VIDEO TRANSCRIPT

Alison and Chris on the Evolving Scientific and Social Understanding of Disability

Link to video.

[**Alison**]: We're both interested in genetics. I'm coming at it from the perspective of prenatal testing, reproductive decision-making, and Down Syndrome as sort of a case study for how we make sense of this genetic difference.

And so, I'll just start by saying I tend to believe pretty, pretty strongly that everything is socially constructed. I'm incredibly skeptical of any "scientific fact" or "scientific truth." I always feel like I need to use scare quotes around them. And you feel, you don't feel that way, you don't agree with me on that.

[**Chris**]: No, you, as so as a geneticist, I appreciate how we've been able to, the power of categorizing people, in order to do genetics. And that it has been very successful in identifying genetic variants that have been helpful in people's lives, in medicine, and just understanding biology in general.

But, from interacting with Alison, have started to understand how, the way we group people in science, and how that can bleed over to the social sides of our lives, and how that, how people then start to think of themselves differently by how we have maybe artificially categorized them to do our work.

[**Alison**]: So, 40 years ago, a child is born with Down Syndrome and the doctor says, based on the scientific fact, and this, I do actually say is, is, is a fact that I don't feel like I need to scare quotes around, "This child has an extra chromosome."

Based on this scientific fact, we know that this child will never speak, read, be able to use the toilet, feed him or herself, be able to live an independent life. So what you need to do is put the child in an institution and, and maybe tell people that you, that you miscarried and start over.

When that is the, the “scientific fact” that you are told, and that's what you do, that's what happens. A person locked up in an institution, not given any stimulation, does in fact, not talk, not learn to use the toilet, etcetera, etcetera.

When my daughter four years ago was born with Down Syndrome, what I was told was, “250 colleges nationwide are accepting kids with intellectual disabilities into the college.”

So that was a really different “fact” for me. And that, that fact, you know, 40 years, the chromosome hasn't changed. In 40 years, our cultural story about the chromosome, our beliefs about the chromosome, have changed. And the fact that the story has changed has caused, I mean, just radical, radical changes in what it means to be a person with Down Syndrome in the world today.

So that my child not only reads and speaks and is potty trained and goes to school, but she's a preschooler. And that is only possible because the story changed. So for me, that's what I'm interested in is the story. For me, the “fact” means almost nothing without the story. It's the story that gives it meaning.

[**Chris**]: Yeah, I completely agree with that, actually. And then when you see some of the work at the GET meeting, when we talk about, you know, if you're interested in, in genetic variation and its effect on say intelligence or learning or other ways in which we think of ourselves popularly as individuals.

But in order to do that work, you have to artificially create groups of people who are a certain way and act a certain way in order for the genetics to work. And I'm interested in, as we create those groups in terms of what we value as intelligent or not, who we think is aggressive or not, is science as we start to look for genetic variation that may have a role in that, also sort of reifying these categories as this is what someone who is aggressive looks like, or this is what someone who is intelligent looks like.