

AT Banter PODCAST Episode 242 - Al Etmanski

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SPEAKERS

Rob Mineault, Steve Barclay, Al Etmanski, Ryan Fleury

-
-  Rob Mineault 00:45
Hey, and welcome to another episode of AT Banter,
 -  Ryan Fleury 00:50
Banter, banter.
 -  Rob Mineault 00:53
Hey, my name is Rob Mineault Oh, and joining me today ... drumroll please. Mr. Ryan Fleury.
 -  Ryan Fleury 01:00
Hello again.
 -  Rob Mineault 01:02
I'm trying to spice things up a little bit. Mr. Steve Barclay.

S Steve Barclay 01:06
I was never here.

R Ryan Fleury 01:09
He sounds like droopy dog.

S Steve Barclay 01:14
All right, he was never here.

R Ryan Fleury 01:18
You know, one of these days, we could turn on our video and record it and people could actually look and see who it is.

R Rob Mineault 01:24
Yeah, I guess .. I don't know what the appeal would be

R Ryan Fleury 01:29
Three balding guys. At least you're wearing pants.

R Rob Mineault 01:38
Well, you assume. It's hot out today, man.

R Ryan Fleury 01:43
I know the last couple of days. It's been like 29 degrees outside Celsius for our American friends.

R Rob Mineault 01:48
Yeah, it's not pants weather at all.

R Ryan Fleury 01:50

No. But I'll tell you what the guitar dungeon is probably. Oh, I don't know. 10 degrees in here. It's nice and cool down here.



Rob Mineault 02:01

Oh, man. This is a perfect time of year for you down there. And especially now that you got rid of the ants. Yep. How's it going?



Ryan Fleury 02:13

It's going pretty good. It's going pretty good. Our last, I think was pub chat we did last Thursday night. One of the regulars in there was mentioning a liqueur made in Nanaimo. And it's in Nanaimo bar flavored liqueur. So on the weekend, Linda and I went to the liquor store, and I didn't find the one made in Nanaimo, but I found one called 40 Creek, and it tastes just like a Nanaimo bar. And is it ever good!



Rob Mineault 02:46

What do you what do you mix it with?



Ryan Fleury 02:48

You don't you just pour it in a glass and you drink it. It's just like you're it's it's it tastes like the Nanaimo bars. It's the chocolaty and coconutty



Rob Mineault 02:56

Wow.



Ryan Fleury 02:56

Oh, it's smooth. It's not super sweet, but it's sweet enough to give you that flavor. It's really nice.



Rob Mineault 03:04

Interesting.



Ryan Fleury 03:05

Yeah, downside to it is my mini fridge is down here and the guitar dungeon where my office is so it'd be really easy at lunchtime to go over and take a little snooze.



Rob Mineault 03:15

Well, yeah, you know, liquers are a weird thing. Like I don't know how I feel about liquers because on the one hand, I feel like they don't really get you hammered because they're not strong enough alcohol. And so I don't know, I guess I don't understand alcohol that doesn't -



Ryan Fleury 03:30

But you got to find one that really tastes good too. Like we've we've tried some blueberries and cranberry like yours and lots of different types of stuff. But this is this would be so good. Either attitude, like your coffee, or to like some vanilla ice cream.



Rob Mineault 03:45

Damn.



Ryan Fleury 03:46

So good. You got to find it. Try it.



Rob Mineault 03:48

All right. All right. You sold me this. Okay, I listened to you about Tarantula, and you were damn right about that. At least this is your getting me addicted to something that I can actually buy in this province.



Ryan Fleury 04:02

Well, let me ask you what's new with you over there?



Rob Mineault 04:05

Are you throwing me for a loop? I'm not used to that. I'm the one that

R Ryan Fleury 04:10
Nobody knows what's going on in Rob's world.

R Rob Mineault 04:13
Yeah, you know what, I've had my head buried. It's been very, it's a very busy time. Over at Blind Beginnings. We're doing some some infrastructure work. So there's a lot of admin stuff. We're bringing in this new this new database system. And it's, that's that's been a lot of work. And we're also prepping for our big annual general meeting later this month. And so there's a lot of work around that. So yeah, I've been I've been very busy. So I'm going to be I'm looking forward to two weeks from now when things will sort of go back to normal.

R Ryan Fleury 04:51
Well in to check out what's going on over at blind beginnings. Where can people check that out?

R Rob Mineault 04:58
They wonder welcome To go to www.blindbeginnings.ca

R Ryan Fleury 05:04
Excellent. There's lots of events going on there non stop over there.

R Rob Mineault 05:08
Well, that's right. You know, we got the the limitless podcast that is going strong and they were pretty excited because next week, we will be recording our one year anniversary show.

R Ryan Fleury 05:19
Well just give them a cowbell for that.

R Rob Mineault 05:23
They've been working hard all year. Hard to believe it's been a year. I know. Yeah, it really is easy. Yeah. It'll be 52 episodes in the bag as of next week, so well.

