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"WHAT IF THERE'S SOMETHING WRONG WITH HER?" – HOW BIOMEDICAL TECHNOLOGIES CONTRIBUTE TO EPISTEMIC INJUSTICE IN HEALTHCARE

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ABSTRACT: While there is a steadily growing literature on epistemic injustice in healthcare, there are few discussions of the role that biomedical technologies play in harming patients in their capacity as knowers. Through an analysis of newborn and pediatric genetic and genomic sequencing technologies (GSTs), I argue that biomedical technologies can lead to epistemic injustice through two primary pathways: *epistemic capture* and *value partitioning*. I close by discussing the larger ethical and political context of critical analyses of GSTs and their broader implications for just and equitable healthcare delivery.

Access to basic healthcare and equal forms of medical care is considered essential on distributive theories of justice (Daniels 1979). Yet, the practice of medicine is a human affair, and humans are notoriously prone to obstinate cognitive biases (Kahneman 2013). Such biases result in medical errors that would undermine diagnosis, treatment, and care even in ideal healthcare systems. Furthermore, there is a steadily growing body of research examining how such biases give rise to medical errors that are not equally shared by all, but instead disproportionately affect the health outcomes of vulnerable medical patients and historically oppressed patient populations (Reiheld 2010; Carel and Kidd 2014; Blease et al. 2017; Maina et al. 2018,

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Reynolds and Peña-Guzmán 2019). This research, which typically focuses on patterns of patient-provider communication, institutional norms, and the effects of historical and sociopolitical factors on medical practice, also makes plain how such cognitive biases are rooted in oppressive systems and processes of racism, sexism, cissexism, ableism, and classism, et al. However, there is little work on the ways in which the development and use of recent biomedical technologies themselves contribute to epistemic injustice in healthcare and beyond. In this essay, I address this lacuna by exploring the role that biomedical technologies play in harming patients in their capacity as knowers.

Criticisms of new technologies, including biomedical technologies, invariably run the risk of overgeneralization. To appropriately restrict the scope of my analysis, I focus upon clinical applications of genetic and genomic sequencing technologies, including whole genome and whole exome sequencing as well as chromosomal microarray, and I do so with respect to return of results of variants of unknown or highly variable significance in prenatal and pediatric settings. I believe that my arguments extend to other sorts of technology, biomedical and otherwise, but I do not put forward the case for that extension here. For shorthand, I will refer to these jointly as *genetic and genomic screening technologies* (GSTs). Given the purposes at hand, I group these technologies together because of the way in which they each produce excess information beyond the discrete, animating clinical concerns in any given case and thereby produce information that can be medically unactionable or fundamentally ambiguous.

My central argument is that GSTs cause epistemic injustice through what I call *epistemic capture* and *value partitioning*. Epistemic capture occurs when fundamentally ambiguous information is transformed into and treated as definite knowledge. Value partitioning occurs when variously available hermeneutical resources are restricted to an inappropriately simplistic evaluative scale or set of appraisals. In the cases of GSTs, this restriction leaves open just two possible appraisals: positive or negative.[1]

I begin by analyzing a set of qualitative research detailing the psychosocial impact of GSTs in the aforementioned clinical settings. Then, I lay out the argument that GSTs cause epistemic injustice through epistemic capture and value partitioning. I close the paper by discussing the larger ethical and political context of critical analyses of GSTs as well as the

[1] Of course, the concept of value partitioning could describe a situation where the scale consists of more than two values or where a given set of appraisals operates with an intricate and far more complex relationship than that discussed here.

broader implications of this analysis for addressing epistemic injustice in healthcare and for the practice of just and equitable healthcare delivery more generally.

Three initial clarificatory comments are in order. First, my use of the term "epistemic injustice" goes beyond its typical scope in much of the literature (Fricker 2007; Hookway 2010; Kidd et al. 2017). I focus neither on harms caused by another individual such as one's provider, nor on harms caused by institutions. Instead, I focus on harms caused by the *epistemic frameworks* at play in the development and use of biomedical technologies, which is to say, in the interpretation of the data and information they produce as well as in the many practices and activities such interpretations generate and shape. Put differently, my focus is on harms resulting from the specific hermeneutical resources and processes *put to work* by and through biomedical technologies in the sorts of cases under discussion. In this way, I hope to contribute not only to the literature on epistemic injustice, but also to the more specific project of understanding how "certain newborn screening results," as well as pediatric screening results, "have been demonstrated to cause distress, alter behavior, and even to influence the formation of new parental and family identities" (Grob et al. 2018). I leave open for future research the extent to which this analysis applies to GSTs in different clinical contexts and cases, including returning results other than those discussed here, and I also leave open the extent to which this analysis applies to different sorts of technology.

Second, when one studies biomedical technology, one is dealing with an especially complicated phenomenon. With respect to a technology like whole-genome sequencing, for example, there are hundreds, if not thousands of people who play roles in the many processes leading up to and extending through its clinical applications as they exist today, ranging from computer scientists and lab technicians to various clinicians and genetic counselors. "Biomedical technology" often functions as a synecdoche for a large and labyrinthian network of interactions between a variety of actors in biomedicine and a host of technological tools and processes. In short, this complexity makes "biomedical technology" a difficult object for epistemological inquiry, including "genomic sequencing technologies" more specifically. Speaking of the practices and concerns captured by the umbrella terms "genetics" and "genomics" as well as "postgenomics," Colin Koopman rightly notes that "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"

(forthcoming). One upshot of my analysis is that studies of epistemic injustice in relation to biomedical technologies may present special methodological issues and require a thoroughly interdisciplinary and transdisciplinary approach.

Third, insofar as epistemic injustice contributes to distributive injustices (Coady 2017), it is a compounding form of injustice in the context of the US healthcare system, for this system is infamously unjust and inequitable both historically and today (Washington 2008). Writing about biomedical technologies is an inherently political endeavor if for no other reason than that many of the technologies discussed in journals of philosophy, sociology, anthropology, bioethics, and public policy are technologies that the majority of humans on Earth cannot access. That they cannot do so is not primarily a question of bad luck, but of histories of colonization and imperialism (Wolfe 2006). The benefits of GSTs, for instance, are typically enjoyed by a demographically small slice of the white, middle- to upper-middle class in the global North. Until the profound inequality of access to such biomedical technologies is addressed, inquiries such as the one I am undertaking risk missing the actual moral and political forest for the privileged trees.[2] I take this concern very seriously and discuss it at length in the concluding section of the paper.

