Title
‘To Be Seen Whole’: The Racialization of Disability After World War II

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Publication Date
2018

UNIVERSITY OF CALIFORNIA SAN DIEGO

‘To Be Seen Whole’: The Racialization of Disability After World War II

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy

in

Ethnic Studies

by

Maisam Alomar

Committee in charge:

Professor Patrick Anderson, Co-Chair
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2018

The Dissertation of Maisam Alomar is approved, and it is acceptable in quality and form for publication on microfilm and electronically:

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2018

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ACKNOWLEDGEMENTS

I would like to thank my dissertation committee for their encouragement and support throughout the various stages of this project. I cannot fully express my appreciation for their honest feedback, invaluable advice, many letters of recommendation, and their presence and patience when I most needed it.

I owe a great debt of gratitude to my undergraduate mentors, who galvanized this process with their passion, brilliance, and generosity. I am inspired to live and work by the example of their levelheadedness, even in the face of prominence and their tenacity, even in the face of adversity.

I could not have completed this dissertation without an exceptional cohort of friends and colleagues who worked tirelessly alongside me, day and night for years. I am grateful to have shared this experience with them, and they have surely shaped my thinking in ways reflected in this work.

Last but not least, I am thankful for my friends, family, and loved ones who kept me grounded and sustained me in ways big and small, and who reminded me to step away from the work (occasionally).

The epilogue, in part, has been submitted for publication of the material as it may appear in *Catalyst: Feminism, Theory, Technoscience*, 2018. The dissertation author, Maisam Alomar, was the primary investigator and author of this paper.

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ABSTRACT OF THE DISSERTATION

‘To Be Seen Whole’: The Racialization of Disability After World War II

by

Maisam Alomar

Doctor of Philosophy in Ethnic Studies

University of California, San Diego, 2018

Professor Patrick Anderson, Co-Chair
Professor Sara Kaplan, Co-Chair

In this dissertation, I put disability studies scholarship in conversation with black studies scholarship to read for the ways that medicine, law, and popular culture grapple with, create, and contest the boundaries of an acceptable range of (white) difference and diversity of embodiment and ability, and for the ways this negotiation takes place against an always already present “contempt for the categorized difference of the Other,” particularly the black Other. I situate this inquiry within several key debates in disability studies, most notably the debate between the "medical" and "social" models of disability, as well as what I will call the "discursive" extension of the social model of disability. To this end, this dissertation examines a set of laws, films, and historical documents through the combined frameworks of intersectional race studies, disability studies, and film and media studies to ask how racial ideologies and practices have constructed disability as a social and medical category in law, scientific inquiry, and cultural production since the mid-twentieth century. My methodology is insistently interdisciplinary, including archival research, legal analysis, the collection of original social science data from public databases, and film and literary analysis. I have organized the main chapters of this dissertation to explore four key developments over the last half century that address my central questions: post- World War II rehabilitation efforts and their relationship to the Tuskegee Syphilis Study; the War on Drugs of the 1980s and its relationship to the "special needs" category in adoption law; contestation over the "companionship services" exemption to the Federal Labor Standards Act; and the contemporary Transhumanist movement. Disability studies raises important questions about inclusion, access, representation, embodiment, space, and reproduction. By incorporating critical race scholarship, I analyze the way extant racial categories shape most profoundly: 1) *what* conditions qualify as a recognized disability, 2) *who* counts as a legible and legitimate disabled subject, and 3) *how* legal and labor practices govern and respond to disability so defined.

Introduction

Hate

How does a father
with a son struggling
to be seen whole
in the eyes of the world
forget the son long enough
for a slip of the tongue
to be recorded forever
for posterity's sake?

How does a father not think
that a son will ever know
what he said that day at the rally
when he slipped
and he, the father, revealed
his true feelings
about him, the son,
the same feelings he feels
about other different people?

How does a father
slip off one tongue
while he rallying
his Confederate troops
and slip on another
later
after the rally
when he is home
with his son,
gentle inheritor of his name?

He does not.
The slippery tongue
is one and the same.

What could make you
forget your son?
A fight over an old flag?
The heat from a simmering
hundred-year-old war?

Hate stops at nothing.
Not even the sacred door
of a son's private room.

Award-winning poet Nikky Finney's 2012 book of poetry, *The World is Round*, includes a poem entitled "Hate." The poem is about a "slip of the tongue" made by Arthur Ravenel, a Southern Carolina Republican Senator who, at a Confederate flag support rally in 2000, called the NAACP, the "National Association of Retarded People." The poem opens by quoting him: "I made a mistake and I feel very badly about it because I said retarded people and I have a retarded son. This does not mean I'm apologizing to the NAACP."[1] Arthur Ravenel held a long career as a state senator from North Carolina. Ravenel's son William has Down's Syndrome. He and his former wife Louise Rodgers Ravenel have been championed as some of the earliest disability rights activists to push for legislative reforms on behalf of people with disabilities[2] and their families.[3] Finney's poem meditates on the relationship between Ravenel's hatred for the NAACP, and by extension black people, and the hatred he feels for his own son, revealed by this "slip."

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[1] In a 2012 interview, journalist Quintin Washington, who is black, interviewed Arthur Ravenel for WLCN-TV, the "home for Christian television in South Carolina." Given the political leanings of this network, the interview included no direct questions about this statement from the year 2000, but Washington asked vaguely, "Now I know you've said some controversial things. Do you regret anything?" Ravenel responded: "You can't go through a long political career without cracking a few eggs. You want to make an omelette, you have to crack some eggs. And the omelettes that I've made by cracking a few eggs, they've been good eatin' for the community ever since… So anyhow there are a lot of things that I said or did in my career, if I had to do them again, I would have, uh, rephrased them, gentler, you see?" In cracking this particular egg, one wonders, what kind of omelette did Ravenel imagine he was making for "the community?" What was he defending here, and for whom?

[2] Gabriel, Pam. "A Bridge to History: Arthur Ravenel Jr." Mount Pleasant Magazine, March/April 2014.

[3] Louise Ravenel, in particular, has led the South Carolina Protection and Advocacy System for the Handicapped, Inc., the Advocacy for Handicapped Citizens group, the first disability advocacy group in South Carolina. She also helped establish Camp HiHopes, the Hope Center, and the Charleston Rehabilitation Center.
South Carolina General Assembly, 110th Session, 1993-1994. Bill 4908. http://www.scstatehouse.gov/sess110_1993-1994/bills/4908.htm

Black scholars and artists have long maintained that racist contempt is less about its targets than about the psychic and material needs and benefits of its originators. James Baldwin put it fittingly in the 1963 televised interview, “Take That Hammer”[4]: “What you say about somebody else reveals you. What I think of you as being is dictated by my own necessities, my own psychology, my own fears and desires… I’ve always known, I had to know by the time I was seventeen years old, what you were describing was not me and what you were afraid of was not me. It had to be something else. You had invented it so it had to be something you were afraid of and you invested me with it.”

What fears and desires motivated Ravenel’s description of the NAACP and inspired him, consciously or otherwise, to connect the hatred he feels for the NAACP to his son? The comparison Ravenel draws between his son’s Down’s Syndrome and racial inferiority has a long history that might provide some insight. In an 1867 issue of the medical journal *London Hospital Reports*, British physician John Langdon Down published the essay, “Observations on an Ethnic Classification of Idiots” based on his experience as a medical superintendent of the Royal Earlswood Asylum for Idiots. He posited that “congenital mental lesions” causing “idiocy and feeblemindedness” took various types that fell along the same criteria used by proponents of scientific racism to categorize human races. He declared, for example, that a number of “imbeciles and idiots” in his clinic were of the “Ethiopian variety” although they were white: “They have been specimens of white negroes, although of European descent.” He devoted most of his attention to what he called the “Mongolian type”: “The number of idiots who arrange themselves around the Mongolian type is so great, and they present such a close resemblance to

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[4] James Baldwin. “Take That Hammer.” National Education Television, KQED Film Unit, 1963.

one another in mental power, that I shall describe an idiot member of this racial division, selected from the large number that have fallen under my observation." Following this piece, "Mongolism" was used to classify the disorder in Medical Subject Headings, an international and comprehensive vocabulary used to regulate the categorization of medical books and journals, until 1975 when it was replaced by "Down's Syndrome." Today, the latter term is used interchangeably with "Trisomy 21."

Down used this theory, perhaps ironically, to argue against polygenetic theories of scientific racism that postulated that "different races" of people had different origins and/or belonged to different species: "Here, we have examples of retrogression, or at all events, of departure from one type and the assumption of the characteristics of another. If these great racial divisions are fixed and definite, how comes it that disease is able to break down the barrier, and to simulate so closely the features of the members of another division." In 1924, British epidemiologist Francis Graham Crookshank published *The Mongol in Our Midst*[5], which made similar claims, arguing that the syndrome was a manifestation of a different racial "type," but used these claims instead to argue in favor of his belief in polygenetic theories of scientific racism. Specifically, Crookshank believed in "three irreducible human stocks - white, yellow, and black, respectively derived from three primate stems and referred to as the chimpanzoid, the orangoid, and the gorilloid stocks," different types that represented three different stages of human development. He claimed that "mongolism occurring among the white races is an atavism to the orangoid stage of development" and that "it is confined to European whites, since they constitute the only race more advanced than the Mongolian and hence the only race from which

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[5] Crookshank, F. G. *The Mongol in Our Midst*, ed. 3. New York, EP Dutton & Co. (1931).

there can be a regression to the Mongolian characteristics." By that time, polygenism had fallen out of favor in the scientific community with the predominance of Darwin's theories in the mid-nineteenth century, even amongst practitioners of scientific racism who had shifted toward monogenism, and Crookshank's publication received some backlash. In 1931, he published a 524-page response to the criticism, under the same title, defending and elaborating on his earlier theories, claiming that the "regression" occurred as a result of ancestral "admixture" between the "white stock" and the "yellow stock." In attributing the syndrome to "admixture," Crookshank maintains Down's earlier postulation that racial categories are not entirely fixed, despite that he believes them to have different origins.

