

Georgia Bondy - Edit

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SPEAKERS

Miggy Barker, Cerys Bradley, Georgia Bondy

Cerys Bradley 00:01

Hello and welcome to It's Ableism, a new podcast about disability and ableism, a podcast in which we talk about the lighter side of ableism by getting, like, really into the heavy stuff.

Miggy Barker 00:11

Well normally, yes, but today, we're actually going to talk about something positive.

Cerys Bradley 00:14

Yes, yes and I'm very excited about it. My name is Cerys Bradley. I'm an autistic comedian and A Level maths teacher,

Miggy Barker 00:20

and my name is Miggy Barker. I am a poet, performer, and I'm a wheelchair user.

Cerys Bradley 00:27

In this episode, we're talking about disabled joy, the wonderful positivity of being disabled and being part of a disabled community,

Miggy Barker 00:34

as well as the expectations around joy, happiness and positivity as disabled people.

Cerys Bradley 00:39

Yeah, we also have to talk about ableism in the It's Ableism podcast, so we're gonna talk about ableism, about how and when disabled people get to be happy. We are joined for this chat by Georgia Bondy, a performer going by George Lou Bon, content creator and the founder of Well Adapt. Well Adapt supports chronically ill people to manage symptoms like pain and fatigue, while partnering with healthcare providers and policy makers to build better chronic illness care systems, which sounds very cool, but before we get into that, we have to do ableism of the week. This is where we share a thing

that has happened to us, which we think is ableist, and because I'm a very competitive person, one of us is going to win this conversation. So Georgia, welcome to the podcast. Thank you so much for agreeing to chat to us today. Can you please introduce yourself to the listeners through your ableism of the week? What has happened to you this week?

Georgia Bondy 01:30

Yes, I can. And thank you so much for having me. My ableism of the week... So I'm doing a part time PhD looking at disabled people's experiences of kink and BDSM, and I'm having a very non disability friendly experience with the institution I'm doing the PhD with, and it's basically been a scenario where they are like, yes, we do reasonable adjustments. Like, of course, we will fulfill all of your reasonable adjustments. We are inclusive, and we have inclusive plans. Yet, every time I ask for an adjustment that they don't understand, they just tell me it's not part of the methodology. It will be things like, can you tell me in advance what we will be discussing at this meeting so that I can adequately prepare, and their response will be, well, actually, this methodology means discussing on the fly how we do things, and so it's not possible to do that, and also it takes up far too much of your supervisor's time, which is just not fair. It ups her workload. And so I'm in this position where I'm constantly fighting for things that are, in my mind reasonable, reasonable adjustments, but in their mind constitute, I don't know that whole thing like it sounds inconvenient, we'd rather prefer to think isn't, this isn't a reasonable adjustment. So that's, that's my ableism of the week.

Cerys Bradley 03:00

Yeah, we do, we do reasonable adjustments, where reasonable is defined by us and what we feel like doing, that's what the reasonable - reasonable adjustment means. It means it doesn't put out any abled people. That's the definition of it.

Miggy Barker 03:13

I love the idea that it's it's just like, oh, well, that's just not how we do things. When it's like, yeah, that's and then now you learn and you change to accommodate the person you're saying you can accommodate. Yeah, oh, it's ridiculous. I actually have so many from this week. I have so many little ones from this week. However, last night, there was a post on Instagram that I read that made me want to scream, and I'm going to read it for you. And it was like, it's like a picture of post of a thing or whatever, but it says, "in a training session, a doctor said, "just because your patients are resilient doesn't mean they aren't suffering." The concept of coexistence struck me, resilience is often out of necessity, and doesn't mean someone is okay. #medtwitter" now, yes, this is, how is this new information? How is this like? Oh, interesting. That's that struck a chord with me. Just do people not understand what the word resilient means? and I shared it. and everyone who looked at it, who I know that is disabled, like messaged being like, Oh, this is awful. This is evil. So, like, I know it's not just my brain. This doesn't make sense. Why is this a thing that is being said like it's new information. I'm furious.

Cerys Bradley 03:59

I think it is very funny that it takes someone getting a medical degree to realize that other people like have to live through pain, that's that's a wild thing that you have to learn from a textbook, and not from your life or experience or the experience of the people that you, you surround yourself with.