R Ryan Fleury 05:36
And Shawn still sounds really, really good. I'm glad that equipment's working out for us, right.

R Rob Mineault 05:40
Yeah. Yep. All thanks to you

R Ryan Fleury 05:44
Everybody owes everything to me.

R Rob Mineault 05:50
You know what, before we get too far down the rabbit hole. Why don't we tell the fine folks what we're doing today.

R Ryan Fleury 05:57
Today we are speaking without Al Etmanski who is an accessibility advocate, as well as author of a book called The Power of Disability which you and I have both read and found really very interesting.

R Rob Mineault 06:08
Yeah, after I loved this book, and I was really excited that you managed to, to grab him as a guest. We got turned on to Al's book, The Power of disability by Stephanie from the Plan Institute when we had her on the show a few weeks back. And you know, I consumed that book in just over a weekend which is which is kind of unusual for me because I find that that find reading is a lot harder to do these days because just because there's so many distractions these days, but I you know, I burned through it in a weekend and absolutely loved it. So I'm really excited to be talking to out today.

R Ryan Fleury 06:47
Yeah, it took me probably about a week and a half to read the book is like you there's distractions that go on. But yeah, it's available. I got it from audible. So the audio version, but I believe it's also available in Kindle as well or paperback so definitely pick it up.

- R** Rob Mineault 07:03
Look at you plugging today. You're just plugging up a storm like
- R** Ryan Fleury 07:07
plug plug plug
- R** Rob Mineault 07:14
You doing some sort of deals with some people that I don't know about?.Some backdoor deals with the liquer maker? Yeah.What was the name of it?
- R** Ryan Fleury 07:30
40 Creek
- R** Rob Mineault 07:32
Big shout out to 40 Creek in Ontario - send me some free samples. Thank you and Taratula tequila.
- R** Ryan Fleury 07:45
Yeah, still not available in British Columbia. Hmm. I still want to try their strawberry version though.
- R** Rob Mineault 07:53
So good, man.
- R** Ryan Fleury 07:55
They also have a mango flavored.
- R** Rob Mineault 07:58
Mango? Yeah. I mean, I'd be intrigued. I'd be intrigued by a mango flavored tequila.



Ryan Fleury 08:04
Roadtrip.



Rob Mineault 08:05
Yeah, there you go. Joining us now is Al Etmanski, author of the Power of Disability.



Ryan Fleury 08:46
I thank you so much for taking some time out of your busy busy day. I am Ryan Fleury. And joining us today are Steve Barclay.



Steve Barclay 08:54
That would be me.



Ryan Fleury 08:55
And Rob Mineault



Rob Mineault 08:56
Oh, good afternoon.



Al Etmanski 08:59
Hello, sir. Three of the velvet-est tones I have ever heard in one place. All right, we're promoting this podcast. That's literally the only thing we have going for us. Thanks again for joining us. I can't even tell you how excited we are to have you on I finished reading the book this over the weekend. And I have to say I love it. And frankly, you know, we've been doing this this show for about - we're going into our sixth year. And I wish we had talked to you three years ago four years ago five years ago. So it's it's great that we've we finally have you on and that we finally met you. But it's a pleasure and thanks for those are really really kind words and I'm glad the book found you. It dropped. I went with the mainstream publisher in a drop just as COVID did fun and so all of my you know I bought lots of new shirts and a new hat, etc, and was set to go on the road, and, of course, none of that's happened.

R

Ryan Fleury 10:07

So, so maybe a good place to start is, maybe if you could just tell us a little bit about your background, and just how your journey through the disability community started.

A

Al Etmanski 10:20

My background is as a community organizer. So I've always been involved in grassroots movements of one kind or another, and had no involvement with the disability community, community until my daughter, Liz was born, and that almost 43 years ago now, and so that that experience changed my life and in a variety of ways, and, you know, gradually got pulled into all of the challenges that people with disabilities face in society and, and so I simply transferred, whatever aptitudes I had in the trade of community organizer into the, into the disability world. And so since then, I've been involved in everything from closing the three big institutions in British Columbia, closing segregated schools, integrating classrooms, all the way through to, you know, helping to create the, you know, the registered disability Savings Plan, which is, you know, I was looked at as a source of economic power for people with disabilities. So, I've run the full gamut of public policy issues, advocacy issues, both, you know, myself, as you know, as a father, but also, as, as I've experienced them with my daughter release, but also for individuals, all the way through to national and international work.

R

Rob Mineault 11:52

Well, that must have been such a fascinating journey to step through to because you've really seen things at all different types of stages.

