



Fables and Futures: A Reading and Discussion With George Estreich

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Sponsored by the Paul K. Longmore Institute on Disability, the Health Equity Institute, the San Francisco Public Library, and the Center for Genetics and Society

Marcy Darnovsky: So a more formal introduction of George is that he has published several books of poetry as well as the memoir, “Shape of the Eye,” and several of those have won awards and he has also published essays and articles in outlets in addition to the CGS blog, *The New York Times*, *Salon*, the literary journal *Tin House* and a number of others. And, I thought I’d mention he’s part of a band called Mule on Fire whose members describe it as semi-acoustic Northwesticana.

Did I get that right?

George Estreich: Yes.

And plus he teaches writing at Oregon State University. Great pedigree, George.

So Marsha [Saxton] has been thinking for a very long time and very, and Marsha thinks very well about the intersections that actually George makes in the subtitle in the book about disabilities, biotechnologies, and the stories that we tell ourselves, the stories that we tell ourselves about ourselves and the kinds of shared future that we want to build. And she has, [inaudible] has written and edited a lot as well. She’s edited several books of stories about people with disabilities and she’s written, I found this on your bio, over 100 articles and essays and book chapters on topics that, among others, include disability rights and genetic screening. She served as a member of the important working group called the Ethical, Legal, and Special Implications Working Group of the Human Genome Initiative, which she has stories about, and also on the board of the wonderful public interest organization Our Bodies Ourselves and the Council for Responsible Genetics. She is a teacher, she’s a trainer, she’s a speaker, and her day jobs are as the Director of Research and Training at the World Institute on Disability and she also is a lecturer in Disability Studies at UC Berkeley.

Okay, this is going to be a great conversation and before you start I just want to tell you about a sentence or two about the sponsoring, cosponsoring organizations. First, the Paul K. Longmore Institute on Disability at San Francisco State University, which studies and showcases disabled peoples’ experiences in order to revolutionize social views through public education, scholarship, and cultural events [inaudible] the institute shares disability history and theory and promotes critical thinking and builds broader communities. And, I’ve mentioned that Emily Beitiks, the Associate Director, is here and Cathy Kudlick, the Director, is also here. The Health



Equity Institute is also a cosponsor. They are also at San Francisco State University and the Health Equity Institute's Mission is to create an intellectual environment that encourages diversity of perspectives, challenges conventional approaches, and produces innovative action-oriented research in the biomedical, social, and behavioral sciences in order to improve health, eliminate health disparities and establish equity in health. Good idea. And Laura [inaudible] the Associate Director of the [inaudible] is here as well too.

And, let's see, the Center for Genetics and Society is my organization. We're a non-profit social justice organization based in Berkeley and we work to ensure an equitable future in which human genetics and reproductive technologies benefit the common good. Part of what we do is work to ensure that a broad and inclusive range of public and civil society voices are included in deliberations about human biotechnologies and by that we want to explicitly include both scholars and advocates who stand for reproductive, disability, racial, LGBTQ, and environmental justice. And Katie Hasson, our Program Director and Charles Garzon, our Admin Director, are here as CGS people that you can talk with.

Finally, I want to mention [inaudible] services at the San Francisco Public Library also a cosponsor of this event and, of course, [inaudible] support. Jane is with us tonight. And just to give a [inaudible] to the library which has been such an important San Francisco institution that we owe a lot of gratitude to too. So with that [inaudible].

A little closer to the microphone.

Marsha Saxton: Closer. Okay, welcome again. So I read your book and I loved it so much that I asked her to send me the previous book, "The Shape of the Eye". So I want to describe the cover because it's beautiful and I want to [inaudible] audience and readers. And I'm sorry that there aren't more pictures for books for adults because the pictures are wonderful.

The cover has what looks like the feet of some people standing in line in the water color and it's the shadow that predominates the cover and I think there's probably a back story there. I think that the cover of books are very important and I'm curious, at some point, if we can get George to talk about the cover.

Okay, so George, tell us about the book and I understand that you want to [inaudible].

George Estreich: Yeah, I thought I would just read a short section. But, yeah, I do want to talk about the book a little bit.

Can everyone, can you hear all right? Is that good? Okay.



So you know my line on this book is that the elevator pitch requires a very slow elevator in a very tall building. It's hard to explain but it basically, I see us as being at a pivotal time in human history, and which is to say that, and most acutely in the United States, cultural and legal gains for people with disabilities are on the rise. We are not remotely near where we need to be but there have been significant gains.

I see this partly through the lens of raising a daughter with Down syndrome. The very fact that she has the legal right to go to school would not have been the case when I was born, when I was a child. Obviously, still, there's a long way to go.

At the same time, there are, our technological ability to both read and write DNA allows us the ability to select and shape future people. Often, those technologies are rationalized in terms of preventing, fixing, or even eliminating disability. I see these two developments, these two cultural developments is like two large rivers colliding and I see us as living all in the cross currents. It's just this swirl of conflicting ideas about disability, about the value, value of life and which lives we value.

The premise of the book is that once we have this power to select and shape future people, either to pick, you know, one embryo or not another or to actually tinker with the DNA of one embryo, the [inaudible] a question of belonging. That raises a question about which bodies and minds we welcome. So that's the premise of the book. The book itself is a bit, it's on the model of an essay. It's not a scholarly book, just by all the long words in the subtitle, it is really kind of a non-specialist wander through this strange territory, my attempt to keep my head above water where these two streams intersect, my attempt to think through all of these conflicting meanings. And it's an invitation to the reader to come along with me. To do that, I've both analyzed the stories that we're telling ourselves, I look at the way we're talking about biotech and disability, and at the same time I tell stories, mainly about my daughter, Laura.

