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ARTICLE

Genopower: On Genomics, Disability, and Impairment

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ABSTRACT. Since the completion of the human genome project in 2003, genomic sequencing, analysis, and interpretation have become staples of research in medicine and the life sciences more generally. While much scholarly ink has been spilled concerning genomics' precipitous rise, there is little agreement concerning its meaning, both in general and with respect to the current moment. Some claim genomics is neither new nor noteworthy; others claim it is a novel and worrisome instrument of newgenics. Contrary to the approaches of Foucault scholars in both of these camps, in this paper I utilize research in philosophy of disability to argue that genomics is indeed noteworthy as a unique form of biopower and that its primary function is to precisify impairments in contradistinction to disability. I call the force at play in this process *genopower*. I discuss how this impacts Foucault-inspired debates in philosophy of disability and critical disability studies over the meaning of the disability-impairment distinction, and I argue that insofar as genopower gears into powerful cultural tropes that promote individualistic solutions to social issues, the socio-political effect of genomics with respect to disability—despite the aims of many of its practitioners—is to normalize what Rosemarie Garland-Thomson calls "velvet eugenics."

Keywords: Philosophy of Disability, Genomics, Biopolitics, Disability Studies, Eugenics

INTRODUCTION[1]

> It was life more than the law that became the issue of political struggles, even if the latter were formulated through affirmations concerning rights. The "right" to life, to one's body, to health, to happiness, to the satisfaction of needs [Le droit à la vie, au corps, à la santé, au bonheur, à la satisfaction des *besoins*]…was the political response to all these new procedures of power which did not derive, either, from the traditional right of sovereignty.
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> —Michel Foucault[2]

> It would be wonderful if, as Left-leaning social genomicists…hope, their research could enable social scientists to control for genetic differences and thereby do better social science research, leading to more effective social programmes. But even if that vision materialises, Left-leaning social genomicists must face the fact that their big politically relevant insight – that what we achieve is due in part to our draw in the genetic lottery – can readily be recruited by those leaning Right. Today, more than ever, it's a mistake to soft-pedal that danger, and more important than ever to curb optimism about the political benefits this research will yield.
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> —Erik Parens[3]

We live in an age of genomics. Research and Markets, the world's largest market research company, reports that "the Global Genomics market is expected to reach $33.46 billion by 2026 growing at a CAGR (compound annual growth rate) of 10.1% during 2018 to 2026."[4] In light of the fact that the human genome was first mapped in 2003 in an effort costing roughly $2.7 billion, these numbers represent the results of massive investment in both clinical and consumer sectors as well as a meteoric advance and interest in sequencing abilities, informational processing, and translational research. Whether one looks to the initiatives, policies, or rhetoric of local healthcare systems, national governments, or

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[1] My gratitude to Lauren Guilmette, Robert Leib, Lynne Huffer, Erik Parens, Eva Feder Kittay, Becca Longtin, Jen Scuro, Devonya Havis, David Peña-Guzmán, Don Deere, Ege Selin Islekel, Perry Zurn, and the entire 2019 Foucault Circle crew for many fascinating conversations and provocations that animated, sustained, and improved this piece. Thanks as well to the editors and anonymous reviewers for helpful feedback.

[2] Michel Foucault, *The History Of Sexuality: Volume 1: An Introduction* (New York: Vintage Books, 1990), 145. M. Foucault, Sécurité, Territoire, Population, cours au Collège de France. 1977-1978, éd. Gallimard/ Seuil, 2004, p. 93.

[3] Erik Parens, "Social Genomics Can Combat Inequality or Be Used to Justify It – Erik Parens | Aeon Essays," Aeon, accessed November 16, 2020, https://aeon.co/essays/social-genomics-can-combat-inequality-or-be-used-to-justify-it.

[4] Research and Markets, "Global Genomics Market Analysis 2020," Accessed September 2020. https://www.researchandmarkets.com/reports/5024850/global-genomics-market-analysis-2020#pos-0. Valuates Reports, another such company, has similar expectations: "the global Genomics market size was valued at USD 13.4 Billion in 2019 and is projected to reach USD 27.8 Billion by 2026, at a CAGR of 11%."[4] https://reports.valuates.com/market-reports/QYRE-Othe-4C280/genomics

international bodies over the last two decades, genomics has been and still is today treated as a frontier of knowledge-building in the life sciences.[5] However, multiple scholars have used Foucault's oeuvre to downplay or equivocate about the import and novelty of genomics. For example, Marilyn E. Coors argues that genomics does not lead to any distinctive forms of oppression; Thomas Biebricher endorses the genomic enterprise as a form of counter-conduct; and Ladelle McWhorter finds genomics' valence and impact mixed.[6] Yet, while many Foucault scholars claim genomics is neither new nor noteworthy, other scholars across a range of fields claim it is a novel and worrisome instrument of newgenics.[7]

Contrary to the approaches of Foucault scholars in both of these camps, in this paper I utilize research in philosophy of disability to argue that genomics is indeed noteworthy as a unique form of biopower and that its primary function is to precisify impairments in contradistinction to disability.[8] I call the force at play in this process *genopower*. I discuss how this impacts Foucault-inspired debates in philosophy of disability and critical disability studies over the meaning of the disability-impairment distinction, and I argue that insofar as genopower gears into powerful cultural tropes that promote individualistic solutions to social issues, the socio-political effect of genomics with respect to disability—despite the aims of many of its practitioners—is indeed to normalize what Rosemarie Garland-Thomson calls "velvet eugenics."

An initial qualification is in order. What follows is not a blanket indictment of genetics or genomics as such. It is also not a blanket indictment of the many researchers who work in or with close relation to genomics-related and genomics-informed scholarship. Despite how many might interpret the phrasing and framing deployed so far, I am myself

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[5] That is to say, whether one looks to the National Institute of Health in the United States, the National Health System in the UK, or the World Health Organization, to take just a few examples, initiatives and funding for genomics is treated as a vanguard.

[6] Marilyn E. Coors, "A Foucauldian Foray into the New Genetics," *Journal of Medical Humanities* 24, no. 3 (December 1, 2003): 279–89, https://doi.org/10/fdrbz9; Thomas Biebricher, "(Ir-)Responsibilization, Genetics and Neuroscience," *European Journal of Social Theory* 14, no. 4 (November 1, 2011): 469–88, https://doi.org/10/bpwxsh; Ladelle McWhorter, "Governmentality, Biopower, and the Debate over Genetic Enhancement," *Journal of Medicine and Philosophy* 34, no. 4 (2009): 409–37, https://doi.org/10/fttd36. On the relationship of disability to a subset of *genetics*, see Anne Waldschmidt, "Who Is Normal? Who Is Deviant? 'Normality' and 'Risk' in Genetic Diagnostics and Counseling," in *Foucault and the Government of Disability*, ed. Shelley Tremain (Ann Arbor: University of Michigan, 2005), 191–207; Shelley Tremain, "Reproductive Freedom, Self-Regulation, and the Government of Impairment in Utero," *Hypatia*, no. 1 (2006): 35, https://doi.org/10/cp2jgj.

[7] Kimberly TallBear, *Native American DNA: Tribal Belonging And The False Promise Of Genetic Science* (Minneapolis, MN: University of Minnesota Press, 2013); Rosemarie Garland-Thomson, "Eugenics," in *Keywords for Disability Studies*, ed. Rachel Adams, David Serlin, and Benjamin Reiss (New York: NYU Press, 2015), 215–26; Jasmine Zahid, "A Defense of 'The Case for Conserving Disability,'" *AMA Journal of Ethics* 18, no. 4 (April 1, 2016): 399–405, https://doi.org/10/gh52q7. To get a grip on the wider stakes of "newgenics," I highly recommend Robert A. Wilson, *The Eugenic Mind Project* (Cambridge, MA, USA: MIT Press, 2017).

