

# AT Banter Podcast Episode 340 - Brooke Ellison

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## SUMMARY KEYWORDS

disability, life, people, feel, questions, disabilities, society, experience, years, community, accident, canadian, world, talk, stem cell research, book, important, thinking, kinds, thought

## SPEAKERS

Ryan Fleury, Rob Mineault, Brooke Ellison, Steve Barclay, Lis Malone

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**R** Rob Mineault 00:38  
Hey and welcome to another episode of AT Banter.

**S** Steve Barclay 00:43  
Banter, banter.

**R** Rob Mineault 00:46  
Yeah, I know that he's been really he's been really loud this this week. Hey, this is of course a podcast where Rob forgets his notes. This is of course the podcast 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 and joining me today ... Mr. Steve Barclay.

**S** Steve Barclay 01:12  
Hey, I get first billing. That's exciting.

**R** Rob Mineault 01:14  
Shoot he noticed. Hey, we've also got Ms. Lis Malone.

**L** Lis Malone 01:19  
Check me out, out of the cellar.

**R** Rob Mineault 01:22  
And Mr. Ryan Fleury. Hey, he's also very important. You're not bringing up the rear. You're just ..

**R** Ryan Fleury 01:33  
number four.

**L** Lis Malone 01:36  
He says with enthusiasm.

**R** Rob Mineault 01:39  
Yeah, yeah, that's right. How the heck is everybody today? Just golly, gee, dandy. Excellent. Excellent. Yeah, it's hot here. Fabulous.

**L** Lis Malone 01:53  
Yeah. Yeah. So down by me we're entering into an air quality alert issue because of some smoky wildfire action in Canada that's making its way down here.

**S** Steve Barclay 02:08  
It's reaching it all the way down there. Wow.

**L** Lis Malone 02:10  
Yeah, we have a really have a red we have a red alert tomorrow. They're saying don't come out if you don't have to.

**R** Ryan Fleury 02:16  
Oh, yeah, that's really interesting. So you get a red alert for for forest fire smoke, but no red alerts for Chinese balloons flying overhead?

**L** Lis Malone 02:24  
Well, you know, I mean ..

**R** Ryan Fleury 02:25  
That's bizarre.

**L** Lis Malone 02:29  
I mean, the balloon is only going to harm us if it lands on our house. Well, yeah, actually that that is probably a possibility. Considering the route it was on.

**R** Rob Mineault 02:40  
And you can't shoot down smoke.

**L** Lis Malone 02:44  
True. True.

**S** Steve Barclay 02:47  
Oh, no, it's America. I wouldn't put it past them.

**B** Brooke Ellison 03:07  
In New York, we have like a Red Sky around the clock lately. There's the old addage red sky morning, sailors take warning. Yeah, the other half goes but it's around the clock. So I don't know if they ever anticipated that kind of situation.

**L** Lis Malone 03:25  
Oh, you could thank Canada for that.

**R** Rob Mineault 03:28  
Listen. Is that is that the Quebec wildfire? Is that what's causing it?

**B** Brooke Ellison 03:33  
Yeah, and it started with the Nova Scotia and now I think it's Quebec.



**S** Steve Barclay 03:37

That's right.

**L** Lis Malone 03:41

The local news down here is just calling it Canadian wildfires.

**R** Rob Mineault 03:46

Really interesting.

**B** Brooke Ellison 03:50

New phenomenon, a new problem.

**S** Steve Barclay 03:53

Well, there's always been there's always been forest fires up here, but we've never had them this early and in this volume, it's getting worse every single year.

**R** Rob Mineault 04:01

I noticed that they they're quick to label smoke Canadian, but media darlings Ryan Reynolds and Michael J. Fox are often overlooked in the fact that they are Canadian as well.

**S** Steve Barclay 04:16

Don't forget that Atlantis Morissette is secretly Canadian. That's true.

**R** Rob Mineault 04:23

Avril Lavigne. Canadian.

**L** Lis Malone 04:26

That's true. Bryan Adams.

**R** Rob Mineault 04:30

Yeah. Rush

L Lis Malone 04:32  
Canadian.

R Rob Mineault 04:32  
Yep. See ya. No. Yep. Yep. All right, we need to we need to move on, we need we could just go on all day I think.

R Ryan Fleury 05:33  
We've never done

B Brooke Ellison 05:36  
I am a Self honored honorary, Canadian all my life. My brother and I used to play Winter Games or Summer Games or World Games or something on the computer years and years and years ago. So like, one of those like Apple, two E computers or Commodore 64. Canada was the country that I chose. Every time and I don't even consider myself an expat or anything like that. But yeah, like, I have I have some affinity for Canada.

R Rob Mineault 06:08  
So there you go. We have so I mean, we can only speak for the AT Banter podcast, not Canada in general, but we we welcome you into the fold and make you an honorary Canadian for the next hour. Well, hey, Ryan, that's a good segue. Let's tell the fine, folks, what the heck's going on around here today?

R Ryan Fleury 06:31  
I wasn't sure, but I know we had a guest planned for this week. And she's here. So I'd like to introduce Harvard Graduate, Champion of Persons with Disabilities and author Brooke Ellison to the show. Brooke, thanks so much for joining us.

