Stories from the brainreels podcast transcript

September 1, 2016

[music]

Introduction

CHERYL: Welcome to Stories from the brainreels monthly podcast about brain injury and disability with a focus on art, culture, and disability pride.

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A quick film update that "Who Am I To Stop It" is jumping off with its educational release through <u>New Day Films</u> this month! The film is off being turned into a DVD as I type this, and it will be available in DVD or streaming for colleges, community groups, and other institutions very soon. Be in touch with me any time for more info on educational licenses or hosting a community screening event.

For the podcast, I'm taking a brief break from my feminist filmmakers to bring on my good friend, Michael Miller. Michael's currently studying Critical Disability Studies in a faraway land called the UK, and I was lucky to catch him with my microphone before he moved. Maybe he moved because I recorded him. Because one of October's podcast guests also moved right after I scheduled a recording. Hmm. I might need to work on my hosting skills. Michael and I talked about his relationship to disability, we criticized capitalism, and one or maybe both of us enjoyed some cussing here. As you do in podcasting, because you can.

There's a bit of background before we dive in. Michael and I started using this made-up term "neurojustice" with each other a while back. It's totally possible someone else invented that we before we thought of it, but we did happen upon it quite by accident. We spend most of this episode talking about what neurojustice would be in the case that it's a real thing. The other thing we talk about is neuroplasticity, but we didn't really define it. Now, we know that's a real thing. So let me lay that one out a little here.

In a nutshell: Neuroplasticity describes what happens to your brain when you do stuff, learn stuff, practice stuff, or rehabilitate yourself by taking on more stuff. Because your brain isn't like bone or like a rock. It's plastic-y, moldable to some degree. Your brain changes where one brain cell connects to another brain cell. Learned a new skill? That might mean more and/or stronger connections between and among cells that you used in learning and practicing that skill. Injured your brain, lost a skill, and then figured out a different way to do that skill? That might be some rerouting around the damaged area to build up connections somewhere else. This is happening inside your skull on a scale that is so tiny as to feel impossible. It's kind of magical. It's a big reason that people with TBI and PTSD are often taught to meditate.

But despite the fact that it really involves neurons, neurotransmitters, electrical impulses, and ions, Michael and I have a very strong opinion that it's not OK to talk about neuroplasticity outside of the context someone lives in. Exposed to lead as a child? You might have learning and developmental disabilities, and your neuroplasticity can be affected. Not your fault. Not you being lazy or not trying hard enough. Exposed to severe trauma? Holding on to the idea that if you just focus on practicing hard and trusting in your neuroplasticity to heal your brain doesn't account for what happens when you are

still living in a traumatic circumstance, don't have the money to get intensive therapy, have someone who refuses to accommodate your needs, and you see where I'm going with this. Though brains are isolated inside our heads, they are very much alive in society. And the types of things we're exposed to make a big difference, whether it's love, tolerance, pain, abuse, junk food, drugs, healthy food, healthy food that you're allergic to, pollution, music, schools with outdated textbooks and racist practices, or multiple languages. And the list goes on infinitely. It's everything we do all the time. Our brains change as we experience our experiences. There are limits to it, of course. You can't learn so much stuff that you essentially have a new brain one day, and you know all the world's languages and all those math proofs. And that's OK. That's part of neurodiversity and reality. Enough from me, and enough anatomy talk. Let's talk to Michael. And thank you for the music, Kopeika!

The Interview

CHERYL: I'm really excited to be here with my friend Michael Miller.

MICHAEL: Yay! Hi. So I'm Michael Miller. I went to school at Portland State University, and I got a Bachelor's of Science in Psychology with a minor in Community Health Education. Through the minor in Community Health Education, I became sort of aware of disability studies, through a roundabout way. But that is how you and I met, through seeing a flyer of yours for a talk you gave at Portland State University called Undoing Ableism. It was tragic because I had to work that day.

CHERYL: No, no, no. The presentation was also tragic. So don't worry about that. But carry on.

MICHAEL: [laughs] Through that, I introduced myself to you via the internet, and we connected from that. It was this new idea, this ableism and this "crip" and like, what are these words really? And how does capitalism have to do with anything, you know? I'm still on this process of figuring out the world [laughs]. I don't even know!

CHERYL: Yeah. When you first reached out to me, it was very exciting because I was nervous about giving that talk. I was nervous about tomatoes being thrown at me. My audience was speech therapy students, and I'm about to tell them, "You may have some misguided notions about the disability community." Then, when your email popped up like, "Wow! This looks great! I wish I could go," I was so reassured.