Although monogenism began to rise in prominence among scientists in the mid-nineteenth century, the opposite was true among Southern slaveholders. While polygenism was more popular among scientists in the late eighteenth and early nineteenth centuries, most Southern slaveowners opposed it on religious grounds, believing all humans to be descendants of Adam and Eve. With rising threats to the institution of slavery, Southern slaveholders increasingly favored polygenism, which made the case that the separation between races was innate and therefore more justified.[6] This was so much the case that in 1860, Southern pastor James Thornwell gave a speech condemning the growing popularity of the "infidel ideology" among what he called the "Confederacy." In his own defense of the Confederacy 139 years later, Ravenel slips by making a connection between race and intellectual disabilities. More specifically, as his apology to his son makes clear, his comment resurrects a long-held belief in the relationship between Down's Syndrome and racial inferiority, or at least a kind of

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[6] Christopher Luse. "Slavery's Champions Stood at Odds: Polygenesis and the Defense of Slavery." *Civil War History* 53, no. 4 (2007).

evolutionary "atavism" among white people that resembles it. Ravenel's "slip of the tongue" betrays his anxiety that his son's Down's Syndrome might signal that the racial hierarchy is *not,* after all, biologically fixed and immutable, that the presence of physical and intellectual disabilities among white people, among his own kin, might signal that the criteria by which they have long held themselves to be racially superior is ultimately erroneous and that the resources, benefits, and protections they have enjoyed on this basis might therefore be illegitimate. Like his confederate forefathers, the seeming tenuousness of his social position only deepens his investment in the hierarchy.

The question of who is human, and the establishment of white people as decidedly human against the dehumanization of black people allegedly on the basis of intellectual, physical, moral constitution, has always been central to the production of racial hierarchies. In 2017, renowned author Toni Morrison published *The Origin of Others*[7], addressing themes and questions that have long been central to her literary and scholarly work and were at the forefront of the political climate in the direct aftermath of the 2016 election of Donald Trump as president. In her meditation on the origin of race and the reasons for its persistence, Morrison introduces this history by quoting the writing of Southern slaveholder and physician Samuel Cartwright in "Diseases and Peculiarities of the Negro Race." It is not an accident that Morrison, who "ranks among those who understand the hold that history has on us all," writing in 2017 in a text that is "grappling with how that grip [of the past] came to be," centralizes science, medicine, and the scientific racist production of disorder in this inquiry. Morrison argues that, "One purpose of scientific racism is to identify an outsider in order to define one's self. Another possibility is to

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[7] Morrison, Toni. *The Origin of Others*. Harvard University Press, 2017.

maintain (even enjoy) one's own difference without contempt for the categorized difference of the Othered." In other words, not only does the production of a racial Other, especially when made objective with the guise of scientific empiricism and legal authority, allow for a construction of the self as the opposite of that Other, but it also allows for the possibility of diversity and individuality that, because of the existence of an essential racial Other, can be spared the most extreme levels of pathologization and contempt and can sometimes even be celebrated.[8]

"Disability" is a broad category encompassing a multitude of often unrelated symptoms, conditions, and experiences. What gives it coherence as a category is its distinction from an imagined "able" body, one that has historically been constituted as white. If blackness in an antiblack world is always-already marked as cognitive and bodily impairment, then who is the proper disabled subject? The presumption of a normative absence of impairment is a necessary precondition to being marked as disabled, as having a distinct or noteworthy "impairment." This gives new meaning to Sharon Snyder's and David Mitchell's contention in *The Body and Physical Difference* that the marking of disability relies on a "violation of expectations" (4) and the violation of a particular "culture's predictive capacities and effective interventions" (3). In this dissertation, I put disability studies scholarship in conversation with black studies scholarship to read for the ways that medicine, law, and popular culture grapple with, create, and

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[8] Morrison makes this point again in analyzing the violence to which Mary Prince was subjected by her mistress: "The necessity of rendering the slave a foreign species appears to be a desperate attempt to confirm one's own self as normal. The urgency of distinguishing between those who belong to the human race and those who are decidedly non-human is so powerful the spotlight turns away and shines not on the object of degradation but on its creator. Even assuming exaggeration by the slaves, the sensibility of slave owners is gothic. It's as though they are shouting, 'I am not a beast! I'm not a beast! I torture the helpless to prove I am not weak.' The danger of sympathizing with the stranger is the possibility of be-coming a stranger. To lose one's racialized rank is to lose *one's own valued and enshrined difference*" (emphasis added).

contest the boundaries of this acceptable range of white difference and diversity of embodiment and ability, and for the ways this negotiation takes place against an always already present "contempt for the categorized difference of the Other," particularly the black Other.

I situate this inquiry within several key debates in disability studies, most notably the debate between the "medical" and "social" models of disability, as well as what I will call the "discursive" extension of the social model of disability. Whereas "the medical model" conceives of disability as a personal and physiological impairment that should be treated medically, "the social model" conceptualized by British activists in the mid-1970s attempts to counter the medical model by arguing it fails to distinguish between impairment and disability, the former being a physiological condition or defect of part of the body and the latter being disadvantages socially imposed through that impairment. According to disability studies scholar Shelley Tremain (2005), Michel Foucault's formulation of power calls even this distinction between impairment and disability into question by demonstrating that bodies do not have natural or preexisting impairments per se and that the construction of corporeal difference itself emerges to justify the social and governmental practices that constitute that difference and produce the illusion that it is natural. Foucault's formulation of biopower is concerned primarily with the management of life, particularly at the level of populations, as opposed to earlier forms of sovereign power that held the right to impose death. By the beginning of the 19th century, the right to "take life or let live" was replaced by the power "to make live and let die." This new form of power, biopolitics, targets populations through such mechanisms as statistics and measurement (including rates of birth, death, reproduction, etc.). Biopower produces a "norm" through these mechanisms, and "normalization" compels individualization toward this norm in a more efficient and totalizing form of government, even though it is less obviously brutal than older forms of sovereign power.

In recent years, many disability studies scholars have cautioned against throwing out the medical model altogether, or at least throwing out medicine, rehabilitation, and the lived experiences of people with different kinds of disabilities. “To what extent can a disability studies that rejects the medical model adequately take into account and be responsive to disabled people who might desire a cure? To what extent is the social model equipped to address the lived experience of pain? To what extent does rejection of the medical model ignore complex, fraught relationships to medical diagnoses” (Hall 2015)? In this dissertation, I hold in tension these two perspectives (the social/discursive model and its critics) by offering an analysis of the production of disability that does not simply validate medical intervention or romanticize rehabilitation, but also is not premised on a rejection or denial of physiological symptoms or medicine wholesale. Rather, what I hope to show is that the condition that might be classified as “impairment,” and the attendant experience of symptoms, is not in itself sufficient for categorization as “disabled,” real as it may be. Social and political forces are still at work in both the production of the “impairment” and the *recognition* of disability as such.

As Alison Kafer (2013) notes, science studies scholar Chris Hables Gray reinforces the natural/cyborg disabled/non-disabled binary when he begins his essay, “The Crippling of Superman,” with the story of actor Christopher Reeve, the award-winning actor and philanthropist who became quadriplegic following a equestrian accident in 1995. Kafer critiques Gray’s characterization of Reeve as the prototypical “cyborg.” Gray asserts it is “obvious” that “here is someone who transgresses boundaries between machine and organism, someone whose body doesn't end at the skin," a claim that works to "perpetuate distinctions between 'normal' and 'abnormal' bodies" (110) and, further, to essentialize such distinctions. Though Gray notes that all bodies are, to some extent, "cyborgs," this focus works against his own argument. Throughout this dissertation, I attend to histories and popular culture depictions of conditions that technically fit the legal classification of disability but are not "obviously" disabilities, like sexually transmitted illnesses or substance use disorder, challenging the binaries between disabled/non-disabled. In light of Kafer's critique, such a focus seeks to denaturalize distinctions between "normal" and "abnormal" bodies and to reassert the significance of the "social" and the "discursive" in determining when and for whom a condition, even the same condition, constitutes a disability in legal and medical settings. In other words, I contend that the implications of the social model of disability are of urgent material consequence. This is true both for the significance of material conditions in understanding the prevalence and development of particular medical conditions, and for the divergent outcomes faced by people living with them, depending on whether these conditions are framed as disabilities or as inherent impairments, either biologically or as an effect of a disposition.

In a 2015 review essay, "Cripping Feminist Technoscience," Aimi Hamraie argues that what is missing in the conversation between feminist disability studies and feminist technoscience studies is the "technoscientific elaboration of crip theory." Hamaraie defines crip as a "contested term marking resistance to what Robert McRuer calls 'compulsory able-bodiedness'. Cripping actively resists compliance with supposedly normal embodiment, behavior, and desired features. Instead, it understands disability as productive possibility and resource" (307). McRuer understands rehabilitation, and the compulsory able-bodiedness it enforces, as a logic to which both queer and disabled populations have historically been subjected as a means of regulation and control. He notes that disability-themed memoirs or journals are often marked by a "conflict over rehabilitation - or, more precisely, over the 'return' that rehabilitation (which at its root suggests the return to a former role or capacity) might or might not facilitate" (McRuer 103). In other words, the conflict arises when a return is not possible, or when it is not desired, amid the violent process of socially enforcing that return. As McRuer notes, implicit in rehabilitation is the concept of "return to a former role or capacity," as one who is able-bodied, having more capacity (especially to labor), or a prior state of normalcy. This analysis offers a useful intervention into the medical model of disability insofar as it presumes disability is a fixed, negative, and delineated set of conditions and, moreover, that rehabilitation is always desirable. Still, this conceptualization of rehabilitation relies on the presumption of a universal subject for whom there exists an idealized normalcy and on the universal application of power that seeks to compel all subjects, equally, toward that state.

An analysis of race might intervene here by providing different thresholds and standards for what constitutes "normal" and what constitutes "disorder" requiring intervention. I do not intend to challenge the argument that treatment and rehabilitation are often violent forms of control for disabled people - that much seems well established - but rather to argue that they may not be the primary form of government and control for all subjects with conditions that might otherwise be classified as disabilities. On this score, the questions that remain to be addressed are: What are the racial and gendered ideological assumptions that determine the form and direction of the return to normalcy and when a body has "strayed" from a given norm enough to require such a return in the first place? Finally, when might such an identification mark a disabled subject who can be rehabilitated, and when does it mark other forms of “intrinsic” deviance?

To this end, this dissertation examines a set of laws, films, and historical documents through the combined frameworks of black studies, disability studies, and film and media studies to ask how racial ideologies and practices have constructed disability as a social and medical category in law, scientific inquiry, and cultural production since the mid-twentieth century. Disability studies raises important questions about inclusion, access, representation, embodiment, space, and reproduction. By incorporating critical race scholarship, I analyze the way extant racial categories shape most profoundly: 1) *what* conditions qualify as a recognized disability, 2) *who* counts as a legible and legitimate disabled subject, and 3) *how* legal and labor practices govern and respond to disability so defined.