1. GENETIC AND GENOMIC SEQUENCING TECHNOLOGIES

GSTs have been used in clinical settings for decades. These technologies use modern computing power to analyze particular portions of the genetic material in a human organism primarily with the aim of detecting medically actionable (or potentially medically actionable) variants. Since 2010, the American College of Medical Genetics has supported chromosomal microarray as a first-tier test for individuals with several types of suspected genetic diseases (Miller et al. 2010). Whole genome sequencing (WGS) technologies, unlike chromosomal microarray and other methods that sequence individual genes or specific sets of genes, analyze the entire genome of an organism, including chromosomal as well as mitochondrial DNA. WGS

[2] See "Access to Healthcare," Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, https://www.cdc.gov/nchs/fastats/access-to-health-care.htm. My thanks to Chris Lebron for graciously leading me to engage these concerns in far greater depth.

provides significantly more data and is increasingly preferred by clinicians as a diagnostic test.[3]

However, due to their breadth and depth, these tests can uncover information that is incidental to the initial concerns that prompted the test in the first place. This includes information that can be fundamentally ambiguous and, at times, without known medical significance. As Eric Green, director of the National Human Genome Research Institute at the NIH put it in 2016, "we are overwhelmed by the amount of data coming out of these sequencing instruments . . . it's a new circumstance . . . reading out a genome sequence is not the hard part [anymore]; the hard part is progressing on and figuring out what to do with the information about the variants in our genomes."[4] This situation is historically unprecedented, and it is faced by clinicians and researchers at the same time that whole genome sequencing and related techniques become more common in clinical and other settings that translate the findings of basic research.

As Khoury et al. argue, "Our current translation landscape in genomic medicine has major gaps. The science of gene discovery is relatively well funded and moving forward at a rapid pace, yet the translation sciences, including both clinical trials and large, well-designed observational studies, are lagging behind. Often, a gene discovery per se is simply assumed (incorrectly) to have clinical validity and utility for the practice of medicine (for example, genetic variants for susceptibility to diabetes…)" (2008). Put bluntly, the tools to meaningfully understand a significant chunk of the raw data being produced are lacking.

[3] A recent study in the *European Journal of Human Genetics* concluded that "initial evidence suggests that the diagnostic performance of WGS is superior to conventional genetic tests," such as chromosomal microarray. Although the overall cost-effectiveness is currently unclear, the authors of that study state that "it is expected that technical costs associated with high throughput sequencing will continue to decrease and that diagnostic performance will continue to improve" (Hayeems et al. 2017). A more recent metaanalysis suggested that "among studies published in 2017, the diagnostic utility of WGS was significantly greater than CMA." The authors also noted that "the diagnostic utility of WGS and WES [whole-exome sequencing] were not significantly different" (Clark et al. 2018). Whole-exome sequencing, in contrast to whole-genome sequencing, focuses specifically on the ~1.5–2% of genes that code for proteins. In summary, it is likely that the clinical use of whole genome and exome sequencing across a wide range of therapeutic contexts will continue to grow in the coming years, overtaking older and more limited GSTs, such as chromosomal microarray. It is also likely that whole genome and exome sequencing will become increasingly incorporated into clinical contexts wherein GSTs were used less frequently in the past and also increasingly used in contexts where GSTs have already made inroads.

[4] See Eric Green, "The Genomic Landscape circa 2016," part of a conference on Current Topics in Genome Analysis 2016, hosted by the NHGRI on February 24, 2016. Available at https://www.youtube.com/watch?v=mhD3-_5Ee-A.

This is therefore an especially important juncture to investigate the epistemic frameworks shaping our efforts to interpret genomic data and the effects these frameworks, these efforts, and our interpretations have on all those who interact with and are affected by genomics research. It is in this light that I begin with an analysis of recent qualitative studies detailing how parents interpret genetic and genomic sequencing results.

2. KNOWLEDGE, MEANING, AND GSTS

Werner-Lin et al. (2017) report the case of a mother who underwent chromosomal microarray screening and whose baby tested positive for a copy number variant with a highly variable phenotype. The mother reported that provider reactions ran the gamut from**:**

> "Doom and gloom" to "(t)his baby's perfectly fine, why are they putting you through this?" As her daughter reached 6 months, she said: "I'm constantly questioning 'is this because of her disorder?' For example, she's a really bad sleeper so for the longest time I thought 'wow, is this her deletion or is it just that she's five months old and she sucks at sleeping like most babies?'" (Werner-Lin et al. 2017)

Even though the meaning of the baby's "deletion" was fundamentally uncertain, and even though the opposing responses from providers demonstrated this, this mother struggled to resist taking the ambiguity of the GST information to be *knowledge* of something being wrong. Another parent said,

> Once or twice it's crept into my head where I've been like "what if this microarray result . . . like there's something wrong with her and we don't know and one day she just has SIDS [sudden infant death syndrome] and stops breathing." She's got such a strangely mellow temperament, so I think, "is there something wrong with her that she's just so lovely"—which makes no sense. (447)

"*Which makes no sense.*" This parent, even more explicitly than the one quoted beforehand, recognizes that it is unreasonable to take the uncertainty of the copy number variant to be evidence of, to be a piece of knowledge demonstrating or suggesting that, something is wrong. Yet, the epistemic inertia from uncertainty and ambiguity to certainty and clarity that something is wrong is powerful enough that some parents even began entertaining concerns about assumed social repercussions and difficulties. Another said,

> 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. (449)

"*Even though the results don't say anything definitive.*" In each of these cases, the epistemic (and existential) inertia generated by the uncertainty does not lead to the general assumption that their child may have something different about them; it leads more specifically to the assumption that they *will* have a disability, an impairment, and one that causes disadvantage—that will, it is assumed, make their life, on the whole, go worse.

Take the case of a mother who had been told that the screening results for her newborn suggested the possibility of PKU (Phenylketonuria), but not definitively so. She originally "sloughed off" the information. And yet, she stated,

> Then you go on the Internet and it's, like, if the levels are like this, you know he'll become retarded. He's losing IQ points by the second. And I'm, like, oh, my gosh! I'm looking at him, and, like, he seems fine. Is his brain, you know, getting destroyed by the protein that's in my breast milk? (Timmermans and Buchbinder 2010)[5]

"*You know he'll become retarded.*" Here, the clinical encounter itself does not directly animate the shift from ambiguity to certainty to specific concerns about disability. Instead, a complex, social repository of varying forms of information (the internet) leads to it. The levels, which are in fact ambiguous, are taken to be definitive. And the experiential outcome of that taken-as-definite-knowledge is further interpreted to mean: "you know he'll become retarded."

Even when screening results were not related to the initial reasons for a diagnostic test, in one study parents reported "a sense of self-imposed obligation to take on the 'weight' of knowing [this information], however unpleasant" (Anderson et al. 2016). Parents reported a duty to know if something was *wrong*, even after being told that incidental or secondary variant information could be ambiguous and without actionable medical significance. Based on this study, it seems as though the very framework of GSTs creates—or at least sustains—a pressure *to know*. 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 prima facie contradictory phrase lays bare the existential impact of GSTs in cases such as

[5] This last study is with respect to tandem mass spectrometry technology for metabolic diseases, which are screened via a blood sample. I do not have space here to defend this claim, but I would argue that the results hold, *ceteris paribus*, for my claims about the epistemic framework of WGS/WES/CM.

these.[6] A fundamentally ambiguous piece of information, a possibility untethered to evidence of the sort that is to be modern medicine's lifeblood, transfigures into a piece of knowledge that something bad is going to befall one's child—and that something bad is their becoming disabled. I will now turn to use the tools of social epistemology to better understand how and why this happens as well as what harms such situations bring about.

