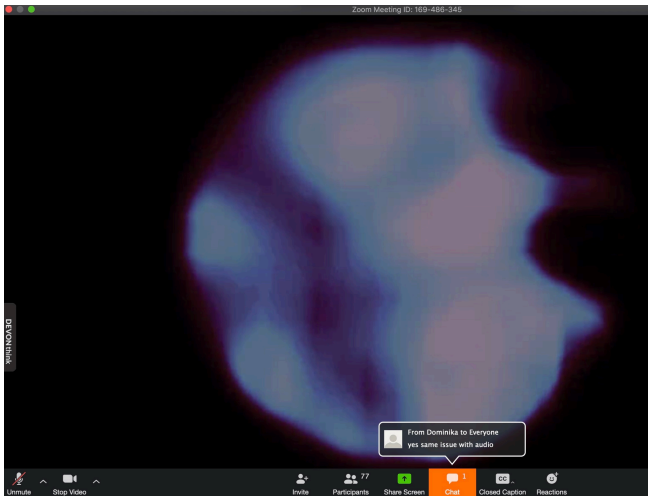


# JESS THOM

Interview Date: April 20, 2023

mage Description: Text reads “The Remote Access
chive” atop a screenshot of a Zoom shared screen,
which shows a work of art by Yo-Yo Lin. The art is a
white and grey blob on a black background. The
ottom shows a series of grey buttons, along with an
orange chat button that is lit up. A speech bubble
above it “From Dominika to everyone” says “yes
same issue with audio.”

## KEYWORDS

2010, 2014, 2016, 2017, 2020, 2021, celebration, COVID-19 pandemic era, creativity, disability arts, disabled kids, disability community, festival, Digital Heroes of the Imagination (DHOTI), in-person, joy, play, playground, pre-COVID remote access, remote socializing, Touretteshero, United Kingdom

## IDENTITIES GIVEN

white, woman, disabled, neurodiverse, chronically ill

## LOCATION

United Kingdom

# Introductions

Kelsie Acton:
Thank you so much for doing this. Can you start by telling us your name, and where you call home?

Jess Thom:
[chest hit, vocalization]
Yes, I'm Jess Thom, and London has been my home for a long time.

Kelsie Acton:
Awesome. What words do you use to describe your race and gender?

[cross talk]

Jess Thom:
[chest hit, vocalization]
I'm a white woman with curly hair and very cool wheelchair. I identify as disabled and neurodiverse and chronically ill.

Kelsie Acton:
And do you consider yourself to be part of disability community or disability culture?

Jess Thom:
I consider myself to be part of disabled communities, plural. And I have a deep love for disability culture. Yeah… I'm all for disability culture, I think.

# Heroes of Imagination and Touretteshero

Kelsie Action:
So, just for the transcript, I'm going to say that this is a companion interview to my interview with Katie, where we talked a lot about Heroes of the Imagination, which is a project rooted in play. Stop me if I'm getting any of this wrong. But about creating protective memories that disabled kids can

use as shields against the ableism they encounter. And this project went through a number of versions in-person, digital and hybrid. Do you mind describing the in-person version of this for me?

[Jess chest hit, vocalization]

Jess Thom:
Yeah, and I suppose it's worth acknowledging that Heroes of the Imagination has roots that run deep and parallel with the very start of Touretteshero, where it wasn't necessarily called Heroes of the Imagination. But it essentially was. I suppose it's worth acknowledging that Matthew, he's the co-founder of Touretteshero, and I worked for a long time on London's adventure playgrounds together for the inclusive adventure playgrounds for disabled and non-disabled children.

We started increasingly together, working on big creative events for the children and people at the projects that we're working on, and partnering with organizations to do takeovers and create encounters and do residencies at those spaces, and to really think about imagination and play and artistic practices and cultures, and how all of those linked.

And we continued to work on adventure playgrounds until 2016, quite well into the life of Touretteshero. We still are connected to many of those spaces and people [chest hit], and I suppose in 2010, when we co-founded to Touretteshero, that Christmas, December 2010, we held our first big children's events at Michael Tippet School in Lambeth, and it was a superhero-themed event. Children from all over the country were invited to come, and particularly children with Tourettes were invited to come and help us counter a “dull wave” that was spreading through the UK.

We made a video explaining about the “dull wave”, and there was a sort of character of the bureaucrat who hated imagination, and only likes gray, and that we needed children's energy, creativity, and imagination to help protect the world and our communities from the dull wave. So it was a narrative event. It was the first time that we had done that as Touretteshero, and it was the first time we've done that in our own right. I think that lots of what we were excited about with Touretteshero, was doing lots of the things that we have been doing within other organizations, but doing them in a way

where we have control of the ethos, and where things succeeded or failed based on our ideas and energy and approach.