My methodology is insistently interdisciplinary, including archival research, legal analysis, the collection of original social science data from public databases, and film and literary analysis. My project treats the scientific inquiry that seeks to identify disability not as an objective description of bodies to be taken at face value but as a social process that can only be understood in the context of its regulation by law, medicine, popular culture, and a variety of social practices from the interpersonal to the institutional. My interdisciplinary methodology has helped me address the way such context, in the United States and elsewhere, is structured by long-standing racial hierarchies I have collected primary documents from archives available at UC San Diego libraries, the U.S. Department of Health and Human Services collection, and the National Museum of Health and Medicine in Washington, D.C. I have analyzed legal documents available through online legal archives. I combine cultural and film studies, archival work, legal analysis, and literary and discourse analysis to bring into conversation black studies and disability studies texts and ask how disability as a category might be rethought. In his critique of multiracialism in *Amalgamation Schemes*, Jared Sexton examines what he calls "keynotes in the formation of multiracial discourse," including "influential philosophical meditations, political manifestos, historical studies, social scientific investigations, and autobiographical accounts" to ask "what lends this discursive field its coherence." I borrow his methodological conception of "keynotes" to ask what lends disability studies as a "discursive field its coherence." I analyze a variety of disability studies texts, laws, and popular representations to ask what lends the category of disability its coherence.

In each chapter I pair relevant legal, medical, and historical documents with a popular film, allowing for an analysis of how technical concepts circulate in the social sphere. The four films are, respectively, *Home of the Brave* (1959), *Losing Isaiah* (1995), *The Intouchables* (2011), and *Gattaca* (1997).. In *Monstrous Intimacies: Making Post-Slavery Subjectivities*, Christina Sharpe reads visual and literary texts by contextualizing them historically in the moment that they are produced, but without severing them their relationship to past and future historical moments. For example, Sharpe analyzes Gayl Jones's neo-slave narrative *Corregidora* for what it reveals about the horrors and raced sexual violence of slavery and freedom, situating it in the context of Brazilian slavery in 1871, and the Free Womb Law. This kind of pairing allows me to historically and politically contextualize my texts and, at the same time, move away from a literal or "objective" reading of historical texts or moments toward an identification of what remains implicit in them. Cinema presents a unique, albeit aesthetically mediated, perspective on the lived realities and dire implications of pervasive ideological assumptions that reproduce the normate. As Kara Keeling makes clear in *The Witch's Flight*. Borrowing from Deleuze's theorizations of "the cinematic," Keeling understands the cinematic as "part of reality rather than as a reflection or representation of it." She therefore focuses her analysis on images that constitute the common sense (4). In my project, such a focus is important for analyzing how categories of difference, as they are commonly understood and contested, are discursively constructed.

I have organized the main chapters of this dissertation to explore four key developments over the last half century that address my central questions. In the first chapter I situate the Tuskegee Syphilis Study in the context of the post-World War II "rehabilitative turn" in the 1940s and 50s. I trace the study's relationship to the only black veterans hospital in Tuskegee, Alabama to show that rehabilitative efforts had vastly different trajectories for black and white veterans. Born out of the Progressive Era, the "rehabilitative turn" that began in the aftermath of World Wars I and II shifted the care of disabled veterans toward, primarily, rehabilitation and incorporation, as opposed to compensation and ostracism because the latter was seen increasingly as costly and unsustainable. This turn spurred the rapid development of rehabilitative technologies. My chapter shows that black veterans were largely excluded from these efforts and that the only large-scale rehabilitative project geared toward black communities quickly became the longest-running experiment on human subjects in the history of medicine. Where masculine notions of productivity and control were used to spur the rehabilitative turn for white veterans, racist conceptions of hyper-masculine sexual excess and a presumed apathy regarding self-care were used to legitimize the Tuskegee Syphilis Study for the black men who were its subjects. I use this case study to illustrate my argument that it is not simply a matter of physiological condition that lead to the "return" implicit in rehabilitation but rather the construction racialized subjectivities that call for that return in the first place.

In the second chapter I turn to those cases where a difference from the norm signifies, instead of disability, more "intrinsic" forms of deviance. I focus on the emergence of the "special needs" category in the foster care system, which in practice characterizes all black children and in some states other non-white children as special needs. I argue that this categorization and other relevant shifts in the foster care system in the 1980s and 90s were born out the War on Drugs and the racialized discourses it produced. Overblown and highly racialized fatalistic predictions about the damaging and allegedly permanent effects of crack cocaine use on babies born to addicted mothers have since been disproven by long-term studies that show these effects can be reversed and that they were likely caused and compounded by other factors. Still, they were frequently cited in proposals to shift adoption policy toward easing the process of separating children from their birth families in order to speed the adoption process. Not only were these changes effected but the same ideologies, I argue, continue to inform the categorization of all black babies, and in some states other non-white babies, as "special needs" for the purpose of adoption. I make the case that these changes were motivated less by concern for the children placed in foster care, and more by a punitive state response that blamed black women for the material conditions in which they lived.

In the third chapter I address the labor, life, and energy that are sacrificed in service of a "return," either to "normalcy" or empowerment, once a subject has been marked as properly disabled. I read, primarily, the award-winning French film *The Intouchables* (2011), which relies on the circulation of racialized images of the proper disabled subject and the caretaker familiar to

U.S. audiences because of such films as *Driving Miss Daisy* (1989). I analyze this film alongside two memoirs on which it is based, and a forthcoming American remake, in the context of what is known as the "companionship exemption" to the Federal Labor Standards Act, which leaves care labor for disabled and elderly people as the only form of labor that is not protected by this law, with no minimum wage requirement or mandatory overtime pay. This labor has historically been performed primarily by black women, and continues to be performed disproportionately by black women and women of color. The chapter makes the argument that race and gender structure the care labor relations that produce a proper disabled subject who can be legible and empowered, and whose "independence" is achieved through the elision of this sacrifice.

Finally, in the fourth chapter, I turn my attention to a present-day movement to produce a universal able-body, as well as disability rights efforts to push back against the movement. I consider the movement known as "transhumanism," which seeks to use technology to "enhance" humans intellectually and physiologically and eliminate disease and mortality. The chapter argues that disability studies critiques of the movement do not address its existing and potential harms to racial minorities, particularly in the movement's opposition to research ethics guidelines that were established after the Tuskegee Syphilis Study. By looking at how both the movement and its opposition recycle false universalism, I illustrate the ways that each side of this negotiation relies on the figure of blackness against which to make its case. I conclude the dissertation by way of an epilogue, with a brief consideration of the contemporary so-called "opioid crisis," which has been framed as a white rural and suburban crisis. I ask how this framing shapes legal and medical responses to the crisis, and makes possible the official categorization of "substance use disorder." I contrast this development with the legal and the medical response to the so-called “crack cocaine epidemic” of the 1980s and its *ongoing* consequences for poor black communities. Through this focus, I combine arguments from several different chapters to close with what is a key claim of this text: that the proper subject of disability is situated at once by the coercive government of normalizing biopolitics as well as by the myriad resources that accrue to whiteness in a racially stratified state and civil society.

Chapter 1: Treatment and 'Death-Watch' in Post-WWII Rehabilitation

> bring them to autopsy
> with ulcerated limbs,
> with howling wives,
> bring them in, one coon corpse at a time.
> (says Dr. Dibble)
> "a dollar a year for forty years
> to watch these shadows rot."
> "they didn't receive treatment for syphilis,
> but they got so much else.
> medicine is as much art as it is science."
>
> Sadiq Bey, performed on Don Byron's *Tuskegee Experiments* (1992)

I.

In 1992, twenty years after the end of the infamous forty-year Tuskegee Syphilis Study and five years before President Bill Clinton would issue a belated apology to its victims, jazz clarinetist Don Byron released an album entitled *Tuskegee Experiments*. "Experiments" is plural, Byron explains in the album's liner notes, because the title refers both to the syphilis study and the struggles of the Tuskegee Airmen, a black aviation group in the segregated World War II military that endured mistreatment, neglect, endangerment, and skewed press reports before being lauded for participating in the bombing of key German targets. Byron writes: "To me, these two experiments are metaphors for African-American life. In one, we saw once again that black life is cheap… The aviation experiment reflects the struggle black people constantly face: having to be smarter, better, more qualified simply to justify being given any opportunity."

The album includes a track by the same name, written and performed by Sadiq Bey. The third stanza is reprinted above. The project is well-conceptualized and thoroughly researched and addresses many aspects of the experiment, including the names and specific roles of its principal investigators and physicians, the names of the three black medical personnel who participated, the status of the experiment's subjects, the central role of autopsy and death, key justifications given by the experiment's apologists, and, importantly, the withholding of treatment. The last four lines of the piece exclaim, "no treatment! no treatment! no treatment! no treatment!" with each of the first three exclamations revealing progressively more urgency and disbelief before the last admits, in pained resignation, "no treatment!"

Byron brings together the two Tuskegee experiments, each significant in its own right, in a comment on "African-American life" in the United States more generally. The experiments are related as symbols of that experience. Further, as I argue here, the experiments are also related in a more literal sense. The Syphilis Study was born quite directly out of war-related rehabilitation efforts as well as out of Progressive Era ideology and policies that also spurred the turn toward rehabilitation of disabled veterans. It had direct ties to the only veterans' hospital founded specifically for black veterans, the Tuskegee Veterans Administration Hospital. The vastly different trajectories for efforts to rehabilitate black and white populations reflect and are born out of the same factors that led to different opportunities, experiences, and outcomes for black and white soldiers in the military. In situating the Tuskegee Syphilis Study within this context, this chapter opens my dissertation with a meditation on the "no treatment" involved in the study as a suggestion for how an analysis of race might reshape and contribute to existing disability studies analysis of the post-war turn to rehabilitation that has, ostensibly, compelled "us" all to able-bodied normativity. Though sexually transmitted illnesses are not war injuries in the traditional sense, I situate this study in the context of post-war rehabilitation to show that properly accounting for the role of race in rehabilitation necessitates a more expansive view of disability and post-war medicine, one that includes more than simply those conditions predetermined to have an obvious relationship to war. As I will discuss, sexually transmitted illnesses were thought to reveal information about fitness for military service, and concerns about their spread during military service spurred the institution of the Venereal Diseases division of the U.S. Public Health Service, and influenced the racially disparate training of military physicians.

Reflecting on the Tuskegee Syphilis Study is important because it is the single longest-running non-therapeutic experiment in the history of medicine and perhaps the most notorious scientific breach of ethics on human subjects in the United States. It prompted the development of additional ethics research guidelines and laws like the 1974 National Research Act. Such guidelines, as I discuss in my fourth chapter, are currently receiving pushback from transhumanist advocates who see them as a barrier to scientific “progress” and want to dismantle them. The study has had a continued and extensively documented impact on the relationship between African Americans and medicine. Still, as historian Vanessa Gamble notes, though the study has resulted in heightened suspicion of doctors and medicine and is rightly used as a symbol of a relationship that has long been exploitative, such suspicion and the mistreatment that produced it predate public revelations about the study and continue into the present[9]. Therefore, situating the study within the broader context and racial ideologies that made it possible can allow for an analysis of the ways they continue into the present.

