Transcript of A Conversation with Matilda Feyisayo Ibini Part 2: The Power of Stories

00:00:02:00 - 00:00:09:10

Matilda

I live under a care system that says if I work, then I'm surely not disabled. I cannot claim to be both severely disabled and work.

00:00:09:12 - 00:00:28:14

Matilda

That their limited imagination couldn't possibly perceive or begin to understand of how someone whose claiming to be quote unquote, as disabled as I am could possibly be making a living and earning and working. But not only that, but be good at it.

00:00:28:15 - 00:00:53:10

Chloë

Welcome to Broadcastability, a podcast by for and about people with disabilities. During these past few seasons, we have focused on disability inclusive work. Broadcastability is part of the PROUD Project, which is a research and advocacy institute. PROUD is a Canadian registered charitable nonprofit. It is also affiliated with the University of Toronto Scarborough. You can find out more about the PROUD project on our website:

00:00:53:11 - 00:01:00:11

Chloë

www.theproudproject.ca

00:01:00:12 - 00:01:29:09

Isabelle

The PROUD Project is based at the University of Toronto. Scarborough, which is on the traditional, ancestral territories of the Huron-Wendat, the Seneca and the Mississaugas of the Credit River. Isabelle Avakumovic-Pointon works on the traditional, ancestral and unceded territories of the Musqueam, Squamish and Tsleil-Waututh First Nations. We would also like to acknowledge the other Indigenous lands across Turtle Island, where we conduct our research and record this podcast.

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Chloë

Hi, I'm Dr. Chloë Atkins and I'm the lead investigator of the PROUD project. I'm a political scientist, actually a political and legal theorist, at the University of Toronto, where I do work in health equity, anti-ableism, bioethics and human rights. As a person with an episodic disability, I also have lived experience with employment and disability.

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Isabelle

My name is Isabelle Avakumovic-Pointon, and I'm a research assistant for the Proud Project. I'm also a PhD student at the University of British Columbia, where I research disability history. I identify as a person with invisible disabilities. Welcome to part two of Matilda's Story. Last episode was part one where we met Matilda Feyisayo Ibini, who’s a playwright based in London, and we heard about Matilda's own life and career path and how she became a writer.

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Isabelle

And in this episode, we're we talk more about the lessons she learned from her own path, and the advice that they have for other disabled individuals who are interested in writing, in the arts... Advice for the arts and entertainment industry overall on how to become more inclusive. And also advice for government, for how their policies can support disabled people and disabled artists.

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Chloë

What I was just thinking is, I think one of the things that comes across when we talk to her is she's someone who deals with stories. I mean, narrative is what she's, you know, it's what she's making money off, it's what inspires her. But her own story has given her a sense of wisdom about what she offers in terms of her own experience, to other people, to the arts industry itself, like her peers and that and and people who might be interested in hiring or retaining people like her.

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Chloë

But also she has a view around government policy because she is in this uncomfortable space of somebody who's needing disability services or benefits while also earning an income in the arts industry. And that is an oddity. And she doesn't want that to be an oddity. But it's an oddity, in part, not only because we're unfamiliar with it, but because policies make that difficult,

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Chloë

Make that difficult, right?

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Isabelle

Yeah. It's not naturally unusual. It's that, you know, the policies we've created make it difficult and hard to do. But I think that's really sort of the strength of what Matilda’s talking about, is that we can change what we think of as natural, as normal as... and by changing that, we can change our policies. And by changing our policies, we can change the lives of people.

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Isabelle

So I think that really, you know, the power of stories really, really comes out in this episode. Yeah.

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Chloë

You know, so let's get to it. Tell us a little bit about how you might advise a youngster like someone, a teenager, since we're talking about that period of life who might want to go into the arts, who has a physical disability or even another form of disability. But our study has mainly focused on people with physical disabilities and obvious ones, things that... how do you navigate that?

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Chloë

I mean, what would you advise them?

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Matilda

The biggest kind of catalyst for starting to actually get paid for my writing was when I got an agent, and I know for a fact very few people, disabled or not, writers, start their career straight out the bat with an agent. So one of the things I think if you're thinking about going into this is finding a way to one, finding a way of working that works for you, that works around your condition.