So what I thought I'd do is I'd do a short reading from the book just so you can hear what it's like and then Marsha and I can talk a little bit. So I will do that now.

This, both of these readings are two short excerpts from the third chapter. The third chapter is about people and animals and the premise is that the idea of directing the evolution of people, of managing the way the species goes, controlling the way the species goes, is always wound up with the idea of directing the evolution of animals. And I, to talk about this I reach back into the history of American eugenics but I start with the story in the present.

This chapter begins with an epigraph from a Republican state senator from Oregon from and the epigraph is this. "The people of Oregon have safeguarded the breeding of fancy horses and cattle. They should at least do as much for their people."

In the depths of my hard drive is a photograph of Laura, 13, posing next to an alpaca at the Benton County Fair. They are dressed up as Elsa and Anna, the sisters from Frozen. Magno, the alpaca, is draped with pink fabric and his head sports butterscotch-colored pigtailed made from a braided pack of yarn. Laura's hair is sprayed silver and she is wearing a long, blue dress, elbow-length white gloves, and pink New Balance sneakers. As a then-member of the Lucky Long Necks 4-H club, Laura had spent a year working with Magno, who lived on a farm outside town cropping grass and tending his buried species memory of the Andes. Laura had learned to walk Max forward and backward in a circle. She had brushed his soft coat and learned the names of a couple of alpaca diseases and one day she even gave him vitamin shots with a veterinary syringe.

Laura has since moved on to keeping and showing rabbits and Max has moved on to the great Peruvian pasture in the sky but we remember him fondly. He was old and gentle with an unruly mop of hair and spectacular bucked teeth, like a cross between an early Beetle and a camel.

The Frozen costumes are part of the large animal costume contest, which is a ritual at the intersection of drag show and animal husbandry. For it, the Lucky Long Necks led their [inaudible] in an impromptu parade around the fairgrounds in the blazing heat.

Laura had hoped to sing one of the Frozen numbers for the judges and was disappointed when this turned out not to be an option. Among all of the fears and hopes and uncertainties and predictions I entertained after Laura arrived and was diagnosed with Down syndrome, I can safely say that no scenario involved an aging male alpaca dressed up to resemble a fictional Disney princess at the Benton County Fair. The costumes were Laura's idea though Theresa, my wife, [inaudible].

We like 4-H for the same reason that we like the Special Olympics unified basketball team. It's a place where children of different abilities can be together on equal, if asymmetrical, terms. But in 2017, as I researched this book and Laura researched rabbit diseases so that she could answer the judges' questions during showmanship, the history of American eugenics cast a long shadow across the fair.

It was sweltering, pushing 109 degrees, and as the sweating kids plumped their rabbits on individual carpet squares waiting for judgment, best in breed, best in show, the whole enterprise seemed like an exercise in bunny eugenics, a separation of the fit from the unfit, a careful examination of bunny physiognomy to determine the local pinnacles of the breed.

The directed evolution of people is inseparable from the directed evolution of animals. From Dolly, the cloned sheep, to gene edited mice to CRISPR engineered miniature pet pigs, animals are the models we use to work out the details of the future. But historically, to invoke animals was to invoke intellectual disability. Non-human animals defined the lower boundary of a

human heart hierarchy, which feeble-minded people approached or crossed. It was a racialized hierarchy with whiteness at the top and non-white races at the bottom. That complex set of prejudices is distilled in the phrase Mongolian idiocy, which blends race and disability, and it underlines John Langdon Downs racial system that that loose association of race, disability, and non-human animals is still endemic online.

So for all these reasons, Laura's presence at the 2017 Benton County Fair, a full member of the Claws and Paws of the Roundtable 4-H club, which is not to be confused with the Benton Rabbitears, the Critters of the Valley, or the Happy Hoppers, a high school junior with a Facebook account and a bedroom wall banded with blue ribbons and Star Wars stickers at the high tide line of her outstretched fingers, is a marker of genuine progress.

In the early decades of the 20th century, at the height of American eugenics, a child classified as feeble minded would've present, if at all, as an idea of what to avoid. For a time, in fact, it was people as well as animals competing for ribbons at the fair.

And so what I talk about next is there was this very odd cultural phenomenon during the kind of the golden, I don't know if you'd call it the golden age of American eugenics, the [inaudible] age of American eugenics, the mainline eugenics area, called the better babies contest and the fitter families contest. And these were contests that were held at state fairs where families would undergo extensive examinations, answer questionnaires, they asked about genealogies and to be given a grade about who is fit to breed. And at the end, the most fit family would win a ribbon and a trophy. And you can still see pictures of these contests. They also had the better babies contest where they dressed all the babies up in togas for some reasons and they graded them as well.

And this, you know, this is interesting to me as a writer because central to the whole eugenics projects with the stop breeding metaphor, this idea that, you know, breeding animals and breeding humans is parallel. So this ritual made that literal. And I just want to read a couple of the posters that accompanied these contests.