B Brooke Ellison 06:47  
Thank you. I see another great Canadian. Thank you. It's a pleasure to be a part of the conversation here today.

R Rob Mineault 06:59

Well, thank you so much for for coming on, and not a leaving immediately upon hearing our inane banter.

B

Brooke Ellison 07:06

It was a pleasure. How frequently do I get to be a part of that?

R

Rob Mineault 07:14

Well, let's get down to business because we are really excited to talk to you. You have a really, really fascinating story. And I'm really curious to hear you your perspective on a lot of different topics. So but maybe we can just start with sort of just a brief overview and just sort of briefly share your story and sort of where it's brought to you currently in your life.

B

Brooke Ellison 07:42

Sure, absolutely. So I was raised, born and raised here on Long Island, off the East Coast, New York City. And I've lived in the same spot for most of my life, Stony Brook, Long Island is about an hour and a half east of New York City. And my childhood was very reminiscent of I think many childhoods in suburbia, I was involved in many extracurricular activities, physical activities that I think come to define childhood, I was about the dancing and karate, and martial arts and sports, singing in my church choir, and these are the things that gave my life a lot of flavor and character. And it's how I understood my days really was, you know, going to school and being a part of these different activities. When I was 11 years old, I just started High School, it was actually my very first day of junior high school and friends and I decided to walk home from school. And in doing so I had to cross a big major highway here on Long Island and I was hit by a car that was traveling southbound on a major highway. And so the accident did extensive damage to my body, I cracked my skull, really extensive damage to all of my limbs in one way, shape, or form. And emergency responders got to the scene of the accident almost immediately, actually, the accident happened right outside of a local firehouse. They immediately started CPR and other kinds of resuscitative measures. I was in cardiac and respiratory arrest when they arrived on the scene of the accident and I was taken immediately to the nearest Trauma Center here on Long Island, which fortunately was just several 100 feet away, Stony Brook hospital and immediately all of these Herculean efforts went into place to save my life. There was a tremendous amount of questions as to whether or not I would survive. My parents who were called to the hospital, you know, it was immediately thereafter, were told that, you know, I was in a very severe accident, and I suffered significant damage to my head. And if I were to survive the extent of my accent injuries extend to my injuries at all that I would likely be significantly cognitively impaired. And yeah, that's kind of what my parents were told to expect. And it was very dire in terms of what my prognosis might look like. So I was in, in a coma for 36 hours, during which time the EEG readings, the electroencephalogram readings were flat and completely you abnormal, not showing any brain activity really at all. But somehow they righted themselves after, after about a day and a half and I was able to make eye contact with my parents, it was clear that I can recognize their faces. And I understood that something traumatic had happened to me, I didn't know exactly what it was. But I understood that that was the case. And I wasn't able to talk, I wasn't able to breathe or move my body. The injuries that I had experienced was done to my spinal cord, a

high level spinal cord injury, C2, C3, so the second and third cervical vertebrae. It doesn't really get much higher up with a spinal cord than that. And that left me paralyzed from my neck down and on a ventilator to breathe. Now what was really kind of front and center in my mind, even at that time, and you would not know what had happened to me or what my future might look like, I was very concerned about making sure that I could return to school. And that was a commitment that my parents made to be very early on, after my accident, you know, despite the extent of my injuries and the enormity of them, you know, my parents said, we're going to do all we can to make sure that you can get back to your school or with your friends. And I didn't know what that might look like, I didn't know how long I was going to be in the hospital, I kind of had thought initially that I'd be in the hospital, maybe for a few weeks, and then by Christmas, I would be walking out of hospital, out the same entrance that I walked in, and things would be just fine and just the same as they as they had. And it didn't take long for me to realize that that was that understanding or that vision for my life was not going to come to pass with the injuries that I was dealing with. And the disability as a result of that would be a much more permanent kind of thing. And we had to think much differently about how we were going to make sure that I could live my life as fully as I wanted to. So my parents kind of made it an additional quest to make sure that I could return to school and be with my friends and be accepted into my community here. Fortunately, there are many people who were very dedicated to my returning home and felt a tremendous amount of community support and making sure that I was a vital part of the community. But at the same time there was resistance to by returning to school, there were some people that thought that my presence in the classroom was going to be disruptive or upsetting in some way to my fellow students. So we had to overcome a bit of resistance to what my parents thought was going to be a pretty simple thing to return to get me to go back to school. But we fought and we prevailed. And yeah, fortunately, despite many of the changes that my family had to make to how it operated first and foremost, my mother's first day as a Special Education teacher was also the day of my accident. So she had to make a decision very quickly to leave her position to leave her new job and be with me to help care for me and make sure that I could do the things that I wanted to do - live my life as richly and fully as everybody was hoping I could. So we did that. And I went to Junior High School. Then ultimately I was accepted to Harvard, where I did my undergraduate degree and then ultimately my Master's Degree and with other things kind of thrown in the mix there. I did my PhD in Sociology of Science and now I am among other things, a Professor of Applied Medical Ethics at Stony Brook University, teaching students about medical ethical questions, many of which my life revolved around. And then I also serve as the Vice President for Technology and Innovation for the organization United Spine to bring technology to the lives of people who can benefit from it the most. And that's what I do. And it keeps me extremely busy.

