### Session Transcript: 27-09-2021   SAMAG Meeting

>> Good evening, Everybody. My name is Sophie Byrne and it is wonderful to have you with us for tonight's conversation. I would like to acknowledge the traditional owners of all the lands we are joining from. I am of the lands of the Gadigal people of the Eora nation.  
  
I would like to think Gadigal Elders for the custodians ship of land, country, and culture. SAMAG is thrilled to be presenting this tonight with our excellent analyst, Morwenna Collett, Jackie Leach Scully, and Dan Graham, to discuss Innovating Art Through Disability.  
  
I will very shortly hand over to Liz Martin to start the event, I just wanted to quickly highlight that SAMAG has an annual series of events to share practical, innovative ideas to grow an inclusive and resilient arts sector.  
  
And we have a couple of great events coming up in October on reopening and what the recently released roadmap means for our sector. Plus a thought leadership event in November. It is a very good time to join SAMAG if you have not already.  
  
Now I would like to welcome Liz Martin, CEO of Accessible Arts to begin tonight session. Thank you so much, Liz.  
  
>> Thanks, Sophie. Thank you and welcome to this evening's conversation. If you have not heard of Accessible Arts we other peak arts and disability organisation across New South Wales. We advance the rights of and opportunities for people with disability or who are Deaf to develop and sustain professional committees and the arts and have equitable access to arts and culture.  
  
Were absolutely delighted to host present this conversation alongside SAMAG, and in terms of speakers I can honestly and personally say that each of the speakers is an absolute delight. I've had the most fascinating conversations with all four of them, and it is with great pleasure that I welcome Eugenie Lee, Jackie Leach Scully, Dan Graham, and Morwenna Collett. Two leaders to the conversation, Innovating Art Through Disability.  
  
>> Thank you so much, Liz. And Sophie as well, and Sasha from SAMAG, and Accessible Arts, for bringing us together this evening to have a conversation with you all.  
  
Hello, Jackie, Eugenie, Dan. Great to see you here and really looking forward to getting into all sorts of things tonight as he talk about our topic, innovating through art and disability.  
  
And why this topic? I suppose, well certainly I feel that artists with disability are making some of the most exciting, experimental, risk-taking, cutting-edge, innovative work on the planet. It is work that I love, it is made by artists who represent 20% of our population.  
  
One in five Australians live with disability, however we know only 9% of our professional artists with disability in Australia identify as artists with disabilities. Sadly those artists with disability only on 42% less of what artist without disability earn.  
  
There is definitely some road blocks and barriers which I'm sure we will get into tonight. But the kind of come back to our premise, we are talking about this area because it is exciting. Artists with disability are talented, they are elevating our collective experience of art, and transforming how we understand the world. And they've got some really innovative ways of working as both artists, and we are finding innovative ways to include audiences with disability in the arts as well.  
  
What we are going to do is I will introduce our three panellists this evening, and I will do them one by one and I will then ask for each of you to speak for a couple of minutes about your practice. What you would like to share with us around this topic, and then we will get into the conversation part of this evening.  
  
As you are watching along at home, if you would like to ask any questions of any of our speakers tonight please feel free to enter those into the Q&A box in the chat. And we will be those into the conversation as they come up. Don't be shy, questions from the audience are more than welcome.  
  
OK. Let's begin with Jackie if that's OK. Jackie Leach Scully is Professor of Bioethics and director of something called the Disability Innovation Institute at the University of NSW, Sydney. She is a very proud and b disability activist as well.  
  
Over the years Jackie's research hazard to people with disability in medicine and healthcare, including some pretty controversial topics such as prenatal genetic selection, assistive technologies, and access to care in health emergencies. Jackie is a fellow of the Academy of Social Sciences, of the Royal Society of Arts, and of the Hastings Center in New York. In 2020 she was named as one of Australia's outstanding 50 LGBTI+ leaders by Deloitte Australia.  
  
Jackie, I would love to hand over to you and he would little bit about you and your work. You are just on mute at the moment.  
  
>> That was a really good start to the evening, thank you. I'm very pleased to be here. As you said, I am a bioethicist, Professor of Bioethics at UNSW, and also the director of the Disability Innovation Institute there.  
  
I think as you mentioned in my career I have worked on a lot of controversial topics, particularly in the disability space. I don't think many disability activists feel very warmly sometimes towards bioethics as a field because it is so bly associated historically with some pretty controversial opinions, and sometimes some very hostile to disability opinions.  
  
In my work though I do try to work against that and make it a space in which people can ask some serious questions about what we mean by disability, what we mean by difference and divergence and so on. About accommodation, about acceptance, although sorts of topics.  
  
But I've also also been very interested in the arts and despite the fact that I've been profoundly deaf since childhood, I lost my hearing with meningitis when I was a small child. I've been married for 35 years to a professional musician. A classical musician.  
  
So we have some very interesting discussions about sound and music and arts practice in that area. And at one point my partner was what we call a (unknown term) which is basically the principal of musical Conservator in Switzerland and that had a b connection with the local art colleges well.  
  
