



BIOPOLITICS

Module 1

The Past and Present of Eugenics

Transcript

1.1 Introductions

RSC: OK, I'm Ruth Schwartz Cowan. I'm a member of the faculty at the University of Pennsylvania.

RGT: It's very good to meet you. I'm glad to be with you today here, Ruth. I'm Rosemarie Garland-Thomson. I'm a professor of women's studies and literary studies at Emory University.

RSC: And I also ought to say that my field is the history of science, technology and medicine. So we come at this subject from slightly different disciplines but we have lots to talk about.

RGT: I think that's exactly right. I think one really interesting correlation that we have between our work is that we both approach our topics from a humanities perspective in that your work as a historian feels to me like it's deeply influenced by the questions that humanistic inquiry asks. And my work in literary studies and the analysis of representations and cultural studies in general is influenced by those questions as well.

1.2 Defining Eugenics

RSC: So let's get started. We've kind of agreed that a good place to start would be talking about what eugenics is. From my perspective as an historian, eugenics is a social—or rather was—a social and political movement that was popular in the first half of the twentieth century. It was a movement that was literally worldwide. There were eugenics movements in North America, South America, Central America and of course also in Europe and in India. And each of those movements had a slightly different political goal. So there were eugenics movements that were interested in wanting to improve the race—whatever race it was that the eugenicists favored—they wanted to control the race by controlling reproductive practices of people they thought were defective. But there were also eugenics movements for example in France that had a completely different take on what eugenics meant. The word itself means “good birth” or “good breeding.” And in France eugenics meant financial supplements to mothers, public health measures to control syphilis so babies wouldn't be born with incipient syphilis or wouldn't be born blind (which is one of the consequences of syphilitic infection in a woman). And so there were hereditarian eugenicists and there were environmentalist

eugenicists. So the eugenicists we think badly of, for very good reasons, are the ones who practiced what historians call “negative eugenics.” And that was prohibiting the reproduction of— or trying to prohibit the reproduction of— people they deemed defective on way or another. And the two places in which those movements achieved some political success were the United States and Nazi Germany. And it’s those kind of practices that give eugenics a bad name. That is: sterilization of presumed defectives, both in the United States—I believe every state in the union had a law either mandating or permitting some appointed officials to sterilize people who were regarded as defective. In Nazi Germany, there were forced sterilization laws, but there were also laws prohibiting the marriages of certain people and there were laws that remanded “defective” individuals to institutions. And in some of those institutions, the ultimate eugenics was practiced; that is, the residents were killed. That’s my definition of eugenics.

RGT: I think that’s a really useful way to begin the conversation, with the specific history located in time and in cultures to give our listeners a sense of what eugenics is as historically practiced. The kinds of questions I’d like to engage in would be the questions that come out of philosophy, although I’m not a philosopher. But the questions I would want to ask have to do with what we mean by human, what we mean by flourishing, what we mean by health? These kinds of questions that I think are really important to put in conversation with the actual history of eugenics as it has been developed and practiced. So a definition (which does not conflict with yours but I think compliments it) that I would want to offer is to think about eugenics as a way of shaping human communities or shaping human populations. Although eugenics itself—the word, as you well know and have pointed out—comes from a very specific history within the development of medicine and science, in some sense what we might call eugenics—that is to say the shaping of human communities—has been practiced in lots of different ways over the course of history. The crudest way, obviously, to shape a population is ethnic cleansing, which has been done. The kind of shaping of human populations that took place over the very specific era that you’re referring to is a different *kind* of shaping, but still the hand of culture and the hand of various groups is involved in determining, to use Ruth Hubbard’s phrase, “who should and should not inhabit the world.” The questions I’d like to raise that I think are interesting are about what kinds of beliefs and what kinds of assumptions shape that shaping.