R

Rob Mineault 15:20

And you're and we have to mention in there as well, is that you also wrote a book called *Miracles Happen* in 2002.

B

Brooke Ellison 15:33

Exactly, exactly. Which, yeah, feels like a very long time ago. So I graduated from Harvard, the first time in 2000. And there was a lot of attention, media attention that was directed towards my graduation. And after that, there was a lot of interest in me telling my story, or writing a

book and collecting my thoughts and sharing it. So that's what my family and I did that year. And plus, I guess, I after I graduated from college we wrote *Miracles Happen*. My brother and I wrote it together with the input of other family members kind of chronicling our experience from the time of my accident to 10 years later, when I graduated, Harvard. And actually, that book, was made into a movie directed by Christopher Reeve. It is a very important book, and one that captures I think, a really pristine time in my family's life.

L

Lis Malone 16:40

I just have to point something out that I don't think we've had any other guests who could say, when I grew up, I graduated from Harvard the first time. Like, that's just that is just awesome. I mean, amazing on its own. I'm kind of speechless, because you make it sound so easy. And I believe me, I know it's not but the just hearing like and listening. I'm like, oh my god. Like I it's it's no surprise that it was made into a movie. I mean, it just reads like one it's such an amazing story.

B

Brooke Ellison 17:29

Thank you. I appreciate that. And if sometimes, when you live in that, in the thick of the story, right, it's hard to see its significance, I think, clearly, sometimes I can forget that it is a very special and unique life, right? It is a set of circumstances that I think very few people have the opportunity to be a part of, and not necessarily for their own, because of their own lives because of circumstances in society and how society has organized itself and prioritize certain people over others. So I feel very fortunate to have been able to experience things that I've experienced and to like, it took me a long time after my accident to understand that my disability was not going to be a detriment to me. There were obviously physical limitations that I experienced and continue to experience right, there are co-morbidities that go along with spinal cord injury that have made challenges my life in really significant ways. But because of my life lived with disability, I've become much stronger and more resilient, and more creative and tenacious person. And I never would have understood that about myself at the time with my accident even via many years thereafter. So I feel very privileged to be able to look at my life from this vantage point and understand it for all that it has given me and all the opportunities that I have been able to take advantage of a job as a result of it.

R

Rob Mineault 19:15

Yeah, I find it really interesting when we talk about disability because, you know, so often we paint it as sort of a very sort of negative experience. And yes, there certainly are aspects to that, but it's also a transformative experience. And there's, there's there's positives being brought in along with the negatives, you know, we've talked to so many people on the podcast, who, you know, have gone through their, their disability journey. And, you know, there definitely are positive things that it's brought into their life, whether that be opportunities that they never would have had otherwise, or it's taken them down a route that they never dreamed of prior. So, you know, I think that's an important thing to talk about when we talk about disability. It can be transformative in a multitude of different ways.





**B****Brooke Ellison 20:18**

No question about that. And that is the message that I have been trying to espouse. I've been trying to be for years and years now that this was very much the case for me, right that after my accident, I was the product of as much social indoctrination as anybody else, believing that disability was this completely categorical negative in somebody's life, that people with disabilities are the ones to be pitied or felt sorry for, and the ones that are not going to be able to participate in the world or make a difference in any real way. Like that was just what I understood, it was the logical conclusion that I was drawing about in my life. But that was not satisfied with that. And I wanted to do more than what I thought society was telling me I would be able to do. And I'm very thankful that I didn't buy into that for very long and for years, since I think many people with disability have also gone through this kind of almost like a coming out process or a social transformation where the social constructs are social limitations that are put on the disabled life become unnecessary barriers and unnecessary impediments in our in our thinking. And we can be viewed instead for the virtues or the kind of knowledge set or the skill set, that disability actually does engender in a person. And that's something that I feel very, very strongly about. Were it not for the disability that I have faced, I don't think I ever would have understood myself, or would really be forced to understand myself in terms of these really important strengths. Whether it's, you know, the ability to navigate a world that's fundamentally not set up for you, or having to implement your creativity and hopefulness into your life on a daily basis in order to just deal with life changes. These things, I think, are really important, valuable skills that any organization, any family, any community benefits greatly from, and if people with disabilities should be understood in those terms, right, we shouldn't be talking about disability without also thinking about all the virtues that it creates not only for the individual living with disability, but for everybody around him or her.

**R****Rob Mineault 22:45**

Yeah. And do you find that that is some of the sort of the more challenging aspects when you when you talk to people and you're trying to educate them is that because we're very used to as a society looking at disability a very specific way. Do people sort of get uncomfortable when you when you try to sort of shift their perspective and to look at it in a more positive way?

