

The logo for 'JUST 3' features the word 'JUST' in a yellow, sans-serif font, oriented vertically. To its right is a large, bold yellow number '3'. Below the text is a horizontal bar composed of three segments in shades of blue and white.

# JUST 3

## JUST THREE Podcast: A Conversation with George Estreich

Episode 7

February 24, 2021

Host: Catherine LaSota

Total Length: 26:58

[*Music*]

[00:06] **Catherine LaSota:** Welcome to the JUST THREE podcast, a project of the [Center for the Study of Social Difference](#) at Columbia University. I'm your host, Catherine LaSota. On the JUST THREE podcast, we talk with artists, activists, and other scholars who are deeply engaged with issues of social justice.

On each episode of our podcast, we have one guest, someone who's connected to one of the many working groups here at the center. And on each episode, I ask the same three questions: one, how does your work engage with issues of social justice? Two, what do you see as the biggest social justice challenge of our current time? And three, how can we foster ethical and progressive social change? I hope you enjoy this episode of the JUST THREE podcast.

[*Music*]

[0:54] **George Estreich:** I think that the longing is the ideal that we are working towards, and writing is, at least in a small way, can kind of push the needle in that direction.

[1:08] **Catherine:** Today on the JUST THREE podcast, I have the pleasure of speaking with writer and musician [George Estreich](#). George Estreich blends personal narrative and scholarship in his writing, to argue that, with biotech able to select and shape who we are, we need to imagine what it means to belong. George Estreich's publications include the chapbook *Elegy for Dan Rabinowitz*, and a full-length poetry collection called *Textbook Illustrations of the Human Body*. *The Shape of the Eye*, his memoir about raising a daughter with Down syndrome, received the 2012 Oregon Book Award in Creative Nonfiction, and his book *Fables and Futures: Biotechnology, Disability and the Stories We Tell Ourselves*, was named the Best Science Book of 2019 by NPR's Science Friday.

George's most recent writing project is his collaboration with Rachel Adams on Alison Peipmeier's [\*Unexpected: Parenting, Prenatal Testing and Down Syndrome\*](#), which was recently published by NYU press, and celebrated in a launch event hosted by the [Motherhood and Technology working group](#) here at the Center for the Study of Social Difference. The Motherhood in Technology Group explores how technological innovations have radically transformed the biological and social experience of motherhood in recent decades.

It was my honor to talk with George and to learn more about his work. Our conversation took place on February 12, 2021.

Welcome to the JUST THREE podcast. I'm so excited to be here today with George Estreich. And before we get started with our three questions, I just want to welcome you George and say hello, and ask if you could tell our listeners where you are right now, a little bit about how you're doing, before we dive into our three questions.

[03:06] **George:** Thanks so much, Catherine. I'm really happy to be here. My name is George Estreich. I live in Corvallis, Oregon, on the left, you know, near the left coast. And like everyone else, I'm adjusted to this pandemic as best as I can. So we're holed up and doing okay. Writing, reading and we have, you know, three screens on in different corners of the house at any given time.

[03:36] **Catherine:** Sounds very relatable, George. Yeah. Thank you. Thank you for that. So as you know, the questions of the JUST THREE podcast are very broad, and we welcome people to answer them however they see fit in whatever way intersects with your own expertise or what you feel like speaking on. So with that in mind, I am going to go ahead and get us started with the very first question, which will be a nice introduction to more of what you do, I think and that question is: how does your work engage with issues of social justice?

[04:10] **George:** So the short answer is through writing, and, you know, I started as a poet and, and now write prose mostly. But in writing I, I try to use personal experience as a springboard to raise questions about belonging. And more and more, I try and use a critical approach looking at texts, looking at advertisements to think about belonging and its obstacles. So that's the short version.

The longer—slightly longer version is that, you know, I kind of describe myself sometimes as a poet who wandered out of his enclosure. You know, I began, I got an MFA in poetry and I was mainly interested in writing mostly short poems, mostly personal. And then my younger daughter, Laura was born and she was diagnosed with Down syndrome. And I kind of switched overnight to prose. I realized pretty soon I was going to write about it. And I realized I wanted to connect with people. And though you can write poetry about Down syndrome, it didn't feel like the right form.

And looking back, I think that this was the first time where I was really beginning to think about audience as opposed to like, if I perfect this little thing, then, you know, five or six people in the



world will read it and enjoy it or whatever. And this time, it was not, I didn't think of it as a didactic impulse. But I realized I had a relatively unusual experience, and something to share.

