Revised version 14 December 2020
Routledge Disability Bioethics Reader
Joel Michael Reynolds & Christine Wieseler (eds.)

Eugenics, Disability, and Bioethics [4500 words]

Robert A. Wilson

University of Western Australia

rwilson.robert@gmail.com

1. The Eugenic Touchstone

Despite having peaked in worldwide influence approximately 100 years ago and having few unbridled advocates since 1945, eugenics continues to serve as a touchstone for a number of core debates and issues within disability bioethics today. Eugenics is both a set of ideas and a historical social movement anchored in the thought that we should use scientific knowledge and technology to selectively direct the traits of future generations of people. In short, the overarching aim of eugenics is to bring about *intergenerational* human improvement. As a project that takes itself to be ameliorative, to make things better, eugenics rests on a distinction between some notion of better and worse traits and, seemingly, better and worse sorts of people.

I begin by saying enough about eugenics to explain why disability is central to eugenics (section 2). I then elaborate on why cognitive disability has played and continues to play a special role in eugenics and in thinking about moral status (section 3) before identifying three reasons why eugenics remains a live issue in contemporary bioethics (section 4). After a reminder of the connections between Nazi eugenics, medicine, and bioethics (section 5), I return to take up two more specific clusters of issues at the intersection of eugenics, disability, and bioethics. These concern questions of life, death, and reproductive value (section 6) and the value of standpoint theory and epistemology for understanding some of the tensions between bioethics and disability in light of a shared eugenic past (section 7).

2. Eugenic Traits and Disability

Eugenics is typically thought of as a set of ideas that began in the writings of Francis Galton in the nineteenth century, developed as a social movement in the first half of the twentieth century, and ended with the atrocities of the Nazi regime, including the murder of millions of people deemed to be of inferior stock. There are limitations to this received view of the history of eugenics, including neglecting the perspectives of survivors and creating the false impression that eugenics is only of historical interest. The recent sterilization of Latina and African-American women in the California prison system and of girls and women with intellectual disabilities in Australia underscore the limitations of this "eugenics past" view (Wilson 2018a: ch.1). Recent defences of eugenics by philosophers and bioethicists reinforce the naivity of such a view (Wilson 2019; see also section 4 below).

Galton's eugenics arose within a broader context in which evolutionary thinking had been adapted to social transformation and change, with forms of artificial selection occupying centre stage in the opening chapters of Charles Darwin's *On the Origin of Species by Means of Natural Selection* in 1859. Darwin's classic "one long argument" for natural selection begins with an extended analogy between the power of artificial selection, directed by human agency and applied to farming animal stocks and plant species, and the idea of selection without such direction: natural selection.

This analogy and focus on human improvement can create the impression that early eugenic thought was chiefly directed at what later would be called *positive* eugenics—the selection of desirable traits to be passed down to future generations. Yet the development of eugenics in North America around the so-called *eugenic family studies* in the 1870s with their focus on so-called degenerate families should remind us that negative eugenics was an integral part of eugenic thinking from that outset. So while the distinction between negative and positive eugenics is useful for some purposes, the two are closely entwined historically as well (I would suggest) conceptually.

Galton brought two general ideas forcefully together that go far beyond the bare-bones idea that eugenics is a project of human improvement. These are the idea that *human reproductive value is unevenly distributed* both within and across human populations and the idea that *we can direct the constitution of human populations over generational time* by harnessing the insights of science and technology. Galton defines the term "eugenics" as "[t]he science of improving stock, not only by judicious mating, but whatever tends to give the more suitable races or strains of blood a better chance of prevailing over the less suitable than they otherwise would have had" (Galton 1883: 25n).

The so-called science of eugenics sought to provide two ways of achieving this goal of improving stock. First, eugenics provided the means to distinguish those of higher quality reproductive value from those of lower quality reproductive value; second, it provided the means to guide, constrain, and even shape human populations to promote higher quality people in future generations. Intelligence testing was co-opted to play this first role early from early on in the twentieth-century, following the advance it made through the introduction of what later became a standardized test by Binet. Policies of eugenic sexual sterilization and immigration restriction laws were determinate forms of eugenic policies that guided, constrained, and shaped future populations that many states and nations adopted in that century's first half (Wilson 2018a: ch.2).