[8] The term 'precisify' was coined and has been used since at least the mid-1990s, starting in sub-disciplines within Anglo-American philosophical traditions. Although never widely adopted, I find it very useful for this project, and I explicitly and gratefully follow Eva Kittay in her recent adoption of the term. See Eva Feder Kittay, "We Have Seen the Mutants—and They Are Us: Gifts and Burdens of a Genetic Diagnosis," *Hastings Center Report*, June 29, 2020, https://onlinelibrary.wiley.com/doi/abs/10.1002/hast.1155.

skeptical of claims about "genomics" as such, and whether or not such claims are in fact defensible at that level of generality is not addressed here. As Colin Koopman astutely notes, "it is by no means the case that these varied scientific projects are all, at bottom, somehow the same. Rather, there is increasing complexity in the very practice of the genetic sciences."[9] My aim, on the contrary, is to focus upon the socio-political *uptake*, clinical or consumer, of research in contemporary genomics.[10] Whether or not genomics is in fact the monolith that such socio-political uptake assumes (unsurprisingly, non-genomicists are not well-informed regarding the complexity of the state of the field and its many peripheries) will be set to the side, and I defer to the significant amount of scholarship that takes that concern seriously.[11] Here, my focus is instead on the import of genomics for life, not theory—life as it is lived in the wake of knowledge, the determining contours of which are all-too-often out of our grasp and which, if we are to even attempt to grip them, require a continual return to animating conditions, from archives to habits to apparatuses of power. This is, put crudely, part of what makes the following a genealogical as opposed to an historical analysis. With such an aim in mind, I find myself in this project far closer to the contemporary practices and norms of sociology than those of many practitioners in philosophy in the sense that my animating concern is less what X means and more on how people live with the meanings they ascribe to X and the sociopolitical implications of such living in contexts wherein X exerts significant power and force to shape one's world. To those who might balk at such an alignment, one could conceptualize this in a more philosophy-centric way by simply thinking of what follows as pragmatist: it is a project that attempts to take seriously aspects of our current moment and ask what might *be done* if our hermeneutic lodestar shines in the sober light of *how we tend to feel about and use* genomic knowledge.

I. THE SOCIOPOLITICAL POWER OF GENOMICS

Nikolas Rose and Carlos Novas argue:

> The responsibility for the self now implicates both "corporeal" and "genetic" responsibility: one has long been responsible for the health and illness of the body,

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[9] Colin Koopman, "Coding the Self: The Infopolitics and Biopolitics of Genetic Sciences," Hastings Center Report (John Wiley & Sons, Ltd, June 29, 2020), https://onlinelibrary.wiley.com/doi/abs/10.1002/hast.1150.

[10] There are multiple spaces where instead of uptake, one finds refusal. I am thinking, for example, though especially, of 2013 TallBear; Jessica Kolopenuk, "Provoking Bad Biocitizenship," Hastings Center Report (John Wiley & Sons, Ltd, June 29, 2020), https://onlinelibrary.wiley.com/doi/abs/10.1002/hast.1152.

[11] Consider the work of Sandra Soo-Jin Lee, Catherine Bliss, Jenny Reardon, and Kaushik Rajan, among others. Sandra Soo-Jin Lee, "Excavating the Personal Genome: The Good Biocitizen in the Age of Precision Health," Hastings Center Report (John Wiley & Sons, Ltd, June 29, 2020), https://onlinelibrary.wiley.com/doi/abs/10.1002/hast.1156; Catherine Bliss, *Social By Nature: The Promise And Peril Of Sociogenomics* (Stanford, California: Stanford, California : Stanford University Press, 2018); Jenny Reardon, *The Postgenomic Condition: Ethics, Justice, and Knowledge After the Genome* (Chicago; London: University of Chicago Press, 2018); Kaushik Sunder Rajan, *Biocapital: The Constitution Of Postgenomic Life* (Durham: Duke University Press, 2006).

> but now one must also know and manage the implications [the "facts" of one's past, present, and future] of one's own genome. The responsibility for the self to manage its present in the light of a knowledge of its own future can be termed "genetic prudence." Such a prudential norm introduces new distinctions between good and bad subjects of ethical choice and biological susceptibility.[12]

The norm of genetic prudence and the practices to which it relates are predicated upon the fact that the knowledge arising from genomics is *true;* that the informational outputs of genomics accurately tell one about the material reality of one's body from the womb to the grave. And one is *responsible for* learning these truths. "Several scholars," Sandra Soo-Jin Lee notes, "have theorized that market capitalism and neoliberal governance have created a set of expectations that individuals should be responsible for their health status and that it is incumbent on them to apply individual risk information in their daily decision-making to improve their health."[13] Rose, Novas, and Lee each focus on the implications of genomic knowledge for one's present and future, but there are also implications for one's past. In fact, the "womb to the grave" phrase used above is too narrow a qualification, for this information concerns "facts" from before the womb to after the grave; this information is fundamentally about the lineage, the links, and the threads from where one comes, how one becomes, and after which one is.

Ancestry-related genomic testing is a massive and growing sector of the genomics industry, and this is a cultural moment in which the import of genomics to *determine* the truth of one's past can hardly be overstated. A particularly striking example comes from the United States' 2020 election and the case of Democratic presidential nominee Elizabeth Warren. She responded to disputes concerning her self-proclaimed Native American ancestry by publicly releasing a "DNA Test" carried out by population geneticist Carlos D. Bustamante.[14] Just two days after this news hit the national media, sociologist Alondra Nelson responded in a profound, hard-hitting op-ed in *The New York Times*, stating, "the truth is that sets of DNA markers cannot tell us who we really are because genetic data is technical and identity is social."[15] Warren assumed that the public would judge the truth or falsity of *who she is* in light of the results of genomic sequencing. While the pushback from experts on the issue, including and most importantly Indigenous experts, was notable and pointed, Warren's ploy seemed to work on the whole, for polling did not show a

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[12] Nicholas Rose and Carlos Nova, "Biological Citizenship," in *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems | Wiley* (London: Wiley, 2008).

[13] Sandra Soo-Jin Lee, "Excavating the Personal Genome: The Good Biocitizen in the Age of Precision Health," in *For "All of Us"? On the Weight of Genomic Knowledge*, special report, ed. J. M. Reynolds and E. Parens, *Hastings Center Report* 50, no. 3 (2020): S54– S61. DOI:10.1002/hast.1156

[14] Asma Khalid, "Warren Releases DNA Results, Challenges Trump Over Native American Ancestry," NPR, October 15, 2018. https://www.npr.org/2018/10/15/657468655/warren-releases-dna-results-challenges-trump-over-native-american-ancestry

[15] Alondra Nelson, "Elizabeth Warren and the Folly of Genetic Ancestry Tests," New York Times, October 17, 2018. https://www.nytimes.com/2018/10/17/opinion/elizabeth-warren-and-the-folly-of-genetic-ancestry-tests.html

significant dip in overall support due to her efforts on this front.[16] On the contrary, her continued support could be interpreted as a reward for her demonstration of the requisite "genetic prudence" and adherence to the "duty to know" one's genomic information; she turned to genomic knowledge to *prove* the truth of *who she is* and, correspondingly, claims concerning her present and future.

