

AT Banter Podcast Episode 276 - Ableism Part 3

Mon, 3/7 3:17PM 1:03:07

SUMMARY KEYWORDS

ableism, disability, people, blind, person, sighted, shawn, world, cane, internalized, attitudes, drive, feel, ryan, thought, amy, kid, find, talking, blindness

SPEAKERS

Rob Mineault, Steve Barclay, Amy Amantea, Ryan Fleury, Shawn Marsolais

R

Rob Mineault 00:54

Hey and welcome to another episode of AT Banter.

S

Steve Barclay 00:59

Banter, banter.

R

Rob Mineault 01:01

Hey, this is the podcast, of course, where we talk with advocates and members of the disability community to educate and inspire better conversation about disability. Hey, my name is Rob Mineault. Oh, and joining me today. Mr. Ryan Fleury.

R

Ryan Fleury 01:18

Hey, I'm Ryan Fleury.

R

Rob Mineault 01:20

Hey, that's my gig. Also in the room. Mr. Steve Barclay.

S

Steve Barclay 01:26

Hey, I'm Mr. Steve Barclay.

R Rob Mineault 01:29

Okay, I don't like where this is going. And of course, we are missing somebody. We are missing the lovely Lis Malone. Who is off today. So is just the three dummies today.

S Steve Barclay 01:47

Dum Dum Dum.

R Rob Mineault 01:50

But I am very excited about tonight's episode. Why am I excited? You might ask me.

S Steve Barclay 01:56

Why are you excited?

R Rob Mineault 01:58

Thank you for playing along. I'm very excited, because today we are recording part three of our Ableism series. Yes, that's right, we are going to be talking all about Internalized Ableism, which I feel like a lot of people may not really know about or understand. I feel like it's a very nuanced sort of segment of ableism. So I'm really excited to see what the panel has to say. And speaking of our panel, Ryan, could you tell the lovely people at home, who's joining us?

R Ryan Fleury 02:42

We are welcoming back to the show, Shawn Marsolais from Blind Beginnings and the Limitless podcast. Hello, Shawn.

S Shawn Marsolais 02:49

Hey, I'm Shawn.

R Rob Mineault 02:57

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R Ryan Fleury 03:01

And also our expert on the panel welcoming back to the show, Amy Amantea. Hello, Amy.

A Amy Amantea 03:07

Hey, it's Amy Amantea.

R Rob Mineault 03:14

Very funny. Everybody's a real comedian. Alright, let's get things started. Who would like to tackle the task of defining what internalized ableism is?

A Amy Amantea 03:28

Would you like an actual definition Rob?

R Rob Mineault 03:30

Yeah, sure. Let's do it.

A Amy Amantea 03:32

Shall I read you the definition that I found for this particular episode?

R Rob Mineault 03:36

I would love it.

A Amy Amantea 03:40

internalized ableism is when a person with a disability discriminates against themselves, or other people with disabilities by holding the view that disability is something to be ashamed of, or something to hide, or by refusing accessibility or support a lot to unpack there.

R Rob Mineault 03:59

There's a lot to unpack there.

S Shawn Marsolais 04:02

You just described my teens 20s And halfway through my 30s.

A Amy Amantea 04:09

And I would submit that, that, even if we, like I don't know, was able to remove it entirely, we're always going to experience moments of it.

S Shawn Marsolais 04:17

Definitely. Right.

A Amy Amantea 04:18

Because you're always gonna do something. We're like, oh, you know, "if I could see better and do this" or whatever. And that's, I think, part of internalized ableism, how much pressure we put on ourselves to like, you know, for those of us who have acquired disabilities, who we were before, you know, the things we could do before that we can't do now and reframing your mindset.

R Ryan Fleury 04:38

I say that all the time. Yeah, coming from a sighted world to no sight. It's like, "Oh, I wish I could still see that" or "I wish I could still do that". Just part of my vocabulary.

R Rob Mineault 04:49

So yeah, and I feel like the the tricky part of this too, is that there does seem to be a lot of ways that this can manifest because you know, especially when you're talking about anything that's internalized, where, you know, your your own emotions, your own ways that you see the world are are influencing it. There's so many variables, that it just it can manifest in multiple different ways.

A Amy Amantea 05:16

If this happens, you know, this, this could happen internally. But I think part of the nuance of this is what we what we experience from the outside world. So what media tells you disability is, about what family tells you what disability is about, and then what you take on in terms of how that impacts your own self worth, which I think is an important statement. And so like, for example, my grandmother, my grandmother is 97. She's still kicking, love the bones of her. Mostly deaf, mostly blind, and it no longer is able to you and walk with her walker. So she takes every pretty much disability box that exists. But even from her, she says to me things like this, "gosh, you really could have been somebody, if you hadn't been blind, you could have been somebody" and then she said to me, once I did this made me laugh, and then made me cry. "You could have been the president." And I was like, Well, why don't we have a president, but to, I still could be, right? And so when you hear those kinds of things from people that are supposed to love you, and she does love me, but she comes from a world where, you know, having a disability is so damaging. And it just been so disparaging in her life that she projects that on my life. And then I have to sit with that and wonder about what I do with that. And that

can be a heart and like not everybody can negotiate that I've come to a place in my life where I can hear this outside like world's stimulus and compartmentalize it to some extent, but it does make me think every once in a while, like, goodness, do, I wish I could drive life would be so much easier if I didn't have to carry an umbrella and a cane, and a backpack full of crap. And all these things, I just would like to be able to drive my car again, please. And that's a moment of internalized ableism, where you start to hate yourself, or feel icky about something. And largely, it's because of the way that that the world interprets you.

S

Shawn Marsolais 07:13

I think it's growing well, for me growing up in a world that views disability, as you know, definitely less than or not as good. That's kind of where it starts. So if you experience ableism, all around you, it's not surprising that you're going to internalize it. So my family, you know, they, they didn't even want to tell me that I was going blind. So because it was so devastating to them. So of course, when I find out, I'm blind, I'm like, this is terrible, I should keep it a secret, I should hide it, I should try to fake being sighted, you know, try to fit in and be as quote unquote, normal as possible. So I think those strategies like one strategy is educating everybody about disability, right? That's definitely why I'm so passionate about trying to showcase the capabilities of people who are blind. Because if the rest of the world starts to see our capabilities, then maybe, you know, if we can convince everyone else, we can relax ourselves a little bit.