MICHAEL: Oh, good.

CHERYL: The other thing is, you and I talk a lot about things around racial justice and our roles as white people to be fighting for racial justice, social justice in general. I really appreciate those conversations, which is why I wanted to bring you on today. I do understand, also, that you have a couple of dogs. Is that right?

MICHAEL: Oh, well, a couple of entities. They are creatures. I guess they're dogs: Oscar and Beast. They're Boston Terriers, and they're the most precious, amazing things that I've ever been able to try to perceive.

BOTH: [laugh]

MICHAEL: So, hi, Oscar and Beast!

CHERYL: Oh, you guys, we have some biscuits here for you. Not really.

Education, a brain tumor, and asking, "Why?"

So you did mention that you studied psychology, behavioral neuroscience, community health. I think you had kind of an interesting educational process, like putting together music, psychology, neurology, a brain tumor, public health, critical disability studies, social justice.

MICHAEL: I started school to do music because that's what I liked to do. But then why came up. Why am I just pursuing something for myself? So then music therapy came on my radar, so to speak. So OK, cool, I can still do music, which I like to do. But I can do it with and for other people. Then, within psychology, it was behavioral neuroscience, and this "why?" was always there, this lingering "why?" I'd get into something, and I was like, "OK, why psychology?" OK, behavioral neuroscience, yeah, that's why. But that's not an answer! So then behavioral neuroscience and "why?" And that's sort of the theme: trying to find this why, this ambiguous why.

Then, it culminated in having a brain tumor. I was wrapping up my degree in psychology at PSU. I was a volunteer in a lab at OHSU, which is a coveted position for an undergraduate. I was in a lot of behavioral neuroscience things. Then I had this brain tumor. Priorities started to shift. Maybe it's a "Why me?" a little bit come up. I have a brain tumor. What do I do with that? What [chuckles]? [sigh] So much was exposed with that brain tumor. I guess it's not this revelatory thing, that this brain tumor was this pivotal point in one's life. But having a brain tumor and having the support, particularly with Lindsay, my spouse, and my immediate community around me and Oscar and Beast giving unconditional support, which is something that's very special. Support to explore what was coming up about having a brain tumor. The should I get it removed? What if I don't? What if I do? What would happen if this happened? You know, honestly, a lot of my internalized ableism was exposed. What if the surgeon slips, and I can't walk again? It was in my cerebellum. What if I'm constantly dizzy, or my eyesight's gone, or I lose the ability to do any whatever?

These things were really deep, embedded fears that I had and I didn't even recognize within myself. But with that support of being able to explore that and ask, so what if that does happen? Who will you be? Are you defined by your ability to walk? Who are you, first of all? If your brain gets tinkered with, are you a different person now? That was a huge question: Who are you? Who will you be? Cuz you can choose. I have the privilege to choose and the privilege to have the support. I always asked the why, but it this ambiguous poor me sort of thing, or woe is me sort of thing, this why.

This was even before I knew the term "ableism." I just knew that these fears and these thoughts were coming up. And it was really important to me to address those and have answers. Who will I be if I can't or if I can? Cuz what if everything works out perfectly? Is that like a bullet dodged, right? That was a lot of deep shit.

And I'm so grateful for it. I am different because of it. I see the things that I have accepted of myself that I didn't even really recognize that I have downloaded from the world, from how I'm supposed to act or supposed to think or supposed to be. The normal that I saw myself as, or really I didn't even consider myself normal because I never had to consider that. I never was seen or considered as an abnormal or something other than--

CHERYL: Just person.

MICHAEL: Than person, right. And what a privilege. So yes, when the threat of that was before me, what was exposed was shocking and deep. What a privilege to be able to have the space to be exposed and

exposed to shit in yourself and then do something with it. I hope I'm doing something with it. I am doing something with it. I don't hope. But it is, as you say, a process, and it isn't an easy one.

CHERYL: This is the first time you and I have ever talked about your brain tumor. It's not something that you lead with. It's not like your headline story.

MICHAEL: [chuckles]

CHERYL: If I could make a wordplay with "headline."

MICHAEL: Oh, that's good. All right, all right.

CHERYL: Cuz you have a line on your head from...OK.

MICHAEL: Oh! So many layers.

CHERYL: So many.