That event took place on the snowiest day of that year, and loads of children couldn't make it. Loads more families traveled with ridiculously challenging journeys to get there. One family, I think, traveled five hours, and arrived halfway through the event, but still said really amazing and positive things about it.

At that event there were logo-making stations, costume making stations, moments of parade and playful moments, spontaneous moments, lots of stuff where we followed the direction of the children and young people, and loads of amazing photographs. And there was a software studio where kids could sort of create their superhero identity and then go and share it. I suppose it's worth acknowledging that we are very thoughtful about…we walk a careful line around superheroes and disability, and I think for us, it's always particularly about children and young people feeling powerful, rather than saying “your disability gives you special powers.”

It's about saying your perspective matters. We can all feel powerful and have power in different ways, and we're interested in you taking ownership of your power and using it to do the things in the world that matter to you. I think that sort of superhero is a great, because they're things that lots of people that children and adults can both access and connect with, often very quickly and easily, across a range of different backgrounds and experiences. It doesn't require loads of explanation; kids often, and people often get that very quickly. I think that intergenerational aspect of it is really important, because it's about all people at different points in their life, thinking about who they are and how and who they could be, and what bits matter to them. It's an opportunity to talk about identity and agency. I think that, within lots of our work, lots of those things are really important. But there are complications, nuances around that, and risks, in terms of the history of disability and supercrip thinking. Often, the problematic element within lots of that, for me, is non-disabled people. We’re interested in interfaces where disabled people are defining the parameters of their power. But I think we are increasingly thoughtful about how we frame that with kids and with young people.

It wasn’t called Heroes of the Imagination then. But it was definitely the same event. And then, in 2018— we've done a series of big events. We did We Forgot the Lot with Tate Britain in 2014, which was eleven artists taking over those gallery spaces and inviting children to come and imagine and help us think that Tate had forgotten all the rules about how you behave in a space, how you move in gallery spaces. And so we had this opportunity to reimagine them. It’s worth noting that Tate didn’t really forget, there was a whole moment where we've been planning that event, but about year and a half, and then it came to the point of like, the copy was signed off, and the media team went, “We can't say that Tate forgot anything.” It's like, “Okay, but this is an event for children. Disabled children. It’s called We Forgot the Lot. The whole point is that we're saying that we need children to help us imagine how we enjoy and look at and participate in creative spaces. It’s fine!”

But yeah, we’ve done We Forgot the Lot, we've done Adventures in Biscuitland at Tate Modern, and we've either done or about to do, Brewing in the Barbican and Brewing in Battersea. But in 2017, I think, we were invited — we were talking to Imagine Children's Festival at Southbank, initially talking about a very different project, a project that, again, had its roots back in that very first event. The evening after that first event, I think Matthew has said “The next event we do is going to, we're going to make a big mountain and we got to dive.” And it was this idea that had been around for a long time, about permission to change your environment, to meet your requirements and be about “big” physical constructions in space.

It was very clear, partly because of the festival nature of Southbank, because of their lead times and things, that it wasn't going to work for us to make everything new. And as a disabled-led organization, at that point, it just was like, actually we really want to do Imagine Children's Festival. It feels important for us to place something in this space as a disabled company, but it needs to be something we know is going to work. And so, Heroes of the Imagination was a reimagining of that first event, and things that we've done before. And so we created there, and every child got a superhero passport. That supported them to think about their logo and their costume and their character. And there were different stations, and huge numbers of children. I think a couple of thousand children participated in that. We also did a lot of work with Evelina Children's Hospital, which is down the road. We went and worked with their hospital school in the

hospital, as well as taking Heroes of the Imagination packs to their dialysis unit there, and so I suppose that remote access element was embedded there from quite early on. We were thinking about the children who couldn't be in those big spaces, which is very 2020 of us, but it was 2017.

I think that we had a big team of facilitators, a lot of playworkers. It was colorful, chaotic, and joyful. And that's been something that we have run in a number of other places on different scales. We did it at Bradford, as Women of the World Festival (WOW) Bradford. We did a version in Portland, Oregon, when we were there for a residence in a circus space there. I don't think we did flight, but we definitely did superhero layers as part of that. We bring different facilitators in for those different elements, and often we'll use local facilitators. The last in-person version of that was in Scarborough in 2020, which was a partnership with Scarborough Museums Trust. A lot of that, I suppose, also leads into lots of the ways that we work. By bringing big plays or events or shows or doing something that's inviting specific audiences into a space. Alongside that, we do a lot of training and facilitated conversations around access. Which is how we talk about often the senior leadership training that we do, that helps senior leaders have really frank, open conversations around access; their worries and fears, what's working and not working, and essentially aims to for them to understand their power, to really engage with disabled-led of thinking about disability, and to understand, to have buy-in. It's essentially the layer that needs to happen, really, before you do any training, because if you do training without having that sort of leadership buy-in, then it means that it floats. It doesn't have the same frame around it to really be able to be more radical in the change that you're imagining for an organization.