Miggy Barker 05:01

Yeah, and it's like, the the word resilience, I think, has been, like, mutilated a little bit, because it gets users sort of like, oh, you're just so resilient. You've gone so, like, through so much, and you're still going, that's amazing. You're just so resilient. And it's like, yeah, I'm a fucking shell of a person. Hold me, you know? like resilience isn't I'm I'm great, and everything's fine and perfect, because then what are you working up against? It's like, not what that word means, annoying. anyway. That's my that's my ableism.

Cerys Bradley 05:35

It's two very strong contenders this week. Unfortunately, though, for you, Miggy, I am still really not over my time in academia and Georgia that is just too close to home. The supervisor not doing like. Don't ask your supervisor to supervise you. That's too much. That's too much work. Don't ask your supervisor like to do any prep for your meeting or to prepare you adequately for the academic like experience, because that's too much workload for your supervisor this week.

Georgia Bondy 06:11

Yay. Sure. This is a competition I wanted to win...

Miggy Barker 06:15

It's too late now!

Cerys Bradley 06:27

Being praised for being resilient, and then that kind of like masking what is actually happening, I think, is a reasonable kind of segue into the conversation that we're having today about disabled joy. And so we want to talk about disabled joy and all of its positivity, but also around the kind of like ableism of being able to be happy as as a disabled person. And I think there's quite, quite a lot of restrictions on that. So before we get into that conversation, Georgia, can you tell us a little bit about Well Adapt and that project, and where that came from? Because I think that's such an important, well, first of all, a really important project, but also it's going to be such a great kind of case study to talk about in this chat.

Georgia Bondy 07:18

Yeah. So Well Adapt really grew out of my own lived experience of trying to just, I guess, live life as a disabled person with lots of different chronic illnesses, and I found myself just ending up with, I suppose, crowdsourcing my own wellbeing. So it would be things like, well, mental health services really don't have any idea how to deal with somebody who has chronic pain, because there's this idea, I think, in therapeutic contexts, of like, and it will pass, and we're just, we're waiting for this thing, this horrible thing, to pass, and learning to manage it while it's here. But things like chronic pain, sometimes they only ever get worse. And so I found a lot of mental health professionals to suck at helping me build the skills I needed to manage life with things like chronic pain and fatigue. And I found just all over the shop, things like advice from doctors was like, oh, exercise will help you with your chronic fatigue, but with absolutely no guidance on well, how on earth do I exercise when when I exercise, it causes a massive flare in my chronic fatigue. So all of these, like little questions of just, how do I life with all of

these chronic illnesses? I would Google around. I'd find people on Insta, I'd find like people in the community to help, and it just felt so ridiculous that there wasn't a healthcare system that could answer these questions, that had professionals that were actually qualified or with lived experience to help me, not just throw some painkillers at me that didn't work particularly well anyway, but to actually help me build a life that felt livable and felt enjoyable in the context of my myriad health shenanigans. So when we were sort of in the middle of the pandemic, and I was working, I was working in education tech and doing STEM type things, because my background is chemistry and neuroscience, I decided to leave to try to build something that would share this knowledge in a more useful way, and that was Well Adapt, and I it started very differently to where it's ended up right now. Like it started up because I was working in education techs, I had a bit of a bias towards sort of that way of doing things. And so I originally thought, like, okay, so I'll get disabled people to, like, build courses around stuff they think is useful. And that didn't work very well. And over time, it's very much evolved into I guess a few different things. We still have those courses available, but a big bulk of the work has been very much campaigning, and I suppose advocacy in the health equity space, like equal access to proper health care for chronically ill and disabled people. And that means that right now, I'm working with the COVID inquiry with Disability Rights UK, to try to make sure disabled people's voices are being heard in the inquiry, which is really cool, but also really scary, because I don't feel qualified, but that's a whole other conversation. So the other sort of major project that I've been working on with, Well Adapt, is on disabled joy, which is, of course, the topic of today's discussion, and that really grew both out of Well Adapt, and my sort of background as an artist actually came out of a commission from a lovely organization called the Raze Collective to really explore the idea of disabled joy. But I'm not going to go too much into that, because I know that that is the topic of today's conversation, and I suppose it brings up the question, is it ableist? Is it ableist that we usually talk about disability from a this is bad and sad kind of perspective?