3. THE EPISTEMIC FRAMEWORK OF GSTS

In each of these examples and the larger studies of which they are a part, parents struggle with the epistemic framework and processes put to work by and through these genetic and genomic screening tests. In the analysis that follows, I will focus on the concepts undergirding GSTs in order to understand the larger epistemic framework at play. In other words, I aim to show how these concepts shape larger patterns of knowing and interpretation in these contexts.

I take this route for a number of reasons. First and foremost, I find the concepts central to the development, production, use, and interpretation of GSTs—the conceptual architecture of GSTs, if you will—to fruitfully reveal the epistemological milieu that patients find themselves in when working to make meaning out of the information put before them.[7] The concepts at play, then, are an especially fertile starting point to understand the larger epistemological framework in question because, as I hope to show below, they reveal the epistemological landscape at work in the *lived experience* of receiving and interpreting its outputs, which is to say, the lived experience of taking up and dealing with their *meaningfulness*.

Furthermore, I follow feminist theorists, critical race theorists, and critical disability theorists, among others, in understanding moral labor to centrally involve conceptual analysis as guided by empirical reality, which is to say, conceptual analysis as guided by the actual conditions under which people live and with special attention to histories of oppression and extant social hierarchies. As Charles Mills puts it in, "'Ideal Theory' as Ideology,"

[6] As an anonymous reviewer rightly pointed out, there is a large literature on risk and on health risks in particular. That literature is surely a boon to understanding situations like these, but I do not have the space to engage it here. A more detailed analysis of the specific role conceptions of risk play in relationship to the arguments presented in this piece would require a future study.

[7] Following scholars in science and technology studies, I take this milieu to ultimately touch upon everything from informatics to economics to local, national, and global politics (Reardon 2018).

> Moral cognition is no more just a matter of naïve direct perception than empirical cognition is . . . concepts are necessary to apprehend things, both in the empirical and moral realm. But once one recognizes (unlike Kant) the huge range of possible conceptual systems, then . . . concern about conceptual adequacy becomes crucial. . . . It will often be the case that dominant concepts will obscure certain crucial realities, blocking them from sight, or naturalizing them, while on the other hand, concepts necessary for accurately mapping these realities will be absent. Whether in terms of concepts of the self, or of humans in general, or in the cartography of the social, it will be necessary to scrutinize the dominant conceptual tools and the way the boundaries are drawn. (Mills 2005, 174–75)

One of the ways that dominant concepts obscure instead of illuminate is by hiding their status as concepts—by passing as facts of the matter instead of, as they in fact are, determinate for and shaping of interpretation and judgment.

With these concerns in mind, consider the diversity of dominant, organizing concepts at play in GSTs: disease, disorder, variation, mutation, risk, and typicality, among others.[8] If one heeds research in the philosophy of medicine as informed by the philosophy of disability and critical disability theory, these seemingly diverse and complex terms are grounded in just *one* foundational concept: *the norm* (or, if one prefers it phrased as a state or quality, *normality*).[9] As I have argued elsewhere in light of that research, normality "is the glue that renders any given modern concept of health, illness, or disease coherent. Just as one must assume or construct a moral exemplar in order to articulate a theory of virtue, one must assume or construct a ["normal"] psycho-physiological exemplar in order to articulate a theory of health, illness, and disease" (Reynolds 2018a). Though the concept ultimately originates out of statistics, management sciences, and shifts in modes of governance in the eighteenth and nineteenth centuries, it easily and too often functions ontologically and normatively—it is taken as a measure of how things *are* and *should* be (Davis 1995).

While normality can be applied to any number of phenomena, in each case, its hermeneutical or interpretative function is to bifurcate. Normality is a binary concept. It serves to divide and divide into just two sorts with opposite valences. If a phenomenon is not normal, it is abnormal, regardless of whether its abnormality is construed as deficiency or excess. In some

[8] This claim is easily substantiated by even a cursory search of any leading genetics-focused scholarly journals. To take one historically momentous example—and one which centrally deploys all of these concepts—see (International Human Genome Sequencing Consortium et al. 2001).

[9] This is a very large literature that I cannot rehearse here, but the following are especially helpful entry points: Kukla (2015), Silvers (1998), and Amundson (2000).

medical contexts and with respect to some medical phenomena, the line between these two domains is understood as involving some amount of ambiguity. For example, it is not the case that a blood sugar level of 239 is normal and 240 is abnormal; they both straddle a point that has been established to be of clinical significance and both would be flagged as problematic.[10] While the specific demarcation between normality and abnormality involves pragmatic decisions that are often, or at least ideally, based upon a rich and varied data set, it is nevertheless the case that the conceptual binary of normal/abnormal is regulative for genomic sciences. That is to say, it guides and orients how phenomena that fall under its scope of analysis are understood. The concept of normality, acting as the foundation of the epistemic framework of GSTs, structures information according to the binary distinction between the normal (positive) and the abnormal (negative) (Waldschmidt 2005).[11]

If one recalls the longitudinal study from a newborn screening context cited earlier, parents who received a report of some genetic abnormality—even if its eventual expression was uncertain due to significant phenotypic variability or due to some other reason—started treating their child as already "sick" (Timmermans and Buchbinder 2010). In light of this evidence, the authors of that study suggest that newborn genetic and genomic screening can lead parents to treat their children as permanent "patients-in-waiting." Because of the value we place on being "normal," parents interpret risks, probabilities, and even unknowns as evidence of fated, feared things unseen, as evidence of *knowledge* that something is or will be wrong in and for the life of their child. But what, precisely, does this knowledge *mean* for parents? And do the specific hermeneutical resources and processes *put to work* by and through GSTs, as well as the outputs of those processes, in fact constitute a *harm* to parents in their capacity as knowers?

3.1. *The Epistemic Harm of GSTs*

Using examples drawn from qualitative sociological research conducted in clinical settings, I have suggested that the epistemic framework of genetic and genomic sequencing is defined by the concept of normality. I further claimed that this concept, which is operative in everything from the demand to create these technologies to the sociocultural milieu of parents and clinicians who use them, ultimately functions to classify results into one

[10] I am grateful to an anonymous reviewer for this point.

[11] It should go without saying that abnormality can be transformed into normality if it fits within a valued social practice.

of two domains, normal and abnormal, and one of two respective values, positive and negative. I have not yet explained, however, *why* the effects of this framework constitute an epistemic harm in the senses explored by social epistemologists.

The way in which GSTS are put to work cause harm to people in their capacity as knowers through two pathways: epistemic capture and value partitioning. *Epistemic capture* occurs when fundamentally ambiguous information is transformed into and treated as definite forms of knowledge. *Value partitioning* occurs when variously available hermeneutical resources are restricted to an inappropriately simplistic evaluative scale or set of appraisals. As suggested above, this restriction leaves open just two possible appraisals in the aforementioned cases of GSTs: positive or negative. Epistemic capture mobilizes hermeneutically ambiguous resources as if they are not ambiguous. It passes off fundamentally ambiguous or underdetermined genomic knowledge as if it is reliable diagnostic and prognostic information when it is not. Because of the role played by the concept of normality in genomic sciences in conjunction with the broader social and cultural prevalence of ableism, this can lead directly to value partitioning. This feature of GSTs, as they are in fact *put to work* in relation to the manifold epistemic agents who interact with them, filter lives into being either "positive" or "negative," either "good" or "bad."

