Genopower: On Genomics, Disability, and Impairment

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Forthcoming in *Foucault Studies*

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 ink has been spilled concerning genomics' precipitous rise, there is little agreement among scholars concerning its meaning, both in general and with respect to our current moment. Some claim genomics is neither new, nor noteworthy; others claim it is a novel and worrisome instrument of contemporary, liberal "velvet eugenics." Contrary to Foucault scholars in both camps, in this paper I utilize research in philosophy of disability to argue that genomics is noteworthy as a unique form of biopower, one of the primary functions of which is to precisify impairments in contradistinction to disability. I call the force at play in this process *genopower*, and I discuss how genopower is a product of and intimately related to, but nevertheless distinct from biopower. Insofar as such genomic knowledge gears into powerful cultural tropes of self-knowledge and self-care and affirms 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."

Keywords:

Michel Foucault, Philosophy of Disability, Genomics, Biopolitics, Disability Studies

> 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…was the political response to all these new procedures of power which did not derive, either, from the traditional right of sovereignty.
> —Michel Foucault[1]

> 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.
> —Erik Parens[2]

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."[3] 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 international bodies over the last two

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[1] Michel Foucault, *The History Of Sexuality: Volume 1: An Introduction* (New York: Vintage Books, 1990).

[2] 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.

[3] 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, and Perry Zurn, as well as 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. 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%."[3] https://reports.valuates.com/market-reports/QYRE-Othe-4C280/genomics

decades, genomics has been and still is today treated as a frontier of knowledge-building in the life sciences.[4] However, multiple scholars have used Foucault's oeuvre to downplay or equivocate 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.[5] 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 contemporary, liberal "velvet eugenics."[6]

Contrary to the claims of both camps, in this paper I utilize research in philosophy of disability to argue that genomics is noteworthy because it is a unique form of biopower, one of the primary functions of which is to precisify impairments in contradistinction to disability. I call the force at play in this process *genopower*. Insofar as the vast quantity of genomic knowledge produced by genopower gears into cultural tropes of self-knowledge and self-care and affirms individualistic solutions to social issues, the contemporary socio-political *function* of genomics with respect to disability is indeed, in the end, 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 genomic-related and genomic-informed scholarship. Despite how many might interpret the phrasing and framing deployed so far, I am myself skeptical of

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[4] 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, initiatives and funding for genomics is treated as a vanguard.

[5] 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.

[6] 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.

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."[7] My aim, on the contrary, is to focus upon the socio-political *uptake*, clinical or consumer, of research in contemporary genomics.[8] Whether or not genomics is in fact the monolith that such socio-political uptake assumes (unsurprisingly, non-genomicists aren't 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.[9] 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.

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[7] 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.

[8] 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.

[9] Consider the work of Sandra Soo-Jin Lee, Catherine Bliss, Jenny Reardon, and Kaushik Rajan, among others. Cf. 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).

I. The Sociopolitical Power of Genomics

Nikolas Rose and Carlos Novas argue that "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 [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."[10] 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 truly and accurately tell one about the material reality of one's body from the womb to the grave. It is in light of this temporally distended effect that genetic prudence comes to be not simply about oneself, but about all those with whom one is linked—which, as genomicists constantly remind everyone who will listen, is ultimately not just all human animals, but a host of non-human animals and organisms as well. Commenting on the larger background of such genetic prudence, Sandra Soo-Jin Lee notes that "several scholars 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."[11]

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 once was. Ancestry-related genomic testing is a massive and growing sector of the genomics industry, and in a cultural moment (the length of which can only be speculative) wherein claims about one's ancestry play a crucial and often defining socio-political role, 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

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

[11] 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

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.[12] 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."[13] 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 indigenous people, was notable and pointed, Warren's ploy seemed to work on the whole, for polling did not show a significant dip in overall support due to her efforts on this front.[14] 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."[15] While many 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.[16] 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 defends. 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,

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[12] 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

[13] 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

[14] 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.

[15] 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.

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

in some cases, acts in willful ignorance of that (readily available) knowledge.[17]

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 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 of 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 found and 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 exists within the domain of clinical or corporate practitioners instead of its social uptake risks missing what genomics is in fact *doing* as a human practice and how it in fact affects how we live our lives. 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 one of the primary functions of genomics is to precisify impairments in contradistinction to disability.[18]

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.[19] The concept of "impairment" refers to atypical bodily differences whereas the concept of "disability" refers to cultural, social, and political responses to such bodily

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[17] Idem.

