NED CALONGE: I'm Ned Calonge. I’m the President and CEO of The Colorado Trust. I want to welcome you to the First Health Equity Learning Series presentation of the 2018-2019 season. I couldn’t tell you how thrilled we all are to be here this evening.

At The Colorado Trust, we believe that all Coloradans should have fair and equal opportunities to live healthy, productive lives regardless of race, ethnicity, income or where we live. Or other differences that affect opportunity.

I want to set some context for tonight’s speaker and look backwards to 1932 when the United States Public Health Service and the Tuskegee Institute began a study on 399 African American men to examine the natural progression of syphilis. What this translated to was the misleading and lying to these men, and without their consent, not informing them about their diagnosis and not treating them—including when the cure penicillin became widely available in 1947.

The study was originally planned for a half year. It was continued for 40 years—not ending until the early ‘70s. It took another quarter of a century for an American president to acknowledge and apologize for what occurred.
I’m sure that many of you—if not all of you—have heard this story before. It stands out as a well-known symbol of medical racism. But our speaker this evening, Harriet Washington has researched and written extensively, and points out that Tuskegee is just one of numerous examples of people of color being abused, marginalized and discriminated against in the United States health care system. This racially motivated behavior in health care is something Harriet refers to as “medical apartheid.” I will let her give you a more extensive and better definition, and before we get started I just want to add a few notes.

We will email you an evaluation survey after tonight’s presentation, so please keep an eye out for it. We read all these responses, and they’re vital to helping us plan and improve our Health Equity Learning Series events in the future. Materials will be posted on our website after the presentation today, including the slide set from our presenter and a complete video from tonight’s event.

Please note, the video may take a few weeks to get up on the website, and the written materials get up a little quicker. The video will be available with Spanish subtitles as well. I would respectfully request that you silence your cell phones if you haven’t done so already. Thank you.
I want to acknowledge our 20 grantees for the 2018-2019 Health Equity Learning Series. Today’s event is being recorded, and these organizations will be hosting viewings of the recording in their communities across Colorado. The presentation viewings will all be accompanied by professionally facilitated discussions, and I want to give a shout-out to Transformative Alliances, who is our consultant and partner in this area. Thanks. I know Nicole’s here, too, but I was looking right at Dara.

I also want to highlight the six grantee organizations whose names are bolded on the slide. These grantees comprise the inaugural class of our Community Leaders in Health Equity track. In addition to hosting viewing parties or viewing events, these organizations are taking place in an intensive 18-month curriculum focused on health equity education and awareness. This is a significant time commitment, and I applaud and thank those who are dedicating their effort and energy to be part of it.

If you’d like to find a viewing event near you, please visit the Health Equity Learning Series page on our website. There is an interactive map that will locate the grantee in Colorado closest to you, along with their contact information. And the events will begin taking place around the state in a couple weeks.
Now I'm really excited to introduce to you Harriet A. Washington, our speaker this evening. She is a science writer, editor and ethicist who has been a research fellow in medical ethics at Harvard Medical School, a visiting fellow at the Harvard T.H. Chan School of Public Health, a visiting scholar at DePaul University College of Law and a senior research scholar at the National Center for Bioethics at Tuskegee University. Ms. Washington has also held fellowships at Stanford University, she holds a degree in English from the University of Rochester and a Masters in journalism from Columbia University. In 2016, she was elected as a fellow of the New York Academy of Medicine and she teaches bioethics at Columbia University. She’s written several books, including *Medical Apartheid: The Dark History of Experimentation on Black Americans from Colonial Times to the Present*, which you have—many of you have—in front of you this evening.
This won a National Book Critics Circle award and the PEN Oakland award and the American Library Association Black Caucus Nonfiction award. She’s also written for numerous science publications and journals, and I hope you will help me in welcoming Harriet Washington up to the table here.
HARRIET WASHINGTON: Good evening.

AUDIENCE: Good evening.

HARRIET: It’s such a pleasure to be here with you, although the subject of my talk is not very pleasurable. I wanted to just make a few notes before I begin speaking and that is that I wanted to warn you that, um, I’m going to have a lot of slides here, not all of which I’m going to get to. I’m sure of that. So my strategy is that I’ll show you each slide, but if I don't linger—if I go on to the next one without discussing it—feel free to ask a question afterwards in the Q&A so we can address it.
Um, I’ve just been talking with one of my new friends about the parallels between what happened in Nazi Germany under National Socialism and what happened in this country. What I find especially disturbing is that it was American prosecutors and American physicians who went to Nuremberg to confront the Nazi architects of the Holocaust and accuse them of betraying medicine by using it as a cover for genocidal torture of Jews and other people with whom they disagreed. But these same doctors—some of them—like Dr. Andrew Ivy, were doing the same thing to Black people here in the United States at the same time they confronted the Nazis.

And that actually is one of the more persistent traits of this kind of abuse. What’s, what I really want to convey to you is that despite the fact that we’ve been revered to, raised to revere doctors and scientists—for good reason; most of them are wonderful people, brilliant people—but I think we have fallen into an intellectual trap where we think that science and history are disciplines that cannot be criticized. We think of scientists and physicians as doing good, and often they are.
But the fact is, science and history is only as good as the people who practice it, and when you have humans who are biased, practicing science and medicine and history, you’re going to end up with biased history and biased science. Medicine has a lot of biases, medicine has entire mythologies that have been constructed, and their end effect is to demonize and harm people of color. This is something that is not, part of an individual bias or, you know, an occasional, um, miscreant. This is something that is inbred, it’s bred into the fabric of American medicine itself. In the same way that enslavement was part of the fabric—as Michelle Obama called it, the birth defect—of the American nation, we had the same situation with medical science. Where from the beginning there were reasons why African Americans and other people of color were demonized by scientists and medical people, and the mythologies have unfortunately not abated. They’re still with us.
Structural Racism in US Medicine

Racism
- Reinforcement of mythology, i.e., “Noble savage,” “African subhuman,” “inscrutable godless Oriental”
- Science embodiment of racial bias
- Africans = African Americans

Economics
- Health v. fitness for work
- Direct competition with healers of color

Structural racism. A lot of definitions. But I'm using it to allude to the way in which medicine itself—and scientific philosophy itself—has been co-opted in order to promulgate racist mentalities that are still with us. As I talk about the abuse of the past I'm often going to link to a parallel abuse of the present to illustrate this.
And medical people are not especially venal, especially evil. Medical people are Americans, and they reflect—medicine has reflected society, the larger society. So when we had enslavement as the law in this country, medical enslavement was permitted. When de jure or legal separation by race, segregation was a law in this country, we had medical segregation. And today, when disparate access still governs many, many aspects of American life, from education to employment, we still have disparate access in medicine.

