A Conversation with Matilda Feyisayo Ibini Part 1: Writing as a Career Accessible Transcript

Matilda

And it was then that's like connecting the dots, like, oh, so you don't just like write poetry and it gets published and we have to study it in school - it's a career. And that's when it finally like... Oh, this is interesting, this is really interesting.

Chloë

Welcome to Broadcastability, a podcast by, for, and about people with disabilities and about inclusive workplaces. It's part of the PROUD Project at the University of Toronto Scarborough. You can find out more about the PROUD Project on our website: www.theproudproject .ca

Isabelle

The PROUD Project is based at the University of Toronto, Scarborough, which is on the traditional ancestral territories of 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 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.

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.

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.

Chloë

Maybe we should, as an intro, just... I'll say this is that if you're hearing background noise, it’s because I'm using oxygen today, and it makes a bit of noise in the background, so hopefully it's temporary.

Isabelle

So this episode we're talking with Matilda Feyisayo Ibini, who is a playwright from London, and they're one of the few artists we've spoken to, both in the research interviews and, of course, on Broadcastability. So it's been really interesting hearing their experiences of their life and their education... Their interviews was actually so long and rich that we decided to divide this into two episodes.

Isabelle

So there's Matilda part one, and then next time will be Matilda Part two. In this episode, we're focusing on their life and their experiences, their career. And then in part two, we'll talk about their views of, you know, disability representation, employment, the sort of bigger picture things, though, of course, that that comes up in this part as well.

Chloë

So one of the things I find really poignant about when I listen to Matilda is A. she's so articulate and she's sitting at the center of one of the the world's financial and cultural centers, like where people do a lot of speak from, like there's a force to where she is... She's she's at a locus or a focus point, but she's also experienced all sorts of marginal identities, things that have affected her, the fact that she's a child of an immigrant, the child of a single mum who was a very forceful character, who expects a lot from her kids, that she's Black, that she's queer, that she's disabled, that she's a woman.

Chloë

So in a sense, even the quality of her voice is very assured, and it, and it comes out very clearly. But you're also aware of how much that voice has been derived from experiencing all those other those identities. But she's also really fortunate in that it's that she's at the center there. She's in London, which is a, you know, I hope helps magnified some of her voice and what she has to say.

Isabelle

As a historian, I'm really interested in Matilda's discussion of how family and cultural and religious attitudes shaped their upbringing and how, yeah, these intersecting identities, but also intersecting expectations and beliefs about what people should be able to do, what is it normal to be able to do, but also how these can be adapted and they can be restrictive or they can be empowering depending on how how we interpret things.

Isabelle

I just want to add that, yeah, again, with this like family expectations, one thing that really struck me was the fact that Matilda’s mom, as Matilda's disability changed over time and the things that they could do changed over time, their mom was still like, You're going to do chores of some kind. Like, you... We will find a way for you to do some sort of contribution to the household, which I think is a really excellent example of how, yes, disabled people do things differently and can't do certain things.

Isabelle

But there are still many different ways to contribute to community.

Chloë

You make amazing point. I think that's that's really... she was raised in an environment in which she was expected to be part of that community, regardless of how she felt physically and how she functioned physically, and that the resource of her mind was a very capable resource. So even if she couldn't move around that well, then she was expected to use her mind to help facilitate the family's functioning.

Chloë

And I yeah, I think that you make a really good point about that, and I think that gets carried forward into the rest of her life.

Matilda

Firstly, thank you for having me. My name is Matilda Feyisayo Ibini and I am a Nigerian-British writer based in London. I have a condition called Limb Girdle Muscular Dystrophy. I'm a full time wheelchair user. I'm supported by a team, a great team of carers and PAs that support me with my everyday living, everything from personal care to also supporting me in my work.

Matilda

I am a freelance playwright, screenwriter and aspiring filmmaker, but I'm getting there.

Matilda

I grew up in a very Nigerian home in East London. I have three other siblings, so an older sister, younger sister, younger brother. So I'm the second oldest. I’m the only person in my family with Limb Girdle. And yeah, that’s about a quick summary. Yeah.

Chloë

Well, that's that's great. One of the things I'm going to... I think, I hope people enjoy is that you're one of the few artists we'll talk to, people who work in the in the art and entertainment industry. And I think your perspective is incredibly valuable.

Matilda

Oh, thank you.

Chloë

You come from an immigrant family, you were born in the UK, but you come from an immigrant family, you're also of colour. And so I think there's... I'd love to know with that experience, that sort of cross-sectional identity of being someone, a woman, someone who's a child of of a parent who immigrated from from Nigeria, as well as being Black and disabled...

Chloë

Can you talk a little bit a bit about that?

Matilda

And I’d also add Queer too.

Chloë

Oh and queer as well!

Matilda

Yeah.

Isabelle

Easy question to get started with, you know.

Matilda

I'd say there are aspects of my childhood that were pleasant, but my childhood is also littered with a lot of trauma. I think growing up, not even just in the Nigerian household, but also a very Christian household, I no longer identify as Christian, I'm not practicing Christian, but I'd say a lot of the kind of early ableism and even some of the internalized ableism that I internalized growing up stemmed from a lot of kind of Christian values mixed in with Nigerian culture of what disability was or what it represented in terms of often negative connotations.

