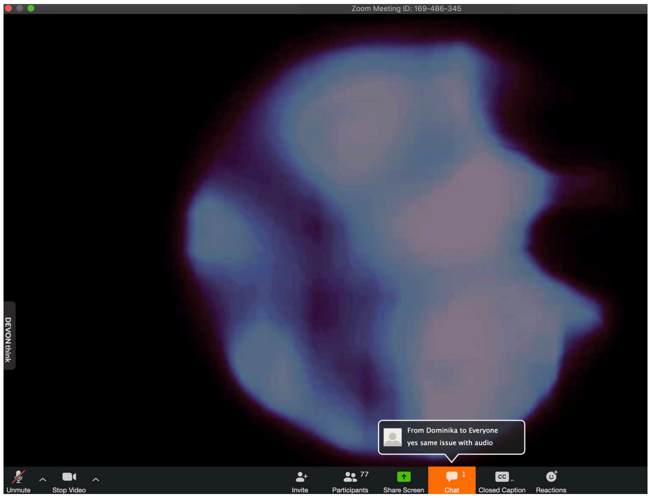

From Dominika to Everyone
yes same issue with audio

KATIE GOLDFINCH

Interview Date: April 12, 2023

Image Description: Text reads “The Remote Access Archive” 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 bottom 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

belonging, celebration, collaborative access, COVID-19 pandemic era, creativity, Digital Heroes of the Imagination (DHOTI), disabled kids, disability arts, in-person, joy, photography, play, playground, Touretteshero, United Kingdom

IDENTITIES GIVEN

white, nonbinary, queer, disabled person

LOCATION

United Kingdom

Introductions

Kelsie Acton:
Amazing, so…Do you mind starting by telling us your name, and where you currently call home?

Katie Goldfinch:
Yeah. So, my name is Katie Goldfinch. I am living in London at the moment, Southeast.

Kelsie Acton:
And what words do you use to describe your race and gender?

Katie Goldfinch:
I'm a white person, and I normally say that I'm a non-binary person, or just a queer person overall, to kind of all encompass.

Kelsie Acton:
Do you mind giving a brief visual description of yourself for the video?

Katie Goldfinch:
Yeah. So I'm, yeah, as I said, a white person, I've got a ginger mullet at the moment, and I've got a blue jumper on, and I'm sitting against like a pale blue background.

Kelsie Acton:
Cool, and this is Kelsie conducting this interview. I’m a white woman. Late thirties. Today I am wearing blue ear-defenders and a white mask, and I am set against a white background.

Katie, do you identify as a disabled person or a person with a disability? Any other words?

Katie Goldfinch:
Oh, I'd call myself a disabled person quite strongly and proudly. Yeah.

Kelsie Acton:

Amazing. Do you consider yourself to be part of disability community or disability culture?

Katie Goldfinch:
Yeah, big time. I think anyone who's been— who is disabled or chooses that word to describe themselves automatically are part of, has that right to kind of involve themselves in disability community, and is part of that, whether that's passive, or more active. But I feel quite actively entrenched in it, and disability culture, specifically like the arts — the disability arts scene in the UK at the moment. That's owed largely, that kind of cultural aspect, is owed largely to my involvement with Touretteshero, though I do have a personal practice that's kind of fallen by the wayside at the moment. But I was kind of dipping into stuff with Shape Arts and so on before my involvement with Touretteshero. So, yeah, I do consider myself to be both professionally and personally involved in those kind of scenes.

Kelsie Acton:
Do you want to tell us a little bit more, maybe both about your personal artistic practice and also what you do at Touretteshero?

Personal Artistic Roots

Katie Goldfinch:
Yeah, so my personal practice I graduated from a photography degree in 2020, so in the middle of the pandemic, and my focus kind of shifted very strongly at the end of that, towards a kind of centering, disabled joy and collaboration. And yeah – co-production with disabled people. So it kind of culminated in a project called "It's a Jungle Out There" which is kind of speaking to my lived experience and my mum's lived experience because she was my subject, like my visual subject at least, in the photoshoot we did. And we did that kind of in the midst of the pandemic and it was kind of a surrealist absurdist approach to kind of a rebuttal to pitiful, charity models of disability. So we did that together in lockdown, but it also kind of spoke to our collective experience working in disabled-centered environments. So you know, like accessible playgrounds or SEND [Special Education Needs and Disabilities] schools, or kind of, yeah, that kind of environment. And it was just a very playful, brash, vivid and garish kind of approach, rather than

the kind of monochrome blue-tinted, pitiful children in need, kind of approach to disability.

So that's kind of what my personal practice is, it's been in a - it's stagnated recently because making in a pandemic when you're not motivated by like an academic push – is kind of difficult. But I'm getting back into it.

