



BIOPOLITICS

Module 1

The Past and Present of Eugenics

Annotations

Abstract

One of the most hotly debated concepts in contemporary bioethics, eugenics is often reduced to an evil of Nazism that should have been discarded long ago. In this video dialogue, two leading scholars of eugenics—Ruth Schwartz Cowan and Rosemarie Garland-Thomson— contextualize and complicate the current discussion of eugenic practices.

Beginning with a discussion of the definition of eugenics, the dialogue then examines how the history of eugenics can help us understand contemporary reproductive practice practices that are often labeled as “eugenist,” including prenatal screening and the selective abortion of fetuses with disabilities. It then examines the relationship between disability discrimination and reproductive freedom, and concludes by addressing the extent to which the association between eugenics and Nazism is useful to understanding contemporary medical practices.

ANNOTATION

Rachel Adams

Families of children with Down syndrome “suffer terribly,” Ruth Schwartz Cowan says, looking confidently into the camera. She repeats herself at least twice, adding that, as a result of Down syndrome in the family, “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.” As the parent of a child with Down syndrome, I listened to these statements with incredulity. The writing of parents like Michael Berube, Martha Beck, and Jennifer Graf Gronenberg tells a very different story about the rewards of raising a child with Down syndrome. And when it comes to siblings, it would be hard to say that Dr. Brian Skotko of the Children’s Hospital in Massachusetts, Tiger Mother Amy Chua, or Olympic snowboarder Kevin Pearce were damaged by having a brother or

a sister with Down syndrome. I know hundreds of more ordinary families who would probably describe themselves as experiencing degrees of suffering similar to those of the rest of the population. Very few would attribute that suffering to Down syndrome. And, as Rosemarie Garland-Thomson rightly points out, when we do experience suffering, its causes are structural. We suffer when we hear “retard” jokes in Hollywood films and coming from the White House, when teachers think our children can’t learn, or when they are excluded from the opportunities that others enjoy. These problems aren’t caused by Down syndrome, but by ignorance and social prejudice.

As someone who has devoted much of my career to the study of disability, my response to Cowan’s remarks is somewhat more nuanced. With Garland-Thomson, I object to the implication that disability comes hand-in-hand with suffering. We live in a moment where medicine promises to eliminate pain. People with disabilities inspire fear and disgust in the able-bodied because they seem to suggest the limits to this promise. But research shows a dramatic difference between non-disabled people’s perception of the quality of life of people with disabilities and the way people with disabilities describe themselves. When asked, they claim levels of satisfaction commensurate with those of the general population. My experience tells me the same is true of their families. This anecdotal evidence is supported by studies showing that the families of disabled children are no more likely to be broken or dysfunctional than the families of typical children.

Ruth Schwartz Cowan is a good historian, and she makes sure to tell us where her evidence comes from. Her sources are doctors who have worked with the families of children with Down syndrome. But any person with a disability will tell you that doctors are questionable authorities on the quality of life of their patients. For one thing, a doctor’s job is to treat pain and suffering. This means that doctors tend to see cases in which disability is linked to illness and impairment. This doesn’t make them experts on an entire population. The more self-reflective doctors I’ve talked to admit to knowing relatively little about healthy people with Down syndrome because they lack opportunities to study them (research on Down syndrome is woefully underfunded by the National Institutes of Health, compared to rarer conditions like cystic fibrosis and muscular dystrophy). Ignorance is part of a bigger problem, which is that doctors have trouble accepting the healthy disabled. In my experience, it’s hard for doctors to believe that a person with a disability can thrive without need of cure, correction, or other medical intervention.

Cowan asserts that Garland-Thomson and other advocates of disability rights are barking up the wrong tree when they criticize current protocols for prenatal testing. Let me explain where she is wrong. I strongly believe in the right to reproductive freedom, as do many advocates of disability rights. I also have no objection to prenatal testing. But I object to the context in which decisions about genetic testing

and selective abortion are made. I object to the way that pregnancy advice manuals, medical pamphlets, OBs, and genetic counselors (many of whom admit to never having met a person living with a genetic disability) conflate conditions like Down or Klinefelter's syndrome with universally fatal conditions like Trisomies 13 and 18. I object to the association of such conditions with a catalogue of every scary medical symptom that might befall a child between birth and adulthood. I object to the suggestion that genes tell us something definitive about the child a fetus will become, or what it would be like to be the parent of that child. Providing women with such biased and inaccurate information curtails their reproductive freedom and shapes their perception of living people with disabilities.