A

Amy Amantea 08:26

Breaking through that attitudinal barrier, right?

S

Shawn Marsolais 08:29

Mm hmm.

R

Ryan Fleury 08:29

Right. And I think for me, I come from it from a bit of a different angle, because when I lost my sight, you know, my family didn't really well, like I've mentioned before, on the show, I wasn't even living in the same city or province as my family. So when I lost my sight, the CNIB was really my go to first stop. And then they paired me up with another blind mentor who had a very similar situation, let's say in a car accident, yada, yada, yada. And so I had a positive influence, a positive role model to kind of model myself and my behaviors after. So I totally understand the whole societal impressions that are placed upon people with disabilities. And yet, you know, we still see this happening today, Rob sent over a link on Twitter, about a Victoria's Secret model with Downs Syndrome, and a bit of the tirades that are happening on Twitter. I think sometimes people need to be uncomfortable, in order to maybe wake up and see the person for who they are. And reach out and find opportunities. Find mentors find except positive examples to reinforce a person's attitudes.

A Amy Amantea 09:53

And you know, Ryan, just what you're saying like where did we as society learn that a Victoria's Secret model can't live with Downs Syndrome? Where did we learn that? Yeah. Because media told us that you had to be a size 00 Not even a 000 and a five foot 10 and whatever, right, to be able to fit that mold. And then when when somebody comes in, that isn't the convention, we question and we criticize. Why can't that person just be who they are? Right? I mean, we have a long way to go. And a part of this for me is, you know, it's a different thing. When you acquire a disability, because there was a, there was a grieving process, there was a before and after, and oftentimes I to, you know, fall into that trope of, well, this is what I did. You didn't know me when I could do these things, right? And I've had to refocus my learning, because I don't think that I do any service to anybody who acquires a disability or is born with a disability after me, by by framing things like, well, I could drive and I, you know, that's, you know, I, I am constantly, I guess what I'm saying is, I'm constantly working on reframing that in my own mind. So that I'm not projecting those things on anybody else. So that my, well, all I'm doing is empowering them. Like you said, Ryan, as a positive role model of somebody who can live a successful life with a disability. That's good for other folks in the disability community. It's also good for folks are TAB friends (temporarily able bodied). You could join this club at any time. So I think it's I think it's a good message that we need to continue. But it's interesting.

S Shawn Marsolais 11:41

It's, it's interesting that like, it seems to me, I mean, I have a degenerative eye condition. So I guess, I did lose vision, but I was never fully sighted to begin with. So I'm sort of like somewhere in the middle. But yeah, the fact that you can draw a line between person before and person after and make a choice about is one or was one better than the other? I feel like for me, I just always knew I wasn't good enough. Like I wasn't, I didn't live up to what society would say is good. So I think it comes across in everything. Like, when I was considering employment, it was I knew, and we talked about this at camp. Like all me and my blind, teenage friends talked about how we would have to be better, we'd have to have more education, more volunteer experience more than the average person in order to be treated equally, we believe that that's probably true. I feel in friendships, I need to like, give more than everyone else, because I can't do some of the things, like driving. So whether, you know, it's like that's internalized ableism, I do believe that I have to work harder, in order to be seen as equal. So in order to combat that, do I just not do more and see what happens? You know, is that gonna work?

A Amy Amantea 13:06

You're the one who has to pay for the meal in order to get a drive arrived to the restaurant?

S Shawn Marsolais 13:10

Yeah. Right.

A Amy Amantea 13:12

That's how you compensate

S

Shawn Marsolais 13:15

Or gush with thanks and appreciation for every little thing. When, you know, even like, the fact that somebody has to guide me to the washroom during the meal. I feel bad about that. Sometimes, like, I just feel like what am I doing in return? And even though in my mind, I'm thinking, it would be no big deal if it was reversed, and I had to guide somebody, like, I'm going there anyway, what's the big deal, but there's still that part of me that's like, cringing, because I have to ask for this additional thing.

R

Rob Mineault 13:46

What kind of a difference do you think it makes, depending on when somebody first encounters a ableism and then subsequently internalizes it? So I guess what I mean is that say somebody who sort of was born blind versus losing their sight later on in life, because we know that, you know, especially when you're dealing with with, you know, internalized things during the formative years, when you're a kid can impact you a lot harder than as an adult, you just have a different way of perceiving that. What are your guys's thoughts on that?

A

Amy Amantea 14:26

Shawn, you're the expert in that realm.

S

Shawn Marsolais 14:28

Yeah, I mean, that's, I hope that this generation, any any kids who are kind of connected with Blind Beginnings, you know, from really young would hear the 'No Limits' philosophy would meet, you know, competent, blind people, like have those and their parents as well would like shift those perceptions and those attitudes right away early on. It doesn't, it's not going to like negate all the things that are going to happen in the world but I definitely think when when you are born blind, initially, you don't know you're any different. It is from the people in your environment that you learn that you're less than in some way, or broken in some way, or whatever that messaging is. So if families don't see their kids as broken, and don't talk to them that way, and don't really let anyone else talk to them that way, then maybe that child isn't going to have the same level of internalized ableism. As I do, for example.

A

Amy Amantea 15:30

I was just on a webinar this morning with a group called Realize Canada, which is a new group that I have stumbled upon, and they did a webinar on it was called Blackness and Disability. So the intersection of being somebody who's black and somebody who has a disability. And so they were talking a lot about this intersection of internalized ableism and internalized racism. And so it was a reminder to me that while we talk about this in the disability context, there are other groups of diverse people that are experiencing very similar things, for lots of reasons,

right? Like this is this is not specific to our community. Which again, is you know, the constant reminder that, like, this is just, this is just one angle of the conversation. I don't know what it's like to be a racialized person, because I'm not a racialized person. But certainly listening to these folks share their experiences about, you know, I'll just quickly share with you one of these gentlemen identifies as living with HIV, also a double amputee, also a gay man, so all these different intersections, and he says, you know, when I go to the hospital, they say to me, how did you get HIV? And it's like none of your business how I got it, right about what they're asking what he said, what they're looking from me is, am I a drug user? Because that's a stigmatization that people in the black community face where it's not necessarily a stigmatization that all people with disabilities face. And so when you meet these intersections, there are layers of privilege that get stripped out of the conversation, when I go into a hospital, with all my medical stuff, and I say, I need a painkiller. They don't look at me like I'm drug seeking, probably because of my white privilege. And so it was a great reminder to me about privilege and these conversations that are so important to continue to be had.