Touretteshero Roots

Katie Goldfinch:
And as far as TourettesHero goes, they created a solidarity worker position in response to the pandemic, which felt very significant that a position was created that wasn't just directly like a COVID response. It was solidarity worker with the idea that ideally that it would be a disabled person who ended up being in the role– so I am disabled, working with a community of different disabled people, within a disabled led team, responding to the needs of our own community. So it wasn't outreach, and it wasn't charity work. We're not a charity, very consciously not a charity, but we kind of– and it's not outreaching because we're not necessarily reaching out to a non-disabled audience, certainly that isn't our primary focus. We're reaching within our community in a kind of effort of solidarity. And so I joined during that kind of I think, early 2021 is when I joined? So we were kind of used to the pandemic by that point unfortunately, but responding and thinking about how we could provide help to disabled people and our community in terms of essential resources, but also creative responses**.** So like young artists' funds and commissions and digital traineeships, and various other methods of consultancy and things that were kind of – it was a learning curve for everyone involved because it was a new pandemic. And a new position for me, and a new kind of position for the company. So I kind of have shaped it over the last three years, and I'm now a solidarity coordinator. So I'm kind of higher up in the company, and overseeing more. Which is nice, but it feels kind of – it feels kind of like a sofa seat that you've sat in a lot so it's shaped around you. But like ultimately, if you left the sofa, it could be taken on by someone else.

But at the moment it feels like I'm in a very big groove within a very small organization at the moment.

Kelsie Acton:
That’s a really beautiful metaphor. I love that. [laughs]

Katie Goldfinch:
[laughs]
Yeah, like, it's not my seat always, but it is at the moment, you know? Like it's– I'm not expecting to be in it forever and ever, at the moment I'm very happy. No question about leaving or anything, but I could pass that on to someone else, and the sofa could get reshaped to someone else's. But for the moment, it is a very comfortable groove that I'm very happy with.

Heroes of the Imagination

Kelsie Acton:
Nice. So tell me a little bit about Heroes of the Imagination

Katie Goldfinch:
Yeah, so, Heroes of the Imagination was originally a pre - COVID project which I was not part of, but it was a kind of a creative response to - because Jess is “Touretteshero” - she's got the superhero persona, which is not to be conflated at all with the kind of like euphemisms around disability of superheroes, and overcoming and overpowering, nor the rhetoric of “it's not a disability, it’s your superpower!” None of that. But it’s kind of more of a playful and anti-charity model, and more like, less dull approach to disability and kind of thinking about the powers that are inherent to kind of – and playfulness, especially with Jess and her tics. So kind of playing off of that and that character that was built. The project was built around kind of responding to that and getting children and young people to think about what their superhero name would be, what their costume would look like, what their story might be. I think they had some adult sidekicks as well. There were little iterations of that. There was one up in Scarborough on a small scale, like 50 children. And there were larger scales, 2,000 children over a period of like a weekend, and that was a physical iteration of it. And I think it, yeah, it was very successful, and I know that within the team, the stories of it are just overwhelmingly positive with kind of children being able to grab a hold of you know what makes them unique and what's not, you know, if you're fed, a story of what's negative or what's to be fixed about you actually flipping that and having,

you know, a superhero in a wheelchair, who's ticcing, kind of coming over to you and saying, “Right, let's play with this, and let's see what makes *you* unique, this is what makes *me* unique and great. What makes you unique and great?”, and kind of flipping that narrative. So that was what happened originally. And then we kind of created digital heroes of the imagination (DHOTI) . And the imagination in response to that later on in the pandemic.

Kelsie Acton:
Cool. You can tell me if this is a question for Jess or someone else. But you talked about the political roots of Heroes of the Imagination. Where did it start - is there more to where it started? Sorry I'm tired, and the questions are, gonna get like, progressively more terrible. Sorry. [laughs]

Katie Goldfinch:
[laughs]
That's completely understandable. I mean, yeah, I do think this is a question for Jess, but I can speak a little bit to it as well, but I think she will be able to provide – I mean, like, I will answer it, but also definitely ask this to Jess as well, because I think she'll have a lot of insight. But one of the things that is pretty central to our practice, and Touretteshero just in general, is that positive memories can serve as protection, and that we kind of appreciate that in an ableist society in a just – for any kind of marginalized group as well – that you know that is not built to kind of accept and uplift, different marginalized groups. We're gonna accept that these disabled children are gonna go into the world and face and encounter ableism and non-accessible environments and bad attitudes to disability, and we can't stop that. But what we can do is create this joyful, playful, ridiculous, embracing, accessible environment, where kids can remember actually, you know, this is awful, but do you remember that time that I was here with Jess, and we were making the superhero and I was talking about what makes me great. And even though this person right now is telling me this is awful about me, I actually can reflect on this and go “you know, this is, it's a protective force”. It means that we're creating protective barriers or emotional grab rails, as Jess calls them, to kind of steady yourself on and ground yourself on when you feel that bit lost and drowned in the kind of masses of ableism that can kind of surround you actually go, “Wait!” This is my anchor point, because this existed, and even though it's not currently happening, it's a big reflection”. And it kind of and also stems back – it's not an original idea by any means. Like the Black Panthers were doing it in

their kind of breakfast clubs for children and young people, like it's just a kind of a mainstay of a lot of solidarity or grassroots-based activism that we've kind of just kept as kind of a core principle and built up on, and thought, how can we provide these areas to, you know, to have little pockets of goodness so that people can reflect on them and be like, “yeah, it was fine once, even if it's a bit crap now”.