So one reads, "How long are we Americans to be so careful for the pedigree of our pigs and chickens and cattle and then leave the ancestry of our children to chance or to blind sentiment." And, as I write, the block letters are handwritten despite the implied ethos of perfection the lines are not quite parallel. The significance of the quotation marks around the word blind is unclear but the parallels with contemporary rhetoric are unmistakable. If human improvement is on stage, disability-based metaphors are usually skulking in the wings.

And I want to, I'll just read a short bit from the end of the chapter. Another thing that I write about in this chapter is de-extinction. That's the idea of bringing back creatures like passenger



pigeon [inaudible]. And I'm really interested in that application of genetic technology and how it might relate to other kinds.

Fitter families, better babies, de-extinction, metaphor, Laura, bunnies, mammoths, Oregon, home, I'm building a Rube Goldberg device [inaudible] a synthetic biologist if a synthetic biologist were a non-linear thinker with a daughter with Down syndrome. Perhaps this is only serious [inaudible] making with a question attached, a non-standard thing built from the registry of standard intellectual [inaudible] words. If this is the case, so be it. I pursue the connections to see if there are any and I try to assemble disparate things into a working picture, to find coherence a stay against confusion.

So as I think about the possibility of mammoths becoming more common, I think about Down syndrome becoming more rare. Live births of children with Down syndrome are currently about 1/3 less than what would be expected and with the increased uptake of new prenatal tests, this trend is likely to accelerate. I don't think people with Down syndrome will go extinct but they may become vanishingly uncommon.

One online graphic used, and this is at the organization Revive and Restore that's used to advance the project of de-extinction, one graphic shows extinct and threatened creatures as shadows in a landscape. I mention, I imagine a parallel image showing silhouettes of people with genetic conditions, Down syndrome, hereditary deafness, achondroplasia. My daughter [inaudible].

For many, I think, more mammoths and less Down syndrome is a win/win, a desirable outcome. The pitches, in any event, are linked. The same people who argued for resurrecting lost species tend to argue for eliminating genetic disease. Whether Down syndrome goes the way of the dodo depends on whether it's considered a disease, whether it is seen as a part of a diverse humanity, or simply as a problem we'd be better off with without. That no official eugenics records office or American Eugenics Society, is vested in reducing the number of people with Down syndrome but no coercive government agency sets current reduction targets, it's not as important as it seems. New prenatal tests are sold to individuals and sold with the rhetoric of individual choice but cultural values influence individual decisions which are, in turn, multiplied by technologies into population [inaudible].

So perhaps one day American fitter families will leave their future firesides, traveling on a Siberian adventure tourist package to see hairy elephants tromping the permafrost. Maybe passenger pigeons will darken the skies above the subdivisions where the New England [inaudible] raining feces on the tract homes of genetically healthy families. Maybe 4-H will add new categories to its small animal competition, best de-extincted, best engineered. There will be Facebook posts, Mackenzie's passenger pigeon won in best in breed, hashtag diybio, hashtag de-extinction, hashtag so proud. There will be super muscular [inaudible] the size of Labrador



retrievers, roosters with perfect, gun-colored [inaudible] so long you could tie [inaudible] with a single feather. If these come to pass, I'm less concerned about animals being shown than the children doing the showing, about who will be present and welcome. Thanks.

[Applause]

Marsha: What, among many things, I love about this book when I read it and I was so pleased with it that I quickly asked George to send his previous book and I read that one, both are very intimate, personal essays, *The Shape Of The Eye* much more a memoir. So I'm very moved by your writing. And, also that there is so much in common with our interests and my work over [inaudible] decades and I've been involved with the disability rights movement for four decades now. My interests [inaudible] and, again, issues in common Down syndrome is a primary target of prenatal screening and selective abortion and my disability is the second most [inaudible]. So that's [inaudible] for me.

I, George mentioned the eugenics movement, which is such a big deal for us to explore and understand. By the way, he said the book is not scholarly but I think it is. It's a very nuanced analysis from a disability [inaudible].

Right into it, okay.

So I encountered eugenic ideology in my childhood. Many medical providers subtly or not subtly made sure that I should not plan to procreate. And my mom had to fight to get me into kindergarten, I being a child with typical cognitive functions. So things, yes, have changed. We've moved light years ahead in my lifetime and we have light years to go around the world as well as in the United States. So I really appreciate George's ...

So we're going to be getting into uses of genetic technologies in our conversation. I do want to mention some basic concepts for our listening audience. One is about what George develops very nicely is the distinction between what we call the medical and the social models of disability. And biotechnologies focus on changing genes to improve people is very much a medical model approach. The assumption is what's wrong with people with disabilities is solely located in that individual's body and from the purview of genetic science, in that person's genetic makeup, their DNA. The social model looks very broadly at the society and locates disability in the environment, in the attitudes, in the architecture and sometimes disability discrimination is literally built into the cement, into the bricks, the stairs, the lack of elevators, or are now with amazing new technologies they believe disabilities can be included in all kinds of ways, cool ways that weren't available in previous decades or centuries.

So we challenge the medical model, I like to call it the medical deficit model because we don't want to blame doctors. It wasn't their fault. These notions are millennia old. And as a result of

Transcript

the confusion set by the medical model, the stereotypes of people with disabilities abound and a piece of the stereotype is don't ask, don't stare, don't learn, don't connect. So I want to ask George to talk about the stereotypes of people with Downs, his daughter and people of all ages.