Matilda

In the sense of, you know, the Christian belief that we're all born in sin and that if you repent enough, you will eventually be healed. And then even in particularly, let's say, the Nigerian culture, having a child with a disability is often seen as the, you know, the punishment from maybe like it's the punishment of the parents or the parents are being punished, or your ancestors, one of your ancestors did something wrong and they've not atoned and therefore your your descendants are disabled or what have you, or that it's a bad omen or that it's an evil spirit and things like that.

Matilda

And a lot of that, as you can imagine as a child, was incredibly damaging to to to listen to and hear and be surrounded by on a daily basis. And if it wasn't for people changing their minds or being open to like understanding that disability is just a part of life, it's a part of it's another way of just existing.

Matilda

I think I probably wouldn't be in the career that I'm in and I wouldn't be doing what... I wouldn't be living the way that I'm living now, basically. And a ton of therapy to unpack all of that. And to be honest, I'm still... there, still so much. I'm still unpacking. But I'd say it also meant just have also having a different.

Matilda

There are other parts of Nigerian culture that also does embrace disability and that was really exciting to discover later on in life that actually the narratives I were I was taught or brought up to believe are not the only narratives out there. Yeah, it's a quick summary, but I would also add that.... Oh, sorry.

Chloë

No, go ahead, please.

Matilda

I'd also add that because I also had three non-disabled siblings, I often what I found difficult was not was not realizing I wasn't like them in a way that like I couldn't keep up with them. I couldn't like play in the same way that they did or what have you. And so I'd often measured myself to their abilities.

Matilda

And that would also kind of - can I swear? - make me feel shit like that. I couldn't keep up with my own siblings.

Chloë

Yeah. And especially when you're the second eldest when you're meant to, in a sense, be the paradigm they're meant to be following.

Matilda

And it's exactly, exactly having my younger siblings support me.

Isabelle

That's really interesting context to be growing up in, because we as, as you may remember, we’re really interested in sort of family of origin and childhood and how, you know, the way your early childhood context affects your expectations for future work and practicalities. So could you just maybe briefly walk us through what it was like? You mentioned a bit kind of growing up with your condition that wasn't really well understood and how that sort of impacted your early life trajectory?

Matilda

Yeah. So for a long time in the beginning, I'd say when the first symptoms, the first symptoms started presenting themselves because doctors couldn't, didn't have the technology back then and couldn't pinpoint what was wrong, I was often accused of faking it for attention. And I remember many, I think I wrote about it in one of my plays, many instances when if my mum wasn't present in the room and I was left with the doctors, I’d essentially just get a telling off that you need to stop doing this and you need to walk properly and move properly or you know, this isn't good.

Matilda

You don't want to be like this forever kind of thing. And so for a long time I started doubting myself, that, Is this real? That if maybe if I just worked hard enough or paid more attention when I was walking, then I would just walk the way that my siblings walk, or what have you. Or that if... I remember though, I'd have a complicated relationship with physiotherapy.

Matilda

And I remember doing doing it like religiously and my mum checking that I'm doing my exercises or making me do them in front of her, whatever, and then going to an appointment, and because there was no change or improvement, being accused of not doing them, that oh, we should have seen a change by now. We should have seen a difference if you've been doing them every day.

Matilda

And I had, but I wasn't believed. And so for a long time I yeah, I was constantly second guessing that is this real? Is this something of my own doing? And it wasn't until essentially until diagnosis, which was - the symptoms started aged five, and I wasn't diagnosed till age 13. So throughout those about a good eight years of just tests until they think they find something and essentially until I was believed, and that was after having a muscle biopsy where they were like, Oh yeah, her muscles don't work.

Matilda

There's something missing here.

Chloë

Well, it's, it's a.

Chloë

I mean, I had a similar experience, and so I totally relate. And I think one of the things that becomes apparent is you're not only carrying the burden of not functioning in the same manner, being excluded for that, but then you’re being, in a sense, psychiatrized, you are then you are then getting a secondary label of somehow you are not as trustworthy psychologically, and to have that as a youngster.

Chloë

When you're developing your sense of self, it is an extra like it's not only it's something to carry, but also it gets weaponised against you sort of developing normally.

Matilda

Absolutely. And I think one of my, back then at least, one of my coping strategies was to like literally throw myself into Christianity. So I would pray, I would fast, I would attend to special prayers, I would do everything possible that okay, if I can appease God, he could take this away tomorrow, I could wake up and jump out of bed.

Matilda

I think for a long while at that age, you know, before at least the ages of, what, 16? I truly believed I could just be cured like that tomorrow because Christianity plays... and not just maybe Christianity, but religion plays such a huge part of Nigerian culture, like spirituality generally. And so for me, I think I tried to like make sense of it that, okay, the doctors are saying that they can't find anything and that there's nothing wrong, then it is it is about my relationship with God and I need to fix that so he trusts me enough to heal me kind of thing.

Matilda

And then I think back and I'm laughing because I think that just because I didn't have anything else like there wasn’t any, I didn't have any relationships or connections to other disabled people. I didn't meet other disabled children. So I held on to whatever I could hold on to. And at that time it was Christianity.

Chloë

What makes me think about is we're interested in that, as you merge into young, your mid teens, and then your later teens, you're then started thinking of career. And if... one one of the things in our... we met previously in a previous interview, one of the things you talked about was how in a sense your family wasn't connected with a lot of the social services that you might have been connected with had you maybe been properly diagnosed.