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Matilda

That's one of the reasons why I'm freelance, I'm self-employed, I work on - though it doesn't necessarily mean I'm financially comfortable every month of the year - but I work on a project-to-project basis, which means I have the flexibility and the time to also look after my health needs and my care needs whilst working so I can work around that.

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Matilda

Whereas a kind of more structured work like working in an office or working for the charity, for example, a Monday-to-Friday job will leave you with hardly any energy left to do anything. All you would, all you'll be doing outside of work is resting because so much of your energy and time is taken up by working. And so I think there's kind of an awareness that, what are you going to do?

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Matilda

How else can you make money in the meantime if the writing isn't making money, or if you're not making money in the the field that you want to go into. You're going to have to find a way of making some money or finding out what type of welfare benefits are you entitled to that may help supplement a lack of an income for a while.

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Matilda

And I wish that wasn't the case. I wish I didn't have to say that. I wish I could just say that you study and then you send out work and you have a portfolio of work and you send it to people and they call you in and you get a job and they pay you X amount of salary.

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Matilda

Like, I wish I could say that, but that's just not the way the world is. It's not the way this industry works, unfortunately. I'm also very cautious of also saying that it's not impossible to find a way that works for you, because if I'm honest, the the courses, all the courses that I went on, all the degrees that I did always spoke of a of a non-disabled, always spoke of a non-disabled way of working and existing in the world.

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Matilda

And I have to tell you, I do not live like that. I do not work like that. I don't, I can't work that. It's physically not possible for me to work like that. I work in a way that my health is always the priority. My care needs are always met first before my work needs. That has... it has to be that way.

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Matilda

It can never be the other way round.

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Isabelle

I just wrote that down. I think that's a very good way of putting it, that we are taught in school, and just generally, a non-disabled way of working and existing in the world. I think that's a, that's a good, a good phrase.

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Matilda

It's not applicable to me.

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Isabelle

Yeah. Yeah.

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Chloë

I agree. And there's sort of things that you're advised even in, as careers and working conditions and that just don't work for someone like you or someone like me that, that gets tired physically. I think the arts is a wonderful realm for people with disabilities to work in. And what do you think would be the government or even the entertainment industry itself, agents,

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Chloë

what should they be doing that makes it better or easier for individuals such as yourself to be part of those communities and to be contributing? Because it seems to me that you've, you know, you're like your mum, you push, you push through that. So not everybody is like that. So what should be happening?

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Matilda

Oooh... there are so many things they can be doing, I think one is being in schools. So we used to have careers, guidance counselors, but I remember very vividly when they were cut before I finished secondary school. So we used to have these centers that young people, both in education or young people that dropped out of education, they used to be called Connections.

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Matilda

And there were these centers where you could go to see what opportunities there are. You know, as a, I think between like the ages of 16 and 19, whether it's work you want to do, whether it's you want to get straight into work, whether it was apprenticeships, whether you want to actually do the exams you needed outside of school to be able to get into university or what have you,

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Matilda

that's, that was the whole point of these hubs called “Connections.” And they got cut, I think, even before the Tory government came into power, they got cut. I don't know why, but we need things like that back in schools again that we're speaking to young people very early on, even if they're not sure what they want to do now. The exposure is so important.

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Matilda

Had I not gone to see that play age 15, that wasn't a show aimed particularly at young people, none of those dots would have started to join. I would still think that it's just something I do for myself, or that your work can't be shed for an audience. So like, there needs to be earlier intervention in schools to talk about careers and most importantly, to talk about what it means to be freelance or self-employed.

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Matilda

Because the only... any time the quote unquote future was discussed in school, it was always about formal, structured, 9-to-5 work. It was never about what does it mean to start your own business? What does it mean to be freelance? What's the difference between a sole trader and a limited company? We didn't learn any of that.

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Matilda

All of that, I had to find out the hard way and the messy way, and making lots of mistakes and almost getting fined for not paying my tax. Like all of that could have been introduced much earlier on in school. And then for those of us that maybe don't even get the opportunity to go to school, yeah, we we’re going to need physical spaces.