Note that the restrictions GSTs place on the relevant hermeneutical resources are many. To borrow a term from Eric Schwitzgebel, there is what could be called *morphological prejudice* with respect to assumptions concerning the variability of forms of the human body and mind.[12] Of course, the idea that there is a "standard" human form is created and gains steam in a specific historical context. That idea requires active ignorance of the de facto range of shapes, sizes, looks, forms, and styles of being of human animals. It also requires active ignorance of the social and political stakes of normalization (Bashford and Levine 2010; Lombardo 2011).

There is also *hedonic prejudice* with respect to assumptions concerning which forms of human life are germane to flourishing and which are not.[13] To assume that a clinically significant genomic variation (not to mention a variant of unknown significance) is automatically negative in the sense of foreclosing one's potential flourishing is misguided. Lastly, there is *scientific*

[12] Eric Schwitzgebel, "The Splintered Skeptic: Eric Schwitzgebel interviewed by Richard Marshall," 3:AM Magazine, Jan. 20, 2012, https://www.3ammagazine.com/3am/the-splintered-skeptic/.

[13] On this point, see especially Elizabeth Barnes's arguments for a mere-difference view of disability (Barnes 2016).

prejudice with respect to assumptions concerning the authority of the modern life sciences to determine the meaningfulness of a life, the forms life can take, and the flourishing various forms of life enjoy.

Crucially, what makes the restriction of value partitioning indefensible also turns on whether the hermeneutic resources in play reasonably include the views, experiences, resources, and research relative to the phenomena over which they are taken to have epistemic purchase and the people who have lived, embodied knowledge of those phenomena. This is not simply a question of epistemic error, but also of injustice, for these restrictions function to uphold extant systems of oppression, systems that subordinate historically oppressed and marginalized groups. It is a question of what Kristie Doston has called "contributory injustice" and an instance of what Gaile Pohlhaus Jr. calls willful hermeneutical ignorance (Dotson 2012; Pohlhaus 2012). That is to say, in order to take the binary value partitioning in question as accurate, one must actively ignore all of the testimony and bodies of knowledge that, if taken seriously, would undermine it.

A more capacious definition can now be offered: GTSs contribute to epistemic injustice by (a) transforming ambiguous information into definite forms of knowledge taken to be true and (b) restricting variously available hermeneutical resources used to interpret that knowledge—knowledge concerning health states, bodily transitions and variation, the communities that form around them, and the life course as whole—to a binary set of domains, values, and meaning: the domain *normal/abnormal*, the values *positive/negative*, and the meaning *everything's fine/something's wrong*.[14] In the cases I have examined, value partitioning occurs after or along with epistemic capture, though I would offer that value partitioning functions in these ways even when epistemic capture is not at play, such as when a diagnostic and/or prognostic result is more or less clear-cut.

There is a further prejudice at work here, however, and one which is perhaps primary or at least a lodestar. If one considers the sociocultural context in which "either something is wrong or everything is right" becomes meaningful, this sort of epistemic partitioning feeds upon and propagates ableism. By ableism, I mean the assumption that being able-bodied and "normal" is better than being disabled and "abnormal" and the many discriminations

[14] To be clear, by the term "domain," I mean it the sense of "a sphere of thought or action; field, province, scope of a department of knowledge, etc." OED, "domain, n." def. 4a. Put simply, I mean a domain as that framework which affords phenomenon interpreted within its scope meaning and does so in determinate or essential ways.

and oppressions people with disabilities face as a result of this assumption. In short, ableism refers to the privileging of able-bodiedness. As it functions in the cases under discussion, value partitioning is fundamentally ableist. It contributes to an ideology that devalues people with disabilities because it *narrows* how and what people know concerning how bodies and minds are, can, and should be. Value partitioning excludes and limits the epistemic space in which, and resources about which, people conceive of and judge the range and wellbeing of bodies and minds.

3.2. *Ableism and Epistemic Harm*

However, it is not just ableism in general that is to blame. Part of the reason the specific hermeneutical resources and processes *put to work* by and through GSTs take this binary partitioned form is because of *the ableist conflation* of experiences of disability with experiences of pain, suffering, and disadvantage. This assumption has many epistemic ramifications in terms of how people judge, interpret, and understand their own lives as well as that of others. What is more, this assumption has historically had and still has today many material effects, including a panoply of discriminations, oppressions, and historical injustices against people with disabilities across the globe (Erevelles 2011; Nielsen 2012). One of the reasons people with disabilities have been among the first targeted by various eugenic programs historically has not simply been a question of "fitness," but also of the fact that their lives are assumed to be fundamentally suffered—lives "no one would want" or, in the Third Reich's formulation, "life unworthy of life" (Garland-Thomson 2015a; Kittay 2016).

Because enormous value is tied to being normal and because negative health risks are tied, as if an ominous bow, to being abnormal, the knowledge produced by this epistemic framework is not animated by a simple desire to learn, but instead a charged desire to know—to definitively know on which of the two sides, normal or abnormal, one's child or oneself falls (Waldschmidt 2005). For many parents, this is the binary division upon which a *life worth living* or, at minimum, a *life enjoyed* falls. When considered in this light, *everything's fine/something's wrong* in fact means *my child is not disabled/my child might be or become disabled.* It is hard to overstate the psychosocial impact of uncritical belief in this binary division. Yet, as I hope to have made clear, it is only under the sway of ableism that something being "wrong" with one's child comes to mean that they are or will become "disabled" in a negative sense of that term.

In at least the cases under discussion, GSTs put to work a deeply problematic binary framework. This should give pause for proponents who suggest that the information produced by GSTs and the methods to interpret and communicate about them are in fact far more complex and diverse. Insofar as ableism is a bulwark of injustice and insofar as biomedical institutions and practitioners are committed to justice, epistemic capture and value partitioning result in epistemic harms that need to be addressed and remedied.

Anthropological and historical evidence suggests an extremely wide range of ideas and attitudes about the numerous forms of embodiment that today fall under the term "disability."[15] Even if the issue of epistemic capture in these cases were sufficiently addressed by, for example, withholding information concerning variants of unknown significance, insofar as the epistemic framework of GSTs involve value partitioning, such technology would still impede people from appreciating the diversity of forms of embodiment, health trajectories, and flourishing bodies, minds, and communities in terms other than *something's wrong/they might be or become disabled* or *everything's fine/they are not disabled*.

One might object that this is not a problem of the technology in question, but of the interpreter(s) of its output. I find this objection to fail because it inappropriately narrows the interpretative field in question to the particular epistemic state of individual agents: in the cases under discussion, parents and practitioners. But knowledge is fundamentally and irremediably social, and these technologies have been developed, propagated, refined, and interpreted at every step by humans and in the context of large-scale human institutions, such as the practice of modern medicine in general and the development of the HGP in particular.