Cerys Bradley 11:17

Yes, yes, it is. It is ableist. Okay, we're done episode over...

Miggy Barker 11:22

So like, yeah, of course it is because I think as disabled people, we don't want to just be complaining about what we're dealing with all the time. But also, if we don't talk about it, no one hears it, and that's worse. And so then things like this happen, where we make podcasts where we end up talking about everything that's wrong with access and disability, and what we have to deal with because it doesn't exist, and people don't know about it, and people don't speak about it. But there are so many positives, and there's so much community in being disabled, and also like so many little joys in like, I don't know, just I'm being really vague, but like the good things that come out of being disabled, the things that you notice more, or like the tiny wins that you get when you're rehabbing or learning to trust your body and work with your body and not against it, or work with your mind and not against it and things like that that I think non disabled people don't get to experience in the same way, but not... we don't... I feel like we don't talk about it, both from a because it sounds too small of a win, or it sounds like not actually a positive thing to a lot of people, and things get misconstrued. And then there's also the as soon as we start talking about good things, people then don't trust us when we talk about the bad stuff, or, like, think, "oh, well, then you're fine. Why are you complaining all the other times?" And I think there's no balance there. That's my first thought on the matter.

Cerys Bradley 13:01

Just just the first one. I think that really speaks to Georgia, what you were saying about this idea that like treating disability like it's a temporary thing, and so there's no space like as soon as you start talking about positive things, then there's no space for "relapse", which I will use in quotation marks, quotation marks, or like, having bad days because you've had, like, a good day. And I think one of the things that people are most frightened about, about disability is the like, the permanence, the inconsistency, the the change, like it is, it is the fact that your body isn't behaving in the way or your mind isn't behaving in the way that is predictable, in the same way that is for everybody else. And so like when you say the good thing, then people think that that's your... this is the new who you are now, and you're kind of fixed, which has huge implications for getting money for things that you need, and medical support and like, goodwill from the people inside and everything. And so it can be, actually quite like a dangerous thing just to admit that you're having a good day or a positive outcome, or any of those kind of victories that you were talking about, Miggy.

Miggy Barker 14:21

yeah, I mean, it's just it's not binary like that. There are so many ways in which something can be good and something can be bad at the same time as well. And I think the complexity in that is something that disabled people understand, or like are beginning to understand, or working on understanding more. But like there is an awareness of that about how much there is that could be good and could be bad within a moment, a day, a week, whatever that I think is lost on other people. That is lost on non disabled people.

Georgia Bondy 14:58

I think, I think in some ways it's a really difficult thing, because I think it's a problem of two audiences, almost. When I'm talking about disabled joy, for the most part, I am talking to disabled people. Because whether I'm joyful or not, I feel it's pretty much none of the business of non disabled people. And it's, it's very much work and art that speaks to us, to us as as disabled people, about like finding joy when we're sort of raised in a world that thinks disability is possibly the least joyful thing that you can have, bar maybe death. And in some situations, people will say, I would prefer to be dead than disabled. So in some ways, just disability is seen as, like, the most negative thing. So when I talk about joy, I can't be bothered to convince those other people like it's not, it's not something I want to do most of the time. And so there is, there is, there is, as you say, there's this risk, particularly with benefits, that if you are seen to be happy in the slightest, that you are now a scam artist who is stealing from the government and from other people, because the only reason you're getting help from the government is because your life is sad, sad and miserable, and we feel sorry for you. But I think, I think there is resistance in talking about joy anyway. And I think if we let that be the guide for how we talk about our own lived experience, it almost self perpetuates the misery. Because when we think that the misery is the experience. It becomes the experience. But when we see people talking about joy, we start being able to find it, find it in little places, as you say, like those little things are so important, and so I, yeah, I it's, it's tricky. Like, I don't want to tell anybody, yes, you should, you know, publicize that you're doing lots and lots of happy things, because obviously we have this situation where disabled people are treated like, you know, possible scam artists at all moments of the day. But yeah, I think just as a as a group, rather than as individuals, we can't let that be the reason that we stop talking about joy, or that we don't try to start talking about joy, in some cases.

