



Dispatch

Disability and Deaf Futures

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This dispatch recounts a panel conversation on disability and D/deaf futurity that took place at the *Crippling the Arts Symposium*. The artists on this panel discuss how they assert disability and D/deaf futurity in the midst of the Anthropocene through their artistic activist practices. By discussing topics such as interdependence, the internet as increasing both community and the privatization of ideas, and how the arts can transform understandings of difference, these artists share their visions for the future.

Elizabeth Sweeney: I'm going to start this panel with the words of Stephen Fakiyesi,¹ a Black visual artist based here in Toronto:

I think there will always be a need for individuals, groups, and most certainly artists, to imagine the world, not as it is, but as it can be. I do not lament the present order of things, rather, one of the privileges of being an artist on the peripherals, as it were, is that you have the distance to more readily perceive the status quo, and possibly challenge it. I have a pretty active imagination and faith in something greater than myself to think that even now, all things are possible.

¹ See <https://stephenfakiyesi.com>



As we think about our futures, I am going to start off by engaging some of our active imaginations and ask you about the ways that disability arts discourse and practice often imagines or re-premises our reality – a reality that doesn't exist yet. What are some of your visions for the future? What are some of your utopias that you're thinking about?

Syrus Marcus Ware: When I imagine the future, a lot of different possibilities come to mind and they may not sound utopic but I'll explain why they are. In one version of the future, we're facing the dreaded effects of the Anthropocene, we're living off grid in small interdependent communities, and we're figuring out how to survive on the changed – radically changed – landscape together. In other versions of the future, we've somehow figured out how to live in harmony with the planet. We're living in communities that are also interdependent and interconnected. In both visions of the future, we're free: we're free from some of the effects of capitalism and how that impacts our lives; we are free from working and working and working and working for money and instead we're able to make art and make love and be with each other in radical and new ways. In both versions of the future, Deaf, disabled, and mad people are leading our societies. We are experts in what we will need to survive – interdependence. We know how to do it, we know how to rely on each other, we know how to show up for each other, and we end up being examples and leaders in showing the rest of the community how to live that life.

In both of these futures – and perhaps one prefigures the other – I hope that we get to the place where we can all live on this planet with dignity and love. Even if we have to go through a sort of post-apocalyptic bunker to get to that future where we all get to make it: racialized, disabled, mad, and Deaf people are surviving and thriving.

Elizabeth Sweeney: Thank you. That's a good way to start us off here.

Annie, you had mentioned to me that the future of disability activism cannot flourish without intersectionality. Could take a moment to expand on that? Perhaps this is a question for everyone.

Annie Segarra: A good way to start this conversation is actually where “The Future is Accessible” campaign came from.² It came directly as a reaction to the lack of accessibility and visibility for disabled activists at the first Women's March on Washington. It was a direct reaction to not seeing the many disabled activists who I know were actually there. They were not visible in the media at all. A lot of disabled activists talked to me about being at the march and it not being an accessible space for them. And I thought that it was really disappointing that in a feminist space, disabled people, disabled women, non-binary – everyone – were neglected. We were not considered in

² See “The Future is Accessible” campaign at <https://annieelainey.tumblr.com/merch>

that space. So, that is why I made my own Internet protest sign with “The Future is Accessible” on it and that sparked the t-shirts.

My disability is Ehlers-Danlos syndrome, which is a degenerative condition that has declined my health over time and in multiple ways. So, I have the perspective of living with able-bodied privilege for most of my young life and then learning through experience about the lack of privilege that disabled people have. I also kind of had this disappointment in myself because I was a feminist and an activist as a young able-bodied person and I never considered accessibility, or anything like that. So, everything I’m working towards now is using what I’ve learned, not just from my personal experience. I’m also using my experience to open a door to everyone else and listen to my community. And I’m creating a world where being disabled doesn’t mean being treated like we’re of a lower social status. I’m creating a world where we see disabled people uplifted in media; where we’re authentically and respectfully represented in media whether in magazines and fashion, film, in the arts, in mainstream arts, in places where we’re often not represented with respect. It’s great that we have claimed our own space, but we deserve to be within mainstream spaces as well. I envision a world where the inclusion of disability in mainstream culture is not a big deal anymore.