MICHAEL: It's over my head [laughs].

CHERYL: It's over your head. So many layers, like the three layers of the dura....Oh, I wish everybody could see him, both eye-roll and head-drop.

MICHAEL: [laughs]

CHERYL: But I just wanted to point out that despite the way this conversation started, that's not the big topic.

MICHAEL: Yeah. I appreciate you saying that.

Neurojustice activism

CHERYL: Speaking of doing something with this situation and these changes, you came up with this really great word, and I didn't realize that you were being tongue-in-cheek when you said it. I was like, "That's brilliant!" The word you came up with was "neurojustice."

MICHAEL: Neurojustice.

CHERYL: Neurojustice!

MICHAEL: Yes.

CHERYL: These days, you can make anything sound legitimate by putting "neuro" in front of it. Oh, everybody wants to talk about brain science, brain science. At the same time, there's this certain way of looking at social justice and neurodiversity together. Let's just unpack it.

MICHAEL: Sure, yeah, let's figure out what neurojustice could be because it was in an email exchange of ours, and it was meant to be like, there's already neuro-everything. There's neuro-law, there's neuro-juice and neuro-water that's gonna make you smarter because neuro.

CHERYL: [laughs]

MICHAEL: And there's a picture of a brain on it or whatever. I was thinking neurojustice in the sense of disability justice and the difference that, at least that I see, that I've interpreted, as a difference, a distinction between disability rights. Not to diminish, in the least, anything that any disability rights advocate or activist has accomplished, because it's entirely necessary to have that accessibility. And it's still lacking, and it's still not enough. And just a point to clarify is that I identify as, like I check all the boxes of the dominant, pretty much, all the big ones. I just wanna place that and place myself in that because we were talking about my brain tumor, and nothing came of it. So I don't have the tumor anymore, and I have every aspect of myself--good and bad--that I had before, with some added clarity and added insight and a commitment to really continue this process. But as we're unpacking what neurojustice could be and talking about society and the dominant norm, I want to just make that clear.

But it's this point of inclusion that's really troubling to me, at least. I see inclusion, and I ask, "Inclusion into what?" Inclusion into--

CHERYL: Into the society that has excluded you.

MICHAEL: Yes!

CHERYL: Please, let me in. Let me in. You're so hateful toward me. Let me in.

MICHAEL: Let me be like you.

CHERYL: Let me be like you.

I'm not the biggest fan of inclusion the way we define it now because you have to act normal enough to be allowed into our normal space. It pretty much goes one way: the normal people are there waiting for us to join them, and some of them will be nice helpers, special helpers. Why doesn't it go the other way? And of course I'm generalizing cuz here you are, identifying as basically non-disabled, but completely interested. I think if you're gonna think about what would neurojustice be, if that was a real word--and by golly, it's a real word cuz we're saying it--it would be social justice movements that are not just defined by non-disabled people, but movements that are defined and led by neurodivergent thinkers as well, and that we're not discounted or discredited.

Let me also quickly identify too that impairments that I have are mostly gone. I've mostly--I don't like the word "recovery," ugh--but I've mostly recovered almost all the impairments that I had earlier on. But I require neurojustice. I require your activist videos with music in the background, they have to have captions, or I'm not included. If there's gonna be a rally, and it's loud and people are waving their arms and waving signs and yelling, I have to have an invitation to a quiet event or some other way for me to participate.

MICHAEL: Yes, yes.

CHERYL: And those things are not actually offered.

MICHAEL: There's the question, "Am I an activist if I can't march with you? How do I be an activist? Or am I an activist?" My initial point with inclusion was inclusion into what? Into this dominant society? But then, it's so important, and I see it as a point of care or critical care to actually critique and question social justice movements that are critiquing and questioning the dominant norms, right?

CHERYL: Yeah. Why would I work so hard to join the group that is excluding me? It's a big struggle that I have around brain injury stuff. It's painful to be in it, but it's painful to observe others and the pressure that we put on ourselves to regain normal so that we can get our status back.

MICHAEL: Mmhmm.

CHERYL: But the question that doesn't get asked is, "Wait a minute. If I lost my status because I got a disability, why do I wanna be in the group that defines me as having a lower status?"

MICHAEL: Yeah, definitely. You bring up a really interesting point--

CHERYL: Why thank you.

BOTH: [laugh]

CHERYL: Well, let's just end there. That's a good note to end on [giggles].

MICHAEL: And podcast over.