While there is now a plethora of rigorous and important analyses of the study, and many have noted that the study was originally conceptualized as a plan for treatment, none in my research have attempted to explain *how* the original stated goal could so easily fall out of the

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[9] Gamble, Vanessa Northington. "Under the shadow of Tuskegee: African Americans and health care." *American journal of public health* 87, no. 11 (1997): 1773-1778.

picture, why such a massive change in course could be permitted with so little contestation, and what this says about rehabilitation more generally. The ease with which an explicitly rehabilitative project became a "death watch"[10] with "no treatment" whatsoever illustrates the problem with assuming rehabilitation targets us all equally in the same way. Prior racialized and gendered assumptions about what constitutes a state of "normalcy" are by definition involved in determining what can be regarded as rehabilitation and whether, how, and to what extent it will be pursued as a normalizing project by the state. Which injuries and illnesses are legible and for whom? Which responses (or non-responses) are presumed warranted and for whom? To supplement this analysis, I read the 1949 war film *Home of the Brave*[11], a story of blackness and rehabilitation in World War II that, by my reading, inadvertently illustrates that the function of rehabilitation for the black subject may resemble more closely a "rite of sacrifice" (to quote Byron and Bey) in service of the maintenance of a racist sociopolitical "normalcy" than a compulsion toward physiological "normalcy."

Though best remembered as a film, *Home of the Brave* was first a play whose central character was a Jewish soldier. Arthur Laurents's 1945 play tells the story of a Jewish American WWII soldier named Peter Coen, or Coney. He becomes psychosomatically paralyzed following experiences with discrimination and the traumatizing death of his friend Finch during a mission they served with three other soldiers on a Japanese-held Pacific island. The play focuses on his rehabilitation at the hands of an army psychiatrist who works to relieve him of the guilt he feels

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[10] James Jones (p. 146) coins this term to emphasize the centrality of autopsy to researcher's explanations of the significant "opportunity" provided by this study. In essence, doctors and researchers spent forty years waiting for the experiment subjects, both the 400 patients who had syphilis and the 200 who were used as a control group, to die so that they could examine their organs up close.

[11] *Home of the Brave*. Dir. Mark Robson. Prod. Stanley Kramer. Perf. James Edwards, Lloyd Bridges, Jeff Corey. United Artists, 1949.

about his friend’s death and to convince him that he is just like everyone else. Having served in the U.S. military during World War II, Laurents loosely based his fictional play on his experiences with anti-Semitism at the hands of his fellow soldiers. In 1949, director Mark Robson and producer Stanley Kramer bought the rights to the play and rendered it into a film. The script was reworked by Carl Foreman in consultation with Laurents. In the process, the main character was re-written from being Jewish to black, and Peter Coen became Peter Moss. The decision was based on Kramer’s belief that it would be more lucrative because “Jews have been done,” specifically in *A Gentleman’s Agreement*, which takes on anti-Semitism. Though the “daring,” “bold,” and “groundbreaking” film received generally positive reviews, the character translated awkwardly, which was attributed to a glaring omission. Laurents notes on the transition that “Not a critic, not a vocal soul was bothered that there were no racially integrated units in the Army like the one in the picture.”[12]

Given that the segregation was official policy in the U.S., and particularly in the military, at the time, and that the film was screened in segregated movie theaters upon its release, this absence has since been noted by many reviewers. In an otherwise glowing review produced for the DVD release of the film, Glenn Erickson[13] notes that the film “soft-pedals the facts about segregation in WWII,” and the assignment of a black surveyor to the mission “would seem an extraordinary circumstance.” The film makes some efforts to address this gap. For example, whereas Finch and Coen meet in the Army and grow to be close friends, Finch and Moss are childhood friends who served separately in the Army before this assignment. Unsurprisingly,

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[12] Arthur Laurents. *Original Story By: A Memoir of Broadway and Hollywood*. New York: Random House, 2000.

[13] Erickson, Glenn. *DVD Savant: A Review Resource Book*. Rockville: Wildside Press, 2004.

Moss was “the best basketball player” on their shared basketball team. Still, Erickson describes this as understated. Even as the only black child visible in his high school flashback, school segregation is not acknowledged beyond Moss’s own apprehensions about social interaction. In the flashback, “Moss is uncomfortable around Finch for subtle reasons, when everyone on campus including Finch would surely be aware that a white student associating with a black student would at best be considered socially ‘uncomfortable'. Even if Moss were a star athlete, it might not have made much of a difference.” In a footnote, Erickson adds, “It sure didn't in my high school, even in 1968.” Still, the film ultimately places the blame for Moss’s psychosomatic paralysis on his “sensitivity” to this racism and his inability to recognize that he is just like everyone else, as opposed to blaming it on the racism itself.

This central message may not have been intentional. Produced by liberals, the film was intended to convey the gravity of anitblack racism within the World War II military. Stanley Kramer was a staunchly liberal Hollywood producer responsible for multiple films addressing racial inequality. In at least two of his films, *Home* and the 1962 *Pressure Point*, he substitutes a black character on-screen for the Jewish literary character on which it is based. Similarly to Johnson and fellow liberal Moynihan, Kramer posits that “a white man can’t know the depths of a black’s suffering. I search for the truth but it’s never there for me in its totality. All I can ever seem to find is part of it.”[14] In accordance with his beliefs and along with a staunchly liberal team, Kramer produced *Home of the Brave* as one in a series of liberal post-war “message movies” in the 1940s and 50s. Director Mark Robson was also liberal, and produced several other films about race. Script writer Carl Foreman had at some point been involved with the

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[14] David Marriott. *Haunted Life: Visual Culture and Black Modernity*. Rutgers University Press, 2007.

Communist Party and was eventually blacklisted for allegedly being uncooperative with the House Committee on Un-American Activities.[15] As a story of racism and psychiatric rehabilitation told from a white liberal lens, the film offers both a historical record of popular conceptions of race during World War II and an important lens through which to rework predominant conceptions of rehabilitation in the field of disability studies.

II.

Within disability studies, historical and otherwise, the notion of rehabilitation has been key to an analysis of the government, care, and oppression of disabled people. Though different disability studies scholars take different stances toward rehabilitation, some more favorable than others, what underlies all the analyses is the assumption that studying rehabilitative practices reveals particular relationships between governing bodies, governed subjects, and medicine that seek to return disabled people to "normalcy," either natural or socially/politically constructed. Though such analyses have proven very useful to understanding the relationship between disability and power, intersecting these questions with race calls into question the idea of an established non-racialized state of normalcy to which all subjects are compelled. In line with the field's broader tendency to view disability as socially constructed rather than as an objective medical condition, the foremost scholars of the field view rehabilitation critically. Tremain's aforementioned *Foucault and the Government of Disability*[16], which uses Foucault's theories of power to understand disability, illuminates the field's critical stance on rehabilitation. Foucault's biopower targets populations through such mechanisms as statistics and measurement (including,

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[15] "Carl Foreman, Screenwriter, Producer, Dies." *The Washington Post.* June 27, 1984.

[16] Tremain, Shelley. *Foucault and the Government of Disability*. Ann Arbor: U of Michigan, 2005.

for example, birth/death rates, reproduction rate, fertility, etc.).[17] Biopower produces a “norm” through these mechanisms, and “normalization” compels individuals toward this norm in a more efficient and totalizing, though less obviously brutal, form of government than older forms of sovereign power.[18] This compulsion to the norm, or normalization, conceptualized as a coercive, if subtle, application of power, is what constitutes rehabilitation. The trouble with rehabilitation, then, is that it is part of this process of coercive government. It pushes, often violently, to produce normalized, productive, universal subjects.

Most disability studies scholars agree disabled subjects are governed by this process, though not all are entirely opposed to it. Some have advocated for increased or improved forms of rehabilitation. One example is Bill Hughes[19], who argues that Foucault’s analysis is too “non-materialist” to result in actual improvements for disabled people, for whom policy changes, assistance, and resources would be more useful. Other scholars view rehabilitative normalization as a repressive process. Martin Sullivan[20] argues that rehabilitative practices in facilities for spinal-cord-injured people work to produce both a “certain type of body – a governable and, hence, productive body.” David Serlin,[21] similarly, studies the proliferation of new rehabilitative technologies in the aftermath of World War II, arguing critically that they represent normalizing

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[17] Foucault, Michel. *Society Must Be Defended*, 1975-76. (Ed. Mauro Bertani). New York: Picador, 2003.

[18] Foucault, Michel. *Discipline and Punish: The Birth of the Prison*. New York: Pantheon, 1977.

[19] Hughes, Bill. “What can a Foucauldian analysis contribute to disability theory.” (2005).
Allan, Julie. “Inclusion as an Ethical Project.” (2005)

[20] Sullivan, Martin. “Subjected bodies: Paraplegia, rehabilitation, and the politics of movement.” (2005).

[21] Serlin, David. *Replaceable You: Engineering the Body in Postwar America.* Chicago: U of Chicago, 2004.

power, the merging of state and corporate interests disguised as benevolence. Robert McRuer[22] understands rehabilitation as a logic to which both queer and disabled populations have historically been subjected as a means of regulation and control. He notes that disability-themed memoirs or journals are often marked by a "conflict over rehabilitation - or, more precisely, over the 'return' that rehabilitation (which at its root suggests the return to a former role or capacity) might or might not facilitate."[23] In other words, the conflict arises both when that return is not possible, in the violent process of trying to enforce that return, and in the assumption that the return is always necessary or desired. As McRuer notes, implicit in rehabilitation is the concept of "return to a former role or capacity," as one who is able-bodied, having more capacity (to labor), or a prior state of normalcy. Though this analysis offers a useful intervention into the medical and social models of disability, its conceptualization of disability and "rehabilitation" nevertheless relies on the presumption of a universal subject for whom there exists an idealized normal and on the universal application of power that seeks to compel all subjects, equally, toward that state. This is the lens through which disability studies, particularly the social model and Tremain's discursive extension, have taken up the historical study of rehabilitation and the study of the political management of disability more broadly.

Yet the assumption of an established state of normalcy, and a governing body that seeks to compel all subjects toward it, cannot be sustained when the subject is racialized rather than universal (or rather, when the "universal" subject is revealed to be a white man). For example, a plethora of World War II documents reveal that military doctors and psychiatrists assumed that

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[22] McRuer, Robert. *Crip Theory Cultural Signs of Queerness and Disability.* New York: New York UP, 2006.

