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Fady Shanouda (host)

Hi and welcome back. This is Disability Saves the World with Dr. Fady Shanouda. I am Fady Shanouda. This podcast brings you insights from leading experts in disability and mad studies from around the world. You'll hear about the research and work of disabled scholars, activists, artists, and our allies. You'll also get some insight into their lives, their favorite non-ds activities, hobbies, and adventures. Most importantly, however, you'll get to hear how they think disability can save the world. My name again is Fady Shanouda. I use he/him pronouns and I am an Assistant Professor in the Pauline Jewett Institute of Women's and Gender Studies at Carleton University on unseated Algonquin territory. On today's show, I'm joined by Dr. Merrick Pilling who uses he/him pronouns. Merrick is an Assistant Professor of Women's and Gender studies at the University of Windsor. I'm excited to speak to him about his two books the Monograph Queer and Trans Madness: Struggled for Social Justice, and Interrogating Psychiatric Narratives of Madness: Documented Lives co-edited with Dr. Andrea Daley. Please join Merrick on June 12th at 3 p.m Eastern standard time for the launch of Queer and Trans Madness. The link to register to this event is in the description. And so in this episode, Merrick and I discuss his work. (Merrick) At that time when I first encountered mad studies, I did not see a lot of representation of racialized voices and experiences, and I did not see much if any representation of queer and trans, and so that really led to my interest in these intersections. (Fady) And his life outside of academia. (Merrick - Something that brings me joy is to grow plants from seeds or to be on trails far away from the city or next to large bodies of water) (Fady) And I get to ask him how he thinks disability can save the world.

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Hi Merrick, thank you so much for coming on the show.

Merrick Pilling (guest)

Hi Fady, thanks for having me.

Fady Shanouda (host)

I want to jump right into the first segment it's called inside the project, the research, the work, the art. I want to know, how you got, how you came to disability studies?

Merrick Pilling (guest)

How you came to mad studies, yeah and so I came to mad studies through the academy my first encounter with it was in Geoffrey Reaume's course in 2008 when I was a Ph.D. student. So I was really excited by mad studies because it spoke to some of my lived experiences in ways that mainstream thinking about mental health and illness really did not so just as one example,

my cousin died by suicide and I really felt ill at ease with the way that her struggles and her death were framed and taken up, and so when I encountered mad studies I felt like this really offered another way of seeing things because it counters this kind of individualized deficit model, and you know, that model that would say there's something wrong with you biologically as an individual and that's why you are the way that you are. And so mad studies kind of gives us back the context it looks at structural violence and the way that that causes distress. And it also looks at the violence of the psychiatric institution itself and the ways that that caused distress.

Fady Shanouda (host)

Well, thank you for sharing - sharing that with us, I mean it's clearly a very powerful story, and I'm not surprised that Geoffrey was your introduction because he seems to be so many of our introductions especially those of us who studied in Ontario and in Canada. What did mad studies provide you that I think other theoretical perspectives couldn't, was there something specific about the theoretical approach that you found more fulfilling to do the work through that - through that analysis, through that narrative?

Merrick Pilling (guest)

Yeah, I think what I mentioned in terms of the context that mad studies give us so, you know, like mainstream mental health research really boils it down to this kind of biological perspective, it's a deficit model, etc. and so I feel like mad studies disrupt that, and like I said it kind of gives us back the context in terms of looking at the structural picture and how that impacts distress, and also because it does give us the lens to examine psychiatric violence itself, right? Whereas you won't find that in mainstream mental health research.

Fady Shanouda (host)

So you have two books that are now out, *Queer and Trans Madness: Struggles for Social Justice*, and *Interrogating Psychiatric Narratives of Madness: Documented Lives*. Can you tell us about the monograph, the solo book, how it came about, and what it is you argue in it?