Chloë

And I also suspect maybe if you had been a different family in a different place, you might have had more access. Yeah. So I'm sort of interested, if you could talk about how that impacted, you know, what were people saying you were going to do for your life? Were you... were they just sort of... was it a dark picture?

Chloë

What were they... what were your expectations given all that?

Matilda

Yeah, I mean, when I was younger, so I've always had a very vivid imagination. And for a long time I thought I was going to be an astronaut, at one point I thought I was going to be a doctor so I could just cure myself. And then I really got into baking for a little bit and I was like, Ooh, I could be a baker.

Matilda

I could open up my own shop one day. And so writing was never on the table. I never... though I always wrote stories just for myself, I didn't, I never connected that it was a career. And so for a long time in secondary school, I won't lie, a lot of teachers were like, I wasn't going to amount to anything.

Matilda

I had a teacher say that to my face and I didn't know what that meant at that age. But when I'm older, I realized that's not something... you should never tell a child, let alone another person. But my mom, who I would describe as a pusher parent, and I kind of am kind of grateful for that, though, when I was younger, I just often thought she was just pushing me away.

Matilda

But as a pusher parent, it meant she didn't expect anything less than from... than what my siblings were capable of. So like my older sister went to uni, so I was going to uni. I had no idea what I was going to study, but I knew that I'm going because my older sister went And then my older sister got a job and then there's just an expectation, yeah, you're going to get a job.

Matilda

So my mum was very much of the mindset, and I think it took a while, she wasn't like this from the beginning, but I think it took a while. Once we got on the diagnosis, she too had to grieve and realize that this isn't something that's going to go away tomorrow. And though to this day she'll still send me prayers and things like that, she is very much aware that we have to make the most of whatever mobility I have at any given time.

Matilda

And so she she adapted in a way that was really enabling. So that was the kind of talks of, yes, what are you going to do at uni? And like any Nigerian parent, they want doctors, they want lawyers, they want engineers. And at that time, I thought I was going to study a psychology degree, but instead I ended up changing it to creative writing and English literature behind her back.

Matilda

So I told her like a term in, Yeah, I'm not studying psychology. But yeah, but like she's always been a pusher parent and has just been like, okay, so I couldn't... when I physically couldn't hoover anymore - okay, I do dusting. When I couldn't do dusting anymore - I fold laundry. So I was always... she'd always find a way of me partaking, even if it's not to, even if it's not exactly like my siblings or to the full extent of something.

Matilda

She was like, there’s always a way. We can do this instead, you’ll do this instead. And so from home... So you can imagine I was getting two different, two different like voices. There’s a voice from school, saying like: you’re not going to, don't think about that, that's not for you, you're not going to go anywhere or go anywhere far. And then home

Matilda

is like: so have a think about what you would like to do, what you would like to study. Even when, yes, she was admittedly upset that I'd changed my degree without telling her, but when I finished the degree, she was like: So, how are you going to get a job? Have you been looking for jobs? Are you thinking, you know, what are you thinking about?

Matilda

What do you think you can do? And it was her and my older sister that encouraged me to... a job came up at a charity that I used to volunteer at from like age 16. And they both encouraged me to apply and I applied and I got the job. And though though the job as good as it was, it was a part time job.

Matilda

So it was flexible enough to work around my condition. It was also actually at the the UK charity of the muscular dystrophy. So they used to be called the Muscular Dystrophy Campaign. And I think they're called now Muscular Dystrophy UK. So I used to work in their campaigns team that was specifically aimed at young disabled people. So I got to do all this learning about how big inequality exists between non-disabled young people and disabled young people and all the campaigns that they did around trying to get better and more reliable and accessible public transport, trying to make city centers around like the shopping malls more accessible, trying to make university a more accessible experience.

Matilda

All of that kind of really compounded some of the like pushing that my mum did, that you are part of this world and you need to actively take up space and be a part of the world. But that didn't.

Chloë

I love the way you said that, but being a part of the world, because I think for many people, people don't see people with disabilities - or you don't like the term - disabled people, we're going to talk about that, but disabled people as being integral parts of the community, right?

Isabelle

Yeah, I have two thoughts. The thing about your mom finding a different chore for you to do every time. Like that's the one constant in childhood is you always going to have to do chores. But I think that's really interesting is like it's a great example of how, you know, disabled people are contributing to society... always are, there's always something that you can do.

Matilda

Yeah, even when I get to the point of like, okay, you're going to write the shopping list, you need to go around the kitchen and see what we're low on. And like that was always a job for me to do. I was never like allowed to just like, sit out and just be like: oh but my legs are tired, and, you know, its like: no, your siblings are doing their chores

Matilda

So here’s your chores.

Isabelle

Yeah. But I think that's that's a great way of sort of showing that, you know, everyone is contributing in different ways. And I also wondered, because you said you never like... you wanted to be like an astronaut and and everything, but you never really considered like writing, that you love to do, as something that could be a career.

Isabelle

I remember in the first interview you had a really funny story about Shakespeare, so I was wondering if you could tell us a bit about how you started to realize that this writing that you did for fun for yourself could actually become a career?

Matilda

Yes. So I used to write, now that we have a word for it, so I used to write a lot of Scooby Doo fan fiction. I just literally replaced the main characters with myself and my friends, and we'd go on all these adventures. And it wasn't until secondary school actually, when I think we did... we started doing poetry and not just reading poetry, but I'm getting assignments to write poetry where it just kind of opened up my imagination even more in terms of being able to talk about things without having to literally say them.