A

Al Etmanski 12:02

Yeah, I mean, when, when, when Liz was born, the, you know, the kind of books that were available for a family presented such a bleak, you know, future. And we still had in British Columbia, big institutions, and the institutions like that lead to institutional thinking, as well. And so the thinking is that, you know, you have a disability, that means you're different, and people who are different are best kept separate, they have that kind of mindset, right? was in the was in the air, you know, it was in the water supply. And so, you know, I joined with other parents, who fought that, who said that this, you know, in my case, my daughter, but, you know, our sons and daughters are revealing in a completely different person to what the status quo or what the popular sentiment is about disability. And so, you know, as families, we, you know, develop the family arm of the disability movement, and as time went by, we joined forces with the individual arm of the disability movement, and, you know, began to look at the physical barriers, you know, basic stuff,

like curb cuts. But also, communication barriers, attitudinal barriers, and economic barriers. So, yeah, so when I began, all of those barriers, we're in full force, you know, in our society, and, you know, I think bc should be really proud of where it's coming from. And a lot of that is the work of legions and legions of, of advocates, or individual advocates, family advocates, in groups of advocacy organizations who made that possible.

R

Rob Mineault 14:06

Yeah, you know, when it's interesting, when we when we did talk to Stephanie, you know, one of the things that we we sort of discussed is that the importance of all of these advocates, but it's almost overwhelming in a way because, you know, there there are so many different organizations that are fighting different battles for different groups, that it almost becomes a real challenge to be able to keep track of, of everything that's out there that could potentially help the disability community.

A

Al Etmanski 14:40

I think it's a it's an interesting and important insight. You know, there are a lot of disability historians out there - I recommend - he's a professor His name is Tom Shakespeare, sir Sir Tom Shakespeare, actually But he's, you know, he's he's a man with a disability. He's an academic. He's an activist. And he's a cultural player. And, and his assessment is that in the early stages of the disability revolution, as people came into for, it was diverse, and people were working on their own agendas. And part of that he says is because the disabilities are so different. But what I've seen, happen more and more recently, over the last decade, and I think we're seeing it more and more as a coming together, of the diversity within the disability movement, to work on uncommon issues. So that's an evolution, I think, we could probably see that, you know, in the, in the women's movement over, you know, we're in the third or fourth, you know, stage of the women's movement, if you go back to the time of the suffragettes and in the early part of the last century, all the way through, so, so these issues evolve, and, and, and there's, you know, multiple ways in which people are responding to them. And overtime, as a movement mature, there's a coming together, and I think there is a unifying factor in the disability movement now.

R

Rob Mineault 16:26

You know, it really feels like we've really made some really large steps in the past three years. The three of us we've sort of been been in the, the assistive technology business for quite a few years. And, you know, and we've been doing this podcast for for five years now talking to a lot of people within the disability community. And it really does feel like we're actually starting to make some real traction in the, in the field of inclusion and diversity in

the past, probably, I would say, two to three years. And I think it's a really, really exciting time. How are you seeing it?

A

Al Etmanski 17:12

Well, give me a second, could you mind if I turn the tables on you for a moment there? Right, what are you thinking? or what are you, you know, observing, sensing that?

S

Steve Barclay 17:23

I'm sitting here thinking thinking much the opposite. Rob, I think we're seeing a lot of lip service these days. That's not necessarily translating into real action.

R

Rob Mineault 17:36

I think I think that, that we're having a lot more conversations.

A

Al Etmanski 17:41

Yeah, I think, I mean, that the culture is much more aware of disability than ever has been, right. Do we have a long way to go? Yeah. You know, compared to other groups who have been marginalized one way or another. I think the disability community is kind of the last to, you know, to kind of have media attention have, you know, the kind of TV movie industry attention that other groups have had, but we're starting to see it. And or was far more of a presence of disability, there are more and more TV shows, in which characters with disabilities actually are played by people with disabilities and people with disabilities are playing other characters in which the disability is not essential to the plot. We're starting to see more of that. I just read something the other day that RJ met, who is the Sunday and Breaking Bad boy, he went through a policy played by a young man who had cerebral palsy is now starting in, in another series. And it's not about disability, but it is about people with disabilities being in major roles. So we're starting to see more and more of that happening. So that's a that's a good sign. I think behind that is something I would call disability pride. And it's kind of taking back the language. It's, it's recognizing that the broader culture uses terminology and has assumptions that make it impossible for you to describe your experience. And so you get together with folks to especially helped and by the artists in the myths to begin to develop a sense of who you are disability and all and and you enter the world with that power, that pride and that perspective. And I think we're starting to see that now. And that's actually going to cause some real challenges for you know, for People like me, for parents, who've had a major role and are kind of used to being, you know, in the lead with regard to our own sons and daughters. And now the

disability movement is saying, Wait a minute, folks, we'll take it from here. And maybe it's time for you to learn to be an ally, or, you know, or an accomplice. So I think we're starting to see those rules changing as well. So I see those pattern shifts happening.

R

Rob Mineault 20:29

Yeah. And and, you know, and going back to Steve's point, because I do think, you know, Steve is also right too. I mean I feel like the fight is sort of taking place on several different fronts. And certainly on the, you know, on the cultural front, yes, we, we are making some headway at but, you know, in terms of, say, some of the physical fights like, you know, to make build environments more accessible, those are places that, you know, there is a lot more work to be done. How do you see it like, because it seems to me that if we can shift perspectives, if we can make these conversations happen, that will automatically trickle down to help? do things like make mandates for better accessibility within the build spaces happen? Or are we doing it backwards? Or is there an overall arching strategy that that needs to happen?