There was a lot of interaction between musical practice and visual and performance arts as well in that college. Again I was drawn into that world. I have to say I'm not a practising artist, except for about 20 minutes a couple of times a week when I call that my saxophone. And I play really, really badly.  
  
I think I played badly not because I'm Deaf but because I'm just… I don't practice enough. We can talk about that more later. I just really interested to hear about other people's views and work in practice in this conversation.  
  
>> Jackie, I have to ask, has saxophone bit a long hobby or was it a COVID take up?  
  
>> A longer hobby. When I first got together with my partner I was being defensive about being involved in music and having to talk more about that later on. She said to me, "OK, when you are 40 I'm going to get you a saxophone." I said, "Yeah, sure."  
  
On my 40th birthday I came out of my bedroom and there was this big saxophone shaped package, I thought, "OK, gotta do it now." I haven't progressed very much.  
  
>> Very interested in that, and there is lots of intersecting parts I think that your work covers, and it will be great to have as part of the conversation.  
  
Let's move on to Eugenie next. Eugenie Lee, she is a Sydney-based Korean Australian interdisciplinary artist with a conceptual focused on her lived experience with persistent pain. Experimentation and collaboration with pain scientists and researchers, who investigate ways in which technologies can assist in pain research on important conceptual underpinning for her disciplinary art practice which includes participatory performances, using technologies, installations, sculptures and paintings.  
  
By appropriating the latest scientific concepts and lab materials including VR and electronics, and reconfiguring them for non-therapeutic uses, Eugenie creates holistic pain experiences, as creative outcomes.  
  
She works closely with researchers and follows their protocols and ethics, notwithstanding using their techniques in ways they were probably not originally designed for. So Eugenie, there is a lot in that.  
  
And I've certainly read about your work but I have not had the chance to experience it first hand yet. And goodness me, it sounds great and terrifying at the same time. We would love to hear from you now a little bit about your work.  
  
>> Hello, everyone. Thank you for having me. My practice, a lot of people ask me what I do as an artist, do I do painting or sculpture? And I say, "No, I actually give pain to people for a living."  
  
If I actually expand that, I am an experimental artist using interactive performance installation to create artworks about persistent pain. Because I've been living with persistent pain for nearly 3 decades. So the artworks are informed by not only my lived experience, but also by pain science and other peoples lived experiences as well.  
  
And I use creative technologies like virtual reality, and hypothetical machines like pain machines and things at that, and a turned that into a custom-built device for each participant to undergo multifaceted experiences of persistent pain.  
  
For example, I invite participant inside a chamber, a very small isolation chamber, and temporarily manipulate their brain using a variety of techniques. While they are wearing virtual reality goggles and a hectic custom-built glove to experience something similar to neuropathic pain on their hands, without involving real pain.  
  
Or sometimes also they are invited to play a simple virtual reality game while wearing a haptic belt around their pelvis, to give them that pain like experience. It is not a pleasant experience but surprisingly I've been very lucky with a lot of people queueing up to experience something quite torturous. And it still makes me wonder why. It takes me a lot of time to prepare and do research because I want to make sure that the experience can be authentic without actually creating a real pain. Because I wouldn't pass the ethics and all that.  
  
Spent several months or over a year to do research, as I also work with other researchers like neuroscientists, linguists who specialise in pain expression through different genders and cultures, empathy experts, psychologists, and so on to make sure that my work is scientifically valid.  
  
The reason why I focus heavily on science is because persistent pain cannot be adequately understood and less pain science and its related neural plasticity is involved. But, having said that, I also focus on disability studies like (unknown term) and things like that to bring different perspectives. It's not only about science and lived experience, there is 1/3 agenda, the social and psychological aspects as well.  
  
I'm also very interested to hear what Jackie has to say because we briefly talked about this before that, you know, when it comes to human experience, disability experience, people talk about social models versus medical models. But, when it specifically comes to persistent pain or chronically ill situations, we cannot deny one way or the other because we live in this body, we have only one body. To live and experience us and our surroundings, it involves a whole ecosystem, ecology, and networks. In that sense, I would like to look both prospectus, or should I say, 1/3 perspective that involves both and focus on the future so that nobody is left behind. Thank you.  
>> Amazing, Eugenie. Can I ask, I'm guessing that you started out as an artist and then science kind of crept in. What was the moment where you realised that science had become a really large part of your practice as well?  
>> That was actually surprisingly through working with neuroscientists who specialised in persistent pain. I was lucky enough to receive the residency grant for Accessible Arts and consequently, Australian network for art and technology afterwards to continue working with neuroscientists based in South Australia. Little did I know that these people turned out to be some of the best scientists in the world, and I have never even heard of pain science before I even googled them.  
  
Just sent an email with the 1st question – like 1st person that popped up on Google research (Laughs). It was almost like a freak accident or lucky. They taught me how to look at my own frustrating, unresolved experience living with pain. From a neuroscientist perspective. But, neuroscientists in Australia, and also some of the top neuroscientists in pain research, they are so holistic.  
  
