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Biomedicalization and the New Science of Race

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In the 1990s–2000s, developments in genetic science and technology ushered in a new era of DNA research focused on "genomics" – the science of DNA sequences – and a massive drive to create technoscientific medicine for the world. Throughout these developments, debates about race dominated the large-scale sequencing efforts that underpinned research and development in the USA. In particular, the US National Institutes of Health (NIH) led the broadest international efforts to simultaneously characterize human biodiversity with genomics and redefine biomedical understandings of race. In this chapter, I explore how a new medical science conducted under the auspices of Western preoccupations about human difference led to critical developments in biomedicalization, namely new forms of what Rose (2007) calls "technologization" and "responsibilization" – the growth and expansion of technological and moral imperatives in science and society – that have placed the definition and management of an increasing number of social processes in the hands of a narrow corridor of DNA science.

I begin the chapter by discussing the theoretical implications of a race-based and genetics-based biomedicalization associated with classification and identification processes of genetics and race. I then investigate biomedicalization in four domains – racial genome projects, health disparities research, gene–environment research and personal genomics. These four areas cement the appropriation of essentialist notions of life in medical science and their legitimization in public health governance. They also obfuscate the social factors contributing to social processes of race such as institutionalized racism and racial inequality and suggest the dominance of a sociologically inadequate framework for assessing and managing the relationship between health and the environment. Finally, I demonstrate that groups, as much as individuals, are politically disadvantaged by these present developments in biomedicalization, especially around issues of group formation and political advocacy.

Medicalization Meets Racialization

A vast sociological literature has emerged to track the ways medicine has expanded its authority to define and govern social processes (cf. Conrad 1992, 2000; Lock 2004). Studies of medicalization, or "the processes through which aspects of life previously outside the jurisdiction of medicine come to be construed as medical problems," show that these processes are intensifying and being transformed "from the inside out" by new technosciences (Clarke et al. 2003:162). In the present genomic era, medicine is increasingly aimed at personal biology and health, sold to the individual based on privately profiled information and distributed through informatic networks connected to intricate research and health databases (Atkinson, Glasner and Lock 2009; Schnittker 2009; Conrad and Stults 2010; Clarke et al. 2010). Internet-based genetic health communities have sprung up as test-buyers struggle to interpret their personal risk profiles and plan their biological futures (Miah and Rich 2008; Reardon 2009; Rabinow and Rose 2006). Thus, scholars who previously illuminated the rapid expansion of the role of medicine in everyday life via physicians' professional expansion, the rise of health social movements and physicians' organizational claims-making have now shifted to studying the way emerging technosciences are changing the nature of that expansion (Clarke et al. 2003; Conrad 2005). New institutions like the pharmaceutical industry, biotechnology and managed care have become major players in the distribution of medical resources and health policy (Moynihan and Henry 2006; Williams, Gabe and Davis 2008; Pollock 2011). Medicalization is now so technologized that it may be better viewed in some instances as "biomedicalization" (Clarke et al. 2003; also see Bell and Figert 2015, Chapter 1, this volume).

The postwar growth of a molecularized "Biomedical TechnoService Complex" has brought a distinctly genetic form of medicalization (Clarke et al. 2003) – a "geneticization" of social processes in which genetics has become a central lens in interpreting their meaning (Lippman 1991, 1992) and in which genetic findings have displaced prior sociological explanations for those processes (Duster 2006; Goodman 2007). The idea that genetics are responsible for processes like homosexuality or learning disabilities (Hedgecoe 2000; Rapp 2011) has created essentialist notions in the broader society that human traits and behaviors are innate and immutable (Hubbard and Wald 1999; Kay 2000). The development of genetic tests for common traits and behaviors has furthered the belief that individuals must move beyond acknowledgment of their biological destiny and take responsibility for it (Rose 2007). In this environment, the individual management of people's own health through consumptive practices has thus not only ensured but also comes with a moral imperative (Clarke et al. 2003). As Rose argues, the rise of the new genetic sciences ushers in a technologization and responsibilization unlike any seen before:

> For even if no revolutionary advances in treatment are produced, once diagnosed with susceptibilities the asymptomatic individual is enrolled

> for a life sentence in the world of medicine – of tests, of drugs, of self-examination and self-definition as a prepatient suffering from a proto-sickness. (Rose 2007:94)

Those that identify as "at-risk" for a specific disease or share a similar chromosomal code are compelled to interact with each other based on their genetic profiles. As they co-manage their somatic selves, new "biosocial" identities arise that are formulated around genetic practices (Rabinow 1996). Such combinations of technologization and responsibilization make for a tenacious form of biomedicalization especially when connected with race.