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Matilda

We're going to need centers where we can make sure people develop not just the not just the skills of wanting to get into said sector, but the skills that we need today, as in, do you have access to the Internet? Do you have a laptop? Do you have a computer? If you don't even have the basics, any industry will be difficult to get into.

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Matilda

I remember we didn't have a computer in the home till some... towards the end of my secondary school experience. I was doing all my coursework - because they no longer accepted handwritten coursework - I was doing all of it at the library! So my mum would be like, You need to be home before seven. I was like, Mum doesn't give me enough time to finish my coursework.

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Chloë

You must have been exhausted.

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Matilda

Yeah.

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Matilda

Yeah. I mean, sometimes when I think back to the... because now I've been a wheelchair user for almost a decade now. I think back to life before the wheelchair and it almost seems like a dream. Like I genuinely can't remember, how did my legs climb all those stairs? How did I have the energy to walk to school, do up and down six different level, six different floors, and then walk back home and then also have to walk up and down the stairs in my own home? Like that,

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Matilda

doesn’t make sense to me, doesn’t even feel possible because of the body I'm in today. I'm like, How the hell was I ever able to do that? But yeah, like there's so much, there's so much that can be done. And I think the industry as well, like the Arts sector, needs to put its money where its mouth is. Like, it generates a ton of income, as we can see in the US strikes, for a small amount of people.

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Matilda

That money is not trickling down to the makers, to the writers, to to even the actors. And we need to see... they need to put their money where their mouth is and put money into investing in the the next generation, because there will always be a next generation, there will always be upcoming generations, and there needs to be a kind of way of filtering, or not even filtering, but like circling off funds or profits, a certain percentage of profits goes to future development of upcoming... creating these lanes, these pathways for, whether it's low income, whether it's to do with disability and access requirements, whether it's even to do with like maybe just the background that

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Matilda

you came... were born into and it means you you haven't even had... for some people, they haven't even had a childhood. So the idea of like now they just need to work and and their life will be fine. Actually, no, it means their life is often delayed. Things come a lot later. They're not going to follow that train of like 18 at university 21, you get a job, 30, you get a house. Like that

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Matilda

doesn't... that that myth we need to like, stop propagating that myth. That, actually, we all come of age at different ages and we all develop at different ages, so we can't have this singular kind of funnel that we're going to try and shove everyone down. We need to create different lanes, different pathways for people to be able to get into this industry because we're not all coming from the same place.

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Matilda

And the industry itself has never been a level playing field for a long time. So we can't pretend that everyone will just find their way in eventually, everyone will have a generous sister or pusher mum, that they will eventually just push through. Like that's unrealistic.

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Chloë

Okay, I want to ask a question that's a little bit aside, but it's one that I've thought about quite a bit as I was reading and listening and watching some of the work that you've done and you have a radio play, “She didn't jump, she was pushed”, which really... where it touches on... there are the two main characters are homeless and there's a game show of some sort, in which they get a lottery maybe win housing and it really brought home to me one of the things I feel about when I write about disability or even write autoethnographic sort of material about my own disability is the line that you walk, the balance you strike when

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Chloë

you... I mean, you have a disability, you're queer, you're Black, you're a woman. There are all these vulnerable identities that can be rolled into one where I worry about and I certainly experience where I am an example in which people are voyeuristic. We're all voyeurs. I was chatting to Isabelle before we started about how I think why we love,

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Chloë

we get captivated by TikTok and all these reels is we get to stare at someone over and over again if we want, and no one like it. There's no issue with that. As we look at our little phones and screens, we get a view into someone's life and we can sort of slack-mouthed and drool if we want, and no one's going to stop us.

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Chloë

So one of the things that I am been intrigued about is you get slotted as someone who's this type of writer, this type of artist, and you become an example of just that. And that worries me and that maybe you become an entertainment. You produce work that becomes a spectacle as an entertainment for others. So I don't know whether I'm being clear, but I'm wondering how you manage that.