So, in retrospect, one of the things I was trying to do was present an image of ordinary belonging. In other words, I was writing about Laura, and about my own, you know, feelings coming to grips with the fact of Laura and reckoning with the, with the diagnosis. And I came to realize there are so many meanings plastered on people with Down syndrome, and most of them are wrong. That I was trying to tell a story about one individual, like a little girl in the Pacific Northwest, started out with some health challenges and then got beyond them. But whenever you tell that story, you're telling that story in the shadow of all the other stories. And so part of that book became about debunking the other stories, about exposing them, about showing the extent to which ableism kind of infects our understanding of the syndrome and, and eventually tracing that back to history. In my case...this also intersected with an understanding of race.

My mom is Japanese. And as it happened, Laura, when she was born, no one knew whether she had Down syndrome or not because people suspected it, but then they were looking at her eyes, and they're thinking, well, maybe is, you know, maybe this is her Japanese heritage, maybe this is an extra chromosome. And this was an odd moment I later learned, because the original diagnosis, the original name for Down syndrome, was Mongolian idiocy, it was a 19th century diagnosis that was racist, that held that people with the syndrome had essentially fallen down the human hierarchy in the womb.

So what I had in my life was this intersection of 19th century error and 21st century science, because we had to do there, you know, there had to be a test to determine the meaning of her appearance, hence the title, *The Shape of the Eye*.

This is getting a little bit further afield, far afield from the question, the original question, but it was my first insight that different prejudices are entangled. That they...I think of it as kind of a, like intersectionality in the upside down, like an evil intersectionality, like in the sense that they can...that different prejudices reinforce and underpin each other. And so I kind of...because this was personal in my life, because this knot of race and disability and error was personal, while telling Laura's story, I explored that. So that was *The Shape of the Eye*.

In the next book, *Fables and Futures*, that takes a broader view, not just about Down syndrome, but thinking about disability, and specifically, thinking about the stories we tell about disability given the power of new technologies. And the book's premise, basically, is that we have new technologies that can both select and have the potential to shape future children. In other words, we're talking about just the ability to prenatal testing and the sense to discern features about a future child. And, potentially, with CRISPR, the genome editing technique to alter future people.

To me, the existence of this technology raises a question of belonging. If we can select and shape future people, then we are really talking about which bodies and minds matter. Our

exercise of the technology and which technologies we choose to develop reflect our values. This makes stories urgent: what stories we tell about people whose bodies are different, whose minds are different, are more important because they will feed into the choices that we make.

So I tried to explain a little bit about the technologies, I tried to look at the ways that people with disabilities are talked about. And much more than in *The Shape of the Eye*, to let people with disabilities speak for themselves. Like if someone, you know...I can't speak to the experience of having Down syndrome, but I have Laura's trust on that. And, you know, I hope, a parent's care to do that, ethically. If talking about how a little person might think about a test for achondroplasia, for one form of dwarfism, I'm just going to quote that person and get out of the way. And so that's jumping ahead to question three about how we can foster social change. But, you know, one of my big things is, is, you know, knowing when to step back and knowing what I can speak to.

And then the last book I would talk about is the one that's just about to come out. And it's not mine, it's a book by Alison Piepmeier called *Unexpected*. And Alison was a brilliant scholar, and activist, and all-around force of nature, and a friend of mine. And she died of brain cancer in 2016, at the age of 43. She had a daughter, Maybelle, who has Down syndrome. That's how I came to know her. And, you know, before shortly before Alison died, I spoke with her about completing her book which was unfinished at that time. It was a manuscript that blended personal report with talking about maternal—the decisions made by prospective mothers, when faced with a diagnosis of Down syndrome in utero, and also about the experience of motherhood. A lot of qualitative interviews.

So long story short, Rachel Adams, a writer at Columbia, and scholar who also has a child with Down syndrome, Rachel and I took this on, and we kind of pieced together the manuscript, and we wrote our own chapters to try and highlight Alison's achievement. And this was, you know, to the extent that this engages with social justice, it is elevating a voice that was kind of piecemeal in the world before that a lot of people knew her work, but now it's in a book, and it's in one place. And, you know, Alison, just was amazing about asking the hardest questions with a smile, you know, and so we tried to capture that, and that book will be out very, very soon.