RSC: OK, I think that actually that’s a terrible definition of eugenics. Because if you regard eugenics as the effort to shape populations in a particular way, then everything in culture could be called eugenics. For example, we try to shape American culture through education. And education is *not* a eugenic practice. If you want to call education a eugenic practice, then we’re talking about something *completely different*. What Ruth Hubbard—what disability rights activists object to—they call “eugenic selection.” And that’s something completely different from the effort to shape populations. I mean all of culture is an effort to socialize individuals into a particular culture. In which case, we’re shaping when we send kids to preschool. We’re shaping when we agree to bilingual education, or prohibit bilingual education.

RGT: That’s true—

RSC: It's a particular kind of shaping that eugenics was about, and that's a biological shaping, it's a shaping by selection of those individuals who ought to have children and ought not to have children.

RGT: Exactly, and that's the kind of shaping that I would want to talk about. But I think that the term shaping is an appropriate one to use and I'd like to continue to try to use it in our conversation because it allows me to ask some of the questions that I think would be interesting for us to talk about.

1.3 Who Determines the Value of a Life?

RGT: The main question that I can offer in our conversation would be the question of why should we have or not have disabled people in the world. And a related question of course would be: what do we gain by eliminating disabled people in the way that eugenicists planned and have planned and have done so? What do we lose and what do we gain by that? I think that question might be an interesting one for us to engage in.

RSC: It might be, but I don't think that that's domain in which the moral crunch comes. The moral crunch—now I'm happy to talk about the question of what do we gain or what do we lose by having disabled people in the world, except that disabled is too large a term to manage. In some ways, all of us are disabled. I'm mathematically disabled; there's just no question about that. And you may be verbally disabled; you may be dyslexic. Or you may not be dyslexic; you may be very abled in some ways and disabled in others. So there were very particular things or there are very particular forms of a disability that the practices of prenatal diagnosis—which is what I have looked at carefully in my book *Heredity and Hope*—and the practice of sterilization, which is what the eugenicists practiced in the first half of the twentieth century—those are directed at very particular kinds of disability. It's not disability in general, in which case we'd all be subject to it in some way.

RGT: Well, that's a good point, and the question that I think comes out of that point is: what criteria do we use to select the traits that we don't want, or do want, in the world? Maybe we can talk a little bit about that question. We could talk for example about specific instances or we could talk in general about some of the traits that are selected for elimination. And usually the criteria for those selections are health and behind that health of course is the idea of both "suffering"—and I'd like to talk a bit about that—and the concept of "burden." Let's go from there.

RSC: Why don't you start then, because you have some things you want to add to the conversation about burden, suffering, health and disability; so lay them out and proceed from there.

RGT: Well, I think one of the most important points in trying to think through what kind of traits we value and don't value is to think about how those traits are manifest in a life. For example, one of the things we value in forming communities is to think about quality of life and to think about potential for contributions to the larger community. And so one argument is that there are certain conditions that will reduce quality of life and that quality of

life can be predicted ahead of time. And so I think one of the most important arguments *against* the idea of selecting against particular traits is the issue of what constitutes quality of life. We can talk about very specific kinds of case studies, which might be interesting. Down syndrome, which of course, is a kind of iconic form of human variation that is understood as a form of inferiority and a form of ill health that we want to select for and that we want to generally eliminate. And yet when we have the opportunity to meet people and to talk to people that have people with Down syndrome in their families, they often say that they don't understand the argument for a diminished quality of life that is necessarily associated with the characteristics that we think of as Down syndrome.

RSC: They do indeed say that.