CHERYL: [laughs]

[music break]

Disability and the self in an ableist society

MICHAEL: You bring up a really interesting point: getting back what you had so that you can be the self that you once were, but never critiquing or questioning the self that you once were or the things that you once did or do or want to do, desire to do. Those are critical questions for anybody, disability or not. Why do we feed into this hierarchical system of haves and have-nots or of people with power and less power or no power? And rather than questioning that, we want to be that. I don't have power right now. So I wanna be the one with power. A lot of people write about the oppressed and the oppressor, and the oppressed only seeing themselves as less than to the oppressors who are fully human, really. That's our model. I do a lot of reading about that, writing about that, is the ideal self of this unattainable, but yet we're always striving for it. We are supposed to, and it's not even in so many words. It's just really insidious, and it's the life that we-- I'm speaking from the Pacific Northwest. I can't speak for everyone's experience, nor would I want to or attempt to. But the people, the communities we're in, the ads we're bombarded with, the education system as a whole, the political system, just the narratives of this American dream and this ideal self and what we should strive to be. And if we're not striving to be this one thing, then something's wrong. And if we're not obtaining that--whether we're able to, whether we want to--what can you do to get as close to that as you can. Well, maybe I fucking don't want to.

CHERYL: Right, right!

MICHAEL: Right?

Bringing it back to my tumor was when none of my fears came to be or manifested in a real way, the thought of "bullet dodged," right? Thank gawd or whatever, that didn't happen. I think that's what a lot of us, or well, I'll speak personally, and back to that point of support. Having that been brought up, what if nothing happens? What if I'm totally fine? Am I gonna be stoked about that?

CHERYL: And if you are, is it from a place of, "Oh! Thank goodness I don't have an impairment"? Or is it, "Thank goodness I'm not gonna have to struggle out there with people who treat me like a puppy dog when they talk to me because they perceive me as unintelligent"? So it's one thing to fear having an impairment, and it's another thing to fear, "I am gonna be treated like dirt now when I try to go out there, and I'm talking or moving in a way that looks unusual to people."

MICHAEL: Yeah, and treated in a way that I have treated others.

CHERYL: Ooh, ouch, yeah.

MICHAEL: Right?

CHERYL: Possibly, yeah.

MICHAEL: You know, talking of subtle ableist language or intent versus impact. I am a product of the system as well. So being honest, yeah. That fear, exactly what you're saying: being treated differently and having to struggle through the oppressions that I see other people go through every day, and maybe I perpetuated--or not even maybe, right? I work in a group home for developmentally disabled adults. That's been amazing. I think I'm six years in now. But we'll go out on the town, as one might, and the way some folks are talked to or treated.

CHERYL: Mm. Mmhmm.

MICHAEL: You say puppy dog, and that's not an exaggeration. Gross, right?

CHERYL: It is, yeah.

MICHAEL: And it's well-intended though, right?

CHERYL: Mmhmm.

MICHAEL: And it's probably speaking through a discomfort they have of themselves.

CHERYL: And I think it's a direct product of the segregation that we have with Special Education and sheltered workshops is that most of the non-disabled world is kind of unfamiliar with disability and confused by it, and people get really comfortable in their awkwardness. "Oh, I don't know. I'm scared I'm gonna say the wrong thing. So I don't wanna say anything." OK, but that doesn't get you off the hook. So you're scared. OK. But in the meantime, while you're scared, you're talking to an adult like they're a puppy dog. That's not OK. I get that you're uncomfortable, but you actually now have the responsibility to learn to stop putting it on the disabled person: "Well, but, they just, they have this thing, and I don't know what to do." No, it's not their problem; it's your problem.

MICHAEL: It's your shit to work through.

CHERYL: Yeah, so work through it. And there are resources. I'm always so skeptical of those, like Scope in the UK had that End the Awkward campaign, and it totally centered and coddled non-disabled people. It was like, "We get it! It's understandable that you'd be awkward around a wheelchair user."

MICHAEL: Wow.

CHERYL: Well, yikes. Stop normalizing this discomfort thing. But also, address why is it awkward? Because of segregation, because people: "Aw, I've never seen anybody like that before." And then, you often get to that stage of, "Well, they're actually a good person. They're actually nice." Well, why are you starting with a default assumption that they wouldn't be?

MICHAEL: How does questioning that come about?