To say that human reproductive potential is unevenly distributed within and across human populations is a euphemistic way of expressing the idea that some people have traits that make them more valuable as hereditary contributors to future generations, whereas other people have traits that make them less valuable in this respect. That is because the traits themselves have differential value to human society and, further, are assumed to be heritable.

Such traits are what have been called *eugenic traits*: traits that are the basis for policies, laws, and practices that differentially treat people thought to have them. Eugenic traits include both valued traits, such as the artistic and scientific talents that Galton began with, and devalued traits, such as low intelligence, criminality, and sexual promiscuity. Historically, the most common eugenic traits that served as the basis for the practice of eugenic sterilization in at least North America were feeblemindedness, mental deficiency, epilepsy, and relatively indeterminate forms of mental illness, such as insanity (Wilson 2018a: ch.3). Here many eugenic traits that are devalued are some form or another of what we categorize as *disabilities*, particularly cognitive and psychiatric disabilities.

This is true not only of the eugenic traits drawn on in practices such as sterilization but of those articulated in the policies and laws governing immigration restriction in the late nineteenth and early twentieth centuries. Immigration has historically been strongly racialized, treating peoples with specific national, linguistic, or cultural shared backgrounds as races. Although the restriction of immigration based on country or region of origin of the immigrant was racialized in countries such as the United States, Canada, and Australia, that racialization itself involved disabling characterisations. Umbrella terms, such as "the unfit", "the "dependent, defective, and delinquent", and "the feebleminded", all indexed disability and were used liberally in describing potential immigrants as racialized others (Dolmage 2011).

This indexing of disability via an encompassing expression is perhaps clearest in Harry Laughlin's attempt to establish the term "socially inadequate person" as the central organizing concept in his model eugenic sterilization law. Such a person "fails chronically in comparison with normal persons, to maintain himself or herself as a useful member of the organized social life of the state" (Laughlin 1922: 446). Most of the ten socially inadequate classes of people that Laughlin specifies designate putative sorts of people with disabilities: the feeble-minded, insane, epileptic, blind, deaf, and deformed. Laughlin then simply extends this conceptualization of state-level sterilization policy to federal-level immigration policy by advocating for the sterilization of all immigrants who are "potential parents of socially inadequate offspring" (p.451).

3. Personhood, Cognitive Disability, and Moral Status

Cognitive or intellectual disability looms large in the history of eugenics, chiefly because the most prominent cluster of eugenic traits—feeble-mindedness or mental deficiency and their determinate forms—were either explicitly named in eugenic laws or policies, or were assumed to underlie or accompany other explicitly identified eugenic traits, such as epilepsy or criminality. The same is true of mental illness and its varieties, such as insanity or psychosis.

Within bioethics, especially that dimension to it informed most directly by moral philosophy, cognitive disability and mental illness have also been of particular importance among conditions viewed as diminishing health and wellbeing. This is in part because of their relationship to the concept of *personhood* that has featured in discussions of moral status and personal identity and their interaction with questions about life, death, and quality of life. Conceptualized as an inherited state or condition acquired early in life, cognitive disability in particular has been taken to compromise one's moral status as a person.

Consider John Locke's claims in *An Essay Concerning Human Understanding.* What makes for the same person over time is not simply identity in substance or continuous life, but some kind of *psychological continuity*. This is what makes persons morally distinctive for Locke, such that they can be the subjects of moral praise and blame. Locke's views continue a long philosophical tradition of defining persons in terms of their cognitive capacities and holding that such capacities differentiate humans from non-human animals and plants. Locke and the neo-Lockeans that occupy a central place in contemporary discussions of moral status and personal identity emphasize in particular the significance of the ability to remember, plan, or more generally to bear psychological connections both to the past and the future.

