

In this last section, I want to talk about normalcy. I said at the beginning that seeing how complicated the notion of disability is in turn will complicate the notion of normalcy for us.

And throughout most of this sequence, we've been focusing on disability. But at the end here, I want to talk instead about normalcy, and what it means to have a normal body, and what role health care professionals ought to be playing in creating and maintaining normal bodies, and what that even means.

There are some theorists who have been quite influential in bioethics, such as Christopher Burris and Norman Daniels who have argued for a statistical biological conception of normalcy and abnormalcy. Roughly, they argue that we should understand the abnormal body as a body that has a statistically aberrant dysfunction that compromises the normal opportunity range of the person who has that body.

The problem is, as we've seen, what opportunity range any given individual has doesn't just depend on their body. It depends on their body in the context of its particular environment.

We've already seen that the opportunities available to deaf people are completely different than they were 15 years ago. We can't judge what the opportunity range is for someone who has statistically abnormally low hearing without knowing when and where that person lives.

Final example-- having a body that doesn't conform neatly to either gender would be a huge compromise of opportunity in a culture that has very narrow conceptions of gender roles and is fearful of bodies that don't fit neatly into the gender binary. This discussion of gender nonconforming bodies leads us to a really interesting bioethical case. And that's the case of how we treat intersex infants.

Intersex infants are infants who are born with ambiguous genitalia or other ambiguous sex characteristics. Now, it used to be that when an intersex baby was born, it was completely routine to correct that baby at birth through surgery to alter its genitals so that they looked more conforming. Typically it was easier to make them into female genitals.

This surgery was done quickly and quietly, with little to no consent from the parents. The parents often didn't even understand that their children had been born intersex.

The reason for these surgeries was to make the bodies normal as opposed to abnormal. But the question for us is, what does this mean exactly?

These infants had no traditional physical disabilities. And their bodies were not dysfunctional in any particular way that the surgery was correcting. In fact, if anything, the corrective surgery often created sexual dysfunctions or reproductive dysfunctions that wouldn't have otherwise existed. So in that traditional sense, the surgeries might be said to make the bodies less normal rather than more normal.

It seems like what we were really doing was correcting the bodies to make them conform to our sense of how normal bodies ought to be. And that raises interesting questions about what the role of medicine is in producing normalcy and what we mean by normalcy anyhow.

Up until 2006, the American Academy of Pediatrics considered the birth of an intersex baby to be, as they put it, a social emergency. And this is what they used to justify doing these surgeries with little or no consent from the parents, and of course no consent from the patient herself who is a newborn.

The assumption was that this was a social emergency because these children desperately needed gender normalcy. And that they would have their normal range of opportunities restored if their bodies could be corrected. And that their lives would be seriously hampered and compromised if they had gender nonconforming bodies that didn't fit neatly into male or female categories.

The assumption was that having an ambiguous body would be psychologically and socially traumatic for the child. It's worth noting that there was no scientific evidence of any kind for this.

It turns out, once we started talking to intersex people, which we didn't do until the last decade, that many intersex people actually really regretted the secrecy around what had happened to their bodies, and regretted having had the surgery at all. And in particular, they felt that the way that the surgery had been done so quickly in infancy marked their original bodies as somehow shameful.

They also resented the lack of sexual and reproductive function which they hadn't been given any choice over. And they wished that they had been allowed to choose for themselves, once they were somewhat older, whether they wanted to have their bodies corrected or not. Nobody had bothered to ask them these questions until quite recently.

As of 2006, the American Academy of Pediatrics changed its policy. It got rid of the language of social

emergency. And now the recommendation is that these decisions be made slowly and reflectively, with at least consent from the parents, and consent from the child when possible. Although practice is only slowly catching up with policy here.

The real point that I want to make here is that the notion of normalcy at play, whether we're talking about social normalcy, physical normalcy, psychological normalcy-- all these notions of normalcy were very unclear and under contest. And we were wrong to assume that it was obvious what counted as normalizing the body and what the role of medicine was in that.

So as we've seen throughout this sequence, there were really complicated notions of abnormality, normalcy, disability at play here.