I actually keep on telling them, you guys are more holistic than tree huggers because they are looking at bio-cycle, -- biopsychosocial. Bio is only a part of it. Psychosocial components, in my experience of living with pain. They introduce this amazing side of it and to be able to understand pain, you have to understand this pain science, biopsychosocial, this network of… Like I mentioned before, the ecology of living experience.  
  
What was the question again? (Laughs)  
>> (Laughs) Art and science, what did they collide? It sounds like it's been a very natural and interesting progression and quite fortuitous. You have come across the right people at the right time.  
>> Yes.  
>> Lots to unpack and ask you about, Eugenie. Really interested to see how the work of all 3 of our panellists tonight are connected and aligned in some way. But, let me introduce you to our 3rd panellists now, Dan Graham. Dan is a young, newer diverse writer and director from Sydney. He directed the Acclaim production Sam I Am and has directed the Crucible, A Kind of Alaska, and Wolf Lullaby just to name a couple.  
  
Dan has directing secondments with organisations like the Melbourne Theatre Company, Victorian Opera, The Ensemble Theatre, and Opera Australia. Bell Shakespeare, Sport for Jove, and he has been invited on a directory secondment for The Book of Everything.  
  
He has a BA on directing from the University of Tasmania and an honours from the University of Sydney. He is a part of the LGBTQIA+ community and is an advocate for artists with disability.  
  
And, I thought it would be great to hear about your professional background and perhaps some of the work that you have been doing recently.  
>> Absolutely, thank you so much for having me, and Liz. We were all discussing before we went live, I think this is a good cop -- time, while, a timely time to have this discussion. I always make the statement that I don't expect everyone who was a young kid, 12 years old who was sent to acting classes, to decide on a career in theatre. Disability or otherwise. But funnily enough, I was sent to acting classes as a 12 year old and people smile and I say this, it took me out of my shell.  
  
I was of a generation, if I can say, that people come and not that people don't now, people didn't understand what your diversity is. I was of a generation where I was too slow, stupid, because people didn't understand your diversity, as well as dyslexia, as well as your diversity as a broader term.  
  
Think it was quite funny that the 12 year old initially was put at the back of the class, and then now is telling people what to do in a nice way of course. I found my interest, I decided on a career in theatre, and it has been, ironically, the last few years, it is starting to take place and what we are talking about tonight, and that is that I didn't see myself or people with disabilities actually being shown on, let's just be blunt about it, the main stages in Australia. That started my discussion, a couple of years ago, there is a discussion which is still happening, which is still important, the discussion on diversity. But very often, I am happy that people disagree with me on this statement, there still is not much talk on disability. It especially when I tell people I am a theatre director and I hear the term disability and your diversity, I get "Oh, is that a hobby of yours?".  
  
I would say that nemesis would disagree on that statement, so just saying, just saying. -- My masters would disagree… So, talking about diversity again, disability wasn't brought up. With my previous research which included being awarded the Australian Council of arts, the culture trust, I was actually awarded in January, trying to remember with COVID-19, it's all blurred, but in January 2019 I was actually awarded a fellowship which took me over to New York for a residency at the Atlantic theatre company which is 1 of the major theatre companies in New York and am sure that you have heard of (inaudible) who studied it. There is a bit of a history.  
  
What caught my eye was discrimination, whatever you call it, I did not identify as having a disability at that stage because as I have said to you,… Bell Shakespeare which hopefully was done, well, it is going to start again once we come out from COVID-19, which is ironically how I see your diversity under the lens of Shakespeare. I heard from another get a company, who I won't mention here, some person, to me that when I outdid myself, the comment was open because what you sound so normal, Dan. How is that possible? Close quote – the"  
  
This is very disheartening as someone who has a disability advocate, and identifies as a person with a disability and possibly someone in the industry. So, when I was in Atlanta, the 1st question they ask me was what access requirements that I need to have? I since found out, who I am still in contact with, that that is the question that they ask every member of staff in the front of house, bar staff, to the artistic director.  
  
Wanted to say that it was heartening, that the theatre company just so it is common policy to actually do have that question. One I have worked with organisations as a director, and also when I was starting out, in terms of access needs, ironically, I didn't really take notes in rehearsals. That is what I call my superpower, my neuro diversity, is that I have a good memory, some people would say great memory, and actually remembering the whole piece even beforehand despite what we were discussing.  
  
People were saying that if I needed a scribe at any time, that was provided, sometimes if I needed a larger text on a script, that was provided, et cetera, and I wasn't made to feel different, if that makes sense. And that has followed me and from that research, I was awarded in pre-COVID-19, the Fellowship which taught me -- took me to the UK which was specifically on access departments which was something, if we have time to discuss in more detail, and how they actually work with professionals. This is another issue that we are also in, and with my fellow is another taking part, the whole idea of professional artists with a disability which I think is really important to note.  
  
I actually met with the access departments to discuss the work with professional artists and I meant pretty much (Laughs) You know, and we discussed this before, from the National Theatre in London, the National Theatre in Scotland, the globe, et cetera.  
  