George: Well, so thank you for that Marsha. It means a lot to me, I am a very, I don't identify as disabled. I haven't faced these things in life. I'm connected to questions of disability through and because of my daughter, Laura. So that raises a whole separate host of questions for a writer. What does it mean for me to weigh in on these subjects at all and it does mean taking a lot of care and trying to defer to other voices when I can but that's [inaudible].

In terms of stereotypes, you know, I covered a lot of this in the previous book, *The Shape Of The Eye*, and I kind of saw that book as driven by attention between two figures. Okay, one is the stereotype of Down syndrome, which is, you know, like, I mean, I don't even need to explain it to you. I mean, I knew it before Laura was born and I think, you know, there is that they are sweet, that they are good natured, you know, sometimes stubborn, musical, and I did a lot of thinking about those. But in the end I was trying to oppose that kind of ghostly stereotype to the real life individual who is my daughter, who is not a generalization of the diagnosis but who is a single person living at a certain time in the Pacific Northwest in a certain circumstance and to kind of contrast the shadow of stereotype versus the full-bodied person. Similarly, for a writer that means thinking about a person having an individual, singular story as opposed to stereotypes, which are extracted from time. So, you know, obviously every, I think, you know, form of embodiment, every form of disability is likely to have some stereotypes attached to it and the problem is that they want, one of many problems, is that they obliterate the perceived identity of the person.

I think that it's, that Allison Carey wrote, *On the Margins of Citizenship*, right, she is saying, you know, we have made great strides. There are rights that are written into law that did not exist before but it's not enough to have those rights there, the person has to be perceived as a bearer of rights and so if that person is perceived only as a medical figure or only as being, kind of, you know, cute or sweet or whatever and then it almost doesn't work.

Marsha: You actually moved me to think a little differently about all different kinds of categories impairment. Actually, that's another piece of disability theory I'd like to share that we call the actual physiologic condition that a person has the impairment because we want to make a distinction between that and the limitation in ability of people with these impairments caused by this society and those that we refer to as the disability. Because people with disabilities have all kinds of abilities.

And so- I think we can do the same history that, analysis that George gives to Down's with every category of disability. It started making me think about, for example, deaf people have written



quite a bit, blind people have written quite a bit about the socialization of the society in relation to those two categories. But I have yet to see a book about dwarfism, for example, [inaudible] history of the seven dwarfs and, you know, court jesters and so on, and so it made me start thinking about spina bifida, what are the myths of spina bifida that I can explore and, you know, get together a focus group of people with that condition.

Jumping ahead to the end of the book, you develop some thinking about Roy Rogers and Dale Evans. How many old people like me here remember that? And I didn't, I haven't thought about this since I was maybe 7 years old. So in my bedroom I shared with my brother there was a light, a night light, of Roy Rogers and Dale Evans and my mom, who was a really great advocate for me, my parents were sort of like you and Theresa. My parents refused to accept the stereotypes about disability and I'm also very [inaudible] by my friends who didn't have that kind of parents who have turned into ferocious fighters for disability rights. But my mom made a point to tell me that Dale Evans and Roy had a child with a disability. I don't know, I don't remember. And I remember, now, no I don't. Now I'm thinking back that my mom wanted to connect with other parents with disabilities and at the time of my upbringing in the 50s, there were no support groups for parents. There were no social workers for parents. There was the doctor and, giving, you know, the best information they could as well as a lot of misinformation about my condition and the conditions of other children that I was meeting in Shriner's Hospital.

So I want to talk some about parents and the marketing to parents about these genetic technologies and the impact on a pretty vulnerable population of people who may have pregnancy and are thinking about parenthood, maybe for the first time or whatever, and how the marketing can influence the way these technologies are used and sold.

George: So, yeah, thank you, Marcia. And then we, we talked about this some before this event just the general idea about it's an impairment in context, it's the body in context that determines the experience, determines the meaning of disability and that you were fortunate enough to have parents who advocated for you, which changed the meaning of the impairment. This is, this was, you know, new to me in 2001, when Laura was born I was trying to sort through all this stuff and just beginning to realize that, one, how many misconceptions I already held about like this is bad news or a tragedy or anything else and, two, realizing that the future is actually up to us, to Laura, and dependent on other things too. So that context is critical.

With respect to genetic technologies, so I write in the book some about a new kind of prenatal test called NIPT or NIPS, non-invasive prenatal screening and it is a, it's a blood test for pregnant women. It is able to detect the chances of Down syndrome and some other disorders based purely on maternal blood sample as opposed to, say amniocentesis, which samples amniotic fluid. It is not a diagnostic test. It's a screening test, which means it tells you chances



but nothing absolutely certain. What interests me about the prenatal testing is the fact that these tests are for-profit products and so they are accompanied by for-profit persuasion. I'm interested in the [inaudible]. And there's a really important distinction to make, which is to say that, you know, genetic counselors I've talked to say that these are reasonably good screening tests, they have their limitations like any test. Many women find them useful.