If these are the basis for rights-imbuing moral status, then individuals lacking those capacities--either because they have never acquired them or because they have lost them--are seen to have a reduced moral status. One way in which the claim that individuals lacking certain capacities have a reduced moral status has featured in discussion of the relationship between cognitive disability and bioethics and moral philosophy is through what Eva Kittay calls "leveling by intrinsic properties" (Kittay 2017), where those lacking the intrinsic cognitive capacities that mark personhood have the reduced moral status of nonhuman animals with comparable intrinsic properties. The centrality of a broad range of cognitive abilities to views of what make human life valuable is also reflected in bioethically-informed decisions about the prolongation of life through medical intervention and the corresponding withdrawal of such life-sustaining treatments and voluntary active and physician-assisted suicide.

4. Eugenics is Alive in Contemporary Bioethics

As a field associated with medicine and health care, bioethics has developed only in the last 50 years, well after the demise of eugenics as a widespread social movement at the end of the Second World War. It is common to view bioethics, at least in the United States, as arising in reaction to knowledge of the atrocities of Nazi eugenics, particularly to how "medicine went mad" under that reign (Caplan 1992). Nonetheless, there are at least three further reasons why bioethics has intervened in the link between eugenics and disability and why eugenics seeps into contemporary disability bioethics.

The first is that those working on the history of eugenics, the sociology of medical technologies, and more explicitly on disability have warned of the possibility of a new eugenics. Here so-called *newgenic* practices and policies primarily operate via individual choice over the use of reproductive technologies, rather than compulsory state mandate. Yet, critics argue, they ultimately achieve outcomes comparable to those of the eugenic past. Such technologies, including in vitro fertilization and prenatal screening with selective termination, provide one way to influence the traits that individuals in the next generation have and so mediate the selective, intergenerational control at the heart of eugenics. Which traits should we select for or select against, when technologies create choices for us here? The deployment of such reproductive technologies also raises questions about the nature of parenting, reproductive autonomy, and what constitutes human well-being and quality of life. These are all questions that bioethicists have grappled with and that are topics of ongoing discussion in disability bioethics.

The second is that some prominent contemporary philosophers and bioethicists have sought to explore forms of eugenics in a more favourable light. Here they respond with seeming bravado to the challenge that the label "eugenics" itself signals a no-go zone, displaying at time what might be thought of as a kind of philosophical shock-jockery. For example, the principle of procreative beneficence, which holds (roughly) that parents have an obligation to select the best possible child they can, has been defended within bioethics as part of such a rejuvenated form of eugenics (Savulescu 2001), suitably distanced from unacceptable forms that eugenics might take; see Stramondo (2018) and Barker and Wilson (2019) for critical discussion with respect to disability. These philosophical explorations might be seen more charitably as aiming to sift the worthy wheat at the core of eugenics from the dehumanizing chaff that is mixed together with it as a result of a contingent and regretful association of eugenics with its Nazification. As Michael Selgelid (a long-standing editor of the journal *Monash Bioethics Review*) says circumspectly, "The fact that the previous practice of eugenics was bad does not imply that eugenics, per se, is necessarily an altogether bad thing or that a better future eugenics would not be possible" (Selgelid 2014: 6).

Third and finally, from the standpoint of many people with disabilities, eugenics does not feel that distant from their lived experience (Garland-Thomson 2012). Whether or not people like Selgelid profess an enthusiastic view of a possible eugenic future, such discussion is itself a red flag from the perspective of those with disabilities, especially for those that were the explicit focus of past eugenic policies, practices, and laws. Since eugenics seems to them in all its variations a project aimed at eliminating people *like them*, identifying a possible "better future eugenics" misses the political forest for the theoretical trees (Garland-Thomson 2012).