Kelsie Acton:
Yeah. So if I was a kid, what kind of things would we do?

Katie Goldfinch:
Alright. Yeah. Again, this is – Heroes of the Imagination is one thing, and I can speak much to Digital Heroes of the Imagination, which is similar, so I might kind of go off that but…

Kelsie Acton:
Yeah!

Katie Goldfinch:
With Digital Heroes of the Imagination – also, just noticed that my battery is about to run out, so I might just – let me turn my video off so you're not swaying around like a sea– like a ship, or whatever. Thank you. I think we should be good now.

Kelsie Acton:
Awesome.

Katie Goldfinch:
Cool. Okay, so yeah, slightly moved position. You’ll get a whole tour by the end of it.

Yeah, so with Digital Heroes of the Imagination I guess the main difference is obviously that it was in response to the digital needs of those same children, you know the need to play, because we're all very centered around play, Jess, Matthew, and Will met at an event– well Jess meet Matthew, earlier on. But they met Will at an adventure playground, and I worked in a different adventure playground for disabled kids, and then I kind of came together accidentally and formed this little play union. But when there was like – there's been several reports on like the access to play of children and particularly disabled children and then how that's been impacted tenfold by the pandemic. And yeah, so Heroes of the Imagination kind of thought, these kids have this need to play, and this need to access imaginative play, and how do we do that? We kind of got together and created, well we trained up makers, for at least in my phase of involvement we trained makers from the National Youth Theatre, who originally were digital and would kind of Zoom in to there and would be a buddy with a child or a young person. And they'd be a buddy and kind of, think about and brainstorm “What would your superhero look like? What would their story be?”.

And then, as the pandemic kind of changed, and schools went back into physicality, then the makers would go into schools physically and actually participate there, but with kind of like video prompts. So it's had different stages of being totally physical, and like 2,000 people and big events, and then we'd have smaller ones that were totally remote when schools were locked down, and then you have ones that are kind of hybrid. But you'd be paired with a buddy if you were a kid, and it come over and they'd ask you, you know what's your superhero name, what do they wear, what do they look like, and then you physically accessorize and think about it, and maybe there's a little booklet, there's a superhero booklet, there's little packs full of kind of materials to make your superhero come to life, and there’s kind of a mission statement from Jess saying that we need your help – well Touretteshero, obviously, not Jess – that we need to help save the world from excessive dullness and…

Kelsie Acton:
[giggles]

Katie Goldfinch:
Yeah, it's great. And the kids would kind of respond to that. And the makers are really more kind of made it happen because of their creative passion, and their kind of ability to kind of – If a kid was not engaging, to kind of think right, how do we then shift onto that and to respond to the communication needs of the child. Like they've been really, really responsive. And also we ended up realizing that teachers needed a bit of training to get on board as well. Because if you just shove in a load of makers, the teachers are more inclined to take a backseat, which is understandable, but limits the potential of the kids’ experience. So, having

a bit of encouragement was always helpful, and the teachers really got stuck in as well. And by the end of it that was kind of the celebratory photo shoot with a professional photographer where you'd kind of go, and with Heroes of the Imagination that was true as well. You'd have a photo booth in a physical space, and then, I think when it wa – I don't know how it happened that, like when it was fully online, but I think it was kind of encouragement to go and take pictures, but then certainly in the kind of hybrid-stage, if you will, there was a photo booth and people would go in, and with support and kind of pose with their fully formed superhero, and… And those kinds of schools, what we were going into are SEND schools, so they're all disabled children, often kind of, you know, more sensory-oriented, and more non-verbal. So, yeah, it's been a really interesting learning opportunity about how to engage different types of children with different communication preferences and methods, to ensure it still feels like a celebration, you know, vibe, and thinking about how we accessorize wheelchairs or mobility aids like to celebrate those as well as part of the person, not just as like an external aid, which I think is often what they're kind of referred to, you know. Which you know they can be, but are also a very important part to your existence and embodiment as a disabled person, so it's hard to separate it, and important to understand mobility aids as more than just objects. But yeah, that's kind of the vibe you go and you'd have a really great enthusiastic maker come in and really support you in whatever way that you needed to create the superhero and your story. That's totally, you know, led by the young person, and then prompted and supported as needed by the maker, and then celebrated in a really cool photo shoot.