[12:53] **Catherine:** Thank you, George, thank you so much for telling us about your books and your writing process and the way that your writing process even changed and what you're doing from poetry to prose, and, based on your own life experiences and your friendships. I feel like we could get into a whole conversation just about that. But I do really appreciate you bringing up the importance of writing and its intersection with social justice. So thank you for that.

We're going to get to the second question, which is indeed, I think one of the...well, they're all big questions, but it's a big question. And I'm curious to hear how you're going to answer question two of the JUST THREE podcast.

[13:31] **George:** Okay.



[13:33] **Catherine:** That question, that question is: what do you see as the biggest social justice challenge of our current time?

[13:43] **George:** So just a quick preface, and I won't do the academic thing of, you know, arguing with the question and then just saying something totally different. But I will say that, for me, it was so useful for me to face this question, because I am just such an inductive thinker. I mean, I'm a poet, I like to start with some image, some word and then just press on it and then see what happens. So to begin at 20,000 feet with the idea, that's a good challenge for me.

So I'll, I'll begin by quoting someone else. So and this is one of the two epigraphs to *Fables and Futures*, is from an activist named Marsha Saxton. And she says: "A world where everyone is welcome is the first priority." So that really resonates for me because it posits an ideal of belonging, and it joins the struggle for access and full social and political participation on the part of people with disabilities to the struggles by others.

In terms of the biggest social justice challenge, I think that you could pick racism, you could pick economic inequality. You could even talk about climate change as a secondary driver that is going to worsen all of those things.

So I don't know, but I thought of one slightly different metric, which is what is the biggest social justice challenge that is the most unrecognized, relatively? And I really think that that is ableism. And, and my focus, just because of my biography, is on discrimination against people with intellectual disabilities. And I think that, you know, I find this in some strange places, but...but, you know, in comedy, for example, if you think about the things that will just end your career, using, say, the R word isn't among them. It's now at the point where people there's backlash, and it's a kerfuffle. But there's this sense in which, you know, trashing someone for being, you know, stupid, or some or, or, or just making fun directly of people with intellectual disabilities is still on the edgy/okay, spectrum. And so, culturally, I think there's a long way to go. And I think the reason that is so difficult is that it is just at the heart of how we think of ourselves, as humans, and especially how we think of ourselves under capitalism, where we are required to be productive, and productivity is often joined to intellect and intellectual performance, you know.

So that's, you know, that's what interests me the most, whether it is the biggest, I don't know. To me, thinking about ableism is really thinking about access. And I'm just going to paraphrase the historian of design, Bess Williamson, here who talks about access in two senses: narrow and broad. So in the narrow sense, access refers to things like ramps or a child's ability to access the general ed classroom. But in a broader sense, access means cultural inclusion, the full access to—of social, or the opportunities for social and political participation.

The writing I was talking about before is split between giving an image of what access might look like because, you know, Laura has been largely included, she does have a good life. And on the other hand, trying to dissect or illuminate the obstacles to access. And those obstacles are often conceptual from stereotypes to old cultural scripts, and so on. The thing is that, you

know, these are big challenges and they're perpetual, but even access doesn't guarantee belonging. And that brings me back to, you know, Marsha Saxton's, quote, you know, "a world where everyone is welcome is the first priority." And it's totally utopian. And in terms of actual effect, I have no idea of what, if anything, my writing does. I mean, it's—I'm—you know, it's not measurable, but it's also like, this is what I am trying to do. It is—who knows what it does, but that is...I think that that belonging is the ideal that we are working towards, and writing is in, at least in a small way, can kind of push the needle in that direction.


[18:44] **Catherine:** Thank you, George, I really appreciate that. And this idea of belonging, which seems we could think about across so many different aspects of society, I think it's a really important point that you bring up and I appreciated the cultural examples that you brought up as well, I think that really helps a lot.

[19:03] **George:** Yeah. I mean, to me, one of the things that Alison does in her book so well, and that I've tried to do, too, is to face the conundrum that, you know, as a writer, as someone who teaches, I perform in...it's performing intellect. It's wit, it's metaphor, it's argument, it's insight. Those are the things that are rewarded. The incentives, you know, the prizes, you know, the approval of others, all those...these are incredibly powerful social forces and they are all structured around, again, the performance of intellect. So, given that I live in that world, have this great sense of self as a writer. How do you think about intellectual disability? How do I square being a parent and a writer, you know? And one answer is a shift in value. And I suppose it's paradoxical, but it's like, yeah, you know, I'm trying to write the wittiest, most surprising, insightful, whatever thing that I can and then to realize that that is not what is ultimately important.