R

Rob Mineault 17:26

What about this idea of learned helplessness? Because I feel like this is another way that it can sort of manifest with people.

S

Shawn Marsolais 17:35

Well, again, I think, probably, well, no, I was gonna say more when you're born blind, but maybe not. If the if the general attitude of society is that when you can't see or when you have a disability, you need a lot of help with most things, which I think is what most able bodied people do. I think temporarily able bodied people think, you know, if you have a disability obviously need a lot of help. So then, as a child, you get a lot of help. And people think, oh, I'll just do that for you. Because it's easier and quicker. And that tends to happen. And then you kind of grow up believing that you do need a lot of help. And to the point where maybe you don't even try things because you've learned now that you need help. And then you have people who are not independent, because they don't actually believe they're capable of being independent. So that's pretty severe, I would say internalized ableism this the belief that you now can't do things because you're blind.

A

Amy Amantea 18:43

And I've seen some extreme examples of that, Shawn, where where the learned helplessness turns into becomes malicious. And so this, this happened to me where somebody from the disability community phoned me at two in the morning, and I I, this is my own problem for not silencing my phone. But I have an 87 year old grandmother and you never know when that call is coming, right? So my phone goes off and I answer my phone, and this person asks me what kind of pizza they should order. I kid you not. So I kind of, you know, I don't know it's two in the morning, blah, blah, blah. I get off the conversation and about 45 minutes later I get another phone call from the same person. But pizzas arrived but I can't pay for it. Can you can you pay for it? What? And so the learned helplessness was like you know if I cry enough if I if I ask enough if I beg enough. You know this person also came out to dinner and said oh, I've had such a hard time I can't afford this and everybody at the table often to be offered to buy this

person dinner and they just about ordered everything on the menu and took advantage of, of that generosity. And so it's, it's a real example to me again, of, of, obviously this person was in a space where people were just doing stuff for them. And they found a way of like, almost making a career out of it and bit of a con artist. But if you make somebody feel sorry for you, that is linked to learn helplessness, and you can get a lot some people have discovered by doing that, and this person in particular, is now blocked from my phone list. This was really early in my, my work with people with disabilities, and I hadn't recognized that that really existed in a way. Because also, you know, there was this bit of almost a White Knight syndrome that was happening, I was like I was, I was this person's go to for anything they wanted to do. They wanted to learn how to make candles, they phoned me and asked me how to do it. I don't know, go to your nearest Michaels and ask them, you know, but but they just couldn't do anything for themselves. And, and I couldn't be there on demand go to person. So you got to set boundaries, too.

S

Shawn Marsolais 21:10

I see that expectation that people will just help in some of the kids I work with, too. And it's scary because you know, people who help them at school, for example, like you've got maybe that enthusiastic classmate who's a do gooder who wants to be helpful. So they always offer to guide the blind student from one class to another, or do you need me to whatever, get that for you or do that for you. And so the blind student now thinks they are their friend. But they're just like, this is great. Like, this person's helping me all the time. So they obviously really like me. And they're my friend. But it might just be that this is sort of like their way of doing some charity for somebody who they see a need. Makes me nervous. And the child doesn't see that, because they're so used to people helping them all the time that, of course, they're going to help me right, that's just the expectation that anybody that helps them is now their friend.

A

Amy Amantea 22:12

And then they turn into this adult that I was just talking about. And as you become an adult, you start to figure out how to manipulate because children, children learn how to manipulate but it's a bit different. But as an adult, you you can figure out how to manipulate somebody into giving you the things that you need. And it feels icky. And it felt to me because I did everything that I could in my early again, my early interactions with folks with disabilities to try and empower this person. So instead of for example, instead of finding the information on how to make candles, I said, google Michaels, and go talk to a staff member there and have them explain, you know, take a take a workshop do or whatever. So I tried to give them the piece of knowledge that they could take into their lives and expand where this person is today and how they interact with the world. I do not know because it was for my own personal health, that I had to set that boundary. And that also is not great for that individual. Because I do know that that individual has whatever language you want to use, but burned many bridges with their church because there was this was a pattern in their life. And that came from somewhere. They learned it somewhere.

R

Ryan Fleury 23:25

I guess I have to step up and say ...

A Amy Amantea 23:28

it was Ryan!

R Ryan Fleury 23:28

I'm guilty. I do I love pizza Saturdays.

A Amy Amantea 23:34

Ryan wants to make candles.

R Ryan Fleury 23:36

That's right. It's interesting when it comes to, you know, tech support or training because again, there it's with some people, you know, there could be a learned helplessness. And a lot of times, depending on what the problem is, it's a lot easier to just do it myself, that actually give them the resources or show them how to do it. So I can fall into that, right. It's just easier for me to do it for them,

S Shawn Marsolais 24:00

And I would definitely have learned helplessness with tech. And I just want to call people and have them fix my problems. So there's my learned helplessness.

A Amy Amantea 24:11

Learned helplessness, or is that the ultimate example of asking for help when you're out of your depth?

S Shawn Marsolais 24:16

Hmm. That's interesting.

A Amy Amantea 24:19

I'm thinking right, because you're not manipulating. And if somebody does it for you, you've probably learned something.

S Shawn Marsolais 24:27

Mm hmm.

A Amy Amantea 24:27

And it's not your go to tactic right?

S Shawn Marsolais 24:29

Yeah, I mean, I don't do the whole asking for help easily in other areas, but for some reason with technology, I'm okay with admitting that it's not my strength and asking for help and I but I'm not getting somebody to like save my files every day. Or it's it's sort of the one off like how do I do that command again, or what I know there's a thing for this, but I don't remember I'll just post asked a question on Facebook and get a quick answer instead of like looking it up or So I guess I'm using my resources, but ...