One can understand that that is the case and that this can be part of a woman's pregnancy decision making in cooperation with a genetic counselor and be reasonably useful in that way and at the same time say that the ads themselves are deeply problematic in the way that one can say that depression is a real thing and antidepressants can help with that and yet that some advertisements and marketing practices are deeply disturbing. So I focused on the ads and what I found was that they were, in a way, really conservative. Not as in Democrat/Republican conservative but in the sense that they showed ideal people in a very, very narrow [inaudible]. They showed mothers who were, leaned towards white; there was some diversity there but they were more white. They were very well off. Their children were chromosomely typical and beautiful. The families pictured were clearly two-parent families in a heterosexual union where typically the husband was, you know, a male model and who is protective and loving. And the woman was attractive and she clearly never had any nausea or excessive weight gain or anything else. And so with this kind of ideal world it's the same kind that is used to sell us everything from Diet Coke to, you know, potato chips and that struck me as itself problematic because this is an incredibly consequential decision and it seemed to me like this information would be better coming from a medical professional and not from an online ad.

So I guess to me this question matters for two reasons, one is that because these decisions are so consequential and because they're so fraught because the desire, the reasonable desire for a healthy child is so strong, this is a very delicate situation and I think words and images can have a greater effect. So that's one reason that this interests me. The second is that future genetic products are also likely to be for-profit and so if we look at the way current products are marketed now we may have a clue as to how to think about the future products that come down. If, for example, something as is advocated by some say, CRISPR- Cas9, which is sometimes called a word processor for genomes, is used to alter embryos, these are likely to be products as well and so we should think about how will they be pitched to us. I think as citizens we should think how will we respond, how can we be appropriately skeptical and evaluate these things in a way that contributes to our happiness, our flourishing.

Next [laughter].

Marsha: Okay, we're thinking about eugenics and we're thinking about CRISPR, which is c-r-i-s-p-r, it's an acronym for a very long, complicated genetic description of the process. And these forces are operating; eugenics operates in an unconscious way in our society. We like to think that that era is over. It is so not. There are still women being sterilized, primarily now black

women in prison, but even up until the 70s, sterilization of women assumed to be problematic in terms of whom they might produce was still operating. So eugenic ideology operates in the realm of procreation but at the more DNA level, the conversation operates without the voices of people, largely without the voices of people who actually know what it's like to live the experience of these conditions and [inaudible].

George: I was promised easy questions but [inaudible].

Marsha: It's a snap for you.

George: Yeah. [laughter] So I was talking about this with Marcy earlier. I think in one way it's the easiest thing to agree on, right? Like, we have powerful technologies and it's no longer notional, we can engineer the species quite easily if we want to. We can do it at scale. CRISPR is cheap, it's easy to use. It's not remotely ready for the clinic but it could be soon. It has error rates, you send it in and make some changes and it can also make some changes you didn't want to have happen. My basic assumption is that given the presence of these technologies, they are more likely to contribute to human flourishing across the board if more of us weighed in. And one reason it is hard to get that conversation going is that there are so many other things to occupy our attention. But even if you forget the games on our phones and Netflix, there is the small matter of climate change and the fact that the government appears to be crumbling. So with all of that stuff it's really hard to think about a slightly more distant thing like well, what if we're engineering the species.

One reason I wrote this book the way I did, to do it as kind of an informal, like, say I'm a non-specialist, I'm actually a poet, I'm going to ramble through these things, is to hopefully give people a little bit of courage to say well, okay, I can ramble through this too. I can learn a little bit more about it I can raise my voice even if I'm not a molecular biologist. I can learn to speak up. But beyond the question of more of us needing to become aware and participate, there is more acute question of what our position is in the conversation. There's a way in which conversation can simply ratify what people are going to do anyway, where it can be like, okay, well, you know, you've spoken up and your position is noted but we're going to leave it with the experts now. And I think that, so, ultimately, it becomes a question, the way I put it in the book is the difference between having a voice and having a say and I think that's a really important distinction. So people like Marsha, who have been raising hell for four decades are going to be really important in this kind of conversation, speaking up and saying okay, well the rhetoric attached to this technology, basically dehumanizes me. It renders me as a problem as opposed to part of a spectrum of human variation or someone who has a creative way of being in the world or anything like that. So I think the conversation needs to be more widespread. I think it needs to include the people who are most likely to be affected by the technologies and my dream is that it will not simply be a matter of consultation but a matter of actual democratic participation. I don't know how to make that happen but that's my Christmas wish list.



Marsha: Okay, good. The lines, if we're using that metaphor, are really fuzzy for those of us in the disability community. We're not advocating that there be more disabled people in the world although I personally am a staunch supporter of the value of lives of people with disabilities. There's lots of [inaudible] stereotypes about how courageous and inspirational we are, which are not that helpful. But I think that people with disabilities have really unique lives and interesting contributions and our perspectives are valuable.

My primary concern that involves disability stereotyping is the notion that the burden of our lives and our suffering can be stopped with these technologies, these assertions made without actually involving the communities of people with these conditions. And we, again, to return to the medical-social model that, from my standpoint having met literally thousands of people with disabilities and gotten close to very many, that a lot, for the vast majority of people with disabilities, the suffering is caused by oppression. That the exclusion, the lack of accommodations, the attitudes, just stop about who we are, not appreciating or accepting that our unique experiences and the way we're moving and the way we look, everything about us is [inaudible] and a lot of creativity and of great value. So I want to talk about how these specific stereotypes can be challenged and I want to engage the audience and I think we're going to move toward questions and comments from you because we want your ideas. We want you to read the book. Mmhmm. And George is selling some, by the way, \$25. And we want your thinking and we want your ideas about how to engage the public, the disability community, your family, your church or temple group, your everybody, your organizations in conversations that will move this thinking forward. So let's turn to the audience.