A

Al Etmanski 21:28

Yeah, well, I certainly would agree with, you know, as well as Steve, that the the overall approach of the governments across the country provincially, and federally, with the possible exception of the BC government, certainly in some areas, has been very poor, as it relates to people with disabilities. And so if you wanted a temperature check, on where people with disabilities fit, these are the every other group in the country, I would say that the disabled community was, was the kind of last to get any attention. And that wasn't during the first wave of the pandemic, it was, well, the second wave was beginning and, and the attention they got was very minimal compared to, you know, to the group. So that's a great in my view, temperature check. And it's one of the reasons why I've joined with, you know, with other people, to essentially advocate for the equivalent of a basic income supplement for people with disabilities. So, and I hope we can talk about that more, because that's on the rise. But But having said that, that some of the challenges with the accessibility agenda are coming out in the critique of the Disability Justice Movement. And I don't know if you've interviewed or talked to Carmen palya, here in, in British Columbia, he's, he's he actually lives in Burnaby. But he's created what some people call an accessibility Manifesto, but essentially, he says that if accessibility is kind of a tick box of things that you're supposed to do, it is important tirely possible that you'll get inside the building, inside an art gallery, for example, and not be welcome there. notwithstanding the fact that you can get into it. The staff who were there aren't as welcoming as they could be the way in which, you know, exhibits are portrayed the descriptions, alternate descriptive medicine, etc, etc, all of which contribute to the fact

that you're still in a very sterile, vile, CRL, unwelcome environment. So so he advocates for, you know, a different perspective than just simply an accessibility agenda. And one of those components, in my view is economic power. we allocate as a society, a lot of money to people with disabilities right now. But it's all program based. And I'm not sure that's the most efficient way in which to support people with disabilities. So in many cases, people disabilities are program rich and cash poor. That would be like saying to the three of you, that I'm going to give you all of the, you know, professional services that you need, you'll have, you know, a certain amount that you can access of all those professional services, which you can't have any money. Those those services that are available to you, they'll help you make your way in the world. And, and you'll still be poor, but hey, you'll have all these access to all these services. That's essentially what life is like for many, many people with disabilities right now. So economic power, in my view is a is a major, either part of the accessibility agenda next wave, or it's another way of looking at it. Yeah,

S

Steve Barclay 25:13

I actually worked with Carmen at a camp for blind kids on boat Island two years ago, and followed a bit of what he's done since. And one of the things that I really love about his art is that he has always tried to make his art as inclusive as, as possible. And I get, I get the, the idea that, you know, you can, you can come to a building, you can walk in the building. And once you get in there, it's not a welcoming environment for you. And I still think that that is a function of the basic education that we're giving our society around disability, because when we, when when somebody with a disability walks into a place, oftentimes the folks who are staffing there are not particularly experienced, and they just see somebody who checks that other box, you know, it's like, oh, I don't know much about this, I don't understand it. So I'm going to avoid interacting with this person as much as I can. You know, we need environments to be more welcoming, but but really, what we need is some really baseline attitudinal change towards disability, because it's not, it's not an other checkbox. It's a checkbox, that we're all likely to check at some point in our lives. And there needs to be a better understanding of that.

A

Al Etmanski 26:38

Yeah, I think that's well said, Steve. And I think that that goes a long way to what I've learned from from Carmen, you know, in some ways, Carmen's manifesto on accessibility, which is essentially his way of auditing public institutions, particularly art galleries, and museums around the world, but would apply to all institutions, for everyone is that, you know, it's it's a, it's a manifesto for democracy, is that likely that people who are working in those buildings are really, you know, part of a pyramid code structure in which they're not treated? With the kind of recognition that they deserve as well. So this attitudinal question

is about habits and attitudes and outdated assumptions. And they certainly apply to people with disabilities. But if you address that, the argument goes, and I've seen it, the world becomes much better for everyone. Yeah, it gets a social justice move. And that's why I like the Disability Justice framework is, you know, I'm using my own language here, because it's my understanding of it, and I don't pretend to have the full, but I certainly, you know, recommend you have a, have a look at some of the material that's out there. But, you know, it's It simply says, the basic ingredient in society is a caring relationship. Which is reciprocal, that justice is love. That can be no love without justice, and there can be no justice without love. And so it's that framework. And you could, of course, that applies to Disability Justice, and to people with disabilities. And of course, accessibility is a piece of it, but it's not the only piece of it. We're wanting a full, contributing opportunity available for everyone with a disability, but we want that for everyone in the society. And so I, for me, it's a it's a really unifying thread in society. As you know, from the book, my argument is that, you know, there there may be many ways to unify our society, but one of them is to pay attention to people with disabilities. And if it starts to work for them, the way it should work, it will work for all of us.