Elizabeth Sweeney: I like that idea as well. Sometimes when we think about the future, we talk about a distant future, but I also like the idea of thinking about the futures of our bodies in our own lifetime. I think that’s a really interesting play on that notion of “the future of this body,” which is going to change and transform and move through the world and all kinds of different ways.

Anyone else want to jump in?

Aaron Labbe: Yeah, I can add a little bit. In a distant future, adding to what Annie was saying, I imagine a space in a world where empowering knowledge is available to the people who need it. So, I remember from my personal experience, the term “Mad” wasn’t available to me when I was hospitalized and incarcerated and was dealing with various challenges. I remember taking a course at Ryerson University’s School of Disability Studies that really empowered me with this knowledge of madness narratives and disability studies in general. I thought it was a real shame that I spent the entire period of being hospitalized being labeled and defined by other people. And I think disability arts has a great opportunity to change the way disabled and Mad people are defined through labels by providing people with this empowering knowledge for themselves. And I imagine a future where children and adults have the knowledge that I was given through education.

Elizabeth Sweeney: I was recently reflecting my own experience with learning disabilities going through high school. I remember thinking: how long do we have to endure ableism?

Increasingly, we see politicians talk about taxpayers instead citizens. When we premise citizens as taxpayers, emphasizing their role in the taxation process, it shifts our entitlement to rights. I wonder how this shift relates to the ways we increasingly experience culture and art through our devices, through our screens and our phones. This brings me to thinking about how technology is moving us into the digital future and impacting the way we see ourselves as artists but also our practice.

Taeyoon, I wonder if we could maybe start with talking a bit about your work?

Taeyoon Choi: Thank you. I wanted to start off by answering the initial question about the futures: What types of futures do we want? I've been thinking about non-binary futures and what does that mean. And to think about that we have to start with the binary futures and look at what binary actually means in the context of art, technology, and society at large.³

If we think about the notion of binary [see slide 1] it's essentially zeros and ones. It's a numbering system. It's a form of containment, of identities and states, into two distinguished finite states. If we think about the digital, which is a term that is oftentimes used and conflated with technology, digital signals are either on or they're off. That's the fundamentals of computation. And we can even stretch this notion to the dialectical or the foundations of Western thinking at large and the binary of true or false. I can even stretch it to the religious notions of heaven or hell. And these are all finite states to which we have subscribed. So, you're either a man or a woman, abled or disabled.

I'm interested in an unknowable future [see slide 2]. In other words, ungovernable or undescribable futures which could potentially be uncomputable as well. Because if we're thinking just within computation or digital thinking, everything is predictable. And it's not very fun. [Laughs]. It comes to the notion of a speculation rather than imagination. I'm inspired by this because a friend of mine has invited me to the wonderful world of disability studies and disability and Deaf culture.

This is Christine Sun Kim [see slide 3], a sound artist based in Berlin. She was born profoundly deaf and she has encouraged me to be part of Deaf culture in New York City. I've been learning sign language and also about Deaf culture. We've collaborated on a performance called "Seven Futures: Imagining different types of deaf and disabled futures." I want to show a quick video. The title of this video is "Future Proof."⁴ There are about 100 audience members who are interacting with us. We are connecting strings that are activating wind chimes that are motorized. In this performance there are about four different languages coexisting: American Sign Language,

³ Choi's comments here reference slides from the slideshow he gave during this panel presentation, which can be viewed here: <http://taeyoonchoi.com/writing/disability-and-deaf-futures/>

⁴ "Future Proof" may be accessed at <https://vimeo.com/220148573>

Korean Sign Language, English, Korean, as well as computer code. This plurality of languages is one thing we think about as the future.