Matilda

I found that incredibly compelling that it almost felt like writing and poetry was like writing in code, that I could express these complex feelings or this pain or this frustration or what I was going through that I often, often couldn't verbally express, in poetry. And encouraged by my secondary school teacher, Mrs. Gallagher, she was like: keep going! I think, you know, you could do this as a career one day. And I was like: okay. I had no idea what that meant.

Matilda

And I remember, was it myself or someone else in class? I might have said that it was me, but it could have been someone else in class when we thought, everyone thought Shakespeare was alive. I was like, Why are we studying this? This is so old, we don’t understand what he’s saying. And it wasn't. And it wasn't until, like, for example, we read Romeo and Juliet, the play script in class and was analyzing it had no idea what this story was about.

Matilda

I was like, Someone love someone. Until we watch the Baz Luhrmann film. And I was like, Is that what the play is about? Oh my God, that is amazing. Like, it was just like, Oh, because the text just alone is very... can read really cold and also can feel like make you not feel smart enough to understand it.

Matilda

So it was until you could see the words in motion in a physical form that I was able to understand the story and, and yeah, and again, making that link of that Shakespeare was paid to write those. He didn't just write them because they were fun, or for himself. Well, he could have, but he was paid to. And I was like what,

Matilda

that's a career? And it's like... And when the same English teacher, when she was like, Yeah, think of all the books you've ever read. So Malorie Blackman's a huge Black British writer who predominately writes for young people and children and like people of my generation, would have most likely discovered her at school or in your local library.

Matilda

And it's like, Yeah, how do you think... Malorie Blackman’s a writer, she gets paid to do that. That's why she writes books. And it was then that I was like connecting the dots like, Oh, so you don't just like write poetry and it gets published and we have to study it in school. It's a career and that's when it finally like,

Matilda

Oh, this is interesting. This is really interesting. And I think it was when I was taken to... So we used to have... we used to go see a lot of pantomime, whether they came and did performances in school or we went to the theater and pantomime wasn't really my vibe like I got. It was very, you know, glittery and funny and campy, but it wasn't quite my tastes until we went to see a play at Soho Theater.

Matilda

And I must have been about 15 at the time. And this was probably the first play that maybe wasn't necessarily aimed at young people, but our drama teacher took us to go see it and I watched it and I was just... I watched the show, but I was also watching the audience because I was just in awe at everyone's reactions to the show.

Matilda

I was like, How is he doing this? How is this writer doing this? And again, being reminded that he was paid by the theater to write this and people bought tickets to come see the show. And I was like, Oh my God, I think this is what I want to be doing. I want people coming to see stories and I want to see them laugh and I want to see them gasp and I want to see them not be able to sit still in their seats whilst receiving this story.

Matilda

And the stories can be about anything, like this particular play that we saw was about race and identity and politics and football, and I was like, Whoa, it's about so many different things. But it was only like an hour and a half, and it was about this young man who'd come from, and I can't remember which African country, but he’d come from Africa to play football on a UK team and gets caught up in a scandal.

Matilda

And I was like, how he was able to talk about all these other things whilst telling this singular narrative. I was like, that really, that was the first stepping stone that I needed to know that stories are useful, stories are, stories are useful and they're needed, and they need storytellers to tell them.

Isabelle

That's such an eloquent way of telling... like you can tell that you're a writer because I wanna... I'm going to go to the theater. Like, I really want to go to the theater now. And that's such a such an excellent way of describing it. And it's such a cool moment when you were like, Wait, Shakespeare was paid? But yeah, it's not something... they don't really talk about the, you know, the economics of theater, but it's really important because, you know, people, people got to pay bills.

Isabelle

But that that's such an interesting way that you found out. So from... so that was in high school that this was happening, and so that sort of pushed you to do English literature?

Matilda

Exactly. So I did English literature in college, and college is just about two years before you start university. And so I also was doing English literature and psychology. So I still... I think there was still the belief that I was going to study psychology because that's what my mum wanted me to do. And you never want to disappoint your parents. So then... but I think when I was going through the course lists of all the courses that the university did, as well as the psychology, that's when I stumbled across creative writing and English literature and all the different like approaches to storytelling that you get to try.

Matilda

So you get to try like not just poetry, not just writing essays, but also writing short stories, writing graphic novels, writing for video games, writing for theater, writing for film and TV for for radio. And I was like, Oh my God, this is for me. But how am I gonna convince my mom that this is what I actually want to be doing.

Chloë

So as you’ve been talking, one of the things I realized, I mean, I don't know whether you've done this. I suspect you have. There are many times when you have an illness like ours, I mean, ours are different, but that you spend a lot of time by yourself and maybe in a bed or in... and there's people milling about, they're traveling, they're doing stuff.

Chloë

And yet you at some level are in a state in which you're not moving around much and maybe not seeing as many people. And actually, I wouldn't mind you talking about this, whether you've experienced it, but for me, what it did for me was in a sense drew me inward to have a more active thinking and maybe even fantasy life, a life in which, in order, in a sense, to stay sane, I knew that I had to be, sort of, be for myself, like find things and and technologies we have are great, like the fact that I, this was years ago, took up the Internet with the old modems and no one ever could get me because I was just always, like, exploring. But just can you tell me a little bit about how your disability might in fact be an asset for you? Or maybe, maybe it isn't an asset?