Furthermore, these clinical contexts involve epistemic agents who are fundamentally asymmetrical with respect to their epistemic authority. Practitioners are experts and patients are not. People assume that if experts are telling them that there is a finding, this must be because this finding matters (otherwise it would not be mentioned). What is more, because doctors and institutions lend legitimacy to GSTs by using them and charging money for them, it is reasonable that patients will trust these technologies even when the results are, in fact, useless or potentially useless data with

[15] Instructively, few of these fit into ideas of normality or abnormality operative in the production and interpretation of genomic knowledge (Kasnitz and Shuttleworth 2001; Reid-Cunningham 2009). As debates over everything from deafness to neurodiversity evidence, such differing attitudes are alive and well today (Davis 2006; Mauldin 2016).

respect to promoting positive health outcomes. The fact that variants of unknown significance are of *unknown* significance is undermined by the default assumption that if they were not significant, they would not be communicated about and would not be part of the practice of GSTs.

But it is not just a question of how a given individual practitioner manages this authority. A practitioner who tries to counter this assumption is likely going to fail because it runs counter to the logic of communicating the results of a test, which is to say, a logic where information that has no actionable meaning is not a "result" at all. From the perspective of parents interviewed above, the fate of their child's life and wellbeing may ultimately be at stake. In these clinical contexts, the existential stakes desiccate all the force of "unknown" and transfer it to "significance." In short, patients hear information about these variants not in terms of *unknown* significance, but unknown *significance*.

To make matters more complicated, when it comes to interpreting sequencing results, providers can find themselves deferring to other experts—whether it be genetic counselors, technicians at the lab(s) where the sequencing was performed, or specialists of another sort. Although there are strong pushes for the increasing incorporation of genomic information into clinical settings, too many practitioners lack substantive knowledge about the current state of genomics (Houwink et al. 2012). This lack of expertise is yet another reason why value partitioning is such a pernicious effect of GSTs: the requisite knowledge to interpret genomic information in a nonbinary, nonableist way appears to be lacking not only for the majority of patients, but perhaps even for the majority of providers. I address how to rectify this issue in section 4 below.

One might also object that there is a third domain at play here: neither "something's wrong," nor "everything's fine," but that of the unknown, indeterminate, or ambiguous. This objection turns on treating the latter as its own category. On the contrary, I find the social scientific research cited above to instead suggest that parents in fact interpret indeterminate results as "negative," "most likely negative," or, perhaps most accurately, "not positive." Indeed, one of the effects of epistemic capture and value partitioning is to close down interpretive avenues that would better deal with the ambiguity that the information provided by GSTs in fact present.[16]

It is important to remember that patients invariably interpret medical information in existential terms. That is to say, the ultimate meaning of

[16] As Chris Lebron pointed out to me, this is surely a form of *disciplining* in Foucault's sense of the term (1979). I sadly do not have space to take up that line of interpretation.

biomedical information and knowledge is determined relative to the meaning of one's life and the various knowledge at one's disposal about it. Insofar as most people do not know that there can be health within illness (Lindsey 1996), that disability is often positive and is not the same as either disease or illness (Davis 2013), and other such evidence from disability communities, the process of epistemic capture and value partitioning at work in GSTs forces parents into one side or the other of its epistemic framework, rendering information that straddles the divide or shows the divide to be misleading difficult to understand.

This is especially problematic in light of the fact that far too much of the research on patient empowerment is carried out in an uncritical mode (Calvillo et al. 2015). That literature often assumes that the more medical knowledge and expertise patients gain, the better, never considering that the very concepts, epistemic frameworks, and other components of modern medical knowing and practice itself might themselves be problematic. When placed in the context of their development, production, use, and contexts of interpretation and meaning, the process of epistemic capture and value partitioning that biomedical technologies put to work rely upon and actively foster ableist intuitions, and it will take concerted critical work to combat these effects.

4. THE ETHICS OF SOCIAL EPISTEMOLOGY AT THE INTERSECTION OF BIOETHICS AND PUBLIC HEALTH

I said above that writing about biomedical technologies is an inherently political endeavor. It is so for many reasons, not least of which is the fact that many, if not most of the technologies discussed in academic journals of philosophy, sociology, anthropology, bioethics, and public policy are technologies that the vast majority of humans on Earth cannot access or to which they have limited access. For example, limiting the scope just to the United States, the basic structures of this settler nation-state not only fail to distribute basic goods such as healthcare services to all its citizens, but are also historically based in a market and political system built upon fundamentally unjust institutions such as slavery and upon the inequality of persons based upon considerations of race, ethnicity, sex, gender, sexuality, physical and mental ability, and so on (Beckert and Rockman 2016; Jay and Lyerly 2016). In many different respects, this has continued through to today (Alexander 2012; McWhorter 2017). What, then, does it mean for bioethicists to engage questions of injustice in the context of a larger system that is profoundly unjust, both historically and today?

I agree with Josephine Johnston and Eric Jungst when they write, "resolving the predictive uncertainties of genomic information is the professional responsibility of the biomedical community, just as clarifying the impact of global warming or assessing the risks of rising multidrug resistance is the responsibility of similar specialists" (Johnston and Juengst 2018). Yet, and as I am sure both of those authors would agree, the constitution of the "biomedical community" is far too narrow and those who have access to the benefits of biomedicine are far too few. The clinically-guided benefits of GSTs discussed in this paper are typically enjoyed not by an imaginary public of all citizens, but by a demographically small slice of the white, middle- to upper-middle class (Reardon 2018).

There is also the crucial and intimately related issue of reproductive rights. What does it mean to critique technologies that, in principle at least, offer more reproductive autonomy when—as this very article is being written—there is an all-out assault on reproductive rights in the United States? This includes lawsuits from multiple states specifically designed to get a hearing in the new Supreme Court to overturn *Roe v. Wade* (Smith 2019). In light of the work of the reproductive justice movement, how does one critique technologies that prima facie offer greater reproductive control (Ross and Solinger 2017)? And what does it mean to contest the categories of normality and abnormality when they help determine what insurance companies will or will not cover and what can be claimed as a harm or infringement in legal contexts (Campbell 2009)?

In short, critiques concerning the downsides of technologies such as GSTs that privileged groups can access and that historically oppressed groups cannot—and in many cases have been actively denied—could rightfully be charged as itself an exercise in privilege. There is much merit to this concern. In fact, this is a concern that all scholars, but especially those working in bioethics, public health, and other health-related fields, should reflect upon as a matter of course. However, I find that this critique—and ones like it—are still worth carrying out. Here are two reasons why.