It was almost a sense of surprise that I was actually asking the questions I was asking because it's so ingrained, and Emily talking about the UK in this instance, that it is so ingrained in the conversation that you don't necessarily… You can be a disabled artist, but if it makes sense, you are not defined by that disability, if you know what I mean. It is just how like any artist, the best work that we created.  
  
So, I bought that knowledge back with me which I am still developing and wanting interested parties to go on my journey. I lasted 10 minutes without mentioning journey (Laughs)! That has taken me to now where hopefully in early January, I will be getting myself back over to New York and I have been awarded the International Society for the performing arts based in New York, I am going to be the Australian fellow.  
  
I have been awarded for my (inaudible) as was my access work, because I still have the discussion that I can't divorce each from the other because it obviously forms my identity and my practice.  
>> Then, there is so much in that. Some of the things that stood out to me in your excellent summation of your work were, which I think are relevant for our audience to know, you know. Diversity and inclusion and making sure that disability is part of that conversation, because you are right, it can kind of be hidden under the carpet in those kinds of conversations. Your ideas and mission around identity and how disability has become a ber part of your identity over time, and, you know, hot tip takeaway, if you're not asking about people's access requirements with all the artists that you are working with in your work, build it into your process. Whether it is your ticketing purchase process, whether it is onboarding staff, what are your key access requirements is the key question. Really interesting to hear about your work with all of those theatre companies  
  
I was on a similar one, everyone that I met asked me if I knew Dan Graham. We kind of stalked each other in the UK. Thank you so much for your sort of, I know five minutes is not at all enough to do any of your work justice, but I would like to come back now to each of you and unpack it a little bit with you individually.  
  
Then I will ask some broad overarching questions towards the end. And again, encourage people to put questions in the chat as we go. I can see a good one for you already, Eugenie, so I will feed that in and you can have a heads up when we come to you.  
  
Jackie, I want to get into some more around music and deafness. And perhaps some of the stereotypes that you might have come across, and also for our audience this evening, can you tell us what it is like to experience music as a Deaf person, and how that works for you individually and perhaps also if you are aware of any of the incredible assistive technologies that are out there around music and Deafness as well?  
  
>> Sure. Obviously there are a whole lot of stereotypes around Deafness and the ability to take part in music in particular. When I lost my hearing as a child, just prior to that I had been learning the piano. Starting to learn the piano.  
  
And my parents were told after I had meningitis that I ought not to have any more contact with music because it would probably upset me too much. My fellow would upset me too much. I was pretty much shielded from it, excused music lessons at school, and it wasn't until I was much older that I really developed any kind of interest in music.  
  
As I said earlier I was very hesitant about it. Until obviously I met my partner whose whole life revolves around music and sound and so on, and it quickly became clear that, you know, the equivalent of standing on the touch alliance with a footballer, as her partner I was going to have to get involved in some ways, if the relationship is going to have any future.  
  
But it has been, it has broken a lot of the stereotypes and the stereotype that Deaf people can't hear music or can't enjoy it. Or they can't take part in it in anyway, no appreciation of it, etc.  
  
I think one of the key things I try to get across when people ask about that is that I do know that what I hear is not what hearing people will hear. Of most kinds of music, let's say. But is that actually important? Because if I enjoy it and not, don't have a sense of inadequacy or resentment or anything like that which I don't, if I enjoy what I am hearing then that is the important thing.  
  
Particularly because all human bodies have limits, and I don't mean the kind of banal thing of, "We are all disabled," I'm not saying that. But we've got certain limits, we can't see certain wavelengths, and so on.  
  
So the things that no human being will be able to hear and what a musical instrument actually produces, I think if we can look at it in that light and say that there are people like me who will be hearing something different, but potentially what I'm hearing is actually interesting. It might be as interesting as the original composition, but actually what I would really like to experience and if anybody out there was involved in a project like this I'd be very happy to learn more about it, is a piece of music which is designed to need other senses and sound to experience it fully.  
  
Say with the vibration, being part of the performance, and not just because the music is so loud that your insides are shaking kind of thing, we've all been to rock concerts like that. But something where the tactile bit of it is an intrinsic part and subtle part of the overall composition.  
  
So what I'm trying to say I think is not just with music in particular, the other forms of art as well, is we try to move from either a sense of if only because make it accessible for disabled people, then they will be able to see or hear or do the same sorts of things as the rest of us can. That is one important aspect.  
  
But another part is, different people will be experiencing this in different ways. We cannot potentially learn and enjoy and understand something different from it than just the standard mode of experience, if you want to call it that.  
  
>> I think that is so interesting in terms of just how we think about access and inclusion in general. It is not trying to bring something up to a certain bar we are trying to meet in terms of matching that experience, but you are absolutely right and that there is more than one way to experience art.  
  
We know that, and there is more than one way to have an experience of so many things. It is not thinking that things have to be done in a certain way and a one size fits all approach, so that is super interesting.  
  
And before they get onto tech, there is a question here in the Q&A from Eugenie, it would be great to ask if you don't mind. She is wondering if you can feel the impact or emotion of the music, Jackie?  
  