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Matilda

Yeah, I think very early... I think it speaks to something, so very early on in my career, I intentionally didn't write plays with any disabled characters. It wasn't until like my yeah, quite a while I wasn't writing disabled characters because I think intended... and because I was aware or was beginning to develop an awareness of the industry that I was in,

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Matilda

I was also very conscious of not wanting to be pigeonholed as the writer who only writes about disability, or even more so the writer only writes about their disability. And... and I used to think that was me being. Yeah, me being aware of the industry or what have you. But I also think some internalized ableism also played into that. That I perhaps also wasn't ready to address the fact that I have this lifelong condition that is progressing and changing and evolving.

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Matilda

And I think it wasn't until I had, again, a lot of therapy before I started writing characters, but I also wrote them in ways that I wanted to see them as well. So I think sometimes when I'm writing, I'm often conscious that I'm writing from... not necessarily like, Oh, I'm writing a disabled character that has my exact disability, but I'm writing it,

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Matilda

I'm writing it in a way that I would like to see disabled characters on screen or in a story presented in a particular way. So I want to see disabled characters as the love interest, I want to see disabled characters as the villain, that goes beyond them being bitter about their condition, I want to see disabled characters as parents,

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Matilda

I want to see disabled characters in positions of power. Like I think a lot of the time when I'm writing, I'm... Yeah, it might be like a personal thing that I want to see disabled people or a disabled character in a particular way. And I think to your question about like, yeah, like how? Yeah, I can't say that I have often thought about that.

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Matilda

I think more so when... Not I have not thought about it, but I try not to let it get into the work, as it were. So sometimes I've got to be really clear when I'm... and even if I'm not yet clear, because that can always change, but sometimes I'm really clear on who, who am I writing this for?

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Matilda

And I have to question that over and over again. So sometimes in the beginning I'm like, this is definitely for disabled people. And later on in the journey, by the time I've written it, I've realized like, disabled people would know this. This is for non-disabled people. This is... I'm speaking directly to them about the way they treat us or I'm trying to paint a picture for them, for them to be able to see their positionality in society and how that impacts our existence and things like that.

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Matilda

So I think maybe actually to answer your question, I think it maybe comes later down the line. I try not to let things... when I'm when I'm beginning, like writing something that's really raw, really messy, really first draft and just pouring everything into it. So even some of the kind of... maybe... I'm sure I'm not immune from having written into stereotypes and things like that, I put everything into the first earlier versions of whatever I've written and as I'm drafting, I'm trying to comb some of that out.

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Matilda

I'm trying to comb some of that voyeurism that you speak about and kind of comb some of the, Oooh, is this...? Am I writing into something, something that's harmful to a community, even if it's a community I already belong, belong to or kind of thing. I think is in the redrafting that I'm often trying to get that out. And I think it's such an interesting question that you pose, because I don't think anyone and any writer really, or any kind of maker can avoid that.

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Matilda

Like, I think it's it's not something you can kind of like, say, Oh I've never done in my work. I think it's more, how do you manage to either address it? How do you try to comb it out of the work, or how do you try and then acknowledge it in the work then? That actually, I'm still going to tell this story, but I'm also going to acknowledge the fact that I might be writing from a place that is outside of the experience of the characters. Or I'm writing a place that isn't entirely from my own experience or what have you, and I can't say that I've always gotten it right.

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Matilda

That's that's the whole thing of writing, is that you write a lot that's so ...more, I will write more that won't ever get seen, won't ever see the light of day than the few bits I'm fortunate enough to get published or produced or what have you. So in my process, I'm I'm writing a lot to to hopefully get better at being able to detect it for future things as well.

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Matilda

If that makes sense.

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Chloë

I love the fact that you say there's so much writing you do that never will see the light of day. And that's one of the the great risks as being an artist is that you produce... You've no idea whether someone will ever... it will ever be seen or heard by anybody else. And yet you spend hours and days and just on it.

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Matilda

Years even. Yeah, exactly.

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Chloë

Absolutely. It's a great deal of investment.

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Matilda

I think one of the things I often try and remind myself is like also my intent with a piece of work that often I'm not someone that wants to write work that harms. So I'm... so that's another way of trying to have at least some self-awareness. That, is this... irrespective of like the characters or who I'm depicting and the story, well, will this harm people?

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Matilda

And if I fear that it will, then I might have to let it go. It might have to already not have... can never leave my laptop. I can still write it just to kind of expel it in a way. But actually I'm very conscious personally, and maybe that's just to do with like my values or whatever, but I personally am not in the... I'm not in in writing to harm.