First, to understand this paper as implying that we should ban or diminish access to GSTs is to fundamentally misconstrue the arguments I have put forward. My analysis has been restricted to demonstrating that the processes of epistemic capture and value partitioning are unjust in the context of GSTs when the epistemic framework(s) upon which they draw are indefensibly narrow. In other words, the normative weight of this paper turns primarily on the question of hermeneutic resources, a question that the work of Kristie Doston, among others, demonstrates to be of the utmost normative and practical import (Dotson 2012). My analysis, in other words,

is less a critique of GSTs or related biomedical technologies as such and more a critique of the *interpretative scenes* that such technologies stage and in and through which various clinical actors play. The agents in these scenes—both the providers and patients, as well as the technicians and other specialists who are part of the larger interpretive processes—can change its interpretive parameters. I have not here made any arguments denying that the epistemic frameworks of GSTs *could* be appropriately expanded and altered.[17] In short, the overarching point is as follows: the problem is less genetics or genomics and more how we interpret these bodies of knowledge.

Second, if one heeds the scholarship of those working at the intersection of disability and race, it becomes clear that combatting ableism without also combatting racism is as problematic and doomed to fail as combatting racism without combatting ableism (Ferri 2010; Bell 2011; Clare 2017). Arguably, it was Foucault who first argued that the historical rise of modern medicine, public health, and modern forms of governance operates though a "racialized eugenics" (Foucault 2008). That is to say, it operates through a principle that differentiates citizens through processes of racialization that function to decide "fitness," a normative ideal of ability, within a given population as well as processes of abilitation/debilitation that function to determine the differential "fitness" of people according to categories of racialization. In short, the binary "normal/abnormal" is of the same cloth as the fabric of racialization that has historically undermined the realization of egalitarian principles and the possibilities of distributive justice in this country (among other places across the globe). In this light, making decisions whose value is based upon the binary partitioning discussed above can be not simply ableist, but also racist—and even when made by those whose belong to social groups that have been historically oppressed.

Having said all this, a more practical concern remains: if one is convinced by my argument that GSTs carry out epistemic injustice against patients through epistemic capture and value partitioning, what is one to do? There are many possible responses, but I will here outline four pathways that could assist in removing or at least ameliorating the harms in question.

[17] Despite the salutary efforts of caring researchers, part of what is at issue here is the larger failure of translational work to be more inclusive and diverse with respect to public and clinical understandings of genetic variation and its links to human wellbeing (Burke et al. 2011).

1. Practitioners need to become adept in the hermeneutic resources of disability communities and other marginalized communities (Garland-Thomson 2012, 2015b). To take just one example with respect to intellectual disabilities, all practitioners should learn about the neurodiversity movement and incorporate its insights into how one thinks, talks about, and, where appropriate, treats cognitive differences. From a neurodiversity perspective, there is no "standard" brain or "default" way that one should think. There are those who are *neurotypical* in various ways and those who are *neurodiverse*. By refusing the binary between "normal" and "abnormal" and between "something's wrong" and "everything's fine," research that centers the experiences of people with disabilities can push back against the harms of epistemic capture and value partitioning.
2. Clinicians have a responsibility to recognize the authority of people with disabilities as experts about their own lives and communities and to elevate their voices (Reynolds 2018b). Medicine deals with biological processes, not with the meaning-making processes of human life as it is actually lived. The *meaning* of cerebral palsy, for example, will not be found in medical textbooks; it will be found by listening to those who live with cerebral palsy. Although the role that medical providers play is absolutely crucial in many respects, one of the more important ethical tasks that medical providers have in many cases is to defer to the appropriate expert knowledge: *those who have lived experience of whatever impairment is under discussion*. To be clear, this does not mean talking to one person and getting their "take" on "what it's like." For over four decades now, a rich literature has grown in the field of disability studies that critically incorporates first- and third-person knowledge about various experiences of disability (Davis 2013). This field spans the humanities and social sciences and can provide significant insight into various sorts of disability experience in a critical, reflective, and more balanced manner.
3. If the many institutions of medicine are to take the call for social justice and equity seriously, there must be political pressure to make those institutions—and those that surround and support it, from housing to food access, from education to fair labor, etc.—better care for and represent people's actual needs. Technologies like GSTs have emerged in a larger societal context with massive amounts of inequality and out of a centuries-long legacy of colonization and imperialism that touch nearly every place on the globe. There are many bodily differences

that do not automatically lead one to suffer or to be disadvantaged, but, given the world as we find it today, do in fact do require more support—In a just society that holds all humans to be equal, that support would be provided.

4. I agree with Koury et al. that the principles of evidence-based medicine must guide clinical decision-making, including decisions that involve genetic and genomic information. They write:

> Genomics is no different from any other scientific field except perhaps in the sheer volume of new information and technology expected to hit the health care market, and the fact that such information often has implications for the families of those who are tested. Although genomic medicine has been slow in adopting the principles of evidence-based medicine, it still needs to follow the principles of comparative effectiveness . . . the paucity of high-quality studies has contributed to the absence of evidence-based practice guidelines and to the differential uptake and reimbursement of these testing technologies in practice. (Khoury et al. 2008)

Evidence, including that from qualitative sociology, must bear on decisions ranging from how various types of genomic information are communicated to *whether* certain sorts of information are communicated at all. For example, while I appreciate the work of Lázaro-Muñoz et al. to provide a rigorous taxonomy of debates concerning return of results in genomics, the question of "unknown impact of RoR [return of results] on participants," as they phrase it, is not taken seriously enough (Lázaro-Muñoz et al. 2018). That empirical issue should, on my view, throw far more doubt on their suggestion—limited in that article to psychiatric genomics research—for providers to offer what they categorize as "likely clinically valuable findings."

More to the point, the analysis provided here suggests that the issue ultimately turns less on *which* findings are offered and more on *how* they offered; this *how* is not simply with respect to modes of interpersonal communication between providers and patients, important as that is, but also with respect to the epistemic frameworks at play in such clinical encounters. One implication of this study is that the latter concern may in fact be more decisive for health outcomes than the former.

In a study I find crucial to understand the ethical, epistemological, and sociopolitical stakes of GSTs, Werner-Lin et al. note that "novel diagnostic tools are often deployed before targeted therapies are developed, tested, or available" (Werner-Lin et al. 2019). That fact should cause far more pause as a notable body of research mounts suggesting that it is misguided

to think that more information is an unqualified good and that, to the contrary, it can in fact cause harm to patients in certain cases. Werner-Lin et al. continue, "this 'therapeutic gap' between the ability to conduct genetic sequencing and the ability to fully understand what the test results mean, much less what treatments to offer, leaves families with complex and unclear information they cannot act upon with confidence during pregnancy." And, I have suggested, this worry extends, at minimum, to pediatric contexts as well. To sufficiently address this issue will require far more research and analysis and must, as I have suggested, extend to interventions that go beyond the clinical space itself.

To recall a concern announced at the outset of this study, "biomedical technology" is a difficult object for epistemological inquiry, including that of GSTs more specifically. Despite its difficulties, it is crucial for medical institutions and society more generally to better understanding the epistemic processes and effects put to work by these technologies. Without such understanding, the increasing incorporation of genomic information into clinical settings runs the risk of inadvertently harming some of the very people it is, however inequitably, currently equipped to help. These are harms that can and should be addressed.[18]

REFERENCES

Alexander, Michelle. 2012. *The New Jim Crow: Mass Incarceration in the Age of Colorblindness*. Revised edition. New York: New Press.