As Catharine Bliss points out, "a collective concept of race that presumes there are, or were at some point in the past, discreet genetic groups that have tracked along continental lines and that those differences are the fundamental basis for our folk and political groupings of white, black, Asian, Native American, and Pacific Islander is a fallacy that will always lead to social inequality."[17] While most working in genomics *know* this is a fallacy and repeatedly talk about how mistaken it is, racial categories are nevertheless used both in the research and the reporting of results in academic and non-academic spaces.[18] There is a fundamental tension between the inaccurate socio-political racial taxonomization utilized in genomics and the knowledge concerning genomically distinct cohort-groups that the field of genomics in fact explores. To risk belaboring this point, while experts know socio-political categories that track race and ethnicity are not what genomic cohorts track—the problem is that much of the public does not know this or, in some cases, acts in willful ignorance of that (readily available) knowledge.[19]

The problems related to genomic descriptions/explanations of disability are in many respects different. To explain someone's form of embodiment in terms of genetic variation is more often than not to explain how/why they *as an individual* are impaired as they are, sometimes in relation to a distinct group-identity that carries socio-political import (like Down syndrome or d/Deafness) and sometimes in relation to a condition that does not (like Lesch-Nyhan syndrome, lymphangiomatosis, or filariasis). Such definitions, if left merely at that, run roughshod over even the most simplistic forms of social models of disability, which suggest that—whatever we make of the phenomena of disability—we must distinguish between impairment and disability; between how we find ourselves and how we treat each other in society. This is why I here focus upon the *socio-political work* of genomic knowledge. To focus upon genomic knowledge as it is understood by clinical or corporate practitioners instead of as it plays out societally risks missing what genomics is in fact *doing* as a human practice and how it in fact impacts human life. Having now provided a cursory background concerning genomics, I turn to the issue of its historical import. I engage research in philosophy of disability to argue that the primary function of genomics is to precisify impairments in contradistinction to disability. To appreciate what that claim means, I'll begin by analyzing and critiquing debates made concerning that distinction by Foucault scholars.

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[16] See Kim Tallbear, "Elizabeth Warren's Claim to Cherokee Ancestry Is a Form of Violence," High Country News, January 17, 2019, https://www.hcn.org/issues/51.2/tribal-affairs-elizabeth-warrens-claim-to-cherokee-ancestry-is-a-form-of-violence.

[17] Catherine Bliss, "Conceptualizing Race in the Genomic Age," Hastings Center Report (John Wiley & Sons, Ltd, June 29, 2020), https://onlinelibrary.wiley.com/doi/abs/10.1002/hast.1151.

[18] Bliss, *Social By Nature: The Promise And Peril Of Sociogenomics*.

[19] Idem.

II. DISABILITY, IMPAIRMENT, AND GENOPOWER

As most historians tell the story, the "social model of disability" is based upon a binary conceptual distinction: impairment vs. disability.[20] The concept of "impairment" refers to atypical bodily differences, whereas the concept of "disability" refers to cultural, social, and political responses to such bodily differences that result in stigma, discrimination, and oppression against disabled people. While one may be impaired insofar as one uses a wheelchair for mobility, is d/Deaf, is blind, or has major depression, etc., what disables one is a world that is inaccessible except for the ambulatory by design, a world that fails to support the widespread use of braille, alt-text, and visual description, a world without audible walks signals and highly expensive or impossible to get guide dogs, and a world demanding constant labor, valorizing positive affect, and operating without, or with poor, mental health services. That is to say, what is disabling is a world that is on the whole oppressive towards, hostile to, and stigmatizing of disabled people.

Shelly Tremain draws upon Michel Foucault's work to combat the social model's understanding of disability and impairment. She argues that both concepts appeared and developed along with bureaucratic techniques and apparatuses of governance in the long 18th and 19th centuries. They are *products* of the historical emergence of biopolitics as a dominant modality of modern governance.[21] Tremain's aim is to "develop a conception of disability that does not rely upon a natural, transhistorical, and transcultural metaphysical and epistemological foundation (impairment)."[22] She writes:

> To understand disability as an apparatus is to conceive of it as a far-reaching and systemic matrix of power that contributes to, is inseparable from, and reinforces other apparatuses of historical force relations. On this understanding, disability is not a metaphysical substrate, a natural, biological category, or a characteristic that

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[20] There are actually *multiple* social models, as anyone working seriously in disability studies knows. I will not place great weight on the many differences at play in these distinct models because they are not relevant for the purposes at hand, but that is not to say they are not of theoretical import. Furthermore, there are scholars who do not treat this distinction necessarily as a binary, but instead as picking out two poles, nodes, or fill-in-your-favorite-metaphor that are in relationship with one another (this is one way to interpret Tom Shakespeare's work). It is increasingly frustrating that decades into the field of philosophy of disability, and many more decades into the interdisciplinary field of disability studies, the thinnest, least sophisticated version of what goes under the moniker of "the social model" often plays a role when the history, use, and theorization regarding "social models of disability" are in fact extremely complex, diverse, and even conflicting.

[21] To get a sense of what this claim amounts to, I suggest starting with Fiona A. K. Campbell, "Legislating Disability: Negative Ontologies and the Government of Legal Identities," in *Foucault and the Government of Disability*, ed. Shelley Tremain, 1st ed. (Ann Arbor: University of Michigan Press, 2005); Shelley Tremain, *Foucault And The Government Of Disability*, 2nd ed. (Ann Arbor: University of Michigan Press, 2015); Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Abledness* (New York: Palgrave Macmillan, 2009); Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity And Sexuality* (Basingstoke; New York: Palgrave Macmillan, 2009); Licia Carlson, *The Faces Of Intellectual Disability: Philosophical Reflections* (Bloomington: Indiana University Press, 2010); Shelley Tremain, *Foucault and Feminist Philosophy of Disability* (Ann Arbor: University of Michigan Press, 2017).

[22] Tremain, *Foucault and Feminist Philosophy of Disability*, 9.

> only certain individuals embody or possess, but rather is a historically contingent network of force relations in which everyone is implicated and entangled and in relation to which everyone occupies a position. That is, to be disabled or nondisabled is to occupy a certain subject position within the productive constraints of the apparatus of disability…Just as people are variously racialized through strategies and mechanisms of the apparatus of race, but no one "has" a race or even a certain race and, furthermore, just as people are variously sexed through strategies and mechanisms of the apparatus of sex, but no one "has" a sex or even a particular sex, so too people are variously disabled or not disabled through the operations of the apparatus of disability, but no one "has" a disability or even a given disability. In short, disability (like race and sex) is not a nonaccidental attribute, characteristic, or property of individuals, not a natural biological kind.[23]

I will call the idea that disability is an apparatus (*un dispositif*) the *apparatus thesis*. Tremain here leverages increasingly common knowledge about the concepts of "sex" and "race"—namely, that they do not refer to purely natural facts of the matter about human difference—to argue that the concept of "disability" is in the same boat. She claims that just as there are many different ways in which people are racialized and many different ways in which people are sexed, there are many different ways in which people are produced as disabled.[24] These processes are not the results of mere facts about bodies but instead emerge from a historical context in which those concepts come to mark social differences between beings in ways that distribute power relations. And Tremain extends the apparatus thesis to the concept of *impairment* as well. "Another aim of my inquiry," Tremain writes, "is to show how a certain regime of power has produced impairment as both the prediscursive—that is, natural and universal—antecedent of culturally variant forms of disability and a problem for this regime of power to which the regime offers solutions."[25]

The apparatus thesis is very compelling, and, importantly, it builds upon what I take to be an exceptionally productive route for research in philosophy of disability. However, the apparatus thesis, all on its own, does not get one very far in understanding the specific meaning of disability in particular contexts. To say that "X is a product of force relations" is a claim that demands further specification. What sort of product? What sorts of forces? What sorts of relations? In what sorts of contexts? Under which sorts of constraints? Etc. In many ways, this lack of clear inferences applies even more so to questions of impairment than of disability, and that is no small matter, for the concept of impairment's fate has very high stakes not only with respect to disability politics but also disability (social) ontology.