Cerys Bradley 17:31

I think the thing that you said about like there's two audiences, and the audience that you care about is other disabled people. Such a great point. I have just finished reading *Sensory Theater* by Tim Webb so he's the founder of Oily Cart who creates immersive theater pieces, particularly for children, and particularly for children with various like, complex and multiple disabilities. So works a lot with children who are deaf, blind, have like, specific sensory needs, and for people who like theater just doesn't cater for and it was such an uplifting book, because there's a big bit right at the beginning, when he was first developing his practice, where he was like very much at a crossroads. And the Crossroads was like, do you make existing theater marginally more accessible, or do you create theater which, like, only makes sense for this particular audience. So like, for someone who is kind of looking from the outside, you've got this really weird theater which is mostly based on on kinesthetic sense, and doesn't have a plot line and doesn't have all of the things that they tell you that you have to have when you go to your first like, how do you plot out a story kind of workshop. But what it has created is specific, unique experiences for people who have not been like forgotten, but like specifically abandoned because they're considered to be too difficult to make theater for and, and I think that was for me that was like such a disabled joy, because it is about, it's not just about, like happiness for disabled people, it is. It is an experience that you can only have if you are disabled. Like it's about how your disability gives you a specific perspective on the world that you can only access because of that. And when that is a good thing, like, that's just that is, I think it's like what you were saying about how disability is often seen as like the worst thing, like, people don't have the imagination to consider that if you have a disability, there are like ways of experience. Things that no one else can access, and that is wonderful and amazing. And everybody should read this book. It was it was great. Changed my life.

Georgia Bondy 20:08

You reminded me of in terms of, like, the way art can be specifically disabled and specifically in disabled joy. I had a horrible day a few years ago, I had multiple sclerosis, which means that occasionally my nervous system just gets rid of something that's probably useful for me. And I had a period of time where it just got rid of the vision in one of my eyes. So I started to go blind in that eye across a few days, which was a terrifying experience, of course, because with multiple sclerosis, you never know what's going to come back. It has come back, mostly. But at the time, I didn't know that, and I was in the Emergency Eye Center, and long story short, the... while there, I was sexually harassed by the guy who was doing the testing of my vision, and then he was also racist. It was just it was a bad day. It was a very bad day. And so I got home and I was painting to try and get the feelings out, and I just had this giant canvas that I hadn't used yet. And I was painting, I was painting, and it looked shit at the beginning, because I was upset, and it was mostly just get feelings out, rather than paint something that looked something that looks nice. But across the next few days, I was sort of completing it as a proper piece. And it was such a weird experience, because I had two sets of vision. I had this very, very low vision in one eye that was changing across the days, and I also had full vision in the other eye. And so I created this painting that I liked with both eyes like that was my goal for that next few days to like close one see like, ah, the painting looks this way and with this eye, and I like it like this, but actually I don't like it with the other eye, so I'm going to tweak it until I like it with both eyes. And while that experience came out of pain, which lots of disabled joy does start with pain, it created a piece of artwork that was very uniquely seated in my disability and in my joy of painting with both of

these eyes, I still have both of these eyes. Sounds like such weird phrase, but anyway, you just reminded me of that with the with the theater piece

Miggy Barker 22:26

That is gorgeous. I'm really sorry that happened. And it's one of those things that it's like, yeah, a lot of a lot of our joy, and a lot of, dare I say, resilience, like a lot of what we go through starts in a very bad place, and we find joy in that. We find ways around, like around and through and all of that, and through doing that, amazing things happen, and that's just a really cool thing to come out of here. I'm gonna paint feelings onto canvas. That's so cool. I love that I feel like, as you were saying that I was like, a really rogue thought that I had of just like, people will go to like, like, go sit in a field and take drugs to like, see the world in a different way, and not that it's the same at all, because it wasn't a choice and it wasn't nice, but like the idea that you had this different perception on stuff, and you chose to go, Well, I have these two different visions right now, I'm going to do something with that and have it be a nice thing for myself. Is like, yeah, really interesting to think about. And I think I feel like that's the thing that disabled people, in a very general way, do a lot. It's like, so this is a thing, how can I benefit from it? Nearly? Like, how can I make this worth it? And back to what you were saying before, because I will never get over it. And it's what Cerys said, the thing of like having two different audiences, and who do I actually want to be like the audience that I'm speaking to, being with, and all of that, that feeling, that joy, or any feeling that comes out of that is not for able bodied people, is not for non disabled people, that is not for them to consume and experience. Those feelings are for us, and whether that's for us as individuals or us as a community, and that wants to be shared in like a you are going through this thing. I have also gone through this thing. This is what I this is what I got to do. Maybe you have a similar story or thing that could happen as well, like that is, and I think that's where the joy comes from. For me is like being able to share, and that sharing. yeah, is not for non disabled people. And I think I just said it, but the idea of like consuming as well, I feel like if, if my if my audience, is disabled people, we are somewhat on a similar playing field. There's an understanding that even if it's not like they understand what I'm going through, specifically, we get there's something to be understood there, like we are, we see each other versus an audience. (And when I say audience, I mean like talking to someone in front of me, not like performing audience.) But yeah, if it's if it's someone who isn't disabled in any way, it's like they are, I am I am entertaining. I am a performer then, and they are consuming my content, of being disabled and of my story and like, it happens, you know, people will ask, like, what happened to me, or or whatever. And then it's like they get a story out of it, they get to say, like, oh, I met this disabled person. This is what happened, or whatever. Like, it's it's a tale for them, as opposed to, like, I don't know, like, part of an experience in their life.