Racialization is another process that becomes an important aspect to understand in relationship to biomedicalization. Racialization, the process by which social processes are assigned racial meaning, is not new (Omi and Winant 1994). But in the contemporary moment racialization intersects with geneticization and thereby expands biomedicalization's imperative to interpret life as genetically determined and thus in dire need of biomedical expertise. The simultaneous racialization of genetics and the geneticization of race encourages even stronger essentialist forms of categorization – the process by which people are grouped according to perceived similarities in traits and behaviors – and identification – the process by which individuals identify with social categories (Daynes and Lee 2008). In today's world, categories that are ascribed to individuals and groups are reconstituted in stark DNA terms (Bliss 2011; Roberts 2011). Individuals and groups internalize these categories and interact based upon a biologically essentialist notion of what a human is and what their own selves are all about.

In this chapter, I examine the ways classification in public health, government-sponsored industry and the public creates a system in which people are recognized by and recognize themselves in terms of new biomedical technologies of the gene. This analysis reveals an even more autonomized and marketized imperative at play than that witnessed before the genomic turn in which a highly rarified technoscientized corner of the medical profession drives the medicalization of social processes, and individuals and groups are prevented from seeing the social and political conditions affecting their lives (Bliss 2013).

Biomedicalizing Race

In the latter half of the twentieth century, as genetic technologies proliferated and new genetic sciences assumed responsibility for defining race, meanings of race rapidly changed in science and society. Starting in the postwar period, the notion that race was a social and political construction took hold within the sciences, displacing earlier definitions that race was biologically determined (Morning 2011). The policies of Affirmative Action in public institutions and legal protections, and campaigns for inclusion of minorities in public health, created an environment in which race began to be viewed not as a biological difference but in terms of institutionalized discrimination, socio-

status and neighborhood effects (Krieger 2011). Yet with the advent of recombinant DNA science in the 1990s, the question of race's biological foundation reemerged (El-Haj 2007). Conceptual debates between evolutionary scientists about the biological foundations of race that had continued to unfold below the radar of major government institutions and the public were once again more publicly debated. Placed within this context, they arose to become public health priorities and policies (Reardon 2005).

The first decade of the twenty-first century witnessed a proliferation of scientific discourse on the biological definition, validity and utility of race (Braun 2002; Hunt and Megyesi 2008; Williams 2011). From the frontiers of genetic science, scientists began exploring how new technologies would affect prior notions of ancestry and evolution (Bliss 2012; Fujimura and Rajagopalan 2011). In addition, public health departments across the world partnered with pharmaceutical and biotech companies in search of new biological models for understanding racial health disparities (Fullwiley 2007a, 2007b; Lee 2007; Whitmarsh 2008). Federal agencies like the NIH and the Food and Drug Administration (FDA) spurred scientific innovation by funding lines for research into racial drug dosage disparities and biomarkers (Bliss 2009), while health organizations co-sponsored race-based clinical trials (Kahn 2012). The consequence of all of these discussions and partnerships was that the social object of race was drawn into the realm of technoscience and medicine, becoming property of the genetic domain and not of social analysis or policymaking.

Nowhere was this shift more apparent than in the burgeoning genetic subfield of genomics. Genomics launched in the late 1980s with a project to map the human genome. At the start of the project, the field did not examine or even debate race (Jackson 2000). Rather, it treated all human DNA as "equal." The Human Genome Project's reference genome was comprised of DNA samples of convenience solicited from various regions of the world (Bliss 2012). In the opening years of the project, its leaders did not participate in public health debates over whether to use federal race standards in research and the clinic (Bliss 2012).

Yet, in the early 1990s, the leading agencies of the US Public Health Department, such as the Department of Health and Human Services (HHS), the NIH and Centers for Disease Control and Prevention (CDC), began to make the implementation of federal race classifications a public health priority. These agencies created policies requiring researchers to use federal race categories in all publicly funded research (NIH 1993; also see CDC 1993; Shim et al. 2015, Chapter 3, this volume). In response, genomic researchers began to reflect on the relevance of race to their science and their science to race. The Human Genome Diversity Project, originally conceived as a diversity-focused complement to the Human Genome Project, criticized genomics for proliferating a dangerous biomedical form of Eurocentrism (Roberts 1992; UNESCO 1994).

The Polymorphism Discovery Resource, formed in 1997 by a cadre of Human Genome Project chief scientists, assumed the federal mandate to create racially apportioned sample sets based on the federal race classifications (Collins, Brooks and Chakravarti 1998). When the leaders of the Human Genome Project began to bring the project to a close in 2000, they started planning the next major global project with project directors from around the world. They decided to base their project for the new millennium, the International HapMap Project, on the same US federal race standards about which genomic science formerly had nothing to say (Bliss 2012). The result was that they established and became the voices of a new science of race.

An important result of the biomedicalization of race was that as scientific projects became racialized and race became geneticized, the moral imperative to biomedicalize race amplified among the elite community of scientists responsible for its biomedicalization. As Eric Lander, leader of the Human Genome and HapMap projects, and founding director of the Broad Institute, Millennium Pharmaceuticals, maintained, "If we shy away and don't record the data for certain populations, we can't be sure to serve those populations medically" (Wade 2001). Lander directed the field into the territory covered by projects like the NIH's US$33 million heart disease study and US$22 million cancer study focused on African Americans, where the imperative to use race in biological terms was not only assumed, but equated with and couched within a language of social justice. Genomic leaders promised to create racial health equity, and thus social equality, through research inclusion. They spoke of inclusion in genome projects as a kind of health-focused Affirmative Action wherein groups would be targeted as racial groups until more personalized medical technologies were available.

