EPISODE 1203

> *"**ERB:** We hear ableist language all the time: crippled economy, that's so lame. Those are ableist words and we don't think about it because like CNN anchor people say them."*

[INTRODUCTION]

[00:00:45]

FT: Welcome to So Money, everybody. I'm your host, Farnoosh Torabi. We're exploring financial issues at the intersection of ableism and money. If you are disabled in this country physically, mentally, we know that comes with a host of challenges. Our country has many systemic problems when it comes to dealing with the disabled population. Many, many inequities, particularly financial ones.

Our guest today is Emily Rapp Black and she's going to help us explore this through her own personal journey of becoming an amputee at the young age of six. Emily is an American memoirist. Today, she's written multiple books. Her latest is called, *Frida Kahlo and My Left Leg.* In addition to being a writer, Emily is also a scholar, a recipient of the Fulbright scholarship. She was educated at Harvard, Trinity College in Dublin, St. Olaf College and the University of Texas Austin where there too, she was a missionary fellow. She's currently an associate professor of creative writing at the University of California Riverside. She's a member of the Inequities in Healthcare Working Group. Her new book explores art and disability through the life of Frida Kahlo.

Here's Emily Rapp Black.

[INTERVIEW]

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FT: Emily Rapp Black, welcome to So Money.

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ERB: Thank you for having me.

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FT: Congrats on your forthcoming book out in just a few weeks here. The new book you have is *Frida Kahlo and My Left Leg*. This is your fourth book?

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EPB: Yes, that's right. Correct.

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FT: You're a prolific author on top of —

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EPB: I don't know what's prolific, but —

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FT: Well, I would say so. I mean, most people don't even write one book, you've written four and New York Times best-selling, and that you are an academic, a scholar, a teacher. We're going to talk about your life's work, but also want to talk about what led you here and what has been often the jumping point. At least for your first memoir was sort of going back to your childhood. That was the memoir you wrote called, *Poster Child.* This was about your life as an amputee, realizing at six years old that you're going to have to go to this radical transformation. Take us back if you would to that period in your life.

Specifically, the question I have is, when you learn the news — and by the way, at six, you were also I believe — it's called *Poster Child* because you were made the poster child for the March of Dimes. You lost your leg, so suddenly you have to grapple with this public sort of embrace of your new body, but at the same time, I'm sure there are other feelings and other learnings at such a young age. Take us back to back and talk about the feelings that you had about yourself and your place in the world at six years old when you discovered that you are going to look different.

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EPB: Well, I mean I think when I was six, I didn't really — thankfully, understand the full implications and impact of what that would mean for my life. My daughter is seven and she's so matter of fact bodies and is always saying things like, "Oh! Mommy's leggy" and she wants to show it to people. I'm like, it's not a party trick, but still, I mean, she's like — she's not weirded out.

When I was a poster child, I actually loved it because I was like, "Oh! All this attention, I'm so special. This is great. What could be wrong with this?" Then of course, I hit puberty and I was like, "Everything is wrong with this." It's like everyone feels only with an additional sort of clunky wooden leg to go along with it. I think that was — I had a really happy childhood actually. My parents never had a lot of money and in fact, my dad worked two jobs to pay for my prosthetic limbs, which were not that advanced, but they were still expensive for them, even though they had insurance. I don't know. It was a very sort of rural, Western, lots of ranches, and horses and lots of hard work, physical work. I really enjoyed that.

I never felt like my physical body was limited. There are certain things I couldn't do, but of course, that's true of everybody. Not everyone's going to be a hurdler for example or a gymnast. But I felt like — I figured out how I wanted to do things and I did them. It was more of the emotional stuff that came later that was harder to unpack and unravel.

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FT: Was that the impetus for poster child start exploring those emotions and coming to terms with them. Tell us about what why you wanted to tell — what was the story you really wanted to tell?

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EPB: I wanted to talk about that it's true — I've read a lot of books about disability. There are two tracks. The sort of sad, really, like tiny Tim-ish kind of, "Oh! Look at the happy, but really depressing-looking disabled person." Then there's the athlete. Those are the two sort of polar opposite narratives that we're used to hearing like, "Oh, poor person" or "Oh, wow! Extraordinary person." I was like, there are plenty of people who just live their lives in different bodies and just get on with it. Like I felt really pushed to be on the athletic side. That's what what I chose for some time, but that also isn't sustainable.