Ruth Schwartz Cowan has devoted much of her career to understanding social prejudice and inequality. Surely she can see that to equate healthy forms of disability with suffering, or to imply that that suffering can be avoided through terminating a wanted pregnancy is wrong and inaccurate.

ANNOTATION

Paul A. Lombardo

The conversation between Ruth Schwartz Cowan and Rosemarie Garland-Thomson highlights the difficulty of reaching consensus on what a term like “eugenics” means, and how it might be used accurately in contemporary discourse. Professor Cowan’s approach emphasizes locating the term in the concrete context of the first half of the 20th Century. During that era eugenics was used to describe a social and political movement that emphasized the importance of measures designed to ensure “well born” children. In the last generation, the most coercive governmental application of one variety of eugenic thinking has been linked in popular discourse with the Nazi agenda that culminated in the Holocaust. Today many people use “eugenics” interchangeably with “Nazi,” to signal coercive sterilization, exclusionary racial policies, euthanasia, and genocide. Because equating eugenics exclusively with the Nazis reduces a complex, several decades long international phenomenon only to its most horrific expression, Professor Cowan would prefer that the word be used cautiously, and certainly not applied to medical practices such as prenatal genetic diagnosis (PGD). She suggests that the legal mandates that some groups urge against using PGD implicates just the kind of reproductive coercion that characterized the worst features of eugenics.

Rosemarie Garland-Thomson prefers to use the term, particularly in its formulation as “eugenic selection,” to designate practices that are hostile to anyone who might be identified as “disabled.” (I intentionally surround the term with quotation marks to

indicate that it too marks contested ground.) She focuses on cultural pressures to “select” children who conform to norms that exclude the disabled and notes that negative attitudes toward disability embedded in the Nazi brand of eugenics still surface regularly in common discourse. Though “eugenic” has become a conversation-stopping epithet used regularly by those who wish to limit all measure of reproductive interventions—from birth control, to artificial reproductive technologies, to prenatal diagnosis and abortion—Professor Garland-Thomson asserts that one who continues to use the language of eugenics to describe technologies like PGD need not also embrace changes in public policy and law that would limit reproductive choice. This conversation demonstrates the difficulty of wielding historically complex and expansive terms like eugenics to debate the most divisive topics of our time— including abortion, a subject that leads everyone’s list of controversial issues. To complicate the matter even further, as a society we have hardly reached consensus on what we mean by disability, and our cramped understanding and limited perspective leaves us struggling to identify the circumstances and conditions that should qualify for that description. Scholarship and activism by the disability rights community has shed new light on the corrosive features of our social policies and laws that touch people with disabilities, and analysis has also been focused on the language within which such policies and law are clothed. That light has just begun to penetrate the consciousness of many who face the task of crafting a morally robust social response to disability.

I agree with Professor Cowan that invoking images of the Nazi death camps by using “eugenics” as the descriptor of choice in debates about reproductive technologies is a troubling strategy. The casual and rhetorically indiscriminate repetition of “eugenics” threatens to distort that term, particularly when it is used as a catchphrase that signals only its most grotesque historical expression, the Holocaust. It also ignores the hopes for future generations of healthier babies that made eugenics popular in this and other countries. If we ignore how positive, uncontroversial ideas of health fed the aura that surrounded the term for decades, we squander the opportunity to have any insight into why the “eugenics movement” captivated so many, as well as why it took its darkest turns. We also deny how popular those ideas of health were among many physicians who spoke vigorously against sterilization, abortion and abusive treatment of people with disabilities whom they attempted to serve. Simply put, identifying everything about the history of eugenics as equivalent to German National Socialism is simply ahistorical. Perhaps most importantly, it seems to endorse the use of the term “eugenics” as it is often used today—as the demagogue’s weapon of choice in the ongoing culture wars over privacy, reproduction and the role of the state.

The worst expressions of eugenics in this country were embodied in laws that restricted marriage among people who were ill, disabled, or of different races, mandated sterilizing operations for people of suspect heredity, separated people by

race, and excluded millions of others from those same disfavored groups from immigrating to this country. Those laws were the concrete expression of the sometimes patent but often unspoken bigotry against a variety of groups, including people with disabilities. It is possible that prenatal genetic diagnosis will be employed in the service of attitudes that both Rosemarie Garland-Thomson and Ruth Schwartz Cowan abhor. It is also possible that people may use PGD to carry out motives that both of them could applaud. But the changes in attitudes, policies and laws that both favor are more likely to occur if descriptions of past ills are addressed with specificity and language used with precision both to label historic abuses and to expose contemporary biases that endure.