Yeah, no, absolutely. I’d almost say as a kind of positive byproduct of it was yeah, my imagination. That the reality is I've somehow found a way to monetize something that started off as a hobby, which was writing stories for myself, like those Scooby Doo fan fictions and even the poems other than the assignments. I wasn't sharing that with anyone.

Matilda

The me. I wasn't yet comfortable in a place where I wanted anyone to read those narratives. They were almost like a creative way of journaling without having to actually say what you feel and what's going on and what's upsetting you. So instead of like writing down an event, I tell a story instead. And absolutely because I... because gradually I became... I started to become very stationary that I couldn't keep up with my siblings.

Matilda

They were often, you know, going on school trips that often, sometimes even meant overnight stays, trips and things that I couldn't go on. Yeah, in order to console myself, I turned to stories, to reading. You know, I got really into comics. I'd spend summers in the library because I really couldn't go out and play with everyone because I often couldn't keep up.

Matilda

But my mum didn't like the idea of me just cooped up in my room. So she was like, Go to the library, then you can go, you know, there's endless books. You read something you can prepare for the following year of school. So yeah, absolutely. And my, my, my current counsellor believes that my incredibly wild imagination was probably forged when, because I was physically losing the ability to move,

Matilda

So my brain often moves very quickly in both good and not so good ways. But absolutely that my imagination essentially created as a child a refuge for myself in a world where I couldn't be understood or was constantly being accused of faking. I was able to create my own kind of imaginary sanctuaries where I could just be and go on my own adventures and have the friends that I didn't have necessarily in secondary school or didn't have in college or uni, because I think I forgot to mention I was like horrificly bullied throughout secondary school and yeah, and also college.

Matilda

So that was like from the ages of 11 to 18 and that had a detrimental effect on my mental health when from 18 onwards and one that I'm still kind of reckoning with today. But my imagination is both a huge blessing but can also be turned against me quite quickly because of kind of internalized ableism, internalized anti-Blackness, internalized homophobia, like all of that stuff.

Isabelle

I'm just going to hop in the narrative now, we’re... this is a non-linear structure we're going for... just because. Yeah, that that's really, really fascinating. But now I want to hop back to... so you you're... after uni after you did your degree, your your mom and sister convinced you to apply for a job with Muscular Dystrophy UK and what was what was that experience like?

Matilda

Yeah, so I only ended up staying a year there and I was the campaign's assistant working on all sorts of projects and campaigns with the hope of having real, not just real-world, but legislative change as well. And there was some real great progress that was made on some of those campaigns in terms of getting it into press, even kind of interviews at prime slots on on news channels about the inequality young disabled people were facing and still are facing in the UK.

Matilda

but what... the thing that I guess I wasn't warned about was that working at a charity that is also about your condition... So like the for every kind of success that they had then all of a sudden the government would announce a new scheme, a new proposal that they're looking at pushing into law or whatever that would undo the months of work or even years that years of work that preceded my tenure at that role that would just undo all that, all those campaigning, all that hard work.

Matilda

And it was it was also, I think, aggravating at the time, which I don't think I'd been I'd have been diagnosed. Yeah. Yes. No, I think I had been diagnosed with depression and anxiety by then. But it was also triggering a lot of those feelings working at that place. And it's nothing to do with the people that works there.

Matilda

It's just the the content of what we're working on. We're working on trying to make the world a better place for disabled people. And the government keeps saying fuck you or finding new ways to fuck us over. And I just yeah, mentally I couldn't keep up with that. It was just this kind of weird cycle that you get into of like hope and then dashed.

Matilda

It's dashed up again and then hope, then rebuilding that hope and then having it dashed again. And I was like, Maybe I don't need to know all of this is happening. In a way in order for me to be able to move on and hold onto my mental health, I don't think I should know like this much in terms of, for some conditions, I think mine included, that we’re nowhere near treatments. Like yes, we're calling up people and emailing people for donations but for conditions like mine, we're nowhere near treatments.

Matilda

What we're, what they're currently focusing on is shortening the diagnosis time. Let's bring that eight years down to like a year or two. You know, it's too long to be leaving people without knowing what they have. And I was like, Yeah, I don't really need to know this. I won't be, you know, I met other people that had other types of muscular dystrophy through that job, and all of us acknowledged that none of us will be alive by the time they find any kind of treatment.

Matilda

Like it won't be in our lifetime, we won't benefit from that. And so it kind of felt like, the job was like a constant reminder of that, and I just really didn't need that. I needed something that enabled me to just keep moving forward that actually let me get to the next age.

Chloë

To live the life that you have.

Matilda

Yeah.

Chloë

Right. I mean, there is always this focus on, oh, medicine will advance. And I have much the same feeling, which is, yeah, it could advance or it could not, but you need to live now.

Matilda

Yeah exactly. And so it was on the advice of one of the friends I'd met through the job. He was like,:What would you rather be doing? And I was like: Really and truly, writing. But I have no idea how you make money. Like I did an entire degree for three years. And the thing they forgot to mention was, Oh yeah, like this is you're not meant to be doing it for free.