Audience Member: This is a suggestion about how we can, you know, treat you better or whatever but I'm really curious if anybody in the technology, biotechnology conversations and genetic testing and all of that are thinking systematic or systemically about things. So, for example, if you edit one set of genes, what are the ramifications in a generation or two generations and how are they connected to other genes down the road. Are people thinking about them or is it truly sort of just my baby, it's going to happen like this for my kid and down the road it doesn't matter. And I'm wondering if that's the way, I know we're not a great society about thinking, you know, [inaudible] but I'm wondering if anybody is engaging in that kind of study and thinking about it.

Marsha: I can answer as a layperson and then maybe there are some science-minded people who know more about that but I think primarily it has frankly been a consumer perspective, that the technologies are being thought of as a way to fix this next pregnancy rather than thinking down the road at all because we don't have the understanding of DNA [inaudible]. So somebody else want to comment [inaudible]?

George: So I think there are, I think there is, it depends on where you look. I mean, obviously, I think as a research question people are thinking about, like, you know, have this understanding of the change you make in one generation may have unpredictable effects in further generations. I would, you know, for this book I was looking less at the basic research than at the consumer decision and in that framework it's purely, you know, about a parent and child. There are many, there are many parents who have children with an inherited disease who are interested in using gene editing as a way to potentially prevent that disease, especially if it's [inaudible]. Yeah, in other words, and I think for some parents who would rather not have an abortion, that the possibility of changing the one letter that is resulting in something is very appealing. And I want to, I feel like I need to read more of that and understand, you know, understand that. So, but I can't, I feel like I can't generalize like across the board whether that's the case but certainly in the consumer perspective it's not about later generations.

Marsha: There are many of us in bioethics concerned about the politics right now. There's debating about whether we should have a moratorium or even a ban on this technology, you know, given the history of eugenics and the assumption that in the heyday of eugenic ideology, there was such arrogance that those people knew. That the appalling research methodology that was operating then has been exposed but now we're at a point in history where we see the assumption all the time that we figured that out, now we can operate with an ethical attitude and we have nothing to worry about and that is such faulty thinking. We don't know what the impact of messing with the genes can be down the road. So, you know, many of us feel very strongly that we should ban this technology because we have so little knowledge of the impact of this editing. So I want to hear from other people.

Audience Member: So I think I agree with or I mostly agree with the disability community concerning these technologies but then I was reading, I think it was [Inaudible Comments] who brought up the idea of polio vaccinations. What I was wondering, I have difficulty reconciling vaccination in the context of these questions and I was wondering how you reconcile with that.

Marsha: Oh, about the polio vaccine?

Audience Member: Yeah or just vaccinations in general. [Inaudible Comments] What's the difference between vaccinations and gene editing?

Marsha: I would say there's a huge difference between vaccinations and gene editing and I'm not going to get into the vaccination debate right now because we don't really have time. We can talk afterwards. In fact, we can stick around a little bit. But I think that vaccinations, the concept of vaccinations are a public health issue and there's controversy because there are children with immune struggles who have negative reactions to vaccines and that's



problematic. But the idea of the polio vaccine being disability discriminatory I think is [inaudible]. So I think that's a clear red line to be drawn, personally. Anybody else want to?

George: So, there's a couple of differences. One, one is that CRISPR Cas9 applied to embryos are experimental, vaccinations are not. Vaccination is treating a single, existing child, altering an embryo is creating something different. So there are two really significant differences there. I'm glad you brought that up because this is one way in which new technologies are advanced is by likening them to the familiar, something that's already accepted. So it does seem as if this technique could be understood as a public health measure, as genetic vaccination but at this point there is a huge difference between something that is proven like the ability of the polio vaccine to prevent polio. You can point to the eradication of small pox; you can point to the, well, unfortunately, the resurgence of measles but the effectiveness of vaccines against measles. So these are incredibly low to no risk interventions as opposed to something experimental and new. So I think the details are really, really important there. Thank you, thank you.

Audience Member: I have a comment and a question. I think in regards to your question, original question, I think that inclusion is so key to people understanding what disability is, understanding the value. And one of the most moving parts of your book came very early where you were talking about your house and you were talking about the door to your house and how, on the outside of your house, is the world and how Laura, in the world, is stigmatized in all these ways and inside your house it's completely different. She gets valued, differences are embraced, and all these wonderful things. And that resonated a lot with me. And my question for you is, and I'm afraid it's not going to be an easy question. My question for you is how has your experience raising Laura, has it and if so how has it changed both how you think about intelligence, which after all is something that I think any of us in the room will say that are things we love the most we might think of as the product of a sharp or heightened or thoughtful intelligence. How has your experience raising her changed how you think about intelligence or how you value intelligence, which is also a category that we associate with our humanity in a lot of senses.

George: I've written about this in both books. So, a couple of things, one is just I had always said that I didn't believe intellect was everything and to some extent this was, you know, being a smart ass 15-year-old rebelling against parents who very much wanted him to go to Harvard and I was like, you know, whatever. I'm going to do something different. But you know, I was like, you know, intelligence isn't everything; empathy matters and all these things. So that's what I claimed and it's what I thought I believed but having Laura called me on that. So to have a child with intellectual disability made me realize that it's one thing to assert that intellectually and another thing to live it. So Laura is, it wasn't, it's partly Laura's arrival and thinking about her, reacting to her changed me in many, many ways but one was to really bring home what it meant to believe what I said I believed.