When Tremain defends variations of the following formula: "impairment—the naturally disadvantageous foundation of disability," she reinforces a version of the bad-difference view of disability.[26] Namely, instead of splitting discrimination from difference,

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[23] Ibid, 22.

[24] The phrasing is difficult here—it would be more accurate to say, however awkwardly, "are disableized."

[25] Ibid, 5.

[26] Tremain, *Foucault and Feminist Philosophy of Disability*, 6.

she assumes that differences (differences described by the concept of impairment as social model supporters on the whole understand it) are themselves bad. But that is by no means a given, and that is certainly not the overarching point of the social model's understanding of impairment as a conceptual category (whether one looks to the complex history of disability activist practitioners of social models in the US, UK, or elsewhere).

Impairments, as most disability activists utilizing the social model make clear, are assumed to be *just* differences or, insofar as they are differences that present functional or other sorts of limitations, differences that *should not make a difference* socially and politically. In short, it is inaccurate to say that "impairment" is conceived to be a naturally disadvantageous foundation in disability activism as well as in disability theory writ large. What's more, many of the debates that gained steam in the 90s about the "forgetting" of chronic pain and chronic illness in discourse and activism around disability rely heavily on this very point: impairments had often been seen as/treated as neutral, but some of them *aren't*.[27] That is to say, part of the reason debates about chronic pain and certain chronic illness launched in the first place is because some disabled people have said, "Hey, my impairment *actually is bad*, is 'naturally disadvantageous,' and it is not so thanks to living in an ableist society or due to the way that biopower has produced/produces disability as an apparatus."[28] If impairment, on the whole across disability activism and disability studies, were understood as "naturally disadvantageous," as Tremain argues, then what were these scholars arguing against?

Tellingly, most of the activists and scholars Tremain references do not in fact give into a simplistic "realist ontology," as Tremain claims they do.[29] They are instead trying to take seriously the ways in which aspects of the suffering of one living in, for example, chronic pain, can transcend the particular discursive (social, cultural, political, historical, linguistic, etc.) processes that a figure like Foucault uncovered. The ancient Athenian in chronic pain and the present-day American in chronic pain, whilst certainly experiencing that

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[27] I am thinking especially of the work of Liz Crow and Susan Wendell, among others. See chapter three of Joel Michael Reynolds, *The Life Worth Living: Disability, Pain, and Morality* (Minneapolis: University of Minnesota Press, 2022).

[28] As Elizabeth Barnes painstakingly points out, to be disabled does not *automatically* mean that one's life, *on the whole*, will go worse. It might, though, go worse in certain ways and with respect to certain local goods. Barnes' choice example is the inability of certain humans (typically called "males") to reproduce human life. From that fact we do not assume their lives will, on the whole, necessarily go worse. Crucially, Barnes' view decidedly leaves open whether or not *some* cases of impairment are in fact bad-differences, whether some do in fact make one's life go worse in at least some respects and perhaps also on the whole (she often cites chronic pain as one such likely exception). Elizabeth Barnes, *The Minority Body* (New York, NY: Oxford University Press, 2016). I can't broach it here, but there is also a whole line of work in disability studies that tries to understand what it means to fight against bad-difference views of disability and, at the same time, fight against the purposeful *debilitation* of certain groups, populations, etc., i.e., targeted debilitations that center on racial, sexual, gendered, ethnic, national, etc., group-differences. See Jasbir K. Puar, *The Right to Maim: Debility, Capacity, Disability*, 2017; Nirmala Erevelles, *Disability And Difference In Global Contexts: Enabling A Transformative Body Politic* (New York: Palgrave Macmillan, 2011).

[29] And contemporary scholars in similar spaces today certainly do not—see, e.g., the 2020 special issue: Corinne Lajoie and Emily Douglas, "A Crip Queer Dialogue on Sickness (Editors' Introduction)," *Journal of Critical Phenomenology* 3, no. 2 (November 2, 2020): 1–14.

pain in differing ways shaped by a host of context-dependent factors, will each require interventions that go beyond the domain of distributive (or other forms of) social justice. To fix chronic pain requires more than a different social order or even a perfectly just world, for there are forms of suffering "which justice [alone] cannot eliminate," as Susan Wendell aptly puts it.[30] This is true of a host of other things, from epilepsy to cystic fibrosis to Alzheimer's disease.[31]

Part of the issue here is that over the last few decades "impairment" has shifted in some people's eyes from an understandable move in multiple political/philosophical projects (disability activism, disability studies, etc.) to a red herring for imprecision. The term has lost its initial analytic power by often being strawed in ways that do not attend to its deployment in specific contexts. This strikes me as a grave mistake—especially with respect to the history of disability activists who have so insightfully worked, and in highly creative ways, with that term in difficult, conflicting, and often hostile environments. I find it quite important to hold onto the concept of "impairment."[32] However, let us do so in a way that is honest about its complexity.

To be clear, Tremain is right that certain groups—the Union of the Physically Impaired Against Segregation (UPIAS), for example—define impairment in a way that *seems* both

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[30] Susan Wendell, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," *Hypatia* 16, no. 4 (2001): 31, https://doi.org/10/fst6qh. Cf. Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections On Disability* (New York: Routledge, 1996).

[31] This is not to say that pain or what we today call "epilepsy" and "Alzheimer's" are thereby "politically neutral," for, to repeat, of course political factors play a role at the level of one's lived experience and the related social-political-discursive recognitive community involved in such phenomena. To claim that the problems a given phenomenon poses cannot be solved by X factor/domain of explanation or is not fully determined by X factor/domain of explanation does not thereby mean that X plays no role in shaping that phenomenon. Consider the following claim from Tom Shakespeare: "impairment is not a pre-social or pre-cultural biological substrate (Thomas, 1999, 124), as Tremain (1998) has argued in a paper which critiques the untenable ontologies of the impairment-disability and sex-gender distinctions. The words we use and the discourses we deploy to represent impairment are socially and culturally determined. There is no pure or natural body, existing outside of discourse. Tom Shakespeare, "The Social Model of Disability," in *The Disability Studies Reader*, ed. Lennard J. Davis, 4th ed. (New York; London: Routledge, 2014). To say that embodiment is shaped by discursive practices is not to say that there is no body to which those practices refer—it is not to say that there is no "there" there which scientists, for example, might garner some insights about that humanists will, given their methods, not be able to uncover. Are words and discourses socially and culturally determined? Of course. But that does not mean they do not, in some way, refer to something real; to something that is *more than* a *mere* product of social-cultural practice. To argue so gives into the sophomoric, straw version of social constructivism as well as an either/or, culture/nature divide that is, for many contemporary disciplines such as evolutionary biology, laughable if taken seriously. And yet that is, strangely, the very point scholars like Tremain and Shakespeare seem to be making. This is a mistake with massive implications, as the turn to "matter" in feminist theory writ large over the last two decades or so has attempted to demonstrate. It is both/and, not either/or.

