Anthea:

Welcome to Sideshow on 2RPH and via podcast. Many of you may remember our first season, Activated Arts. Well, Hanna and I, with the blessing of Accessible Arts and 2RPH have changed our title for the much-awaited second season. There's a couple of reasons for this. Firstly, we were experiencing a lot of name confusion with other similarly named organizations and projects. Secondly, the name felt a little earnest for our very small and renegade team. And finally, I couldn't stop thinking of those expensive almonds that have been soaked for 24 hours.

Hanna and I wanted something that celebrated the history of people in the arts with disability, something that acknowledged how our forebears were often relegated to the sidelines, yet from here, create a diverse, challenging, and often anarchic arts practices. So here you have Sideshow, monthly on 2RPH, and available as a podcast via iTunes, Spotify, TuneIn, Listen Notes, and Google Podcasts. As always, the show will focus on artists with disability from across the creative spectrum. The show is made by artists with disability for people with disability and those who are interested in our cultures and world. The brilliant Hanna Cormack will be joining me monthly for her What's On, where she will tell me what works she can and can't access this month. For more about Hanna, a truly remarkable performance maker and thinker, I suggest you go to our back catalog, online and available for free, and listen to episode four, Value Shift. It's all about Hanna's response to disability and her changing arts practice. But for now, on with the show.

This month, we are talking all things disability and technology. Later in the show, I'll be talking to Giulia Barbareschi. She's a researcher with a passion for disability, technology, innovation and global development. She's a researcher at the Keio School of Media Design in Yokohama. But first, Eugenie Lee. Eugenie is a Sydney-based Korean Australian interdisciplinary artist with a conceptual focus on the lived experience of persistent pain. Eugenie's work includes participatory performances, technology, installations, sculptures, and painting. Eugenie creates holistic pain experiences that her audience can participate in. Hi, Eugenie. Thanks so much for joining us on Sideshow.

Eugenie Lee:

Thank you for having me, Anthea.

Anthea:

So Eugenie, in terms of your arts practice, can you tell me how you got interested in looking at medical science?

Eugenie Lee:

That goes back to my lived experience of pelvic pain. I've been living with pelvic pain for nearly three decades and I just couldn't get the right answers from anybody. And I felt so alone and I've been just sort of twiddling my fingers, Googling away to just try to make sense of my own experience. And so as I started going through all the books at [inaudible 00:03:13] libraries. That's how I basically started, just one publication after the other. And there were a few things sort of stood out to me. Medical research, pain science and neuroscience, and I had no idea pain had anything to do with neuroscience. And s- one of the lecturers actually mentioned to me, "Oh, so, you might be interested in neuroscience." And, and so, it's just purely by accident that somebody just steered me towards that direction and I found this cool person called Professor Lorimer Mosley, and I just sent him a cold email and said, "Would you like to collaborate with me?" And in within three hours he came back and said, "Yes." (laughs)

Anthea:

That's really awesome. So, how did you start using technology in your work?

Eugenie Lee:

Oh, well, I'm not very much of a technology person at all. Um, so I'm still scratching my own head. How did it all happen, you know? Um, but again, it happened [inaudible 00:04:16] my residency to work with Professor Lorimer Mosley at the University of South Australia. He was so generous enough to invite me into his team, his lab, and got me involved with anything and everything they did. Like, all they do was just researching about pain science on human subject and their biopsychosocial response and how cognitive functions are inherently related to persistent pain experience. And, uh, one of the things that they do in their lab is just using latest technology, like virtual reality, TENS machines and some other cool and weird hacked machines. And I, uh, that's how I sort of got exposed to technology. But even then, I still didn't think that I would use those materials for my artwork because I came from visual, um, arts background, like painting, sculpture and installations. But by the time I left that, um, residency after two years, I turned out to be an interdisciplinary experimental artist. So that residency was really significant-

Anthea:

Yeah, that's fantastic.

Eugenie Lee:

... for my career.

Anthea:

I'd love to hear a little bit about some of your works. Can you tell us a little bit about Breakout My Pelvic Sorcery?

Eugenie Lee:

Well, that took so many years for me to get this courage to focus on pelvic pain because I live with pelvic pain and, and I thought, oh, it's just way too close to my own experience. But then again, you know, every time I did my paintings and installations and sculptures, they're all about my pelvic pain experience without saying pelvic pain experience because I just focus more on like, you know, psychological social aspects of pain experience that a lot of people just don't talk about. You know, like when you go and see your clinicians or, um, medical professionals, they never really mention psychosocial components.