[20:22] **Catherine:** Thank you, George. You have given me and our listeners so much to consider already. And I know that we will gain even more in your answer to our third question of the JUST THREE podcast, which is: how can we foster ethical and progressive social change?

[20:42] **George:** So I was reading that and thinking about that, and I really like the question, the specific phrasing of the question. And this is the close reading part of me but, you know, "foster," I like foster because that verb is open-ended. And I like that it's "ethical and progressive social change," because that suggests that the process as well as the result has to be ethical. That we can't be like, okay, in the distance is this utopia and, sure, we're gonna have to throw a bunch of folks off the lifeboat as we sail there, but you know, but, you know, that's, that's, uh...I like the idea that the process should be ethical all along.

Especially having just finished work on *Unexpected*, on Alison's book, I just feel so hesitant to advise others. Alison was an activist. I mean, she was the one with the megaphone, you know, she did so much work. I'll just say that one question that is useful for me, for anyone ask themselves is, where can I make a difference? What's my skill set? What can I speak about? And for a writer, especially a writer on disability, that's really complicated, right? Because there's a lot of times where it's more important to shut up and listen. There's a lot of times where it's more important, you know, not to express yourself in all the witty, thoughtful, insightful ways



because that's off the point, like, sometimes it's better just to show up and be another body, you know, to say "x is wrong" and it's not about you. So what I've, for me, what I've tried to do is to say, "Well, you know, I can write clearly, I can draw links between my experience and ideas, and I can read." So I've tried to make some something out of that. But beyond that, I think that, more broadly, I think it's really important to be able to listen. So going back to the idea of—and I know that sounds just completely milk-toast bromide. I mean, because like, what could be less controversial than asking people to listen. But, you know, to the extent that we're talking about belonging, you can't belong if you're not seen. So the awareness that there are other people who, whose experience is different from yours. And the importance of refraining from telling them what their experience is, judging it, dismissing it, that seems to me critical.


So, and the reason I raise this again with respect to people with intellectual disabilities, they are essentially in epithets, in ordinary speech, in the ordinary way we talk about something being you know, idiotic, or imbecile or "someone's a moron," which are all terms from the heyday of eugenics, intellectual disability becomes a synonym for the kind of speech you should dismiss. So with respect to that problem, specifically, listening to people who advocate for themselves is critical.

I will say, you know, one really hopeful sign to me is that people are...I think there's a little bit more understanding of that, of, you know...Laura and I, for example, we talk to medical students every year about Down syndrome. And it's only the last couple years that Laura has been brought on as an expert. And people ask her: "what do you think? What should doctors know?" And to me, that's a hugely helpful development.

[24:19] **Catherine:** Yes, I love that development. And I love that you really drove it home with the power of the language that we use in different contexts, too, as a writer. I appreciate that you brought that in as well. And the idea of listening, you know, it's easy to say we need to listen, it's another thing to actually know how to listen and do it.

[24:41] **Greg:** It is and I would say, too, the other...the flip side of that is that, you know, I'm a writer, I think about language, language is important. But it's also...it's only so important. And the example I give is, in terms of Down syndrome one says the convention is to use person-first language to say a child with Down syndrome, not a Down syndrome child. Right? Okay, so that's, that's, that's fine. I much prefer the sentence: "The Down syndrome child is included in the general ed classroom" to "The child with Down syndrome is segregated in special ed." You know, it's not just about, you know, you can use the right language and then if it just stops there like that's the whole battle or the procedures and practices don't reflect that, then it's almost worse than meaningless because then saying the correct thing has replaced action, has replaced substantial action. So that's that special ed part of me that's just like, "Okay, but what's the end result? What's the practical result? Are things actually better?"

[25:44] **Catherine:** Yes, yes, thank you. Thank you for complicating that, as we necessarily must. I really appreciate that. And George has just been such a pleasure to talk with you today. Thank you so much for being on the JUST THREE podcast.



[26:00] **George:** Oh, thank you so much, Catherine. It's really been a pleasure.

[*Music*]

[ 26:10] **Catherine:** Thanks for listening to the JUST THREE podcast. To find out more about our guests, please visit the show notes. To find out more about the Center for the Study of Social Difference, go to [www.socialdifferencecolumbia.edu](http://www.socialdifferencecolumbia.edu).

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I'm your host, Catherine LaSota. Thank you and catch you next time on the JUST THREE podcast.