And so, yeah, and everyone would have their own packs and their own kind of materials. So it's, you know, everyone's been considered and thought about in this really cool, golden envelope that you open up and have a little prompt in. So everything– think what Jess is really keen on is feeling like when you're receiving physical materials, that they feel special and they're not just like printed off on random bits of paper and then shoved into postal envelopes, instead that they feel special and considered. And you know they were still receiving something really nice that you might want to show to people, and that you're producing something nice at the end of it as well.

Kelsie Acton:
So this, I'm really interested in. When you were doing fully online were you mailing the materials out to young people?

Katie Goldfinch:
So again, I wasn't there for the full online version. But there's a little prompt, I think– Yeah I believe it was either sent out, or depending on locality, it could have been delivered by our van. In the prompt video certainly children are under the illusion that Touretteshero is coming to your house and delivering it personally. I don't know how much truth there is, but you know, I think probably the superhero is the Royal Mail or the postal service! But yeah, that they would receive kits to their doors, and then would be given an online buddy to come with. But yeah, certainly it would go to their individual houses via superhero truck or postal truck. Yeah. But the kids will think that Touretteshero has come delivered it and left it because there's a totally – it's an animated video, kind of a prompt video, that Jess made where she drew herself and has been animated and voiced over by her explaining what the mission is. Kind of feels like one of those old school like Danger Mouse or one of those cartoons almost. So, yeah, it's a lot of fun.

And that's kind of another thing that Jess' really good at is making things feel really fun and exciting, and even though there's this really scary pandemic, that might be hard to understand for the best of people let alone people who might be learning disabled or have certain complications going on like, you know it's – you've got this really exciting thing to kind of grab and anchor yourself on and not really worry about the rest for a moment, because you've got a superhero mission. So, yeah.

Kelsie Acton:
Yeah. Can you tell me about what both the digital and hybrid forms have enabled that maybe, like an entirely in-person present version couldn't?

Katie Goldfinch:
I think it enables, from my perspective, just as a personal standpoint, is that it enabled us to think more creatively about what digital and hybrid participation means. It's not just a Zoom call link. Maybe it is, maybe isn't. But it's also like, how can we physically integrate things, like a physical

thing that a child can hold. And then how can we still form new connections? Like a lot of connections were lost during the pandemic, and or they'd be very concentrated to your teacher or your hospital, you know, whoever's in the hospital appointment, or your immediate family and PA's, and it's like, actually, it enables a new form of connection with maybe a digital maker or kind of by proxy with Jess as like the creative prompt person. Jess and the team certainly think about, you know, how can we get things involved that aren't just an online-only understanding of hybrid, which is just a Zoom call, whatever. It's getting physical elements and nonphysical participation, not just meaning a Zoom call, but meaning different elements and different materials and thinking about how creativity can happen without a physical person enabling that at all times.

And I think it – Yeah, it reaches a lot of young people that wouldn't necessarily have gotten reached otherwise because there might have been children who wouldn't be able to go into a physical classroom regardless , for their own reasons, you know, because disability doesn't stop existing when a pandemic ends. You might have energy or medication-related issues that mean you can't go to school all the time. Having that kind of prompt that you can access in your own time means that the child can produce something that is kind of self-led and in as much that you can kind of choose when you use it, and you choose when you interact with it. And it's still coming to your house, and there's no pressure, and there's no time limit. You could kind of – and so it kind of encourages that self-led investigation. Obviously, probably with the prompt of a support worker or parent, but it kind of allows for access of people that won't necessarily have gotten it and maybe not would have turned up to our kind of physical events with the 2,000 children or whatever, 'cause it's not something they can access, or parents who don't have that spare bit of time to go out and take their children somewhere. Or who aren't centered, you know, in a position to be able to take their kids into Central London, or whatever. Like it's – yeah enabled a lot of that. And I think it enabled an investigation into what play meant in the pandemic. And on a small scale, but a meaningful scale to address that kind of lack of access to play for sure.

Kelsie Acton:
Yeah, that's amazing. I'm so struck by, like the temporal accessibility that– It's not just about physical distance, it's also about asynchronous access, as well.

I know we're off script, so say no to any of these questions, but I'm getting curious. Were there any particular challenges inherent to the digital and hybrid?

Katie Goldfinch:
I think the most notable challenge that I certainly was kind of present for, the – cause I kind of joined in later in the game. And Will, our director of research, he was kind of co-leading on this project and then asked me, “Do you want to come and be involved with this amazing thing?”, and I obviously said yes, because it's the best. And one of the things that I helped to kind of facilitate was teacher training, as I kind of alluded to earlier, is that when children were kind of getting involved in the more physical sense and the makers came in from the National Youth Theaters, the teachers kind of took a step back. As I think it's kind of their right, in a way, because it's like “God, you've taught and supported these kids all throughout a pandemic, maybe you want to take a moment to chill out!”. But I think it became so much more meaningful when the teachers saw it, not as a lesson, but as a cool, creative experiment with kids, because how much do kids get to play and mess around at school other than like a 40-minute play time? So I think the challenge was kind of figuring out that that training was needed for teachers as well, and how to fit that in, because we trained the makers, and that's one thing. But then training the teachers and how to interact with their kids, they probably know inside and out, with kind of saying, you know, you need to interact with your children that are under your supervision you know, 8 till 3, 5 days a week. But we kind of noticed from the feedback from the makers that the teachers weren't really getting to grips with it. And then, as soon as we kind of nailed that teacher training, it was like, “Oh, suddenly it's so much more.”