So medic, medicine and science have been subsumed under American culture. They’re part of American culture, and they have their own culture of mythology and bias, which is harmful to people of color, and ultimately it’s harmful to all of us. Because we’re medically interdependent. Despite the fact that African Americans have been singled out and treated especially poorly, this hasn’t gone well for anybody’s health in this country. Nobody can be, um, avail themselves of the bounty of the American health care system until everyone can.

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<th>Sociopolitical</th>
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<td>Enslavement 1619–1865</td>
<td>Physician-owner dyad; Medical enslavement; clinic confinement; involuntary surgery and research; black bodies conscripted for anatomical dissection</td>
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<td>De jure Segregation ~1865-1960s</td>
<td>Continued forced subjection to research; Black patients barred from white hospitals; “Negro ambulances” Black hospitals; Black medical schools (closed after Flexner Report), dispensary movement, Black MDs barred from AMA, hospitals, etc</td>
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<td>Disparate access –1960s-present</td>
<td>Continued forced subjection to research; Reduced access to care; higher morbidity and mortality rates; disparate access to standard of care; tissue appropriation</td>
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<td>Racial disparity in scrutiny</td>
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This slide—there’ll be a quiz later, no, only kidding—this slide is only to show you that there are 15 chapters of the book, which means there were at least 15 separate areas of American medicine in which I was able to show a long and profound history of medicalized abuse of African Americans. So, it’s not a matter of a syphilis study, or children in one study, or one study of reproductive technology. It’s a matter of every aspect of American medicine being infected by this bias and by these harms. And believe me, I had other chapters that did not end up in the book, so I could’ve written more.

- Chapter 1 Southern Discomfort: Medical Exploitation on the Plantation
- Chapter 2 Profitable Wonders: Antebellum Medical Experimentation
- Chapter 3 Circus Africanus: The Popular Display of Black Bodies
- Chapter 4 the surgical theater: Black Bodies in the Antebellum Clinic
- Chapter 5 The Restless Dead: Anatomical Dissection and Display
- Chapter 6 Diagnosis: Freedom: Fin de Siècle Medical Research
- Chapter 7 ‘A notoriously syphilis-soaked race’: What Really Happened at Tuskegee?
- Chapter 8 The Black Stork: The Eugenic Control of African American Reproduction
- Chapter 9 Nuclear Winter: Radiation Experiments on African Americans
- Chapter 10 Caged Subjects: Research on Black Prisoners
- Chapter 11 The Children’s Crusade: Research Targets Young African Americans
- Chapter 12 Genetic Perdition: The Rise of Molecular Bias
- Chapter 13 Infection and Inequity: Illness as Crime
- Chapter 14 The Machine Age: African American Martyrs to Surgical Technology
- Chapter 15 Aberrant Wars: American Bioterrorism Targets Blacks
- Epilogue: Medical Research with Blacks Today

5/29/18 © 2012 Harriet A. Washington
So, when we talk about the history of race in research, unfortunately a lot of this history has been written out of the history books. A lot of this history has been hidden from us. And so it’s sometimes hard to understand or believe that things could’ve happened. But I’ve included some advertisements that appeared in newspapers to show you how common and how open was the abuse of African Americans.

Basically doctors would advertise, “Slave owners: bring me your sick slaves, bring me your useless slaves, too old to work. I’ll put them to good use. I’m going to use them in research.” These were ads that ran in the, in the regular newspapers that everybody read. That’s how common it was, and that’s how accepted it was.
And I don't know how many of you have heard of this, but I'm actually very proud of this. I'm heartened by this development. Um... in New York City, within the last month, the statue of James Marion Sims, a surgeon of the Victorian era, was toppled, taken down and moved out of Central Park. This is a result of my publicizing on the true nature of his work. In 2007, when *Medical Apartheid* came out, I wrote about the fact that James Marion Sims had been praised as the father of American gynecology and a selfless savior of women, but really what he had done was he had used enslaved Black women, who he locked in a shack on his property and repeatedly subjected them to painful, distressingly intimate vaginal surgeries as experiments to see if he could find a way of correcting a condition called vesicovaginal fistula.

He wanted to correct it because he knew it would make his fame and fortune if he were able to cure this. And he did find a way of correcting it and he immediately left New York, went to Paris—I'm sorry, he immediately left Alabama, went to Paris and then to New York—and basically ruled the Academy of Medicine. And the statue sat across from the Academy of Medicine until last month.
When, when my work publicized the fact that his image was a myth and the statue was a beautiful lie about who he was, the medical students in the audience jumped up and said, “We ought to tear that statue down.” I said, “If you do that, don’t use my name. I’m already in enough trouble.” But of course, they did not, they could not tear the statue down. But for 10 years, medical students and the women of color who lived in this neighborhood fought City Hall and said it had to be taken down, and finally the city agreed. The statue was taken down and removed. And that’s heartening to me because it shows that, um, people can accept that these mythologies are false and demand that they be eradicated. Not everybody of course, but enough.
And I've already explained to you what vesicovaginal fistula was. Basically it was a horrible complication of childbirth in which the tissues of a woman's productive genitalia fell apart and she was left incontinent—you know, so her opening is between her rectum and vagina—and it was a horrible situation. It condemned a white woman to face a social death. You read Victorian novels or something that will allude to some poor woman who has to live in the attic, can't come out into company. That woman often had vesicovaginal fistula.
But it affected more slave women than white women. Why? Dr. Sims explained to us why. He said slave women were dirty and sexually profligate and that’s why they had it. But he was wrong. This was, this condition was actually created by enslavement. Malnutrition, including Vitamin D deficiency, caused bone problems including a flat rachitic pelvis—a pelvis too small to admit the baby’s head, leading to long, protracted and long, difficult labor and ending up with the baby dead and the woman’s tissues falling away from her body. That’s what caused it.

Also, Black women were made to have children three years earlier than white women. Why did I say “made to?” Because they were forced. Having children by enslaved women multiplied the slave owner’s wealth. They wanted their slave women to have children. In fact, Thomas Jefferson wrote in Notes on the State of Virginia, he wrote, “I consider a slave woman who gives birth every two years as profitable, as the best worker on the farm.” So slave, um, slave women were encouraged to have children early and often. And when they didn’t comply they were forced.
20th-century ‘Jezebels’

“I have have very serious doubt as to whether the crime of rape can be committed upon a negro.”

—Cole Blease, Governor of South Carolina, 1910-14

No Southern states made it legally possible for slave women to file rape charges against a white man before 1861. Historian Danielle McGuire writes “Between 1940 and 1965 only 10 white men were convicted of raping black women or girls in Mississippi despite the fact that it happened regularly.”

Why? The medically supported image of the black Jezebel.

First Nations women paralleled by the transformation of squaw from a revered, politically powerful member of society to an easily accessible brown-skinned woman who is raped with impunity, even today.