Georgia Bondy 26:14

Yeah, because if I told that story to an abled person, to a non disabled person, there is a 95% chance the response would have been that's so terrible. You're so brave. I could never have done that. Oh, what an inspiration you are, which and as disabled people, that's not our response. It's just like, Oh, cool. And you take something from it, and you're like, at least when people talk to me about their disabled joy, I'm like, ticking over with like, how, okay, how can I get more joy in my life? And what can I take from this? Not just *strange noise, sort of angelic-esque that festichises the mythical inspirational disabled person*

Cerys Bradley 26:56

What I love is that you've made a thing that that was meaningful and beautiful to you from both eyes, as opposed to you've got two different kinds of vision. Like, there's a painting there which contrasts those different kinds of vision as a demonstration to non disabled people, like, what the difference in your vision is, whereas, actually what you did was, like, I'm going to make something which, like, speaks to both of those kinds of visions. And it's about bringing those things together. That's such a cool way of responding to that thing happening. It is not about education. It is about like a personal connection between you and the art like I want to do more of that.

Miggy Barker 27:34

You're blowing our minds, Georgia.

Cerys Bradley 27:38

Can you tell us a bit more about your disabled joy project?

Georgia Bondy 27:42

Yeah, so it's been like a... it's not it now can be described as one project, but it's been like a series of like, essentially, like little bits of funding that have allowed me to do, like, little pieces of work that now are kind of like becoming some kind of, hopefully wider project that I can continue. But the first one was just this little commission from the Raze Collective, just, I think I just literally pitched to them, like, I'm going to do something, probably multimedia, that looks at disabled joy. And in that piece of work, I spent some time just like literally recording myself rambling about what I thought disabled joy might mean to me. And then I used that to sort of create a piece of music that was about that meaning, and then that - I'm also a pole dancer - and then that turned into some pole about the same thing, and it became this sort of multimedia piece that just sat there, and I haven't really done anything with it, and I keep thinking like, oh, maybe I should put that somewhere, but it's not currently anywhere. And after that, I was very luckily selected as a finalist for something called the Sony Talent League, again, in and around disabled joy to try to develop the idea, and I didn't win, and they didn't give me any funding, but what they did give me was a bit of a platform to then go and get some other funding. And that other funding just gave me a half day to pay some wonderful disabled people to just come and tell me what they thought disabled joy was, because so far I just had this, like single perspective had very much grown out of so I'm queer and I'm also Black and so there are pretty big bits of the internet on queer joy, which I love, and on Black joy which I also love, but a very small comparative bit of the internet about disabled joy. And so I really wanted to hear more about, like, what other people thought. And so I had this half day of talks where people I just told them, like, just come in and tell me what you think it is. And that was really, really wonderful. The format was a terrible idea because it was a half day, and I was exhausted by the end of it. So that little half day was funded by the Collective Imagination Group, who do wonderful things. When I then eventually got the next bit of funding and this next bit of funding was from the Joseph Rowntree Foundation, and it, funnily, was supposed to be giving hope for the first 90 days of Government, for this, this Labour Government, which feels ironic, felt ironic at the time, but feels more ironic right now. And so we did a tour around the UK, going to different cities and talking to different disabled people in those cities about what disabled joy meant to them. And that was so cool. It was so so cool. I we managed to sort of choose, like people from very different spheres, so like performers versus athletes versus artists, like visual artists versus entrepreneurs. And it just, it showed me that the