I mean, Jess can speak way more to the kind of challenges of the original, just pure digital one. I'm sure that had a lot of battles, but as I kind of came later stages, I can't speak to that myself, but certainly the teacher training transformed a challenge that we kind of only realized existed so prominently when it had been resolved, because it was like the teachers just got it as soon as we gave that time to them, and got really excited to be creative with their kids. And have fun and take the afternoon off from teaching and worrying about all of that, and just going with it. Obviously both things like medication and personal care needs, and so on, that are immovable. But other than that, it's like, just get stuck in, which I think they really enjoyed.! But they just kind of needed that permission to do I guess?

Kelsie Acton:
So is it about shifting their relationship to how they're engaging with the kids?

Katie Goldfinch:
I suppose so. I suppose also like when you do have other – ’cause I have had experience in SEND schools, and I think when you have an external facilitator, come in, it's like all right, you don't want to interrupt them, you don't want to get in their way, and they probably got a specific way of doing things or they come from a company with deeply held knowledge. And you know NYT do have deeply held knowledge, but probably not about your children, or how to interact with SEND children in general. And even if they do, if you've met 8 SEND children, you’ve met 8 SEND children, and you know, how useful or appropriate is the term SEND anyway? That's a whole other discussion.

But it's like, yeah. So I think it's saying, you know, we really value this knowledge you have about your children, and we value the time that you take to educate them. And time you spend planning and attuning yourself to what they need. But right now we're kind of saying, “But could you help us do this really exciting thing, by playing with them?”. And we don't need you to be that teacher who's vigilant - they can make mistakes, and they can be a bit naughty, and they can mess around, and that's fine, and we're not expecting you to kind of teach or have that monitoring over them. You just need to be there and get involved and kind of show the kids as well that “Wow! This teacher is not just a teacher, they can be really playful and amazing”. Which I'm sure they are, anyway, but even more so because they're kind of getting involved, truly. And I think, yeah, from the feedback from the maker they really really – the kids – benefited from it, the makers benefited from it. And the teachers loved it too. So I think – yeah that shift in perspective. And also that permission, and like saying, “we need your help because you're an integral part of it as well”.

Transitions After the Height of the Pandemic

Kelsie Acton:
Yeah, you can tell me if this is out of scope, but I'm thinking about transitioning, that very weird transition moment of like… I think, especially here in England, of just like, “It's over!”. And I'm wondering if you were like, because you were doing this, I think, sort of in those first moments after kids were back into school…

Katie Goldfinch:
Yeah.

Kelsie Acton:
Yeah, like, what were you seeing? How were kids experiencing that moment?

Katie Goldfinch:
I mean, I think that's one thing is that we weren't physically in the room, as in the Touretteshero team weren’t on the ground - it was just the NYT makers that were there. And I think that's – just that in general “getting back to business” in a way is gonna be a massive transition for anyone. But I think children who are in those environments, it's just… nice to be back in, I imagine. And I think there probably are transitional challenges behind the scenes.

But again, in terms of providing that moment of like protective memory, and that moment of pure access intimacy, and just getting with it, and having people who are trained to be creative and having your teachers who are trained to be with you, and you, who are just expected to show up and be there, and whatever you are – like it was one of those moments where I think young people just really appreciate it. Being able to be in those moments, and certainly from the feedback we have from the makers, we had overwhelmingly positive feedback from all the children, and I don't think – I think it was one of those rare things where it wasn't this huge stress because it was just a nice thing that you could do at school, which is in a familiar environment, which you may have been separated from for a while, and it isn't straightforwardly learning. It's just, you know, having fun and thinking about what makes you excellent, and having a really enthusiastic person to support you.

And I'm sure those transitions by, you know, from any disabled person—any person, but particularly disabled people and people in their networks, are going to tell you there’s huge transitional difficulties.

But I think the DHOTI environment created a place where we can kind of step back for a moment, and like this is all very difficult, but for now we're just gonna go in. And I mean also the makers might have different individual experiences, but certainly from the feedback we got and the feedback from – yeah, just the general vibe from people who were there, it was overwhelmingly positive.

So I think those – it might be a signal that the transitional difficulties kind of set back for a moment just because it was allowing that protected positive space.

Continued Remote Access

Kelsie Acton:
That’s amazing. Is there anything else you want to tell me about this project, or remote access in your role at TourettesHero?