A Amy Amantea 25:03

And don't forget that, Shawn, whether you have a disability or not tech is a thing that many folks can't wrap their brain around. Yeah, you know what I mean? Like, if it was disability specific, then maybe I could see that as more of an internalized ableism thing, but this is like, world relatable.

R Ryan Fleury 25:19

Well, a lot of folks can't wrap their head around disabilities, right? "Oh, I can't imagine being blind. I can't imagine having to be in a wheelchair."

S Shawn Marsolais 25:27

I just feel like, this is some, I don't know, I have a confession, or it's an it's a part of internalized ableism, that I'm sort of embarrassed to admit, but I think I'm probably not alone, although I don't know that if Amy or Ryan feels this way. But I, when I see people who are blind, not doing things that I know, they could be doing. I have this like, "Oh, you're, you're letting down the team, you're, you're like, everyone's gonna think I can't do that thing", if this other blind person can't do that thing. Like I sort of have this. Come on everyone, let's be our best versions of ourselves for the common good of, you know, raising awareness. And I had to check myself about that, like, we're all different. We all have different strengths. Not everyone's going to, you know, want to do the things that I do, but I don't know that I think that's definitely my internalized ableism.

A Amy Amantea 26:27

I totally get that. Because sometimes I'm in spaces with folks. And I think, oh, goodness, is everybody looking at me and looking at this person? Or if that's the only person with a disability

everybody looking at me and looking at this person. Or is that's the only person with a disability or blind person that they've ever met? Does that change their view of the community?

S Shawn Marsolais 26:42

I mean, I do it to myself, too. So I don't, I don't really cook. And every time I say that, I have to add, it's not because I'm blind to lots of blind people cook. It's just I don't enjoy it. And I've never really invested the time in it. And yeah, so but I always have to add that, like, it's not because I'm blind.

A Amy Amantea 27:06

Doesn't mean you can't. And, uh, you know, and you had to survive, you would figure that out.

S Shawn Marsolais 27:14

And I did live by myself and survive. So yeah.

R Ryan Fleury 27:18

Well, I don't know, bagels ... Come on.

A Amy Amantea 27:22

A lot of cereal.

S Shawn Marsolais 27:30

I can scramble an egg. I can make Kraft dinner, you know.

R Ryan Fleury 27:34

It's interesting, though, like, because Shawn, I look at you a lot of times I'd listen to Limitless and you know, you're a Paralympian, you have this attitude that I'm going to show the world that I can be truly limitless. And there are other examples out there in the disability community doing that. So let's just talk about myself for a second. Because I'm an introvert, because I'm lazy is am I internalizing my ableism? Or am I jealous because you're out in the community, you're out and about you're you've gone to England, you've gone to the Paralympics, is there a fine line between being jealous of someone or just internalizing that?

S Shawn Marsolais 28:19

Well, interesting, you bring that up because this has been kind of in the last two years

Well, interesting, you bring that up, because I've realized, kind of in the last two years, probably since COVID, that my over functioning is completely around anxiety that I have around this internalized ableism. So this belief that I'm not good enough, is what motivates me to push myself so much as a strategy like as in response to feeling like I'm not good enough. So I'm going to show you I am going to be better than the average person in order to be seen equally. So I don't know how healthy it is, I feel like you can, you know, you can either become depressed and, and sort of that learned helplessness or you can become anxious and over function. And that's been my strategy. So I don't know if it's something to be jealous of, because I gotta tell you, it's exhausting. Sometimes I just like to be introverted and lie on the couch and do nothing, but I would have so much guilt about that. Because then it's like yelling in my head like you're a lazy blind person.

A

Amy Amantea 29:27

I think maybe it's about the internal narratives that we tell ourselves. So yeah, I'm jealous that Shawn is a Paralympian. It's not something that's going to happen in my lifetime for me, but I don't sit around and say, I don't tell myself that I'm not good enough to be a Paralympian. This is a choice that I'm making to not put my effort into. You know, being a professional rower at my age. I have other things that spark joy. So for me, I think it's it's it's really about analyzing the things that I want, as opposed to the things that I think that I should have. Because the world tells me I should have them or the things that I think that I can do. That doesn't mean that I don't come across things and wish that I could do this easier or faster, or more efficient. But it does mean that I set up my world in a way where where I can maximize my effectiveness and my efficiency. So that when I want to be lazy, I can because I know that the minute I go back to my computer to work on something, it's my computer in my space, the lighting I need and the temperature I need and all of the all of the pieces that make me thrive in that environment. So so I can so I can enjoy myself some Netflix when I go to bed at night, right? Let's like It's like this. I think that's that's part of the work life balance in general. And I and I've come to a place in my life where as much internalized ableism as I haven't probably for me, it's more about we've talked about this before the disability hierarchy, which is trying to not look at other people with disabilities in that way.

R

Ryan Fleury 31:09

Well even take take disability out of the equation, you know, like like, I've got family members who are able bodied, who are musician to have golden platinum records on their walls. And you know, I've been jealous or been wanting to be like them all my life, or a part of that family even though I'm a cousin, I'm not their son. Right? So I've I've struggled with that for decades. And am I jealous of my cousin? Damn right I am. I just don't know how to get past that. So it's not even really disability related, it can be that I'm striving to be alright. I'd love to be like somebody else like an able bodied person.

A

Amy Amantea 31:53

I'm curious Ryan, do you think if you were an able bodied person that it would make you a better singer? Like, what? Like, what are the reasons why you don't have a platinum album on your wall?

R

Ryan Fleury 32:03

Cuz I'm lazy.

A

Amy Amantea 32:05

Okay, but that's not a -

R

Ryan Fleury 32:09

Well, yeah, I guess I'm not driven. I'm not driven. Maybe lazy is not the right word. I'm not driven. If I was driven, if I had the desire, and really started reaching out to people in the industry saying, look, here's a song, blah, blah, blah, here's a video blah, blah, blah, you know, how do I get in front of people, then I could probably be at a better level than I am. And I struggle with that, because part of me wants to be there. And the other part of me is like, hell, no, I don't want to be there.