[18] 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 (2018).

[19] There are actually *multiple* social models as anyone working seriously in disability studies knows. I won't 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 aren't 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 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.

difference that result in stigma, discrimination, and oppression against disabled people. Some proponents of social models, whether rooted in activist or academic concerns, conceive of "impairment" in a straightforwardly naturalistic sense. For example, if you are blind, you are impaired in the sense that you *lack* the organismically typical ability to see; put otherwise, you experience a *defect* relative to the phenotypical norm of human (visual) sight. What disables you, however, is a world without curbs cuts and audible traffic signals, a world that largely fails to support the widespread use of braille, alt-text, and visual description, a world that makes getting a guide dog hard or even impossible, and a world that is, on the whole, hostile to and stigmatizing of blind people.

Shelly Tremain draws upon Michel Foucault's work to powerfully combat this naturalist understanding of impairment and, to a degree, this ahistorical understanding of disability simply as stigma/discrimination/oppression. Focusing on the former for a moment, she argues that the concept of "impairment" appeared and developed along with bureaucratic techniques and apparatuses of governance in the long 19th century. It is a *product* of the historical emergence of biopolitics as the dominant modality of modern governance.[20] In this light, Tremain aims to "develop a conception of disability that does not rely upon a natural, transhistorical, and transcultural metaphysical and epistemological foundation (impairment)."[21] In short, impairment is no less social and no more natural than is disability (in the sense of the social model). Tremain 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 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

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[20] 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).

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

> 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."[22]

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 are historical products and do not refer to mere 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 disabled.[23] These processes are not the results of mere facts about bodies, but they instead emerge from a historical context in which those concepts come to mark differences between beings in ways that distribute, among other things, power. "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."[24]

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, doesn't 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 claim that demands further specification. What sort of product? What sorts of forces? What sorts of relations? In what sort of contexts? Under which sorts of constraints? Etc. And this lack of clear inferences applies even more so to questions of impairment. For example, it does not follow directly from the apparatus thesis that the concept of impairment *just is* one of its effects. That is a further argument that would need to be demonstrated. And it is no small matter: the concept of impairment's fate has very high stakes for not only disability politics, but disability (social) ontology.

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[22] Ibid, 22.

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

[24] Ibid, 5.

On the last point, when Tremain defends variations of the following formula: "impairment—the naturally disadvantageous foundation of disability," she gives into a version of the bad-difference view of disability.[25] Namely, instead of splitting discrimination from difference, she assumes that differences (differences described by the concept of impairment as social model supporters understand it) are themselves bad. But that is by no means a given and that is certainly not the point of the social model's understanding of impairments (whether one looks to the complex history of disability activist practitioners of the social model 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 limitations, differences that should *not make a difference* socially. In short, it is inaccurate to say that "impairment" is conceived to be a naturally disadvantageous foundation in disability theory writ large.

Whatever negativity might come along with certain cases of impairment (bracketing the important question of how one defines "negativity"), the upshot is not that impairment is merely or primarily a product of discursive/socio-political/fill-in-the-blank practices. This is part of the reason why debates about chronic pain and certain chronic illness have been so contentious in disability activism and disability studies over the last thirty-plus years—some disabled people have said, "Hey, my impairment *actually is bad*, and it's not bad just due to living in an ableist society." As Elizabeth Barnes painstakingly points out, to be impaired does not *automatically* mean that one's life, *on the whole*, will go worse. It might, though, indeed go worse in certain particular respects, but that is true for any given form of embodiment whatsoever.[26] Crucially, such a 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 (as in certain cases of chronic pain). Part of the problem here is that over the last few decades "impairment" has shifted 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

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

[26] Elizabeth Barnes, *The Minority Body* (New York, NY: Oxford University Press, 2016). Barnes' choice example is the inability of certain humans (typically called "males") to create life. From that fact we don't assume their lives will, on the whole, necessarily go worse.

find it quite important to hold onto the concept of "impairment."[27] But, 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—defined impairment in a way that seems both evaluative and also naturalistically so.[28] 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." One should keep in mind, however, that the UK disability rights approach was operating within a largely 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 first centered 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 if 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."[29] Roberts implicitly refers to the impairment-disability distinction here, but leaves open whether it is a lack, defect, or mere difference. But he is crystal clear that when another takes his way of being in the world *as negative*, when taken as making him less-than or not human, 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 less-than-human, but instead just as human as anybody else.