ANNOTATION

Marisa Miranda & Gustavo Vallejo

Prior to reflecting the state of eugenics today, it is necessary to examine the history of eugenics. A historical consideration makes it possible to notice a basic distinction running through the differing varieties of eugenics highlighted by Ruth Schwartz Cowan and Rosemarie Garland-Thomson. In effect, the categories of eugenics that they identify all involve direct interventions either on bodies (sterilization, euthanasia, genocide, etc.) or on the environment (education, health, etc.). This difference regarding the object of intervention is the criterion for distinguishing between “negative eugenics” (the first group) and “positive eugenics” (the second group). However, these categories deserve to be rethought based on the experiences of Anglo-Saxon countries as well as those of the Latin world. Unlike what occurred in Anglo-Saxon nations, in cultural universes strongly influenced by the Catholic Church, eugenics could only prosper on the condition of abandoning direct interventions on bodies. As a result, eugenics became primarily concerned with controlling chance via modifications to the environment. These modifications involved the moralizing reaffirmation of customs designed to prevent “detours” in conduct that would necessarily bring about “dysgenic” descendance.

By supporting this form of intervention on the environment—and interfering with direct interventions on bodies—authoritarian governments generated a model for the military control of civil society that became implemented in Latin America through successive state coups. The form of eugenics employed in these interventions cannot be easily identified as “positive.” It was a eugenics that—with the blessing of the Catholic Church—charged itself with exterminating any form of otherness, even as it extracted all offspring capable of being “recuperated” through education in an “atmosphere supersaturated with morality” capable of modifying their “unworthy” genetic stock. For example, in Argentina, the actions of the Grandmothers of the

Plaza de Mayo have made it possible, in recent years, to recover the identifies of more than a hundred children who, during the last military dictatorship (1976-1983) were the object of a systematic plan to remove the children of “subversive” mothers and give them to “well constituted” families. In Spain, analogous procedures are currently awaiting the outcome of political decisions necessary to make judicial intervention possible.

Thus, this version of eugenics—which we could call “Latin”—though seemingly distanced from sterilization, shared a coercive root (the symbolic or physical elimination of otherness) in common with the negative eugenics of Anglo-Saxon countries. Based on this commonality, it is worth rethinking the oppositions between “negative” and “positive” or “genetic” and “environmental” eugenics in favor of an understanding of eugenic logic as being based on the exaltation of hypothetical differences between the “worthy” and “unworthy,” between those who deserve to reproduce and those who do not. At base, the point of commonality for all these actions inherent to eugenics is a will to exercise the power—which is never innocent—of identifying, classifying, hierarchizing, and finally excluding the “disagreeable.” Of these four instances, the mechanisms of exclusion are ultimately what distinguish the forms by which eugenics was carried out in Latin American and Anglo-Saxon countries.

From this perspective, if experiences not so distant in time and surrounded by a halo of “beneficial environmentalism” had the tragic consequences we have sketched out here, it is worth remembering the risks contained in the central idea of all eugenics: the preconceived idea of human inequality.

Translated by Harold Braswell

INTERVIEW

Nikolas Rose

What do you see right now as the promise and perils of so-called “new” eugenicist technologies and practices?

Ok, well I suppose I have to go back to the question of whether or not it makes sense to call what’s going on today “eugenics” or “new eugenics” or “flexible eugenics” or “consumerized eugenics” or whatever.... I have to say that I’m quite skeptical about whether or not it is useful to redeploy the term “eugenics” in the contemporary context. There is one basic reason for that, which has to do with historical accuracy at one level, but it’s also about trying to characterize what eugenics was as it took shape from the late 19th [century] to the 1950s. Essentially

the focus of eugenics was on the population – in particular the quality of the population. Eugenic politics took shape in the context of a concern with the biopolitics of population— if I can put it like that—in many Western countries and indeed in other regions as well. So eugenics was about managing the quality of the population. And within that problem of management of the population, many different strategies could be employed. The ones that usually come to mind are strategies of curtailing reproduction and of restriction and of elimination and so on. But those were by no means the only strategies that one saw.