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Matilda

It's often to put light over things that are not seen enough or heard enough or understood enough. But yeah, I don't I, I'd like to think part of my like ethos of my practice is I don't write, set out to harm people with my work.

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Isabelle

I just I think that's an interesting point you were talking about. This is just something that that's come up is that like, are you... I know I've noticed in newer shows you're seeing more disability or disabled representation, slowly. What do you think is the future of disability and like performing arts just in terms of both like the front end of what people see on screen as well as who's in the background working on it?

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Matilda

I think there's still quite a lot of imbalance in the sense of who gets to tell what stories. We still have far too many, and it's not to say that they can't tell the stories, but we still have far too many non-disabled people telling the narratives of the disabled community. And I'm not saying that can't happen, but it's... if we look at the present situation that we exist in, not the utopia that we would love to exist in,

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Matilda

disabled people don't even get to tell their own stories. So why are other people telling our stories? Like I often feel like when we think about representation, it's, I wouldn't say easy, maybe just like more comfortable that we're still almost training our audiences, because of the centuries of capitalism and white supremacy and everything, that we're still training audiences to be comfortable with just seeing different disabled bodies on screen or on stage.

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Matilda

Rather, we're demanding that disabled people get equitable space and resources to tell their own stories, as well as stories that have nothing to do with being disabled. We are not at that point yet and we still have a long way to go. And I think I feel like the back end, I would say maybe just from my experience, my... from the people that I've spoken to, I'd say the back end is still very far behind the frontend because it's much, not easier, but it's... there are more resources put to get more disabled, deaf, disabled, neurodivergent faces characters on our screens, on our stages.

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Matilda

That is not happening backend-wise. There's just a lot of talk. We're having far too many fucking panels about why are we not having disabled representation? Or like, what's happening backstage? And I'm like, Well, speak to your governments because if disabled people are barely able to survive, how are they expected to make a living? If we're if we are legislating disabled people out of existence, you want them to tell a story too? Like...

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Chloë

No, I mean, you make such good points and it's ones that we've seen. I mean, what's so important about what you do is you're communicating. Your job is to communicate this experience, this experience of being human and facing your community of fellow men, with the various traits that you have and the barriers that you encounter, right? And one of the things mean you talked about when we first spoke, which was how important it would be to have disabled people in government. Like, that

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Chloë

they are bureaucrats, that they are elected, that they, that they... and so can you talk a little bit about that?

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Matilda

Yeah. So, yes, we definitely need more disabled people in positions of decision-making because, I'll be honest, non-disabled people cannot be trusted.

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Matilda

They cannot be trusted.

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Matilda

When it comes to what is quote unquote, best or in the best interest of disabled people, point blank period. And a lot of that could be over... A lot of that could be addressed, not necessarily entirely fixed or is the complete solution, but by simply having us in the room, at the table, also involved, I think would change a lot.

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Matilda

Absolutely. But not only that, I'd even take it a step further that maybe by having disabled people at the table, you may have to change the table. You may have to then change the way that you work, because actually what has kept us out of those rooms, out of those decision, decision-making powers are often like intentional barriers because disabled people are not trusted or believed to know what is best for them or how services should be provided for them.

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Matilda

We’re met with, we're given a kind of ultimatum. Take it as we deliver it for you, or you go without. And I've had that experience far too many times where essentially non-disabled people or people with very, very limited proximity to disabled people are making fucking big decisions about my life, and me, I'm not considered for whatever reason, I'm not considered an expert in my life.

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Matilda

But they'll then gaslight me by saying, But this is a person-centered way of working. And I'm like, No, it fucking isn't. You can say that until the cows come home. This isn't how you center someone and their needs and more importantly, their voice. Because the number of times I'm just not listened to until I get a doctor's report that says the exact same thing that I said, before

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Matilda

they decide, Oh, that email from your nurse or your doctor, yes, we will take that on board now, even though I said that to you. So I feel like to say people need to be in the room at the table and will will make hopefully make people see, Oh, we can't work the way that we've been working.