Now, with respect to this book I want to go back to something Marsha said, which is about the claim that like the old eugenics, what's called the mainline era of eugenics, classical American eugenics 1900 to 1935, it's often said that's like completely different from now. But there's the historians that I really value have charted many continuities, the double desire for health and human improvement is one that Nathaniel Comfort writes about very convincingly. But the other strong connection between the old version of eugenics and whatever is happening now is the over-valuing of intellect, the enshrinement of intellect as the main feature of interest. You know, you have this in the dreams of, you know, maybe engineering or selecting, you know, ever smarter people. I find that problematic and so Laura's arrival really had me thinking differently about intellect and IQ and all the rest and so in this book I tried to push that [inaudible] further. Thank you.

Audience Member: You raise this very important distinction between getting a voice and having a say and I was wondering if more and more people were able to have a voice, especially people from the disability rights communities, what would you urge them to say? And I was wondering, and I hope to read the book and then I'll know, in that discussion of what you would urge them to say, do you in your book make a distinction, the distinction [inaudible] between somatic editing and germline editing and is there information there for people in the disability rights community to know so that somatic editing might affect them without problems but germline editing could be a problem and would you urge that to stop?

George: Thank you. That's, and I'm glad you brought that distinction up because I want you to mention that after, with Marsha's [inaudible]. So there's a critical distinction between germline editing, which is editing either sperm, egg, or embryo, which means those changes will be passed down in perpetuity, and somatic editing, which affects one person. Like, for example, if you, you know, editing someone's stem cells and restoring them to that person so they can [inaudible]. The somatic editing I don't have a problem with in principle and, in fact, some of the people doing that work, one reason they hesitate about germline editing is the fear that a high profile disaster in inheritable editing can screw up all the other useful clinical applications. I can say too, just speaking generally, I don't have a problem with CRISPR per se, it's a tool, a useful tool. My wife actually uses it in her lab so the problem is not CRISPR to me nor is it somatic editing. I'm really pretty closely focused on germline editing as something that is, there would be a great concern.

I am really hesitant, kind of for the reasons I mentioned before, to urge people with disabilities to say anything. I want to hear what they have to say including the difficulties to say like, well, what are, you know, what are the aspects of this impairment, what are the grey areas say involved in chronic pain [inaudible], you know. What are the things that are less affected by stigma, what might you want to change? I would want to hear all of them and then take it in but this is, I don't have a something to urge. I more want to, I just think that there's a huge



dearth of voices of people living with, creatively with disabilities. As often pointed out, is our resource of how to live with technologies, we're talking about technologies, the people who are living in the closest interface with technology are people with disabilities [inaudible]. Yeah?

Audience Member: Just a follow up.

George: Yeah.

Audience Member: That's very interesting. So how would you suggest we avoid the problem that I think you also referenced, which is about [inaudible] that the more we discuss the more we normalize something that perhaps instead of saying this is not a good idea, we shouldn't be doing it, the more people that we bring to this table the more normalized the idea that this is something that actually has [inaudible]. Like, what's wrong with germline? You know what I'm saying?

George: I think it depends on how we talk about it. I think it, I think that, that's a really good question. I actually think of this as a little bit of a tangent but I think about this in terms of the movies, which is to say there are superhero movies all have enhanced people, right, genetically technologically enhanced people. And some of them have a really strong message of warning. Like I wrote about Spiderman, the 2012 Spiderman, in here, which has a fairly strong anti-corporate message, a very strong message about the abuses of technologies and the way the wish for cure can slide into the wish to become a giant lizard guy, I don't know [laughter]. But, you know, even so, even as the movie is clearly giving this skeptical message, it's making it all look really cool, it's normalizing it. So even a warning can normalize. So I don't have an easy answer for that but I think one thing that is useful to do is to ask emperor's new clothes questions. Like, okay, so what error rate is acceptable? Like let's say we start, you know, even let's say that we're not talking about enhancements, you know, we're not talking about ultraviolet vision, wings, any of that trans human stuff but say that like we're going to focus on things that everyone agrees are diseases, right? What error rate is acceptable? Who is responsible, you know? Who gets to say? Who's going to govern these things? Because it's easy to talk about this in the abstract but this thing is going to come down to actual people visiting actual clinics. How expensive is it going to be? If this involves large-scale harvesting of eggs, who is going to be donating the eggs? And so now you're into quite, and then to some extent you're displacing the question just from the technology, which is the shiny cool stuff, is the old questions that I hope would interest us anyway, which are questions of equity and fairness. So that's, you know, off the cuff that's the best I can do. Thank you.

Marsha: I want to, we do mean not to romanticize disability. It can be, disability can be somewhere between very inconvenient and devastating including early death and tremendous pain. But I absolutely agree that the voices that we want to hear will change the dialogue and you're right, we can't speak for anybody else. So I'm speaking for myself, you know, as I



mentioned the main concern that I have is that stereotypes of the burden and suffering of people with disabilities are being exploited by the marketing of these technologies. But, and there are other constituencies at stake here. Racism is a huge factor in the applications of, potentially applications of these genetic technologies and gender identity and so on. And so we need to hear from all marginalized constituencies in this conversation to have a better picture and I'm intrigued with this notion of normalization. But I'm not so worried about that yet as much as getting the marginalized communities engaged and outside of our denial and despair I have a concept of eugenic denial, sort of analogous to climate denial. You know, if you think somebody else is handling it you are in denial because no. So I want us, we really need to wake up here and engage in our community groups, conversations about these technologies [inaudible].