I wanted to write a book that was basically like, this is what it's like to live a life in a different body. It's not so different or not so different or tragic than anyone else's. Even though there is this additional struggle. A lot of it is financial, a lot of it is emotional, a lot of it is societal, because we have lived in a very ableist culture. I mean, I wanted to track that middle ground.

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FT: Well, at the intersection of emotion and money, I was reading about how you wrote like, there was a point where you couldn't gain much weight. You're told to sort of try to not gain weight, because otherwise, you'd have to be in a wheelchair. What was that like? Because I feel like that's rough, that's a lot of pressure.

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EPB: Well, I mean, when I wanted to have children and the second time I was pregnant actually, I went into the leg guy, the prosthetist and I said, "I'm pregnant, whatever." He said, "Well, you don't want to get too big or you'll be like a pogo stick." I'm like, "Are you kidding me?"

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FT: Who said this?

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EPB: A professional, a medical professional in 2013. I'm like, "Dude?" I talked about that actually in the book. Yeah, I mean, they they're like, "Basically, you'll grow out of this leg. You have to get another leg made." In places like the UK, the National Health Service just covers that for pregnant woman. They just get a pregnancy leg. I didn't have that, so I was super, super careful. I did not gain a lot of weight. I gained just enough to make a baby, but not enough to be kicked off my prosthetic leg. That's like in another level of stress, because I don't have $50,000 lying around.

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FT: Yeah. I mean, talk a little bit about the expense that goes along with this. You brought up the UK, there are — sadly, as developed as we are as a country, we are so behind on some really basic stuff, including taking care of our citizens, including our disabled citizens to tell us badly. You have good healthcare.

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EPB: I have a great healthcare.

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FT: Yeah, a great healthcare.

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EPB: The one I had. I mean, my mom and dad always emphasized to me like, "You can never just not be covered, you have to." Because I have a preexisting condition, no one will take you. If no one will take me, I can't get the prosthetic that I need to do my work. But then it's my fault for not working, because I’m not trying hard enough. It’s just lots of ripple effect there in terms of our social inequities and deficiencies frankly.

Yeah, the average leg and I don’t have a super state-of-the-art one is about $50,000. I am out of pocket for the new ones, which I haven’t had. I don’t have new ones made that often, like three to five grand. Every couple of months, it’s a couple of grand for like parts and stuff that gets worn out.

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FT: The luxury car.

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EPB: More than luxury car. The other prosthetic limbs that celebrities have are like millions of dollars. They take a graft of your skin, they match it exactly, they have these computer knees. I always had like a little wooden leg, so I just want it to function so that I can be active and do the things I do and be athletic without having to run a marathon. Mine are actually on the lower end I would say, of pricing and still a lot.

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FT: In some ways, when this happened, you were six versus maybe somebody who was 36. You’ve had a lot of years to sort of get used to this and have it feel normal. Although, I don’t know how it feels, I don’t want to assume that you wake up every day feeling normal or whatever normal means. What are some things that you still feel like you miss out on or this has maybe been a roadblock for you?

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EPB: I would say that probably — first of all, let me answer the normal question. I definitely fell like this body is the only one I’ve ever known, but now it’s getting to be like in my 40s, I’m like, “What’s happening? I don’t know this body? Why?”

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FT: Oh, please. That is very normal indeed, yes.

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EPB: It's not something that I think consciously until I have to, and then it's like a massive pain in the butt. But I will say that it's not so much I have to say, I always wonder what it would be like to be a man with a prosthetic limb. Like I think my life would be really different if I had been a man. just because as in most cases, prosthetics are first made for men and then for women. I used to go into prosthetic clinics and there would be pictures of men everywhere and none of women. Then I once asked someone, "Why aren't there any female athletes? Because I knew some, I was one." They said, "Nobody wants to see that."

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FT: This is a whole Pandora's box. I've talked to men and women who are in the drug and medicine field, and you're right, there is a whole like so much sexism that goes into effect, like with all the trials and one even is on the market. That's a whole other show. But that's interesting that you picked up on that quite quickly.

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EPB: Well, I also had to wear a man's foot until I was about 20, because they didn't make feet for little girls. Of course, I'm actually pretty tall, but I have elf feet as they call them. I have size six feet and I'm almost 5'9". So it's like tiny tinny and I have massive like man foot. So two pairs of shoes. My parents had to buy two pairs of shoe so that I could walk in shoes. I mean, it's just like, "Come on! That's changed."

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FT: You wrote a book recently, your fourth book, which I want to talk about. You are prolific, I will say that again. The book is called again *Frida Kahlo and My Left Leg.* I honestly don't know Frida Kahlo had a disability. I didn't know that she didn't have a leg.