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Chloë

You're so articulate about this. I wasn't going to ask this, but I’ll ask last one last, final question, which is it brings me to around the performance of disability and there's sort of a theme what I... in my life, but I can see that yours, which when you were younger, you weren't believed and so you were trying not to be disabled and you weren't performing your disability in the way that they expected.

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Chloë

And the same thing when you, particularly when you have a rarer condition that not many people experience, is that there is... you're meant to behave in a certain way. And I find myself actually - for systems - behaving in that way because it's just easier. So while they see me, I behave that way. But... and yet we're just... with the other part of, side of that is we're parents, we’re children, we’re colleagues, we’re friends.

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Chloë

We’re just like anybody else. So I just... Can you talk a little bit about that, that performance, that expectations of stereotypes of disability and how that affects you and what you think about it?

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Matilda

Yeah, this I mean, this even speaks to a recent encounter that I've had where... yeah, it's, it's a very... it stirs a lot of feelings in me because I think what I've learned is that I've never... I will never perform in the way that they want me to. I will never perform in... I will never be able to give the performance that will justify me getting the services that I need or getting the funding that I need or what have you.

00:29:45:11 - 00:30:16:06

Matilda

Because the reality is most of the population has been conditioned to see disability as something very narrow, very small, very rigid, something that doesn't change, something that doesn't evolve, very static. And the reality... and then the reality is, nobody lives up to that, that model that ideal of what a disabled person is, or a wheelchair user is, or a blind person is, or a deaf person is.

00:30:16:06 - 00:30:41:13

Matilda

Nobody lives up to the white supremacist ableist ideal of what that looks like. So I've often, when I was younger, definitely I was having... I had to learn, I was learning what does that performance look like? What do you want me to do and I'll do it. That that's very easy to get a child to do that. But as an adult, I've I've just gotten more angry,

00:30:41:13 - 00:31:11:10

Matilda

is the thing that has happened. I've gotten more angry at the fact that I have a care system, I live under a care system that says if I work, then I'm surely not disabled. I cannot claim to be both severely disabled and work. That their limited imagination couldn't possibly perceive or begin to understand of how someone who's claiming to be as quote unquote, as disabled, as I am could possibly be making a living and earning and working.

00:31:11:12 - 00:31:35:10

Matilda

But not only that, but be good at it. Like, it doesn't register in their mind. All I get... the thing I keep getting, keep bumping up against or getting pushed down against is that well, if you've done you've gone to university and you've done all of these things, so surely you can't be as disabled as you're claiming, then. Things must be alright for you. And, and, and all that

00:31:35:10 - 00:32:06:02

Matilda

does is just make me incredibly angry because I've never been able to quote unquote satisfyingly do the performance that they're looking for, because the performance that they're looking for isn't real. It doesn't exist. It never has. And for a long time I think it was like impacting my mental health because you can imagine, right? So it was impacting my mental health that you can imagine as a child who wasn't using any mobility aids, I was being told I was faking it.

00:32:06:03 - 00:32:26:13

Matilda

I get a diagnosis, the condition progresses and now I'm walking in with a crutch and they're still telling me, Well, you're still doing well because you're still walking. Even though it's with a crutch. And then when I get, when it progresses and there’s changes, I'm now a wheelchair user and they're still telling me, Well, you're still able to work, so surely it can't be that bad.

00:32:26:15 - 00:32:45:02

Matilda

I've never been able to live up to this ever-changing or ever... this just not real ideal of what the performance is. Like, no one can give me like a ten point plan of if you do all of these things, then, yep, you've proved to us that you are you are disabled or you are you need you need access to these services.

00:32:45:05 - 00:32:54:14

Matilda

I've constantly been denied over and over and over again and literally told I am not disabled enough and I don't even know what that means.