If you just take my own current institution, London School of Economics, the first director, William Beveridge, was interested in eugenics. As was his successor Alexander Carr-Saunders, who spent several years as president of the Eugenics Society. He received the Galton prize – Galton was of course the founder of eugenics – in 1946, presented by no less a person than John Maynard Keynes, who described eugenics as “the most important, significant and, I would add, genuine branch of sociology which exists.” Note the date – this was in full knowledge of the horrors of Nazism. So these people—Beveridge, Carr-Saunders, Keynes, Richard Titmuss, who is most famous for the kind of “gift” relationship argument against the commercialization of blood donation and so on—these people weren’t eugenicists in the sense of the elimination of “bad stock” and so on and so forth. They were eugenicists in the sense that they thought it was an obligation of governments to try to improve the quality of populations by whatever means necessary. And many of those means were social and environmental.

So this is why I think that to do eugenics justice, both critically and historically, it’s necessary to kind of understand the style of thought that it was associated with and also... the problem space in which those people who called themselves eugenicists were working, as well as focusing on the technologies. The attempt to argue that what is going on today is flexible, consumerized, neoliberal eugenics focuses on the technologies, but it ignores or forgets that more general concern with population that was actually the key to eugenics. It’s not that I think what’s going on today, with pre-implantation genetic diagnosis, or selective abortion and so forth is unproblematic, should not be criticized, etcetera. I just think that it makes more sense to try and figure out what our contemporary problem space is and then try to think about how those strategies and technologies operate today.

Where would you look to analyze how these strategies operate in the contemporary context?

I think it’s interesting to see where one would look for the clues... for the ways in here. And one way in is through the current discussion of the quality of life. Now this is slightly difficult to evaluate because, as I’m sure you know, some of the earliest debates in Germany at the beginning of the 20th century about termination

of the lives of those people who were severely handicapped —Hoche, Binding, and so on—those all used such phrases as “lives not worth living” They didn’t actually use the term “quality” in German, I think, but they said that these were lives that were “not worthy of life.” So one needs to analyze the difference between that argument and the contemporary debates, which would say, well, if you’re in a family with a long history of Tay-Sachs Disease or some other severe and fatal hereditary condition, it’s best to use pre-implantation genetic diagnosis to avoid having a second or a third or a fourth child that’s going to suffer and die. And often that argument is made in terms of the fact that not only is the child going to suffer and die but also that the child-to-be will not have a good quality of life. The term “a life not worth living” or “a life not worthy of life” is not used – so is it the same to frame this in terms of a poor “quality of life”?

So I think one needs to think about the places where this notion of a quality of life appears, making the most out of one’s “quality of life.” Whether people with severe disabilities or who are going to be destined to have short lives are going to be destined to have a worthwhile quality of life – and the ways in which this links to that other key notion today the “value of life.” There are some interesting, heartbreaking legal cases where parents sue medical practitioners, or even children who have been born with severe disabilities sue their parents, for not having had pre-implantation genetic diagnosis that would have enabled the choice to terminate the pregnancy, to prevent a child having a life not worth living. In the case of kids suing their parents, that perhaps it would have been better for them not to have been born at all. Now they’re heartbreaking cases. Mainly the reason why they’re done is to use this technique to get money from insurance companies to support the lives of these children and their families.

Nonetheless there is something to investigate, it seems to me, in the emergence of these ideas of “quality of life” at an individual level and at the population level.

Is there anything else you want to add?

I would just say this: I absolutely understand what the people, those commentators and analysts are concerned about when they talk about “flexible eugenics” and “neoliberal eugenics,” etcetera. It’s not that I want to say that their worries are misplaced or that their concerns are misplaced. It is rather that I think that in order to understand the situation that they’re criticizing, the constant reapplication of the term “eugenics” is actually a hindrance rather than a help to understanding the problems that we face today in the twenty-first century, and the best ways in which we can analyze and therefore intervene in them.

BIOGRAPHIES

Contributors

RUTH SCHWARTZ COWAN is the Janice and Julian Bers Professor of the History and Sociology of Science at the University of Pennsylvania. She has written, lectured, and consulted about topics as diverse as the impact of washing machines on the daily lives of housewives, the impact of genetic testing on the reproductive plans of young couples, and the ironic anti-feminism of women engineers. Her latest book is *Heredity and Hope: The Case for Genetic Screening* (2008).

