

The Laura Flanders Show
S01 E01: Disability Justice

BEGIN TRANSCRIPT

JESS THOM

Three, two, one, I. The idea of independence, just like the concept of normality, neither of those things really exist. Is everyone ready?

ALICE SHEPPARD

Normal is constructed. There actually is no normal.

JESS THOM

Tourette's Superhero. Rather than see myself as the problem, I understood that neurodiversity was my power.

ALICE SHEPPARD

When I'm asked, "What happened to you?" I will often reverse the question like, "What happened to you?"

LAURA FLANDERS

Hi, I'm Laura Flanders. On this week's show, two amazing women, artists and activists at the cutting edge of a burgeoning disability arts movement. Today's guests are not only virtuosic practitioners of their art, they're exploring profound questions of importance to us all. Like what exactly do we mean by the word "disabled" or, for that matter, to be able, so called normal or independent? Is accessibility enough, or do we need to think more broadly about equity and inclusion? And if we do, how will that change not just our lives, but our culture and our society. First up, Alice Sheppard, a dancer/choreographer whose high-speed wheelchair work flies in the face of any of your preconceptions about disability, and I mean that literally. Then the writer, comedian and self-styled Touretteshero Jess Thom. Her performance of playwright Samuel Beckett's play "Not I" celebrates neuro diversity and asks, "Who is allowed to perform what, "and who gets the final say?" This is The Laura Flanders Show, the place where the people who say it can't be done take a back seat to the people who are doing it. Welcome. German playwright Bertolt Brecht once famously remarked that the artist's job is not to reflect reality but to change it. Our next guest is doing just that in stunning ways, blowing open old ideas about bodies, and beauty, and movement, and motion with her visceral performances that feature light, dance, and technology, including wheelchair technology and crutches. Her name is Alice Sheppard, formerly a medieval studies professor. She's now a choreographer dancer and the founder of Kinetic Light, an artistic collaboration with dancer technologist Laurel Lawson and lighting and video artist Michael Maag. Alice, welcome. If you had to sum up, and I'm not gonna ask you to do it in a word, but your passion. What is your passion at this moment in your art?

ALICE SHEPPARD

I am actually enjoying the physical experience of it. There's a moment of actual togetherness that I seek, that I experience, and I want to share it with you. And that kind of wholeness is it's an incredible high, it's an incredible feeling. And finding that, being in that, is what I'm looking for right now.

LAURA FLANDERS

Now, I pushed my father, who is a wheelchair user, down and up many, many ramps. And the issues of inclusion when I was coming up in the 60s and 70s were very grave. Interestingly, he performed on Broadway twice and got a lot of reviews over many, many years, most of which

never mentioned he was in a wheelchair, which was, at that time, people's idea of being nice. Not mentioning it. We're in a very different period.

ALICE SHEPPARD

Well, we are, and we aren't. We are all over the map. There are some parts of our culture that are still struggling with, "What is the polite word to say, and how do we mention it?" Do we mention it? Do we look the other way? How do we even think about the image? Do you shoot the wheelchair? Do you photograph it? Some parts of the world are still wrestling with this. And other parts of the world are like, "Well, I'm here, I'm disabled, but it doesn't define me. "It's not who I am, and you can see me as a person." And there are other parts of the world, and this is the part that I'm most interested in is that this is about the culture, the aesthetics, the politics, the social and political advocacy work. All of this work is embedded in one thing where if you are not looking at the wheelchair and the wheelchair's movements in the same ways you're looking at my hands at my arms, you're missing half the work. So partly, the world that I'm interested in is not about do we have inclusion? We don't have full and equitable and just inclusion, but the conversation is branching around that now to think about what does it mean to have different kinds of equitable participation, equitable experience which is more than the language of inclusion. And that's where I wanna go in my art. It's not enough to be on stage. It's how we're on stage. It's the work that we're in on stage. It's the roles that we're cast in. It's how we're represented in newspapers. It's not just the one. It's the how and the why.