[23] Robert McRuer, 103.

black soldiers did not share the same physical and psychological characteristics and capacities as their white counterparts. As military psychiatrist Ernest Hadley phrased it in a 1942 contribution to the journal *Psychiatry*, “The colored men offered me the greatest difficulty in diagnosis… Poor cultural, occupation and educational backgrounds often made it difficult to decide whether they were defective, preschizoid, or just colored.”[24] Such statements are representative of the more general prevalence of medical and popular racist conceptions that blurred the lines between blackness and neurosis, and they call into question the idea that for black people there was a clear “normal” to which the process of normalization could force a return. This helps to explain why black veterans, in particular, have routinely had the most difficulty petitioning for disability benefits after serving in the military, as documented by historians Larry Logue and Peter Blanck in their 2010 text *Race, Ethnicity, and Disability: Veterans and Benefits in Post-Civil Rights America.*

If the black subject cannot be normalized toward an established normal, particularly in a racist culture in which normalcy is racist, then how might the process of rehabilitation work differently? Racist power does not seek to “normalize” the object, or target, of its power, which it has already constituted as abnormal, but rather to normalize the racist structure itself. As Martinician psychiatrist and decolonial thinker Frantz Fanon explained, “Race prejudice in fact obeys a flawless logic. A country that lives, draws its substance from the exploitation of other peoples, makes those peoples inferior. Race prejudice applied to those peoples is normal.” As a result, “The racist in a culture with racism is therefore normal. He has achieved a perfect

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[24] Ernest Hadley. “An Experiment in Military Selection.” *Psychiatry* 5, no. 3 (1942): 371-402.

harmony of economic relations and ideology."[25] I suggest that the process of rehabilitation works not by compelling black subjects toward a state of normalcy but by using black subjects to produce a state of normalcy and compelling them to maintain it with silence. In *A Freedom Bought With Blood*,[26] Jennifer James notes that black American war writers often downplayed or omitted the struggles they faced as part of a process of "damage control" against both the prevalence of images of injured black bodies and the extra lengths to which they had to go to prove competence. Perhaps, then, that is the compulsion - not a normalization that situates them as part of the norm but a normalization that compels them to maintain it, and to be sacrificed in service of it. The process of rehabilitation, rather than "returning" the black subject to a predetermined state of able-bodied normalcy, mimics the logic of "separate but equal" on which the World War II military was based, where the impetus behind "separate" suggests inequality, but the "equal" commands not equality of conditions or treatment but just enough of an explicit pretense of equality, a rhetoric of equality, to maintain and legitimize the separation.

III.

World War II is significant in the history of American racism in part because of the glaring contradiction between the U.S. military's claim to be fighting racism abroad and its own segregation policies. According to historian Neil Wynn[27], there is some disagreement in the historical literature about the extent to which the Second World War represents a turning point for black people in the U.S. and about whether the impact has been overstated and might instead

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[25] Fanon, Frantz. *Black Skin, White Masks.* 1952. New York: Grove Press, 2008.

[26] James, Jennifer C. *A Freedom Bought with Blood: African American War Literature from the Civil War to World War II*. UNC Press Books, 2012.

[27] Neil Wynn. *The Afro-American and the Second World War*. Holmes & Meier Pub, 1993.

be understood in continuity with other historical events. Still, given that the war highlighted the contradictions of the emerging status of the United States as an empire, the period was characterized by continuous protest against domestic and military segregation policies. The March on Washington Movement managed to force the denouncement of military segregation, and a nominal end to racial segregation within the defense industry. Yet segregation in the armed forces remained official policy until 1948, after the end of World War II.

The storyline of *Home* is likewise characterized by contradictions between the overt racism represented throughout the film and the discourse of universalism that seeks to deny it. Moss, the black protagonist of the film, is psychosomatically paralyzed as a result of such experiences until the psychoanalyst rehabilitates him, and successfully cures him, by yelling a racial slur at him, which leads to Moss's realization that, in his words, "we're all just guys." Though the use of the slur ostensibly rehabilitates him by rousing enough anger that he is able to stand, his anger is fleeting. The use of the strategy thus illustrates Fanon's argument that in a racist society, racism is "normal" and rehabilitates Moss to this normalcy to the extent that he accepts it. The masculine declaration that follows affirms the common phrase "no one can make you feel inferior without your consent," and the oppression disappears to the extent that he denies its existence. The superficial claim to both the universalism implied by "we're all" and particularly to masculine belonging allows him to maintain this illusion. A fellow soldier, Mingo, who lost his arm on the mission, is useful to this end because he helps to universalize Moss's difference. By showing Moss that they are both different, but also "the same underneath," he finally leads to Moss's epiphany: "I am different. Everybody's different. But so what! Because underneath we're all guys."

The universality here is founded on masculinity, which is glaring because Peter Moss is so improperly masculine, in ways that distinguish the film from the play. He spends much of the film either quietly observing the white men as they make comments about him, or lying on his back at the hospital, looking up at the doctor with camera angles that emphasize their relative positioning. He is overly emotional, and in clear distinction from the play, he is not permitted to have any sexual thoughts. In the play, Finch tries subtly to devise a plan to set Coen up with his sister upon their return. Their relationship is so intimate that it borders on sexual; even Laurents later described it as accidentally "homosexual." Most notably, the play's Jewish soldier Coen is allowed to punch a racist soldier in self-defense, a crucial moment that solidifies his character's rehabilitation by "proving" his masculinity. By contrast, in the film, Moss's fleeting anger quickly becomes gratitude. Unlike Coney, he is never allowed a cathartic moment of violent self-defense. Laurents's descriptions of his own encounters with anti-Semitism in the military suggest that the slur could only be understood as fully rehabilitative in relation to the punch (the self-defense) to which it leads. Laurents describes a moment during his military service when his army sergeant describes several of the soldiers, himself included, with an anti-Semitic slur. He was immediately punched by Laurents's friend, Bob Hopkins. "What a lovely irony that slur was!" he exclaims, "In truth, the happy turn in my army life began with being called a kike. I don't know if Bob Hopkins was at all aware how much my life changed."[28] Without the self-defense that follows, the scene only serves to reinforce the legitimacy of the slur and the racism it signifies, and shifts the burden to the victims and their response.

Like the rehabilitated Moss, the film's plot line acknowledges segregation but does not

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[28] Arthur Laurents. *Original Story By: A Memoir of Broadway and Hollywood*. New York: Random House, 2000, 21.

dwell on it. Segregation remains an absent presence in the film, central to understanding the historical context but never explicitly addressed. The film's rehabilitative process involves procuring Moss's denial of the existence of the anti-black racism to which he is subjected throughout the film, even in the process of rehabilitation itself, and against which he is not given the opportunity to defend himself. The simultaneity of racist practices and the verbal denial of such practices also characterizes the World War II military, as evidenced by numerous military directives. Though the military was segregated and military appointments and practices were characterized by clear patterns of racism, military directives often commanded equal treatment for all soldiers. A September 1944 "Directive to specific ships," for example, directs that "commanding officers are cautioned to check closely to assure that Negros are given the same consideration in duty assignments, and are accorded the same opportunities for training and advancement as are others." Less than two months later, an October 1944 directive states that "the activities listed below… the Bureau desires to have considered as not suitable for the utilization of Negro personnel" …and these include various naval flight and tech schools. Similarly, while one directive conceded that "it is recognized that certain officers would [not be] temperamentally suited" to command black soldiers, those who were up to the task should "completely suppress [their] personal attitudes."[29] While anti-black racial hostility was "understandable" and considered as natural, black soldiers' complaints about racist treatment were often met with punishment.

Black newspapers played an active role in covering the experiences of black soldiers in the military and pushing back against segregation and discrimination. *The Pittsburgh Courier*,

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[29] Dennis Denmark Nelson. *The Integration of the Negro into the United States Navy, 1776-1947*. Vol. 526. US Dept. of the Navy, 1948.

for example, launched what it called the “Double V campaign,” which cleverly intertwined support for the fight against enemies abroad, which was necessary to deter sedition charges, with the fight against enemies of democracy and racial inequality at home. Such newspapers also regularly received correspondence from black soldiers who shared their experiences with racism and discrimination in a bid for awareness and support. On August 10, 1944, a black World War II sergeant named John M. Walls, Jr. wrote a letter[30] to the editor of the *Houston Informer* called “Neurosis is on the Rise,” in which he recounted his mistreatment by the military in a plea for awareness and assistance. After being transferred to a “HELL HOLE” in Augusta, Georgia, he began to have severe headaches, chronic pain, and became excessively “nervous” for which he was given “three consultations with the Psychiatrist to see if [he] was on the verge of Insanity.” He was transferred to “a ward that was supposed to be for men whose nerves were in bad order.” There, “[his] torture instead of [his] help began.” He explains, “I had been selected as a Guinea Pig to be tortured until I told the Experimenters everything they wanted to know about myself, and my opinion as to certain race questions.” He does not go into detail about the nature of the experiments, but the letter is very revealing in that it points to some of the contradictions in seeking to understand the rehabilitation of someone whose ailment registers as “trouble” (his words), i.e., as criminality and deviance rather than suffering, to those who are supposed to be treating him. The rehabilitation, rather than seeking to end his suffering, seeks instead to eliminate physical signs and verbal expressions of his racist mistreatment.

As illustrated in this anecdote, the postwar rehabilitative turn did not take black veterans as its intended recipients. Beth Linker explains that “even though white soldiers benefitted more

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[30] McGuire, Phillip. *Taps for a Jim Crow Army: Letters from Black Soldiers in World War II*. UP of Kentucky, 1983.

than blacks, rehabilitation still did not live up to its propagandized ideal. Despite receiving medical care and vocational training, many injured white soldiers found the postwar labor market unforgiving and intolerant of their disabilities."[31] Linker is right to point out the rehabilitative turn's failures to live up to its own dream, even for white soldiers who were the main focus of the project, in part because the turn was (and is) premised on fantasies of individualism and self-sufficiency as well as the "bootstraps" myth of social advancement. Still, she does not meditate on the near-total exclusion of black soldiers from the same "propagandized ideal of rehabilitation," even by her own evidence.

"Rehabilitation propaganda was overwhelmingly white in content and appearance. While rehabilitation officials devoted numerous articles to the Americanization of foreign-born disabled soldiers, they barely addressed the subject of disabled African American soldiers… It was an existence without comment, for rarely if ever did rehabilitation officials actually provide stories of the African American men who had been injured during the war."[32] Linker attributes this to the fact that officials wanted to draw attention away from unsegregated military hospitals which, unlike other parts of the military and civilian life, serviced both black and white veterans in the same facilities. Such images might have shined a light on this fact and produced controversy. But could there have been another explanation? Could it be that black soldiers were simply not the focus of the campaign for rehabilitation? Could it be that the images would not have been as effective *as propaganda* in eliciting the sympathy or admiration such images are intended to invoke and therefore in motivating support and investment in the project?

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[31] Beth Linker, 139.

[32] Beth Linker, 135.

IV.