But instead of admitting that these girls—which is what many of them were—were being forced to have sex with their owners, and with anyone the owner designated for enforcing the pregnancy at an early age, instead doctors said, “Well, the reason why all these slave women are having, giving birth to these mulatto babies is, they’re Jezebels. They’re sexually promiscuous women.” They’re whores, basically. And there are a lot of medical journals testifying to the fact that slave women were actively pursuing their masters and forcing them into inappropriate sexual relationships.

It's laughable at this point because we know better. But at that time it was believed, these were doctors promulgating this. This was their theory, that slave women were Jezebels. And not only Black women, Native American women were considered the same way. Native American women, in their own societies, they often had a great deal of power. They certainly decided who they would marry and have children with. But that changed as whites took over. And soon in the medical journals you see the same dialogue about Native American women. “Well these are cheap women, these are whorish women, they’re, they will have sex with anybody.” Of course this was also a cover for rape. These women were being raped with impunity.
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And, um, so this is something that we find over and over again. People of color being blamed for their own problems, their own medical problems. And rape and abuse being portrayed as something very different. Maleficence. And what’s happening today is a very good example of how yesterday’s mythologies play into today’s abuses.
Victims of Violence

- More likely to be raped with impunity
- 84 percent of Native American and Alaskan Native women surveyed have experienced violence, 56 percent have experienced sexual violence, and, of that second group, over 90 percent experienced violence at the hands of a non-tribal member.
- **Tribal courts do not have the jurisdiction to prosecute non-tribal members for sexual assault and rape.**
- An analysis of 31 websites found that nearly half of victims depicted being raped or tortured were Asian.

Look at Native American women who are the most, like, most frequently raped people in this country. And more than that, when women are raped on a reservation there is literally no legal recourse. The law actually prevents the reservation, um, councils from persecuting non-native people from, for rape. So if you have a First Nations woman who’s been raped or sexually abused, the law actually states that, that if it has been done by a man who is not part of the Nation, that there can be no legal, legal remedy pursued by her. So this is basic, we have laws in this country today that permit their rape and assault. Which is why they are so vulnerable and why they’re so often assaulted.
So one big part of our medical mythology that we have to do away with is our medical heroes. Who do we decide who our medical heroes are? I have a very small pantheon here of people who we decided are medical heroes—these are people whose statues you can find, you go to medical schools and you can find their portraits, you can find documents written in honor of them, even today these are people who are praised as being these great benefactors of medicine.

But all of them have predicated their success on the savage abuse of African American bodies. I can’t, there’s no time to go through all of them, but Taliaferro Clark, Raymond Vondelehr, John Heller, Thomas Parran and Oliver Wenger. They all had something very important in common. Anybody know it was?

These are medical “heroes.” They were also officers of the public health service. Public health service officers. What did they do? These are the men who constructed and perpetrated the Tuskegee syphilis study. Thomas Parran became Surgeon General, and when he became Surgeon General, he was asked, he said, “I’m going to make my mission the eradication of syphilis. We’re going to find a cure on my watch.”
Now, during that time, that was like the Surgeon General today saying I'm to find a cure for AIDS. And few people believed he could do it, but indeed it happened on his watch. Penicillin was found to cure syphilis, uh, to prevent syphilis, and now we could, we didn't have to deal with tuberculosis, I'm sorry, syphilis any longer.

So, but when Thomas Parran was approached and, and he was asked, “Listen, we have all these Black men in the Tuskegee study. Are we going to give syphilis to them and cure them?” He said, “No. The opportunity represented by these men will never come again. We have to keep them infected, to refuse to cure them, refuse to treat them.” And that is actually the Achilles' heel of all these men. All these men—perhaps they did the things that they’re praised for, maybe they did not—but all of them abused African Americans in order to attain their goal, and yet we call them medical heroes.
The problem is in how we define our medical heroes. We tend to define it by an achievement—real or imagined—but we don’t look at how they made that achievement. We don’t care they abused people. Or certain people. We don’t care if they cut ethical corners, if they did things that were wrong in order to get their cure. We focus on what they supposedly did, and that’s a mistake. And that mistake really costs us in terms of not understanding people’s bestial behavior because we call them a medical hero.

So science is considered something that is, um, above reproach. People will say, “You can’t argue with that, it’s science.” Science is pure, science doesn’t have any emotion attached to it, it doesn’t have any opinion attached to it. It’s a fact. These facts constitute science. Unfortunately, that’s not true. Because you have science as it’s idealized. That’s the ideal of science. The way it’s practiced is, it’s practiced by human beings. Human beings who have flaws and limitations and make mistakes. And who embrace mythology.
‘Myth’ and Medicine

“History is written by the victors.” —Winston Churchill
“Don’t let the lion tell the giraffe’s story.” —Nigerian proverb

- Science: Ideal v. Practice
- After the Enlightenment, science grew to trump other ways of knowing Man
- The study of race paralleled the study of animal breeding, genetics and the slave trade
- In the US, the study of race was molded by social political and economic pressures
- Science is thought “pure,” but its practice is not. Science cannot be assessed without regarding its practitioners
- Scientists, like others, cherish their mythologies, operate within them, and typically are blind to them

When you look at how the races were first characterized—this was considered, this was the science of its day—during the time races were first characterized, you had groups of prominent scientists telling us who African Americans were. Who First Nations people were. Who Asians were. But was it really scientific? No. There’s a lot of bias that pre, pre-dated any kind of research. They already had preconceived notions about who these people were. They merely used science to justify these preconceived notions.

We’re not talking about collecting data and coming to a conclusion. We’re talking about taking a bias and an opinion and then clothing it with science. So during the time that African Americans were first brought to this country to work, um, animal breeding was also being studied by scientists. The science of animal breeding focused very heavily on classification of animals and they used the same theories, the same frameworks and technologies to classify people.

Now the interesting thing is that when European scientists classify people, they did not look at differences and consider, well, there is a difference here, a difference there, we don’t know if it’s innate or caused by something in the way they live. No, they looked at hierarchies. What they, what they were focused on was establishing who was at the top and who was at the bottom. And that’s what they did.
Now interestingly, before this science was first promulgated the hierarchy was Europeans at the top, followed by Asians—a little debate there—but then followed by other light-skinned people of color, and Africans always fell to the bottom. And the residents of the southern tip of Africa were always at the very bottom. Various offensive names are given to them—Pygmies, Hottentots, etcetera—but whatever they called them, they were always at the bottom.

Now, unsurprisingly when scientists address the hierarchies, guess what? The exact same categorization existed. You still had Europeans and other light-skinned, um, people of color—notably Asians, some Asians—at the top and Africans at the bottom. And by the way, Africans and African Americans were essentially considered the same people by these scientists. They had some basis for this because until, um, I don’t know, 1850 or so, many, if not most, African American slaves were still Africans. They were people who had been born in Africa. So they did not distinguish Africans and African Americans.