1.4 Is Prenatal Testing Being Used to Foster or Eliminate Diversity?

RSC: Let me start a different way. The practice in which individuals—individuals, not communities but individuals—select against Down syndrome is the process of prenatal diagnosis. So let's be very concrete and ask: First of all, what is it? And who's doing the selecting and why? Prenatal diagnosis is a way of finding out—when a fetus is a *fetus*—*whether* that fetus has or does not have certain genetic characteristics. And in the case of Down syndrome, the vast majority of persons with Down syndrome carry an extra chromosome. They have 3 copies of chromosome 23. So you can find that out by prenatal diagnosis. At that point you say to the pregnant woman and her partner, “there's a pretty good chance, in fact I'd be willing to say it's a 100% chance that when this baby is born this baby is going to have Down syndrome.” Can't tell you how severely affected by the Downs the individual will be. There's a range. IQ scores, for example, is one measure of the condition. There's a range of IQ scores for people with Downs. There's a range of cardiac disabilities that people with Downs have. So, the person doing the test can only say there's an extra 23rd chromosome, can't say what the range is. And then it's up to the parents. In the United States and most of the rest of the world it's up to the parents to decide whether or not they want that pregnancy to continue. OK, so the agents of selection in this particular case that people are so worried about, are *parents*. Parents who are facilitated by or enabled by a medical practice to find out whether or not the fetus that's growing in the woman's womb does or does not carry that 23rd chromosome. So there we've got a situation in which the people making that decision are the people who are going to raise that individual. It's not the individual making that decision about whether or not his or her quality of life is a good one. It's the people who are going to have to *nurture* that individual making the decision. And from their perspective—and I can tell you because this data has been collected, at least in the United States—that overall (it differs by community, it differs by ethnicity, it differs by religion) but overall, 95% of the mothers who are told that the fetus they're carrying has 3 copies of the 23rd chromosome decide not to continue the pregnancy. So the question of selection is a question of that process.

RGT: That's absolutely true and of course that has to do with reproductive freedom which brings us back to the question of feminism. But the question that I would want to ask, which is the question that the disability rights movement asks too, is that the context in which one

makes choices about what kind of child is to be brought into the world is not a neutral context.

RSC: No.

RGT: We live in a society which profoundly values some human characteristics and profoundly devalues some human characteristics. And it also believes assiduously in the idea that we can—and I’m going to use the term again that I offered up— and that is to *shape* not just human beings but the communities in which human beings live. And the question that I think is important to ask is the one that I brought before, and that is: what do we lose when we eliminate some forms of human variation? In other words, what kinds of contributions, what kinds of variations, do we want to have and not have? Now historically of course we know that the modern era is characterized particularly by a kind of impulse to standardize human beings—[Max] Weber called it rationalization—so that we are encouraged in the larger cultural context to work toward a certain sameness, a certain standardization of people. And if we lose, for example, the kind of people that we consider the “people to have Down syndrome,” do we lose something by losing that human variation? Do we lose the actual variety of human beings? And how important is that? If we turn for example to let’s say hereditary blindness or hereditary deafness is another example (which I think are fairly interesting examples) the question would be, what can deafness offer us, and what can blindness offer us? Even though those traits are generally considered to be not just disabilities, but great disadvantages. There’s another way of looking at that. That is, people who are born deaf develop an indigenous sign language that is very useful to human beings because of course toward the end of life, anyone who lives long enough eventually becomes deaf as well. And if we had the variation of modes of communication that deaf people can offer it would be very beneficial for older people when they’re entering into society, to have much more of an acceptance, say, of deafness and much more of a valuing of alternative means of communication—besides speaking and hearing—to make the world actually work better. And so deaf people, particularly people who are deaf from birth, can contribute tremendously to that.

RSC: I think there’s no question that, at least if I were running the world, I would like to see enormous variation in human populations. But to me, as an historian, I have to say that I truly believe—and I’d be prepared to argue at great length-- that we have more variation than there’s every been before. I don’t agree with Weber and the other sociologists who see modernity as an effort to stamp out increasingly mass-produced, identical human beings. Culture has *always* tried to make human beings, populations conform to some kind of ideal.