LAURA FLANDERS

Are you alone in this? What's the context in which you're operating?

ALICE SHEPPARD

I am not, fortunately. So this is a very important moment. I think media and representation tends to pick out one person and will name one person, but I am not alone. I actually am part of a movement of people coming at this from film, from theater, from policy, from dance. And I am also part of a legacy that goes back to the Civil Rights Movement and that world that you were mentioning back and through the 60s all the way forward to where we are now. So I'm here now but as you go through all the materials, there is a movement of us.

LAURA FLANDERS

So would you say it's fair to compare, there was a black arts movement is there now a disability arts movement, aesthetic movement, is that the right comparison?

ALICE SHEPPARD

I hope so, but here's the thing. I think labels get added retroactively or retrospectively. So I would say in some ways there's a disability arts and disability culture manifesto coming out of the U.K. that is much, much earlier than we've seen articulations in American culture. But this is a new moment. And here in New York, this is a new moment. We're really thinking about disability arts manifesting a lot through dance but also in other...in visual arts. We're seeing theater, the National Disability Theater. We're seeing all kinds of people that are somehow in their own disability beginning to just flower in different ways. So I believe, you know, 10, 15 years from now somebody will say this is a renaissance of disability arts. But as we are in it right now, it is a movement.

LAURA FLANDERS

So two questions. One is, we talk about on this show about this sort of insidious normal, the normal economy, the normal cruelty, the normal patriarchal relations. What's the damage that you think ideas of the normal have done when it comes to art, and our bodies, and motion, and movement, and all the stuff you think about all the time?

ALICE SHEPPARD

Wow, the normal. I often say the normative because it gets us away from the notion of normal. And it helps us realize that normal is constructed that there actually is no normal. Right?

LAURA FLANDERS

Which is also true for all those other things but keep going.

ALICE SHEPPARD

Right, right! So how is it that we have this notion of normal?

LAURA FLANDERS

And what does it do to us?

ALICE SHEPPARD

And what does it do? And for me, I think it circumscribes what is understood as aesthetic movement. Which circumscribes how people do, and don't get the opportunities to be on stage. And it also circumscribes the recognition of work by disabled artists as art. So for me, you know, I could be in the space of constantly trying to undermine. Or I could just set up again and start in this different space and ask the question not how do I undo the normative but what is here, what is present? What can we work in and around? What do we know? And then have that feed backwards.

LAURA FLANDERS

You talk and a lot of people talk about a disability perspective. How does it change things, and what things does it change? And can all of us get a disability perspective?

ALICE SHEPPARD

Oh, I wonder. I wonder, okay. No, I don't think you can. I don't think you can because I think a disability perspective is something that is both a combination of how you take in the world, how you experience the world, and the research, the lived experience of being in the world, and the research, and the knowledge, and the interactions with traditions that filter through your body and mind out into your daily experiences. So you can structure a world from a disability perspective. You can like for me, you might make the world only five and a bit feet high. You might think about where the place of architecture and shelves. And you might create the physical space, but partly perspective is also about the way you interact with people in the space. And so I always joke that like on the street the first thing I see of you if I'm looking down is your shoes, right. I know people by their shoes. But I also see an awful lot of bellies and butts because that's what I see at that height. And so I think that the perspective is earned and developed over time. And it interacts with what we know and what we've read. From the outside world you can get an understanding. But from the inside world, yeah, it's from that internal knowledge, that lived experience.

LAURA FLANDERS

You have a long list of things you didn't want me to talk about.

ALICE SHEPPARD

Yeah. Let's talk about the things we didn't want to talk about.

LAURA FLANDERS

Let's talk about why.

ALICE SHEPPARD

Okay.

LAURA FLANDERS

Why is it not helpful to talk about a whole lot of things that people love to talk about when the word disability crops up?