So, what is psychosocial components? People living with persistent pain, we all have this intuitive understanding, but we don't talk about it because they're never validated. You know, like loneliness, grief, question about your own identity, depression. You just completely lose yourself like you don't know who you are anymore because you can no longer participate in things that you used to do. So you just constantly live in this nostalgic idea of yourself, but you can't really accept this current you, because there's a huge gap between those two identities. And naturally, nobody talks about that. So my work, Breakout My Pelvic Sorcery, one of the first things that I really have to get it right was particular sensations that people living with persistent pelvic pain would resonate with.

So I worked with mechatronic engineer to sort of reverse engineer those experiences by using TENS machine. So people, um, who are not familiar with TENS machines, general- generally used, um, to relieve pain sensations, like pain experiences that a lot of physiotherapists use, then you can buy them from anywhere, from eBay, as they're very common. Um, so what I wanted to do is hack pain relieving equipment and turn that into pain giving machine. So I work with mechatronic engineer to intensify some of those pain reliving, um, sensations into intensified pain giving sensations. So what participants actually experience at an exhibition is that they will experience some of these common symptoms. And if I ask them, "Can you describe some of those experiences to me?" They would basically use the same pain adjectives, like, "Oh, it feels like cramping. There's a hammering. There's a stabbing." So I know that these, um, sensations will resonate with people who live with pelvic pain or who don't live pelvic pain. Um, it w- ... It's almost like as authentic as it can get without giving any tissue damage to participants.

So that particular artwork, um, they strap on these pain giving, um, electrodes around their pelvic area and then they put on, uh, via goggles. And all they have to do is really simple task, which is just play, uh, via virtual ball game. You just have to hit the ball against the wall. That's it. But the idea is how distracted would you be if you are to play something as simple as this hitting ball game whilst experiencing pelvic pain? Can you do it? Can you do it as well, as easily as if you don't experience pain experiences like this?

Anthea:

I thought your website was beautiful and there's a section of you ... We'll put your website in the show notes, but there's a section of, um, the website where there's a video of participants, and one participant is talking about an inside thing is hard to describe after he's had the experience. And I just thought that was beautiful because exactly. It's so hard to explain these experiences for other people, yet by making people go through a, um, pretty easy game and trying to do that while being in pain obviously really changed the experience for them, which I thought was remarkable.

Eugenie Lee:

Well, that's an interesting commentary because when it comes to pain, we can't explain through verbal language or body language or any form of language that we know of to communicate to other people to explain exactly what you're going through. Pain experience is so basic, fundamental human. Oh, not human, but fundamental living experience. Yet even though we live in this civilized world, we lack that right kind of language to share some of our basic experiences. But why do we even need to share the experience? Because we're social animals and when we experience pain, it is inherently social. So what I'm trying to do in my work about pain is that I'm just trying to create different type of methodology that we can communicate with others. It's a new type of language that requires embedded experience. So if we can't tackle this shared experience through verbal or body language with others, then as an artist, I can come up with an alternative way to share an experience.

It is precisely the experience, the experiential artwork, and through that we can create some sort of collective shared experience, which makes it social because pain is biopsychosocial. I mean, sure, we do experience our world through the sensory responses, through this body that we have, but how do I know my sensory experience is same as yours? Like my apple taste. I know my apple, what it tastes like, but how do I compare that with what you experience with your taste of apple? You know? Um, so we're just trying to exchange certain sensory experiences through this very thing, this experience, because we can't really talk about that through verbal or any form of language. But if we can create something that resonates with each other, then I would say that's a, that's a great communication methodology. That's almost like a new form of language.

Anthea:

Thanks so much for joining us today, Eugenie, and for sharing so much of your work and how it develops.

Eugenie Lee:

Thank you very much, Anthea.

Anthea:

For anyone who wants to find out more of Eugenie's work and see some of her documentation, go to www.eugenielee.com.au. You'll also find out about future exhibitions. And of course we'll put those links in our show notes. You are listening to 2RPH and Sideshow, art, culture, disability. My next guest is Giulia Barbareschi. Giulia is a powerhouse of disability innovation research. She's worked across the globe in assistive technology and I'm so pleased she's joining us from Japan.

Giulia Barbareschi:

[inaudible 00:13:44].

Anthea:

First of all, can you tell us what is assistive technology?

Giulia Barbareschi:

Uh, yes, of course. I mean, the ... There's many definitions for, um, the terms of assistive technologies, but the easiest way to imagine it is any kind of technology that is used by people who identify as disabled. And, uh, they can be technology that is specifically designed for that purpose, or a lot of times it's even accessible technology. So, mainstream technology that can be used by people that might have different interaction needs. Easiest example of that would be your mobile phone. Um, everyone can use it because it has different features that can adapt to the way people interact with them.