00:32:54:15 - 00:33:16:12

Chloë

I mean, as a political scientist, what it makes me think of, you've captured... you've been so articulate here... is this tendency where we think you must be totally independent, like you have no relationships of care or dependency with others, for you to be a functioning person in our liberal democratic societies, which is unreal. Sorry, it doesn't exist for parents,

00:33:16:12 - 00:33:24:00

Chloë

it doesn't... your your siblings support, like do you know what I mean? There are there are intertwining relationships. And what the demand is, is,

00:33:24:01 - 00:33:24:10

Chloë

How

00:33:24:11 - 00:33:44:06

Chloë

can you be working and needing care at the same time? Well, everybody does that. Like they have spouses who make their lunch or to pick up their kids or the they work together. We all need care and work at the same time. And it's like we cannot frame it. We can't see it somehow, that we that that we're not atomized individuals.

00:33:44:06 - 00:33:55:11

Chloë

It's a false it's a false idea. And yet it penetrates all of the policy and our understanding of ourselves. But I'll stop being a political scientist.

00:33:55:11 - 00:34:16:12

Matilda

No, I find it all fascinating, honestly like, I just think that I was losing it that like, what does that mean? That I'm not disabled? You can see that I'm you know, gradually over the years I've become more and more dependent on my care team. And yet you are saying I am fine. You are telling me nothing has changed or you're trying to convince me that I've improved?

00:34:16:13 - 00:34:18:11

Isabelle

Yeah.

00:34:18:12 - 00:34:26:06

Matilda

The gas is strong in the gaslighting. The gas is so strong, it's so noxious. Yeah.

00:34:26:06 - 00:35:02:07

Isabelle

And, and I mean, as a historian, sorry, Chloë does the political science, I do the history and I think I think your comment about limited imagination is so... This might not go on the podcast, cause this is just me thinking thoughts, but like I think that's such a... kind of the heart of it is that people cannot conceive of living in another body of, you know, mixing these two boxes of the ideal labourer under our current capitalist system versus a non-normative body and how, you know, they don't mesh.

00:35:02:11 - 00:35:31:01

Isabelle

But there's also idea that, it's sort of like, it's always been like this, which is also not true. And I think I think that also helps limit the, you know, the potential things we can imagine the way we can imagine the world, because not all societies do it like this throughout history. And I keep going back to that example of your mom and the chores, but you know, in lots of pre-industrial societies or non-industrial societies, you know, people do have different tasks.

00:35:31:01 - 00:36:03:08

Isabelle

You do what you can, everybody contributes. And that's just how it goes, right? But I think, yeah, it's just those are just thoughts. But I think that the limited imagination is a really interesting way of putting it, especially when it's juxtaposed with the idea that disabled people, often because of the environmental and social barriers, are in a way like forced to create really rich imaginations.

00:36:03:08 - 00:36:16:07

Isabelle

And that's juxtaposed against not-currently-disabled people who are unable to imagine things that are just everyday life for disabled people, and it’s this sort of imagination gap in a way.

00:36:16:07 - 00:36:47:14

Matilda

Yeah, and we need, and that's kind of one of the reasons why I feel like we need, even if at the moment, right, because everything has to happen in stages and steps or whatever. As much as I love saying burn everything down, I'm like, we still have to build something in the interim, whilst we’re rebuilding whatever systems and services. But there's something about at least at the very least we need people who have our experiences having the same power as the non-disabled, not yet disabled people making those same decisions.

00:36:48:01 - 00:37:12:01

Matilda

They need to be on par with them and be given the same resources, be given the same opportunities to make decisions. Because unless that doesn't happen, we're caught up in this cycle where we're forever dictated to how we are meant to live, we’re forever, this kind of patern... yeah, this like paternalizing of that, disabled people are children that don't know what's good for them.

00:37:12:01 - 00:37:42:02

Matilda

They'll never know what's good for them. We must always make decisions on their behalf. And you only have to look at history to know that non-disabled people have not been... their decisions have been poor. And that's me, that me being kind. Like, those decisions have been poor. And that's kind of one of, it speaks to one of like my core values that like... I think I got into writing because it was just fun and freeing and being able to even at times process some traumas that were happening to me.

00:37:42:03 - 00:38:05:04

Matilda

And then as I got older and it became a profession, I've kind of stepped in this respect, stepped into this responsibility with the with the aims and goal that, you know, but specifically for disabled people and Black people and queer people, that the narratives you've been told about yourself can be rewritten. It doesn't matter if you're age nine or age ninety.