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EPB: Yeah, I know. A lot of people don't. They think of her as like the woman —

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FT: I knew that she had a unibrow. I didn't know anything else.

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EPB: [Inaudible 00:11:33]

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FT: As a child who had a unibrow, I love Frida Kahlo for walking that.

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EPB: Yeah. I had been really interested in her from a young age. I saw a photograph or a painting that she had done called *The Broken Column*, where basically her whole spine is like a railroad track and I was in a lot of back braces as a kid as well and in traction. She was also an artist and that appealed to me. I read her journal when it came out. When I went to the Casa Azul, they had just showcased her corsets and her leg for the first time behind glass, with like security guards looking very stern and ready to scold.

I just kind of had this eureka moment where I was like, "Oh my gosh! I feel really weird right now" and I was pregnant with my second child and my first child had died like a year before, a horrible terminal illness. I had a kind of emotional tornado and so I started writing about it. That became an essay and it became the book.

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FT: What most did you connect with her in terms of her journey, and her life and what you are living?

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EPB: I think that she had a strong sense of privacy, which people never think about someone who does portraits for memoirists. I think I share that with her. Obviously, I can't ask her because she's not living. But I write memoirs, a way of maintaining privacy because people will make assumptions about my life. If I say, "Here's a book about it," then the conversation stops and I can maintain my own privacy.

She did self-portraits and people are like, "Oh, you know, she's just like public striptease kind of thing." That's not what it was. It was basically saying like, "I'm going to control the narrative because it's the thing that I can control." She did suffer a lot of physical pain. I did as a child, not so much as an adult. She created despite that not because of it. People are often like, "Oh! Pain is a muse." I'm like, "No, it isn't." Pain is just pain, but she find a way. I really responded to that because I feel like a lot of my life has been finding a way, whatever that meant.

That, I don't want to say inspired me, but it made me feel like I had like a role model. Also, she kind of had this fantastic physical presence, that was distracting. She was really into fashion, so am I, which I can't tell from what I'm wearing. But the outward appearance was a way of passing in a world that is very dismissive, anyone with a different body. I did that in early age. Be funny, dress well, be smart, be as pretty as you can. Then maybe you can pass.

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FT: Then you do all those things, right? Excel at all those things. Don't you feel like — what's at the end of that?

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EPB: No, that's it. That's kind of like what Poster Child is about. It's like that crash and burn moment where I was like, first, I can't keep this up. It's like too much work. Secondly, what's at the end? What's the end of all? Self-acceptance and sort of coming out as a disabled person had never been something even crossed my mind. That was a massive sort of like emotional iceberg if you will that I had to write out for a little bit. Yeah, I think — I teach a lot of writing students with disabilities and I have a class right now and we're talking about disability dulas, which is basically someone who — like someone like me who's had an artificial leg for 40 some years and someone who loses their leg in a freak accident. How does that person support the other person like as a mentor and saying like, "Here's some ideas how to advocate for yourself in the healthcare system" or "Here's some things that worked for me" and all those things. Just some dialogue happening about that. But it's still, we hear ableist language all the time: crippled economy, that's so lame. Those are ableist words and we don't think about it because like CNN anchor people say them.

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FT: Right, and I've probably said that stuff.

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EPB: We do. I say lame. I'm like, "That's so lame."

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FT: I say lame all the time. Was there a parallel between Frida Kahlo's journey to self-acceptance in your own? If not, how would you characterize your coming to terms with it? Was there an experience, a moment or a series of moments?

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EPB: I think it's just an evolution, like I don't know if I can pin point one thing. I mean, I definitely think having a kind of like borderline nervous breakdown in my 20s was like to try to accept it was a moment, a big moment. I also think just with age, it just — things mellow out and you just realized that the world was actually never a hundred percent open to you as promised, and you come to terms with that and it houses up things. I think more for me, it's become a kind of springboard for other things in the world that I'd like to see change, like sexism, and racism, homophobia, like all those things are interrelated, they intersect in many ways.

I also just think, Frida Kahlo was, she definitely has this iconic status. She's on socks, on magnets. She's one of the most recognizable faces in the world. If not the most. People didn't really know a lot about her life, but they thought they did and that appeals to me a lot, because I think that's very synonymous with — a lot of people think they know me because they read my books, but they know that narrative, they know that story and that's controlled, and it's crafted c and it's careful. That's different than who I am just in my body, in an everyday situation.