>> Do you mean do I personally perceive it? Sure. Sad music, I cry. Uplifting music, I feel uplifted.  
  
I have to say that because they came to music late my tastes are quite eclectic, I like some folk music, some pop music, my partner is a classical musician so I've had a lot of exposure to the standard classical repertoire.  
  
Some of that I think for everybody, sometimes a little bit difficult to get what it is that the composer is trying to say. But we can always think get a sense of the affectation to emotional content of a piece of me relatively easily, kids, they don't have to be told about saddle happy music.  
  
I think so that it is a way of communicating something which we all know it is not about necessarily communicating that was, but perhaps if we looked at it from the perspective of perhaps the different emotional residences, that thereafter somebody like me say, where there might be a long almost blank bit in the middle of the piece of me is that, if there was a lot of high frequencies that I cannot hear.  
  
I might be experiencing something which is more about, I don't know, lost nurse or boredom, or isolation or something. Than might otherwise be the case, but they can still be an interpretation of the musical stop  
  
>> Brilliant. I have to ask, have you had experience with any of the kind of, I don't know if technology is quite the right word, but I've come across things like wearables, vests and that kind of thing, in terms of tapping into the vibrations of certain music, I guess mostly amplified music.  
  
And on my visit to the UK that was certainly becoming more common for mainstream arts organisations, to have that sort of gear to hire out, the land out to audience members that wanted it. I just wondered if you had a take on any of that?  
  
>> Have not had a lot of experience of it, I have had some. I think it is a very interesting thing to do in expanding, in a sense, the perceptions that anybody can bring to say a piece of me sick like that. Again, I would emphasise I think it is something that might be, it will make some kinds of music more accessible to standard people. Standard people, nondisabled people. Accessible in a different way.  
  
They might begin also to understand a little bit of what it is like to move through the world in general using vibration and that sort of thing as part of one's experience.  
  
I am a great fan of using technology to expand the repertoire for the ways you can experience something, we can have another conversation about if you are doing something like Bach, what would they think about it? What would he think about it?  
  
>> Thanks, he is not around to let us know. Yes. Thank you, Jackie. Eugenie, a bunch of things to ask you about as well. I would love to hear more about Crip time, empathy, but let's come to Jenny who is put a question in the chat here. For you. It says, how has your practice supported your ability to live with your physical pain, where others use your installations to understand your pain experienced two  
  
>> There first of all is no (inaudible) of physical pain for someone pain is involved it is biopsychosocial. For example if I'm feeling stressed, psychologically or emotionally effective, the physical pain will be a lot worse.  
  
Or if I'm interacting with people and somebody happens to be dismissing my experience, it certainly makes me painless. And also vice versa. If I'm surrounded by people who make me feel safe my pain threshold, unable to handle pain, sometimes I don't even feel pain. There is no such thing as physical pain.  
  
I think the people to consider pain as physical and experienced on its own, that perception itself needs to be changed. There is no such thing. We are holistic beings. My ability to live with my pain through my practice, I mean, how is my practice supported my ability to live with my pain?  
  
And whether my installation and making other people to experience pain is for them to understand my pain, no. My personal experience out of the equation.  
  
When I designed my installation, it is more of an overall experience, the common theme of certain types of pain, for instance whether it is neuropathic pain, complex regional pain syndrome, that often happens to the limbs. It is that.  
  
My personal lived experiences not included. But it is involved in the sense that with a, that pain -- whether that pain experience is authentic or not. I live with persistent pelvic pain so the second artwork of done is about persistent pelvic pain.  
  
But again my own personal experience of my own pain is out of it. It is mainly based on other people who live with persistent pain, and grab their common themes and put that into it. I've only put my own experience through by making things that feel right, that doesn't feel right, it is just an anchor. That's it.  
  
When people common experience something, it is scientifically sound, authentic, but almost it's got nothing to do with me, and that itself is an important factor.  
  
>> Eugenie, let's talk a little bit about empathy because I know this is a word that has come up a lot in your work before. And you know, I guess it would be interesting to know whether your works, you think to conjure up empathy for people and that idea of stepping into someone else's shoes.  
  
In the disability community sometimes we hear about things like disability awareness training through simulation activities like people going around in a wheelchair who were not wheelchair users, that kind of thing. I would love you to sort of touch on that idea of empathy and how that comes through your work.  
  
>> Sure. Empathy and simulation exercise, yes, yes, and no at the same time. Initially when I started creating artworks using VR I did not believe no but I was doing, I am doing simulation art, VR art, but I had no idea basically.  
  
The more I think about it the more I feel like I'm not doing that. Although, I borrowed the idea of simulation exercise, for instance. My intention and outcome though, it goes way beyond that.  
  
If they were simply about simulation exercise, like for instance, some people that say, "What it feels like to be blind." And just walk around the block for half an hour blindfolded or something like that.  
  
If it is just something like that then I would be disrespecting people with lived experiences, you know? If I'm doing a simulation art involving pain, then… It is like, like, fellow disabled people, they would be horribly offended because of his risk of me providing a wrong impression that is stepping into the shoes of someone living with pain, that it's all about alleged failure to function.  
  