These images would have failed to produce the same affective and material response as the images of white disabled soldiers, and this is rooted in preexisting ideas about the naturalness of suffering and the deservedness of well-being. Racist beliefs about black male (hyper)sexuality, immorality, and inferiority created a "common sense" about the "naturalness" of syphilis in the black community, producing the affective and material response that became the Tuskegee Syphilis Study. To contextualize, in 1906, Dr. Thomas W. Murrell, a physician and lecturer at the University College of Medicine in Richmond, Virginia published an article entitled "Syphilis in the Negro; Its Bearing on the Race Problem." In this piece, he identifies the "race problem" as the "one question before the Southern white man," a problem that haunts every other issue in his life. In three pages, he sums up the race problem as "the struggle for race purity on the part of the Caucasian, and the struggle for existence on the part of the Ethiopian." White "race purity" is threatened by "acts of violence, nearly always licentious in character, on the part of the black man" and black existence is, in this fantasy, threatened by "the swift, sure punishment that the white man metes out to him" as a response to these acts. The "ever but one question before the Southern white man," in other words, is that black men desire and rape white women.

The bulk of the short piece is a regurgitation of the popular racist fantasy most famously presented by *Birth of a Nation*, but the piece is about syphilis. Murrell relates this racist fantasy to syphilis by positing that "insanity" amongst the black population has risen by "one thousand percent" since the abolition of slavery, as has syphilis, which was virtually unheard of amongst enslaved black people. He speculates that the two trends must therefore be related and claims that syphilis must be more likely to cause insanity in black people than in white people. How does this “bear on the race problem?” He uses syphilis to establish a connection between his longing for an idyllic slave past and his genocidal fantasy which, through this link, becomes natural and inevitable. The race problem is interchangeable with the “negro problem.” According to Murrell’s theories, the “black man’s burden” is that he is destined to die, to be sacrificed in service of solving the white man’s problem: “Perhaps here, in conjunction with tuberculosis, will be the end of the negro problem. Disease will accomplish what man cannot do… Heavy, indeed, is the black man’s burden.”

Syphilis is convenient as trope and “evidence” of the biology of race because the variety of afflictions to which it leads in its various stages take both physiological and psychological forms and because, as a sexually transmitted illness, it has been used as evidence of immorality and character deficiencies. Murrell’s piece illustrates this well. At once, Murrell uses syphilis to mark black unfitness for freedom, proclivity to “insanity,” sexual promiscuity, “sickliness” (“those that are treated are only half cured”) which signifies inherent biological inferiority, and danger, most especially epitomized by black men’s alleged desire for and tendency to rape white women. The particular symptoms of syphilis by which Murrell establishes these racial differences were all central to broader post-Civil War discourses about the supposed dangers of freedom, both to white people and to black people. In other words, syphilis allows for the psychological, physiological, and moral construction of race simultaneously. And this combination renders “syphilitic” as a potential shorthand for both physical “inferiority” and “moral deficiency.”[33]

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[33] So much so that in a recent *New Republic* op-ed, Dr. Steven Beutler speculates that Donald Trump might have untreated late-stage syphilis, or neurosyphilis, in part because of “irritability, loss of ability to concentrate, delusional thinking, and grandiosity,” in addition to his admittedly “promiscuous” past behavior.

Public health efforts surrounding World Wars I and II exacerbated existing racialized fears about syphilis. The public health emphasis on venereal disease in general was born out of war efforts. In fact, Congress's 1918 decision to establish the Division of Venereal Diseases within the United States Public Health Service (PHS) was prompted by physical examinations of recruits during World War I: "When physical examinations of recruits during World War I revealed high incidence of venereal infections, social hygienists had warned that venereal disease threatened to disable America's fighting men." The PHS was given abundant funding to establish this division, in addition to $1 million to help individual states launch public health efforts to treat venereal disease. In response, forty-four states established separate bureaus to address venereal disease within their own health departments and 202 clinics were organized in thirty states, with more than 64000 patients under care who would otherwise not have afforded treatment."[34]

Support was reduced tremendously after the end of World War I, with the war-related sense of urgency waning. Alabama was one state that tried to maintain the newly established public health program even as federal support came and went with the wars, and the efforts actually resulted in a substantial reduction in rates of venereal disease. Still, "Alabama's treatment program all but ignored rural blacks." The neglect was particularly bad in rural areas because it was less likely that syphilis would be communicated to white residents than in urban areas, where residents lived in much closer quarters and black people comprised a substantive portion of the patients relying on the services of urban public clinics. Dr. D. G. Gill, director of the Bureau of Preventable Disease of the Alabama State Board of Health gave a 1930 speech to

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[34] Beth Linker, 49.

the Social Hygiene Association in which he praised the gains made by these social hygiene program efforts but "admitted that 'the solution of the problem of syphilis amongst the rural Negro population still awaits fulfillment.'"[35]

Efforts to the address the problem were by then underway, led by the Public Health Service, working with what was now the National Negro Health Week and with philanthropic organizations. These efforts, according to James Jones, were influenced by new theories of illness starting in the early twentieth century. The emergence of the germ theory of disease and new studies on the primacy of environmental factors in determining health outcomes "showed" that diseases could easily be transmitted interracially, unlike previous theories that speculated that racial hierarchies determined susceptibility to illness. This led to increased interest in public health programs designed to serve black people in the early twentieth century. "Quite apart from the humanitarian duty to help diseased people the self-interest of white Americans required improved health care and more sanitary living conditions for blacks. Moreover, public health officials never tired of reciting figures documenting the economic cost to the nation of neglecting black health. Black illnesses threatened not only whites' health, but also white pocketbooks," and therefore addressing black public health dually served white self-interest. Philanthropic foundations and public health organizations teamed up to address many public health crises that had heretofore been neglected. The Rockefeller Foundation, in particular, was a key participant in such philanthropic public health efforts and had participated heavily in combatting hookworm and pellagra before World War II.[36]

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[35] James Jones, 51-52.

[36] James Jones, 34.

These new theories stressed that segregation did not prevent contagion. As long as black people and white people could come into contact with one another in public and workspaces, all were at risk of contracting the same communicable illnesses. Black public health became a priority for the federal government only to the extent that it was recognized that the same illnesses that afflict black people also afflict whites, that these illnesses could be transmitted "between races" just as easily as within them and that therefore the refusal to treat black populations is epidemiologically risky for white people. The late legal scholar Derrick A. Bell, Jr. calls this reasoning "interest convergence" and theorizes that policies that address the needs or interests of black people, like the *Brown v. Board of Education* ruling, are only possible when middle- and upper-class white people believe such policies would also advance their own interests.

Bell argues that because white interests no longer converge with desegregation, efforts to achieve it have died down. I would take this further to argue that when seemingly progressive race-related policies are implemented on the basis of "interest convergence," they are inevitably doomed to failure *as progressive policies*. If interest convergence is only possible when dominant interests are being met, and dominant interests could just as easily be met without such convergence, then the driving force remains the maintenance of white supremacy. Genocide can be as much a "solution" as treatment. The leading consideration remains the alleged, real or imagined, concern of white middle- and upper-class people, whether their concerns are about epidemiology or "racial purity." Either way, whether by treatment or genocide (in the case of the threat of contagion from syphilis), integration or genocide (in the case of threats to the social order from opposition to segregation), the imagined problem is "solved." This is what unites

Murrell's proposed solution, medical genocide, and the early 1900s race-based public health initiatives. This is also how a program initiated as an attempt to provide "treatment" to massive numbers of black people can so easily, quickly, and unproblematically become a 40-year "death watch."

In addition to pushing for race-based public health programs, Progressive Era reformers were also the driving force behind the "rehabilitative turn." All wars, including the Civil War, have typically been followed by efforts to rehabilitate war-related disabilities[37]. The Civil War was central in constructing disability and developing rehabilitative governing technologies. The Civil War and Reconstruction "helped to redefine disability for the modern state."[38] The development of new prosthetic devices was conceived and advocated for by figures like prominent academic and doctor Oliver Wendell Holmes as a way rehabilitate and reconstruct the body and the body politic, particularly following a war that posed a major threat to its coherence. Every end of a major war spurred new developments in rehabilitation, and in all cases, the post-war rehabilitation of the injured and disabled body is necessarily tied to the social rehabilitation vital for remedying the social and political fractures and fissures caused by the war. Yet, it was this Progressive Era ideology and its implementation in World Wars I and II that really turned the tide of post-war veteran care toward, primarily, rehabilitation and incorporation, rather than compensation or ostracism. The emphasis was less on providing veterans the means to live,

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[37] Reuben Eldar & Miroslav Jelić. The Association of Rehabilitation and War. *Disability and Rehabilitation*. Vol. 25, Iss. 18, 2003.

Holmes, Oliver Wendell. "The Human Wheel, Its Spokes and Felloes." *The Atlantic Monthly* 11, no. 67 (May 1863): 567-580.

[38] Yuan, David. "Disfigurement and Reconstruction in Oliver Wendell Holmes's 'The Human Wheel, Its Spokes and Felloes'" in *The Body and Physical Difference* (eds. Sharon Snyder and David Mitchell). Ann Arbor: University of Michigan Press, 1997, 71.

which was increasingly seen by reformers as costly and unsustainable, and more on "correcting" their bodies so that they would have the means to provide for themselves.

While Progressive Era reformers pushed for race-based public health programs, they would not have been instituted without at least some convergence with concurrent more conservative strains of racist thought. There are clear tensions between the colorblind environmental analysis of racial health disparities that, according to Jones, became the predominant analysis among medical professionals in the early twentieth century and the social Darwinism that, according to Allan Brandt, became in the same time period the predominant biological explanation for race-based disparities of any kind:

> By the turn of the century, Darwinism had provided a new rationale for American racism. Essentially primitive peoples, it was argued, could not be assimilated into a complex white civilization. Scientists speculated that in the struggle for survival the Negro in America was doomed. Particularly prone to disease, vice, and crime, black Americans could not be helped by education or philanthropy… The medical profession supported these findings of late 19th- and early 20th- century anthropologists, ethnologists, and biologists. Physicians studying the effects of emancipation on health concluded almost universally that freedom had caused the mental, moral, and physical deterioration of the black population.[39]

The two theories are used by the respective scholars to contextualize the development of the Tuskegee Study.

This suggests that Murrell was not alone in asserting that racial disparities in rates of syphilis were the result of ingrained biological differences, impossible to transcend, that represented biological inferiority, sexual immorality, and unfitness for freedom. Nor was Murrell's view a remnant of the 19th century in the process of dying out. While this view seems at odds with what Jones identifies as the predominant view, what both views share is a belief in

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[39] Allan Brandt, 16.

white supremacy and superiority and an investment in designing policies around the best interest of the white population. Studies that emphasized environmental factors and the potential for cross-racial transmission of communicable illnesses did so in the interest of protecting the white population from this possibility. Whereas Murrell and others who espoused his ideology sought to expose the supposed dangers of black men whose lust for white women could not be controlled, Progressive Era reformers sought to emphasize that the white population could also be affected when communicable illnesses were left untreated in the black population. Thus, out of a begrudging acknowledgment of necessity from multiple dominant vantage points, and with the support of black leaders who backed the efforts for entirely different reasons, programs were instituted to address public health in black communities, which had until then been neglected by state efforts.