**B****Brooke Ellison 23:16**

Absolutely. No question about it. And that I think, is, as you mentioned, right, the most difficult part of all of this, right, you can legislate in any number of ways. In the States here, we have the ADA, the Americans with Disabilities Act. And that was a really important landmark piece of civil rights legislation, to shift the thinking about how we can be included in the workplace and in the educational setting, and just the community in general. But at the same time, it's taken from this vantage point of compliance, right? Like what are the standards that we need to enact so that somebody is not going to be challenged or held liable for being inaccessible or not providing accommodations, rather than looking at the question entirely differently? Like how does inclusion of people with disabilities actually benefit everyone? Right? How does a society become better and stronger, because of its inclusion of people with disabilities like that is how we should really be looking at the conversation. And I think those are conversations that are not being had to the degree that they ought to be having and like, that's the message that I

tried to send every single place that I go, it should not be unusual to see somebody with a disability in any legislative body or any decision making body it should be a perfectly normal, perfectly expected.

R

Rob Mineault 24:44

Yeah, and I would argue essential if we're, if we're going to drive the issues forward. We really need people with disabilities involved in the system because a lot of the problems that we're facing are systemic.

B

Brooke Ellison 25:01

Right? Exactly, exactly. And society is so used to thinking that way. So the disability, as I'm sure you guys know, as well as I do has largely been contextualized in many different frameworks. So the moral model of disability understanding, basically understanding disability to be some kind of curse or consequence you have had to accept by wrongdoing in the past. So people think a lot along those lines all the time, we still have vestiges of that to this day. People who encounter some kind of injury or disabled disabling accident feel like "why do I deserve this? Why did this happen to me? What did I do to deserve this?" Right? So there's kind of this morality component to disability. And then there's the economic model, that people with disabilities or some kind of social charge, or public charge, they cost too much money, and they don't give back to society, they don't work for that economically productive and they can't work. So they shouldn't be thought of as valuable members of society. So there's the economic model of disability. And there's the in the medical model of disability, which has been probably one of the most consequential and longest lasting and most influential when it comes to help people with disabilities and how they've been understood. Assuming them to be medical problems that need to be fixed and your products have a medical system that has not fixed them in any real way. So kind of these aberrations in the world, when we really need to be thinking in a much more socially constructed understanding of disability that takes into consideration how the world operates that can either further disable or conceivably enable an individual. And that comes to bear in the policies that we enact the kinds of social services that we put into place and the environments that we build, and the technology that we innovate, all of these things are societies responsive responsibility to help make sure that people with disabilities can be as fully included is fully engaged in the world as possible. And when we understand disability in that sense, I think it's entirely different, right? It's not, it's not just a problem of the individual, or there were some kind of, you know, weakness or vulnerability within the individual, but a consequence of society's entire ability or lack thereof to make somebody a part of the world and give them the tools that they need to participate.

R

Rob Mineault 27:41

You know, the real kick in the pants, too, is that, and we've said this before, on the podcast multiple times, you know, the disability community is a very unique community in the sense that anybody can enter into it at any time. And chances are pretty good that somebody in the course of their of their life from childhood to old age, they're going to enter into that

community, either temporarily or permanently. So really, right there, that's the selling point in terms of how making our society more accessible and have a more open response to disability itself is going to benefit everybody.

B

Brooke Ellison 28:25

Absolutely. So I'm sure you've talked about this statistic in the past, right that the disabled population is the largest minority population in the world. So 15% of the population worldwide ended up growing, growing really at a rapid pace, whether that's the result of an aging population or people living with the consequences of COVID, Long COVID, mental health challenges that have existed as a result of COVID. All of these things are changing the nature of our demographic or demography in significant ways. But because society has not looked at disability from this vantage point and has understood it really only in terms of its deficits in these people. Being afraid of disability makes people afraid of others disabilities makes them afraid of themselves acquiring a disability. I think that's not a vantage point, or not a perspective that's healthy for anyone to have. This really big population, like you said, where people can come in and out at any point in their last lifespan, like that shouldn't be a terrifying prospect, because we can build a society where the kinds of things that people fear whether it's loss of a job or loss of a relationship or loss of the ability to live in the community with their friends and family like those should not be the logical consequences of experiencing a disability. That's completely fixable. That's completely society's responsibility, to attract more interest so that when it comes to somebody possibly living or experiencing disability, they're not terrified about it.

R

Rob Mineault 30:07

You know, people look at disability as either people are either helpless or they're heroes, that's generally the two perspectives that mainstream sort of sees disability. I'm sure people come up to you, I'm sure all the time and tell you how much of an inspiration you are. And it's interesting, because I heard you speak recently, and I thought you brought up a really good point that I hadn't thought of, but you talk about how while that's really well intentioned and, yes, it can feel patronizing or condescending. The real danger, though, is that, that allows people to kind of stop there, like they feel like they've recognized that your inspirational, and they've done their part for disability, and they sort of stop there. They don't really think about what they can do to actually help the situation. Can you kind of speak to that a little bit?