S

Shawn Marsolais 32:45

You know, he said, I just really want to be an able bodied person. And I don't ever feel that way. I don't feel like I wish I could see, I never wish I could see, I just want people to see me. I want people to see past my blindness. And so that's just really interesting to me, because I and I don't know, well, I guess me if you don't feel that either. It's not about like, acquired versus congenital blindness. But yeah, I don't, I don't want to be able to see, I just want people to stop seeing only me as a blind person, like, see the whole picture.

R

Ryan Fleury 33:24

Yeah, right.

A

Amy Amantea 33:26

And that's a different journey for everybody. Right? Again, it's an oversimplification to say that it's easy to come to that realization. But you know, again, we've had this conversation in these spaces before where it's like, you know, the Almighty comes down and says, "Would you like to see you again?", and it wouldn't be my choice.

R

Ryan Fleury 33:44

You know, I'm a better person now as a blind person than I was as a sighted person. I was a jerk. I was an ass, I was a bad person when I had sight. My blindness humbled me and gave me purpose gave me direction in my life. So if I could get my sight back, there's parts of having

sight back, I would love to have -- I'd love to be able to drive again. I'd like to be able to look at a guitar tab and be able to figure out how to play a song a lot easier than I can now. But I don't want to be the person I was when I had sight.

S

Shawn Marsolais 34:14

So when you say I want to be able to see, it's to be able to do specific things.

R

Ryan Fleury 34:20

Yes

S

Shawn Marsolais 34:20

That you used to be able to do, or just to do things you do things a little easier.

R

Ryan Fleury 34:24

Yeah.

S

Shawn Marsolais 34:25

I mean, sometimes I wish I could read any book, because I loved reading as kid and you know, Audible is pretty good. And the library's pretty good. But there are books I came across one recently that was recommended, and I can't find it anywhere. It's not in a format that I can read. So I definitely have those moments of like frustration at sure availability of things

R

Ryan Fleury 34:50

Maybe that's what it is. Maybe it's a frustration right because like I said, I I don't want to be the person I was when I had sight.

A

Amy Amantea 34:56

Listen, if I if I was still a sighted person, I have the tip of my finger because I cut it off on a mandolin, not the instruments, but the thing that you cut potatoes with.

R

Ryan Fleury 35:15

And never having, you know, if I had never lost my sight, I would have never become a member of the community, I would never have gotten a job at Aroga and spent, you know, 22 years with Steve or whatever it's been.

S

Steve Barclay 35:26

You say that like it's a good thing.

R

Ryan Fleury 35:33

But, you know, I, there's definitely times where I'll get off a support call on and and I know that I've made a person's day. I never would have been in that situation if I still had my sight. So there's no way there's no way I'd go back. Blindness has made me a better person and is has made me able to make others lives better in certain ways.

A

Amy Amantea 35:57

One of the things I think about when it comes to my sight loss, I look at it for me personally, and it's not going to be the same for everybody is, it may be inconvenient, but it's not terminal. I still have a life to live, I still have things I want to do. And I'm going to do them whichever way I can figure out how to do them. And sometimes I just have to be a little creative. I don't know if anybody saw my one of my most recent Facebook posts, but I was reminded of a memory as Facebook likes to do a being in Palm Springs a couple of years ago with a good friend of mine. And we wanted to go on the go karts. So we went and of course, you have to sign a waiver couldn't read the waiver, you know, walked up with my white cane, they said no. Next day her and I went back and I said just like stand arm to arm with me walk beside me. And I won't use my white cane and we'll show up there was a different person, you know, handing out the waiver and, and, you know, it's so I faked my blindness, which is probably internalized ableism. But I did that to get on a freakin go kart. And then I was able to drift behind her. Now in all transparency, I would not have done this if there were other people on the track. We went first thing in the morning was like 8am. Nobody was there. And I followed her all the way around the track. Never saw the do that put up, you know, two fingers for two laps or one finger for one lap. I just followed her around. And then when we got out of the go kart, they pulled my cane out of my bag to the shock of the like security guards. But I figured out a way to do it. And I felt really proud of myself for doing that. And then I felt a little icky that I had, like, manipulated some folks. But the truth is, is that I was able to do it all along. It's just that the process needed some accommodation. So it wasn't that I couldn't drive the go kart. It was the attitudinal barrier that other folks thought I couldn't do that and didn't give me the chance to experiment. Right? It's a it's a rubber track, right? It's like, you're not going to hit anything but the other car. And if you're the only two cars in the space, you got all the room you need. So I he's just I want to, like Sean says, I want the world to see me as somebody who's capable or bending perceptions, or I don't know, whatever that language is. And that helps me internally feel way better about myself. Which I think in the long run is is good. It soothes my soul.

S

Shawn Marsolais 38:28

Yeah, I'm thinking about the public's perception. You know, I get most people who've listened to me know, I'm pretty frustrated when people grabbed me in the world. And I think because what happens in that moment is I think they think that I'm helpless. Like they see the white

cane and they they make an assumption that I'm helpless and I need help. And because I've worked my ass off to show how capable I am for anyone who knows me. It's kind of this almost like how dare you not know I'm Shawn Marsolais?! Do you know what I've done? And of course, they don't know because they're strangers. But that makes me want to like kind of grab my arm away abruptly and say I'm fine, thank you.

A Amy Amantea 39:11

It's, you know, like, how dare you?

S Shawn Marsolais 39:14

Yeah, so

A Amy Amantea 39:16

When you're when you're using your cane to, I don't know, either echolocate or find landmarks and it's like, this happens to me at the sky train all the time. We get in these like little nooks. And there's no way out of the little nook, right? But it's like, oh, once I get in there and I tap oh, that's the garbage can. Okay, I know. I have to go like this many steps to the left and, and somebody they're thinking, Oh, they're stuck in this corner, I better go rescue them. And you're like, get away. Yeah, no, I don't know where I am because you pulled me out of my corner.

S Shawn Marsolais 39:47

Totally. Yeah, yes.