The moral imperative rhetoric of the scientists is also apparent in comments made by collaborators in the NIH Pharmacogenomics Research Network. In a series of policy pieces published in the field's flagship journal *Genome Biology* and the *New England Journal of Medicine*, Pharmacogenomics Research Network scientists argued, "A 'race-neutral' or 'colorblind' approach to biomedical research is neither equitable nor advantageous, and would not lead to a reduction in disparities in disease risk or treatment efficacy between groups" (Risch et al. 2002:A17). Like Lander, these pharmaceutically focused project directors popularized the belief "that ignoring race and ethnic background would be detrimental to the very populations and persons that this approach allegedly seeks to protect" (Burchard et al. 2003:1174).

As the field turned its sights toward gene–environment interactions and whole-genome sequencing, more leading scientists echoed the sentiment that biomedicine needed to use race "as a starting point" (Burchard et al. 2003:1174). Amid the launch of two major international sequencing projects, the 1000 Genomes whole-genome sequencing project and the function-mapping ENCODE Project, then-Director of the NIH National Human Genome Research

Institute (NHGRI), Francis Collins, argued that scientists had to take subjects' race into account in order to characterize health and illness:

> We need to try to understand what there is about genetic variation that is associated with disease risk, and how that correlates, in some very imperfect way, with self-identified race, and how we can use that correlation to reduce the risk of people getting sick. (Quoted in Henig 2004)

Collins also claimed that genomics was the field best positioned to study race in an ethical manner:

> I think our best protection against [racist science] – because this work is going to be done by somebody – is to have it done by the best and brightest and hopefully most well attuned to the risk of abuse. That's why I think this has to be a mainstream activity of genomics, and not something we avoid and then watch burst out somewhere from some sort of goofy fringe. (Quoted in Henig 2004)

In launching new projects to the public and arguing for the field's responsibility as a leading science of biomedicine and public health, genome scientists coined a new kind of responsibilization more stringent and essentialist than ever before. From here on, doing something about race would mean not only understanding it from a biomedical perspective, but specifically studying it with DNA science. Genomic leaders posited themselves both as ethical stewards for the public in matters having to do with race and as models for the use of new biomedical knowledge about race in the construction of biomedical apparatuses with public health ramifications (Bliss 2011). They simultaneously created the content of that knowledge and the moral framework for using the knowledge and subsequently publicized it to the world.

Biomedicalizing Disparity

Health disparities research is a related biomedical domain that has experienced racialization matched with a rapid and stark geneticization. When the field of health disparities science arose in the late 1980s and early 1990s (Carter-Pokras and Baquet 2002; Braveman 2006), genomics was busy with its own launch of the Human Genome Project. Just as they initially ignored the institutionalized of federal race categories across US public health in the form of minority inclusion policies in all publicly funded research, the new genetic sciences took no notice of the growing efforts to implement a health disparities framework in biomedical research. Thus disparities research developed with a focus on social epidemiological methodologies and environmental factors, including the critical interrogation of what was then defined as social categories like race (Krieger 2005; James 2009).

Yet, at the close of the Human Genome Project in 2000, the NIH began to reexamine health disparities from a more resolutely biological standpoint by bringing genomic science to bear. The NIH began by mandating minority community consultation in all new genetic studies (NIH 2000) and instituting trans-institute and institute-specific Strategic Research Plans to Reduce and Ultimately Eliminate Health Disparities from a genomic angle (see, for example, NHGRI 2004). These strategic plans effectively geneticized all of the major research funding agencies by stating that the new priority issue of health disparities research would involve the release of funds for genomic research. A total of US$1.3 billion was issued to federal institutes that would dually use a genomics and racial health disparities approach. The HHS and Institute of Medicine (IOM) also put their stamps of approval on the newly minted "health disparities genomics" approach by circulating their own initiatives to eliminate racial and ethnic disparities (HHS 1998; IOM 2002). By 2003, genetics and health disparities were tightly coupled across America's mainstay biomedical institutions.

The characterization and study of health disparities became so ensconced "in the trenches" of emerging genomic science that the HHS turned to the production of race-based medicine as a salve for health inequities. Genome scientists lauded the inclusionary aspects of race-based drug development at the same time as they sung its praises for its potential to save drug makers billions of dollars in clinical trials expenses (Stolberg 2001). As Genaissance Pharmaceuticals' Gualberto Ruaño argued, in a genetically and racially retrofitted biomedicine "efficacy could be proven in small cohorts instead of populations in the thousands" (Weiss 2000:A1). Ruaño and other leading drug makers equated race-based medicine with access to life-saving therapies that racial minorities would otherwise not obtain (also see Goldstein and Weiss 2003).