1.5 Reproductive Freedom and Disability Rights—a Tense Conversation?

RSC: We can talk for example about people with Down syndrome. There are probably more people alive with Down syndrome alive today than ever before in human culture because when a baby was born with the obvious signs of that disability that baby was more often than not exposed or smothered. Anthropologists can tell us that that kind of variation was not permitted to live in other societies. So human societies have always tried to

standardize. That's what culture is. That's what socialization is. To make a "boy" behave like a boy and a "girl" behave like a girl, and that there's no middle ground. There are feminine ways to sit in the world. And there are male ways to sit in the world, as far as cultural norms are concerned. And much of the gay, lesbian, transgender movements of today are to encourage more variability. We will always have the deaf with us, we will always have the blind with us, because deafness and blindness are not just genetic conditions. Brain damage is not just a genetic condition. Life does this to people. I don't see that this disability rights movement is.... Well, let me start that again. I don't think that the enemies of disability rights are the people who practice prenatal diagnosis. And termination of pregnancies with afflicted fetuses. I think that there are way more important enemies out there that it would be much better for those of us that appreciate variability in our communities, in our neighborhoods, in our families, there are much more important things to look at than that.

RGT: I don't want to suggest for a minute that the perspective that I'm putting forward is understanding anyone as the "enemy." I think that it's important to make points about the valuing and devaluing of disability as a human condition. I think that if we have a medical mandate to try to eliminate disability and disease from the world there are several consequences of that that we want to think through. One of them—

RSC: Well, before we think it through, I apologize for interrupting you, but I don't see a medical mandate to do that anyplace. So, I want to ask first: Where is the medical mandate? Who does it rely on?

RGT: Ok, let me go onto another point that I'd like to make and that is if we understand disability as that which we don't want in shaping human populations I think that the problem is—well, it presents several problems—but one other problem that it presents is that it gives a message to the world that disability is that which can be avoided and in fact disability is inherent in the human condition so that, and this is quite often said, that if we live long enough, we'll all be disabled. And so the initiative to eliminate disability in that sense becomes a rather futile undertaking. What I think can be suggested is that accommodating disability, providing services for example, for disabled children who are born into the world, or people who become disabled, to put our time and energy and resources into that might be a better way to think of the human variations that we think of as disability, than attempting to create a variety of procedures that will eliminate disability.

RSC: Well I couldn't agree with you more except that I don't think that the two things are in our society today incompatible to pursue at the same time. There are enormous ways in which the medical community understood large, in its largest sense, has always been in favor of enhancing the life of those who are disabled or those who are ill—that's what medicine is. So that if a physician and a physicist, working together, came up with a device, the cochlear implant, for enabling certain deaf individuals to hear, this is not an effort to eliminate deafness is the whole community. It's an effort to ameliorate a problem that some people would like to have ameliorated. Nobody is forcing, there's no effort to force every deaf child to have a cochlear implant. But to offer to those people who want it, and can, who are lucky enough to live with circumstances in which they can afford to do it, what's wrong with that? That's what medicine is.

RGT: There's nothing wrong with it. I'm not arguing against the idea of choice. I'm simply suggesting that if we normalize all people, and if our goal is to normalize people, then we stand a chance of losing some forms of variation that can offer things to the world.

RSC: You're absolutely right, but I'd like to know who it is that... not we, which is a global we, who it is that is making an effort to normalize the world population.

RGT: I'm not prepared to point figures or say who, I'd like to bring up another question, though, and that is, I'd mentioned quality of life as an issue and potential contribution, and I think that one of the most important questions around the issue of prenatal diagnosis is that it assumes a couple of things: one of the things that it assumes is that suffering is that which can be predicted, that which can be avoided, and that which is associated with disability in all cases. And I think that's an important question to ask, for several reasons, because disability, as I mentioned, is part of the human condition, and most disabilities are acquired, of course, after birth, and also, the presence of a disability does not necessarily suggest that suffering will follow or that life is burdensome as a result of a disability. In fact, many people with disabilities as you know and I think everyone recognizes are quite compatible with flourishing and making contributions that are important.

RSC: There are two... In prenatal diagnosis, there are two—I'm hearing an echo, is that coming through...

RGT: Not too much on this end.

RSC: Ok, so we can continue.

RGT: Let's give it a try.

RSC: In the practice of prenatal diagnosis, there are three individuals or three groups of individuals. One are the parents. One are the physicians and the other healthcare professionals. And then there is the individual, the fetus, in the case of prenatal diagnosis. And whether or not we refer to the fetus as an individual is very important and, in policy terms, crucial, but, for the moment, I'm just going to refer to them that way, because otherwise my sentences will get very awkward. So the question is: Whose suffering is the practice of prenatal diagnosis meant to abate? It's not the suffering of the physician. So we're talking about the individual who will be born with that disability, and we're talking about the parents.