ROSEMARIE GARLAND-THOMSON is a professor of Women, Gender, and Sexuality Studies at Emory University and the author of *Staring: How We Look* (2009) and *Extraordinary Bodies: Figuring Physical Disability in American Literature and Culture* (1996). Her work develops the field of disability studies in the humanities and women's and gender studies. Her current book-in-progress concerns the logic, space, and design of euthanasia in the Holocaust and American culture.

RACHEL ADAMS is the director of the "Future of Disability Studies" at the The Center for the Critical Analysis of Social Difference at Columbia University, where she is also Professor of English and American Studies. She specializes in 19th- and 20th-century literatures of the United States and the Americas, media studies, theories of race, gender, and sexuality, medical humanities and disability studies. She is currently writing a memoir about raising a child with Down syndrome called *Aiming High Enough*, which will be published by Yale University Press. She is also the author of *Sideshow U.S.A.: Freaks and the American Cultural Imagination* (2001). Her articles have appeared in journals such as *American Literature*, *American Literary History*, *American Quarterly*, *Minnesota Review*, *Camera Obscura*, *GLQ*, *Signs*, *Yale Journal of Criticism*, and *Twentieth-Century Literature*. She has also published widely in the popular press, most recently with "Breaking Down Barriers—Seen and Unseen" in the *Chronicle of Higher Education*.

PAUL A. LOMBARDO, Ph.D., J.D., is the Bobby Lee Cook Professor of Law at Georgia State University. Professor Lombardo is currently a Senior Advisor to the Presidential Commission for the Study of Bioethical Issues, in Washington, D.C. He served on the faculty of the University of Virginia Schools of Law and Medicine from 1990 until 2006. His most recent books are *Three Generations, No Imbeciles: Eugenics, the Supreme Court and Buck v. Bell* (2008) and *A Century of Eugenics in America: From the Indiana Experiment to the Human Genome Era* (2010).

MARISA ADRIANA MIRANDA is a Doctor of Legal Sciences. She is a

Researcher at CONICET and Professor at the National Universities in La Plata and San Martín. In 2003, she held a position in the Spanish National Research Council (CSIC) as a result of a MAE-AECI grant from the Spanish government. In 2010, she was a Visiting Professor at the University of Chile. In addition to editing, with Gustavo Vallejo, the collections mentioned below, she has also edited, with Álvaro Girón Sierra, the collection *Cuerpo, biopolítica y control social* (2009). She has recently published the *Controlar lo incontrolable. Una historia de la sexualidad en Argentina* (2011). She is co-director (with Gustavo Vallejo) of the Investigation Group on the Human Sciences at the Institute of Biotechnological Research (IIB-INTECH/CONICET-UNSAM).

GUSTAVO VALLEJO is a Doctor of History. He is a Researcher at the National Council of Scientific and Technical Investigation (CONICET-Argentina) and Professor at the National Universities in La Plata and San Martín. In 2003, a sabbatical granted by the Spanish Ministry of Science allowed him to hold a position in the Department of History of Science of the Spanish National Research Council. He is the author of *Escenarios de la cultura científica argentina. Ciudad y Universidad. 1882-1955* (2007) and *Utopías Cisplatinas* (2009). With Marisa Miranda, he has edited the following volumes: *Darwinismo social y eugenesia en el mundo latino* (2005), *Políticas del cuerpo* (2008), *Derivas de Darwin* (2010), and *Una historia de la eugenesia argentina y las redes biopolíticas internacionales* (in press.) He has received several awards, most recently from the National Academy of History in 2010. He is co-director (with Marisa Miranda) of the Investigation Group on the Human Sciences at the Institute of Biotechnological Research (IIB-INTECH/CONICET-UNSAM).

NIKOLAS ROSE is James Martin White Professor of Sociology, Convenor of the Department of Sociology and Director of the BIOS Centre for the Study of Bioscience, Biomedicine, Biotechnology and Society at the London School of Economics and Political Science. He has published widely on the social and political history of the human sciences, on the genealogy of subjectivity, on the history of empirical thought in sociology, and on changing rationalities and techniques of political power, and he has also published in law and criminology. His current research concerns biological and genetic psychiatry and behavioural neuroscience, and its social, ethical, cultural and legal implications, notably how these change ways of thinking about, and governing, normality and abnormality. His publications include *Governing the Soul* (Second Edition, Free Association Press, 1999) and *The Politics of Life Itself* (Princeton University Press, 2006).