To run together the UK and USA disability rights activists (as well as disability scholarship as practiced in those places and beyond and over many decades and shifting political contexts) as if the concept of "impairment" is definitely treated as a "natural disadvantage" far oversimplifies the picture.

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[27] 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" 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.

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

[29] 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.

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 off of the Realpolitik in which activists are engaged just as one cannot simply read a detailed politically-engaged account off of the theory-building in which scholars (typically, if not always) are engaged.

Upon a closer examination of the history of disability activism and disability studies' scholarship, impairment *functions* more often than not as difference, not detriment.[30] This is part of the explanation of why there was such a strong and notable push by scholars such as Liz Crow, Susan Wendell, and Tom Shakespeare in the mid-1990s onward to bring the *negativity* of certain impairments (esp. those related to chronic illness and chronic pain) back into the disability politics fold with respect to both activism and the academy. It is the forgetting by disability studies and disability activism writ large of *disadvantage due to impairment* that these scholars fight against. Tellingly, many of those authors did not (and contemporary scholars in that space certainly do not)[31] give into a simplistic "realist ontology," as Tremain claims they do. They are instead working 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 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. As far as humans have been able to figure out over the historical record, many forms of chronic pain require *drugs*. And one would be hard pressed to argue that the production of, research concerning, and distribution of germane drugs are products of a just world.[32]

To fix chronic pain requires more than a just world, for there are forms of suffering "which justice [alone] cannot eliminate," as Susan Wendell aptly puts it.[33] This is true of a host of other things, from epilepsy to cystic fibrosis

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[30] By my lights, how, why, when, and where it plays this function further demonstrates that interpreting the impairment/disability distinction in terms of the sex/gender distinction is largely a mistake and betrays a misunderstanding of each. Given constraints of space and given the aims at hand, I can't here go into this argument in any more detail.

[31] See, e.g., the 2020 special issue of *Puncta: A Journal of Critical Phenomenology* on the topic of "Critically sick: New phenomenologies of illness, madness, and disability."

[32] Among the many, many texts one could cite concerning the history of medicine, consider Harriet A. Washington, *Medical Apartheid: The Dark History Of Medical Experimentation On Black Americans From Colonial Times To The Present* (New York: Anchor Books, 2008).

[33] 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).

to Alzheimer's disease. 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.

Yet, to treat that inference as valid is a mistaken habit of thought that strangely appears over and over again in disability scholarship. Consider the following argument by 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."[34] 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 doesn't mean they don't 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 Shakepeare 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's both/and, not either/or.

To better understand these stakes, 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 (genomic or otherwise) meaning to the term "Black," there is no biological (genomic or otherwise) meaning to disability, including things like "Down Syndrome."[35] But that analogy makes no sense. While it is certainly

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[34] Tom Shakespeare, "The Social Model of Disability," in *The Disability Studies Reader*, ed. Lennard J. Davis, 4th ed. (New York; London: Routledge, 2014).

[35] 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.

not *all* that Down Syndrome means, there is a specific biological meaning to the term: it means that a person has extra genetic material from chromosome twenty-one.[36] That's 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.[37] 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.[38] One is, fundamentally, a socio-political term; the other is, fundamentally, a genetic-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* entitled, "The Last Children of Down Syndrome." "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.'"[39] Furthermore, this is not to claim that we should hold onto the term "Down syndrome" in the sense of "extra genomic material on chromosome 21." My point is not that Down syndrome is fully captured by a genomic (chromosomal) difference—my point here is to show that 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

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[36] 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 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.

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

[38] 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 don't 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 doesn't 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.