Anthea:

And how have you been using assistive technology with the disability community?

Giulia Barbareschi:

In many different ways. Um, what I'm interested very broadly in research is how people use technology, how people with disabilities use technologies in their everyday life to basically do what they want to do. Um, and that can involve anything from using a wheelchair or a pair of crutches to move, um, using a speech recognition application in your mobile phone to communicate with others, um, using alternative interfaces to draw, using your computer. Wh- ... A variety of input that varies from your gaze to your voice, um, to maybe a combination of switches that you press. Um, so I'm very much interested in all those different kinds of uses regardless, let's say, of a particular application.

Anthea:

So you've been in Japan for about one year now, and you're at the Keio school there. Can you tell us a little bit about that school and your project there?

Giulia Barbareschi:

Yes, of course. So I am based at the, um, Keio Graduate School of Media Design. It's a department that collects really people from all walks of life. Um, there will be people with a background in engineering that will do design of, uh, technologies for various purpose from media entertainment. We have lots of people working in, um, sports and social activities, um, to Japan being Japan, um, media technology linked to the otaku culture. Um, so people that, uh, might do cosplay or play video games or, um, play role playing games and things like that. And people like myself who are interested in how people who have different access needs, um, use technology for various purposes. The project that I work on specifically, um, look at how artist, um, disabled artist use technologies being either their own particular assistive technologies or mainstream technologies, um, to produce different kind of art outputs from dance to, uh, music performances to visual arts. I'm recently becoming, uh, interested as well in, um, sculpture and another form of like tactile art as well. Um, so that is what my, my project is, is all about. Uh, I'm really interested in exploring the intersection, if you want, between disability, technology and art.

Anthea:

That sounds absolutely fascinating. I'd love to hear some more stories about that. Can you tell me some specifics around some of the people you've been working with?

Giulia Barbareschi:

Yes, absolutely. So the, the principal reason why I got interested in, in this is because when you think about, uh, assistive and, and accessible, um, technologies, um, we often describe those kind of tech as something that is used to bridge a functional gap. So, uh, you know, you have maybe difficulties walking and then you use a wheelchair or you use a pair of crutches. Um, I don't particularly like that interpretation because it promotes an image of disability that it's always negative. Uh, it ... So it means that someone always has something less. I got interested in art because disabled artists leverage these technologies to produce something unique. So rather than trying to bridge the gap and, and if you want, like, uh, be like everyone else, uh, they, they leverage what they have and they're different than, than everyone else.

And I think the most poignant example of, of how I got, you know, this particular idea switched into my head, um, I was watching a performance from an American disabled dancer at wheelchair dancers called Alice, Alice Sheppard. Um, and the choreography that, that was on, on stage, I ... It was during the pandemic, so I was watching that on my laptop. I was like, this is absolutely incredible. Like the fluidity of movement, the choreography, um, the intersection between the two dancers will never be possible if you had two standing dancers. Um, so I started to think about like other situations in, in everyday life where, um, disabled people like use the skills and, and capacities that they have developed as a result of their everyday experiences to, to do something unique. And, and I started digging in with more and more, um, artist around the globe.

Um, I have a very good friend as well who, who helped with some of my research. He is a digital artist in ... uh, base in the UK. His name is Jason Wilsher-Mills. Um, and he always says that acquiring a disability and having to stop, uh, to make art in the conventional way is what trigger his ability to embrace the pixel, um, and, and really pivot into digital arts. And Jason now makes anything from, um, you know, light boxes, so, um, flat pictures that you can il- retro illuminate to create different effects, um, to inflatable sculptures that are as big as a box of [inaudible 00:20:55]. Uh, and he would never have been able to do that doing so the sculpture in the traditional way in which he was trained.

Anthea:

That's amazing. Um, I love that. And I think it's really fantastic to hear you talk about, um, your issue with the term bridging the gap, because actually sometimes difference is just difference and difference can be glorious. Um, can you tell me a little bit about the technology that you've designed to help with some of these projects?

Giulia Barbareschi:

Sure. So, um, one, one of my favorite projects that we worked on, uh, recently, it was, uh, in collaboration with a Bangalore based, uh, DJ, um, who is, uh, a wheelchair user as well. And, uh, what he really wanted to do was to increase his stage presence. Um, so what, what he was saying is that, you know, like a l- a lot of time you make all this people dance, um, and, uh ... but at the same time you're, you're hidden behind the console. Um, especially if you use a wheelchair, you become very much less visible, uh, because you tend to be at a lower height. Um, so he wanted to sort of increase like his, uh, visibility and presence on the stage. Um, we worked through different solutions and what we came up, um, was, uh, something that we basically made covers for his wheels that integrate LED patterns that are activated by the music in the club and create, um, cymatic patterns, so pulsating waves, uh, that respond to the rhythm of the music.