5. Nazi Eugenics, Medical Ethics, and the Birth of Bioethics

In Germany, eugenics or "racial hygiene" antedates the rise of the Nazis in the 1930s, though the Nazis did come to tailor their specific eugenic laws in light of developments in the United States, including Laughlin's "model sterilization law". As in North America, physicians came to play important roles in Nazi eugenics, including in the passage and implementation of the original Nazi sterilization law. This law came into effect in January 1934 and led to the sterilization of over four hundred thousand people, chiefly those deemed to have one of more of the disabilities specified in the law. Doctors also actively directed a program of supposed mercy killings focused initially upon psychiatrically diagnosed patients. This program, known as the T4 program, began in 1939 in German hospitals and was extended by law in 1941 into concentration camps, killing over 200 000 people on the basis of their having putative disabilities. The implementation of these large-scale and long-lasting programs of eugenic sterilization and euthanasia required the sustained activity of doctors and other medical professionals, offering diagnoses, performing surgeries, and supervising injections and gassings.

As mentioned in section 4, the origin of at least American bioethics is sometimes described as a counter-reaction to revelations arising through the Nuremberg Trials about the role of racialized and ableist medicine during Nazi rule in Germany. Yet this view of the relationship between bioethics and eugenics ignores or even obscures how entrenched eugenic ideology was within the medical profession during the 1930s and 1940s.

In Nazi Germany, eugenic sterilization and euthanasia were motivated and justified by an appeal to medical ethics (Caplan 2005). Doctors, including paediatricians and psychiatrists, largely saw themselves as behaving morally in recommending sterilizations, undertaking non-consensual medical experimentation, and overseeing a program of euthanization directed at people with disabilities. The view of bioethics as arising as an antidote within medical ethics to the dehumanizing medical treatment of people, including people with disabilities, is not only difficult to square with the actual roles that doctors played in Nazi Germany; it also ignores the widespread support that the Chicago-based physician Harry Haiselden's advocacy of the euthanization of what he called "defective infants" had within both medical and popular culture in the eugenic 1920s in the United States through his 1917 silent movie *The Black Stork* (Pernick 1996).

6. Newgenic Traits and Reproductive Technologies: The Expressivist Objection

Reproductive technologies—including contraception, prenatal screening, and in vitro fertilization—are generally viewed by able-bodied citizens and in public discourse as increasing parental autonomy and are portrayed within medical contexts as health-conducive. Such optimism is often viewed within disability bioethics, however, as naïve and ignorant about the realities of the eugenic past. In addition, for those with the traits that are seen as important to prevent the occurrence of in future generations—for example, Down Syndrome, spina bifida, and blindness—the enthusiasm for the view that such technologies provide for the means of human improvement is often itself taken to be problematic.

Disability bioethics has thus identified a complacency in the endorsement of technologies that enhance reproductive choice and challenged some widespread practices in reproductive health. The best-known of these challenges has focused on the routine practice of prenatal screening with selective abortion. Often called the *expressivist objection*, this is the claim that the practice of prenatal screening with selective abortion expresses a strongly negative view of people with those traits. This objection, originating in the work of Marsha Saxton (who has spina bifida) (see Saxton's chapter in this volume) and Adrienne Asch (who was blind), reflects the standpoint of those with the newgenic traits targeted in prenatal screening.

Th expressivist objection rests on three claims:

1. The practice of prenatal testing functions chiefly to detect foetuses that have a biological profile predictive of postnatal impairment.
2. The general expectation (but not requirement) in individual instances of this practice is that a foetus with such a profile will be terminated, rather than carried to term.
3. That expectation implies the judgment that such a foetus is not worth carrying to term to become, in turn, a baby, infant, child, then adult with that impairment.

Although one might challenge any of these claims, it is typically the inference from these to the expressivist conclusion—a conclusion not about the fetus terminated but more generally about people with these negatively valued traits—that has been challenged. For example, Bonnie Steinbock says that "From the fact that a couple wants to avoid the birth of a child with a disability, it just does not follow that they value less the lives of existing people with disabilities, any more than taking folic acid to avoid spina bifida indicates a devaluing of the lives of people with spina bifida" (Steinbock 2000: 121). What these claims about a practice that, in effect, aims to prevent the birth of a child with a given trait indicate, one might think, is simply that the corresponding *trait* is not value neutral but negative. And that need not express anything about those with the trait.