B

Brooke Ellison 31:01

Exactly. Right. I think that that's exactly exactly the point, how you characterized that as your as people with disabilities as being either helpless or heroes. So I have a nephew who lives to have down the street and down the street from my house. And yeah, he and his brother, they dress up as superheroes right all the time, right? They want to be those heroes. When it comes to disability, you consider somebody a hero, but you don't really want any part of it. You want to hold to hit that heroism at arm's length, don't let me get too close to it, it's not something that I really, really think of as a hero. Because otherwise, I'd want to emulate that or have that part of as part of my life. And I think that's often the kind of in the same vein that when people say, if you've got to be very frequently and say, you know, your life is so inspiring, you're such

an inspiration, or you know, that I could never do the things that you do. And I understand the motivation behind that I understand that people want to pay some kind of compliment, or offer some kind of acknowledgement that what the life that I have lived is difficult, right? It's more difficult than other people's lives, for whatever reason, right? They don't necessarily go any deeper to understand why that's the case. They see circumstances that are different, and by many standards more difficult than they just want to acknowledge that. But without thinking about anything beyond that, like why is it more difficult? What role could I play in it, possibly making things less difficult? You know, you're an inspiration, you know, patting me on the head or, you know, giving me their phone number or whatever, Is that, is that enough? How about actually trying to make the world different for me? I think we all as a society have a role to play in trying to mitigate, the level of difficulty that other people experience. And by just saying, you know, your life is interesting, your life is difficult. And I recognize that I don't think that that's enough, because we in order for the real kind of social change and social movements to actually take place, every question require everybody no matter where they are in this overall spectrum of ability to disability.

L

Lis Malone 33:23

And that reminds me of when we had done an episode with Shawn from from Blind Beginnings, which is the organization that Rob is associated with. She had made the comment that, you know, find the fact that I started a nonprofit, that's the inspiration. It's not, you know, my disability. I mean, and you went to Harvard again, twice, I mean, that it has nothing to do with your disability, because that is just a remarkable feat on its own. And I wanted to just get your thought about, you know, the when you brought up the different models of or schools of thought of when it comes to disability, I mean, one of the biggest challenges is that we what we've talked about on the show is that the various schools of thought, also apply to the, the members of our community, where there's so much disagreement. I mean, many people in the disability community who do subscribe to the medical model, and they want to be fixed and they want to, and, and, you know, I think we've all encountered the situations where sometimes, even myself as a member of the blind community, get pulled in multiple directions. On one hand, it's yes, accessibility, yes, inclusion and then someone else's whisper near oh, but no, but we need you to speak because we need to raise money and we need to fund research because we're going to fix you. So I was just curious what your what your thoughts are in when when it comes to those those sort of converging circles of of influence?

B

Brooke Ellison 35:08

Absolutely, absolutely. This is something that I've struggled with mightily for years and years and years because I fall on all sides of this. And there are many years that I have been ridiculed or called into question for perspectives. I have very strong perspectives I have in stem cell research, advocacy, and finding treatments and therapies to diseases and conditions like that has been work that I have championed for a very, very a lot of time. So I understand the importance of that work, what I come down on is that There shouldn't be really any perspective that people should feel ashamed of. They shouldn't feel like they are not living up to some standard or some ideological perspective, because they feel like possibly they would rather not live with disability that live with it. Like I couldn't say, really, that there's a day that goes by where living with disability would be my preferred choice, right there. The physical consequences that I have experienced, or physical changes in my life that make my life much

more difficult. The fact that I'm on a ventilator, and you should I become disconnected from my ventilator, I would die, right like that is a constant fear that I live with, I can't breathe on my own at all. So it's constantly nagging in my back in the back of my mind, like it wouldn't be quite incredible to live a day or you know, an hour a day or a minute and a day without having to think about that. Or when I have to get me up my lungs suctioned, you know, in the course of a day, or having to you grapple with the physical spasms that I have, in the course of the day, like all of these things are things that I would prefer not to live with. And that does not in any way, minimize the worth, that I ascribe to my life. And I think that that is a really important distinction, that people's desire to not necessarily live with some of the challenges that disability creates is not the same thing as saying that they don't believe these lives ought to exist, or that there's not value to be found. And I can say, without any hesitation, or equivocation that my life lived with disabilities is a much more significant important life than my life really ever would have been had I not live with disability, when I guess I can say that without a second's hesitation. And I know that to be true.

R

Rob Mineault 37:48

And that's such a powerful message, and something that is so counter to sort of the narrative of disability. And those are the messages that I feel like, that's what we need to get out there. People need to look at disability differently, so that we can change it. Because in some ways, you know, trying to legislate change, you know, that's not really going to move the needle. We need to really get in there and figure out this systemic changes and stuff. And and I want to get your opinion. Because there's something that we also haven't mentioned, but you also have had an experience in the political system. So tell us a little bit about about your experience with politics.