[32] I am thus, I think, at odds with Barnes on this particular point. Cf. Elizabeth Barnes, "Against Impairment: Replies to Aas, Howard, and Francis," *Philosophical Studies* 175, no. 5 (2018), https://doi.org/10/gf9gdj. I say "I think" in part because the context of Barnes' argument there is operating primarily in the space of contemporary debates in social ontology and not in the space of debates, methods, and concerns related to genealogy.

evaluative and also naturalistically so.[33] UPIAS defines impairment as "the lack of a limb or part thereof or a defect of a limb, organ or mechanism of the body" and disability as "a form of disadvantage which is imposed on top of one's impairment."[34] One should keep in mind, however, that the UK disability rights approach was operating within a Marxist framework—"from each according to his ability, to each according to his needs"—such that making a claim about basic "ability" phrased in terms of lack or defect was thought to lead to claims of social obligation regarding needs. It is telling that, by contrast, one of the earlier disability movements in the USA (which centered in part on Ed Roberts's fight with UC Berkeley and came to be called the Independent Living Movement) did not conceive of the impairment-disability divide in this way. Ed Robert's writes, "If someone comes up to me and doesn't look me in the eye, if all they see is my ventilator and my chair, I can tell right away. If they don't see me as a human being, if they only see my equipment, I know that I can get whatever I want out of them. As long as this is not used pathologically, but to create beneficial change for others, it is a strength. Disability can be very powerful."[35] Roberts implicitly refers to the impairment-disability distinction here, and he is crystal clear that when another takes his way of being in the world *as negative*, this becomes a tool for him to fight—but, to belabor the point, only and precisely insofar as his impairment does not *in fact* render him defective, lacking, or naturally disadvantaged but, instead, just as human as any other human.

To run together the UK and USA disability rights activists (as well as disability scholarship as practiced in those places and beyond over many decades and across shifting political contexts) as if the concept of "impairment" is definitely treated as a "natural disadvantage" by and across both contexts and spanning decades of on-the-ground political battles far oversimplifies the picture. Furthermore, it makes a generalization across activism and the academy that is tenuous at best. One cannot simply read a made-for-academics theoretical account from the Realpolitik in which activists are engaged, just as one cannot simply read a detailed politically-engaged account from the theory-building in which scholars (typically, if not always) are engaged.

II.I RACE, THE DISABILITY/IMPAIRMENT DISTINCTION, AND DEBATES IN PHILOSOPHY OF MEDICINE

To better understand the stakes of interpreting the apparatus thesis, consider the example of race that Tremain often deploys to make analogies concerning disability. Tremain's arguments would lead one to think that in the same way that there is no biological

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[33] Shelly Tremain, "On the Subject of Impairment," in *Disability/Postmodernity: Embodying Disability Theory*, ed. Tom Shakespeare and Mairian Corker (London: Continuum, 2002), 33ff.

[34] It would be an uphill battle to construe "lack" and "defect" as neutral here, although it would not be impossible (perhaps by linking them to questions of typicality in a purely statistical sense).

[35] Ed Roberts, "On Disability Rights: Highlights from Speeches by Ed Roberts" (World Institute on Disability), accessed February 27, 2021, https://www.commonlit.org/texts/on-disability-rights-highlights-from-speeches-by-ed-roberts.

(genomic or otherwise) meaning to the term "Black," there is no biological (genomic or otherwise) meaning to a disability like "Down syndrome" (or, so the argument is also supposed to go, to impairments that comes along with the disability category of "Down syndrome."[36] But analogizing across race and disability in this way makes no sense. While it is certainly not *all* that Down syndrome means, there is a specific biological meaning to the term: it means that a person has extra copy of chromosome twenty-one.[37] That is not at all the same as claiming that being "Black" means, to take just one egregious example, that one is biologically more susceptible to hypertension.[38] Although arguments over natural kinds are perennially labyrinthian, one can at least say that whatever Down syndrome (in part) refers to biologically, it is disanalogous in important ways relative to a term like "Black," which refers to *nothing* biological at all.[39] One is, fundamentally, a socio-political term; the other is, fundamentally, a genomic term. This is not to say that an extra copy of that chromosome should exhaust the meaning of Down syndrome. Far from it. As former IVF doctor David Sable starkly noted in a recent lead article for *The Atlantic*, "The concept of counting chromosomes as a definitive indicator of the truth—I think we're going to look back on that and say, 'Oh my God, we were so misguided.'"[40] Furthermore, this is not to claim that we should hold onto the term "Down syndrome" *merely* in the sense of "extra genomic material on chromosome 21." My point is not that Down syndrome is fully captured by a chromosomal difference. My point is instead to show how that difference is (a) disanalogous to racial difference/differences of racialization and (b) refers to a "nonaccidental" difference at the level of what on the social model is conceptualized as *impairment*.

Note also that talking about Down syndrome with respect to its status as an impairment is importantly different from talking about, say, congenital blindness. The former is

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[36] To repeat from above: contemporary genomics does hold that there are such things as genetic cohorts, but the point is that there is no one genetic cohort that maps on to those who are racialized as "Black." "Black" is a socio-political-historical designation, not a biological one.

[37] And, to anticipate claims I make in more detail below, knowledge of this information can, in at least certain contexts, be *positive* in the sense that it allows one to better care. See Kittay, "We Have Seen the Mutants—and They Are Us."

[38] The large body of research concerning the development, approval, and marketing of the drug *Bidil* is instructive on this point.

[39] Even if one replaced "Black" with, say, "African-American," the analogy fails. To be clear, one could say that "Black" does refer to something biological relative to contexts where white supremacy and the legacies of white settler colonialism after the Middle Passage structure social life. And thus being "Black" will involve biological differences, namely, those that result from moving in and through an anti-Black world. I appreciate that concern and find it important, but I do not see how it undermines the point immediately at hand with respect to the conceptual and practical differences I am picking out between discussions of race and disability. Even if Blackness does refer to *something* biological in a meaningful sense (bracketing for a moment the tensions between the socio-political meaning of that term and whatever it might mean in various domains of the life sciences), it does not in the same way that having an extra copy of a particular chromosome does. Or, even if one were to maintain that it does in *similar* ways, my argument here hinges on the differences between these cases.

[40] Sarah Zhang, "The Last Children of Down Syndrome," accessed November 24, 2020, https://www.theatlantic.com/magazine/archive/2020/12/the-last-children-of-down-syndrome/616928/?fbclid=IwAR0aUjido-HySTvzBi9sTvw1zAssLrDNOfrqWYeGOxU5MhrGCfxc1fRaOFE0.

a *syndrome*—a catch-all phrase for a *set* of various phenotypic expressions, the variability of which can be in flux but the direct genetic cause of which is known. Yet, often, a syndrome can also refer to "a recognizable complex of symptoms and physical findings which indicate a specific condition for which a direct cause is *not necessarily understood*."[41] To further complicate the picture, some syndromes are diagnoses insofar as they automatically indicate a certain diagnosis, while others do not, and "due to the imprecision of natural language, some syndromes could also imply a simple pathological finding (vasculitis) or just a physical finding."[42] Congenital blindness, on the other hand, is a *condition*—it refers primarily to a state of one's body and not to an array of current or potential expressions.[43] While a syndrome or disease or specific genetic variation may be the *cause* of congenital blindness, the meaning of "blindness" is closer to describing a static state of being (as defined relative to the existence or absence of a major, typically (statistically) present sensory-perception system) than it is to a set of potential expressions over one's development or even life course.

And both Down syndrome and congenital blindness are distinct from, say, fibromyalgia, the medical meaning of which is contested. It was previously understood as "an inflammatory musculoskeletal disease but is now considered to be an illness that primarily affects the central nervous system."[44] Yet, to be clear, even its status as an illness is debated. We do not need consensus over the content of the medical concepts under discussion nor do we need consensus over matters of precision with respect to their analytic boundaries to see that, however we categorize them, there *are* characteristics or properties of individuals at play here. Our words are in relationship with things. They are so in a manner that does not annul the idea that there is *something to which* they refer. This is not to say that humans can comprehend reality without the use of language; it is only to say that the role of the linguistic and the discursive is a *role* played in a very real, very serious, and very high stakes relationship to the world. The fact that genomic explanations provide novel insights into and further precision concerning differences between things like syndromes, conditions, and diseases—as well as differences within such categories—is notable. To reduce such explanations to the level of the merely discursive is to misunderstand the nature and import of such explanations, and what is more, it is to disregard the life-or-death stakes such explanations can carry. Knowing more about these differences can be *the* difference between medical regiments and social policies that save a person's life/make their life livable or not. Knowing more about these differences can also be the difference between becoming highly stigmatized, discriminated against, and oppressed

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[41] Franz Calvo et al., "Diagnoses, Syndromes, and Diseases: A Knowledge Representation Problem," *AMIA Annual Symposium Proceedings* 2003 (2003): 802.