ALICE SHEPPARD

All right, so, almost every journalistic experience that you see and even if it's not the first paragraph in a night newspaper article, it's in the second paragraph. You know and it almost always begins every interview story, is the narrative. Like what is it, the constant accounting of what happened to you. And sometimes nothing happened. Sometimes, you know, you were born with a disability. But the constant idea is that somehow disability has to be explained. You have to give your diagnosis. And then you have to explain how you arrived at this diagnosis and what the implication of this medicalization of disability is. And it sets disability up as a medical situation, something that is wrong, a deficit and something that always has to be accounted for in this kind of personal and narrated way. And never actually allows for an understanding of the disability as an embodied whole experience that just is. I often, when I'm asked that question about "What happened to you?" I will often reverse the question like, "What happened to you?" Or why do you want to know? What will you know?

LAURA FLANDERS

What will you do with that? How will it help you talk to me?

ALICE SHEPPARD

Right, right, right. How will that help you talk about my work? Well it doesn't. How will that help you talk about whatever situation we're in right now? If I'm at the post office and you want to know what happened to me.

LAURA FLANDERS

The British.

ALICE SHEPPARD

Yeah.

LAURA FLANDERS

You and I share something to do with the British. Are they doing it better? And if so, what are they doing better or different?

ALICE SHEPPARD

Because the government, because of the social systems, we're able to think about funding and supporting individual artists. Somehow the world shifted. People were exposed in a way to the art, to the work, and one by one, and it was sadly one by one, programs popped up, podcasts popped up, disabled actors popped up, independent artists were funded. There were performances, that was funded for groups. And so by these seed fundings in all of these places, you can begin to gnash together a culture of disability. Not the same culture by any means, but maybe I should say cultures of disability. And that gave space for different languages about disability. And I'm not gonna say that the U.K. not that we're doing it right, because there are many ways in which things are awful but I will say that the language and the kind of casual representation, I mean I remember once there was a Channel 4 ident of a wheelchair user, radical. Just like a couple of seconds. Somehow by thinking about how to get people into the space and the terms on which they wanted to be included so both important. Not just the representation of one but the terms by which somebody wants to be represented and the art that they make there change the culture of expectation around disability. There's a growing awareness that disability is more than a circumstance of the body and that it can and does positively contribute to art.

LAURA FLANDERS

In New York they recently opened this public art thing called The Vessel--

ALICE SHEPPARD

The Vessel.

LAURA FLANDERS

Which looks to me sort of like a temple to stairs. And it's almost made worse every time someone says to me, "Yes, but there's an elevator."

ALICE SHEPPARD

The elevator takes you to the top, but the experience of the artwork is stairs. Why would you construct a public work of art that is massively and culturally inaccessible?

LAURA FLANDERS

It does reflect the drawbacks to the ADA though. Because if it's just about can you get to the top--

ALICE SHEPPARD

This is the problem with inclusionary and compliance related thinking, right? Inclusionary thinking, compliance kind of thinking is the elevator that will get you to the top. Participatory, cultural, and aesthetic thinking is about what is the experience being in the art itself.

LAURA FLANDERS

You touched on it earlier, but we often ask our guests what's the story you would like the future to tell about this moment? Um, what's yours?

ALICE SHEPPARD

That after the many, many 50 to 60 years of work, the disability arts movement exploded across the United States, across the world. That there was a rising wave and suddenly the wave just kept going. And that disabled artists and culture makers were recognized.

LAURA FLANDERS

From your lips...

ALICE SHEPPARD

...to the world.

LAURA FLANDERS

Hi I'm Laura Flanders. This time coming to you from BRIC in the heart of downtown Brooklyn. A community arts and media space that also is a community access television station. This winter the Under the Radar Festival, which is produced by the Public Theater in New York City, hosted the most extraordinary performance right here at BRIC. It was a return performance for the star of the show, Jess Thom who performed "Not I" a piece I had only seen entirely abstracted from any human participation on a little screen on television. Jess made it into an entirely different performance. Jess, you want to introduce yourself?