Steinbock's example of taking folic acid is developed in terms of the decisions of individuals, rather than in terms of an overall societal practice. Yet it is worth asking whether there is something distinctively devaluing of those with the trait that lies in the practice described by (1)-(3), i.e., something that is not present in other societal practices, such as taking folic acid, that aim to avoid or prevent those traits in future generations. One relevant difference that perhaps allows us to understand the attribution of devaluation is that 1-3 describe a practice of termination of an otherwise desired pregnancy, whereas the general practice of taking, recommending, or even prescribing folic acid does not. The first expresses a view of the trait that is so negatively valued that its presence provides a sufficient reason to terminate a process that would otherwise produce an child with that trait; the second only the view that it would be better, other things being equal, for that individual not to have that trait. That expression needs to be understood against the historical reality of the devaluation of the lives of people with disabilities. As Adrienne Asch writes,

> For people with disabilities to work each day against the societally imposed hardships can be exhausting; learning that the world one lives in considers it better to 'solve' problems of disability by prenatal detection and abortion, rather than by expending those resources in improving society so that everyone—including those people who have disabilities—could participate more easily, is demoralizing. It invalidates the effort to lead a life in an inhospitable world (Asch 2000: 240).

The demoralization here is directly connected to the perception of devaluation, as it would be for parallel cases of sex selection or selection for lightness in color of skin. In these cases, screening and selective termination arise against a background, respectively, of ableism, sexism, and racism. Traits such as Down syndrome, spina bifida, or blindness, unlike other less desired traits (such as having an elevated risk of high blood pressure or having hemophilia) are sufficiently devalued that individuals with them are better prevented from coming into existence than accommodated with the challenges they will face as people with those disabilities.

Like the eugenic traits of the past, such newgenic traits serve to identify individuals whose lives are not viewed as being as valuable as those without such traits. It is that connection to shared practices of non-inclusion or even outright elimination that makes the contemporary uses of reproductive technologies a site for a form of devaluation of people with a variety of disabilities, one perceived to be continuous with the eugenic past. From the standpoint of those with kindred disabilities, contemporary technologies deployed to prevent or eliminate disabilities in future generations raise more than the spectre of eugenic devaluation.

6. Disability Knowledge and Standpoint Eugenics

One theme arising in the preceding sections is that disability bioethics offers valuable perspectives on the relationship between disability and bioethics in part because of its distinctive embrace of the standpoint of those with lived experience of disability. In contrast with bioethics more generally, which often abstracts away from particular life experiences to arrive at general principles for decision-making and public policy, disability bioethics ascribes a central role to the perspectives of those marginalized by ableism and are often those whose lives are made worse by it.

Here the disability activism slogan *nothing about us, without us* should be understood more strongly than simply a call for inclusion. Instead, it needs to be seen as entailing the epistemic point that knowledge about disability fundamentally derives from knowing what it is like to have an embodied life with disability. One way in which this insight has been articulated is via standpoint theory or epistemology applied to the case of disability. Incorporating what has been called the *inversion thesis*—that those most deeply, negatively affected by a practice of oppression are sometimes in the best position to understand the nature of that oppression—standpoint theory provides general resources for articulating why reliance on the third-person epistemology dominant in bioethics is likely to limit thinking about how disability is best incorporated into bioethics. Part of the relevant standpoint is a commitment to recognize and change the conditions of disability oppression.

Recent recognition of the continuation of policies and practices of eugenic sterilization in the United States, Canada, and elsewhere beyond 1945 has created a space for what we might call a *standpoint eugenics*, eugenics from the standpoint of those who have survived it (Wilson 2018a). The Canadian province of Alberta's eugenic sterilization program, in place from 1928 until 1972, has been explored through video oral histories centred on the experience of eugenics survivors (http://eugenicsarchive.ca/discover/our-stories), which also structure the documentary film *Surviving Eugenics*. Such oral histories add further layers to the relationship between eugenics, disability, and bioethics. This is in part because many eugenics survivors in Alberta were wrongfully institutionalized and sterilized, and in part because self-advocates in the local disability community in Alberta, particularly those parenting with disability in some way, identify as survivors of the eugenic legacy in Western Canada. For them, eugenics is not a distant historical episode that ended in Germany in 1945 but part of the backyard in which they grew up.