R

Rob Mineault 29:10

In your in the book, you talk about how I think the stat was something like four out of seven people in the world is somehow touched by disability, whether that's they they themselves have some sort of a disability or they have a family member or a friend or so it's just it's an overwhelming majority of people. Disability is just a part of being human. Yet we there are these misunderstandings that people are uncomfortable about having those conversations or at least they were historically. Why do you think that that is?

A

Al Etmanski 29:50

I'm a community organizer, so I always look at it from the point of view is Do people know each other? Are they able to come? together and form a relationship where where Trust has the potential to grow within the context of that trusting relationship or caring relationship? Is there an opportunity to begin to develop an agenda in which there's some clarity about what they might have in common? And if that happens, can we then work together on that common agenda? So that's sort of, that's what I've done all my life is. So I look at that stat, you know, whether it's four sevenths of the world, or, you know, in Canada, the stats are but, you know, three and five Canadians are touched by disability. Yeah, so I anyway, and the foreign seven staff worldwide is, it's phenomenal. And so I just think that maybe we don't need more policy. Maybe what we need are more community organizers, who work to bring us together to look at the common agenda that we have to create a, you know, intellectual and values framework around that, and an agreement to

work on common, uncommon issues. That's certainly the approach that we're taking with regard to the candidate disability benefit is doing our best to unify the disability community, which has multiple objectives and multiple priorities. But our hope is that we can find a way to appeal to everybody, despite those differing perspectives and priorities, to join forces to end the poverty experienced by disability, people with disabilities once and for all. It affects roughly 2 million Canadians, in total, 2 million Canadians with disabilities. And it's it's between 30 and 40% of the people who are poor in our country, so. So we're asking people from every, you know, walk of life, and from every perspective on disability, and from the broader Canadian society to join forces in this regard. So that's a kind of practical manifestation of the question you asked about? Why have we not been able to achieve the change that we have? And I just think the opportunity has not been there to come together the way I'm describing.

R

Rob Mineault 32:25

Given that, are we close then?

A

Al Etmanski 32:30

I mean, I take a lot of hope from the #CripTheVote hashtag in America. And the Disability Justice folks, they're all of the Democratic Party presidential candidates workshop, their policy on disability, with people in the Disability Justice Movement. Biden certainly did. And I think at one time, he had two disability engagement specialists working for him, both of whom had disabilities. And that has rolled over into the Biden White House, if you begin to think of the the attention that he has paid, in his policy announcements, and in his funding announcements, to people with disabilities. And the presentation is not just that this is an important thing, because it's a social issue. The presentation by Biden is also that this is important, because it's important for the economic restructuring and well being of the country. So it's become more fundamental than a nice to have social add on, if you see what I mean. So that didn't start out of the blue. And politicians just all of a sudden didn't get sensitive to this issue. That was a whole lot of community organizing work that had been done beforehand. So yeah, I'm very optimistic. And I see the same thing happening in Canada, there certainly was a lot were a lot of people that came together for the accessible Canada act. And we're hoping that that same those same numbers plus plus plus more will come together for you know, achieving the end of poverty for people with disabilities in Canada. In fact, if it is achieved, and I should say will be achieved, when it's achieved, will be the only country in the world that's ever declared that we're going to do it. And we'll have done that.

R

Rob Mineault 34:26

That's exciting. We've talked to folks from places like the President's Group, they make that business case to companies that, that people with disabilities, it just makes perfect sense to, to be employing them. And it's those types of organizations and advocates, I think that are really making that difference, especially in that economic space.

A

Al Etmanski 34:50

Yeah. And just recently, I don't know if you follow Caroline Casey's work in the valuable 500. Internationally, we just recently they announced the 500 You're a member. So 500 of the world's biggest corporations have now declared that they will put on the board agenda, the employment of people with disabilities, that's, that's being hurt. Our partners are the Microsoft's of this world are major advisors, Richard Branson, whatever. But Carolyn Casey, who is a woman who's blind from Ireland, you know, started this three years ago at the World Economic Forum in Davos and and she's she's achieved that narrow argument is that if it's not on the board agenda, if it's not reported on regularly, it doesn't get done. And that despite the broader diversity agenda, and its prominence within that people with disabilities have been left behind. So that's a major shift now, invite your listeners to just google the valuable 500 and, and to see what's going on there. And I think that will play out in terms of economic opportunities, employment opportunities for people with disabilities. And you're right, the President's group here is a great example, to the best of my knowledge, there's no other group like it in the country, that, you know, has corporate leadership saying we can do this, this needs to be done, there's no reason why this shouldn't be done.

R

Rob Mineault 36:19

So I want to shift gears a little bit and talk a little bit about the book. First of all, I guess, what, what prompted the book, what what made you write it?