And, we, they had this mythology about who’s at the top and who’s at the bottom, they used their idea of science to buttress it, and the science was not only biased but also supported some very important things in the Southern culture. It was in the South where the Africans and the African Americans lived, and in the South, enslavement and scientific assessment of slaves’ characters were in support, they supported the slave system.
Medical myth of health v “fitness”

- Organized conventional medicine cherishes its myths, too. *Mythology-based medicine* helps foment disparities.
- Fitness for work, not health, was the goal
- The physician-planter dyad: Who is the patient?
- Today the physician-state dyad: Black woman is still not the patient
- Blaming the victim: Medical dimorphism, not disparate treatment and environment spawned ‘black diseases’

One of the ways they supported the slave system was providing free labor. The Victorian era was filled with scientists who also said that they were Christians. If you’re a Christian and a Victorian gentleman and a scientist, how do you justify taking people, kidnapping them from their homeland, forcing them to labor, raping the women, forcing the children—your children now by these women—into enslavement, beating them, using them for medical research, how? You can’t justify that, can you? But you can justify doing this to people who are not really people, and that’s exactly what the science of that era said.

They said that these African, African Americans are not really, they don’t, they don’t fit into *homo sapiens*, they’re not part of our species. They were lower form of, of life. And, um, having established that, they went on to say they differ from white people in every way possible.

Now one of the things I often heard at the beginning of—when my report first came out—they said, people would say, “You say that slave owners beat and abused African Americans and failed to treat them medically. They wouldn’t do that. These are their workers. They wanted them to be healthy, they needed them to be able to work, you know?”
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Those are two different things. Being healthy and able to work are two different things, and that’s something that was at odds with Western healing philosophy. The Western, Western healing philosophy was based on the dyad, physician-patient dyad. Two people—the physician and the patient—the patient, the physician had a sense of love and of care and responsibility for the patient. “I’m going to care for you and make sure that you’re healthy. I’m gonna do everything necessary to keep you alive.” And the patient had unending trust in the doctor. A beautiful relationship, but it did not apply to African Americans.

With African Americans it was not the slave, but his owner who decided if he would get treatment, what kind of treatment he would get, whether he’d get an abortion, uh, whether she’d get an abortion, whether he’d have an amputation, whether he would get malaria treatment. Only the owner decided that. The owner would decide whether to call in the doctor or not.

Also, when the doctors treated the patient—treated the slave—it was the owner who had to be satisfied. The owner had to be happy at the end. The doctor had done his job well. No one cared what the enslaved person thought. No one cared what the enslaved person felt. Whether the enslaved person had ‘wanted’ the treatment, quote, unquote. Or whether the enslaved person felt satisfied with what had been done with him. That was not part of the equation.
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So they had a dyad between the physician and the slave owner, with the enslaved person left outside and unconsulted. A nonperson. So this myth of treatment of slaves is just that. They were not being treated; they were being maintained in a state fit for work.
Economics and Medicine

“Competition: ‘There are no practices wherein which] the female practitioners are less educated, being chiefly negroes or mulatresses, or foreigners without anatomical, physiological and obstetrical education. . . . That such uneducated persons should be generally successful is owing to the fact that [in] a great majority of cases no scientific skill is required, and thus a lucky negress become[s] the rival of the most learned obstetrician.’”

—Dr. R. H. Whitfield, 1855

It’s important to note that there are many diseases that were compatible with being able to work. You can be mentally ill, you can be profoundly depressed, you can be ridden with parasite, I could go on and on. And sometimes have. But the reality is, that these were not patients, okay? These weren’t entities. It was the slave owner who had the care and concern of the physician.

Also, there are economic issues. As time went by, Africans who had brought their own brand of medicine with them, um, in midwifery but also surgical treatment. You know, Africans were responsible for a lot of our health innovations, but they were not acknowledged in history books and medical books. So for example, people tend not to know that Africans first introduced citrus for scurvy. The Africans did the first cesarean sections. The Africans showed white physicians how to do inoculations against disease.
These things all came from Africans. All, including midwifery was heavily practiced among African American women, and sometimes men, and they did so well—relative to the white doctors—that many whites as well as Blacks would prefer to have their, have Black people treat them. What would happen is that, especially after forceps began being used, Black healers had fewer infections, they lost fewer child—fewer babies and people were happy with their care. So white doctors were quite concerned about this. This was in direct competition for their services.

So they set about denigrating these white, these Black women who are rendering excellent care. But what did they say? Did they say, “Well, they’re not treating the patients well, the patients are dying?”

They couldn’t say that because the patients were doing better. So they said that they’re uneducated. And, uh, they also went on, uh, elsewhere to say that these are like occult, uh, non-Christian practices they’re, they’re doing. So denigrate them basically for being Black.
Now, the, you know, ironic thing is that during this time, many white physicians did not have MDs. It wasn't required. One didn't really expect a physician to have an MD, necessarily. That kind of professional came along later, later on. So calling them uneducated was kind of silly because they were not so much better educated themselves.

The competition actually grew deadly after a while. Um, oh, I have to point out that they had to allude to the fact the Black women were having better success. So what did do they do? They said “Oh, a lucky negress. You know. I'm a learned obstetrician, you're a lucky negress.” It was pure luck apparently.

But then things got deadly, because what happened was the competition grew so bitter, so bitter among white doctors and Black male practitioners especially, that they began killing Black doctors. The claim was usually that the Black doctor or doctoress—as they were called then—had poisoned the patient or caused the patient’s death. But the real reason sometimes was that the doctor simply did not like the competition.

Also there was some discomfort because households—even though doctors and scientists would characterize Black people as being unintelligent—households in the South were dependent on the expertise of Black people. You know, you had Black cooks who also were nurses and herbalists.
So you had, um, they knew they were putting their own life in these people's hands, but the reality was that slave insurrections were so frequent and so bloody that they were, they didn't really trust the people who they, who their lives depended on. So when they had a death—when someone died in treatment—sometimes they overreacted. “Oh you know, that slave woman she must’ve killed that woman. She wouldn't have died otherwise.”

And that was often enough to go on in court. You didn’t have to present evidence against the slave as you did a white, a free white man. You just had to testify that you did not, you never trusted that person. If that enslaved person could not find enough white people to testify on their behalf, that they had a good character, they were likely to be killed.

And what's happening today with Black healers? First of all, Black male healers, their numbers have been plummeting. According to some reports, the peak year for graduating Black male doctors was 1974. And how are Black women healers doing? At first glance they're doing well. When I speak at medical schools and spend time there, I find that, you know, women are now the majority in medical schools and Black women—you see them frequently. But how are they treated once they get out into the world?
Remember those Delta flights when two Black women, on separate occasions, had responded to a call from the crew for assistance—they had a patient who was very sick—and they said, “Are there any doctors on board who can help us?” The Black woman who volunteered was told, “Sit down, we’re looking for real doctors.” Even when she showed her credentials and insisted, they would not let her help. She said, “The patient was in distress. I wanted to go to him. They blocked my way and would not let me go help him.”