References

http://eugenicsarchive.ca/discover/our-stories .

Asch, A. (2000). "Why I Haven't Changed My Mind About Prenatal Diagnosis: Reflections and Reminders" in E. Parens and A. Asch (eds) *Prenatal Testing and Disability Rights*, Washington, DC: Georgetown University Press, pp.234-258.

Barker, M.J. and R.A. Wilson (2019). "Well-Being, Disability, and Choosing Children" *Mind* 128 (April 2019): 305–328.

Caplan, A.J., ed. (1992). *When Medicine Went Mad: Bioethics and the Holocaust.* Totowa, NJ: Humana Press.

Caplan, A.J. (2005). "Too Hard to Face", *Journal of the American Academy of Psychiatry and the Law Online* 33: 394-400.

Dolmage, J. (2011). "Disabled Upon Arrival: The Rhetorical Construction of Disability and Race at Ellis Island", *Cultural Critique 77*:24-69.

Galton, F. (1883). *Inquiries into Human Faculty and its Improvement.* London: MacMillan.

Garland-Thomson, R. (2012). "The Case for Conserving Disability," *Journal of Bioethical Inquiry* 9(3): 339-55.

Kittay, E. (2017). "The Moral Significance of Being Human", *Proceedings and Addresses of the American Philosophical Association* 91: 22-42.

Laughlin, H.H. (1922). "Model Sterilization Law", ch.XV of his *Eugenical Sterilization in the United States.* Chicago: Psychopathic Laboratory of the Municipal Court of Chicago.

Pernick, M.S. (1996). *The Black Stork: Eugenics and the Death of 'Defective' Babies in American Medicine and Motion Pictures Since 1915.* New York: Oxford University Press.

Savulescu, J. (2001). "Procreative Beneficence: Why We Should Select the Best Children", *Bioethics* 15 (5/6): 413-426.

Selgelid, M.J. (2014). "Moderate Eugenics and Human Enhancement" *Medical Health Care and Philosophy* 17: 3-12.

Steinbock, B. (2000). "Disability, Prenatal Testing, and Selective Abortion", in E. Parens and A. Asch (eds) *Prenatal Testing and Disability Rights*, Washington, DC: Georgetown University Press, pp.108-123.

Stramondo, J. (2018). "Disabled by Design: Justifying and Limiting Parental Authority to Choose Future Children with Pre-Implantation Genetic Diagnosis", *Kennedy Institute of Ethics Journal* 27(4): 475-500.

Wilson, R.A. (2018a). *The Eugenic Mind Project*, Cambridge, MA: MIT Press.

Wilson, R.A. (2019). "Eugenics Undefended", *Monash Bioethics Review* 37(1-2): 68-75.

Further Reading

Campbell, S.M. and J.A. Stramondo (2017). "The Complicated Relationship of Disability and Well-Being", *Kennedy Institute of Ethics Journal* 27(2): 151-184.

Garland-Thomson, R. (2017). "Disability Bioethics: From Theory to Practice", *Kennedy Institute of Ethics Journal* 27(2): 323-339.

Miller, J., N. Fairbrother, and R.A. Wilson (2014). *Surviving Eugenics.* Vancouver: Moving Images Distribution. http://EugenicsArchive.ca/film .

Scully, J.L. (2019). "The Responsibilities of the Engaged Bioethicist: Scholar, Advocate, Activist", *Bioethics* 33:872-880.

Shakespeare, T. (2019). "When the Political Becomes Personal: Reflecting on Disability Bioethics", *Bioethics* 33: 914-921.

Shea, M. (2020). "The Quality of Life is Not Strained: Disability, Human Nature, Well-Being, and Relationships", *Kennedy Institute of Ethics Journal* 29(4): 333-366.

Wilson, R.A. (2018b). "Eugenics Never Went Away" *Aeon Magazine*

https://aeon.co/essays/eugenics-today-where-eugenic-sterilisation-continues-now