Amundson, Ron. 2000. "Against Normal Function." *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences* 31 (1): 33–53.

Anderson, J. A., M. S. Meyn, C. Shuman, R. Zlotnik Shaul, L. E. Mantella, M. J. Szego, S. Bowdin, et al. 2016. "Parents Perspectives on Whole Genome Sequencing

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for Their Children: Qualified Enthusiasm?" *Journal of Medical Ethics* 43: 535–39. https://doi.org/10.1136/medethics-2016-103564.

Barnes, Elizabeth. 2016. *The Minority Body*. New York: Oxford University Press.

Bashford, Alison, and Philippa Levine. 2010. *The Oxford Handbook of the History of Eugenics*. Oxford: Oxford University Press.

Beckert, Sven, and Seth Rockman. 2016. *Slavery's Capitalism: A New History of American Economic Development*. Philadelphia: University of Pennsylvania Press.

Bell, Christopher M. 2011. *Blackness and Disability: Critical Examinations and Cultural Interventions, Forecaast*. East Lansing: Michigan State University Press.

Blease, Charlotte, Havi Carel, and Keith Geraghty. 2017. "Epistemic Injustice in Healthcare Encounters: Evidence from Chronic Fatigue Syndrome." *Journal of Medical Ethics* 43 (8): 549–57. https://doi.org/10.1136/medethics-2016-103691.

Burke, W., K. A. Edwards, S. Goering, S. Holland, & S. B. Trinidad (Eds.) 2011. *Achieving Justice in Genomic Translation: Re-Thinking the Pathway to Benefit*. Oxford: Oxford University Press.

Calvillo, Jorge, Isabel Roman, and Laura M. Roa. 2015. "How Technology is Empowering Patients? A Literature Review." *Health Expectations* 5: 643–52. https://doi.org/10.1111/hex.12089.

Campbell, Fiona Kumari. 2009. *Contours of Ableism: The Production of Disability and Abledness*. New York: Palgrave Macmillan.

Carel, Havi, and Ian Kidd. 2014. "Epistemic Injustice in Healthcare: A Philosophical Analysis." *Medicine, Health Care and Philosophy* 17 (4): 529–40. https://doi.org/10.1007/s11019-014-9560-2.

Clare, Eli. 2017. *Brilliant Imperfection: Grappling With Cure*. Durham, NC: Duke University Press.

Clark, Michelle M., Zornitza Stark, Lauge Farnaes, Tiong Y. Tan, Susan M. White, David Dimmock, and Stephen F. Kingsmore. 2018. "Meta-Analysis of the Diagnostic and Clinical Utility of Genome and Exome Sequencing and Chromosomal Microarray in Children with Suspected Genetic Diseases." *NPJ Genomic Medicine* 3 (1): 16. https://doi.org/10.1038/s41525-018-0053-8.

Coady, David. 2017. "Epistemic Injustice as Distributive Injustice." In *Routledge Handbook on Epistemic Injustice*, edited by Ian James Kidd, José Medina, and Gaile Pohlhaus, 61–68. London: Routledge.

Daniels, Norman. 1979. "Rights to Health Care and Distributive Justice: Programmatic Worries." *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine* 4 (2): 174–91. https://doi.org/10.1093/jmp/4.2.174.

Davis, Lennard J. 1995. *Enforcing Normalcy: Disability, Deafness, and the Body*. Brooklyn, NY: Verso.

———., ed. 2006. *The Disability Studies Reader*. 2nd ed. New York: Routledge.

———. 2013. *The Disability Studies Reader*. 4th ed. New York: Routledge.

Dotson, Kristie. 2012. "A Cautionary Tale. On Limiting Epistemic Oppression." *Frontiers: A Journal of Women Studies* 33 (1): 24–47. https://doi.org/10.5250/fronjwomestud.33.1.0024.

Erevelles, Nirmala. 2011. *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic*. New York: Palgrave Macmillan.

Ferri, Beth. 2010. "A Dialogue We've Yet to Have: Race and Disability Studies." In *The Myth of the Normal Curve*, edited by Curt Dudley-Marling and Alex Gurn, 139–50. New York: Peter Lang.

Foucault, Michel. 1979. *Discipline and Punish: The Birth of the Prison*. New York: Vintage Books.

———. 2008. *The Birth of Biopolitics: Lectures at The Collège De France: 1978–79*. London: Palgrave Macmillan.

Fricker, Miranda. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.

Garland-Thomson, Rosemarie. 2012. "The Case for Conserving Disability." *Journal of Bioethical Inquiry* 9 (3): 339–55. https://doi.org/10.1007/s11673-012-9380-0.

———. 2015a. "Eugenics." In *Keywords for Disability Studies*, edited by Rachel Adams, David Serlin, and Benjamin Reiss, 215–26. New York: NYU Press.

———. 2015b. Human Biodiversity Conservation: A Consensual Ethical Principle. *The American Journal of Bioethics* 15 (6): 13–15. https://doi.org/10.1080/15265161.2015.1028663.

Grob, Rachel, Scott Roberts, and Stefan Timmermans 2018. Families' Experiences with Newborn Screening: A Critical Source of Evidence. *Hastings Center Report* 48: S29–S31.

Hayeems, Robin Z., Jasmin Bhawra, M. Kate Tsiplova, Stephen Meyn, Nasim Monfared, D. Sarah Bowdin, James Stavropoulos, et al. 2017. "Care and Cost Consequences of Pediatric Whole Genome Sequencing Compared to Chromosome Microarray." *European Journal of Human Genetics* 25 (12): 1303–12. https://doi.org/10.1038/s41431-017-0020-3.

Hookway, Christopher. 2010. "Some Varieties of Epistemic Injustice: Reflections on Fricker." *Episteme* 7 (2): 151–63.

Houwink, Elisa J. F., Lidewij Henneman, Myrte Westerneng, Scheltus J. van Luijk, Martina C. Cornel, Jan Geert Dinant, and Cees van der Vleuten. 2012. "Prioritization of Future Genetics Education for General Practitioners: A Delphi Study." *Genetics in Medicine* 14 (3): 323–29. https://doi.org/10.1038/gim.2011.15.

International Human Genome Sequencing Consortium, Eric S. Lander, Lauren M. Linton, Bruce Birren, Chad Nusbaum, Michael C. Zody, Jennifer Baldwin, et al. 2001. "Initial Sequencing and Analysis of the Human Genome." *Nature* 409: 860. https://doi.org/10.1038/35057062. https://www.nature.com/articles/35057062#supplementary-information.

Jay, Bethany, and Cynthia Lynn Lyerly. 2016. *Understanding and Teaching American Slavery*. Madison: University of Wisconsin Press.

Johnston, Josephine, and Eric Juengst. 2018. "Are Parents Really Obligated to Learn as Much as Possible about Their Children's Genomes?" *Hastings Center Report* 48: S14–S15.

Kahneman, Daniel. 2013. *Thinking, Fast and Slow*. New York: Farrar, Straus and Giroux.