And they are supposedly having an impaired ability to contribute to what society is a non-pained person would. Almost steer their focus as to what it feels like to have a certain type of pathological pain, because they heavily advocate biopsychosocial holistic experience of pain, of human experience, that pain happens to be just one of them.  
  
Assimilation exercise what kind of make it like a freakshow or charitable works to those living with pain. So, what I offer to the interactive experience in my work instead is more about the understanding and reflection on the fundamental experience of living. As a social being.  
  
I am creating opportunities for people to change their idea from the preconceived notions of pain into reflecting our future. Like, what would our lives be like if we all had a better understanding of social and emotional influence of pain? And imposing questions like, you know, can we all contribute to this? As part of society, as part of members of society, do we all share some form of responsibility? Yes stop it's a big, capital yes.  
  
The whole point of my work is to posit an idea that whether there is something that we can all do as a member of society towards a better future without leaving behind those living with pain to deal with it on their own. I mean, is pain indeed just an individual experience that should be treated as a single isolated phenomenon that simply has nothing to do with anybody else? Or, could it possibly be, instead, to realise that pain holds a multidimensional relational, cultural, political, and social influence that affects far more than just a single, isolated entity.  
  
I mean, I know the answer to that. And hopefully, people going through my interactive experience would come to the conclusion. I mean, it takes only 10 minutes are up to one hour to experience, but I am hoping that the experience itself will be able to transform the attitude permanently.  
  
Persistent pain is a disease and its own right. There is a difference between acute and persistent pain. It takes an entire person, society, and culture to understand pain because it is so complex. I'm talking about human justice, social studies, anthropology, and philosophy to understand pain. And we are nowhere near close to grasping the whole picture yet because we are so far and far behind from understanding us human or animal beings.  
  
In a way, it gives me an exciting opportunity to be able to tap into some of these elements. This is about changing the culture of pain because I am actively trying to break down the layers and barriers that hinder us from moving away from the old, stagnant misconception about what pain is. It's because it can do more harm than good.  
  
Our misconception of pain can seriously do is more harm for people living with pain. It instead, I advocate the accessible methodology as an artist to disseminate the knowledge of pain to everyone that doesn't discriminate, education, gender, age, race, whatever demographic, whatever their demographic status. And I'm still learning. My works will always be a work in progress because I just tapped into learning more about disability studies and theory and things like that. Every time I learn something new, I can translate that into my work to share with my audience.  
>> Thanks, Eugenie. Again, there is so much to hear that in great to hear about how it is evolving over time and bringing new ideas and new theories. Great to think about how that fits into a pain framework and what that looks like.  
  
I was watching on, so I want to come to Dan before we have a general conversation about arts and disability. But Dan, you have had 2 incredible overseas trips read before COVID-19. And you got to see some of the leading practice in the world in terms of theatre organisations really innovating around arts and disability. I wondered if you could share a couple of highlights of which theatre companies were doing great work and what were they doing and what good ideas might we be able to pinch back here in Australia?  
>> Again, like everyone said, this could be a whole discussion in itself, but it's a small discussion now. I would have to say that it depends. Being in the space, in the -- as a disability rights advocate, as a person with disability and as well as a director, I was in different seats at the same time. I have one example that I do love.  
  
I saw a production at the National Theatre in London which was literally I think between 60 and 80, so it was a big show. At the very top, it was pretty much in the vein of almost like this godlike character up above, at the top of the stage. And I thought open court that a really clever device" and it was only when the audience… It was revealed to the audience that they were a wheelchair user. In a sense, it was showing obviously that the person is a person with disability, but it was something that we are discussing here. The whole idea of almost glorifying nondisabled people people with disabilities. They thought that was a very important thing to show.  
  
Think it is very interesting in that note, even simple things like Sam I Am, my most recent show, which answers the question where it was to intersection analogies, both the performer and I, the cocreator director being part of the disability community as well as the LGBT QR community. But at the same time, -- LGBTQIA+ community. I thought that it was really important to get the support from the Deaf community. And yes, I had this idea of what it was going to be, but as someone who has been on the other side of the coin, I didn't feel that I could, in all good consciousness, give my support or, you know, give what I wanted to do. Amazingly, I am still in contact with all of those in the Deaf community.  
  
In the UK, what I investigated in that was that it gets back to what some of what you said earlier Morwenna, I know it sounds really really almost… And I'm talking about performing arts here, it all comes down to having the conversation. Because for such a long time, arts, as artist with a disability, have often, and it still does happen, trust me, it does, we still have people thinking on our behalf. And yet, it is important obviously to have representation.  
  