Um, and now what, what that caused them to be is that now he is more visible than, than, you know, like more, more stage appropriate if you want, than, than, you know, like, than a regular DJ. And that is because he just embraced the possibility that, that were, you know, created by the fact that, that the wheelchair becomes actually par- in a way, part of the console, um, setup. And, you know, he wouldn't have that if, if he was just like a regular DJ that, you know, stand behind the console.

Anthea:

That is so exciting. And where do you see your, uh ... Well, your ... I was about to say your art practice because I, I know that you, you say on your website that you don't identify as an artist, although having this conversation with you, I, I feel like I want to challenge that. But where do you, you see your art practice or your, your design practice going?

Giulia Barbareschi:

So I ... You are correct in that. I do not identify myself as an artist, nor I am identify myself as a disabled person. Well, I identify myself as is someone who is lucky enough to work with a lot of cool people (laughs). Uh, so, um, I ... One of the things that, that we've tried to do as part of this project is to reach out to artists, um, ask, you know, what could be useful, how can we help, um, how would they want to enhance their, uh, performance, um, or their practice or access it in a different ways and be able to leverage their skills. And I just try to bring my own expertise, the expertise of lots of collaborators that have volunteered their time to help with, um, design or, uh, writing bits of code for, uh, for different applications. Um, and just put them out there. We ... Whenever we, we create solutions, um, we've developed a website and we share this ... all these solutions open source so that any artist or to be honest, any disabled person that has a creative whim and, and wants to uh, use those technologies is free and able to do so.

Anthea:

I might be in touch in the future about projects. Giulia, I know that our listeners are gonna want to know more about this, and I believe you have a website that's about to come live with everything you're doing. Can you tell us about that?

Giulia Barbareschi:

Yes, of course. So as I mentioned earlier, all the solutions and all the designs or guide on how to pimp your assistive technologies and, and make them more artistic, uh, we're making them available as we do them on our website. It's called www.accessibleartistictechnologies.com. All one words, no space, no hyphen, no nothing. Accessible artistic technologies.

Anthea:

Thank you so much. It's been glorious to have you on.

Giulia Barbareschi:

Thank you so much for having me.

Anthea:

When we recorded this interview, we were expecting it to go live much later in the month. So the accessible adaptive technology website won't be live for a couple of weeks yet. But in the meantime, I suggest you go to Giulia's website linked in the show notes. And now my buddy with the great big brain, Hanna Cormack. Welcome back, Hanna, to our newly named Sideshow. So tell us, what are you excited about seeing and not seeing in the coming months?

Hanna Cormack:

Well, Sydney Festival is here this month and there are many shows I wish I could attend. But this one in particular, Debra Keenahan's new performance work, Othering. Drawing upon Deborah's own lived experience, Othering reverses and inverts the gaze of the audience, encouraging them to experience the world as if they're a person with dwarfism and reflect upon how we use words and actions to other people who are seen to be different. It's on at the Casula Powerhouse Arts Centre with evening performances on the 13th and 14th and matinee performances on the 14th and 15th. Audio description and tactile tours are available, and the evening show of the 14th will be Auslan interpreted. Trigger warnings include references to violence, sexual assault, and medical intervention, and there is a general warning that the production includes use of haze. Latecomers are admitted at appropriate breaks in the performance. So if you have any timing access barriers, early arrival is recommended.

What I will be catching at SydFest this year is The Air Between Us. It's an aerial duet created and performed by New Zealand dancer choreographer Chloe Loftus and Maori dance artist and wheelchair user, Rodney Bell with Rigging by Tim Miller-White. It's wheelchair accessible, it's outdoors, it's free, and I love works like this that are very consciously working towards removing some of those less acknowledged barriers to accessing art, like financial barriers and social barriers of being inside institutional buildings. So this is going to be on the lawns of the Museum of Contemporary Art outside, and you can find it at various times on the 20th to the 22nd of January. Or like me, you can catch the livestream showing on the 22nd, which is available to watch for free via Sydney Festival at home, as well as on demand on the website after the performance. Information, tickets, and/or streaming is available at the Sydney Festival website, sydneyfestival.org.au.

Anthea:

Awesome. Thank you so much for those recommendations, and [inaudible 00:28:47] lovely to hear that one of those has an [inaudible 00:28:50] connection. And now to play us out, Going Soon by Eliza Hull. If you would like your music to be featured on Sideshow, please do get in touch with us.