Kasnitz, Devva, and Russell P. Shuttleworth. 2001. "Anthropology in Disability Studies". *Disability Studies Quarterly* 21 (3). https://doi.org/10/gfkmbd.

Khoury, Muin J., Al Berg, Ralph Coates, James Evans, Steven M. Teutsch, and Linda A. Bradley. 2008. "The Evidence Dilemma in Genomic Medicine." *Health Affairs* 27 (6): 1600–11. https://doi.org/10.1377/hlthaff.27.6.1600.

Kidd, Ian James, José Medina, and Gaile Pohlhaus, eds. 2017. *Routledge Handbook on Epistemic Injustice*. London: Routledge.

Kittay, Eva. 2016. "Deadly Medicine: Project T4, Mental Disability, and Racism." *Res Philosophica* 93 (4): 715–41.

Koopman, Colin. Forthcoming. "Coding the Self: The Infopolitics & Biopolitics of Genetic Sciences." *The Hastings Center Report* Special Issue.

Kukla, Rebecca. 2015. "Medicalization, 'Normal Function', and the Definition of Health." In *The Routledge Companion to Bioethics*, edited by John D. Arras, Elizabeth Fenton, and Rebecca Kukla, 515–30. New York: Routledge.

Lázaro-Muñoz, G., M. S. Farrell, J. J. Crowley, D. M. Filmyer, R. A. Shaughnessy, R. C. Josiassen, and P. F. Sullivan. 2018. "Improved Ethical Guidance for the Return of Results from Psychiatric Genomics Research." *Molecular Psychiatry* 23 (1): 15–23. https://doi.org/10.1038/mp.2017.228.

Lindsey, Elizabeth. 1996. "Health within Illness: Experiences of Chronically Ill/Disabled People." *Journal of Advanced Nursing* 24 (3): 465–72. https://doi.org/10.1046/j.1365-2648.1996.02135.x.

Lombardo, Paul A., ed. 2011. *A Century of Eugenics in America from the Indiana Experiment to the Human Genome Era*. Bloomington: Indiana University Press.

Maina, Ivy W., Tanisha D. Belton, Sara Ginzberg, Ajit Singh, and Tiffani J. Johnson. 2018. "A Decade of Studying Implicit Racial/Ethnic Bias in Healthcare Providers Using the Implicit Association Test." *Social Science & Medicine* 199: 219–29. https://doi.org/10.1016/j.socscimed.2017.05.009.

Mauldin, Laura. 2016. *Made To Hear: Cochlear Implants and Raising Deaf Children*. Minneapolis: University of Minnesota Press.

McWhorter, Ladelle. 2017. "From Scientific Racism to Neoliberal Biopolitics Using Foucault's Toolkit." In *The Oxford Handbook of Philosophy and Race*, edited by Naomi Zack, 282–93. Oxford: Oxford University Press.

Miller, David T., Margaret P. Adam, Swaroop Aradhya, Leslie G. Biesecker, Arthur R. Brothman, Nigel P. Carter, Deanna M. Church, et al. 2010. "Consensus Statement: Chromosomal Microarray is a First-Tier Clinical Diagnostic Test for Individuals with Developmental Disabilities or Congenital Anomalies." *American Journal of Human Genetics* 86 (5): 749–64. https://doi.org/10.1016/j.ajhg.2010.04.006.

Mills, Charles. 2005. ""Ideal Theory" as Ideology." *Hypatia* 20 (3): 165–84.

Nielsen, Kim E. 2012. *A Disability History of the United States, Revisioning American History*. Boston: Beacon Press.

Pohlhaus, Gaile. 2012. "Relational Knowing and Epistemic Injustice: Toward a Theory of Willful Hermeneutical Ignorance." *Hypatia* 27 (4): 715–35. https://doi.org/10.1111/j.1527-2001.2011.01222.x.

Reardon, Jenny. 2018. *The Postgenomic Condition: Ethics, Justice, and Knowledge after the Genome*. Chicago: University of Chicago Press.

Reid-Cunningham, Allison Ruby. 2009. "Anthropological Theories of Disability." *Journal of Human Behavior in the Social Environment* 19 (1): 99–111. https://doi.org/10/d9m87r.

Reiheld, Alison. 2010. "Patient Complains of . . . : How Medicalization Mediates Power and Justice." *International Journal of Feminist Approaches to Bioethics* 3 (1): 72–98. https://doi.org/10.2979/FAB.2010.3.1.72.

Reynolds, Joel Michael, and David Peña-Guzmán. 2019. "The Harm of Ableism: Medical Error and Epistemic Injustice." *Kennedy Institute of Ethics Journal* 29 (3): 205–42.

Reynolds, Joel Michael. 2018a. "Renewing Medicine's Basic Concepts: On Ambiguity." *Philosophy, Ethics, and Humanities in Medicine* 13 (1): 8.

———. 2018b. "Three Things Clinicians Should Know About Disability." *AMA Journal of Ethics* 20 (12): E1181–E1187. https://doi.org/10.1001/amajethics.2018.1181.

Ross, L., & Solinger, R. 2017. *Reproductive Justice: An Introduction*. Oakland, CA: University of California Press.

Silvers, Anita. 1998. "Fatal Attraction to Normalizing: Treating Disabilities as Deviations from "Species-Typical" Functioning." In *Enhancing Human Traits: Ethical and Social Implications*, edited by Erik Parens, 95–122. Washington, DC: Georgetown University Press.

Smith, Kate. 2019. "Abortion would automatically be illegal in these states if Roe v. Wade is overturned." CBS Interactive Inc. Accessed April 30. https://www.cbsnews.com/news/new-abortion-law-abortion-clinic-automatically-illegal-roe-v-wade-overturned-2019-04-22/.

Timmermans, Stefan, and Mara Buchbinder. 2010. "Patients-in-Waiting: Living Between Sickness and Health in the Genomics Era." *Journal of Health and Social Behavior* 51 (4): 408–23. https://doi.org/10.1177/0022146510386794.

Waldschmidt, Anne. 2005. "Who is Normal? Who is Deviant? 'Normality' and 'Risk' in Genetic Diagnostics and Counseling." In *Foucault and the Government of Disability*, edited by Shelley Tremain, 191–207. Ann Arbor: University of Michigan.

Washington, Harriet A. 2008. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*. New York: Anchor Books.

Werner-Lin, Allison, Judith L. M. McCoyd, and Barbara A. Bernhardt. 2019. "Actions and Uncertainty: How Prenatally Diagnosed Variants of Uncertain Significance Become Actionable." *Hastings Center Report* 49: S61–S71. https://doi.org/10.1002/hast.1018.

Werner-Lin, Allison, Sarah Walser, Frances K. Barg, and Barbara A. Bernhardt. 2017. "'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 (2): 444–51. https://doi.org/10.1002/ajmg.a.38042.

Wolfe, Patrick. 2006. "Settler Colonialism and the Elimination of the Native." *Journal of Genocide Research* 8 (4): 387–409. https://doi.org/10.1080/14623520601056240.