[42] Idem.

[43] There are storied debates in philosophy of medicine and philosophy of science over these terms. I do not want to get into those debates here, and I realize some will disagree with my gloss of terms like "syndrome" or "condition." However one prefers to define these terms, the fact that the referents ("Down syndrome," "congenital blindness," etc.) in the cases under discussion are distinct allows my larger point to stand.

[44] Gold L. Donberg and et al., "Understanding Fibromyalgia and Its Related Disorders," *Primary Care Companion to The Journal of Clinical Psychiatry* 10, no. 2 (2008): 133–44.

in various ways (whether within the clinic or outside). But neither the type nor the precision of knowledge at play is in and of itself determining whether it turns out to be negative or positive for a person, a family, or a community.

It would be very strange to say that no humans were born with an extra copy of chromosome twenty-one before 1866 (when the category of "Down syndrome" came to be). But to deny the concept of impairment any "prediscursive" meaning alongside that of disability and to claim that disability is "not a nonaccidental [i.e., it is accidental] attribute, characteristic, or property of individuals," as Tremain does, commits one to such a view. Even if how we categorize and conceptualize various characteristics or properties (such as those captured by the term "Down syndrome") is always a product of shifting epistemes and larger forces of relation (a claim I wholeheartedly accept à la the pioneering work of Foucault, Kuhn, and, later, Rose, McWhorter, and others), the idea that (at least certain) "impairments" are a biological fiction in the way that "race" is a biological fiction is simply untenable. That does a disservice to careful thought on both issues and the many fields that try to carry such work out. There are important differences between disability and race (and sex, which I do not have space here to discuss), and in the long fight to improve philosophical thinking about disability, it is crucial that we attend to such differences.

Importantly, my claims so far do not in fact undermine the apparatus thesis as a whole—far from it. As I hope to have made clear above, I find this thesis helpful and productive in many respects. I have instead argued that (a) conceiving of disability as an apparatus does not entail that there is no such thing as impairment or that impairment is social all the way down (that it is fully "discursive") analogously to race, (b) treating disability as a product of forces of relations requires a significant amount of downstream theoretical labor because, among other reasons, the heterogeneity of cases and processes at play is enormous, (c) giving credence to the concept of impairment in contradistinction to disability does not commit one to a bad-difference view of disability, and (d) treating the concept of impairment as a bad-difference is an inaccurate way to describe its actual *function* across the complex history of disability activism and scholarship.

II.II ON GENOMICS AND THE MEANING OF IMPAIRMENT

A further comment is called for at this point. It is telling to me that arguments against the concept of impairment are often anchored in analyses whose respective central concepts, methods, theories, and cases do not straightforwardly align with those guiding much research and practice in *contemporary* biomedicine and its omnipresent connection to political economy. Namely, they are not anchored in the massive and still ongoing transformation of the life sciences, basic and clinical medical research, and medical practice since the completion of the Human Genome Project (HGP) in 2003.[45] Under

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[45] Jenny Reardon, *The Postgenomic Condition: Ethics, Justice, and Knowledge after the Genome* (Chicago; London: University of Chicago Press, 2018); Kaushik Sunder Rajan, *Biocapital: The Constitution of Postgenomic Life* (Durham: Duke University Press, 2006); Catherine Bliss, *Social by Nature: The Promise and Peril of Sociogenomics*

contemporary medical paradigms of knowledge, what a "real" impairment consists of should have (or at least could have) a genomic explanation, not merely an explanation in the flesh, in tissue-damage, the brain, or the like. If this seems absurdly reductionist, just consider those who are actively working to explain what we today take as largely behavioral differences (and differences that are so varied the term "spectrum" is regularly deployed) like Autism in primarily genomic terms.[46]

Yet, genomic explanations come in many different varieties, and they do not function in the exact same way that other explanatory domains—whether vis-à-vis physiology, biology, anthropology, or what have you—do. For example, some genomic explanations are at bottom claims about risk; claims about the propensity or disposition towards some specific bodily state. Some genomic explanations are claims about cause; claims about why one's body is the way it is. Some genomic explanations are claims about being; about how one's body fundamentally is or a cohort-group of bodies fundamentally are. This taxonomy could go on for quite a bit, and I leave sketching out its complete parameters to others. While these explanations are often run together and, in certain cases, even belong together, the point I wish to highlight is the distinct force of each with respect to the constitution of impairment.

It is profoundly different to be told that one has the HD gene on chromosome 4, which means that one *will*, assuming one lives long enough, develop Huntington's disease, vs. being told that one has the Celiac genes HLA DQ1 and HLA DQ3, which *generally predispose* one to the disease. Thirty percent of the general population has a genetic susceptibility to celiac disease, but only three percent develop it. It is also profoundly different to be told that one has three copies of chromosome twenty-one instead of two in each cell of the body (such that one *will* develop certain expressions correlated to "Down syndrome") vs. being told that one has a polygenetic predisposition for epilepsy. "It is estimated that there is an underlying genetic predisposition for epilepsy in approximately half of [all] individuals, with monogenic epilepsies accounting for less than 1 percent."[47] And even if one ends up with epilepsy, what that impairment will mean varies significantly between various social contexts, access to effective medications such as phenobarbital, and questions of accessibility along a number of axes.

One effect of genomic information has been to make more precise, to *precisify*, how we think about various impairments and between impairments that, for example, differentially track the concepts of "syndrome," "disease," "condition," etc.[48] This is simultaneously a strength and a weakness. Getting more precise genomic information can be a boon—it can sustain, save, and further lives. It can also be the beginning of new and even life-ending processes of surveillance, discrimination, oppression, and other such forms of

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(Stanford, California: Stanford, California : Stanford University Press, 2018). Since 2003, there have been numerous large governmental efforts to increasingly translate genomics directly into clinical practice such as the 2016 Precision Medicine Initiative, which is today's All of Us research program of the NHGRI.

[46] Cf. Robert Plomin, *Blueprint* (Cambridge: MIT Press, 2018), https://mitpress.mit.edu/books/blueprint.

[47] Jennifer A. Kearney, "Advances in Epilepsy Genetics and Genomics," *Epilepsy Currents* 12, no. 4 (2012): 143–46, https://doi.org/10/ghj5s2.

[48] Cf. Kittay, "We Have Seen the Mutants—and They Are Us."

subjugation.[49] As I argue in more detail below, the true danger of the precisification of impairment is the way it can totalize the meaning of *disability* (whether one wants to hear that in a social model, apparatus-based, or some other critical sense).

Furthermore, insofar as the socio-political uptake of the precisification power of genomics—of what I below describe as *genopower*—contributes to and culminates in a focus on the individual, it cannot but evoke the terrifyingly unjust origins of medical practice. It returns us to frameworks that focus on privileged individuals (those who have money and/or access to medicine's wares and who are "lucky enough" to have some important aspect of their experience in the cross-hairs of its contemporary methods) instead of a focus on society and the goal of caring for everyone justly and equitably. This, as work in public health and social epidemiology has made painfully clear, is a grave mistake and a problem we are witnessing in real-time and real deaths as COVID-19 rages highly inequitably within countries and across the globe as a whole. As the now canonical research finding goes: your genome is not the best predictor of your health…*your zip code is*.