Katie Goldfinch:
I think, just in general, the approach to remote access, etc., coming – because I came in relatively new. Obviously the organization is 13 years old, and I came in kind of 2-3 years ago now, and everyone else in that team has been there quite a while longer, especially on a director level, and coming in as a fresh face to it and seeing their approach to just how to operate as an organization and how to care for your staff while also responding to the needs of people at large during pandemic is just mind-blowing in terms of like, you know – I think Jess is very, very keen to not think of remote access just as a zoom link, just as a phone call, but also, like she sent out like hundreds – I don't know if it's hundreds – but there's certainly a lot of boardgames to disabled children during the pandemic. And we kind of did a delivery service which wasn't announced, but it was just that supporting our local community, who may have been clinically vulnerable, or, you know otherwise needing that support, and delivering essential goods to them. And that continued far longer than you'd expect it to I think. And just different ways of signaling that “Yes, we can't

be there in a room, but we can deliver something to your doorstep, or we can send something in the post, or we can do a Zoom call, but we can also do all these other things”. And I think, yeah, my role is in particular, it was facilitating, in those early stages at least, just Jess’s fantastic ideas, like distributing essential goods through our practical intervention fund to families in need, and young people in need. Like relaxation items as well. It wasn't just essential kind of “batten down the hatches” stuff, it was just like, you know, maybe you really could do with a weighted blanket at this time, so we're gonna find money and fund that, and now that's another mainstay, regardless. And commissioning young artists during the pandemic, that was another thing we did kind of through remote mentorship and guidance, and being able to sustain that creativity during the time where it was kind of shaky at best, and we ran a – again Jess’s idea – to run a remote traineeship for visual artists. It's like these are all kind of her and Matthew's brainchildren that kind of came together, and it was like, there are so many ways that we could be doing this in so many ways that just felt gentle and nice and full of care.

At the end of the traineeship that I helped to facilitate we sent lovely vegan and gluten-free snacks to everyone at the end, so that they could all have it, and we had, like a little party at the end. And it was like, yeah, we can’t – we have to do this by Zoom, but we are sending things to your door, and we're letting you know that we’re here for you.

I've not come across an approach like Jess and Matthew’s and just the ethos of the organization, and the fact that we've got a risk matrix for covid. So we look at it and think, where are we sitting at? Do we need to stop activity? Do we need to limit it? And if we do need to break for a moment, we can – like we've shut down before for a week to be like actually, we can't do this. We need to prioritize ourselves, or it's not safe for us to continue. And having breathing weeks and stuff like that, and well-being days and it's just like the most incredibly well thought out thing. And it's kind of like, I wish I was in the room where those conversations were had with Jess and Matthew, it’s obviously something that happened way before the pandemic, but in a pandemic it has come into its own to show how useful it can be. I think they are like, in terms of artistic vision, they are so ahead of their time in terms of thinking about how you really care for people with different needs and different, you know, clinical vulnerabilities for things. I mean, having Jess as a CEV [Clinically Extremely Vulnerable] manager and director of the company has transformed a lot of our things, and setting boundaries and stuff and just being able to say, “No, that's not safe for us, or “No, we can't do that”, and just being able – having that confidence to be like “actually no” like…I just think the fact that this role even exists for me and came, was born out of such a shaky time, and a really uncertain and terrifying time. And that Jess as someone in one of those vulnerable groups, was able to go, “Right. That's really scary. But this is also what I need and this is what I'm going to build within my own infrastructure”. It's just like – I think it's really significant. I'm talking about remote access, because I think they've kind of got it nailed. But I also think they could probably do more. Not that they necessarily need to, but I'm sure Jess has got a million ideas that she could probably put into place, and you'd go, “Wow! How did you ever come up with that?” Like, yeah. So I think that's kind of what I wanted to get across. It's just because I also don't know whether Jess herself would articulate – I think she knows the great ideas, and Matthew knows the great ideas, but I don't know whether they'd be able to speak to it as like complimentary as I have, because I as an outsider have come in and gone “This is incredible” and like, “Wow! Why isn't everyone doing that”? You know? Because it makes it seem so seamless. But I've never come across any organization who's done something like they've managed to do. And at the time of the pandemic it's just been really meaningful, especially as a disabled employee working within a disabled-led organization. Just having a disabled manager is amazing. Like the best. So yeah, no, it's fantastic.

Kelsie Acton:
Amazing, yeah, I have so many questions, are you okay If I like, pick up on Touretteshero?

Katie Goldfinch:
Yeah, sure.

Inclusive Outreach

Kelsie Acton:
So talk to me about how you're connecting with communities… like, how are the callouts to trainees and families going? How are you receiving, how are you making contact and building those networks?