CHERYL: Yeah, and how can we steer the questions to not, "What's wrong with you for not achieving that?" and saying "What have we left out in society that is not allowing you to achieve what you want to achieve?" Which is in addition to the question of, "Why do you want to achieve that?" But still, there's so much emphasis on you need to rehab and recover and get these things back that we as a society value, as opposed to we oughta have more neurojustice and include neurodivergent people as they are, without saying, "You need to be medicated. You are a political candidate I don't like. So I'm just gonna armchair diagnose you as mentally ill." Years ago, after Hillary had that mild TBI, which she recovered from-- Did you know about that?

MICHAEL: I didn't even know about that.

CHERYL: Yeah. So it would've probably been about 2013. Somebody had posted, "Oh, definitely if Hillary ever runs for President, don't vote for her, cuz she's brain-damaged." Which shows, obviously, a misunderstanding about what a mild TBI is and how possible it is to function at the same level you did before. But it also just shows our ingrained hatred of somebody who might not be considered to have "normal" neurology and "normal" thinking and "normal" behavior.

MICHAEL: It's also assuming she was "normal" in the first place or this ideal in the first place. And now with this TBI, she can't be trusted, certainly.

CHERYL: Mmhmm.

MICHAEL: Whether or not that is true in general, as a politician or whatever.

BOTH: [laugh]

CHERYL: And as a woman, cuz you know how moody they are. They can't be trusted!

MICHAEL: Oh, yes.

CHERYL: Three weeks of the month they can.

BOTH: [giggle]

MICHAEL: They're too emotional anyways.

CHERYL: They couldn't hold a position of power, but now she's brain-damaged so she's really, really quite inferior.

MICHAEL: I'm coming at it from an educational point. That's been a lot of my self-research has been within education. So having a critique on education and the education system and what is taught and what is ingrained and imposed upon us. We have all, to one extent or another, been a part of the system that perpetuates and thrives off a certain narrative, off of a certain history that is taught to us. And we

have to maintain this timeline of progress deemed appropriate and normal by these invisible, ambiguous forces that just are just the way it is. It's just the normal progress of a child or a person in general, and you have to keep up. And God help you if you don't. So having a critique on, well first of all, that we're all supposed to progress at the same amount of time, at the same rate, with the same achievements. And comparing each other just by age is totally, I don't know how that came about [chuckles] let alone who you are or what you might like or how you might learn or what your social class might be or what oppressions you might be having or going through within the education system itself, let alone the society that it's an aspect of. So yeah, never mind your home life, never mind who you are, never mind this individual aspect of it, lest you need to be pathologized.

CHERYL: Yeah, right.

MICHAEL: You're the problem. This individual pathologization of the child as the problem or the individual as the problem. I wasn't just born with these thoughts. I didn't just wake up one day having these deep, embedded fears or hatreds or acting in certain ways. It was all around me, and it was taught to me. So exposing and then challenging these ways that we are taught. And we're taught ableism, and we're taught exclusion and good and bad, and us and them, and this really particular history and this really particular way of life or looking at life, looking at who, well one, who is worthy of life, and two, who is worthy of certain types of life.

CHERYL: Yeah, yeah.

MICHAEL: Social justice is not in any school I ever went to.

CHERYL: Mm-mm, no.

MICHAEL: That wasn't a term really used. Maybe it was written on some page: Civil Rights Movement. They might've slipped it in there somewhere, but that's just history. Racism's over anyways, right?

CHERYL: [chuckles] Aw yeah.

MICHAEL: I hope my sarcasm came through.

CHERYL: Yes!

Intersectionality in neurojustice

MICHAEL: I think another point with neurojustice that we should add is a term that gets thrown around a lot, but <u>it's intersectionality</u>. So not just focusing on neurodivergent or just specific types of inclusion, but incorporating race and class and gender and etc. I think something with disability is people are seen as that disability, like they encompass and embody that, and they are just that, let alone that they're ready and willing and should be able to speak about it at all times and to explain it to anyone who asks at any point. But it's erasing--not that there's not problems with identity in general, but they're erasing--other parts, or they're not even giving any sort of space for any other part of oneself. So you're disabled? You're just disabled, let alone whatever else you might identify as. So that should definitely be a part of neurojustice, if we're creating it as we go.