Then a white doctor jumped up and said he was a doctor, did not show his credentials, and he was led to the patient, who fortunately was fine. And then it wasn’t, I think maybe a week or two later, the same thing happened to another Black woman doctor who tried to respond to a distress call, and was told, “Sit down, we’re looking for credentialed people.” So there is a certain, certain denial, tendency for denial of Black women’s scientific expertise.
There also have, a very recent study showing that scientists of color who are Black women and Hispanic women and First Nations women, 60 percent of the time, they have been mistaken for assistants, for secretaries or technicians. So the acknowledgment of their expertise can be very hard to come by.

These scientists who characterized Black people for the nation, the American School of Ethnology um, the most prevalent, famous scientists in the, in the world frankly, during their time, came forward with a lot of categories, a lot of these categories showing how Blacks fell to the bottom on every list. But also they talked about the character and the physiology, the physical compliments of Black people. What were Black people like physically. And they found some very disturbing things. The disturbing things they found they didn't offer any evidence for, they had no data, but it was a case of the doctors agreeing that everybody knew.
It was a case that Black people's bodies were inferior. Black people had lower intelligence, and they had childlike judgment, they were not like adults. That their sexuality was dangerous. That not only were Black women these Jezebels or whores, but Black men had a tendency to want to rape white women. They also said that Black people all had sexually transmitted diseases and, significant for today, scientists of the era said that Black people were not good parents. Black people, Black women were indifferent mothers and Black men were absent fathers. They cared nothing about their children, and they also had a slew of imaginary diseases that only they had.
And, um, what were these diseases? They were things like “dрапетомания.” “Hebetude.” “Aethiopica.” Names don’t mean much to us today, but basically these, all these diseases were things that only Black people had. Not white people. And, um, they were characterized by things like disobeying a white man. Hitting one’s master.

In the more infamous one that someone—I know someone here knows about it—dрапетомания? Drapetomania was a disease shown by a slave who ran away. So if you’re a slave in ancient Greece or Rome it’s logical to run away, but if you’re a Black slave in the Americas and you run away, now you have a psychiatric disease, with a strong forensic component, so you have these diseases. Also it was held that Black people were all syphilitic, their children died very early because they were such poor parents. Actually, their children died very early because their children were slaves and starved and beaten and worked unmercifully and got no medical attention. But they, it was characterized as the parents' fault.
Antebellum “Black” diseases

- Overlaying = indifferent mothers
- Infant mortality, Low birthweight
- Syphilis, STDs (import for black men)
- Pellagra
- Malingering
- Drapetomania, Hebetude, Dysthesia aethiopica
- “Freedom”

Also pellagra was called the Black disease. Pellagra is a disease, um, charac— that had, characterized by roughened skin initially but later goes on to madness, mental illness and death. Horrible disease. They said Black people got it because they’re dirty, and it’s an infectious disease because they’re, they’re never clean. In reality, pellagra is a deficiency disease. People who don’t get enough niacin get pellagra, so the fact that Black slaves were being routinely starved is what gave them pellagra.

So Black people also all had malingering. In fact, I found two doctors who wrote their Masters thesis on malingering. And malingering is simply pretending to be sick when you’re not. Now what’s the importance of malingering? Well, you’re saying that Black people have all these diseases, right? But you’re also saying that they malinger—pretending to be sick when you’re not. If you have slaves who are refusing to work because they’re sick, what better way to force them out of the sick house and have a doctor declare that, “They’re malingering. They’re not really sick. They are fit to work.” And they’re back in the fields, well or not.
Antebellum black immunities

- Pain
- Anxiety, mental disorders, heart disease
- Fatigue
- Heat-related illness
- Malaria
- Yellow fever

So there were also immunities against disease that Black people had. One of the biggest immunities—for our purposes, really important—is that Black people did not feel pain. This is because scientists told us they had a very primitive undeveloped nervous system that didn’t register pain. It didn’t register anxiety.

Black people didn’t have heart disease, because back then people thought that heart disease was caused by anxiety. Black people did not have mental disorders because they had no real mental acumen, they had no nervous system, really, so how could they have a mental disorder? They're happy, right? They’re singing and whistling all the time. They didn’t get fatigued and they didn’t suffer from heat-related illness, because of course they’re from Africa. So you’re not gonna get heatstroke, you’re not gonna die from being overheated. And they didn’t get malaria. They didn’t die from yellow fever.
Antebellum black immunities

- Pain
- Anxiety, mental disorders, heart disease
- Fatigue
- Heat-related illness
- Malaria
- Yellow fever

These are nonsensical. If you look at the physician's memoirs of the day, it's filled with records of, of treating slaves with malaria and yellow fever. Why are they saying that Black people didn't get them? Because that statement supported enslavement. If you are a planter and you had acres and acres of fertile ground that you stole from the First Nations people and you want, you need bodies to work that ground in the hot Southern sun, in malarious climate—what better gift than someone who didn't get malaria? Who didn't suffer from heat stroke. Who's not going to get yellow fever. Who's not going to feel pain or fatigue. So, the slave body was constructed by science to meet the needs of the enslavement system.

Keep in mind that many, that, that doctors at this period were utterly beholden to, plan—, to, um, slave owners. You know, physicians today—a very high status profession, right? They—among other things—they make a good living if they choose to. But back then, it was a hard, it was a hardscrabble existence. Dr. Sims' father did not want him to be a physician. It would disgrace the family, you know. So it was hard to make a living, and they didn't have high status. They had to ingratiate themselves with slave owners. And so, espousing these beliefs that fit the needs of slave owners was a logical thing for them to do.
Antebellum black immunities

- Pain
- Anxiety, mental disorders, heart disease
- Fatigue
- Heat-related illness
- Malaria
- Yellow fever

And bear in mind that many physicians themselves were slave owners. They sometimes owned slaves in order to have research subjects and sometimes just to, to do things that other slave owners did with them. Have them do all the work in the household. Plow the fields, have sex with them. Because you could not legally rape a Black woman. Just like today you cannot leave legally rape First Nations women on the reservation, back then you could not legally rape a Black woman. So these Black immunities were useful, promulgated by scientists, to support the enslavement system.
And we laugh at them today because they're so laughable. How can you say that Black people don't get yellow fever? Or don't feel pain? But you know what, we do. We have Black diseases today that we believe in. Sickle cell disease. Most people believe that that's a Black disease. If you are white and have sickle cell people begin asking you about your Black forebears, but the reality is, it's not. It's not a racial disease. Disease in people from areas where the Anopheles mosquito was common. Sickle cell disease is a horrible disease. But sickle cell trait—when you have only one gene for sickle cell—is actually a beneficial state if you live in an area near the Anopheles mosquito. Because Anopheles mosquitoes transmit malaria. And if you have a sickle cell trait, it gives you protection against malaria. So people in areas where there's a lot of sick, a lot of, um, Anopheles disease, a lot of malaria, they tend to live longer than people who don't have sickle cell trait.

