

[APPLAUSE]

Several years ago, I found myself at a bioethics conference having dinner with a group of colleagues. One of the gentlemen with us happened to be someone with no limbs-- no legs, and to be specific, very foreshortened arms with hands right at the end. This was a gentleman who was born in the era where women were given Thalidomide to help them deal with extreme nausea, and it led to severe deformities of limbs, like he had.

A delightful and highly accomplished gentleman, he viewed his body as perfectly delightful as well. As did his family. Absolutely amazing stories, fascinating stories about his parents' attitude. They'd actually seen his condition on the ultrasound and said, well, yes, people come in lots of different shapes and sizes. For him, what he had was a normal human body.

Now, using that body in the built environment he found himself in sucked. It's a world built for people who are bipedal, so steps everywhere, even in the restaurant, curbs. All those familiar issues we know about ways in which we erect barriers to people who have different modes of mobility. So for sure, he regarded himself as having a disability relative to the environment he was in. But understood intrinsically in terms of the function of his body, he was perfectly satisfied.

What is a disability? One of the most fascinating issues in bioethics asks us in the last few years to look at this question, to ask conceptual questions about quality of life, to raise queries about whether we've made assumptions, those who are able-bodied, about what different forms of life might be and whether we've mistaken our lack of imagination with an ethical conclusion. Well, to explore let's return to the gentleman without limbs. So I made a strong statement. I said that while he saw his body as having a disability relative to a world built around a bipedal assumption, intrinsically he didn't see his less functional than any of the bodies I look before me here and see.

Now, I imagine that some of you, even if you wouldn't raise it publicly, might disagree. Surely, there's less function to somebody who has fewer limbs. But let me ask you now to imagine a fanciful example of interplanetary travel and a new form of life comes down that looks a lot like you and me, except they have four arms not two. They look at us and they would think of us as incredibly incapacitated, because they can do so many things with their four arms, and we have but the two. If one of their babies was

born with just two arms, they would think it an incredible tragedy, they might even abort the baby.

Does the fact that they, this fanciful species, had four arms make you now, suddenly, right now, in this moment feel now disabled, deformed, less functional? I doubt it. Also, when we think about why a disability must be intrinsically more problematic, and not just relative to the environment, sometimes what we're thinking of are people who incur a disability in the midst of their life. For instance, war veterans. Wars all over the world leading to lots of limbs lost.

Now, to be sure, that is a devastating occurrence, that is a full-blown trauma. But in part, that's because of the pain and the suffering of the injury, not the resulting end state. And in deep part, it's because the person is undergoing what we might call a radical existential disruption.

The body they once knew, by which they understood their place in the world, their relationships, their projects, the trajectory they had imagined for themselves was with their prior body. And without asking for it and in a sudden, often violent manner, suddenly the trajectory stopped. And they'll have to build a whole new one. Down to every detail of your life, assumptions you make every day and it's so familiar, you don't even realize it.

How will you get up the stairs? How will you feed yourself? What will your career be? How do others see you? So those are real and huge issues.

But those are what we might call diachronic issues. Across time, if you start with a baseline of one body, and without asking for in violent ways, get switched to a different body, that's a loss, because it's a loss of what you knew, what your bodily home was. That's different from the gentleman I was talking about who was born with that body.

That body was his home. And every bit of detail you think about, of how you navigate your physical world, the trajectory you imagine, what your projects are, how others see you was already started and given. And to him, it might be like the thought experiment of suddenly asking to graph new limbs he had no idea what to do with or wanted, that would be the deformity. What is a disability?

Well, mentioning loss of limbs in bioethics and biotechnology makes many people think of prosthetics and the amazing advances that we are making with prosthetics, sadly, often as a result of how many war amputees are coming home. As we've learned, a lot.

And most of you will have seen the pictures of Blade Runner, the amazing athlete who was a double amputee, but used the metal blade running prosthetic devices and kept up his athletic career. Now, interestingly, when they did studies of those using the blade runners, it turns out that the extreme springiness of them combined with the light weight of the material meant that those folks are on average 15% to 30% faster than a "regular" human. The same muscle effort would yield 30% better speed.

OK, well, now here's a question that bioethics loves-- now are we talking disability or enhancement? So what if we could totally magically make the recovery from amputation seamless, that it wasn't painful, that we didn't have difficulties with wound care and difficulties fitting prosthetics, which is a huge part of rehab now, very difficult. But imagine, we could magically get all past that.

And now an athlete comes up and says, you know what, I was born with these things, but I want what he's got. I want better legs. So now we're talking cyborgs-- combination of animal and machine. And enhancing ourselves, not just to make us well after being ill or to recover from a disability, but make us better than the average human being is.

Genetic enhancement ups the ante. So here now we're talking about the potential to change the human genome in ways that selectively make things that are problematic in us less and make what's good about us more. And it ups the ante in part because then we are choosing for future generations, right, because if we change the genome, we pass it on.

So there's a new camp called transhumanists, a set of bioethicists who are very excited by this idea. After all, they say, evolution gave us a real grab bag-- some things are good about us, some things are problematic. You know, we're just sort of put together as a set of accidents, it's not like we're perfect.

And as we start to understand the human genome, if we see places where we can selectively make a difference, splice something in, we could make people better in ways that benefit future generations. So they are talking about how they would love a world where you live twice as long, you are twice as smart, and you need half the sleep you need now. The last one sounds pretty good to me.

Well, lots of questions here. Some of them are really in principle. Is it OK to mess with human nature? Is there something inherently problematic about that?

Or again, those public policy questions, even if it's in principle OK, do we really know what we're doing?

Are there too many possibilities of unintended consequences that might be terribly, terribly dangerous? Or here's a question-- what if some people get the enhancements, decide for their children that that's what they want to do-- and some people don't-- they can't afford it, they don't want to do it, they want to go au naturel-- so then, if the enhanced are significantly enhanced, we really could end up having two different species of humans roaming the Earth, the enhanced and the normals.

It might be like that seen, the bar scene in *Star Wars*. Do you remember that? We're all of the very different kinds of species, and creatures from all over the galaxy came together and more or less got along well and even tried to date each other. I mean, that's one possibility. Another one is that there's a super race of enhanced who would look at us as great slaves to capture and oppress, and, I don't know, maybe raise us for food.

So what would it be like in just political terms for the human community to have radically different kinds of humans trying to share the Earth? Interestingly it's an experiment that the Earth might have seen play out once. So as they do research on the deep history of human genetics and how the genome is changed, really cool evidence about the Neanderthals, who are our closest evolutionary relatives, our cousins, if you will.

So we all started in Africa. They left 300,000 years ago and populated Europe. Our ancestors hung out in Africa longer, only going up to Europe 70,000 years ago. But the Neanderthals were still there.

Turns out, they were contemporaries of each other. And some interesting evidence is that they did hang out together and interbreed. And especially, if you're from northern Europe, you have 1% to 3% Neanderthal in your genome.

Now, we don't know what it looked like. Did the humans oppress and enslave, eat the Neanderthals? Did the Neanderthals fight back? Did they all just party together, and then some accident happened that the Neanderthals didn't make it through?

We don't know. But what some people are asking is whether intentionally we should run that experiment. And bioethicists are asking should we? Thank you.

[APPLAUSE]