The FDA has required drug makers to use federal race categories in clinical trials of new drugs since 1998 (see FDA 1998). Yet, its 2005 approval of the race-based medicine BiDil signaled the crystallization of the US government's moral imperative to use technoscience as the ultimate resource for social processes associated with race and inequality even, as I show, at the expense of careful science (Bliss 2013). BiDil is a fixed-dose combination of a generic antihypertensive and a generic vasodilator that was developed solely for use in people of African descent. The ethics of this more expensive combination of two safe and efficacious generics was debated immediately (Kahn 2012). However, after a blacks-only randomized clinical trial demonstrated a 43 percent relative one-year mortality decrease in research subjects, the drug was slated for approval without further debate or research (Temple and Stockbridge 2007).

BiDil's "success" cannot be attributed to a successful race-based clinical trial, because drug makers had already proved that its components worked in all populations. BiDil was successful for the same reasons of responsibilization

witnessed in the case of racial genome projects, where scientists appropriated social justice language and targeted racial advocacy groups to popularize their products. BiDil's makers were able to recruit the most powerful race-based advocacy organizations to support their cause, thereby sedimenting the moral imperative to biomedicalize health disparities and race across governance and within the public (Rusert and Royal 2011).

Throughout its clinical trials, representatives of the National Association for the Advancement of Colored People (NAACP), the Association of Black Cardiologists and the premiere African American health advocacy organization, the National Medical Association, publicized the benefits BiDil would have for rectifying racial health disparities. The NAACP went so far as to donate US$1.5 million to BiDil's maker, NitroMed, for three years of exploratory health disparities research (Rusert and Royal 2011). As BiDil's principal scientist and patent-holder, Jay Cohn, remarked, revealing the prevailing sentiment in science, public health and the extant advocacy leadership:

> Here we have the black community accepting the concept that African Americans need to be studied as a group, and then we have the science community claiming that race is dead ... It seems to me absolutely ludicrous to suggest that this prominent characteristic that we all recognize when we look at people should not be looked at. (Quoted in Stolberg 2001)

Cohn's statement exposed the extent to which scientists, policymakers and the public supported the biomedicalization of health disparities. To them, race-based pharmacogenomics was the most race-aware weapon against health disparities, and thus the only truly socially responsible choice in addressing social processes of inequality.

In the wake of BiDil's 2005 approval, the FDA and the American College of Medical Genetics have petitioned drug makers to reanalyze their blockbuster drugs – drugs that make over US$1 billion in revenue per year – using federal race categories. The HHS has also partnered with a range of regulatory agencies, health justice groups and community-based organizations in support of race-based medicine (Kahn 2013). Statements from a representative of the National Minority Health Month Foundation further express the moral tone of this position:

> Underrepresentation of African Americans in clinical studies might partially explain the development of a standard treatment for heart failure that has proved to be less effective for them ... Race may be the coarsest of discriminators, but it now has proven life saving potential for heart-failure patients. The evidence that convinced the FDA predicts a dramatic increase in black patients' survival rate. (Puckrein 2006:371–2)

Racial advocacy organizations have since further coalesced in support of accepted biomedical definitions of race and set their political sights on fighting

disparities from a biomedical angle. Exclusion from genomics research has become the new target of minority justice campaigns.

Even racial advocates most known for their work on the sociological factors that contribute to inequality have come on board the genomics bandwagon. In a spate of mini-series and television shows, famed African American Studies scholar Henry Louis Gates, Jr has featured race-based genomics in his recent efforts to draw critical attention to racial inequality in the USA. Gates first loaned his intellectual and political celebrity to a two-part mini-series that mapped the genealogies of famous African Americans, called "African American Lives."[1] This series popularized genetic ancestry tests that assign continental origins to personal DNA, thereby creating a racial DNA profile with which to redefine a person's racial ancestry in genetic terms. Gates has since launched his own line of genetic ancestry tests that he has used for his prime-time television series "Faces of America."[2] Gates is also a board member of a pharmacogenomics company that targets diseases in people of African descent. Gates has not only put his money where his mouth is, but also put his body into his message, becoming the first African American to have his whole genome sequenced. Gates' efforts illuminate how the moral imperative associated with contemporary constructions of race and disparity reconfigures biomedicalization in deeply essential ways that draw on a personal and individual sense of responsibility (Bliss 2013).