Matilda

How do you actually make this a job? And he advised, look at like some of your favorite writers, like just have a read of their journeys if they're on Wikipedia or whatever. And I did, and I noticed a lot of them had done some kind of postgraduate degree in writing for performance. And just the initial Googling that I did about, Oh, okay, a degree... another.

Matilda

And also I didn't have the best time at uni. Not necessarily... my course was great and the friends, the lecturers that I had were brilliant. It was actually the uni itself and getting support I needed put in place was incredibly slow, impacted my mental health and actually that's what made me get that depression and anxiety diagnosis - going to university.

Matilda

So that should tell you all about the experience. But it wasn’t until...

Chloë

It shows you... Well, just as you’re talking, as you're talking, look, anybody who's confronted by some of the issues you faced, if you didn't have depression and anxiety, I think you wouldn't be human, at some level. It's interesting. We talk about ,we talk about people, you know, the whole things about terminology - people with disabilities, disabled people. And I actually I'm intrigued by the French concept of “personne en situation de handicap,” which is a person in a disabling context, which just sort of shows that there are things around you that actually make it worse.

Chloë

It's like you in yourself are fine, but it's how you interact with all these other things that actually can, you know, in a sense, create, because you’re human, your response to these these barriers, these difficulties, these - the bullying, whatever it is or the the rigidity of systems can create actually the issues rather than...

Matilda

Yeah. Right. That one of the things that when I got my first wheelchair - so I didn't get a wheelchair till I was 22 - and one of the things I remember being told by the, maybe the occupational therapist at the time, was like, you needed a wheelchair. What you would like 13, 14. Even if it was a part time one, I needed a wheelchair much sooner.

Matilda

And the consequence of not having a wheelchair much sooner is that now as an adult I have arthritis in my ankles, but it's so far progressed that someone my age shouldn't have such extreme progression of arthritis. But it's most likely because I would walking on my legs longer than I should have. That actually, had I had breaks of having, you know, if I was a part time wheelchair user as a teenager where there were days where I can walk and other days where I used a wheelchair, maybe my arthritis wouldn't be.

Matilda

So as progressed as it has now and it's like... and... but in order to do that, it would have meant not going to the school that I went to because I didn't go to a a a school that was accessible. There was a school with lots of stairs and I had to climb every single step. There was no other way of getting around.

Matilda

So it was a school that was incredibly like mainstream inaccessible and it was a Catholic school. So we had the extra layer of judgment because God and Jesus is everywhere. And it meant now I'm paying the price as an adult for support I didn't receive when I was younger that I should have gotten in terms of being able to look after the wear and tear in my joints.

Matilda

But everyone, I remember the advice that I was getting from everyone in terms of physios, occupational therapists, and doctors was keep walking, keep walking, keep walking, and you have to keep walking. The moment you stop, the moment you lose it, it's not going to come back. Keep walking, keep walking. And actually it should have been: walk sometimes rest other times, you know.

Isabelle

That reminds me of. Oh, sorry. Are you? Yeah, yeah, yeah. That was. Yeah. That reminds me of a term I encountered and I can't remember who it comes from, but the idea of “curative violence,” of the extra damage done to disabled bodies in attempts to cure it, to cure them where that by trying to, you know, cure you of something that is just not curable big big scare quotes that they actually end up doing more damage to your body and I just think that's such a messed up cycle.

Matilda

and mental health.

Isabelle

Yeah. Oh yeah. Yeah. Which is of course intimately connected with embodied experience. So that's a really interesting one. And was was it just because of your school that you didn't have a wheelchair or was there other barriers?

Matilda

Most schools in my area were not wheelchair accessible and I couldn't even tell you if they were today, is the thing as well.

Chloë

Right.

Matilda

Not much has probably changed. So most schools weren't accessible. And I think the one the one school that I was aware of that had a lot of young disabled people with maybe learning disabilities and things like that didn't necessarily cater to someone whose condition only affects them physically.

Matilda

So I would have also been in an environment that also kind of wasn't necessarily meeting my needs because they... there... there... what’s the word? at that, at least at that time it was mainly: we accept students with learning difficulties or differences.

Chloë

I mean, even if you'd had a wheelchair, like they could have planned your classes, especially in maybe secondary schools so that they were all on one level, or even if you had a wheelchair available on that level that, where a lot of classes were, that you could at least sit and use that.

Matilda

Exactly. So they tried something like that when I... so there was an upper school and a lower school, so in the lower school, worse access. Yeah, just not possible. In the upper school they tried putting my classes on one level, but the teachers whose classrooms we'd occupied would get upset that, you know, if you're having science, you can't have science on the English floor or you can't have this subject on this floor, like that's their classroom.

Matilda

We don't want to have to give up our classroom just because one student is disabled. So there was a lot of like politics around, like classrooms and like, no, we're not in that room this week. She doesn't want us to be in her room. We're actually on the third floor. And I'd be like, Oh, great.

Chloë

Yeah, no. I encountered much the same thing. And to be honest, I think people... it's good you say it because I think people forget how traumatic that can be. And yeah, and it's traumatic psychologically because you've you're hoping it's a simple solution, but in fact, people resist it because of their own actually mental proclivities. Maybe they're anxious and they don't feel comfortable.

Chloë

I mean, there are all sorts of things that have to be navigated. And if it's not openly talked about, then it's not well managed. But just so you know, I have terrible arthritis as a result of the same thing. And so I've had joint replacements. And so it's again, it's these are things that result.