III. THE BOOK OF LIFE

Just three years before the map of the human genome would be fully completed, Francis Collins, Director of the National Human Genome Research Institute, spoke at a large press release at the USA's White House. With characteristic—and, to be fair, funding-necessitated—political bravado, he proclaimed, "today, we celebrate the revelation of the first draft of the human book of life," furthering declaring that this breakthrough would let humans, for the first time, read "our own instruction book."[50]

It is hard to overstate the sociopolitical power wielded by concepts like the "book of life" as well as less explicitly metaphoric concepts utilized in genomics research, such as "race" and "ancestry," "allelic shifts" and "allelic drifts," "mutations" and "abnormalities," or what have you. At the very core of genomics' socio-political import is the idea that it tells us *the truth of where we come from, who we are, and what we will become*. The concepts that mediate this truth are, more often than not, taken to be descriptions, not interpretations, of how the world works.[51] The enormous labor that in fact goes into the interpretation of this knowledge—an effort of translational work within the life sciences which requires systemic coordination of computer scientists, biologists, and clinicians, among many others—is too often taken for granted. Part of the reason is because of the simultaneous mystery and prestige of work that goes under this name. The truth of genomics is

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[49] Joel Michael Reynolds, "Health for Whom? Bioethics and the Challenge of Justice for Genomic Medicine," *Hastings Center Report* 50, no. S1 (2020): S2–5, https://doi.org/10.1002/hast.1149.

[50] Katrin Weigmann, "The Code, The Text And The Language Of God," *EMBO Reports* 5, no. 2 (2004): 116–18, https://doi.org/10/bcpwz4. As historian of science and philosopher Lily Kay argues, "the information-based models, metaphors, and linguistic and semiotic tools that were central to the formulation of the genetic code were transported into molecular biology from cybernetics, information theory, electronic computing, and control and communications systems" (1995, 611).

[51] Cf. Alondra Nelson, *The Social Life Of DNA: Race, Reparations, And Reconciliation After The Genome* (Boston: Beacon Press, 2016).

a truth whose veracity is thought to be decided by genomics and genomics experts—a self-verifying, closed, albeit ever-evolving, system.

What the preceding analysis shows is that the socio-political work of genomics—which is to say, the general socio-political effect of all that led up to and has followed from the Human Genome Project—is to *define and delimit the capacity* of human beings at the level of their individual possibilities. Genomics transforms health futures into health fates, one primary effect of which is to delimit the more meaningful frameworks in which and through which care could actually be provided—namely, socio-political frameworks.[52] In short, genomic knowledge fixes bodies and minds to themselves, in effect excising them from larger communal practices of care that might otherwise provide equitable support to them. As I argued above concerning the impacts of genomic precisification of impairment (it can be a boon; it can be a detriment), this does not follow necessarily from genomic sciences. If genomic knowledge production was tied to a just society, a society that provides basic supports for everyone, this story would certainly become more complicated. The power of *fixing* a subject to their genome would still be at play, but the meaning of that fixation might look different and might gear into creating a more equitable world.

In defense of the claim that genomics—relative to its socio-political uptake today—more often than not transforms health futures into health fates, consider qualitative sociological work concerning how parents interpret certain genetic and genomic sequencing results. Take one parent interviewed with respect to a chromosomal microarray screening.

> I never shared it [the results] with any family [members]. My dad would treat [the child] differently even though the results don't say anything definitive. If she drops a ball or says something really stupid, he would say 'oh, there's something wrong with her; she's retarded, or she's autistic.' He would just go there.[53]

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[52] By "care," I in fact mean "CARE" as Kittay defines it in Eva Feder Kittay, *Learning From My Daughter: Valuing Disabled Minds and Caring That Matters* (New York, NY: Oxford University Press, 2019).; i.e., this is not a question of caring interpersonal relations but of socio-political norms that obligate one to care. I should also add that there is a second component to the move towards fate or, rather, one which is already implied in the way that fate, as a trope, is more often than not indexed to the individual (such as in Attic tragedy). Nicolas Rose notes, "The responsibility for the self now implicates both 'corporeal' and 'genetic' responsibility: one has long been responsible for the health and illness of the body, but now one must also know and manage the implications of one's own genome." Nikolas S. Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton: Princeton University Press, 2007). Rose terms the "responsibility for the self to manage its present in the light of a knowledge of its own future" genetic prudence. As Sandra Lee notes, "these technological developments [following from the HGP] frame personal genetic information as an extension of the body." Lee, "Excavating the Personal Genome." Among other effects, this makes such information a question of "a right and not a luxury."

[53] Allison Werner-Lin et al., "'They Can't Find Anything Wrong With Him, Yet': Mothers' Experiences Of Parenting An Infant With A Prenatally Diagnosed Copy Number Variant (CNV)," *American Journal of Medical Genetics* 173, no. 2 (2016): 449, https://doi.org/10/f9ptcp. Cf. [redacted]. I discuss this example and others in far more detail (with very different aims at hand) in Joel Michael Reynolds, "'What If There's Something Wrong with Her?'-How Biomedical Technologies Contribute to Epistemic Injustice in Healthcare," *The Southern Journal of Philosophy* 58, no. 1 (March 2020): 161–85, https://doi.org/10/gh52z7; Joel Michael Reynolds, "Health and Other Reveries: Homo Curare, Homo Faber, and the Realization of Care," in *Normality,*

In a study where secondary or incidental findings became available (those that were not indicated by the child's medical condition or concerns), parents reported "a sense of self-imposed obligation to take on the 'weight' of knowing [this information], however unpleasant."[54] That is to say, even after being told that the information could be ambiguous and without *any* actionable medical significance, parents reported an obligation to know this information. One parent stated,

> How is he supposed to go on and live a happy and productive life... when... he has pretty much a guillotine hanging over his head of all these possible things that are going to go wrong? (Anderson et al. 2016)

"All these *possible* things that are *going to* go wrong…" This knowledge, explicitly presented to patients as knowledge concerning one's essential self—even when fundamentally ambiguous in nature—is in fact predicated upon a foreclosure of the meaning of oneself as a being who cares, a being whose fate is just as equally, if not better, predicated by practices of communal hope, not individual fate.[55]

While there are certainly downstream exceptions, the "normal science" of genomics functions today in society to singularize the patient-subject as a product of its genomic fate and divorce its connection to communal practices of caring (living wages, universal healthcare coverage, equality regardless of social identity, guaranteed housing, truly equal political representation, permeable/open borders, etc.). This is the dangerous side of *genopower*: the foreclosure of a complex, human past, present, and future invariably lived in community that limits its meaning to an individual's genetic expression understood in terms of individual diagnostics, symptomatology, and assumptions concerning one's own "book of life." Even though the force of this power originates from research on populations, the ultimate object of genopower is the individual. Whereas biopower is a question of governance of populations, genopower is a specification of that power by fixing individuals' socio-political fates relative to genomic science…and the way we typically fix those fates today is unjust, inequitable, and demands change.[56]

Abnormality, and Pathology in Merleau-Ponty, ed. Talia Welch and Susan Bredlau (New York: SUNY Press, 2022), 203–24.

[54] J. A. Anderson et al., "Parents Perspectives on Whole Genome Sequencing for Their Children: Qualified Enthusiasm?," *J Med Ethics*, no. 43 (2016): 535–39, https://doi.org/10/gbxvdr.

[55] Alexandra Stern, *Telling Genes: The Story Of Genetic Counseling In America* (Baltimore: Johns Hopkins University Press, 2012).