Commodification has also proven fundamental to the new biomedicalization, as scientists whose research or products are simultaneously academic, industry and government sponsored have created therapies and technologies that they characterize as social justice weapons and use across these domains in the service of profit to biomedical and pharmaceutical companies. Successful political framing of therapies and technologies like BiDil generates chains of legitimacy, authority and monetary gain (Bliss 2013). For example, when another "blacks only" clinical trial of the race-based pharmacogenomic beta-blocker Bystolic showed efficacy in a study population of self-identified blacks, the FDA approved its maker, Forest Pharmaceuticals, for further race-specific trials of Mexican Americans. Forest Pharmaceuticals then went on to file a number of race-specific patents for new drug applications (Kahn 2009). The president of the Association of Black Cardiologists, Paul Underwood, would later herald the Association's support for Bystolic, stating: "We're excited to add another therapeutic tool to the armamentarium in the treatment of high blood pressure in African-Americans" (British Cardiovascular Society 2012). The Association of Black Cardiologists and other minority advocacy groups have continued to petition insurance companies to place race-based medicine on their formularies, and target minority physicians to prescribe them.

The result of all of this is that a number of international bioethics advocates have now asked pharmaceutical companies to create race-based medicine for the developing world as a stopgap solution to what they refer to as the growing

"genomic divide" between regimes in the global North and South. Some have even voiced support for drug makers to investigate "whether their unsuccessful chemical combinations [can be] resuscitated" and repackaged for distribution in markets of the global South (Daar and Singer 2006). These ethicists recommend racial analysis "to perform a sort of economic triage to focus on those for whom the test is most likely to produce a useful result" (Kahn 2009:82). Framing race-based drugs as a necessary shortcut to leveling the playing field, they encourage the fight for rights and resources through the further production and consumption of pharmacogenomics. Such neoliberal strategies plug racialization and geneticization into uneven market dynamics, effectively allowing market forces to determine how health disparities will be handled and how race will be defined.

All these changes create a highly racialized transnational biomedical system, replete with racialized databases, protocols and standards in the service of biomedicalization – a system in which the questions asked and answers sought are entirely focused on the body. The sociological concerns with transgenerational health effects, institutionalized forms of discrimination and social environments disappear from the research and debate. The quality of food supplies in various neighborhoods, discrimination-related stress, access to jobs with clean and safe working environments and items that cannot fit on a genomic "microarray" assay are but some of the issues that are pushed out from under the scientific gaze of biogenetics.

This new form of biomedicalization also means that systemic racialization and geneticization are more than the scientific sum of their parts. Social processes associated with health disparities and racial inequality are not only cast as race-related or genetic, they are imbued with a technologization and responsibilization that only allow for genomic biomedical solutions, such as pills and genetic tests. Neither the state nor the public holds any responsibility for health disparities in this moral framework beyond facilitating the work of genomic science. Government agencies fund it, while the public consumes it. Genomics is the great fixer.

Biomedicalizing the Environment

The combined racialization and geneticization of race, and conceptions and approaches to health disparities research, have implicated another object of biomedicalization: that of the environment. The past decade witnessed a turn in genomic science toward study of gene–environment interactions, epigenetics and translational medicine (see Richardson and Stevens 2014). Just as public health agencies increasingly prioritized the study of race and health disparities from a genetic perspective, federal mandates came to highlight the need to fund research that examines genes in context (HHS 2011, 2012). Yet, with the continuing emphasis on funding health disparities genomics approaches,

gene–environment research has only served to divest in studying the environment, in ways that further the authority of the genomic profession and detract from social and political forms of knowledge, actions and policies.

The major large-scale sequencing gene–environment projects and funding mechanisms of the US public health establishment's leading health disparities genomics initiatives are cases in point. The Gene–Environment Initiative, initiated by the HHS in 2006 (NIH 2007), and its National Human Genome Research Institute branch, GENEVA, touts "pathways to disparities in health outcomes" as one of its three foundational aims (GENEVA 2012; HHS 2012). However, its objects of analysis are genetic variants and epigenetic pathways, garnered from genome-wide association and whole-genome sequencing technology. Nowhere do these projects examine social hierarchies, the politics of race or institutionalized discrimination.

Similarly, The NIH Common Fund, the central trans-institute administration that was initially launched to bring genomic funding to all federal health institutes, has also issued funding strategies that prioritize projects that take a genomic tack in studying noncommunicable chronic diseases that exhibit a disparity between whites and blacks. For example, its cornerstone project, the Synthetic Cohort for the Analysis of Longitudinal Effects of Gene–Environment Interactions, targets three diseases for health disparities gene–environment research – diabetes, hypertension and prostate cancer – and supports a range of projects that include what genomicists refer to as "next generation sequencing" (see FUSION, FBPP and C-GEMS partnerships in NIH 2012). Again, these studies all seek to apply novel sequencing technologies to the question of genetic determinants of health in ways that stay intricately tied to the body.

Even the most systems-biological and developmental approaches with which the NIH rationalizes its gene–environment approach to health disparities genomics allude to the environment, but do not provide guidance for its analysis. The NIH states:

> [E]nvironmental exposures are varied ... Disadvantaged populations may experience greater exposure to these hazards and exhibit higher rates of disease incidence, morbidity and mortality. Understanding and modulating this risk in humans during critical windows of development offers the promise of primary prevention for many of these [noncommunicable chronic diseases] and may result in reducing health disparities. (NIH 2012)

While this statement makes clear that trans-institute projects must include a biomedical health disparities component to their gene–environment and epigenetic programs, it does not require measures for exposure that go beyond analysis of biomarkers (see Shostak and Moinester 2015, Chapter 11, this volume). The NIH instead argues that epigenetics and intrauterine interactions communicate the necessary information about the environment

in the context of developmental or systems biology approaches (also see HHS 2012).