But in this country, where we don't have malaria, it's of no use to us at all. The thing is that it's—only way I can put it is publication bias. If you read the medical journals, they will focus on Black people with sickle cell and discuss sickle cell as if it's a Black disease, but it's, but it's simply not. And this is information that is, hidden. It's hidden information. People don't realize it.
And then there are a lot of other diseases suffered by Black people and white people but characterized as Black disorders—“only Black people get them.” They’re told that, “Well, it’s because you’re Black.”

For example, low birth-weight babies. When I first went to Harvard as a fellow we were talking about low birth-weight babies and the head of Child Maternal Mortality told me, “We don’t know why Black women have so many low birth-weight babies. It’s something innate in them. Something inherent in them.” I thought, “What a thing for a scientist to say.” But no one was disagreeing with her.

Then, crack babies. That’s an invention, of course. But it was an invention that characterized only Black babies. I was a newspaper editor for about 18 years. I never saw a photo of a white crack baby. If it’s caused by—it was not caused by crack use—but if it had been caused by crack use, there would’ve been more white crack babies than black crack babies. There were more white crack users than black crack users.

But it was a racialized disease, and it turned out to be an imaginary disease. It doesn’t exist. But it was created by the media, supported by the medical system and only refuted, what, within the last 10 years?

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**Today’s “Black” diseases, immunities**

- Sickle-cell disease
- Diabetic Endstage renal disease
- Low birthweight babies
- ‘Crack babies’
- Skin cancer
- Unqualified malarial immunity
- Napthalene exposure
- Innate subnormal IQ
Today’s “Black” diseases, immunities

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Then, skin cancer. Only fairly recently have, there’s been a widespread realization that Black people get skin cancer. Certain types of skin cancer like acral lentiginous melanoma are more common among Black people. But for a long time, it was considered a disease that only a white person got. That Blacks are fairly immune to it.

I could go on and on and on, but the one other one I want to mention is that having a subnormal IQ. There’s a 15-point gap demonstrated between the IQs of Black and white people in this country. And it’s usually characterized by hereditarian scientists as being something innate in Black people. There’s something that you’re born with, it, it makes you have a lower IQ. So many people believe this. Many intelligent scientists believe this.

I don’t think it’s a case, I think you can only arrive at that opinion by completely ignoring the disparate environments in which Black and white people live. Especially environmental toxicity, which we know has profound effects on the brain. Not just lead, but mercury, other heavy metals, hydrocarbons, all kinds of things affect cognition, thinking, the brain, very, very heavily. And Black people live in a witches brew—a sea of these toxins—and no one is asking, ‘Could this have something to do with this IQ gap? Should it exist?’
So we have our own immunities fed by the same kind of biased mythology among scientists as well as laypeople. So remember I mentioned pain? Scientists of the Victorian era all agreed that Black people did not feel pain, and we even have these little, clever little quotes from doctors testifying to this belief. Charles White said, “I've taken the legs off many African Americans who held their leg themself, they're not feeling a thing.”

Well you can believe that if you want, but the fact is as much as we find that laughable today, what are we—yesterday—what are we doing today? Today, we still discount claims of pain when made by African Americans. There have been numerous, consist— studies consistently showing that Black people, presenting to the doctors in pain, do not get effective pain medication. They’re often dismissed as drug-seeking, and I think that study, it came out only last year or so? Yeah, 2016. This study showed that half of medical students believe that Black people did not feel pain as white people did. They believe that Black people had different bodies than white people. All these things, all these beliefs—promulgated in the 18th century by the school of ethnology—are still with us today. Doctors believe this. It affects how they treat people.
And I mentioned that just as Black women were seen as being Jezebels, Black men were seen as being rapists. Especially dangerous to white women. And we can see this quote by W.T. English—I think it was, it was the 19th century when he made that quote—but we still behave as if we believe that today.

I don’t know if any of you remember Nushawn Williams, who in the mid-1990s was, uh, very interesting. His picture and his name were splashed across newspapers as being the demon who infected a bunch of young girls with HIV. These girls were all white. And I was an editor then, I was reading the stories, I was thinking, “Wait a minute. There are one million unanswered questions in these stories. You’re assuming that he infected these girls. These girls are all living a chaotic lifestyle. We don’t know if he infected them, we don’t know if one of them infected him.” But the assumption has been that he did this. At that time, the, confidentiality and privacy of people with HIV was sacred. We were not publishing the names of people in the paper who had HIV—only those who voluntarily gave their names or wrote about their experiences—and yet they had no problem splashing his name across the paper.
Hispanic ‘aggression’

- Hispanic Latino men also tainted by this medical slander, hence the facility with which invocation of undocumented immigrants as ‘rapists’ has been accepted.
- Negative invocations of *machismo* for behaviors of exaggerated masculinity that are equally common in white US men.

So it’s just an example of how readily people accept dystopia of Black men as rapists. And men of color, in general, because Hispanic men suffer the same sort of bias. And the use of the word machismo, for example, Latino and Black men for the same behaviors exhibited by white men. Men in general. But for Hispanic men it’s demonized, it’s considered something even worse. It, it takes on a sexually aggressive nature when it comes to Hispanic men.
And Asian men are not immune. During [the] last war is where you saw the most dramatic and egregious illustrations of, you know, our enemy, the Japanese, as being bloodthirsty rapists. And I mean, these images were everywhere.
Absent, indifferent, fathers?

- Scientific racism held that black men sperm donors unconcerned about either their mates of children
- Today, modern media perpetuate this image spotlighting hyperfertility, low marriage rates and absentee fathers

- Although about one in three American fathers lived apart from their children in 2009, some, including men of color, are the primary or sole caregivers for their children.
- Yet, as reported by Division of Vital Statistics National Health Statistics Report, African American fathers tend to be more involved in their children’s lives than fathers of other ethnicities.