Public health officials enlisted the help of both philanthropic organizations and black public leaders, who supported the project in hopes that resources and care would be directed at black communities that had previously been neglected by public health efforts. Booker T Washington was one such leader. He had already founded the Tuskegee Institute, a historically black university, in Tuskegee, Alabama and came to be greatly involved in these public health efforts, which officially came to be known as the National Negro Health Week in 1915 and lasted into the 1950s. Washington passed away just before the efforts came to fruition. Robert R. Moton, who succeeded Washington as president of the Tuskegee Institute, took over the initiative, which was then based in Tuskegee, and led it into becoming a national project by 1930.[40]

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[40] Roscoe Brown. (1937) “The National Negro Health Week Movement*.” The Journal of Negro Education* 6 (3). pp. 553-564.

The same logic of contamination behind such public health programs (that became the syphilis treatment initiative that became the Tuskegee Syphilis Study) was also used to determine the training of black military physicians. “So far as the records show, there were no black physicians in the Great War who were trained and practicing in orthopedic surgery and who would advocate for specialized attention to black soldiers. Instead the Surgeon General’s Office assumed that those black physicians permitted to serve in the medical corps should put their energies into combatting contagious diseases - such as tuberculosis and syphilis - which were believed to be rampant among black troops and a direct threat to healthy white soldiers.”[41] Orthopedic injuries in black soldiers, non-communicable and experienced foremost as personal suffering, apparently did not warrant the same attention from military health officials who trained black physicians for military service.

This disparity in training, in addition to mistreatment within rehabilitative facilities, led to demands by both black physicians and servicemen for separate veterans’ hospitals that would specifically service black veterans. Post-war rehabilitative procedures originally stated that black and white veterans, despite serving in a segregated military, should be rehabilitated in the same facilities. This policy failed to be effectively instituted and was met with criticism in multiple forms. Many black physicians were opposed to the policy because they noted that black veterans were not getting adequate care in these facilities and faced much higher death rates due to neglect. The highest appointed black military official, Emmet J. Scott, the Special Assistant for Negro Affairs to the Secretary of War, produced a 1917 report from Camp Hill in Virginia showing that “while white soldiers had ample hospital accommodations, sick black soldiers

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[41] Beth Linker, 88.

during a cold winter of 1917 'were huddled together… eighteen in one tent, without any wooden floors in the tents.' Scott directly attributed the 'abnormally high death rate' among black soldiers to the blatant negligence of the black man's health and basic needs by the Surgeon General's office."[42]

Despite the fact that veterans' hospitals were nominally integrated, many hospitals, particularly in the South, refused to hospitalize black veterans in the same facilities.[43] Other patients themselves often contested integration. "Certain white disabled subjects, intolerant of the fact that they had to share rehabilitation quarters with black soldiers, demanded transfers to all-white hospitals,"[44] some even going so far as to hurt or kill black soldiers, starting "riots" like the 1918 Camp Merritt riot that began when several white soldiers demanded that the YMCA segregate their medical facilities. Having been pushed out of medical and rehabilitative facilities or neglected within them, black soldiers demanded medical facilities where they could receive proper care. So, "by 1923, when the federal government instituted a system of veteran's hospitals (what we know today as Veterans Administration Hospitals), the committee on hospitalization created one black veterans' hospital, the Tuskegee Veterans hospital, while designating the remaining 26 hospitals for whites."[45] Because race-based public efforts were already underway and because of the prominence of the Tuskegee Institute, Tuskegee was chosen as the location for this Veterans Hospital. The first and only hospital instituted specifically for black veterans

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[42] Ibid.

[43] Vanessa Northington Gamble. *Making a Place for Ourselves: The Black Hospital Movement, 1920–1945*. Oxford: Oxford University Press, 1995.

[44] Beth Linker, 137.

[45] Ibid.

happened to be instituted also in Tuskegee, where race-based public health initiatives were also underway. The hospital, the only one to focus on the rehabilitation of black veterans, came to be involved in recruiting and referring people for participation in the study. This is why the Tuskegee Syphilis Study is inseparable from the broader context of post-World War II rehabilitation.

Around the same time, at the beginning of efforts to treat syphilis in black communities neglected by earlier public health programs, Tuskegee became one of several locations in the black rural South where officials planned to launch the treatment efforts. Michael M. Davis of the Rosenwald Fund met with Hugh S. Cumming, the surgeon general of the United States Public Health Service to propose a program that involved increasing the number of black health personnel, sanitation programs, and other public health services, including a treatment program for what was believed to be a widespread incidence of syphilis among the rural black population, due to the aforementioned neglect of previous public health programs. Cumming agreed, on the condition that Davis would provide $10,000 to fund the program. Davis countered that the Rosenwald Fund would provide the necessary funds, so long as the treatment program stayed true to the goals of the foundation. Even as the course of the program strayed, this funding was maintained.[46]

Dr. Oliver Clarence Winger, director of the PHS's Venereal Disease Clinic in Arkansas, had previously conducted a survey showing a high incidence of syphilis among the rural black population and became involved in the proposal, chiming in with discussions of balancing ideal goals with feasibility and affordability: "Going for 'the cure' was simply too costly. The best he

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[46] James Jones.

could hope to accomplish was to render infectious patients noninfectious" with controlled doses of neoarsphenamine and mercury. This was one early indication that the course of the experiment was straying away from treatment. In November 1929, the Roswenwald Fund and the Public Health Service came to an agreement that $50,000 would be spent in 1930 to "control venereal disease in the rural South, in cooperation with the United States Public Health Service and with local authorities,"[47] with a recommended focus on six black rural Southern areas in Mississippi, Tennessee, Georgia, Alabama, North Carolina, and Virginia. The other sites were eventually dropped from the study, and its efforts became focused on Macon County, Alabama, where the need was dire: the county did not have a health department at all, and the study, still believed to a treatment initiative, received enthusiastic support from local authorities and an endorsement from the Tuskegee Institute.

The idea that the affordability of these treatment centers was a reasonable or inevitable concern ignores that treatment centers for venereal diseases had already significantly reduced the rate of syphilis, without concern for cost, in white rural areas and generally in urban areas where, because of the higher concentration of people, the interracial spread of syphilis was more likely. So, the fact that cost arises as a concern at all is the first indication that the treatment and well-being of this particular population, black people in the rural South, is not the point of these initiatives. The fact that the proposed solution to cost-related concerns is to treat only until the syphilis becomes non-communicable, rather than treating until the patient is cured, further reinforces this point, even before the actual experiment begins without even the pretense that treatment is the goal.

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[47] James Jones, 60

In *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*, Harriet Washington explains that racist medical experimentation has historically been defended on the basis of utilitarianism, or the idea that the suffering experienced by the subjects of these experiments eventually leads to benefits for many people. Washington explains,

> This essentially utilitarian argument presents an ethical balance sheet, with the savage medical abuse of captive women on the one hand and countless women saved from painful invalidism one the other. However, such an argument ignores the ethical concept of social justice, and these experiments violated this essential value because the suffering and the benefits have been distributed in an unfair way, leading to distributive injustice. In this case, the most powerless group, which is also a racially distinct group *and* a captive group, is the group upon which doctors inflicted harm 'for the greater good.' Another, privileged group enjoys the benefits but shares neither the pain nor the risks. Thus the moral unacceptability is clear.[48]

The longstanding pattern along which this distributive injustice falls also marks the distinction between white people, whose illness and disability is recognized as valid and supposed to be rehabilitated and black people who serve as a vehicle for the development of rehabilitative technologies, to be rehabilitated only in the event that it would be necessary to maintain white well-being. What the Tuskegee Study makes clear is that the risks involved in the development of many of these technologies could *only* be inflicted on a captive population to whom the risks have not been made known, and whose bearing of these risks actively benefits another population. This study could not have happened consensually, and so its distribution among the powerful and the powerless could not have been even. The existence of a population for whom such risks were naturalized was an essential part of this study and many others like it. Not only

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[48] Harriet Washington, 69.

does this history challenge the utilitarian argument, then, but it calls attention to a problem that is more severe than just distributive injustice. In other words, it is not simply that the development of rehabilitative technologies happened to take antiblack forms; it is that antiblackness has enabled the development of rehabilitative technologies.

With each change in the goals and plan for the experiment, cost and the presumption of noncompliance (by an "untreatable" population) were cited as reasons why treatment would be less and less likely until it was simply dropped from the research proposal altogether. Surgeon General Cumming began to call it a "study in nature" and gushed in a letter:

> The recent syphilis control demonstration carried out in Macon County, with the financial assistance of the Rosenwald Fund, revealed the presence of an unusually high rate in this county and, what is more remarkable, the fact that 99 percent of this group was entirely without treatment. This combination, together with the expected cooperation of your hospital, offers an unparalleled opportunity for carrying on this piece of scientific research which probably cannot be duplicated anywhere else in the world.[49]

Alan Brandt explains that though the Tuskegee experiment was regarded as a "study in nature," it did not meet the criteria for that category, as conceptualized by French physiologist Claude Bernard in 1865, because the criteria held that the observation would be entirely passive whereas in this study, "the very act of diagnosis altered the original conditions."[50] Even more so, the process of categorization, active prevention of access to treatment, testing, and administration of faux therapies involved in the study certainly altered original conditions. It is also not "natural" that black rural areas like Macon County were left completely untouched by previous public health efforts to control syphilis and other venereal diseases. Still, that it was *regarded* as a

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[49] Letters from Tuskegee Archives – Cumming to Moton, importance of study. Papers of the USPHS Study of Untreated Syphilis in the Negro Male in Macon County, Alabama.

[50] Allan Brandt, 18.

"study in nature" by the very doctors involved in the study to assess the possibility for treatment speaks to the fact that for black people in the United States, illness, not health, is regarded as "natural." Illness *is* the presumed state of normalcy. Thus, a reading of rehabilitation as a process that enforces "health" and "ability" as normalcy upon everyone cannot account for this racial distinction. This "observational" study was initiated in 1932 and then assessed by the USPHS in 1933 and approved for continuation indefinitely *with USPHS funding*. Though the USPHS did not have the funds to provide treatment to this population, they had funds, in the midst of the Depression, to watch these men suffer for 40 years and die, and to collect their corpses for further examination.