Isabelle

I want to hop back to your master's because that seems like a very... I know we're kind of.... yeah, non-linear. Yeah. Yeah. No, but that seemed like a really sort of pivotal, pivotal moment. So how were you able to, like, choose your program, pay for it? If you want to talk about that, you don't have to.

Matilda

Yeah, absolutely. It was a huge, pivotal moment. And it's also what compelled me to leave the muscular dystrophy job. So it was not long after that friend that advised to look at other writers’ careers. Yeah, see how they got into into making it a profession. That's when I noticed a lot of them had done master's. So I searched up all the master's in London because I knew I wouldn't be able to go outside of London.

Matilda

I also did my undergraduate in London as well, so it felt not that dissimilar from school because I would go to university, then come home because I couldn't, I didn't have the support. My mum was still my, somewhat a carer at the time for me, so there was no way I could have lived in another city and not get the same support or I didn't know how that worked.

Matilda

There is, I only discovered after, like in my master's, or, no. I only discovered in working at the Muscular Dystrophy Charity that it was it would have been possible for me to study in another city and get a care package that the city or the university or the local authority that I was based in would have funded carers and PAs to support me whilst at uni.

Matilda

However, I didn't know that at the time, so I ended up going to university in London and just going going home at the end of the day. And so that was the same thing for when I did my master's. I did it in London because all my support is here. And by this time actually what was different was that I was... I had moved out.. so I’m, so I'm jumping all over the place.

Matilda

I had moved out of the family home. Well, not long after I'd graduated and just before I started the muscular dystrophy job, I had a very helpful physiotherapist who went above and beyond their role in showing me how to apply for housing, because she could see that my, the home, that the family home that I was living in, that I'd lived in most of my childhood wasn't meeting my needs and was also putting me in danger.

Matilda

And I wasn't able to have a wheelchair because of the house that we lived in. It was this old Victorian house. The walls are too weak to be able to put a stairlift in. So I had to be moved out and because I was over 18, I would have been like 21 at this time, the local authority said, Yeah, we can move you out, but just you, not your family.

Matilda

So I was also embarking on living on my own for the first time. So when I did my master's, it's almost like I got a slight uni experience because I was, though I was still living in London, I was now living on my own and studying. So I had left my, the muscular dystrophy job because I couldn't work and study, went back onto benefits

Matilda

The way I was able to even do the Master's is because I got a scholarship from BAFTA and Warner Brothers. Had I not gotten that scholarship, I would have not done a master's and I would still be at the muscular dystrophy job. If all those things hadn't fallen into place, I would have kept my job and, you know, maybe found another way to get into writing a different way.

Matilda

But it meant then I now lived on my own, had the wheelchair that I finally needed after all those years. So I was 22 when I got my wheelchair. I was 22 and I started the Master's and was now using my wheelchair at home. But I could also walk around my flat, and also using the wheelchair, more importantly, when I traveled to uni. And the university was wheelchair accessible and I did get the support I needed from like day one of uni.

Matilda

Yeah, so I was now at uni with... and using a wheelchair. So to help me get about I had a note taker in class that could also help me take notes and would either type them up and email them to me or just give me their written notes. I was also... because of the scholarship, it also came essentially the scholarship opened a lot of doors for me, so it gave me mentors who are writers and working in in the industry.

Matilda

And I had access to all these masterclasses with makers of... writers, filmmakers of different levels that I got introductions to. And it was through the scholarship that I got my first, essentially, yeah, my first proper paid opportunity through one of my mentors because of the scholarship. So that scholarship, yeah, it was incredibly pivotal and it's still running today.

Matilda

The BAFTA scholarship. So if anyone is ever interested and based in the UK, but I also think they do it in, there's BAFTA Scholarships in America and more recently BAFTA scholarships somewhere in Asia, because I remember there was, yeah, it's on the website that they've got lots of different... they're operating in not just the UK but to train people from low income backgrounds or who've not had the opportunity to study in a field related to, I think TV, film or games and they will pay your full tuition, which is amazing.

Matilda

And so that's kind of what enabled me to be able to, one, feel like I was being taken seriously, that this wasn't a hobby anymore. And two, that because I got my first job through the scholarship, through one of my mentors, it also led me to finding an agent, which is also what kickstarted more regular, frequent employment.

Matilda

So I've been writing now for just over a decade and being paid to write for like just over half that time. The first half was writing whilst either when I was doing my master's and so I wasn't able to get work during then because I, because I already had such limited energy, limited mobility. I can't do everything. I can't study part time and work part time.

Matilda

It's one or the other. So if I was studying, it meant I was living off benefits and benefits are pennies, and it just meant living a very... it's... I don't even know how you describe it. Like I think, because I grew up poor, like I used to joke with my siblings that like, oh it doesn’t matter if I never make any money from writing because it's not any different from our current existence.

Matilda

And so living off benefits, yes, was a struggle, but I had already had experience of having to live very a very not financially kind of comfortable life like I'd already lived so many years where we don't turn on the heating when it is freezing. We don't... you know, making sure lights are always switched off, making food stretch far longer than it than it should or whatever.

Matilda

Like we'd already grown up like that. So living off benefits and writing and not being paid, though not ideal and I wouldn't recommend it to anyone. I kind of made do until I started getting paid for it in a way. And it kind of lives, it kind of it's kind of weird, like thinking that in some way I was a kind of starving artist, but the starvation wasn't new.