00:38:05:05 - 00:38:45:04

Matilda

Those narratives can be rewritten. You can pick up a pen, rewrite those narratives, or even better, tell a new one. And because for me, that's been vital in my survival. It is why I can be sat here with you today speaking about this, because the narratives I was told about myself or people like me, I've had to abandon and not just abandon, expel and burn to ashes and tell new ones that I can actually... new ones that grant me joy, new ones that enable me to reach out and feel supported.

00:38:45:04 - 00:38:57:14

Matilda

I'm part of a community and also provide support. Narratives that enabled me to want to see tomorrow and tomorrow and tomorrow, because if I held on to those narratives that I was told, I would not be sat here.

00:38:57:15 - 00:39:28:05

Chloë

You know, listening to Matilda, I love listening to her. And I have a lot of affinity with her. In part, I don't know, I just... some parts of our stories are similar, but I think some of our observations are similar. But what I really like about what she says is there's a call to action and a call to action not only by the broader community, but also by people within the disability community to become engaged and become politically active because it's only really through political engagement

00:39:28:05 - 00:39:47:14

Chloë

are we going to change some of these really hindering policies that prevent people from contributing to their society. And one of the things that's really clear is Matilda has a lot to contribute and she is contributing, despite all the barriers she's encountered. What do you think?

00:39:48:00 - 00:40:18:07

Isabelle

Yeah, I mean, particularly Matilda’s emphasis on the need for not just disabled people to consult and to advise, but to be policymakers and decision-making and having like the sort of the final say. Because often, you know, we have a lot of consultation, a lot of, you know, talking to people, but who actually gets to make the decision? And then the ways that the whole system has to change when you need to accommodate disabled people at that decision-making table, I think was really powerful.

00:40:18:09 - 00:40:51:15

Isabelle

I also really was struck by Matilda’s discussion of sort of an information gap and a sort of imagination gap where, you know, non-disabled people, there's a lot of things we think we know, but we actually don't. And it's hard for people to imagine living in another body and in a different way and you know, that our imagination of disability and what disability means and what it entails is really constrained by the narratives we were brought up with.

00:40:52:00 - 00:41:03:13

Isabelle

So going back to Matilda's argument that, you know, narratives and stories are so, so important because they help shape what is imaginable for us...

00:41:03:14 - 00:41:19:07

Chloë

Right, I mean, I think the quote that we have at the beginning, that opens up, that that we've chosen, is in part because it really connected with me, I think it's so true is that there's a lack of public and social imagination for someone who may need... may need a personal attendant carer to come in and help them get out of bed.

00:41:19:07 - 00:41:44:00

Chloë

But it doesn't mean that they can't contribute later in the day and make an income. And why are we missing out? That individual misses that if we don't recognize that, but more importantly, we as a community miss out on the talents of individuals who simply aren't just being seen to be there. And what this project has shown us is there are so many talented people out there really talented, flexible, adaptive, innovative individuals.

00:41:44:02 - 00:42:15:09

Chloë

And you know, the current policies silence them or, you know, they siphon them off to the side and don't allow them to participate. And that's why I really like what Matilda what Matilda is saying. And I'm hoping that that will... yeah, will transform, you know, us, you know, all of us in thinking about these things. And her stories themselves is, you know, she wants people to recognize that people disabilities are parents, they're siblings, they're they're probably bad people.

00:42:15:09 - 00:42:26:05

Chloë

And just the range of humanity. And right now they get they got pushed off to one sort of category and a wall gets put up. And really, we're trying to break down that wall.

00:42:26:06 - 00:42:42:06

Isabelle

Yeah. And how arts and entertainment and playwriting and movies and stories just generally can tell new stories and change beliefs and then change policies. And that's a really hopeful message. And as you said, a call to action.

00:42:42:07 - 00:43:07:06

Chloë

Yeah, yeah. Thank you for listening. We hope you've enjoyed this episode of Broadcastability. You can find us on the web at broadcastability.ca and theproudproject.ca. You can also find us on social media at The PROUD Project on LinkedIn, Facebook and YouTube, and we’re theproudprojectCA on Instagram.

00:43:07:08 - 00:43:33:05

Isabelle

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00:43:33:07 - 00:43:54:08

Isabelle

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