So this plays into another characterization of Black men and men of color as being indifferent fathers, absent fathers. So basically there’s, there are sperm donors who don’t care about their kids or their wives, et cetera. But a study done by the Division of Labor Statistics show that even though that in this country there are a lot of absent fathers, one in three fathers is—of any race—is an absent father, but Black men are closer to their children. They’re more likely to be the primary—I know many Black men who are the primary caregivers of their children, sometimes sole caregivers, and they are present in their, in their children’s day-to-day life in the way that men of other races are not. And yet this bias, this myth of Black men as being abandoners of their families, persists.
You know the abandoner of Black children, the original one, the one whom we would never castigate? This guy. Many slave owners had children with the women that they owned. And when they—these children—were born they inherited slave status, which by the way, is contrary in English common law. They should have inherited the status of their father and become free. But no, they became slaves. That’s more profitable. And so they abandon their own children to enslavement in huge numbers. But I see a lack of outrage around, around that as we see, the outrage around men of color.
Bad mothering

- “What are black women doing wrong?”
- 1987-1992 ‘Something inherent in black women causes infant mortality.’
- Personal responsibility: Focuses on (largely nonexistent) internal causes, not environmental harms, stress and provider bias

And Black mothers today are still castigated as being very poor mothers. Posters like this one, and the belief that part of the crack baby myth was to denigrate Black mothers by saying that they cared more about their drug use and their drugs than their children.
Posters like this were put up. “Don’t let a pregnancy ruin your drug habit.” People offering to pay women — women of color — to have, you know to be sterilized, or to take contraceptives. Implanted contraception. Get birth control, get cash.
Ethnic Mothers ‘prefer drugs to children’

- In 1989, the Los Angeles Times wrote of how “Parents Who Can’t Say ‘No’ Are Creating a Generation of Misery”
- The Washington Post told us “For Pregnant Addict, Crack Comes First”

So this embracement of the image of parents of color as being malevolent.
And even today we have women of color being incarcerated just for poor birth outcomes. If your baby is, is born dead, if you have a stillbirth, you might be investigated. This Regina McKnight was investigated, um, for drug, for killing her baby by drug use when she, when her baby was born dead. But she didn’t use drugs. More to the point, the prosecutor offered no evidence that she used drugs, and she was convicted anyway. That shows how prevalent this myth is. They needed no evidence to convince judge and jury that she indeed was a drug user, whose drug use killed her baby. And she’s only one among many.
When it comes to intelligence, I love this quote by Stephen Jay Gould. I use it whenever I can. There has been a lot of investigation—much of it rigged and flawed—into Black and people of color intellectual ability. Endeavoring to show that it’s lower than whites. In the past, we had people filling empty skulls with marbles and shot to measure the volume, and then show the volume of a Black person’s skull was lower than that of a white. And the same for other people of color. It’s nonsensical of course, but today there are genetic tests that turn out to be dubious or outright, or outright unscientific. They are also focused on showing that African Americans, that Latinos, First Nations people all have lower intelligence.
Now, one interesting thing is that you'll frequently hear, “It's not racial. After all, Asian people have high intelligence. Asian people have a higher IQ than whites.” Some Asian people. Asian people from relatively affluent countries. Other Asian people fall right into the scale of African Americans, with the same 15-point gap emerging. So Asians are only brought into the conversation in order to denigrate Latinos and African Americans.

Here is an example I talked about before, the taxonomy of the, the catalogs of showing where people fell. On the, basically the, the ladder of humanity. Tied to skull shape in the past, today it’s tied to genetics. The genetics are often very, are laughably badly done.
So, so with Asians the problem is there, but it's more subtle. Because they're often thought of as a model minority, with a higher than average IQ. But as you can see on the slide, it's not always higher than average, and more to the point, this higher IQ is a two-edged sword. It's not always a good thing. When it's said of whites it's always a good thing, but with Asians you find that calling them, for example, gifted in math and science, translates to being devoid of creativity and lacking interpersonal skills. “Polite” means inscrutable and submissive. “Hard-working”—unfair competition for well-rounded, normal people. “Family oriented”—clannish, too ethnic.

You could see how every positive attribute has its negative obverse. And so Asians also—a little bit more subtly—are being castigated by scientific... there’s current research substantiating a lot of these beliefs. But they look very much like the bias espoused in the 18 century, in the 19 century.
In fact, Asians are often held to be too intelligent. There’s a Princeton lawsuit brought in 2015 by Asians who complained that Princeton’s policies were setting up hurdles for Asian students that were higher than those for other students of color. That African Americans and the Hispanics are being favored. Now, they lost the lawsuit. But I don’t think there, I think they had some merit there. I think it’s very likely that subsequent lawsuits will show this is indeed the case. We were finding that people expressing concern—as I heard at Stanford, for example—that there were too many Asians on campus. It’s a merit-based system. You know, get over it.

So, but it’s also an illustration of bias. That despite achievement, you know, these standards of achievement that were set by whites themselves, when Asians exceed them, they’re being castigated for it sometimes and punished for it.
I mentioned the fact that—poor people of color, in particular—but all people of color are more likely to be exposed to these pathogens these brain-eroding pathogens and toxins. But that's left out of discussions around intelligence.
And now I want to go to something else, a little bit different. Today, what are the contemporary research issues in this country we should worry about? I would say that aside from the persistence of these mythologies that cause us to treat people of color differently in the medical arena, we have other things to worry about. And these include what I call the erosion of informed consent. How many here think that if you are engaged in medical research, you have to have informed consent? Someone who’s gotta ask, get your permission after telling you a lot of information about the study and giving you a chance to make a choice. Who believes that? [To audience members] You don’t believe in informed consent? You don’t think that's happening?

Well, people who don’t think it’s happening are, are wrong. It is happening. But it’s also being eroded. It’s also being worn down. And there are also cases where it’s not happening.
Contemporary Research Issues

- Historical culture
- Dearth of consent
- Therapy/law enforcement line blurred
- Researcher mythology
- Patents, not patients
- Elision of researchers’ benefits
- Questionable subject benefit
- Disproportionate enrollment/ Stigmatizing initiatives
- Failure to acknowledge

So if you belong to a group of people—trauma victims—a huge group of people, by the way. If you are a trauma victim hit by a car, shot in the chest, then you can, people can do research on you without asking your permission, without even telling you. Without telling your family. This has been done in at least 20 studies I identified to date. The law was changed in 1996—the Code of Federal Regulations was changed to allow involuntary research with trauma victims, and the rationale is completely absurd. I asked some other ethicists, “How can you justify this? Why, why do you support this?” And the response I got most often was, “Oh, it’s used very rarely.”

That’s not an ethical defense. If I murder somebody, I can’t say “but I so rarely murder anyone.” It’s wrong. And the rationale given in the law is that these people are unconscious, they can’t give their consent. So that’s completely absurd. You know Nuremberg Code—which is not legally binding—but is a model for ethical laws, the Nuremberg Code says you have to get the voluntary consent of the subject. But we in the U.S. have decided, no, you don’t. Because research demands it. If you want to do research and involuntary consent is standing in the way, then you can get it out of the way, using this rule.
But if you were doing research in the developing world, you don’t even have to do that. It’s a lot simpler. All you have to do is lie. If, because we rely on the word of researchers in the developing world that they have given informed consent. If they say they’ve done it we say “oh, okay.” No one double-checks, there’s no oversight, and in many cases it has become quite clear to anybody who is investigating it that there has been no informed consent.

The most infamous case I happened on recently was in Kano, Nigeria. Where Pfizer tested a new drug for meningitis in the middle of the meningitis epidemic. They set up a tent next to Doctors Without Borders. People who lived in the area didn’t know that at one tent you had the selfless doctors of Doctors Without Borders working to help save your children, the next tent you had Pfizer doctors who were there as researchers, testing a new un—, untried, um, modality that caused deafness and killed some of these children.