[56] Cf. Michel Foucault, *The Birth Of Biopolitics: Lectures At The Collège De France: 1978-79* (England; New York: Palgrave Macmillan, 2008); Michel Foucault, *Security, Territory, Population: Lectures At The Collège De France, 1977-1978* (New York: Picador/Palgrave Macmillan, 2009). In this respect, genomics, understood as a body of knowledge and practices whose force relations constitute *genopower*, is a form of prophesy. By that, I do not mean the contemporary sense of that term which assumes prediction concerning the future but instead the ancient sense of warning people about the implications of past sinful actions, as in the traditions of the prophets of the Tanakh/Christian Old Testament. The "truth" of "heredity" is always present in genopower, as is the "truth" of "fate" and "destiny."

IV. TRANSFORMATION, ACCESS TO TRUTH, AND THE SUBJECT

I hope to have demonstrated that the meaning of genomics cannot be decided solely by what it has produced or produces today. How it is produced, how its production is interpreted, and the power wielded by its production are results or factors relative to its uptake in a given milieu. So, what then does this critical analysis of genopower imply for the relationship between humanity and genomics? In order to approach this question, one must, I think, turn to the fraught, historically variable relationship between truth and the subject/self. Insofar as genomics promises to deliver truth directly to oneself about oneself, one must assume that the knowledge genomics provides is not only true, but that one has immediate access to its truth. In other words, genomic knowledge must be the sort of knowledge that is imparted solely through the mere passing of information. As Foucault writes, "I think that if we do not take up the history of the relations between the subject and truth from the point of view of what I call, roughly, the techniques, technologies, practices, etcetera, which have linked them together and established their norms, we will hardly understand what is involved in the human sciences."[57]

Genomics is a paradigmatic example of the idea that one can have access to knowledge without transformation. One can know one's ancestral past, present, and future by simply reading the *output* of bio-informational sequencing. One can know the truth of one's body, one's genetic code, by simply *reading*. Near the outset of the 1981-82 lectures given under the title of *Hermeneutique du suject*, Foucault offers a distinction between philosophy and spirituality, a distinction which he at times treats as a mere heuristic and at other times as a powerful *hermeneutic* insight into the history of philosophy. This distinction is made as part of a larger inquiry into the relationship between the subject and truth. He there defines *philosophy* as "the form of thought that asks, not of course what is true and what is false, but what determines that there is and can be truth and falsehood and whether or not we can separate the true and the false…[philosophy] asks what it is that enables the subject to have access to the truth and which attempts to determine the conditions and limits of the subject's access to the truth."[58]

Spirituality, on the contrary, refers to "the search, practice, and experience through which the subject carries out the necessary transformations on himself in order to have access to the truth….["spirituality" is the] set of these researches, practices, and experiences, which may be purifications, ascetic exercises, renunciations, conversions of looking, modifications of existence, etc., which are, not for knowledge but for the subject, for the subject's very being, the price to be paid for access to the truth." Put simply, traditions that align with the philosophical assume the subject to have access to, to be "capable of truth," just as they are, and those that align with the spiritual assume the subject to not have access to, to not be "capable of truth," as they are. Yet, it should be noted that this distinction requires a horizon in which such philosophical determination and such

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[57] Michel Foucault, *The Hermeneutics Of The Subject: Lectures At The Collège De France, 1981-82* (New York: New York : Picador, 2005). 188.

[58] Idem, 15.

spiritual practice have social meaning in the first place, namely, a recognitive community. Neither philosophy (so construed) or spirituality (so construed) can have an impact on a life except insofar as they can be taken up in ways that others recognize.

It is for these reasons that I think the historical stakes of the relationship between the self and truth are not best captured through the distinction between spiritual and philosophical attitudes towards truth; between an understanding of the self as needing to be transformed and prepared for truth vs. the self as an open receptacle. This relationship is instead ultimately captured through the distinction between *individual fate* and *communal hope* as differing attitudes towards the plight of others, between the self as predestined to its own fate and responsible solely for it and the self as responsive towards and responsible for the suffering of others. Individual fate and communal hope are two profoundly different answers to the question of the meaning of care as the ground of the relationship between the self and truth.

V. WHAT, THEN, ARE WE TO DO?

I began this essay by stating that we live in an age of genomics. Part of what such a claim implies is, to return to the opening epigraph from Foucault, that we live in age wherein "the 'right' to life, to one's body, to health, to happiness, to the satisfaction of needs" is in part determined by the knowledge provided by genomics. As Erik Parens' insight adds to this dilemma, we must come to appreciate the fact that this credence is shared by people across political spectrums but in ways whose *practical implications* are in tension. While we can disagree about Zeno's paradoxes or the Sorites paradox without much effect on our lives, it is another thing to disagree about the role that genomic knowledge plays in the fate of individuals and societies. Genomic interpretation is not simply debated/debatable. The political implications of contestation over it are enormous because they go to the very heart of disagreements concerning how we ought to treat one another.

Are we human animals that are genomically different in ways that, while having no bearing on worth, bear upon how we should treat each other given those differences such that we should aim to create a world that is equitable in light of such differences? Or, are the differences genomic science discovers ultimately *irrelevant* given the tasks that confront building equitable societies, meaning that we should instead aim for a world that is just and equitable without needing to or caring to take into consideration such differences? The impact and import of these very different responses to the "facts" of genomic difference can hardly be overstated.

However one responds to these questions, the primary uptake of genomics has been and is today to tell us about how human organisms are *different* (presumably, both relative to differences within *homo sapiens* and also to other species), and, it seems to me, the differences in question, given our highly social nature and given the increasingly wide dissemination of genomic knowledge, cannot but be translated into frameworks of comparison like that of equality and/or inequality ("natural ability," "congenital defect X," etc.). In this light, the problem with genomics is not a problem with genomics per se—it is a problem with society. On egalitarian frameworks, precisifying impairments could be a boon. On non-egalitarian frameworks, precisifying impairments seems to play directly into multiple historical legacies of inequality and even the aims animating eugenics.

At the same time that whole genome and whole exome sequencing enters into an increasing number of clinical and consumer spaces and funding for genomic research continues to expand across multiple sectors, there are—to focus just on the USA—growing state and federal-level attempts to weaken the Americans with Disabilities Act, undermine equal access to education, and destabilize just forms of care for underserved groups. At the same time that prominent geneticists like Richard Plomin argue for a "new genetics of intelligence,"[59] racialized and ableist eugenics of mass incarceration continue unabated along with systemic police brutality, gun violence, and tax policies that are systematically stripping social supports from economically-insecure citizens and redistributing wealth upwards, as codified in the most recent federal tax bill.[60] Added together, these concerted domestic policies show that eugenics has not gone anywhere in the USA and that genomics is increasingly susceptible to becoming one of its more potent arms, especially potent because it operates under the longstanding aegis of scientific prestige. It is in this sense that the socio-political *function* of genomics today far too easily supports what Rosemarie Garland-Thomson calls "velvet eugenics."[61] This is not the only outcome of this research. But given the conditions under which the genomic sciences are carried out today, its current socio-political effects are hardly surprising. Perhaps this should cause those carrying its banner more pause.

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[59] Robert Plomin and Stumm Sophie Von, "The New Genetics of Intelligence," *Nature Reviews Genetics* 19, no. 3 (2018), https://doi.org/10/gctn8m.

[60] This paragraph was written in 2019. See Liat Ben-Moshe, *Decarcerating Disability: Deinstitutionalization and Prison Abolition* (U of Minnesota Press, 2020); Michelle Alexander, *The New Jim Crow: Mass Incarceration In The Age Of Colorblindness*, Revised edition / (New York; Tennessee: New Press, 2012).

[61] Garland-Thomson, "Eugenics."

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