A

Al Etmanski 36:27

Well, I've, I've been collecting stories, I guess you could call them alternate stories about people with disabilities ever, personally, ever since Liz was born. And I, my last book I written was on six patterns that successful movements use to make change. And I ended the book with, you know, essentially, with the understanding that the, the area that that most movements do not pay attention to, and therefore it limits their success, is the area of culture is this question you've raised to before about habits and attitudes and and beliefs have to be addressed in the popular culture? Otherwise, stuff starts to slide backwards. And so I thought, well, a natural succession to that, you know, my previous

book was a book on culture. And rather than make it a general kind of book, why don't I make it specific to the community that I've been part of for over 40 years. And so that, that led to to the book. So in many ways, as you know, I opened the book by saying this, it's mostly disability book and not a disability, but you know, it's about the cultural determinants of change. And we're just happening to use people with disabilities as our examples. Having said that, you know, I wanted to enter the culture with the kind of lessons that I had learned from, from the disability community over the years, that I think are lessons that the culture wants to hear, or needs to hear. So that motivated me. And, you know, my silent companion on this all the way along, it's been, you know, it's been my daughter, because I would say that the stages of my relationship with her have gone from, you know, cure to conformity to culture, you know, over the last 40 years, so I've landed with Liz at the same spot that, you know, that the book is at, which is that this is a book about culture.

R

Rob Mineault 38:59

Like, how long have you been collecting stories for the book?

A

Al Etmanski 39:05

It's been about 40 years.

R

Rob Mineault 39:07

Wow.

A

Al Etmanski 39:08

And so they were newspaper clippings, you know, just start. You know, I remember you know, Merritt, who's known in popular culture as the Elephant Man, but I remember collecting a story about him in newsprint years and years ago about how he was in a very wealthy individual for his time. Not just in the disability community, but just generally, he had well, and he was an entrepreneur, and he he sold his disability in quotation marks, but he was in control of his his career. It's already remember that Well, that's a story you don't hear about often, you get the you know, the movies about the Elephant Man. It's all about pity and you know, kind of what people tend to call the inspiration porn nature of it, and you In this noble man enduring suffering on his own, and there's no sense of his own agency in that regard, and it's not about ignoring his disability. But you know, that's the real deal. But it is about ignoring other parts of his life because it doesn't fit the character cultural story to people are. So that's, that's one example of what I collected way back.

And, you know, he began to look at all kinds of famous people where their disability wasn't mentioned, or if it was mentioned, if it was massaged to conform to the cultural narrative. You know, Helen, Helen Keller was a communist. She was a socialist. She was a campaigner for birth control, she ran as a socialist candidate for a political office, but the cultural story is about her learning to write after putting her hand and learning to read and write after putting in her hand and water and right, and the miracle worker, who was her teacher, and so on, and so forth. And that's kind of the consistent story as opposed to this broader view of her. So yeah, so I just started collecting those stories. And, and, and then once you realize that the historical view of somebody isn't completely accurate, then you go looking for it. And then you find these other parts to the story. And so that's what the book is, I hope is a broader understanding of these at least people who are famous and or who should be,

R

Rob Mineault 41:44

Yeah, I mean, and actually, it's funny, you bring that one up, because that was one that really stood out to me too, because I was just like, I had no idea about all of that about Helen Keller, because I was, I was like, a lot of people, I just, you know, I certainly knew that she was an advocate, but I had no idea of just how far that reached. So and I think that that's, that's the real power of the book, at least for me personally, because when you when you collect all those stories together, and you start consuming them, one after the other, and really get this, this broad picture of all these people, throughout the years in society contributing all sorts of things, from minor things, two major things, from regular people to famous people, it, it really just drives this, this idea home, of the fact that disability shouldn't be viewed as this all encompassing attribute. For people, it's, it's just, it's another, it's just an attribute, as opposed to one that should be at the forefront. And to me, that's, that really speaks loudly and in what we need to how we need our perspective to shift in society. And just look at people as people first and disability wherever they wants to place it.

A

Al Etmanski 43:11

Yeah, I mean, it's both, I think, listen, so many words is said to me many, many different times, it's both, you know, her Down Syndrome is the real deal with who she is. And it's no big deal. So it's both part of her. And it's a fact of her life and influences the way she sees the world. she's proud of it, she thinks it's rad. But in the meantime, she's an artist and a spoken word poet and makes most of her money as a graphic facilitator. And so she's got a job to do. And, and, and, you know, sometimes those appear at the same time. But I mean, that, I think I worry all the time, because as you know, I've done now, I've taken the stories, I didn't make it into the book, and I've created a disability digest and, and I've

produced one pretty well, once once a week, and there's four or five stories in every one. And I'm, you know, I'm worried that I'm only, you know, I could be accused of going the other way, and just only presenting the positive side, but I think they, you know, the argument I make is that history, you know, the past the stories of the past, the history, that that we use as our basis for going forward is what influences the future. And if that history contains all of those negative attitudes and stereotypes, or is all about the only role for a person with disability is to be someone to be pity to be an object of our charity, or to be a source of our inspiration. Right. "Thank you very much. And now we don't need you anymore because we've got our inspiration hit." That's all there is. Then we're going to continue into the future with those assumptions. So What I'm trying to do is break that right. And and say that the disability is real, and it does have consequences. And there are still a ton of barriers there. But in the meantime, this is a class of people who have shaped the world, who shaped our world. And if you took them away, you wouldn't recognize the world. So it's sort of a, you know, it's kind of serving that trend to serve that up. And the really interesting thing is that people are now sending me more and more. It's like, it's like a can opener. Alternate perspectives on this, it's really opened the floodgates.