B

Brooke Ellison 38:30

I want to touch on that point that you just raised -- none of these arguments are simple, right? None of these debates are black or white, right? They're very nuanced. And unless you take the time to really think them through you could possibly legislate or, or policy make in a way that I think is not necessarily as thoughtful as it could be, right. And so we need to have these conversations, we need to be talking about things and all of their sides, all of their facets and the kind of granular details. Because otherwise we just, you know, use broad brushstrokes for really important things. I think they deserve more consideration than that. We've kind of glossed over this before. So when I was at the Harvard, I was there from 2002 to 2004, I was probably one of the most transformative experiences that I ever could have imagined. I took a class there on leadership and your lab like you know, who's gonna run to the top of the mountain and get everybody to follow. Leadership has an exercise as an understanding of the kinds of challenges that this that society or communities face and how to mobilize people to think about those challenges and your work collectively to address them. Challenging their own biases, understanding the roles that they play, you could conceivably fight that. When it comes to making things better for the greatest number of people, that class was completely motivating and inspiring to me. It was actually in that class that I really gained by voice in terms of things that I could be a part of conversations that I ought to be a part of. And I could have opinions in ways that I never thought of before. Like, I was always a bit of an introverted, kind of quiet or meek person. I wasn't really ever thinking that I could have my own opinions or really your take you to that to the center stage. But that class taught me otherwise. So and I

graduated from the Kennedy School, I came back to Long Island and started a PhD program in Political Psychology, which was immensely interesting, you know, just fascinating, and you dealing with a lot of the questions that the United States is facing right now in terms of political ideology, and what it means and how people become tied to it and all these really complex questions. But I knew that I wanted to get my hands a little bit dirtier, right, especially coming out of that class. So I had met with my local state Senator, he was giving me an award. And we had a conversation, he asked me, you know, what issue is, he should be talking about up in Albany that were of significance to me. And I don't know what he was expecting me to say. But I mentioned the importance of stem cell research and embryonic stem cell research and how, you know, at that time here in the US, there were many restrictions being put on biomedical research is stem cell research, in particular, in different states, most notably California. They were taking it upon themselves to enact state based funding initiatives to fund this really important work. And I said you I think New York should be on the forefront of this. New York is a hotbed of scientific, activity and brilliance and why shouldn't your fee help these kinds of questions? So my state Senator said, you know, well, I don't really know much about the topic, I'll do some research and get back to you. And he never did. So I said, okay, well, that's not the person I want representing me, so let me try to take your job away from you. So I was only 26 years old at the time, and fresh out graduate school, but with a tremendous amount of enthusiasm and optimism and hope for how things could conceivably be done differently. So I ran a state Senate campaign in a district that was a 2 to 1 Republican majorities. I was running as a Democrat. But it generated a tremendous amount of attention. It was endorsed by the New York Times, The Today Show did a feature article, a feature story on my campaign. It was really an incredible experience. And I talked about things that I thought were of tremendous importance to me and can gain some kind of opposition on whether it was access to affordable housing or health care, or environmental protections and education for kids. All of these things that are deeply embedded in who I am and how I think the world can be improved upon. So yeah, so I did that in 2006. And it was a tremendous experience, one that didn't ultimately go in my favor. But I learned an immense amount from and one of the issues that brought me into the race to begin with the state funding for stem cell research. It got enacted here in New York, the incoming governor put together a stem cell research initiative, and I ultimately ended up serving on one of the committees of this board, the Ethics Committee of the Empire State Stem Cell Board is I got to be a part of that. Even though I wasn't elected to office, I was really very appreciative of that.

R

Rob Mineault 44:20

See, I love that story. Because really, I feel like that's the template that a lot of people need to follow. Because this is, you know, part of I think the strategy, the winning strategy anyways to really affect change. It's a little bit of trying to affect change from within. Getting people with disability into the system to address that. It's really ironic because I feel like we have a few examples of how a personal a close personal relationship with disability can really affect an organization or a system. You know, I think that a really interesting example of this is Microsoft. You know, right now we've got, we've got the Microsoft CEO. What's his name? Ryan?

R

Ryan Fleury 45:11

Satya Nadella.

R

Rob Mineault 45:13

Yes. Right? So right here, so he lost his son recently to his to cerebral palsy. But, you know, he brought his that sort of empathy, his perspective on disability, he really changed Microsoft, and the corporate culture. As he's been CEO, and really brought with it, not only not only a change in the in the in the organization, but just more of a inclusive and accessible and diverse corporate culture. So we're seeing corporations, sort of becoming thought leaders in these topics, especially when they have this close personal relationship with disability. So I feel like that could sort of work in in something like a political system.

B

Brooke Ellison 46:09

No question about it. Absolutely. It shouldn't come down to that. It shouldn't take direct experience with somebody with a disability to care about it. But you're absolutely absolutely right, that we need that much, much more prevalently. Right, like any organization can be the testing ground for these kinds of initiatives. One thing that's commonly asked to me is like what can I as your individual X in the community or wherever do to help to help you move through accessibility or disability inclusion forward and that's exactly how. Everybody that lives with a disability you most people, but not everyone will have a family member or friends you will experience disability, but everybody almost everybody is a part of a network or part of an organization or a part of a community with a culture. So be vocal in in those settings. Open a door for somebody with a disability, both literally and figuratively, to to make them you know, part of the group, welcome them and you know, share their experiences. Something that you see in the wild, very isolated and rare situation with people who are deeply embedded and integrated into their communities. That is how social change happens. People understanding that people with disabilities are valuable and not to be feared, and actually can offer really important insights and society is better a better product as a result.