In 2010, the NIH hosted a Global Health Research Meeting wherein gene–environment research was lauded as the basis of a new global health science that would eradicate the polarization between the global North and South. The meeting's participants, a veritable Who's Who of biomedicine, listed "RNAi, small molecule screening, genomics of pathogens, and vaccine development" as the world's biggest hopes for global health equity (NIH 2010). Microbiomics, epigenetics and genomic health disparities research were their newly minted "Priority Areas." DNA technologies of the gene were the only strategies discussed for understanding the environment–gene interaction.

The HHS has since backed up its aims with the launch of the first gene–environment international sequencing project, the Human Health and Heredity in Africa Project, or "H^{3}Africa." Launched in 2010 by the NIH and UK Wellcome Trust, H^{3}Africa sponsors research into functional genomics in order to reduce the communicable and noncommunicable disease burden in populations of African descent. A recent 2013 examination of the research that it has thus far funded shows that only one study has measured an environmental variable that is not associated with genetic markers (Bliss 2014).

The biomedicalization of the environment is inextricably linked to the institutionalization of the biomedicalization of race and health disparities. Since 2003, the NIH has funded Centers for Population Health and Health Disparities programs across the USA. By 2008, five centers had been funded and ten more were scheduled (HHS 2007). In the award's funding opportunity announcement reissue we see the slippage from environment to biological metrics:

> The first funding period of the [Centers for Population Health and Health Disparities] Program has enabled us to understand the persistence of health disparities and to begin to identify approaches to address these inequities . . . Some of these studies have begun to explain how the social and built environments impact biological processes, such as epigenetic modifications, gene expression, endocrine function, inflammation, tumor growth, and cancer-related health outcomes. These types of information are crucial in developing appropriate prevention, early detection, and treatment intervention programs to mitigate cancer disparities. (NIH 2009)

These multimillion dollar institutional awards only fund studies that utilize the latest DNA sequencing technologies to characterize health disparities in terms of biological functions.

Also since 2003, the NHGRI, Department of Energy and National Institute for Child Health and Human Development have funded Centers of Excellence in Ethical, Social and Legal Issues Research. This institutional funding program

initially provided over US$20 million in grants to study issues such as breast cancer and asthma in people of African descent, and has since funded a number of research centers focused on gene–environment research into diabetes, prostate cancer and sickle cell anemia in minority communities. From the outset, Centers of Excellence in Ethical, Social and Legal Issues research sites were envisioned to be hubs of gene–environment health disparities genomics research. Yet, the award has focused on facilitating the spread of the new genetic sciences to new populations by way of increasing access to genomic information, increasing minority community support for genomics and exploring informed consent and decision-making in the absence of a broader understanding of the relationship between environmental contexts and health. Provisions have not been made for sociological research of the built environment in these awards.

Finally, the HHS has established two intramural federal research centers entirely focused on health disparities gene–environment research. In 2007, the NIH inaugurated the Intramural Center for Health Disparities Genomics, now renamed as the Center for Research on Genomics and Global Health. The center began by focusing its gene–environment studies on people of African descent. Today it focuses its efforts more broadly on epigenomics in minority populations. The CDC also established the Office of Public Health Genomics "to convey the importance of engaging communities, investing in [community-based public research] and ensuring that social justice be central to public health genomics" (CDC 2011). In 2011, the office stated racial stratification as one of its foci of gene–environment inquiry.

Taken together, these institutions have steered and ensured the biomedicalization of the environment and moved away from the study of sociological factors. They also standardized racialization and geneticization across American public health. Finally, the sheer amount of funding available for analysis of environments (far outranking other funding mechanisms such as social and behavioral funding offered by the National Science Foundation and other public agencies), has produced a world in which social epidemiologists and other biomedical and nonmedical experts of the built environment must align with genomic science or trade in their nongenomic approaches for genomic expertise.

Biomedicalizing Ancestry

These three instances of biomedicalization dovetail with the burgeoning consumer market of ancestry, or the recreational pursuit of personal genealogy. Through a series of academic-industry partnerships and enterprises, genome scientists have sold racialized and geneticized interpretations of select sequences of consumer DNA, making ancestry and any politicization around it a matter of personal DNA and genomic expertise. Since the turn of the millennium, leading genomic scientists have worked to transfer foundational population-defining

technologies such as mitochondrial DNA and Y-chromosome technologies, which assess the non-recombinant portions of the genome, to the private sector in the form of ancestry tests. One type of test that has dominated the market is the *haplogroup test*. Since haplogroup tests are only able to report on the consumer's maternal or paternal lineage – a mere 2 percent of an individual's ancestry – companies have specifically capitalized off of a client base of African Americans and others who have limited records of their more distant family history. Another popular ancestry test relies on a technology called *admixture mapping*. In admixture mapping, companies select a set of ancestry informative markers, or "AIMs" – gene variants that present approximately 30 percent more frequently in one continental population – and create panels with which to assign admixture profiles. Admixture mapping can also be conducted on groups of samples using principle-components software.