I have been continuing this work [see slide 4] at the School for Poetic Computation, which is an artist-run school based in New York City that I co-founded. We work with students from around the world [see slide 5] – artists, engineers, and designers – to explore what is poetic about computing. Some of the student projects are like this [see slide 6], where Ishac Bertran, a designer from Barcelona, wanted to slow down time. He created a game that operates one clock cycle per day.

Here is another project [see slide 7], a collaboration between the artist and educator Zach Lieberman and his students: “The Drawing Robot Exercise for Signing Coders.” Iterations of this project have been shown in art and music venues, such as Sónar Festival in Barcelona. Central to this project was our idea to think about code itself as an artistic language.

I’ve been teaching Deaf and hard of hearing communities in New York and Seoul how to code [see slide 8]. It’s really important to think about the accessibility of technology and I think this comes to your question about capitalism, because on the one hand, I don’t want capitalism, but I also want students to do well in capitalism and have well-paying jobs and find a language with which they can communicate.

So how do we get to the future?

This workshop is from Korea where we were thinking about languages in code as a form of language. I worked with Deaf and hard of hearing communities, people on the autism spectrum, and other parts of disability communities in Korea, and their families, caretakers, and museum professionals, to run a summer school where we taught code. It was a really good experience to think about languages as common resources because a lot of participants were not able to verbalize their emotions, but they were able to communicate through code and other forms of expression.

I think access to code is very much like access to physical spaces. In this image [see slide 9] we have Sara Hendren, who is a designer and disability scholar, interacting with wheelchair and powerchair users in Korea and I’m translating between them.

This is an image [see slide 10] of a museum educator in Korea holding hands with Hayun Chung, an autism spectrum cartoon artist. 정도운 [Jeong Dowoon] is fantastic – super prolific – but he does not verbalize in the way that we do. And the museum educator was very empathetic and excited for them to work together but they just couldn’t find a way to engage. But through coding and performance art we can find a language that is *shared* and I think that is almost like a future that is present and a present that is the future as well.

Elizabeth Sweeney: That’s so interesting because it’s like we’re thinking about artists as content creators. And also because, for many of us, there are technological devices that move our bodies or move, or verbalize, our ideas

out into the world. It's like finding this hybrid space in which we can also engage in an artistic capacity. It's fascinating.

Aaron, do you want to maybe describe or talk to us a little bit about the "Lucid Project"?

Aaron Labbe: Yeah, sure. The "Lucid Project," like most works in my practice, involves pushing the boundaries of giving people agency to have control over their own psyche and wellbeing.⁵ "Lucid" started out as an art installation that I built for my thesis project. It was designed to read a user's biometric signals and create a personalized music therapy mix to help them de-escalate some sort of distress. It has now turned into a project that has grown into a company. Now that it's turned into this amazing research hub of engineers and scientists, we still describe ourselves as a company that works at the intersection of art, science and technology.

Art was, and is still today, a major part of "Lucid." I'm a firm believer that art moves beyond just pushing social constructs; it can also change the world in a variety of ways. The whole thing started as just a piece of art that was in a gallery and we're now working on tools for people to use at home, to provide safety and wellbeing to people wherever they find themselves. We're working on mobile applications – prototypes that we can bring to different spaces, maybe even therapy centers and places like that. These are the different kinds of environments that we're working on bringing this artwork to.

Elizabeth Sweeney: Your description of your project leads me to think about it within the context of disability studies and disability arts in particular. We have this long legacy of our work being situated only within the therapeutic. And I think it's worthwhile for us, as artists, to say, "actually I want to dig into this notion of therapy from an artistic lens." As disability artists, we're not defined only as "the therapized." It's interesting to be playing with that history.