JESS THOM

Yes, biscuit, I'm Jess Thom. I'm an artist, a writer, biscuit, and a part-time superhero. Biscuit, sausage, biscuit. And I also have Tourette's Syndrome which means that I make movements and noises, biscuit, I can't control called ticks, biscuit. Some of my most regular tics are vocal tics, include biscuit, and hedgehog, and sausage, and cats, biscuit, donkeys. Donkeys want to get in on the action. And biscuit. And so nothing gets lost in translation when I say biscuit,

think cookie. Biscuit. And biscuit, I also have motor tics. That means I move around and bang my chest.

LAURA FLANDERS

So that would be the sound that our podcast listeners are hearing.

JESS THOM

Yes, you can probably hear the sound of my hand banging my chest. But don't worry, I'm wearing padded gloves to stop my knuckles getting sore. I'd never come across Samuel Becket before I didn't train as a performer and I hadn't read his plays or seen them performed. But I was introduced to "Not I" at a time when my tics were intensifying. The movements and noises that I make because of Tourette's Syndrome. And I was finding it really hard to recognize them as part of me, as part of my body, as the product of my brain. And I would talk about THE Tourette's and THE tics, and then here was this text about a character who was distancing herself from probably her own voice and not saying "I" but saying "she". And that felt very relevant to me. Thanks so much for coming, biscuit. My name's Jess, biscuit. And my sign name is, Jess, yikes! Jess, yeah, still Jess. The performance will be about 12 minutes long. After that, we'll have a chance to ask questions and do some shouting together. All being well, we'll be finished within the hour. Is everyone ready?

AUDIENCE

Yes.

JESS THOM

Great, I was hoping you were gonna say no. Great, in a moment, we're going to count down from three. Biscuit. And I'd like everyone to shout or sign, "I". Then we'll bring down the lights. Okay. Three, two one I. Hedgehog, biscuit, cats, biscuit, biscuit, cats.

LAURA FLANDERS

Let's talk about Tourette's.

JESS THOM

Tourette's!

LAURA FLANDERS

You are Tourette's superhero.

JESS THOM

Yes.

LAURA FLANDERS

Touretteshero is the organization you founded.

JESS THOM

Yep. I'll have to make this quick. We don't have much time. For those of you who don't know me, let me introduce myself. I'm Touretteshero. The world's fully fledged Tourette's superhero. This is a masterclass in spontaneity. Biscuit. We have been practicing for this for weeks by doing nothing. Biscuit, hedgehog, I propose, biscuit, that humor and creativity, biscuit, are key tools, biscuit, in encouraging people to think more deeply about an often, biscuit, mocked condition, biscuit. But simply, biscuit, Touretteshero's mission is to change the world one tic at a time.

LAURA FLANDERS

To begin let's just set the context. You say you're a disabled person, but it's not your Tourette's that disables you.

JESS THOM

No, right, exactly. So I understand myself as a disabled person within the concept of something called the social model of disability. And that's a way of thinking about disability that gets away from thinking about it more medically or from a charity perspective and thinking that people need to be cured or pitied, and the only way to resolve issues of disability is to focus on the impairment that someone has.

LAURA FLANDERS

Have you always felt this way?

JESS THOM

No that's definitely, biscuit, I've had the tics since I was about six. As a child they were milder and less noticeable to other people. The earliest things that I can remember are, biscuit, squeaking noises and making facial gestures. And they intensified in my early 20s and began to have a bigger impact on my life. And my initial response was to try and ignore them, to distance myself from that, to try and mask it and hide and fit in. And my life became increasingly restricted as a result. So Touretteshero is all about challenging that way of thinking. It started really for me, one of the big moments of change for me, biscuit, was a conversation with Matthew Pountney who's the co-founder of Touretteshero and the director of "Not I". And he described Tourette's as a crazy language generating machine, biscuit. And told me that not doing something creative with it would be wasteful. And I was able to hear that sentence in a totally different way. We talked about Tourette's loads before but that caught my imagination in a particular way and started to allow me to see that there might be value to my neurodiversity. And that having Tourette's gave me access to a spontaneous creativity that I wouldn't have afterwards. And I've been brought up to think being wasteful was very bad. So rather than waste that--

LAURA FLANDERS

Why waste a super power?