The first genetic genealogy companies on the market positioned themselves as biomedical experts who had the key to knowledge about ancestry that traditional historical genealogy did not have. Companies established a pattern of promising to unlock customers' questions about their biological core, while providing the tools to recreate the public personae, social ties and political narratives about which identity-based groups have raised consciousness (Bolnick et al. 2008; Nelson 2008a, 2008b). Oxford Ancestors, an early company on the scene, characterized itself as the only expert team in the world that could explain ancestral lineages of the British Isles (Sykes 2002). Its founder, Oxford University geneticist Bryan Sykes, released tests alongside a series of bestselling books designed to aid consumers in reading the "truth" of their DNA (Sykes 2002, 2007a, 2007b). Other companies, such as the American firm, African Ancestry, Inc., offered "Certificates of Ancestry," and developed online social networking Web forums to legitimize consumer belief in the meaning and significance of their tests.

The routinization of the genomic technologies used in scientific labs across the world opened the possibility of decoupling the racialization and geneticization associated with modern genomics by generating populations based on statistical clustering instead of using lay or even governmental racial categories. Yet, although companies marketed their ancestry tests as keys to a person's true self, they built business models that used emerging technologies to recode consumer data in racial terms. Companies with names like "African DNA" and "DNA Tribes" not only used mitochondrial DNA and Y-chromosome tests to determine haplogroup membership, but they imparted a racial connotation by interpreting haplogroup affiliation in terms of continental race (e.g., "African" and "tribal") (Bliss 2013). Other companies like Roots for Real, a European company that targets African American root seekers, and DNAPrint Genomics, an American company known for its forensic technologies that have been used by police agencies around the world, marketed their admixture tests as indicative of unknown racial ancestry (Roberts 2011; Bliss 2012). Companies

were thus not only positing tests as better than historical or genealogical knowledge, but they were also positing them as better than social knowledge.

In fact, from the outset, companies portrayed their tests as tools useful for consumers who would like to change or confirm their racial identity. For example, DNAPrint Genomics acquired the indigenous American forensics company Trace Genetics, Inc., so that it could be the leading firm to test for Native American tribal membership. Many companies advertised to people who suspected they had indigenous American origins in order to sell them proof of this "biological citizenship." For example, DNAPrint claimed its tests could produce credentials with which to register for tribal membership so that nonmembers could petition for resources from tribal councils or the US government (TallBear and Bolnick 2004). DNAPrint Genomics also encouraged clients to use their personal ancestry reports to petition for Affirmative Action consideration and to inform medical decision-making (TallBear and Bolnick 2004). By 2006, Oxford Ancestors and African Ancestry followed suit (Harmon 2006). In encouraging consumers to take advantage of an affirmative action policy or a legacy clause, or to use their newfound ancestral profiles to support their college admissions, these companies more tightly coupled the ensuing racialization and geneticization in biomedicine's new realms, pushing yet another brick into the wall of a social justice ethics based on DNA code. To date there have been no published statistics on how many genetic genealogy consumers use tests to this end, but in 2006 *The New York Times* ran an article exposing the practice (Harmon 2006). The article demonstrated that companies were encouraging customers to associate their reported ancestry with governmental classifications by using federal classifications to represent their test findings.

In their marketing of ancestry tests, companies have also more systematically relied on racial models that embed the foundations of genomic technology. While companies have purported to target the individual by tailoring genomic knowledge to the individual consumer's personal DNA, all have offered medical readings of consumer DNA. They have also made probabilistic claims about the individual's genome based on the body of genome-wide association literature that uses the racial terms of the global genome projects. Many companies have even required consumers to affiliate themselves with a preestablished racial group before running the tests in order to triage their analyses. In all cases, consumers have either had their results read or have had to actively read their results through a racial rubric.

Still, the clearest way that ancestry has been biomedicalized is in the move from traditional genealogy practices to the creation of online DNA racial "families." As companies have opened up databases and social networking platforms to encourage socializing and launched products that match "genetic cousins" in their databases, consumers have moved racial organizing, socializing and health advocacy online. In 2011, the Google-backed personal genomics

company 23andMe – a firm that also reports personal genetic susceptibilities data by race – launched a race-specific research campaign "Roots into the Future." Roots into the Future challenged African Americans to "Be part of a 10,000 person movement to power genetic research for African Americans" (23andMe 2013). The project promised to create a black database within its research branch, 23andWe, to spur race-focused medicine and technologies. 23andMe partnered with the founders of AfricanDNA and African Ancestry, Inc., to foster a new era of bioinformatic social organizing. "Roots into the Future" set a precedent for linking direct-to-consumer marketing, a commodified version of personal genomics, with calls for the altruistic lending of one's personal DNA for a racial cause.