Aaron Labbe: Yeah, for sure. It's actually funny too. I did a kind of a test when I presented the work. At first, with my thesis presentation, I decided not to disclose my Mad identity. And people saw the innovation of the work and were very inspired by it. Then I did a follow up show where I presented myself as a Mad artist and people were like, "wow, this must have been therapeutic for you to create," which I thought was funny because by simply adding 'madness' to my name and identity, people responded by understanding my work as therapeutic.

Elizabeth Sweeney: Anyone else want to talk about art and technology?

⁵ To read about the "Lucid Project," see <https://www.thelucidproject.ca>

Annie Segarra: Sure. I wanted to mention how I'm filled with gratitude for the Internet every single day of my life. Without the Internet I wouldn't have found my diagnosis; I would have continued to be gaslit by my doctors telling me that nothing was wrong because they didn't know that my disease existed. It was through the Internet and through community – spoonie community and chronically ill communities – talking about symptoms and exchanging that information through people on the Internet, that eventually led me to finding out the name of the thing that I have, which, again, is Ehlers-Danlos syndrome. And being able to take that knowledge and advocate for myself in medical spaces, was so helpful. Just to get that diagnosis on a piece of paper...

Honestly, we can't do a lot to help me in medical spaces but having that diagnosis and not having doctors tell me, "there's nothing wrong with you," and acting like I'm a hypochondriac and my mobility aids are not necessary. I experience medical ableism, like, "do you really want to be using that wheelchair?" I don't know what they wanted me to do. Just pretend that I was able bodied, I guess!

Elizabeth Sweeney: Endure.

Annie Segarra: Yeah, I don't know – it wouldn't have worked.

Elizabeth Sweeney: No, exactly.

Annie Segarra: I would have just disappeared from the world because without mobility aids, I'm stuck in my bed. So, that's essentially what they were asking of me was to just disappear because, "we don't know what to do with you."

The community that helped me find my diagnosis was also liberating in terms of self-love and self-respect. Previously, starting from 2010 to 2014, my focus and activism was in body positivity because I had recovered from an eating disorder and found a hardcore passion for body peace. I was trying to provide online content that helps other people find body peace within themselves. But because my inspiration for that work was from an eating disorder, it was very weight-focused. Eventually, I found intersectionality in body positive activism in regard to, obviously, racism and ableism and how those impact how we are both oppressed and discriminated against based on our appearances. That all goes under the umbrella of how we feel in our bodies and of body activism, period.

In that work, I found a movement called "Cripple Punk" by (rest in peace) Tyler Cruella.⁶ It was through that movement that I found a radical self-confidence with my mobility aids, feeling totally badass using my cane and

⁶ To read more about "Cripple Punk" see <https://twitter.com/annieclainey/status/933004772537438210?lang=en>

my wheelchair. I found incredible friends too. We could laugh at able-bodied people who do not possibly relate to us; we could use this humour to make ourselves feel better. So, the community that I found, the diagnosis that I found, and the fact that we can use the Internet to uplift our narratives and ourselves in a way that has never been done before, shapes my appreciation of the Internet. We are continuously misrepresented by mainstream media and through the Internet we can tell our own stories, which means that more people are getting to experience our stories and that helps to start to remove the pieces of prejudice that have been thrust upon us.

Elizabeth Sweeney: That's a good reminder that in the utopia of the Internet, which was meant to be a democratization of content and voices. And although capitalism was like, "I need to get in on that!," we have this potential to reclaim the Internet.

Syrus and Taeyoon, do you want to follow up on that?