JESS THOM

Yeah, because I'm like, you know, my life was changed by a single sentence. I connected with a different approach to my body. And rather than see myself as the problem, I understood that neurodiversity was my power and had power. But we have to get as many people talking, and thinking, and connecting with each other and now more than ever.

LAURA FLANDERS

To what extent do you think we are also called upon to reconsider our sense of the hero, the solo hero, and this aspiration that we want to be independent, meaning, you know, relieved of needing help or we want to be normal even, whatever that might be.

JESS THOM

Biscuit, yeah I mean, and the idea of independence is actually like... Just like the concept of normality. Neither of those things really exist. Because none of us are totally independent beings. We are codependent on each other in different ways and at different points in our lives. For me a big moment for me in my journey as a disabled person was realizing that independence didn't have to mean doing everything for myself. Being in control of the decisions and being able to know the things that I need and then ask for help when I need it and have the language and confidence to do that has been incredibly powerful. And that's what independence means.

LAURA FLANDERS

So I could keep talking with you forever.

JESS THOM

Biscuit, sausage.

LAURA FLANDERS

And I could hear about the other plays you wanna do but just quickly give our audience some sense of where they might see more about your work or even catch a performance or be part of Touretteshero.

JESS THOM

Biscuit.

LAURA FLANDERS

And then finally anything you may just maybe mouth like wanna express and you haven't had a chance.

JESS THOM

So to find out more about Touretteshero people can start by going to the website, touretteshero.com. I have written a blog for almost a decade. So there is lots about my day-to-day experience as someone with Tourette's. And some of that's funny. Some of that's challenging. There are also tics on there. Over six thousand things that I've said as tics. And they are there to be used as inspiration and catalysts for other people's creativity. So we invite you to make artwork in response whether that's poetry or imagery or performance.

LAURA FLANDERS

You have a book?

JESS THOM

Biscuit, I have a book, "Welcome To Biscuit Land", biscuits. And the thing that I want people to know is that when I say I'm a disabled person, that doesn't say anything negative about me at all. It doesn't diminish me in any way. It isn't related to ability. I am a person who experiences barriers because of how my body and mind works. But disability isn't a dirty word. And there is an incredible rich arts scene and cultural scene that comes out of the experience of those barriers. So I am one of many disabled artists making credible, important, and challenging work. Not that my work's incredible but there are, there's this rich scene.

LAURA FLANDERS

It is incredible.

JESS THOM

And I would really like people to, like, that's for everybody. And disability isn't a niche issue. One in five of us identify as disabled, and it is relevant to everyone who has a body and a mind. And we all have the power to be inclusive and to support, you know, to support each other and to make and shape a world that works better for us all. And arts can be part of changing that and helping people connect with each other.

LAURA FLANDERS

Alice Sheppard, when she's on the show, the choreographer who works with Kinetic Light, said she feels she's part of a disability arts movement. Sort of like the black arts movement maybe of the 20th Century. Is that what it feels like to you? Do you feel like we're at a turning point or sort of and efflorescence of this work?

JESS THOM

Yeah, absolutely. And when I say I'm a disabled artist, I feel proud, and I feel strong. And I feel connected to a group of people who may have very different impairments from me but who have shared experiences. And I can give and receive solidarity within that. And I think that at the moment now more than ever, it's so easy as a disabled person for your life and your expectations to be impacted by the politics of where you live. And to be defined by the politics of where you, of place. We have to have those conversations about disability arts, culture, and justice and rights across borders. And we as an international movement of disability disabled artists and activists I think connecting with each other and challenging each other to keep making ambitious work and having high expectations of the world around us is essential.

LAURA FLANDERS

Beautiful.

JESS THOM

Sausage.

LAURA FLANDERS

Thank you so very much. This has been the Laura Flanders show with Jess Thom. You can find out more about her and her work and Touretteshero at our website, thanks. Cats.

END TRANSCRIPT