Audience Member: Yeah, I want to jump back briefly to you mentioned the possibility of [inaudible] and I wondered if that's, something we've had to grapple with in the deaf community over the last 15 years with respect to cochlear implants is that there is [inaudible] feedback. It's here so we had to sort of reframe how we think about our community and who belongs in that community and what it means to have a cochlear implant and also be a deaf person and all of these things. So I'm wondering if that is [inaudible] with respect to CRISPR where in particular, given it's [inaudible] that we're past the point [inaudible] that we're past the point of a ban or a moratorium and have to start grappling with it's out there what do we do next [inaudible].

George: I would say I think that's a really good point but I would say a key difference is that cochlear implants are widely used and there's a whole network of, you know, teaching of like, my friend Laura Mauldin wrote a great book called Made to Hear about that and so, you know, there are therapists who teach [inaudible] parents on their use when children are born deaf and there is, so there are many people using them now. CRISPR, so far as we know, has been used to edit embryos twice, in the case of Chinese twins who were born [inaudible] and then the same scientists, [inaudible], seems to have initiated a second pregnancy with this. But a moratorium is reasonable, I think, because the technology is out of the bottle but the clinical practice is not, at this point. Now, whether a moratorium would be effective, whether one should have a moratorium or a ban are different questions but I would say at least in terms of uptake there's a pretty significant difference between the two. I might be giving a very different answer in like 10 years but I hope not. Does that make sense?

Gina, [inaudible].

I know but I'm [inaudible].

Audience Member: So a couple of things, first of all, thank you both. I appreciate your book [inaudible]. So I was thinking [inaudible], one is the question of how we move the conversation

and I think that actually education provides us with lots of opportunities to have that conversation but I don't think in many cases teachers feel equipped. You might've seen the article that we just spoke about a couple of weeks ago about climate change, which the vast majority of parents across, you know, the political spectrum, would like their children be engaged in issues of climate change and then we get to the teachers there are a variety of reasons why they don't teach it. Most of them feel ill-equipped but also they don't have the resources to teach it. So I do think that there actually is a space to sort of move this conversation to the classroom. You have to think creatively about creating some curriculum and scaffolding it but my hunch is that the students want to be in the conversations anyway [inaudible] the adults that are the impediment. So I think we could think creatively about how to [sneeze] bless you, create a series [inaudible] scaffold and resources we could engage in conversations and I think move them down to younger folks so that they're in the conversation early so that it's not something that they are scared to go into later. We normalize the conversation about [inaudible] is a huge opportunity.

Yeah.

The other one I'm thinking about is that also the need to destabilize this sort of idea that we're over and done with eugenics because I would agree with, you know, the both of you that there are a tremendous number of continuities and I'm thinking about some very, what would it look like to do some very particular studies where we look at the relationships between the institution that [inaudible] promulgated eugenic notions and thought and actually are consistently engaged in technology that seem to be reproducing the same sense of devaluation and rooted in the same sense of assumptions. Because, you know, the more I look there is no bright line and there is no consistent pattern of sustaining [inaudible] and so the intellectual [inaudible] behind these ideas, I would argue, still, moving full speed ahead with [inaudible] maybe picked up steam. So I'm wondering about the idea of intervening with a series of particular historical case studies that might help to draw out [inaudible].

Marsha: I'm just going to agree wholeheartedly. I have the privilege of teaching university students and I have a lot of hope in young people. So I don't want to succumb to the scare that we can't change the conversation and change policy but [inaudible] that justice, environmental justice, or [inaudible] applications of CRISPR and the human genome. So I'm hanging on to hope. Other [inaudible], do you want to?

Off Camera: I was going [inaudible].

Marsha: Yeah, we're going to get [inaudible] out at 7:30 because the library closes. So we're going to make some closing comments [inaudible].



George: Yeah. Everything Marsha said [laughter]. No, I guess the one thing I would add to what we've been saying is a short pitch for the value of literature, which is to say that in disabilities and diseases are not simply abstractions or diagnoses but are experienced by people in particular places and times. It's to literary techniques that we need to turn to see that. We need the best writing to help us grasp what these conditions mean in context. At the same time, it's literary techniques that are being used, metaphor, story, and the rest, to sell new technology. So we need to learn to read more critically so that we can understand when that spell is being cast in a maybe not so helpful way.

Marsha: I want to close with sharing my thought in social justice movements and the Disability Rights International [inaudible] movement in particular. I've been involved for 40 years in this movement and I just did a focus group and interviewed young people about transportation issues for disabled people getting around and being able to go. And the expectations over my lifetime have changed so profoundly. People with disabilities expect to be able to go where everybody else goes. Like what, yeah. And I particularly was moved by a high school student that I met at a conference on Saturday who knew her rights under the Americans With Disabilities Act. Yes [inaudible]. We have come so far in such a short time. just, you know, within my lifetime from the charity model, I was hospitalized at Shriners', which is a charity hospital and they did the best they could in that era, the 50s and 60s, to a very powerful social understanding of the nature of disability [inaudible]. And I'm expecting in my lifetime and I expect to live, you know, a few more decades at least, that the worldwide movement for disability rights and full inclusion is and can expect to be continued to be one of the most powerful movements in the history of the world and I believe that. Join us. Read his book [applause].

George: Thank you all for coming.