R

Ryan Fleury 47:52

So are you saying we can't use a big stick?

R

Rob Mineault 48:11

Generally doesn't work in history.

R

Ryan Fleury 48:19

Whack a mole.

B

Brooke Ellison 48:22

But it's like, I don't want to minimize the difficulty in that. It's hard, especially when you live with with disability, right? Getting through the day can be difficult, right? It can be burdensome, and exhausting to feel like you have to take on the world every single day. Sometimes certain

days you have more resilience and willpower than you do on other days. But like it's a really important fight and unless it gets fought or inroads are made to get into it, getting thoughts and things are just going to perpetuate themselves.

R

Rob Mineault 49:01

Right? Well, I do want to talk about the new book, "Look Both Ways". Can you tell us a little bit about what prompted you to write the second book and kind of how is it different than that first book?

B

Brooke Ellison 49:17

Sure, sure. So like we talked about "Miracles Happen" was published in 2002. So quite a number of years ago, 20 years ago, that's time of the publishing. And all throughout those two decades, I knew that I wanted to write another book. I knew that I had at least another book in me more than I wanted to write about or to share. But I wasn't quite sure what your what it was going to look like if it was just going to be a continuation of the chronicling of my life or if it was gonna be something different. I wasn't really sure, so I was kind of dragging my feet with it. I was not taking it as seriously as I think could have or should have. But it was around my 40th birthday, I became very sick, I developed a pressure ulcer, which is a problem that is a real risk factor to many people that with paralysis, you know, from sitting in one position for so long. I developed a pressure ulcer and it became very, very infected with all sorts of infections that put my life in question. I was treated, you know, fortunately, I was treated with round after round of IV antibiotics. But I was very close to losing my life as a result of this. So that summer, my birthday was in October of 2018 and for an entire year, up until April of the following year, I was being treated off and on. And then that summer, the summer 2019, I said to myself, you need to get serious. This experience of healthcare needs, ought to tell you that you have to you there's things that are important for people to know about you and about your experiences and the tremendous lessons that you've learned in your life, the depth of your experiences that you need to get on paper. So that summer, I locked myself away in my bedroom. And I just wrote and wrote and wrote and wouldn't let myself experience a day without writing at least, you know, a couple of paragraphs. And just that summer, I put together what was and is one of the biggest accomplishments I ever did. This book "Look Both Ways" is tremendously important to me. Deeply personal, so not so it starts with some background in terms of my accident and what happened to me. And then I delve into really difficult questions that people with disabilities experience, you know how to navigate the world, especially you somebody who is ventilator dependent, really, like how do you incorporate technology into your life. I talk about what it means to be the disabled individual in a family, and how difficult that was, and what that meant to my sense of identity and how I misunderstood my family members' roles in my life, and what kinds of things they were dealing with. The grappling with at that time, and how I've been approached by other families who experienced in my circumstances and kinds of advice that I've given them. And then I talked about instances of infantilization and invisibility that I think was very common among people with disabilities. And then I kind of turn things around and look at the virtues of disability, the kinds of really important strengths that I gained, and lessons I've learned that are central to who I am right now and have made me you know, a stronger and more vibrant and more accepting and all around better person. I think, you need to look at both the difficult times in your life and the strengths that come out of that in order to fully understand who you are. So the title really is a recognition of that, right? And look, both



ways could be understood as like, you know, the the, the advice before crossing a road, right, obviously, that's kind of the obvious interpretation that people might have. But it's much deeper than that. We need to really look at all parts of our lives in order to understand the beauty of them.

R

Rob Mineault 53:36

I just feel like I could talk to you all day. We would absolutely love to have you back because there's so many other ethics questions I have. I have questions up the wazoo.

B

Brooke Ellison 53:49

I'd be delighted to come back.

R

Rob Mineault 53:51

Well, excellent. Well, thank you so much for coming. Coming on for round one.

R

Ryan Fleury 53:56

Where can people find out more information about you?

B

Brooke Ellison 54:00

Absolutely. Well, I have made my website is kind of the hub for a lot of this [www.brookeellison.com](http://www.brookeellison.com). There's places to reach out to me on my website. And yes, my book is available on Amazon and Barnes and Noble and yeah, I think it was one of the most important things I've ever done. So I think people who are interested about and interested in knowing more about me would gain a lot from from reading that.

R

Rob Mineault 54:43

And we'll be sure to actually include that in the show notes. So anyone who's listening, just go to the show notes and will include the Amazon link to that one. Thank you. Well, thank you so much again, best of luck with everything and come back anytime.

B

Brooke Ellison 54:59

Be a delight to do that. I really enjoyed the conversation thoroughly. And I admire the work that you do.