Merrick Pilling (guest)

Yes, so that book really comes out of or kind of the seeds were planted when I took that course with Geoffrey Reaume as a Ph.D. student because, at that time when I first encountered mad studies, I did not see a lot of representation of racialized voices and experiences, and I did not see much if any representation of queer and trans voices and experiences, and I found that really odd because I knew that there was so much resistance in queer and trans communities to the pathologization of queerness and transness, and so that really led to my interest in these intersections but at the same time mad studies really allowed me to see some of the issues with the way that gay and lesbian, as well as queer and trans activists, have resisted psychiatry and the ways that they have resisted pathologization so, and there are others who have written about this sense so Regina Kunzel, Helen Sandler, Sarah Carr, Cathy J. Fitzpatrick, and Jijian

Voronka, just to name a few but there's this problematic distancing that happens so this idea that we trans and queer people we're not mentally ill, and that's the hook that we're going to hang our activist strategy on, and of course there's sanism that's embedded in that position. And it's also a really narrow way of looking at things because it focuses on specific diagnoses. So historically that was the diagnosis of homosexuality and gender identity disorder. Currently, it's the diagnosis of gender dysphoria, but it really begs the question, you know, what about the rest of the DSM the diagnostic and statistical manual mental disorders, you know, what about the biomedical model as a whole, and so my book shows the ways in which queer and trans people are pathologized and psychiatrized beyond just these diagnoses that target us, and why that's a problem, and that we need mad studies to help us broaden the critique to be about the biomedical model of mental illness as a whole and not just these really specific diagnoses.

Fady Shanouda (host)

You know, I have this section in my - in my class with these like these two images that I show one of them is off, it's an old suffered jet picture where the suffragette is in a cage with someone who's lunatic and another person who's a convict, and it's a - it's a metaphor about how or it's a - I guess illustration of like how - how dare women be compared to these individuals and not have the vote, right? Similarly to them. And similarly I have another photo that I show where there's a protest sign that says homo is healthy right and both of these ideas these like claims to like further humanity or claims to a kind of brushing aside or disregard of disability or difference in order to claim sort of like rights or entitlements and similarly to what you were saying I think, you know, does ratifying normalcy right ends up really being harmful so the fact that your book looks at like how the entire medical practice and the entire biomedical model needs to be addressed reconsidered, restructured is wonderful. I know from many of my students, I've already picked up the book and are reading it as part of their comps, so thank you for writing it.

Merrick Pilling (guest)

That's awesome to hear.

Fady Shanouda (host)

So tell me about the second book I know it came out in November, and it's co-edited with Dr. Andrea Daley, and it's titled *Interrogating Psychiatric Narratives of Madness: Documented Lives*. So how did that co-edited collection come about?

Merrick Pilling (guest)

So that book is based on a project for which Dr. Andrea Daley was the principal investigator, so that project was a retrospective chart review project. We reviewed 161 psychiatric inpatient charts with discharge dates between 2013 and 2016. To look at the way documentation practices tell a story about gender by using an intersectional lens that also considers race, class, sexuality, and disability. So each chapter of the book is written by members of that

research team and the book was edited as I said by Dr. Daley and myself. So my chapter in the book is called Sexual Violence and Psychosis: Intersections of Rape Culture, Sanism, and Anti-Black Sanism in Psychiatric Inpatient Chart Documentation.

Fady Shanouda (host)

I wondered in doing this kind of work for as long as you have I wonder about the response that you get, I wonder about what it's like to - to do this kind of work in the space that you're occupying now in Women's and Gender Studies. Yeah, what - what has been the reception. (Merrick) So my current position in Women's and Gender Studies has been very open and receptive to the work that I do. Also when I was originally doing this work it was within the Gender Feminist and Women's Studies program at York University so Women's and Gender studies has been a very open place to do this work but generally speaking, and I talk about this in queer and trans madness, any work that challenges the biomedical model of mental illness is always met with a lot of resistance, and a lot of hostility. I think we are really bombarded with the medical model and a lot of times people interpret what I'm saying as that, you know, experiences of mental distress don't exist so I have a section in the book that is called mental distress is real or something like that right because that's not what I'm arguing, and I understand the response and the emotional response to it right because people can feel like their own experiences or the experiences of people they love are being invalidated somehow.

Fady Shanouda (host)

Exactly.

Merrick Pilling (guest)

So I really was careful in the book to try and make it clear that that's not what I'm arguing I don't know we'll see - we'll see what the response is to the book I guess if I succeeded in making that clear or not.