The training and those conversations, we often find, are really useful, if you then partner with those people actually in the space, so that people can put those skills into practice immediately. And also where you can be like "These are community. These are all communities, all already, but you're not serving them. And actually, this is why it matters." I think that was some beautiful, really powerfully articulated feedback from the event in Scarborough which we were then able to feed into a training session the next day, which is like, "this is why it matters."

I think when during the pandemic, Touretteshero, as a disabled-led company, as a company with CEV [Clinically Extremely Vulnerable] team

members and leadership, locked down earlier than lots of other people in the UK. We had to make difficult decisions to not tour at key moments. But I think we were also very quick to understand that the barriers for lots of disabled people have moved radically overnight and accessing basics was really tricky, and it was really tricky for our team. Just accessing food, accessing PPE, feeling that you would be able to access healthcare. All of those things were just not givens at that moment, and so we very quickly moved to essential work only, and by essential work only, for us, that was like we're concentrating and understanding essential work to be what the relates to the survival of our team and communities, and that puts disabled people at the heart of that.

We've been quite careful to talk about loads of what we did really, publicly, because it hasn't felt…because lots of people were talking about what they're doing publicly and I didn't feel clear on why it was being publicly discussed. I think we were also very aware of our own capacity. We needed to set up systems and do what we could, but also within the understanding of having to manage change and increased barriers and our own and the well-being of our team. There were things that we did very quickly from that first week of lockdown that we were providing up until the summer of 2021. We were providing a food delivery service for disabled Londoners that addressed both access barriers to food and financial barriers to food. For some people, they were the same, and for some people they were different. But it was a disabled-led food service, and it was responding. We were using the Touretteshero van and team. And that started off very naturally, being like, "we need to just make sure our networks of disabled people that we're connected to have food in those first weeks," and that grew. We also did things like the lockdown play funds, where we were thinking about funding play equipment for disabled children, for in summer holidays, where they were not able to access the range of play provisions or services that they might otherwise access.

So there were a few different things like that. We generally weren't taking on any creative work except for some creative projects that related to prioritizing disabled-led opportunities to speak to what was happening within our community. So we did do Pandemic Postcards. That was led by Alex Bulmer at the Harbourfront Center. And we did do Vacuum Cleaner's Heart of Glass project. So we weren't doing a load of other stuff, and we also weren't trying to replicate our services. We do big events, playful

events for children, young people. It wasn't going to work too straightforwardly for our communities to try and replicate that on Zoom. That was pointless. But what we did to do was think about why we do those events, and that's about moments of pride and connection and joy. And so for Christmas, 2020, we did Biscuits in Space, which was a boardgame that went out to a hundred disabled children, young people with Tourettes, and it was about moments for them to cut come together in their families to celebrate neurodiversity, to celebrate playfulness, and to have moments of silliness and connection. It was like, “what are the reasons that we do something? And then what's the best way to do this now?” rather than “what is a ‘now’ version of what we we do other times?”

We were very careful about not taking on new work, and certainly not taking on new partnerships, but we were very aware that there was definitely a group of people missing, particularly learning disabled young people, with lots of online stuff and these opportunities. We were approached by National Youth Theatre, who we had not worked with before, and what they had was loads of young creatives who had time and energy and imagination, and wanted to do something, and we also knew that there was this gap around multi-sensory engaging remote activities, particularly for learning disabled young people, but for disabled young people generally, and it was like, “Oh, maybe there is an opportunity.” National Youth Theater had understood those things, but they didn't necessarily have the disabled leadership to think, how do we shape them into something that doesn't just feel like a group of non-disabled young people doing something worthy, and actually feels like something that is building community in interesting creative ways.

They also had been doing lots of work within schools, around inclusive training and thinking about who was underrepresented within their programs, and how to support learning disabled young people to think about creative careers and possibilities and artistic lives. And I think that's interesting, because lots of that does definitely go back to the very, you know, pre-Touretteshero role, what Matthew and I were interested in doing for the children and young people. We were working on playgrounds, thinking about and encountering artists, and lots of that stands from our own memories and experiences of growing up in the city, in London, and having access to creative projects at key moments in our lives. It’s funny, we're definitely meeting lots of young people that we worked with on those

playgrounds, who were disabled children, who are now, amazing disabled artists. There's a number of them, and that feels really exciting. Actually, we had an amazing conversation just before the pandemic with a young person who we bumped into at The Albany in Deptford, who is now just doing incredible work. He talked in really interesting ways about the importance of those play spaces and access to artists at those moments for him. So we were tentatively like, “alright, this connection with National Youth Theater feels good.” I think it helps that it felt very quickly like that there was lived experience of disability within their teams. It felt like there was a depth of understanding and an openness. It also helps that I got that contract, and it was written in a way that made me feel confident in that partnership, and it also taught me something about the importance of contracts for the messages that are embedded within them, and how and how powerful that could be.