**L** Lis Malone 55:08  
Thank you. And we'll practicing "abouts"

**B** Brooke Ellison 55:14  
I am really going to be an honorary Canadian.

**R** Ryan Fleury 55:17  
Definitely

**B** Brooke Ellison 55:22  
Maple syrup testing

**L** Lis Malone 55:33  
Great to meet you, Brooke.

**R** Rob Mineault 55:35  
Nice to meet you. Bye. Well, once again, feeling like an underachiever.

**L** Lis Malone 55:43  
I know!

**R** Rob Mineault 55:49  
How many times you go to Harvard?

**R** Ryan Fleury 55:54  
I've never been to Harvard.

**R** Rob Mineault 55:59  
You know, I'm going to start a school called Harvid.

**R** Ryan Fleury 56:01  
I went to Harvid for three times.

**R** Rob Mineault 56:02  
They won't even let me on the campus. Such an interesting conversation. I love it. I love her perspective on things.

**R** Ryan Fleury 57:14  
Yeah. And I don't know if the movie is still out there. My wife and I had watched the movie years ago. Yeah, it's been years. And I don't even think it had audio description. It might now but it was really good. And, you know, I haven't looked at the books, but I'm sure they're available from our online libraries as well. Yeah. Yeah. I'm totally gonna read I'm gonna read Look Both Ways. For sure. So I encourage everybody out there to do the same.

**L** Lis Malone 58:18  
There's Kindle and hard hardcover, no audio.

**R** Rob Mineault 58:26  
You know, and especially, you know, even with something like stem cell research, because back in whatever it was, it would have been the late 90s or whatever, that was a whole there was a conversation around that and there was, there was a lot of controversy. People didn't think that we should be doing it. And, you know, that directly impacted a lot of research that that was being done and probably did impact it for years. I mean, I'm sure that things are better now, but it definitely slowed things down. Lots of lots of really interesting conversation, so we'll definitely have to have her back.

**R** Ryan Fleury 59:00  
Indeed. So there you go. There you go.

**L** Lis Malone 59:06  
Good. Guest Yeah, yeah, I don't even know. Ya know, her press people reached out to us.

**R** Rob Mineault 59:26  
Yeah, it's always a good sign when our guest has a press person.

R Ryan Fleury 59:31  
Because Lis is our press person.

R Rob Mineault 59:35  
Lis is our press person if I ever have to, if I ever decide to get interviewed, I'm gonna just direct them to Lis. I'd be like yeah, no, just talk to talk to my press person.

R Ryan Fleury 59:47  
I have emailed her, but she never replies. So she's either really really busy, or I just don't pay her enough.

R Rob Mineault 59:55  
Yeah, that could be. Returned emails are based on a sliding scale, so let's see .. let's do the math on zero. Delete.

L Lis Malone 1:00:14  
Zero equals a block.

R Ryan Fleury 1:00:19  
Mark as spam.

L Lis Malone 1:00:24  
I haven't heard from Ryan. Oh, I haven't checked my junk folder in awhile.

R Rob Mineault 1:00:36  
There you go. All right. Everybody ready to go?

R Ryan Fleury 1:00:39  
Yeah, dinnertime. All right.



**R** Rob Mineault 1:00:42  
Let's get. Let's get out of here. Hey, Lis. Where can people find us? The cheque is in the mail.

**L** Lis Malone 1:00:53  
Oh, please I've heard that. Aside from the cheque, we can be found [www.atbanter.com](http://www.atbanter.com).

**R** Rob Mineault 1:01:02  
Hey, they can drop us an email if they so desire at a cowbell. [at@banter.com](mailto:at@banter.com). Well, I heard that we've got some sort of social media stuff. But yeah, maybe people should just kind of look around. Yeah, that's right. But especially Instagram or Facebook, perhaps?

**S** Steve Barclay 1:03:52  
Yeah. Probably a good place to start. Yeah. Yeah.

**R** Rob Mineault 1:03:55  
Yeah. Hey, so can I just say to and I'm gonna tickle the audience with a feather a little bit and give you guys a heads up but yeah, we got some we got some plans going on for the the anniversary show in a couple of weeks. So expect expect an email soon. with all the deals.

**S** Steve Barclay 1:04:13  
I will wait with bated breath.


**R** Rob Mineault 1:04:15  
So check your spam folder.


**S** Steve Barclay 1:04:17  
No serious at all. I'll eat like herring or something.

**R** Ryan Fleury 1:04:21  
Don't hold your breath though.


**R** Rob Mineault 1:04:23


 Rob Mineault 1:04:25  
Yeah, that's right. Oh, I just got that.


 Ryan Fleury 1:04:27  
The bated breath?

 Rob Mineault 1:04:28  
I did. I know about as much about fishing. But you catch up catch fish with other fish?

 Steve Barclay 1:04:48  
That is a traditional way of doing it.

 Rob Mineault 1:04:50  
Monsters. Cannibal fish. Well, we've learned a lot today. Rob. Yeah, well, your precious. Lis is gone.

 Lis Malone 1:05:14  
Oh, goodness.

 Rob Mineault 1:05:15  
All right. Are you ready to go?

 Ryan Fleury 1:05:18  
Yep.

 Rob Mineault 1:05:21  
Well, that is going about do it for this week. Big thanks to Brooke for joining us. And we will see everybody next week.