R Rob Mineault 39:50

I mean, I but I've also heard stories you know, of, of things going the other way the opposite direction where people actually say use a mobility cane when they don't necessarily need to, to just quote prove -

S Shawn Marsolais 40:03

I think more, I think you mean more like if you're partially sighted. And you can navigate without a cane, but nobody understands that. So like when I was in that situation if I went into the grocery store and asked for assistance to find my groceries, because I could only see like looking through a toilet paper roll. So it's really hard to like, scan the shelves and find what you need. But if you don't have a white cane, people, you know, people are just like, what's your problem? Or you ask a bus driver, what bus is this? And they're like, What are you blind? And you're like, yeah I am!

A Amy Amantea 40:35

yeah, exactly. Because it is true that you can go into any local place and buy a white cane without being a card carrying member. Yeah, so there is there is actually somebody that I know who I go, who refers to themselves as visually impaired, because they're sensitive to light. And then they get to their car, and they drive away. What and that irks the bones of me. And she, she believes if she uses the term visually impaired, it's like, well, I'm not calling myself blind. I just have a light sensitivity, but she'll go to concerts with a cane. She'll she'll navigate the world with a cane.

S Shawn Marsolais 41:22

I thought that was illegal.

S Steve Barclay 41:26

Light sensitivity can be a legitimate concern. Like you know, a place like a concert where they've got you know, strobing lights and flashing and stuff like that, that could that could completely mess with their functional vision.

A Amy Amantea 41:42

Yeah but it does not mean that they have the right to have a cane and, you know, get priority seating and like, because this person is taking advantage of whatever few perks we might get, you know, pre boarding on an airplane.

S Shawn Marsolais 41:56

It's kind of like somebody using a disabled parking pass when they don't need one, I don't know, just so they can get the better parking spot, it kind of feels like that.

A Amy Amantea 42:05

It's, there's some ick to it.

R Ryan Fleury 42:08

There's only an ick to it ... Because I have one, even though I don't drive, there's only an ick to it if you pull into a parking spot and the person you get out and you're walking with your wife or whatever, to the doctor's office or grocery store. and then you see somebody else park, you know, a little ways down from you and they haul their wheelchair to the car.

A

Amy Amantea 42:28

I was talking about it because I also have a an accessible parking permit. And it's not because of my blindness because actually that doesn't qualify. If you actually know the rules of the pass, it doesn't qualify. Qualifying for that is if you can walk 200 meters or less. And because I have diabetic neuropathy, I can't walk that far.

R

Ryan Fleury 42:50

All I had to do is fill out paperwork.

A

Amy Amantea 42:52

I know your doctor can sign any paperwork they want, right? That's that's the thing.

S

Shawn Marsolais 42:57

Okay, so this is my thing. And it's happening right now in this moment. Like, it drives me crazy that a lot of people have said to me, Oh, can you get a disabled parking pass? And like, yeah, I probably can. But I'm not going to ever because I can walk.

A

Amy Amantea 43:13

Yeah, so just so you know, I actually had my accessible parking pass before I was a blind person. I had it in my car when I was driving because of diabetic neuropathy and I couldn't walk long distance two entrances or back and forth.

S

Shawn Marsolais 43:26

I'm really happy to hear that that's the criteria actually. That it's not just a stamp you're blind you get one that it's supposed to be because it because that's ableism right there. There's this assumption that if you're blind, you can't walk more than 200 meters. Like why not? Our feet aren't blind? Like maybe we don't know which way to go.

R

Ryan Fleury 43:46

But then why do we get pre boarding?

S

Shawn Marsolais 43:50

I don't think we do need to.

R Ryan Fleury 43:54

So we need to get rid of all the perks.

S Shawn Marsolais 43:56

No, no, no, no, no, I like I like the two for one at the movies.

R Ryan Fleury 43:59

Do you need a free transit pass?

A Amy Amantea 44:01

Because I can't drive. Yeah, so and because not all the stops are accessible.

S Shawn Marsolais 44:06

Okay. I feel like if I go to the theater, I am still missing part of the experience. So I should have a discount there. If I go to Disneyland, I am missing a lot of the experience so I should have you know description and and I mean I don't know why don't don't get to Disneyland, though. No, you don't but you don't have to wait in line. As you know you get you get the exit pass kind of thing which honestly, I can wait in line but I'm not gonna fight that. That was an amazing perk. And Disneyland's overwhelming.

A Amy Amantea 44:40

And I take the pre boarding and it's really only because I don't want to fight with all the people that are trying to get in the plane. I usually do even though I don't necessarily need it.

R Ryan Fleury 44:52

Oh, absolutely. I'll have the option. And I'm playing devil's advocate because I'll take it every time.

S Shawn Marsolais 44:56

Yeah, I It depends, but I usually will and But I don't like that they force me to sit there till everyone gets off the plane, right?

A Amy Amantea 45:05

So sometimes happens to me

R

Ryan Fleury 45:06

What are you talking about?

S

Shawn Marsolais 45:10

If you're getting assistance, they will tell you to stay in your seat until everyone leaves and then you can get off the plane. So if I don't want to do that, then I'll go without the pre boarding so that I can leave like everyone else.

A

Amy Amantea 45:23

You know, they've changed that whole thing now with the airlines to the one person one fare program.

S

Shawn Marsolais 45:33

Okay, I haven't flown for ages.

A

Amy Amantea 45:35

No, no, I Well, you know, just as a tangent, I had to go to Calgary to see my 97 year old grandmother, just over over the New Years. And, and I tried to book because you know, if you if you need a companion, want a companion you can buy a ticket and get the second ticket free with WestJet. Yeah. And I phoned up and they said, Oh, just so you know, our policy has changed. You need to go fill out all the paperwork again, because it's expired. And I was like, I've been on this program for 10 years. Are you telling me that I no longer have a disability. But they were they were, I guess, technically speaking, giving them out like candy. And because of the pandemic, we're losing money. So they changed that system. So there was a time where you could have that. But if you actually booked without using that program, you know, you can't have one and not the other. Yeah, you couldn't go by yourself and go by yourself. Because that means you can go by yourself all the time. Yes. Right. Yes. And so it got to be tricky. So now I'm not going to renew it, because I need to be able to have the ability to fly on my own. Yeah. And sometimes I don't declare to them until I am in the airports, right. And so then I asked somebody, if I'm by myself to maybe escort me to the gate, but I don't do it when I booked my ticket, then it's not on my file, right? Then you can get away with that. I don't need whatever. Because if you can get yourself off the plane, Shawn, all you got to do is wait at the you know, at the top of the gangway for somebody there and just say can I have an escort to baggage or whatever.