I do have great… I don't want to see arguments, but great concerns, I guess that's a polite way to put it (Laughs). When disability is represented by people with no lived experience. But, this is something that I have tangled with, in the UK and hopefully in New York in January again, hopefully I don't exclusively want to direct disability work. And it's so funny, with this discussion of diversity, people are certainly starting to have an understanding. But, they are saying 'so, you just want to do disability work.' That's like saying, do just want to do LGBTQIA+ work or Jewish work.  
>> Is limiting, yes.  
>> You know? No, but I think what I noticed with the UK was that it was literally, and they were trying to promote themselves, they will listen to me, this colonial from Australia, perhaps, you know. I thought it was very interesting in that it was so ingrained, and we had this discussion with your fellowship to Morwenna, that it was so ingrained not just in knowledge, but in discussion.  
  
Think it was very interesting that I, remaining in contact with the head of access at The Globe Quote… He wanted to know that someone with a disability were basically, when they can learn. That's what I was thinking of doing, basically, it gets me going in terms of a consultancy model because obviously, I would like to thank that in my lifetime we will have an artistic director who does identify publicly as having a disability. It would be my hope. Just putting it out there.  
  
Yes, I would like to think that at the same time, would it be the issue? Something as important as this discussion is tonight, I would hope, and as I have had numerous discussions and one good thing from COVID-19 is that I can spread my manifesto, so to speak, I think without it we wouldn't have had to have this discussion in the future. That would be my hope. And at the same time, I do know that of the generation 1 or 2 after me, a lot of the issues, let me just say it bluntly, art skills are still facing the same challenges that I experienced as a BA in communication studies.  
  
It is very disheartening that I have both, older and younger people coming to me to say to me, and if I can be very blunt, saying to me especially if it is a 'head and' disability, whatever that means, if I do disclose -- 'hidden'… That people would understand. -- Will not understand.  
  
In a culture that wants us to represent all voices, it's not good enough to represent all voices. It is to basically have the proverbial, not just a person on a wheelchair on a stage saying 'hey, we have ticked that box.' To me, look what I just said a moment ago, I can only talk about my lived experience, and I stressed that all the time when people ask me for my opinions or my views.  
  
But at the same time, I think it is really scary that if you do have people with lived experience, I don't want to see used because this is what does happen more often than not, but actually not just have the rebuild by line in a mission statement but actually talk the talk, as good as they walk the walk, maybe that's a bad example (Laughs). So apologies if anyone is offended (Laughs).  
>> (Inaudible) right now, Dan.  
>> If we can try to create this kind of not just openness, but realise that I think it is very important, if I can give you an example, there is an actress who I've been working for years and years who is a wheelchair user. She has been cast in a TV show that is coming up, and like I said to her last week, she has been cast in a role as a tough CEO of a company. To me, that is progress. It's not the poor, disabled person. It's actually, this is someone given the opportunity you can achieve… You know.  
>> Great things. And everything – like everyday things as well. Then, again, there is so much in that. You product a real important distinction between arts and disability and disability arts… Any of lived experience and so. You know, there are 2 very separate things. And your point about leadership as well is so important and valid, and it was great to see the Australian Council recently released their equity report which is starting to head towards measuring what our leadership looks like across the arts and cultural sector in terms of diversity. So, it really promising to see how the tracks over time and arts Council England has been doing that for a really long time.  
  
OK, so I'm going to have one last question and then I think we are going to have to say good night and let people get back to the wine and cheese. But, I think let's finish by talking about you know, artists with disability. And what makes artists with disability distinctive, if anything? And why is this an area that interests you as individuals. And why is it an area that should interest all of the people listening tonight, and all of the arts organisations across the country. What is it about artists with disability that is innovative? Who would like to have a go at that?  
  
>> Are you throwing that open to everybody?  
  
>> Yes. I like to hear from each of you if that's OK.  
  
>> What is interesting, I think it's a complicated question because I think our cultural attitudes to disability are complicated. I think we've made enormous progress towards understanding that people are varied, towards understanding that having a disability, being disabled, being a person with disability, however you want to express it, it's not just part of being human but it's a normal part of being human.  
  
It is what happens to everybody if they are lucky enough to live long enough, and for some people early on in their life. It is not something that we should be in a sense trying to sidestep or avoid a bit frightened of, but we just need to engage with and understand it as part of what happens. There are bad aspects to it and there are some very good aspects to it.  
  
We've made progress in that direction as I said, I think underlying that is still an awful lot of fear and anxiety, and a desire not to be confronted with something which is difficult which people find difficult. You can see that I think in some areas of disability where there are things that are sort of acceptable and expected in the mainstream if you can say that.  
  
Then there are other things which just don't make it into the mainstream because they don't quite fit the box of what either a disabled artist is supposed to be like, or disability art is supposed to be like. Or what the artistic expression of disability is supposed to be like.  
  
Talking about the grace of a wheelchair user, for example, in the enjoyment you can get over using a wheelchair very skilfully. That doesn't make it into soap operas, on Australian TV. So I think there is, there is interest there but we are always going to have to be, one foot on the outside and looking at what that interest is really about.  
  
Is it about freakshow? Is it about reminding people that they're so lucky not to be like that? Is it about telling people that you're so progressive, such a good person? What is it really about? Sometimes I think the thing which would be most useful and revealing and expressive for people with disability is going to be the thing that the audience or the organiser likes the least.  
  