So informed consent is something that we are slowly losing our grip on, and it’s a big, big problem for all of us. My fear is that when it’s completely gone or more broadly gone, it’s going to be too late. And the American people will not know about it in time.
There's also problems with reproductive technology—in fact, reproductive technology in general—but I'll focus on, let me focus on one aspect. One of the problems with reproductive technology is that it has no ethics itself. You can have the same technology and use it for good or use it for bad. You can use it for healing or you can use it to harm people. You can use it to remove bias or you can use it to reinforce it.

That's exactly what's happening. When we read newspaper articles or see TV shows about men who have been exonerated from prison by genetic technology, that's wonderful, right? It gives, it's heartening, it makes you, it gives you a sense that these technologies are liberating people, are creating justice. It's a wonderful thing.

The exact same technologies, though, have been used to unfairly stigmatize more men of color than they will ever exonerate. And let's be clear, we're talking mostly about men of color here. White men have been exonerated, too, but it's mostly Black men. Mostly Black men, a matter of fact, who have been convicted of assaulting white women, who were exonerated by these technologies.
So the genetic technologies, um, one example is a DNA screen, uh, sweep. If you have a DNA sweep, basically you have a crime. You have biological material left behind by the assailant. And you're testing the material to try to find out who did this, right? That sounds fine. The problem is how you test it. What's being done are frankly racial DNA sweeps, where for one reason or another, the lawmakers have decided, “We are looking for a Black suspect. Or Latino suspect. We're looking for a man of color.”

Okay, now what is done is you go to a community where this all took place and you “convince.” You convince men of color to give up their DNA. It’s very coercive the way this is done. The men are often threatened, “Either you give us your DNA now on the spot or we'll take you to jail.” They are coming, they are approached in their workplaces and told, “Listen, give us a sample, we’ll go away. Don’t make us get, let your boss get involved and tell him what’s going on. Your, that there’s a murder or a rape crime and we're looking at you. Just quietly give us your sample.”
The Janus of reproductive technology

- Genetic screening that can detect illness risks is not an unalloyed blessing, because it now considered an essential part of preventive medicine.
- Reprogenetic technologies that involve genetic selection shift responsibility for promoting wellbeing from the government to individual women by making them responsible for ensuring the genetic fitness of their children.
- But cash-poor women, especially Black women, currently face financial and other barriers to receiving reproduction assisting services, such as in vitro fertilization (IVF)

In this manner they've gotten a sample of many, many men of color and now they have a database of criminals. Seven thousand such samples were taken in one study in the U.S. You know how many crimes they found with it? One. And the one sample that turned out to be a crime came from a man who had offered his own DNA. So all these coerced men were innocent, but now their genetic material resides in a database. Next time they're looking for criminal they're gonna go to that database. It's, you know, a collective presumption of guilt for these men of color and that's what's happening with the same technology used to exonerate men from prison.

That is our big concern today. We have all this genetic technology and the ethics have not caught up with it. We have not considered how we're going to use it, what's acceptable, what's not acceptable. In fact—going to the law arena, look at what happened in 23andMe recently. They actually found the murder suspect based on someone's attempt to find their genealogy. Because they can look at your DNA, your sample and get information about people related to you. Your children, your parents and your siblings and maybe even other people.
So when I tell people that I would not have my, um, give up a sample for these kind of programs because we don't know what use this technology can be made of in the future. You know, also it gives information about other people. If I had a risk of Huntington's, I'm not only giving a sample that talks about me, but they can find out if my kids have it, or my parents had it, you know? And also there are, there are a lot of potholes in this road, and we're not looking at the signs, we're not looking at what could possibly happen. We're just seizing on technology and using it.
Disability, technology and ethics

- Down syndrome
- Peter Singer has offered a baby with Down syndrome as an example of a ‘killable’ infant; developmentally and cognitively disabled human beings have less value than other humans
- Tiergartenstrasse 4 Berlin; physicians killed the disabled as “useless eaters”
- Harry Haiselden, MD the Kevorkian of sick or ‘defective’ newborns
- XYY & abortion in Scandinavia
- Reproductive technology mandated/ criminalization

A similar situation exists with disabilities. Technology is affecting the way that we look at disabilities and what we do about it. The interesting thing is I remember when I took my first human genetics course in the ‘70s, the discussion around Down Syndrome was simply that most people were told, “institutionalize your child.” You know, put them someplace where they can care for them appropriately. There’s like not, there wasn’t any consideration that maybe you could take the child and raise them yourself. And a lot of the discourse in national magazines about the Sturm und Drang, all the trials and travails of raising a child with Down Syndrome, how hard it is. It gave people a very negative view of them. A challenging medical state, of course, but the ease with which people talked about institutionalization quickly gave over to an ease of talking about euthanasia. That’s a misnomer, in my opinion. Euthanasia means “good death” and killing a child because he’s differently abled is not a good death, in my opinion.
But, so today, we have not gotten away from that. Today, we have ethicists like Peter Singer, he gave an example of a baby with Down syndrome as an example of a ‘killable’ infant; developmentally and cognitively disabled human beings have less value than other humans.

- Tiergartenstrasse 4 Berlin; physicians killed the disabled as “useless eaters”
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- XYY & abortion in Scandinavia
- Reproductive technology mandated/criminalization

But, so today, we have not gotten away from that. Today, we have ethicists like Peter Singer, he gave an example of a baby with Down syndrome as a baby that should be killed. He didn’t think that you know, “Why keep a person like that alive and not fully human? He’ll never be fully human.” His definition of fully human has to do with intellectual capacity, and he ought to go back to a genetics text, because intellectual capacity is not always affected heavily with Down Syndrome children.

But the idea is that the technology is making it easier and easier to make decisions that are poor decisions about the fate of people with disabilities. I can only think about when I read about Singer’s claim, about in Berlin, on Tiergartenstrasse, during World War II and even before World War II, physicians were killing infants. You know, “useless eaters.” They’ll never be productive members of society so we need to dispense with them. And this mentality of judging people by what they can and can’t do by standards that are by no means humane or accepted standards, and then taking the draconian step of killing people—people who already have been robbed of most rights—it’s very, very, it’s very frightening to see the alacrity with which people discuss this.
You know, today you hear this discussed like it’s just another ethical problem, instead of the outrage that it is. And also, um, I did a paper on boys with XYY syndrome. For a long time, people thought that these boys had double the risk of ending up in prison as a violent offender. In Scandinavia, most boys with this anomaly were aborted. But today, we know these boys are normal. There's nothing wrong with them and, um, the fact is, all these children were killed because of their “disability.” It turned out not to be a disability. We didn’t understand the genetics then. So we have to be very, very careful that we don’t use technology as we used scientific theories to simply buttress our biases and our fears. But rather we actually use the data and use principles of humanity to determine how we treat people in the medical sphere and outside it.

Thank you so much for listening to me.