Katie Goldfinch:
I think the team have a lot of deeply held connections, especially with local community. They kind of hold a lot of those things, and have done for a very long time, and they make a very concentrated effort to remain part of those communities and to focus on areas that might not have as big Tourettes-specific support. So maybe that's just being in a Facebook group for like a random town in Yorkshire or whatever, like that might be it. And also connecting with any, you know, larger figures in those areas and those regions. And also kind of we've got a very like, very big like hyper-local connection in terms of South London and working with, like Heart and Soul and others – I mean I could name a million, but like, Sounds Like Chaos, and so on, that they kind of go through. And obviously, all of those networks have a network, and it just kind of expands out. But yeah, Touretteshero has, like a — we have a kind of a marketing to disabled audiences strategy in terms of supporting outreach, identifying what/who isn't being reached, and who doesn't– you know addressing digital poverty and thinking about how we can reach people who might not be seeing digital marketing and approaching people and asking them and saying, “Would you like to do this? Would you be interested in that?”. I think a lot of it is word of mouth as well. But there are lots of different strategies. And it's definitely something that we're developing as kind of like an ongoing thing, because there are certain areas, and like demographics of people that I've noticed have been missing. But I feel no, you know, worry about going to the team and going, “Right, you know, I'm noticing we're missing this chunk of people. Let's do something about it”. And every time we have. And I know that there are certain things that– I think it was “Making routes”, I may be wrong, which is a thing that Will kind of co-lead in association with South London Gallery and Oasis.

Kelsie Acton:
Yeah.

Katie Goldfinch:
And they kind of noticed that they weren't hitting a demographic they really wanted to reach, so they kind of went right back to drawing board, and said, “Right now we need to recruit these people. How do we recruit them”? I think they got confidence to kind of go back and say, “Who are we meeting? Who are we not”? I think we've got those kinds of really strong connections and you have the whole disability art scene, which at least

online feels very broad, but then… yeah, so we're able to kind of scale back and go “Right, we've got this really broad community. But who is missing in that?”. And I think connecting with other people is integral, like just chatting to other people and being like, “How do we reach this group? What do you think”? And having that ongoing conversation.

And I think with our Practical Intervention Fund – which is the items – that was mainly parents. And parents spread like wildfire. If you hear that people are gonna distribute things without, you know, largely based on trust to disabled households or households with disabled people in them, you're gonna get a lot of applicants very quickly, and we were interested to see that it wasn't just London-focused, it was quite a national demographic.

And with, like the traineeships, that was one of those moments where I said, “Right, we're not getting enough – no racially minoritized people have applied. What can we do about that”? And that's the kind of point that we did targeted marketing, and more outreach. And that was another moment of kind of going “Right, this isn't meeting – what are we doing”, and thinking about how we monitor and so on. But it's definitely a learning process, and one that's kind of ongoing. But I feel like it's a very open approach to it as well.

Kelsie Acton:
Yeah, and it sounds like it's evolving, which I think is… what the best outreach does, but often doesn't happen.

Katie Goldfinch:
For sure!

TourettesHero Risk Matrix

Kelsie Acton:
Do you feel okay talking at least in vague terms about the risk matrix – how are you making, in broad strokes, how are you making some decisions about what the company will and won't do?

Katie Goldfinch:
Yeah, so again, this is a question more for Jess. But I will go into it broadly and she can kind of narrow it down as much as she wishes at that point we

have that conversation, but it's kind of a six tiered approach, I think? So there's six kinds of ranks of risk, and it was based on, at the time, government restrictions in relation to COVID. And it was like, you know, if this government restriction is true, then this is what Jess might need. This is what the organization might need. This is whether we've, which you know, which activity do we continue? Do we continue, you know, physical stuff? And if so, what size of physical events? And if not, then like, do we just cut off all kinds of artistic events altogether, and focus on consultancy, or like what kind? Or do we just focus on entirely solidarity-based stuff, like just providing basic emergency stuff. It's very detailed and well-thought out about what–if one thing is true in terms of the environment, then what are we doing as a company, like what – are we operating fully, or are we completely locked down? And it does go from like that full, like no COVID, nothing, everything's fine, we're operating fully to "Oh, my God! Emergency protocol!" you know? We have done that once at my time here, we just went, "We're shutting down for a week, because this is not conducive to us being able to work, because as well, we're only seven people big". Or eight, I always say it wrong. I say seven and it's eight or I say eight and it's seven, but seven or eight people big. And so when it works well, it's working really well, if more than two of us are struggling, and it gets to be quite a struggle. And having that kind of "break clause" feels great. It's like – and we don't need to use it very often, but when it does it's very helpful just to know that the risk matrix is in place, because it's like, and it's being monitored, and we get updates on it. And now it's kind of more based on our own comfort levels as staff, and like any COVID data that's available, which is getting smaller and smaller as time goes on. But like it's kind of more done on like a, you know, a discussive — and yeah, conversational basis of how comfortable we feel. And you know, as Jess as a clinically extremely vulnerable director to how she feels about activity and her kind of state of having a PA in place, or whatever, and it's just…So it's an ongoing thing as well that was based on government guidelines, and then we realized that government guidelines aren't something to go on anymore, became more kind of ad hoc and chatty almost. But it's still something that we are, and now we have, in place. And that Fred, our executive director, she does look at whatever data she can find, to kind of inform us. Yeah.