CHERYL: Yes. Do you know Lydia Brown? They have a blog called <u>AutisticHoya.com</u>. They're currently a law student, a very prolific writer, blogger, presenter, speaker, activist, advocate. They recently posted on Facebook, in a nutshell, "everybody comment in the thread if you know the name of a disability organization that serves communities of color where 50% or more of the leadership are people of

color." People were writing in, and Lydia would write in, "Nope, not them." Or someone else would write in, "No, no, no. I know their leadership's not people of color." Or the other thing that made me sad was when Lydia would comment, "That one's already on the list." So someone would think of a brilliant, "Oh, what about these guys?" Well, yeah, that's the one. Everybody already wrote Sins Invalid.

MICHAEL: Right.

CHERYL: There were some, but there were not very many groups that people could come up with. And then Vilissa Thompson just wrote this beautiful blog in response to that. Vilissa has a website called Ramp Your Voice. She used the #Unbothered.

MICHAEL: Mm!

CHERYL: She basically was like, yeah, I was part of that conversation. And you know what? White people, I'm gonna make my own thing over here. That's why I have my website Ramp Your Voice. I'm doing my own thing.

[music break]

Neurojustice and brain injury

CHERYL: There's still more pieces to neurojustice that I wanna talk about, especially how they relate to brain injury and life after brain injury. So I know it's really hot to talk about neuroplasticity, which is kind of in a nutshell, the idea that you can grow new brain cells, you can grow new connections. I mean it happens. That's what learning is. You have a new experience, and brain connections: maybe you get new ones, or your old ones get strengthened. That's one of the big things about brain injury rehab is banking on that neuroplasticity, the fact that you can change some of the pieces of your brain by practicing and learning. I see this concept being used a lot to motivate people: you can change your brain! Neuroplasticity! But I think it has some limits, right?

MICHAEL: Oh yeah. As I understand it, it's hinging on hope. I hope you get better. I hope you get back to normal, the person I knew you as, with all your behaviors and quirks and whatever else.

CHERYL: Well, it's kind of unrealistic, right? I mean, maybe if you have one mild traumatic brain injury, most people end up symptom free pretty quickly. I mean the vast majority of people, and even people who've had a severe or moderate TBI often get better, get skills back. But I feel like the hope thing is blown up bigger than the actual neuroplasticity. Because if we could totally, actually rest on that, there would be no brain injury disabilities. I feel like people use it: they don't talk about the hope part. They just say, "Science proves that you can grow new brain cells. So try harder." But neuroplasticity can't do that completely across the board for everyone, right?

MICHAEL: And what is it saying about people who don't get better? You're not trying hard enough. You're not good enough.

CHERYL: Because neuroplasticity. See? What if you can't?

MICHAEL: Right.

CHERYL: What if you don't want to?

MICHAEL: Oh, yes.

BOTH: [laugh]

CHERYL: Or both. Should you be faulted?

MICHAEL: Right.

CHERYL: I love that you used the word "hope," resting on hope with neuroplasticity does not lead us to neurojustice. It ranks us. You look like you tried harder, so I praise you more.

MICHAEL: So I accept you more, more than someone who "isn't trying as hard" or isn't showing the same sort of recovery.

CHERYL: Right. I really love the peer support movement in general, because it often takes experts and clinicians out of the picture, and the conversation is among people who maybe are not equal, but they have this one factor in common of having a disability or being a patient. One of the things that I struggle with, that I think we need to work on if we're gonna have neurojustice, is this idea of something worked for me, so I tell all the other people with brain injury that they oughta try it too. I'm thinking primarily of adjusting your diet to eat things that are like "brain healthy" and good for you.

MICHAEL: Yeah. It's coming from a good place, right? It's coming from an energetic, hey I wanna help. But it's not really considering do you have access to these things?

CHERYL: I'm thinking about how many people live on the streets, with brain injuries, who don't have a refrigerator, that don't have an income. This isn't about judging those things. It's about the harsh reality that not everybody has a refrigerator. If you're sleeping in a shelter, you don't have your own kitchen. You don't have the money to go to the farmer's market or buy organic food, no matter how good it might be for you, if you don't have the income to get it. Are we really helping by telling people they're wrong if they don't eat this organic stuff?

It is really beautiful to be able to share with other people the things that work for you or help you. But I think it's important to be really careful because you don't wanna shame anyone for living in poverty, and they can't afford this kind of food. Or it's not part of their culture or their religion. I guess I fear that sometimes the neuroplasticity and the food recommendations and the therapy recommendations accidentally end up shaming the people who can't access them, instead of bringing them in.

I think if we're gonna talk about how do you make neurojustice, it would have to be in community, don't you think?