R

Rob Mineault 45:48

Yeah, yeah.

R

Ryan Fleury 45:49

Well, and that's one of the things I was saying to Rob the other day when I had just finished reading the book as well, is that our inter dependency on each other, you know, a gold medalist doesn't become a gold medalist on his own. He has parents, coaches, trainers, to get them to that point, you know, I'm totally blind. And my blindness is a disability. But going into a restaurant that does never bring on menu is disabling me from independently ordering a menu choice. So yeah, it's shifting that perspective. Right. And those are the two things I really got from that book.

A

Al Etmanski 46:26

Well, thank you for for saying that, Ryan. And I wonder, too, if we're what you thought of the chapter that that began, there's no independence without interdependence. I mean, I think this often, this is a hard one for the culture, because especially the you know, we really influenced a lot by the American view of the world, that is the is the great person, usually a man, and they, you know, against all odds achieve something insane, you know, very significant that most of us could never achieve. And that that's the sort of story that we follow. That's the template, when, in fact, the real template is exactly what you said

that there's no successful athlete who gets where they are just on their talent. It's the social network around them. It's the recognition of their interdependence on other. And in fact, our culture thrives on vulnerability. But you won't, you won't get that in most Hollywood movies. And maybe what people with disabilities represent is that a reminder that that time in fact, the truth of God, vulnerability is that's who all of us are, to maybe that's the, the source of the antipathy that a lot of people in society feel toward people with disabilities. I mean, was the way I felt I have to be honest about it. Before this was born, I never thought much about disability and couldn't figure out why, you know, people I knew were, were working in the disability field, I'm not ashamed to be I'm ashamed to be saying this. But, you know, there's the way I felt. And so the book, in a sense, allowed me to come clean on that, but also to unpack, you know, where that came from. And I and I think part of it is just is is recognized as you go there, that we're all vulnerable.

R

Ryan Fleury 48:30

Absolutely. Like, like you're mentioning about the inspiration porn, you know, people see, you know, I don't know, a blind person crossing the street. Oh, wow, you're so brave. And, you know, most of us are sick and tired of that. We're not an inspiration. We're just trying to get by trying to get to our job trying to do whatever we need to get done.

S

Steve Barclay 48:51

But I think this, this leads back to, you know, something I said earlier, we're not we're not doing a good enough job of, of creating the right attitudes in our young people yet. And I think, you know, I think we're, we're starting to get there. But we're, we're not there yet. And the whole focus has to be that all of us, with or without a disability are humans first. The Disability might define your character in some way, but put your human first. And it's, it's frustrating that when you see people reacting to people with disabilities, oftentimes the response is one that's based in their own fears or misconceptions. Those those started in early age. I just think we really need to do a better job right at the outset of, you know, letting our kids see examples of people who, you know, are not the cookie cutter person there. They're, you know, they've got diverse abilities, different ways of doing things, but understand that at the core, they're just a human being.

A

Al Etmanski 50:09

Yeah. And I what I see an opportunity with COVID I don't know if the three of you and your other guests have brought this up. But you know, this, this whole question of, you know, in the book, I described it as life comes from life. You know, it's, and it's life in every shape, size and background and condition. It's, you know, messy lives, start mean lives, complex

lives, funny loans, mysterious lives, beautiful lives, sacred lives, sensuous lives. Life comes from, you know, from life. And in that context that, you know, we we only all of us, we thrive in life by having a nurturing environment of family and friends, who care about us, but also a society that cares enough about us to allocate the resources to put in place the effects of quality mechanisms, so that everyone can live life to their fullest. And when you couple that with the fact that, that life is also about vulnerability, that's the kind of complex nature messiness nature of our life. Well, COVID has just put that on full display who is not vulnerable? And, and how did we get out of this, how have we gotten out of it, we've gotten out of it, not by exclusively relying on the people at the top. But we're by relying on the people, you know, at the bottom by doing things together, that's been my experience all the way through this. Little things and big things already through. So a new narrative is emerging out of COVID, we have to be careful to preserve it, because the old narrative will overshadow it and get back to the way it always made stories sold stories told stories. But I do think there is an opportunity there, and that there is an alternative to the the lone actor, epic hero story that's out there. But instead of story that that celebrates our deep connections to each other. And that reminds us that none of us get where we're going on our own. From any book, I say, and that success doesn't come from rising above. But by rising with. And I think people with disabilities can lead that charge, they can roll forward on that, in that way, in whatever way they mobilize us mobility to get, but I think that's actually, that's the other flip I want to make here is that, you know, is to make sure people understand that power, and then have people with disabilities lead us out of this mess that we're in that the pandemic has revealed. Mess was here before, the pandemic is revealing. So I don't know what you think about that. But that was why I titled The book, you know, 10 lessons for surviving. thriving. Yeah. And changing the world. And here, I mean, I wrote this before the pandemic, but I believed it, then I really believe in that, yeah. That if we get people with disabilities and people in positions of power, they will change the culture.