Matilda

Like I had had a history of having to do that growing up anyway.

Matilda

If I'm being really frank, what got me through that was benefits, having a generous sister, an older sister who was working full time and things like that, who could lend me money to cover rent and things when I didn't have enough. And I know not everybody has that.

Matilda

And I'm very aware that that in itself is a kind of privilege. But like, yeah, for a long time it was just like benefits and my older sister lending me money.

Matilda

At times it almost felt like you had to make a choice of Do I work or not? Because if I work, I risk this very precarious safety net of benefits.

Matilda

But if I don't work, I'll never be able to save even for a holiday on benefits. Like which one do I... I had to kind of make a choice of which one am I going to do? And because I had the, again, precarious safety net of a generous sister, I thought, Fuck it, if everything blows up, I'll go back to benefits and know that actually I can't work then.

Matilda

It's not because I don't want to, but because the system won't let me. Or unless I get some big job that pays me an incredible amount of money that I'm able to sustain myself for five plus years or whatever I won't be able to take on work until the system changes or something changes. So there was that leap that I had to take when I informed them that I no longer needed benefits anymore and I can't... again...

Chloë

And it’s scary, it’s scary when you do that. Because I made the same decision.

Matilda

Yes. It’s frightening, absolutely frightening.

Chloë

It's terrifying like, are you sure? It takes so much to qualify.

Matilda

Cause I was like, if this fucks up, I'm screwed. Absolutely.

Chloë

And there's no guarantee that the bureaucracies you would have to navigate to get it all back, that they'll be, it'll be as... that you’ll get and that you’ll the supports you need. So it's terrifying. And in that sense, the systems are set up in a sense to enforce you to be unproductive, like to not take part.

Matilda

Exactly. It is far less stress if you just don't earn. And I was like, but that's just not possible. Like, I see my siblings earning, working, going on holidays because they're entitled to annual leave. All that stuff. Okay, I can't work in those structures. There is not a job, or at least for me at the time it didn't felt like, didn't feel like that was the type of work structures that I could work in.

Matilda

That wasn't a job that would be that flexible, that understanding of me not showing up one day or rocking up at 1 p.m. instead of the morning or whatever to be able to work and earn and thrive, not just survive and exist, but to actually thrive. And I wanted to thrive the same way my siblings did. And in a way like that’s... for a long time, in both unhelpful and maybe some useful ways,

Matilda

I often used to compare what my what my siblings have, do, or where they go that I should also be able to partake. We are the same, we are blood, at the end of the day. I should not have to be excluded from things they are doing. Okay. Admittedly, I can't do it exactly the way that they do, but there should be another way for me to partake and that's kind of like maybe a bit of my mum's pushiness that I’d internalized, that push aspect of like I have to keep up because whatever they're doing, I should be able to do. Whatever they can access,

Matilda

I should be able to access, Yes, it's not going to be identical to the way that they do it, but I should still have the same rights as they do. Am I not one of them? Am I a different sibling?

Isabelle

This reminds me of, going back to the chore thing, is that you're still doing the same thing in a different way, but you are all in community together, having access to the same things, I guess. Yeah. Yeah.

Matilda

And so sometimes that was helpful in also pushing myself and also pushing past some of that internalized ableism as to not write myself off. Because I think I did that a lot where I'd just be like: It’s cool, I’ll sit this one out. Yeah it’s cool, I won't go. Yeah it’s cool, I won't kick up a fuss. Yeah it’s cool. And actually it's not always cool.

Matilda

Sometimes I do have to kick up a fuss. Sometimes I do have to say this is unacceptable. Sometimes I do, and sometimes I don't have the energy to. But someone else will step in for me and and say, this is, this, this can't run.

Chloë

What I think about Matilda's is is just that force that she was brought up with to participate and to be a member of, her intimate family community. But then that drove her out into the community itself. And I think what we're what we've heard and what we'll hear in the next episode is how important stories are, about how she as a writer, it's important that her voice, whether she's even talking about disability or not, how that's an important voice to be there and that the the story she's telling even in these two episodes is also very important and one that we don't usually hear about, and I think can not only

Chloë

be useful people with disabilities, but people just people who are in the world, to understand how, when you're faced with different issues or different traits or different sort of contextual difficulties or arrangements, that there are ways for you to problem solve around those and, and go ahead.

Isabelle

Yeah. And, and Matilda's very clear about how her own life story intersected with different government programs, NGOs, organizations and how the wider, you know, political economic social context impacted their experience of disability and how what they think we need to be doing as a society to better include and support people with disabilities or what we as a society need to be doing to better include disabled people.

Chloë

Well, trust you as a historian to make the political science point. But you're absolutely right. I think her discussion does show how much she is influenced by whether there is a government program in existence or it isn't in existence, whether there's a granting agency. And whether that facilitates her making this leap into wanting to earn a salary. And she also talks, I think, quite clearly, as do many people we've talked to across the world, about how much programs for people with disabilities discourage them from going out and being productive and trying to draw a salary, that they’re punitive.

Chloë

So she's very articulate about, you're right, about how government intersects, intersects with her experience and her success or failure. Yeah.

Isabelle

So so tune in next time for part two of Matilda’s story as they talk about, yeah, their views on disability and society at large.

Chloë

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 @proudprojectca on Instagram.

Isabelle

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