MICHAEL: Yeah, that's pivotal. That's so important. And showing up and hearing people. That's hard: to hear people and to meet people where they're at and to accept being met or being heard. But part of that is in community building, it would be sharing recommendations but also staying with it and staying with the people and hearing: Is this recommendation appropriate? What do you do, as the person giving the recommendation? What do you do when the person that you're giving the recommendation to can't access these foods? What do you actually do? Concrete, here and now: this works for me. So here's the food? I'll prepare it for you?

CHERYL: [chuckles]

MICHAEL: I don't know. I don't know.

CHERYL: And that's hard in the internet age when we're sharing stuff to places where we couldn't actually go shopping with someone. But I like your idea of figuring out what is it that you can do. And maybe one of the things that you do is you totally non-judgmentally remind people that we have Supplemental Nutrition Assistance Program, formerly called "food stamps" and say, "Don't be ashamed if you need to apply for this. Here's the place to find where to apply for that." You know, if we can give recommendations in a way that we don't shame the people--even inadvertently--who can't access those recommendations. I feel like that's better community building too.

So when we only consider people who look like us or live in a house like us, we're not acknowledging a lot of people with brain injury live on the streets. So if I think the path to healing is to change your diet, I've left them out. I don't know what the concrete steps are, but it might not make sense to come up with a list of concrete steps. It might make more sense to say, "Think about all the people who could possibly be in your community or your audience, and what can you offer to a range of them so that you're really compassionate to all people?

Wrap-up

CHERYL: Is there anything else that I didn't ask you about that you wanna talk about?

MICHAEL: Oh gosh. Did I mention Oscar and Beast?

CHERYL: Yes, you did, but you can always tell me more about Oscar and Beast.

MICHAEL: I always love to talk more about them [laughs].

CHERYL: Yes!

MICHAEL: They're everything.

Maybe I'll end with a point that I see as very central to myself, and that one that I'm struggling with all the time but is a point of critique as care. Challenging someone, something, oneself certainly, as an act of care rather than it is often seen as, or felt as, like you're coming at me, or you're challenging me. And so you're challenging my entire identity, and you're being mean or something. It's oftentimes met with-and may be intended to be mean or disrespectful or something, but it's often met with--resistance. For myself and I know a lot of people are understanding challenge as care, as an act of care and ultimately what is best. This discomfort that I feel in looking at myself in the mirror and in being honest with my privileges and being honest with where I'm an oppressor, where I'm an agent, that's uncomfortable. That sucks. But for myself, it's so crucial to get comfortable in that discomfort because my resistance to feeling uncomfortable is coming from such a closed-off, privileged place. It's not my sole task, certainly, nor is it anyone's individual task, to end oppression [chuckles]. But ending oppression is in my selfinterest. It is what's best for me. Whatever's best for everyone is best for me as well. So it's this weird thing to grapple with. But I'm reminded, always--I'm reminded often--that being challenged with my privilege, being challenged with my position is supportive. Even if it's meant to be diminishing. How I take that is what counts. If I see something that's messed up with myself or that I don't see as best for myself or anyone else, then thank you for exposing that, right? Cuz I don't want that in me. I don't wanna be that! So thank you for calling me out, or thank you for exposing this within me that I'm totally uncomfortable with and wanna retreat from. And I have the privilege to do that. I have the privilege to just retreat whenever I want or change the subject or leave or whatever, yes.

CHERYL: Cry.

MICHAEL: Cry. And feel bad about myself and loathe myself and just hate myself. That does a whole lotta good, right?

BOTH: [chuckle]

MICHAEL: I've tried that.

CHERYL: Yeah!

MICHAEL: I've had a life of that.

CHERYL: Don't recommend it.

MICHAEL: No, no. To challenge yourself and to challenge your automatic thoughts that aren't even thoughts. It's certainly easy to say, rather than do, but challenging everything about yourself.

CHERYL: Well, thank you so much for coming on the show. I really appreciate it. I know that you're a relatively quiet person and that you don't really like taking up space as a white man. But I invited you on the show. I really wanted to have this conversation. So I appreciate that very much.

MICHAEL: I appreciate you asking. You brought up a lot of stuff that we've talked about and even more. So I appreciate that.

CHERYL: Thanks for joining me for another episode of Stories from the brainreels. Find more handy info on brain injury and disability art and culture on my disability arts blog, Who.aml.com.

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