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FT: I was going to ask, although I think you pretty much answered it. But if there's more to say, I'm going to ask it again, just that correlation or connection between your life's struggles and pains, and the creative and professional traces that you made in your life. Looking at your bio, you're very curios, you're an academic, you're a Fulbright scholar. What is that relationship? I mean, part of it I hear is, you want to be able to control your story. Part of it is, pain is just pain and then there's, your professional life is like something else, but is there more to be said about that?

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EPB: I mean, I always thought and I don't know if this is — I've read Frida Kahlo's diary and some of her letter, and I don't know how — I think her sense of community was more of a radical political community, mine was not. But I think it comes down to community. I grew up in an intergenerational nest if you will. Because my dad was a pastor, so everyone was so different. Like there's so many older people, I love hanging out with older people, and I love being with the little kids. I had this sort of scope of the lifespan. I think that really serves me in the professional choices I've made because in this particular sort of Swedish Protestant culture that I grew up in, it's all about helping people and being of service. I really think that writing is that, it serves people. It's like you write a book you wished you had to read when you were going through the thing that you're going through and someone gives you a book where at the end like everybody dies. It's super helpful.

You want to write something that's going to provide soulless to the person who's sitting on the floor of the hospital room and like feels completely alone, and not seen, or heard and just so isolated. That's kind of why I write books, and I think that it has to do with the community that I was born into. With Frida Kahlo, she was very provocative in her work, like she did things people didn't like, that no one had done. She talked about issues that nobody wanted to address. She busted through stereotypes and I think a lot of that was just that she had aligned herself with kind of radical community of artists and thinkers. It probably encouraged and emboldened her to do that.

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FT: Where would you like to see the thinking shift when it comes to issues related to ableism , or we talked about some of the words that we use that are not helpful in society, and we've talked about the healthcare, the financial toll in your case and I'm sure a lot of cases where your needs are not covered. But where do you think we need to shift the conversation, or what are some questions that you want more people to be asking in this space. Frida Kahlo had that sort radicalism in her life that was supportive, what is the radicalism that we need today?

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EPB: I mean, I think it boils down to this sort of singular fact, which is that everyone will have a disability if they live long enough. You're either a decade, or a random disease or an accident away from having one. This kind of full separation, like people say to me a lot like, "Oh! I couldn't do what you do." It's like, "Yeah, you could because you have to. Otherwise, what are you going to do? Nothing? No. That's not what people do. They don't just lie down and just not do anything." It's like, bodies change, bodies are different just because of a body uses a wheelchair, a body uses seeing eye dog doesn't make that person less valuable or less capable. It's just that their capabilities aren't like everybody else's. That's a positive thing.

I think a lot of it has to start to with the kind of — People are saying like, “Oh! Having a disability is an absolute tragedy.” That’s just not true. It’s certainly an identity shifting moment and it’s not easy. I wouldn’t say, “Yay! Let’s do that.” It’s not like something I would suggest as like a resilience-building exercise, but it’s also not tragic. If you think of it as like something that you’re going to have to contend with at some point in your life, then kind of get on board with like valuing all bodies because some day, you’re going to need those services and you’re going to be like, “What happened?” Ableism. Pretty been busy fighting all those years.

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FT: You think some of that reckoning would have happened in the last 14 months, where with COVID, the people who survived COVID even, long-term disability some of them. Still, we don’t know the what the repercussions are going to be for people. Sometimes, extreme things have to happen broadly in order for a sweeping change. You’re seeing that a little bit on issues pertaining to race in this country, and family care. Those were like the fractures that were only were amplified I think in the last year because of the things that we had to go through. I hope that’s not what we have to do to understand exactly what you just said, that we all are going to experience the disability probably at some point if we live long enough. Are you hopeful that we’ll get there?

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EPB: I mean, I think it’s kind of the final frontier in some sense because it’s also very, you can be any color, any class, any age and fall into the disability camp with us. Welcome! I think it’s hard to focus the agenda in a way that other movements have been able to do. I am hopeful. I mean, I’m hopeful and I mean, you know, every once in a while, I’m in the grocery store and I’m having a conversation usually with an older man, who’s asking me questions. I’m just like, “I really just — no. This conversation has — ”

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FT: What are they asking you? What annoys you? Tell me what’s so annoying? I mean, there are so many things.

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EPB: Yeah. It's like —

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FT: I probably asked annoying questions a lot.

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EPB: I'm sure I have too. It's like people taking elevators. It's like, what happened to you? What's wrong with you? Like you're in an elevator, you've just met this Rando, right? They're like, "Oh! Do you shower wearing it?" I'm like, "Okay. Now we're talking about me taking shower." Like what? All the time, so many times.