S

Shawn Marsolais 47:08

I will follow people all the way to baggage. People are just that's the thing. If you wait till

everyone leaves, there's no one to follow. You have to go with the people.

A Amy Amantea 47:20

Yeah, all sorts of ways of screwing up now navigating our world. Hmm. But then can you can you identify your luggage?

S Shawn Marsolais 47:31

I literally would touch every bag as it came around. And but that doesn't take very long for someone to say, oh, did you want some help? What color is your bag? Yeah. And as long as you know what color your bag then they can help you.

A Amy Amantea 47:46

But yeah, I bought the brightest orange bag I could possibly find.

S Shawn Marsolais 47:50

That's smart.

A Amy Amantea 47:50

And so when when it gets close enough to me with my partial sight, I can make out the orange. And then it's, I can pull it off myself. But everybody around me wants to do that for me. And I really am like, just don't stand in my way, so I don't hit you. Yeah, I just need the swing radius, please. But it's the asking. It's it's the you know, can I assist you with this, as opposed to let me do it for you.

S Shawn Marsolais 48:13

Mm hmm. Right.

A Amy Amantea 48:14

I think that there's a difference there.

R Rob Mineault 48:22

So it seems to me like this is the the other really hard part about internalized ableism. And I've been listening to you guys talk and, and I've even caught all of you sort of almost almost unsure of whether one of your thoughts or feelings was actually internalized ableism. So it

unsure of whether one of your thoughts or feelings was actually internalized ableism. So it seems to me that it this can be really hard for people to sort of unpack, because these can be attitudes that have been baked in since childhood, or a lot of people might have attitudes that they don't even realize is internalized ableism. How do we sort of deal with that?

 S Shawn Marsolais 49:07

Well, yeah, for a long time, I just thought it was like, I knew that I was embarrassed to be blind, or, or that I had shame around it. But I didn't know the word, internalized ableism. I didn't know I just thought it was my my own insecurity. And I didn't really understand that, where it came from. And I think as I've learned to figure that all out, like of course you have internalized ableism. Of course, you're embarrassed to be blind because the whole world thinks it's better to be sighted. So if you know that, then of course, you're going to have feelings around it. So I actually feel better about myself and those feelings. With that understanding. Like it's not actually my fault. I'm not a bad person, because I'm embarrassed and I'm not actually embarrassed to be blind. Like, as I guess blanket statements like I, I'm proud of who I am. But that doesn't mean that I don't have those moments when I don't whether I bring as much to the team as someone cited. So it's still an insecurity. It's underneath everything.

 A Amy Amantea 50:14

But I don't think as as a human race, we ever get away from that. Whatever it is from you, for you personally, right? And I think, Shawn, what you've what you've hit on, if it's the big takeaway is understanding what that means to you. So you can better maybe better better be at peace with some of your thoughts, when you understand why you're having those thoughts. And again, that's like, it's like a check in. Yeah, okay. I'm experiencing this. I know what this is. Okay, I can move on. Right? Because I think it's when we stop doing those things, because we don't have the tools to recognize the why or the how, or the where it came from, or why we feel like this, that can do the most damage.

 S Shawn Marsolais 51:02

Possibly, yeah.

 R Rob Mineault 51:04

Very well put. And yeah, and I think I really do feel like, you're absolutely right, Amy, that some of this is just the human condition. Because you're absolutely right, whether or not you're, you know, temporary able bodied, or if you have a disability. Everybody has those, those thoughts. We all battled those, I guess my thought is that sometimes that must be really difficult to sort of untether those feelings from something that is specifically internalized ableism.

 S Shawn Marsolais 51:37

It's kind of like trying to separate blindness from who you are. It's, it's all kind of just, it's all lumped together. I think a lot of my insecurities are related to my blindness. If I was sighted,

I'm sure there'd be something else I'd be insecure about. But it is the biggest, most glaring thing that people are going to notice about me right off the bat, the fact that I'm really competitive, and that can be annoying, they're not going to know right away till they get to know me, right. Like, there's other things that will show up later. But I think people are going to make judgments based on the white cane. And, and so that's, that's the first thing. That's the biggest thing.

R

Rob Mineault 52:22

And so let me pose this to you guys. So how do you see this playing out? Like, what's the solution to internalized ableism? Do you feel like a really large shift in sort of society's attitudes would solve it? Or do you think that it would still sort of exist even if we managed to do that?

A

Amy Amantea 52:43

How do you how do you answer that question, Rob? Because like, what if I ask people of color? You know, what's the solution to racism? Does it ever really disappear as the question or as generations change? Does it just manifest in a different way?

S

Shawn Marsolais 52:59

I sure hope that more education, I mean, you know, I think I think that things have evolved, like, when I was a kid, my parents said they never saw people with disabilities walking on the street, or going to school with them or, you know, in a workplace. And now, I think there's more of an expectation that if you're growing up, as somebody who's blind, you can work you can, you know, you're gonna be walking on the street at some point. Like, at least people are more used to seeing us around, which is an improvement, I think the expectation that we will be part of society, I mean, that's a low bar, but at least there is that and that didn't used to exist. So hopefully, with more, you know, as you start to see characters on TV, that are blind, just sort of not not as the hero or the helpless victim, but just as a person in society, then I think society starts to expect to see that maybe somebody that works at their bank is blind or somebody who, you know, works in their kids school is blind or whatever. So I think it will get better, I hope.

R

Ryan Fleury 54:12

And I think, Shawn, you know, because you work with youth and families, you've probably seen attitudes change, you know, when they first come to you. They have no idea what their child may be capable of. Right? They have no idea of what's, what's available to them. And in your dealings with them and the youth, the teens, whoever, you see those perception shifts, you see their eyes open up and the sky becomes the limit.