[39] 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=IwAR0aUjidoHySTvzBi9sTvw1zAssLrDNOfrqWYeGOxU5MhrGCfxc1fRaOFE0.

blindness. The former is a *syndrome*—a catch-all phrase for a *set* of various phenotypic expressions, the variability of which can be in flux but the direct cause of which is (we think today) genetically 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*."[40] 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."[41] 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.[42] 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 not of a major 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 highly 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."[43] Yet, to be clear, even its status as an illness is debated. My point here neither relies upon consensus over the medical taxonomies under discussion, nor on matters of precision or clarity with respect to the analytic boundaries of concepts like 'syndrome,' 'condition,' or 'disease.' My point is to show 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

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

[41] Idem.

[42] 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 defines 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.

[43] 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.

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's 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 that save a person's life/make their life liveable or not. Knowing more about these differences can also be the difference between becoming highly stigmatized, discriminated against, and oppressed in various ways (whether within the clinic or outside). But the precision of knowledge at play is not 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 copies of chromosome twenty-one instead of two before 1866 (when Down syndrome was first described). But to deny the concept of impairment any "prediscursive" meaning alongside that of disability and then to claim disability is "not a nonaccidental [i.e., it is accidental] attribute, characteristic, or property of individuals," as Tremain does, seems to commit 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 not just Foucault, but also many of those who build therefrom like Kuhn, Hacking, 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 don't 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. One of these differences is that, however multifaceted it may be, there is such a thing as impairment (at least in certain cases) that is distinct from disability.[44] To argue otherwise does a massive disservice to many people, but especially those living in chronic pain and with chronic illness.

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

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[44] I am here making an ontological claim, but there are good reasons to make such an argument politically as well. I discuss this in more detail below.

fully "discursive") analogously to race, (b) thinking about the way in which disability is a product of forces of relations requires a significant amount of precision because, among other reasons, the heterogeneity of cases and processes at play is enormous, and (c) giving credence to the concept of impairment in contradistinction to disability does not commit one to a bad-difference view of disability and, furthermore, is not an accurate way to describe its actual *function* across the complex history of disability activism and scholarship.

A further comment is called for at this point. It is telling to me that many arguments against the concept of impairment have often been anchored in medical and political genealogies 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, with respect to 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 contemporary medical paradigms of knowing, 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 mind, 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

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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* (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.

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 and die from it) vs. being told that one has the Celiac genes HLA DQ1 and HLA DQ3 that *generally predispose* one to the disease. It is also profoundly different to be told that one has three copies of chromosome twenty-one instead of two (such that one will develop certain expressions correlated to "Down syndrome") vs. being told that one has a genetic 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 *wildly* between various social contexts, access to effective medications (such as phenobarbital), and various sorts of accommodations.

One of the effects 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 its strength and its weakness. For, as I argue below, the true danger of precisification and of the power of the concept 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). 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 subjugation. 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, then 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 across parts of the globe. As the now canonical

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[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."

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."[49] 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.[50] 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 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 a truth whose veracity is 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

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[49] 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).

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

which care could actually be provided—namely, social frameworks.[51] 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. If genomic knowledge were 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.

In defense of the claim that genomics 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.[52]

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

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[51] 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."

[52] 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 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.

knowing [this information], however unpleasant."[53] 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.[54]

While there are certainly downstream exceptions, the "normal science" of genomics functions in the public socio-political realm 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 *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 diagnostics, symptomatology, and assumptions concerning "the book of life." Even though the force of this power originates from research on populations, the 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.[55]

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[53] 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.

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

[55] 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, just as is the "truth" of "fate" and "destiny."

IV. Transformation, Access to Truth, and the Subject

The dilemmas introduced by genomics will not 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. 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, then 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."[56]

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 1981-92 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."[57] *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,

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

[57] Idem, 15.

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 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 suffering 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 riff off of 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 more than one sense diametrically opposed.[58] 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 an individual. Genomic interpretation is not simply debated/debatable. The political implications of contestation over it are

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[58] See fn. 3 above.

enormous because they go to the very heart of disagreements concerning egalitarianism.

Are we human animals at bottom that are genomically different in the sense of being *unequal* with regards to our "bodily capacities" and animals that must learn to deal with that inequality? Or 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, and 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 power 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 uptake 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, precisfying impairments could be a boon. On non-egalitarian frameworks, precisfying 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 that 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

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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.

upwards, as codified in the most recent tax bill.[60] Added together, these concerted domestic policies show that eugenics has not gone anywhere in this country 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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[60] 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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