R

Rob Mineault 53:47

Ryan, get busy.

A

Al Etmanski 53:51

Well, it's all of us if that's the thing is, is how do we so that's the difference between now and then, in the stage we're at in the movement, right, is that we're at the stage in the movement, where the move, it's the unifying move that in my view, is the best move. It's the essential move, is the move that will that will topple the out of date assumptions and attitudes and habits. So yeah, in a sense, we all have to get busy but I would say we all get busy in as in the way that we all can, that we don't have to do it. on our own, that

we're in this together we have this mantra and the work that we're doing on a disability without poverty movement that we're that we're creating, and will soon launch and in a couple of weeks, you know, the website and all that other stuff, but is that the the critical ingredient of the movement is a caring relationship. And the reciprocity involved in that. It's not just the person receiving care is the person giving cares both together. And so we don't have to do big things, we have to do things together. That's the big thing.

R

Rob Mineault 55:11

I agree, we have to change from the bottom up instead of the top down. And I think that that's, certainly we can see that in even in just talking in this conversation, when you're talking the difference between the cultural shift that we've been able to have in the past three years versus policy shift, which has, you know, been not great. It just goes to show you that where, where that power is, and I really do feel like it's, it's as the group it says, the collective that's, that's how we get through change. And it's not through policy, you know, handed down from the from the top. But before we let you go, though, the name of the book, of course, is the power of disability. 10 lessons for surviving thriving and changing the world. Recommend all of our listeners go out and grab it. Where can people find the the disability digest?

A

Al Etmanski 56:04

Oh, my goodness, maybe I'll just give my website. There's a way to sign up there. That's probably the easiest, right? So it's aletmanski.com o And just on one of the headings there, there's, you know, blog digest heading, click on that you can sign up there.

R

Rob Mineault 56:26

Perfect. Yeah, well, and we'll include that too, in the show notes. So anyone who's listening, just go check out the show notes. And we'll have a link out. Al, it's been an absolute pleasure. Thank you so much for taking some time out and in chatting with us. And hey, I'm already looking forward to having you on again.

A

Al Etmanski 56:49

Well, I love your velvet tones. Oh, my goodness. This is a really skookum trio you've got here. So I think I'm surprised you're searching for gas. I doubt you are.

S Steve Barclay 57:02
Well, you fit you fit right into you've got that that nice whiskey tone to your voice. They're fitting right in here.

R Rob Mineault 57:09
Maybe we get a barbershop quartet going.

A Al Etmanski 57:12
It's been cured. Well, let's put it that way. All right. Take care, guys. Okay, thanks. Bye. I don't even know where to I don't even know how to close that out, man.

R Ryan Fleury 57:26
Well, his, his book and our discussion covered so many topics. You know, he mentioned early on when his daughter when he found out his daughter had Down Syndrome. You know, one of the phases he went through was trying to find a cure, and then coming to acceptance. You know, we all kind of deal with that at some point with our disability, I think. But then you move on, right? And you start researching more and more about how you can get involved in the community, how you can advocate for persons with disabilities, and identify with them to the your best. The best way you can, like you say, there's so much there that it's definitely worth a read. And everybody I think will take away something different from that book.

R Rob Mineault 58:18
Yeah, I really do. I think, uh, yeah, you know what, I'll tag on to that too, and just say, highly recommend this book. We will definitely include a link to purchase it on Amazon in the show notes. You Ryan, you got it on Audible, correct?

R Ryan Fleury 58:34
I did. Yep.

R Rob Mineault 58:35
Yeah. Or audible? Yeah, yeah. It's I think it's a great read for anybody. There we go plug in again. And this is just a plug show. I love it, though. Excellent. Hey, Ryan.



Ryan Fleury 58:51

Rob.



Rob Mineault 58:53

Where can people find us speaking of plugs?



Ryan Fleury 58:55

Well, as usual, they can find us at atbanter.com



Rob Mineault 59:04

That is correct. They can also drop us an email if they so desire, at cowbell@atbanter.com



Ryan Fleury 59:14

And they can find us on Instagram, Twitter and Facebook or wherever you listen to your podcasts. Right. Or back out on our respective decks sipping on Nanaimo Bar liqueur.

That's right.



Rob Mineault 59:31

Well, I think that is just about going to do it for us this week. Thanks, everybody for listening in. Huge thanks to Al Etmanski for joining us, and we will see everybody next week.