COVID Safety Advocacy

Kelsie Acton:

Yeah, can I ask about that? Cause I am the only person who masks in my workplaces. It often feels like England has declared the pandemic over, and all us disabled folks who know or feel…who know differently, are left to negotiate that on our own.

Katie Goldfinch:
Yeah.

Kelsie Acton:
I mean, without giving more details than you feel comfy, when you've had to put boundaries around COVID safety, around like preferring remote work maybe, what's the reception been like?

Katie Goldfinch:
I think with… because that will mainly be Jess, who's putting on the, or at least it's coming from Jess– in terms of issues, [she's] the most public facing of all of us. She's the one who's booked for events or whatever, and I think, like, we're very fortunate that we have kind of such a strong kind of infrastructure as a company with what kind of clauses in contracts say. Like if Jess is unwell, then it stops. Or you know, "this is the boundaries"– we've got access riders, we've got COVID-19 access riders, we've got, you know, organizational access riders that always get sent out beforehand, and it's like so people know, at the point of booking that this is, and even if if they don't, then it means they haven't read the document. It's kind of like, well, we've set this up as a possibility, and if it happens then it happens. Jess is probably more equipped to say how the reception has been in terms of receiving venues. But I feel like in my experience being on the periphery of that, it's been accepting.

And I think, in terms of the like, the community aspect, which is what I'm more focused in, and when I've had a out-of-office reply, saying, like, "we've shut down because it's just not safe at the moment" it's been like "this is great, and I didn't know this was an option", and for many people, it's not an option. And I think it's a nice signal to a community. I think I notice it more in the community– that people are paying attention, and that, you know, I know that Touretteshero is very small, but other people might not know that and think, "Wow! An organization is making steps to protect its staff and protect the wider…" and I know that at Liberty Festival, when Jess said "actually I can't do that" 'cause she didn't feel safe at the time, it meant that

Jamie Hale then opted to go remotely and so it's had like, a community impact. And I think that's what sticks with me more like, I'm less kind of interested in the wider – cause the venue knew the risks of booking us in, I mean like, at the time, and if they didn't, and again they haven't read documents. But the community stuff has been like, “Wow, actually, this is good. And I'm glad that you've been protected”.

I think, on a personal level, when I've kind of said to friends and family like “I need you to test before seeing me, my system is extremely vulnerable and also there's just a pandemic happening” I've had more kind of shock and surprise. But I think that's just the experience of any disabled person who's being more COVID conscious, because if you do ask for those things, then in your personal life, it can be challenging. But I think on a kind of within our communities and within communities I have definitely seen. Of course, it kind of ripped to like, “actually, this is a good thing”, and the signaling solidarity which is kind of the whole point, Isn't it? Yeah.

Final Comments on Remote Access

Kelsie Acton:
Yeah. So we've got five minutes, is there any last things you desperately want me to tell [ask] you, or– I always like to imagine, like somebody 200 years from now, watching, I hope, watching this interview? [Laughs]

Katie Goldfinch:
[Laughs]
That's a little pressure like, what do I say in a time capsule?

Kelsie Acton:
[Laughs]
Sorry. Forget I said that then.

Kaite Goldfinch:
I know. I just think– no, I think the only thing Touretteshero has been really good at is centering disabled joy in a time where everything's really been not joyous. And in times where it's been scary, both kind of on a global scale and on a personal scale we've still managed to be that kind of hub, and like, as a personal, just for my own self, it's like when everything else around me is saying, “the pandemic's over”, or that “there's no support” or

“that disabled people are crap” or that, you know big charity-model stuff I *know* that I work for an organization that has such like socialist and disability justice-focused views. And it's like, you know, I've got my ten Principles of Disability Justice pasted on my wall of work, and I've got a big thing saying “disabled liberation”. And it's like just looking around and seeing our Trojan horse diagram, which kind of explains like how we work, and all the different regions we work in that's a massive miracle of our office wall, and it's like sometimes I'll just stand there and be like “everything is really bad, but this is really good”, and I think that's what TourettesHero is really good at. Like yes I talked about the protective memories and positive memories as protection, and I think that works for communities, but it also works for us. I think it works, you know, as being a staff member or someone who's kind of closely linked with Touretteshero, whether it's professional or personally or whatever level like it's just nice to know that you – like that that's there for you, and that even if you're in the midst of it, as a solidarity coordinator it can get really overwhelming thinking about the support that you could be doing that's like, we're just trying our best and we're just navigating a very choppy water as much as we can. I think we're doing quite a good job of it. And I think we'll see that we'll continue to improve upon the job that we're doing. And we'll never say you know, we're never gonna be those people who are set in our ways and going, “No, this is the only way we're gonna do it”, like we're always evolving and that's really exciting and it's really encouraging in a time of very scary global situations. It's just nice to know there's a little pocket of good. So that's all. I think. Yeah.

Kelsie Acton:
That's amazing. Thank you so so much.