It would be very easy for us at that moment to say “no” to things, and we were having to say “no” to lots of things. But it felt exciting to say “yes.” Then everything, sort of happened with Digital Heroes of the Imagination which happened in and around Peckham and was developed remotely, including, we made loads of drawings, and then they were animated by Eric, who was our production manager. He was also living with me because he got stranded here from what he was doing in Spain, and he was supporting me with loads of stuff around who was in this space. We also worked closely with the National Youth Theater. We thought about Heroes of Imagination as an event, and how there would often be stations that would look at different things. We updated the booklet so that it would so that it had a range, a standing body and a wheelchair-using body, and updated that so that worked within the plan for this event, which was essentially that all the that young people would get a box of resources. Some of it was also, to be quite honest, a sneaky way to get creative resources into children's homes, so that they had pens and paper and tape and fabric and stickers. All of the things. It was always about giving them lots of those options, so that there was plenty for siblings, so that there was plenty to be used in lots of other ways. Getting resources into homes was definitely as important as any other element of that.

The other idea was that the young people get a box that was a big size. It had “Top Secret” on it. It had a gold envelope in it, which had a letter that used words and pictures and symbols to introduce Touretteshero, and their

mission. Each had four other boxes that were your identity, your costume, your space, your moment, and that was essentially thinking about different aspects. Some of that was also to understand that for some young people, a box full of resources would have been overwhelming, and to break it down into more manageable chunks. We did partnerships, and The National Youth Theater recruited teams of mentors and teams of buddies, creative buddies and creative makers. The makers put together the boxes, and we thought about those being really multisensory, having lots of options, having lots of room to customize chairs, and also for them to be able to use in people's homes. The idea was that they were mainly going directly into childrens' homes. Sometimes they were going into schools and then going home, depending on whether they were the childrens' key workers or not, whether they were still receiving some school services.

And for the creative buddies, we did training with all of the young creatives who were involved in that project. We talked with the makers, we talked through the approach to the boxes, and why certain materials were chosen. We talked about the importance of choice-making and an abundance of materials, and having lots of scope for reusing and remaking and reshaping. The creative buddies were then partnered with individual young people in their homes, all in with classes, and they would then do a Zoom session that was then supporting and going through one box at a time, and each session dealt with a different box, and they were supported to think about their superhero identity, think about a costume, think about where they were like, what their background and environment was, and then think about their moment, their message to the world.

Kelsie Acton:
I'm just going to do a time check. We wanted a hard stop at 5:30.

Is there any last thing you desperately want to tell the future about Heroes of the Imagination?

Jess Thom:
[chest hit] Sorry. I'm terrible for rambling. I've been talking unstoppably.

Kelsie Action:
No, it was beautiful. You hit, like, five of the questions.

Jess Thom:
The cat has come, I think. I think he reached the calendar. I suppose… what are the things?
I suppose the things that were interesting was that my colleague -

AI Voice:
Could you try again?

Kelsie Acton:
[Laughing] Sorry!

Jess Thom:
My–! Stop it! We'll have to remove the cat.

## Backstage Moments

Jess Thom:
I remember my colleague, Bill, saying something interesting around that, this moment where they have all the creatives in the Zoom room. National Youth Theater supported this, because they had lots of experience in managing those digital spaces by that point, for young people, and there were spaces that they'd come into if they had a problem. But there was this moment where they were getting ready to go out into all the sessions with the young people, and Bill described that as being like it felt very much the backstage moment before you go out. It was funny how that translated.

Digital Heroes of the Imagination continues, and it continues in lots of different ways. I think what it has in common with the very first incarnation is that it has a sort of prep video, which is about capturing children or people's imaginations and getting their buy-in and what the mission is. It is about resources and creativity and agency, and it's about the process much more… it doesn't matter what the thing is. It's about having those opportunities and those moments of connection. As a play worker, what I've had to learn as my body and patterns have changed, is that I've had to learn to play in different ways. With the pandemic, I had to do another round of like, how I play and how I connect. I think that's exciting. And the thing I suppose I want other disabled people to know is that actually, changing your practice, evolving your practice in response to your own

requirements, or the requirements of the times you're living with, often leads to really interesting, exciting development and knowledge of yourself and others.

Kelsie Acton:
Amazing. Thank you so, so much. It's been such a pleasure. I will email you the transcript in a little bit. Have a lovely evening.

[Jess chest hit, vocalization]

Jess Thom:
Thank you so much, I love the idea of this archive. So thank you.

Kelsie Acton:
My pleasure.