Fady Shanouda (host)

But I think - but I think it's important for like listeners and people who come to this podcast, later on, to know like that like those, you know, those distinctions are important right that we're not denying that people experience pain, right? And that pain that might be you know mental or experiences that are that, you know, Brenda LeFrancois talks about mental anguish, right? That it's addressed holistically, right? In the introduction of Mad Matters, she says this, or Menzies, LeFrancois, and Reaume say this. And to me I think it's - it's not just like how we conceptualize it but also how it's we respond to it, right? And so, and of course, a lot of people have struggled so long to get diagnosed in order to get treatment, and I think that's also why they value it so much and are very terrified when someone comes around and says, you know, it's bad, it's dangerous, it's unhelpful, right? Yeah.

Merrick Pilling (guest)

Yeah, for sure, and the way that we conceptualize it shapes the way that we respond to it, right?

Fady Shanouda (host)

Exactly, yeah. So I wondered if you could tell us a little bit about what you learned in the process of publishing these two volumes.

Merrick Pilling (guest)

I feel like I still have a lot to learn in terms of how academic publishing works but I do want to mention the hideously expensive price of both books. I'm disappointed in the price because it puts these works outside the reach of people outside of academia, you know, people who don't have access to university libraries essentially, and that was not what I wanted for either of these books. I don't profit from this either by the way but this represents a bigger problem in academic publishing and if there are people listening who publish academically who have thoughts about how to effectively navigate or challenge some of these issues, I would definitely love to hear from them. And I also always request that people ask their public libraries to carry the books so not their institutional libraries but their public libraries because it will just make it that much more just marginally more accessible to people who don't have access to university libraries.

Fady Shanouda (host)

Well, I think that's a wonderful intervention and one I've never heard before to request the public library to - to hold it. Yeah, I'll do that here in Ottawa. That seems like something that I can do.

Merrick Pilling (guest)

Shout out to Lori E. Ross for that suggestion (laughs).

Fady Shanouda (host)

Yay Lori E. Ross. Yeah, well let's move on to segment two: The middle or the liminal and speaking of Lori E. Ross maybe she is your academic crush, maybe not but who is the person that you are you're reading now that you just can't stop reading or someone who you've always really admired in the field?

Merrick Pilling (guest)

I don't know if this is an academic crush but I can say that I'm really looking forward to Sami Schalk's new book: Black Disability Politics. I also love that she twerked on stage with Lizzo.

Fady Shanouda (host)

Yes, I feel like that should be an intro to disability studies like classes be like one of your professors is a superstar (laughs) leader in the field. And Merrick, do you have any advice for younger academics?

Merrick Pilling (guest)

So I tend to give really practical advice the program that I work in doesn't have a graduate program so generally when I'm giving advice it's to undergraduate students who are considering whether they want to pursue grad studies. My best advice for people who want to enter academia is to have a realistic picture of what the current job market is like, I hellscape (laughs) Also (laughs) just saying.

Fady Shanouda (host)

Yep.

Merrick Pilling (guest)

Also, I provide as much information as possible on how academia works. This information is not readily available, and there's this assumption that you will just know things somehow. Maybe a lot of people who pursue academia have academics for parents, and that's how they know I don't know but if that's not the case for you there's just a lot of things you don't even know that you need to know if that makes sense. And so, you know, I always think of this example for myself. It took me a very long time before I learned the difference between what is an assistant professor - professor, and what's an associate professor. So you know given that I wouldn't have been able to even look at job as and distinguish what am I eligible to apply for right so it's a very practical and fairly simple thing and I remember feeling really embarrassed when I did learn what the difference was in kind of a harsh way actually (laughs) but at the same time there's just this information isn't really out there right and yeah so if you're not - if you don't have a strong mentor, if you're not connected to you know to a network of senior scholars then it can be really hard to figure out just the basics of how - how things work or what information you might even be lacking. So I just seem to be really forthcoming and supportive of other academics or would-be academics by sharing as much information as possible to try and demystify academia and not just also being very realistic about the job market, and I also advise students to seek strong mentors when possible because personally, I've found that that really makes all the difference in surviving academia and again shout out to Lori E. Ross on that one.