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FT: Now, **[inaudible 00:23:07]** I'm not sure I like where this is going.

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EPB: Right, or how far does it go up? I was asked that at a faculty symposium, which I can say now that I have tenure. From across the room, two dudes shouting, "How far does it go up?" I turned around, I was like, "Nope." I shouted back. I was like, "The only way to know that is if I took my clothes off, which I don't want to do." But yeah, those kind of questions I get asked all the time or I'll be all like, I will walk with a limp, someone will like limp up to me like, "Hey! What's up with your bombed leg." I'm like, "Why are you doing this?" Like it's a joke. Or like, "Hey! Someone is an intruder." All the time. "If there's an intruder, you'll have your leg taken off and hit the person, because that's going to work.

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FT: Because that's your instinct.

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EPB: Or you have a 105-year-old grandfather who lost his leg, "You remind me of him."

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FT: Oh, thanks.

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EPB: "Do you know this amputee like person?" I'm like, "No, we don't all know each other. There's like eight million of us. I don't know that person." That's just so funny. It's funny but it's also sad.

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FT: Earlier, you're talking about these two extremes, where there's like the athlete, the Olympian and then there's — or the war hero, and then there's tiny Tim and you want to be a voice for the many who are in the middle. Who else is doing the good work? Who's else is on the frontlines? Are there communities? Are their resources? Where should people turn to?

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EPB: Yeah, I turn to writers, Julian Vice, Meg Day, Molly McCully Brown. There's a series in New York Times called *Disability*. It was like a series of essays around becoming disabled was the first one. Rosemarie Garland-Thompson who's one of the architects of disability studies and academic discipline, like started a few decades ago and has gained traction since. That collection of essays or op-ed pieces was compiled into an anthology called *Nothing About Us Without Us,* which was an early disabled rights mantra, when they were shouting in the streets and protesting in the '60s and '70s.

That's a great way to start because I learned about a lot of different kinds of conditions and embodiments that I wasn't aware of. That would be a place to start just for someone who's never thought about it before and there are a lot of great resources. *Beauty is a Verb* is a great sort of collection of poems and essays. There's definitely work happening that works and that space, still needs to be diversified in terms of race and class and sexual orientation. But I think that that's also slow-moving moving process, because publishing is still very white. I look to writers. Ilya Kaminsky, a deaf writer, poet. There's a lot. I think part of it has to do with social media because people are just like showing their bodies in a real way, also while curating a particular brand of some kind. But it's like, that never would — obviously, there was no internet when I was growing up. Thank God.

But you know, no one was going to be showing pictures. You just didn't do that. Now, that's so much a part of the culture. People are claiming their different bodies, just because that's part of the culture now.

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FT: Like that gentleman told you, we don't put a disabled woman on a poster. Nobody wants to see that and yet, yeah, we do actually. We need to see that. What are the untold stories that you have yet to write? Because I think you've got more books in you're really talented and funny. I hope you will continue to write important books, but what do you think is next? That's a horrible question to ask an author. It's hasn't even come out yet, her latest but —]

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EPB: I want to do more like writing for TV. I have a couple of writing partners. We've done a few sort of trying to send things out. I love that. It's super collaborative. I'm working on a book called *I Would Die If I Were You,* which is a collection of essays that kind of covers these topics in a humorous way. It's also about craft and what I've learned about teaching, about writing from teaching. Then I want to work on a novel that I've been like working on for a really long time, which about is sort of a woman has an experience of the afterlife while she's still living. There are a lot of projects.

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FT: That like that show *Soul*, that movie *Soul.* Have you seen that with your daughter? It's a real favorite in our house. It's so existential and deep. I don't know. My kids love it.

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EPB: I know. Kids like that stuff because they know —

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FT: They get it.

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EPB: Yeah, so those are my upcoming projects, the ones that I'm working on, in addition to having my business and teaching, and all the things.

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FT: Yeah, you're just a little busy. But in the meantime, I hope everybody will check out your latest, *Frida Kahlo and My Left Leg*. Emily Rapp Black, thanks for joining.

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ERB: Thanks, Farnoosh.

[END OF INTERVIEW]

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FT: Thank you so much to Emily for joining us. Her book is available on preorder and that link is on the So Money podcast website. You can learn more about her at emilyrappblack.com. See you back here on Wednesday when we're talking about the financial benefits of equal shared parenting, important advice for divorced couples. Thanks for tuning in everybody and spending part of your day with me. I hope your day is so money.

[END]