Syrus Marcus Ware: Yeah, as an activist, the Internet has been invaluable. I'm an organizer with Black Lives Matter Toronto,⁷ and we are a disability justice, art-based, radical, challenging anti-black racism group that has done a lot of organizing around the killings of Black Mad people.⁸ For example, in 2016 we organized "Tent City," where we took over the police headquarters specifically to call attention to the killing of a Black Mad person, Andrew Loku. In a very performative way, we took over the 2016 Pride Parade.⁹ In particular to try to get the instruments of our torturers – the police – out of the parade. But, also to specifically demand an increase in accessible content at Pride, including increasing the number of Black and racialized Deaf interpreters in the space. Our organizing was largely fueled by social media. In "Tent City" when things went really rough – the police attacked the encampment – people knew about it within seconds, which allowed people to come down and bring reinforcements. The Pride actions were broadcast internationally as everybody had their phones out to watch what was happening because nobody knew how it was going to turn out. In terms of organizing around Black Mad people and the premature deaths that we often experience, social media has been essential.

As an artist, I've met collaborators online. I've met people through sick and disabled queer and trans people of colour; that's just been such a valuable space. I'm able to collaborate with other disabled artists in the United Kingdom and South Africa in ways that we would never have otherwise been able to do because of travel, because of what it means to be cripp bodied and have to do a lot of travel. If I do get to travel at all it has to be infrequent

⁷ To read more about Black Lives Matter Toronto see <https://blacklivesmatter.ca>

⁸ See "Disability Justice Network of Ontario" at www.djno.ca

⁹ In 2016, Black Lives Matter were the Honoured Guests at Toronto's Pride march. They used this platform to make a number of demands of Toronto Pride to make their festival more accessible for, representative of, and safe for Black queer people.

because it's just too much for me. So, you know, being able to meet as often as we can because of Skype has been amazing. So, I'm also all in favour of the Internet revolution.

Elizabeth Sweeney: Thank you. Taeyoon?

Taeyoon Choi: I'm gonna ruin the "Internet party" for a minute. [laughter]

Elizabeth Sweeney: We like disruption here.

Taeyoon Choi: So, okay. The Internet was initially a network of computers and databases that were hosted in academic institutions, people's garages, or by the military. It's been commercialized in the past 20 years to the point where it's a feudal relationship which we have with the landlords. We're renting servers from these massive five companies that own the Internet infrastructures and our access to them. They're the gatekeepers to our platforms; we're never really free from their controls and terms of services. Who actually reads Facebook's terms of services? Not a lot of people. They are really hard to read because they're designed so that we cannot understand them, and we don't have authorship and ownership of these platforms. We have ownership of our content, but we can't actually do anything if they censor us. And they're always surveilling us to increase profits.

So, what is the media or technology that we *actually* own and use? There are options. There are options for decentralized networks that are peer-to-peer. These are open-source projects where social networks could be used to access certain communities directly. Imagine more like a community radio. There's distributed networks that are – and these are still in early phases – but there are non-commercial applications that a lot of engineers are creating because people are sincerely concerned about the privatization of the Internet. And I just want to make a note that it's privately-owned public spaces that we are using. We are always a user and a content creator, not the owner of the space. So, we can't actually take care of it and we can't change how codes of conduct are created for these spaces. I agree that the Internet is great for mobilizing large groups of people and connecting but I think we have to know the price that we are paying for it. And I feel like the disabled community is always the last to be considered by tech companies. Codes and designs are embedded with ableism and severely exclude a lot of people. I have friends who are in the engineering sector as advisors to make these products more accessible. I support their work, but I also think we need to look at the plan – plans that are not part of consuming these services.

Elizabeth Sweeney: When we were talking about access, this really shitty thing happens when we think, "if we do this, it'll be good for everybody." And I think that's super problematic because it is actually good enough if it's

just good enough for us – you know, like it doesn't have to be good for everybody.

I remember Catherine Frazee, who lives in Wolfville, Nova Scotia some of the time, and she really wanted to access this store and they refused to put a ramp in. And the shop owner's response was, "well, it'll be inconvenient for other people." And she said, "but it's inconvenient for me." It's actually already happening but you don't seem to think that I matter, right? And I think that shift to, *it doesn't have to be good for everybody. It's okay if it's just good for us.*