have to put more thought into how we are targeting our time and be, be a bit more strategic. Which definitely as we sort of grow and hopefully incorporate more people with, within the organisation so that we have increased capacity but also so that it goes beyond, we can support creative voices and disabled people beyond just mine. And, but also particularly I think one of the things that is unique about our work and our practice, or certainly not very common is the combination of play, visual arts and performance.

And I think in most of the projects we are talking about in the future that is becoming more and more the emphasis that we're looking at and we're looking at methodologies, we have a number of different methodologies for events that um mean that we can roll them out and do (..) Like tour ideas I suppose and events rather than performances. But also looking, er to really large-scale ambitious creative events that are a core, because we consider the events a core part of our creative practice, they're not just a sort of social add-on, they are part of the art that we make. Um and being able to yeah continue to develop ways that um visual art, play and performance can be used to create inter-generational experiences, but that also have access embedded within them. *Biscuit*.

When we did 'Invention in Biscuit Land', which was a Tate Exchange project on Level Five, where we..

A: A Tate?

J: Yeah. In Tate Modern we took over their um, the fifth floor of their new, their new building in 2016, no 2017, and um we basically, we took the play of Biscuit Land, we split it up out into the

different themes and so created them as activity areas, so physical areas that you could explore, there was a garden area, there was a welcome *biscuit* area, there was a bedroom area with autumnal, there was a bathroom area, there was a game show area. And in each of those areas children, you could go and add to them, you could go and play in them, there were lots of different activities that brought them to life and actually children and adults participating helped add to them and make the set. And then that set was performed in, we did a child-friendly version of 'Biscuit Land' twice a day, once a day sorry, and as a promenade performance, moving through these areas. And what that also felt like to me was that by the time that the performance happened the children had created these areas and were really familiar with them. And then saw them brought to life in a new way and saw a story told through them.

And there was elements, this is just a really extended touch tour. Like there's an ownership of the space through play, through making, through touching and feeling and really having the sort of multi-sensory environment that then means that this performance can land in a really, can land in a totally different way and can be accessed by people who might find a more, a different context challenging. So.. And it just felt brilliant and beautiful and like something that was definitely room to explore with other ideas.

And so there are a number, one of the things, the way that we kicked off this year, 2019 um was um by putting two weeks aside for planning and discussion. And it was the first time in nine years that we've done that. We've set that time aside in that way and Matthew, will who is the (...) Director and supported by the people that we work with and sort of crucial friends and allies and partners just had loads of time talking. We often talk at TourettesHero, Matthew and I for years have talked about this ideas shelf, which is basically an invisible shelf where we keep projects and it's like we put things on the ideas shelf and then they come off at, at the right time with the right people or the right money. But we work with an amazing live scribe who we work with a lot called Amber Anderson who brought our ideas shelf to life. So we basically told her the different areas and projects that were sitting on that shelf and she made that visible. So we then were at that point where we can really carefully think about which ideas we, we work on next.

A: I'll come back and ask you for DAO, but for this interview tell me a bit about the Battersea stuff.

J: Cool. *Biscuit*. So I suppose the things I haven't mentioned are, one of the things that Tourette'sHero has always been really thoughtful about has tried to balance the relationship is between, we're a Community Interest Company, we deliberately didn't set up as a charity, but in a social enterprise model. We wanted to have control, we wanted to have independence, we wanted to not be thought of in terms of charity but we are asset-locked and all of the proceeds go back into the organisation. It means that we can be flexible and responsive. If we make our own money we can then spend it in ways that we feel is needed within the community rather than necessarily having to keep changing to meet the agendas of funders. But, however, funding partners are crucial to grow the organisation, do particular projects at

particular times, but we're really careful about what we take on because we don't want to, we don't want to get tied down to a load of outcomes and delivery and lose our flexibility, which is a crucial part basically for what makes it interesting to us all I think.

But we, Matthew and I are the first joint Wellcome public engagement fellowship, which has been crucial for us to be able to have the time and space to engage more with academia, with disability theory and with academic discussion. Also we are exploring ways to share knowledge that, that are creative and equal, both the sort of are equal I mean by people with professional and lived expertise can exchange knowledge in ways that are more non-hierarchical than previous ways that that happened. Um er, Will who is the first TourettesHero director is a researcher who specialises in sonic inclusion, so looking at how sound can be, exclude and include people. He is doing a PhD at the Helen Hamlyn Centre and that definitely feeds in to lots of the work um we've done lots of work with him and with young people with Tourette's around sonic inclusion, but that is an element of our work and research that's been continued to develop and I think lots of research around, there's so much focus on medical research I think it's really easy for research that's around the way that disabled people live or that we've like the way that we create environments just gets overlooked. So I think that that, exploring that and building evidence for different ways of doing things is something that we're keen to do.