Fady Shanouda (host)

Yeah, Lori E. Ross, Geoffrey Reaume, I feel like there's like been really important people in I feel like I can say that we're - we're both emerging scholars if I can use that and not - and not sound horrible but like, you know, I feel like there have been lots of people who've supported our generation and so, yeah it's kind of wonderful that we've had them. I really appreciate all that

feedback and I think, you know, concrete feedback is really important. I remember when I went to the UK I also learned that they don't call them assistant associates there, right? It's a lecture senior lecturer and a whole bunch of other readers, right? So it's not even that it's the same every place that you go, yeah. So let's move outside the project, the research, the art. We're in segment three now. Who is the most famous person you've met and what was it like?

Merrick Pilling (guest)

I haven't really met that many famous people but I sort of met the Red Hot Chili Peppers.

Fady Shanouda (host)

Wow.

Merrick Pilling (guest)

I got autographs from them, it would have been probably, late 90s or early 2000s when they were doing a free concert downtown Toronto and an interview with a radio station, so yeah.

Fady Shanouda (host)

Cool! Do you carry around an obscure fact and what is that obscure fact?

Merrick Pilling (guest)

Honestly, I cannot retain information like that it just goes in one ear and out the other. Yesterday I was trying to remember the postal code for my previous apartment and, like it was like three months ago I moved and the information is just gone. My brain just disposes of it when I don't so.

Fady Shanouda (host)

Not even so no obscure facts and not even like general important information sometimes.

Merrick Pilling (guest)

Exactly, it's just erased.

Fady Shanouda (host)

I feel like people like most people don't answer this question on the podcast, it's just because I really like obscure facts so that's why- that's why this question is there. What are you reading now, besides, of course, your own work but, what are you reading?

Merrick Pilling (guest)

Just sitting at home reading my own book (laughs) No, I've been reading a ton of fiction lately it's really nice. So some of the things on my coffee table are: People Change by Vivek Shraya, Little Fish by Casey Plett, Five Little Indians by Michelle Good, and Butter Honey Pig Bread by Francesca Ekwuyasi so far amazing.

Fady Shanouda (host)

That's great. Are you reading them all at the same time, or you finish, them or...

Merrick Pilling (guest)

And two of them I'm about halfway through just kind of switching back and forth.

Fady Shanouda (host)

Awesome. And is there a hobby that you do um or is there something that you do that brings you joy?

Merrick Pilling (guest)

The question about hobbies makes me think of awkward tinder days (laughs) Or like a lady of leisure

Fady Shanouda (host)

Or ladies who lunch yeah.

Merrick Pilling (guest)

Someone who's not being ground into a fine dust by capitalism (laughs)

No, but something that brings me joy is to grow plants from seeds, or to be on trails far away from the city, or next to large bodies of water.

Fady Shanouda (host)

Wonderful. And finally, how do you think disability can save the world?

Merrick Pilling (guest)

There is such a huge number of disabled people but there are so many things that stand in the way of claiming disabled identity including things like the narrow way that disability is defined by

the state and by various institutions to limit benefits. Also, the way that some disabilities are invisibilized by mainstream understandings of what disability is, and how that stands in the way of people even realizing that the word disability applies to them. So I'm thinking of things like vestibular issues, chronic back pain, endometriosis these are just a few examples so this could be very long. And there are so many things that stand in the way of discovering a disability justice politic we're all so bombarded with the medical model of disability, and we are all bombarded with this very ableist way of understanding our own bodies, and the bodies of those around us. But if everyone who was sick, chronically ill, and disabled claimed that identity connected with disabled community and took on a disability justice politic, there would be no stopping us.

(Music)

Fady Shanouda (host)

Thank you for coming on the show. I really appreciate it.

Merrick Pilling (guest)

Thanks for inviting me, Fady.

Fady Shanouda (host)

Thanks again to Dr. Merrick Pilling for coming on the show. Get in touch by sending us an email at disabilitysavestheworld@gmail.com. If you're interested in learning more about me, check out my website Fadyshanouda.com. This podcast is hosted, produced by me, Fady Shanouda, and edited by Yhasmina Garcia. Thank you for listening and see you next time on Disability Saves the World.

(Music ends)