The availability of these new personal genealogy tools and racial political forums has not displaced prior forms of root-seeking (Nelson 2014). However, it has succeeded in infiltrating the domains where historical genealogy is used, serving as a supplement to historical claims. It has also succeeded in gaining entrance into minority community centers, where academic-industry partners and science "reps" and advisors have garnered new markets for their research and community support for their biomedical enterprises (Bliss 2012).

Biomedicalization thus has serious consequences for racial and personal identity processes. Sociological research on race has established that identity is made and remade through a dialectic of classification and identification (Omi and Winant 1994; Brubaker 2009; Daynes and Lee 2008). Individuals see themselves in terms of the social categories ascribed to them. Groups form around shared conceptions, practices, treatment and experiences. Against this knowledge, in the current climate, racial classifications are conceived as entirely inherent in the unchanging DNA code with which a person is born. Their ideas, experiences and action are to be interpreted in terms of the genetic ancestral cluster a particular technology assigns them. Their sense of belonging to a group thus forms around an idea of innate biology. With genetic race as the official classification frame, and the guiding framework for biomedicine, the most authoritative notions of identity become synonymous with innate biology.

As seen in the discussion above, individuals are affected, but so are groups. New racialized groups are formed through virtual participation and membership instead of social action, activism and collective experience. Groups align with and through genomic science. Thus, the responsibility for group formation is relinquished to genomic scientists, or the uppermost elite experts of DNA science. People in racial groups will know no more about the basis of their groupness than the aggregate designations of membership that genomic scientists have provided them.

This model of genetic "groupness" biomedicalizes former conceptions of relatedness, such as familial and communal notions of connectedness, on a political level as well (cf. TallBear and Bolnick 2004; TallBear 2008). Even racial groups that have traditionally put a high value on cultural and familial kinship

are turning to DNA and replacing former notions of social connectedness. In the case of Native American polities, which typically require proof of familial descent from one or more registered grandparents, or some proportion of maternal or paternal lineage, genomic ancestry tests have become a new way of evaluating kinship (TallBear 2013). Some of these polities have publicly encouraged individuals to use tests as proof of membership in order to amplify numbers and gain US Bureau of Indian Affairs recognition, or to limit the circulation of tribal resources to genetic nonmembers (TallBear and Bolnick 2004). Genetic proof and biological citizenship are fully equated and encouraged or required.

Conclusion

In this chapter, I have shown that new intersections between geneticization and racialization are creating new domains of biomedicalization – the biomedicalization of race, disparity, environment and ancestry – but also a new *form* of biomedicalization itself. Because today's biomedicalization is based on DNA technoscience, it creates more fixed and essentialized notions of racial identity and difference. Further, it puts the onus of responsibility on genomic scientists to interpret inequality and the social environment in DNA terms, and on individuals to manage their biological predestination with DNA solutions. It also shifts debates about societal impacts on healthcare disparities to the province of science and scientists.

The result of the four strands of biomedicalization discussed in this chapter is that basic politics, such as articulating and petitioning for equal rights, increasingly filter through genomics. The field is continually providing new biomedical angles for social justice, which governments are adopting as frontline weapons against inequality. Leading advocates are accepting pharmaceuticals and biotechnologies as solutions to the social ills that their constituents face. They are replacing talk of broader environmental and social factors of racial inequality with drug-seeking advocacy for individual constituents potentially affected by diseases characterized as racial. Genetic claims about race increasingly serve as the dominant language and the dominant framework for understanding and managing inequality in biomedicine, public health and the wider public sphere.

The new biomedicalization results in an individualization of identity and groupness and a depoliticization of advocacy. Accessing rights shifts from being a matter of political participation to scientific participation, specifically DNA science participation. That these changes in politics are attached to the construction of racial meaning only serves to reify essentialist notions that DNA is the key to understanding individuals, groups and disparities between them, and the social and built environment. Genetics is the arbiter of a person's race and a person's environmental experience.

These developments have important consequences for how individuals conceptualize race, and thereby interact based on race, but also for groups' formation and deliberation. For individuals, political action around race is geneticized and individualized at the level of demands pertaining to personal DNA. Taking genetic tests and buying pharmacogenomics become personal priorities. For some groups, making tests and drugs readily available to their constituents become political priorities. Furthermore, group affiliation via DNA identification comes to serve as the indication of legitimate membership. For both groups and individuals personal experience and political organizing around shared social experiences recede. Thus even collective disputation is individualized and made real in terms of DNA. In sum, changing forms of technologization and responsibilization make for a powerful biomedicalization in which alternative social relations and conceptualizations are pushed out in favor of a highly specialized framework of expertise.

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Notes

1 www.pbs.org/wnet/aalives/ (accessed March 31, 2012).
2 www.pbs.org/wnet/facesofamerica/ (accessed March 31, 2012).

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