1.6 The Cause, Extent, and Alleviation of Disability-Related Suffering

RSC: Now it may be the case that some people, adults, with that particular disability that the fetus may or may not carry, do not regard their lives as lives of suffering. But it's a different question how their parents felt about it. And in the prenatal diagnosis decision, it's the parenting of a person with disability, the physicians that have worked with these parents for

much of their professional lives, they tell you—they've told me when I've interviewed them—that families suffer terribly. The data out there is clear with regard to Down syndrome. Marriages break up. Fathers disappear. Siblings are ignored. Siblings resent being ignored. Siblings worry about who is going to take care of that individual after the parents die. Physicians who care for these families know that there is an enormous amount of suffering involved. Even if the individual with the disability doesn't suffer. And so suffering is an important question in everything that physicians do. If they make an effort to reduce suffering in a particular way, they are, in the case of prenatal diagnosis, referring to the suffering of the parents, as well as to the suffering of the potential child.

RGT: And that's certainly the case. I think that the argument that I would want to make is that that's a structural situation that has to do with the lack of supports and services and understanding on the part of the society in general about what disability is and how disability operates and is in the world. And the argument that I would want to make is that if we changed the structure, the suffering, then, can abate. Suffering is not inherent in these conditions necessarily, but the unwelcoming aspect and unwelcoming attitudes in society in general are what need to be changed rather than simply eliminating the people with these forms of human variation. And we lose something when we understand suffering as being a product of disability and suffering as being something that is not particularly experienced by people who are non-disabled. In other words, quality of life and quality to society can't be predicted ahead of time.

RSC: Did you say “can” or “cannot?”

RGT: *Cannot* be predicted ahead of time.

1.7 What Role Should Reproductive Choice Have in Promoting Disability?

RGT: I mean the stories that you tell, that you're bringing forward are certainly of course, I mean I wouldn't be calling them into question particularly, but I don't think that they're necessarily universal in families that have children with disabilities. For one thing, disabilities as I mentioned are acquired more than they are born into society, therefore, if we have the belief that disability is that which we can eliminate before people enter the world, then that changes the attitudinal environment for people who become disabled after they are born, and of course this is the major way that people become disabled.

RSC: There is a good deal of what you have just said with which I agree completely. We certainly should, as individuals, and as a society, be directing our efforts toward making what is now the term disability less of a disability by every effort, social effort, we can make. But I part company with you at the point where we are asking parents to do that with their own children. That is, do you as a parent, choose a child who is going to confront the society as it is—and you as parents are going to confront the society as it is—as part of the effort to make the society better? Do you want that to be the goal of your parenting? Or should it be the

goal of your life? If all the other things that you do in your life, do you actively want to bring a child into the world in order to ameliorate that social situation? Some parents decide that they want to do that. There are a very large number of people that I know, who have had more children than they actually wanted to have, in order to make up for, for, and many Jewish couples feel this way, they have to make up what ceased to be a part of Jewish populations by having more children than they otherwise might. People make those decisions. People make the decision to adopt disabled children. But the objection that you and other disability rights activists raise to the practice of prenatal diagnosis is asking individuals to carry that burden forward for you, in your political interests, in line with your political beliefs. And I don't think that we should do that through the reproductive practice, in fact I think that doing it, trying to do it through the reproductive practice is a form of eugenics. It's a form of saying to these individuals you must carry that child to term and you must raise that child because *I* think it's better for society. And that's *exactly* what we object to in eugenic practices of the Nazis.