S

Shawn Marsolais 54:43

Yeah, it's pretty awesome. To kind of watch that shift happen. It doesn't always happen. There are cases I have worked with a few parents who just couldn't couldn't see past it. So like, but a

are some I have worked with a few parents who just couldn't, couldn't see past it. Sadly, but a lot to do. And then I think even if even the most accepting parents, at some point the child is going still going to have some feelings, you know, it's not. It's not like, oh, just it's all on the parents, I think they're still living in a world that, unfortunately does, you know, still like, we want to strive for everyone to be sighted. And when that's not possible, then you know, you're going to be up against that, but, but yes, I do. I do see the shift and it's very rewarding to see that.

R

Ryan Fleury 55:37

Yeah. And so I think it goes back to you know, what, I think Amy was saying, it's that, that human behavior, right, it's that ingrained human nature in us as kids on the playground, you know, if there's a blind child and a sighted child, the blind child might, may I start having those feelings, right? Oh, I wish I could see. So I could run up the slide and go down, like my sighted friends. Right? There's, there's all of that. And that's just part of, you know, has been part of the human nature of human behavior.

S

Shawn Marsolais 56:09

I don't think kids think "I wish I could see", I think they think "I wish I could run over there and go down the slide". And then maybe somebody says, "Hey, little kid, you want to run with me? I'm going to the slide". Like, I think that's the Yeah, I don't know if it's that because if you've never seen I don't think you wish to see I think you just want to be part of things wanted

R

Ryan Fleury 56:36

Interesting, interesting conversation to have some time with, with other family or, you know, because I've no idea, like I said, approach this from somebody who was sighted. So yeah, it'd be interesting to know, does a child born blind wish they could see, and I'm sure that's different between everybody.

S

Shawn Marsolais 56:52

But like, most are just curious about what all the fuss is about. I had a weird situation yesterday, I was at my son's Cubs. And we were at a barbecue for the Cubs and Beavers and, and there's a kid in my son's cub troop that uses a wheelchair. And our, our friend was our neighbor friend was there. And she was saying to us how she's just so happy that her boys are part of such an inclusive group. And that's all she said. But I like the the takeaway for me was because there's a kid in a wheelchair, it's an inclusive group. And it just, it was one of those moments where I was feeling cringy because I'm thinking just because he's here doesn't mean that this has been working for him or that he's enjoying himself or that things are inclusive, like you're making a lot of assumptions just because he's allowed to be a Cub. This is an inclusive group. Like that's a pretty low bar. I mean, maybe it is hopefully it is really inclusive. I don't know. But yeah, it's just like, I want to be more than just allowed to be there actually want to be seen as like an equal and be able to do all the things that everyone engages with.

A Amy Amantea 58:13

Yeah, yeah. I think that's very well put. Kind of sad, huh? But that's still the attitude, right?
Yeah.

R Rob Mineault 58:25

Well, we can't have that, we can't end the show on a downer.

R Ryan Fleury 58:31

Well, we're gonna have a part four. So wait till part four, we'll wrap it up with a party of some sort.

R Rob Mineault 58:35

Like, it's like Empire Strikes Back. Don't worry, people, everybody, Ewoks are coming. Once again, we've done it again. We've had a spectacular episode, all about ableism. And it's been very interesting. And I don't think we've solved the problem of internalized ableism. But you know what, maybe some people hearing this help bring it into the public sphere and you know, we can do something about it.

A Amy Amantea 59:16

Just keep talking about it.

R Rob Mineault 59:17

Just keep talking about it. And that is something that we can do here at AT Banter. And we do it ad nauseum. Thanks for disagreeing with me, everybody.

A Amy Amantea 59:32

That's like the whole "I have a face for radio" comment.

R Rob Mineault 59:40

All right. All right. Well, does anybody have any final parting thoughts?

A Amy Amantea 59:44

What are we talking about in episode four Rob?

R Rob Mineault 59:46

That's a really good question. Actually, I was going to ask

R Ryan Fleury 59:49

I think Amy and I talked a little bit about that. I think we're going to talk about the disability hierarchy and there was something related to that.

A Amy Amantea 59:59

Yeah. Stay tuned, that'll be another rip roaring, interesting discussion.

R Ryan Fleury 1:00:03

Yeah, we're just gonna find the date that works for everybody.

A Amy Amantea 1:00:06

Connect with each other, you starting to see the language and ableism and internalized ableism and performative allyship. And all of these things thread through each other.

S Shawn Marsolais 1:00:17

I don't know if I know what the hierarchy is, but I hope I'm at the top.

A Amy Amantea 1:00:24

You'll know what when you hear it, Shawn, you'll be like, oh, there's a name for that.

R Ryan Fleury 1:00:29

Oh, that's interesting.

R Rob Mineault 1:00:32

I'm intrigued. I know nothing about this. I'm like, there's gonna be some learning for me. I love it. Well listen, Amy and Shawn, we want to thank you once again, for participating in this roundtable. Shawn, where can people find the Limitless podcast and any information about

Blind Beginnings?

S

Shawn Marsolais 1:00:53

www.blindbeginnings.ca and www.blindbeginnings.ca/limitless. Or you can find the podcast on all the places that you listen to your podcast.

R

Rob Mineault 1:01:05

Awesome. And Amy, how about you? Where can people find you?

A

Amy Amantea 1:01:10

Oh, gosh, that's a very large question. Rob. I also have a podcast. It's called Accessing Art with Amy. It's an AMI original podcast. So you can find that on any podcast platform. You can find me on Facebook where we have lots of if anybody's still using Facebook these days at Amy Amantea, and it's spelt like a man drinking tea. Ah, man tea. So there you go, easy peasy friends.

R

Rob Mineault 1:01:38

Awesome. Okay. Hey, Ryan.

R

Ryan Fleury 1:01:40

Rob.

R

Rob Mineault 1:01:42

Where can people find us?

R

Ryan Fleury 1:01:44

They can find us at www.atbanter.com

R

Rob Mineault 1:01:47

Hey, they can also drop us an email if they so desire at cowbell@atbanter.com

S

Steve Barclay 1:01:56

And if they're so inclined, they could also look us up on social media. We are out there on the Twitter sphere and the Facebook sphere. Or is that a meta sphere now?

 Rob Mineault 1:02:15

That will do it for us this week. Thanks, everybody, for listening in. Thanks, of course to Shawn and Amy and we will see everybody next week.