definition of disabled joy is as broad as there are disabled people and everybody they they seem to and it, it is, I think, a lot like queer joy and Black joy, very rooted in struggle. And it's almost like a joy that comes from resistance, which in some ways, I feel like is the best kind of joy, because we are. We're resisting this idea that we should be miserable. We're resisting the pieces of our lives that could we could let drown us, right? They could drown us like I wanted to drown when I was losing vision in that that one eye was not a great moment for me, and I could have drowned in it. And I did let myself grieve, as I think we all need to grieve when we lose bits of bodily function. But I think, as in all pieces of life, there is joy to be found. And and I am 100% committed to go hunting for it whenever I can, like, that's the kind of life I want to live. And that's really been the, the seed of of this project. And I'm we had, like, these recordings of the the talks in each city, and it's supposed to be becoming vaguely podcast ish at some point, but like, run out of money, and so it's like, on the back burner, it's on pause, but as soon as I have some more money, I don't know where it's going, but I hope it's going somewhere.

Cerys Bradley 29:38

What you were saying there about, like, it's okay to grieve, and it's important to do that. What that is making me think, is that the way that you're describing disabled joy, like it is necessary for and is the thing that allows you to feel that grief like you can't, I think you can't just feel sad about being disabled, because it not just because, like, obviously that would suck, but also, like, if you just have that one emotion, then that kind of ceases to be an emotion. And so like having the joy enables you to sit in the other feelings, because it provides contrast to them. And so you have the disabled grief, which is a necessary part of the healing process, but only because you know that that feels different to the disabled joy.

Georgia Bondy 31:02

Yeah, I like that. Like that framing. Because I think, I think the thing about grief is that it, it requires movement of the way you're feeling right because there's a temptation, and I have certainly given into this temptation to numb, to numb what's going on, either emotionally or physically, right? Like to try to remove yourself from it, because it's hard to sit with, pain is hard to sit with, loss is is hard. But what grieving, I think, really means to me, is that you are letting yourself move through it, you're letting yourself feel all the feelings about it, and that means you can also have joy, but if you just numb, then you can't you, numbing unfortunately, at least unfortunately, to me, sometimes it feels that way is it goes across the board. It takes away all of your feelings, not just one of them. And it took me a really long time to realize that. And I've had a terrible relationship to numbing in both substances and just like actions, like constantly, like listening to an audio book so that I'm not really present in my own life. Yeah, and as I've recovered from that numbing, I've had greater access to joy, but yeah, as you say, like the grief, it has to happen to be able to access that.

Cerys Bradley 31:56

I think unfortunately, that is - just there's so much stuff, other things, other questions I want to ask, and other thoughts that I would love to hear, but I think that might have to be what we have time for. Okay, so we will be waiting very excitedly for the podcast, or equivalent, or like, whatever form that project is going to take, hearing about those conversations from from different cities. Do you have any other work that you want to tell us about, and where can people find your stuff if they want to see your performance or read about your research or anything.

Georgia Bondy 35:25

The thing I probably want to talk about the most is just part of one of the big pieces of work that I'm doing as part of Well Adapt with Disability Rights UK, so the COVID inquiry work, and the reason that I want to plug that is because we are constantly wanting more disabled people to come forward and share their experiences of the pandemic with us. This is a pretty unique period of time where the government is actually being forced, forced to engage with us about what they did wrong, what they fucked up, how many people were hurt, how many people died, how many disabled people were let down. And the more stories I have, the more I can bring to the inquiry, and the better able we'll be to campaign for changes in the healthcare system and in the government to prevent shit like this from happening again. So if you go to you can go to either the Well Adapt website so it's welladapt.com and then on the homepage, it has, like a link to send an email. Literally, you could send me a voice note if you just wanted to word vomit a horrible thing that happened to you during the pandemic. You can word vomit that at me, if you have anything that you want to share that you think the government should take into account, please, please, please tell me, because my my I see my job as just trying to convey what, what our community wants to convey to government. So yeah, go have a look at the website and let me know iff you have anything you want to tell me.