RGT: I'm afraid that you're assuming that because I'm bringing forward these points of view that I am advocating for changes in policies or laws to outlaw selective abortion and I'm not making that argument at all. I'm making an argument for bringing forward different kinds of understandings about what it means to be human and to do that through education and through the kinds of conversations that we're having. I'm not sure what you think disability rights activists believe or don't believe or want or don't want, but I want to be clear about that. I am both a feminist and a liberal and I certainly support what we think of as reproductive rights and I understand it as being a very complicated conversation and I just wanted to make that clear.

1.8 The Value (or lack thereof) of Nazi Analogies about Eugenics

RSC: Well my problem is that using the term "eugenic selection" as a synonym for prenatal diagnosis leads to precisely the position which you just abjured. That is, built into that term is the negative implication "this is like what the Nazis did." Both parts, not just eugenics, but also selection. Because we all know what the word selection refers to in that context and it actually refers to the selecting of individuals in the concentration camp who would go to the gas chambers as opposed to go to work. Using that term has the politics of anti-abortion and I have to say anti-feminism, built into it. And that's what I object to. I couldn't agree with you more that we have to do whatever we can and I certainly try in my own teaching and the raising of my children and grandchildren—and in other ways as well, in my support for the very structural changes that have been made to all of our environments as a result of the Americans with Disabilities Act. I mean you and I know that, just as citizens, we hear people, business owners, riders on the bus, complain about these things. And we've all had the opportunity to say "Don't complain." This is a wonderful thing that's happened for the disabled and for each of us. Every time I'm sitting on a bus and the bus driver has to stop and the bus driver has to raise the platform and then lower it and then raise it and then buckle somebody in a wheelchair into a seat on the bus, that bus driver, that individual, everybody on the bus is learning something important about accommodating a range of variations in our everyday life. I couldn't agree with you about that more. Where I disagree

with you is in the use of the term eugenic selection, because I think that you may feel but you don't mean to, but it does carry the weight of "this is something I feel this society shouldn't be doing, in fact, I'd be happiest if it was prohibited."

RGT: I want to hold onto the term eugenic selection and part of the reason for that is demonstrated I think quite aptly in your really wonderful book where you talk about eugenics in a capacious and comprehensive and historical way. Eugenics is precisely what you said it is. It is an idea of improving a certain population, improving a community of people. The question I would want to ask is: What do we mean by "improving?" What traits do we select for and against? And I think that the term "select" is a particularly useful one. And I think that the reference to the eugenic euthanasia of the Nazi era is a good one to make in the sense that I think that what we want to do is to ask the ethical and moral question of why do we select for and against certain traits. And how might we examine some of the assumptions that are behind that in moving forward with this process of thinking about how we want our communities to be, who we want them to look like who we want them to contain, which is a process that all communities undertake as I suggested. So I would want that reference to stay there as a cautionary tale for all of us and of course we understand that the Nazi era practiced the most virulent form of eugenics because they could, because it was a totalitarian regime, but that we want to be able to take a less away from that, a lesson about instrumentalizing human value, a lesson about the terrors and the threats of a totalitarian regime, and to be able to ask questions about the practices that we're engaging in now that's part of what can go on in a democracy in which critical questions can be asked. So I don't think we need to jump immediately from a conversation about these practices to the assumption that we want to immediately pass laws and policies that prohibit them.

RSC: Well, you may not want to but there are a lot of people out there who are doing precisely that. The pro-life movements that exist in the United States today and in other countries as well are quite happy to ally themselves with disability rights movements on this issue of eugenic selection, and by continuing to use the term eugenics selection I would argue that liberal disability rights activists like yourself and like many others that I know in my neighborhood in my religious life in my professional life with a political practice and a political impulse that they may not [be inclined to use.]

RGT: Well that certainly is the case. I mean in a capitalist democracy like we live in, there are all sorts of conversations and all sorts of positions that can be taken. And an adversarial relationship is that which takes place around a lot of issues. But I think that it's important to be able to ask the kinds of questions that we want to ask without assuming an adversarial position from the beginning. And I very much appreciate the opportunity to have this conversation with you and I think that the questions that you raise and the material that you put forward in your books is really important. And I welcome the opportunity to continue having these conversations in the future. So thank you.

RSC: Thank you!