So we've got the Wellcome Fellowship, we're also lucky to have um been supported by the Paul Hamlyn Breakthrough Fund, most recently again which is helping us take some of the knowledge that we're learning through the Wellcome Fellowship and put that into, embed that within our work, so that those ideas can really keep being visible in it and shares in ways that are in the race, so that our practice has that um can continue to grow but has that, is rooted in sort of careful thought about how disability is presented, talked about and the impact that can make in people's lives and also helping us think about formalising our offer to children and young people. What creative interventions can we do to try and change and connect families and children to welcome them into a community rather than that feeling like people are being sort of left to, so many people are finding it, people who acquire impairments, people who get diagnosis, there's so much of that that's about trying to find everything out for yourself, so many people have to do the same learning over and over again. In terms of energy as a community it feels like we're not necessarily great at making sure that the work doesn't have to be redone all the time by individuals. Does that make sense? I can't quite communicate it but because the narratives around disability are usually so limited it means that actually when people experience these changes in their body and mind they often have to navigate around all those negative thoughts, ideas, emotions, responses from other people before finding more celebratory or positive ways of um identifying and thinking about their experience.

So it just feels like a lot of people have to do a lot of legwork and it's over and over again and I don't think that that has to be, I think there are ways to change that. So with the sort of support of those organisations I think we're really being able to have a sort of more ambitious vision for what we can be doing. Part of the other um big project we've been working on for

the last two years is um the relaxed venue project, which is an Arts Council England Changemakers funded project. So Changemakers was thinking about diverse leadership and looking at groups who are under-represented in arts leadership and invest in projects led by those people. And so we've had a collaborative working relationship with Battersea Arts Centre since um the creation of 'Backstage in Biscuit Land'. And we sort of shared that there for the first time and they supported us in that process. And so we continued to build that relationship with them so it felt natural to formalise that with the relaxed venue project. And I just felt frustrated with sort of singular relaxed performances and the way that they, that they're sort of there as a tendency to make them exclusive performances for disabled targeted audience but not inclusive, necessarily inclusive of non-disabled people. There was also a tendency for them to really just focus on children's work. And that seems silly, to foster a love of theatre amongst disabled children but then not to be able to access a range of age-appropriate adult work as they get older.

And I think that, and also they were being put on at times that if, there was no consistency of offer and they would often be put on at times that were seen as less pop., you know less popular and there was very little choice and consistency. And I think there was this, it felt, still in some respects feels very much like a sort of charitable gesture that's done for people who might, you know people might find it hard to follow the traditional rules of theatre etiquette rather than understanding that they are a core part of our audience.

So working with Battersea Arts Centre in a really collaborative way and wanted to develop a methodology that flicks that assumption rather than it being a case where you have performances that have the traditional rules and expectations sort of uptight, very normative idea of a singular normative body who is the audience member. And with occasional relaxed or accessible performances. We just wanted to flip that assumption. What happens if you say that all our performances, all of our programme takes a relaxed approach and will meet the sort of seven core elements of a relaxed performance. Unless there is a clear creative rationale why not not. That's sort of a simple, it's a simple flip with a more complicated lot of chatting and learning and adjusting that needs to happen underneath, underpinning it. But I feel really excited by where we've got to and Battersea Arts Centre will launch as a, a fully relaxed venue in March 2019 with a festival, a two week festival of rest and resistance, which is the first time I've curated anything of that, of that length. And, and the hope is that that is a methodology that is flexible enough to go across different organisations, (but it's) not just theatre but is also usable within a museum or gallery context. And that it's also designed to be able to be stepped through by really small organisations with no resources or bigger organisations with a load of resources. Because actually I think some of the principles remain the same. What you can invest in it obviously makes a difference in terms of the impact. But I think that there are some small steps that cultural institutions could make to have a radical, that would make a radical difference in terms of access.

And what's frustrating is that often it doesn't feel like there is that willingness to change. I think there, there's an amazing space called DIY Space London which is a Peckham DIY space

and it's totally volunteer-run. Um and a really small venue, no resources, just using a space and the sort of DIY ethos of doing it yourself. But they've achieved a sort of attitude is everything bronze mark for access. And they've done that by building ramps and by doing it all in a really, without any resources and seeing that and going to that space made me feel really intolerant of other larger organisations. I just feel a bit fed up with excuses. Because actually it doesn't, it isn't that hard and the knowledge isn't that difficult to find. I think there is a confidence issue, but sometimes I definitely feel that there are lots of excuses rather than a sort of real recognition that there is a sort of legal, social and creative and financial reason for making sure that access is considered an asset rather than something you do if you're asked about it. *Hedgehog. Sausage. Bucket. I love dogs. I love tellytubby tits. Biscuit. This is a poem about bears. The bears fucked an octopus. The octopus had gloves on. Biscuit. Nobody smells of wee but everyone smells of smiles. Fuck a goat. I love pitta bread. I actually quite like pitta bread, don't like cats. I don't mind cats. Fuck the cat. Solidly indifferent to cats. Sausage.*

That feels like a natural end point for me, I don't know if there's stuff that you've.

A: I think so.

J: *Fuck.*

Ends