And that is a paradox.  
  
>> Yes. What is the word, I think your motivations for the interest is a really good point. Eugenie, Dan, have you got thoughts as well on artists with disability, and why everyone should go home after this session and you know, seek out another artist with disability to fall in love with or think about as a potential collaborator?  
  
>> I truly find any artist who creates work, it has certain elements of their own lived experience. Whether they are disabled are yet to be disabled or not disabled at all, whatever. It just has a certain element of lived experience.  
  
And the artworks art is just like any other human perspective, so subjective. Just like pain are subjective. It is all abstract. The artist has the ability to transform the abstract subjective experience into something tangible that everybody else can relate to one way or the other.  
  
And I just find that is a real innovation. To be able to transform the metaphorical quality using the medium of art into something that can be communicated in so many ways.  
  
I mean some artists, yes, if they are disabled and they may talk about the creative components of the lived experience, but most actually don't. Some of them use humour, and many ways to (inaudible), I just find that that form of art form and advocacy is something that I just find it highly interesting.  
  
Advocacy about human experience.  
  
>> Beautiful. And then, any final thoughts?  
  
>> Everything my fellow panellists have had to say, I think it is really important also, as a director, forget it director with a disability but a director, at present I'm working on a show that they will be tweeting for Curtin University, (inaudible) COVID, fun, fun.  
  
In terms of that I've been working on what I'm actually looking for in my actors. The first thing I came up with and it does come up unintentionally as my lived experience of disability. I'm interested in people to come at me with lived life experience, that can mean anything.  
  
That can be from someone, I'm not trying to be for that when I say this, but someone who may be from a refugee background, someone from the LGBTQ community, someone who may have a disability, etc, etc, etc. To me I would say to people thinking about employing, and that is a word I wish to say, employ, someone with a disability, is that basically everyone working with us before, everybody's experience is different, but I think if you have someone with a disability just three months on it existence, was trying not to be as heavy on it, but obviously existence, the level have lived experience and some more.  
  
I have memories my mum tells me is a fourthly role, and literally had 10 stuffed monkeys and two of them were getting a divorce and I was directing them in coping with their divorce. This is what you get, Mum. (Laughs) That example, a good example. But I think the thing is basically if you have a person with a disability, actually by that they've had to see the world, I don't want to say any unique way either, but obviously not everyone one way or the other, and I'm not myself, totally understanding of a disability. And someone who actually has the disability.  
  
But I think if we can see what can actually bring more to the party, and it is a whole issue especially where what we talk about maybe the coaching of artists with a disability, for the entertainment arts alliance there was a lot of discussion at the moment if should a person without a disability player person with a disability.  
  
I am on two sides of it, between the side and a disability at so I can see both sides. -- Advocate. What am I saying? If we can actually see that a person with a disability actually has had to, and this is not meant to be a pun, we ate there on stage. Their own world. At sometimes, and not to be or morbid on people, but of survival. At times it has been about survival for me.  
  
And basically at times I had (inaudible) emotionally and physically fearful for my safety as a person with a disability. And I think if you can try to see that the disability as part of a person and see that part, but also back to what we were saying, it is like any kind of diversity. Everyone is different.  
  
And I like the whole thing that I quoted in my year 12, HSC English paper on satire, satire but in terms of art, it is about the human condition of (inaudible).  
  
Who would have thought that would come in use 20 years later? We can think about it like that, what actually makes us? I had a friend of mine who saw a production of The Crucible that I did, that was not the disabled version of The Crucible, the friend of mine identifies as having a disability themselves as well as a clinical psychologist.  
  
They said that it was me, and I said that I'm not John Proctor, I'm not being executed in the Salem witch hunt. Not yet, give me time. But I actually did indirectly or directly, and not trying to be coy when I said it, I did incorporate myself and yes, the disability, I will say to people and people without a disability don't get this, it's something I was born with. It's something I'm living with. And guess what, everyone, something going to die with it.  
  
And as I get older, I don't want to say embrace it, but I see it as part of me that exists and I would say that as another artist gives me a different lens, then another nondisabled people.  
  
>> We are all going to have one at some point.  
  
>> Exactly.  
  
>> Thank you so much, my wonderful panel. We have run out of time but it has been such a pleasure talking to you and hearing about your work and your ideas. And getting some glimpses into what the future is going to look like as well.  
  
We've had some really lovely comments on some great questions come to the chat. But it has been just lovely to spend some time with you, and the audience out there, thank you for joining us.  
  
Do go and seek out the work of our panellists tonight, all incredible, amazing people and very easy to find online as well. Check them out. And thank you very much to SAMAG into Accessible Arts for hosting us this evening so we could have this conversation with you.  
  
And make sure it is continued. Go and seek out the work of incredible artists, from all different backgrounds including artists with disability who very selfishly I think are making some of the best artistic work on the planet, as I said earlier.  
  
And we look, I'm sure you will look forward to your next SAMAG event which Sophie has chatted to you about, and we hope to see you in the future too. Good night, everyone. Lovely to spend some time with you.  
  
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