Though the study was by then completely unrelated to treatment, original advertisements recruiting participants for the experiment, directed specifically at black men in the rural South, promised "free treatment." Throughout the duration of the study, letters were sent to participants to maintain their involvement in the study, including a 1950s letter that exclaimed in capital letters: "REMEMBER THIS IS YOUR LAST CHANCE FOR SPECIAL FREE TREATMENT. BE SURE TO MEET THE NURSE."[51] The letter includes no mention of syphilis despite the fact that it has already been diagnosed and promises a "special free treatment" for "bad blood" *after* deliberate efforts were made to prevent these same participants from accessing penicillin, by this time a widely used and available, virtually guaranteed cure for syphilis. Contrary to the original claims of the researchers, the study did not rely on the subjects' ignorance or apathy, but actively lied to them and led them to believe they were receiving treatment. Had the researchers believed that the study subjects were indeed "untreatable" and that adhering to a course of treatment

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[51] Letters from Tuskegee Archives – Draft Board/Vonderlehr, adding new patients. Papers of the USPHS Study of Untreated Syphilis in the Negro Male in Macon County, Alabama.

would be impossible for them, they would not have lured them to participate in the study with false promises of treatment.

The study was not conducted secretly. Throughout its forty-year tenure, it received approval from hundreds of medical and government officials who repeatedly reviewed and signed off on it. It also regularly published findings in medical journals. Throughout this time, only two medical professionals ever publicly and persistently voiced concern over the experiment. In 1966, a venereal disease interviewer and investigator for the CDC named Peter Buxtun came upon reports of the experiment and became the second medical professional ever to voice moral objections about the experiment to the PHS, specifically to Dr. William J. Brown, the director of the Division of Venereal Diseases. In response, he was flown out to a CDC conference on syphilis where it had been arranged for him to meet with Dr. Brown and another doctor intimately involved with the study, Dr. John Cutler. By Buxtun's recollection, because of his objections, Cutler "thought of me as some form of a lunatic who needed immediate chastisement and he proceeded to administer it." Nothing came of this meeting. As a result, Buxtun resigned his position in 1967 and wrote Dr. Brown another letter in 1968, this time warning him that given the political climate, the experiment would have deleterious ramifications.

In this letter, Buxton described the experiment as "subject to wild journalistic misinterpretations" because "the group is 100% Negro" and expressed concern that it might "support the thinking of Negro militants that Negroes have long been used for 'medical experiments' and 'teaching cases' in the emergency wards of county hospitals."[52] Even as

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[52] Deadly Deception Interview – Peter Buxtun. Papers of the USPHS Study of Untreated Syphilis in the Negro Male in Macon County, Alabama.

perhaps the experiment's most vocal and persistent moral critic of all the medical professionals in his time, Buxton nevertheless expresses contradictory "concern" that the most long-standing and now the most notorious case of racist medical experimentation in the U.S. would be "misinterpreted" (as opposed to correctly interpreted) as evidence for black activists' claims that black people were being used by medicine for experimentation and teaching, rather than treated as patients. In this way Buxton, himself the child of a Jewish refugee of Nazi Germany, replicates the position of the Jewish psychiatrist in *Home of the Brave*, who at once validates Moss's experiences with racism by occupying a sympathetic position made possible by his own background and seeks to dismiss them by denying their significance, the validation serving only to strengthen the subsequent dismissal.

In response to this letter, Dr. Brown and the new director of the CDC, Dr. David Spencer, convened a panel to discuss the Tuskegee study. By this time the PHS had instituted guidelines on human experimentation, but they were not invoked in this panel. The review panel included no black members and only one doctor with no previous knowledge of or connection to the study. This doctor, Gene Stollerman, was the only one to voice concerns about the PHS's moral obligation to treat the men, suggesting that each of the 56 still-living syphilitic patients should be examined individually to determine the best course of treatment. The other doctors ignored this suggestion, and instead "lumped the men together and cited the severe complications that could result from penicillin therapy as absolute dangers… Dr. Olansky, whose named appeared as the principal author and coauthor of more publications on the study than any other investigator, was especially forceful in voicing his concern over the damage treatment might inflict on the men."[53]

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[53] James Jones, 195.

Rather than addressing the immense amount of harm the study had already caused to hundreds of black patients, the panelists instead painted treatment itself as harm. And this was not the first time the experiment had been spun this way. In the 1966 meeting, Cutler staunchly defended the experiment, by arguing that treatment would now be too risky and by citing its alleged potential to "benefit physicians who were treating syphilitic blacks." In this defense of the experiment, the harm became an unspecified, potential benefit and the existing, tangible treatment became potentially harmful. The white physicians' own investments in the study, their perverse scientific curiosity and their personal moral defensiveness, stood in for and were vocally expressed (albeit disingenuously and unconvincingly) as concern for the black subjects of the study and an investment in their well-being. Thus the welfare of black patients, for which the doctors feign concern, is ultimately revealed in fact to be a concern for the state of scientific inquiry, in service of which black people can be sacrificed, and for the guilty white conscience, which must reassure itself that this is acceptable.

V.

"Bring them to autopsy/ with ulcerated limbs"; Byron and Bey re-imagine these to be the instructions of doctors in the Tuskegee experiment. This was indeed the experiment's main goal. As Surgeon General Cumming enthused in his letter, what made the Tuskegee Syphilis Study an "unparalleled opportunity" was the possibility of examining syphilitic corpses. As Dr. Oliver C. Wenger, director of the PHS Venereal Disease clinic in Arkansas proclaimed at the beginning of the experiment, "As I see it, we have no further interest in these men until they die."[54] It is easier to examine damage to organs in corpses because their organs can be removed. Researchers hoped

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[54] Jones, 134.

that examining “fresh” organs of recently deceased people with syphilis would reveal new information about its effects in the late stages of the illness. Poor black men, most of whom were sharecroppers, served as the most convenient source for these organs, both for the presumption that this fate would be “natural” for them, and the fact that they had little power or knowledge (because it was withheld) with which to contest the experiment. The shockingly little contestation to the study by the medical community suggested they were right to think this group could be sacrificed to this end. Is this form of medical genocide, made possible by a movement based explicitly in the rhetoric of interest convergence and supposedly justified by utilitarianism, really any different than Murrell’s wishful medical genocide, based in a longing for slavery and justified by the claim that such genocide would solve the “white man’s burden”? Both take as assumptions that it is natural and inevitable for black people to have an illness like syphilis and to die of it, that treatment is not feasible nor desirable, and that there is something to be gained for the general white population from black death. If anything, the more conscience-appeasing justification of the former allowed Murrell’s fantasy to be implemented and palatable in a scientific setting and to continue almost entirely unchallenged for forty years.

This implementation of racist practice that decries only its most explicit or obvious manifestations betrays an objection to explicit contestation, denunciation, self-defense or subversion against racism and not the racism itself. It also explains the similarities in logic and outcome between social policies and practices that might otherwise seem incompatible or even contradictory. For most of *Home*, Moss’s friend Finch absolutely refuses to “see” that Moss is black, appearing mystified when Moss expresses hesitation about being present in white spaces. When Major Robinson calls the Kernel to complain about Moss’s assignment to the mission, the

Kernel responds that because there are so few qualified soldiers and Moss has volunteered, he "wouldn't care if he was purple all over and had green stripes down his back." This move, denying prejudice against people of nonexistent colors, is typical of colorblind discourse. The denial reaches its peak at the bizarre moment when Finch says "let go of me you yellow-bellied ni-," before stopping himself, then finishing with "nitwit." The film explains this away as a slip of the tongue in a highly tense encounter with unseen Japanese soldiers that left Finch and Moss fearing for their lives. But the film never allows any explicit discussion of *why* Finch, who is adamantly colorblind and comes to Moss's defense against TJ, still harbors this unconscious racism, and *what it means* about white liberalism and the relationship between the two characters. The moment is presented only descriptively, as part of Moss's recollection to the psychiatrist, who asks for neither elaboration nor reflection before declaring to Moss that Finch is his best friend, and that this bond should override his "mistake." In this way, the moment betrays not just Finch's but the film's unconscious. Produced by staunchly liberal white men, the film is committed to its liberalism and insists on it in this scene. However, although the film does not present the moment self-consciously enough to deliberately expose the lie of white liberal colorblindness and universal humanist discourse, it nevertheless works to do just that by producing unresolved tension through this plot point, which sets in motion the events that lead to Moss's paralysis but, we are told, is nevertheless entirely insignificant except insofar as Moss makes it a problem.

While critics have rightly noted the glaring absence of portrayals of segregation in *Home of the Brave*'s story about the segregated World War II military of the Jim Crow-era United States, also notable are all the ways the film *does* portray explicit anti-black racism in various forms, even as it insists this racism is all in Moss's head and upholds an explicitly colorblind ideology. It portrays antiblackness primarily through TJ, who explicitly insults Moss repeatedly and levies a variety of "micro-aggressions" his way ("Wonderful cooks, the colored. Great entertainers, too."), but also through Moss's recollections of the racist harassment, intimidation, stalking, and violence he experienced in his childhood. It appears consciously in TJ's refusal to associate with Moss, casually and carelessly in TJ's micro-aggressions, passively in Mingo's matter-of-fact dismissal of Moss's frustration with TJ's behavior, and unconsciously when Finch nearly calls his dear friend a racial slur before he stops himself. Indeed, the film adds the following line absent in the play, spoken to Moss by the psychiatrist: trying to convey his sympathy for Moss's situation, the doctor acknowledges the "150 years of slavery, of second class citizenship, of being different" that Moss has "turned into a feeling of guilt." Though "150" is certainly an understatement, to connect ongoing discrimination to this history was surely unusual for a Hollywood film at the time. Given this varied and unsympathetic portrayal of anti-black racism, it is strange that the film nevertheless insists not only on relaying a colorblind message to the audience but on making sure Moss speaks the message himself. Thus, when Moss is rehabilitated at the end of the film, he is neutralized *as a problem*, as a threat to the social order with the potential to destabilize it and not in his experience of symptoms that may have been troubling or difficult for him, in the same way that veterans' hospitals focused specifically on the treatment of communicable illness in black veterans, to neutralize a perceived epidemiological threat, and not on orthopedic injuries which would have manifested as a more personal experience.

Like the film's white liberal humanism, which finds no problem with Moss's oppression so long as he willing to deny it, liberal public health efforts find no problem with illness in black communities unless it threatens to appear in white communities, and military and state officials find no problem with military or housing segregation unless they produce opposition that might destabilize the social order. Universalist analyses and critiques of rehabilitation only reinforce this problem by failing to acknowledge racial distinctions in how rehabilitation is pursued as a normalizing project. I use this discussion of syphilis and World War II to argue that addressing the problem of racism, rehabilitation, medicine, and dis/ability requires us to understand the problem at its root, to grapple with those ideologies that unevenly distribute human value and even humanness itself. Such ideologies not only render illness as "natural" for some and well-being as "natural" for others, but show that the "normativity" of well-being, health and rehabilitation (however problematically they are defined) for white people has historically been directly reliant on the racially oppressive "normativity" of illness, suffering, and sacrifice for black people in the U.S.

As an effectively marketed and in some ways unprecedented film about race, *Home* had an international audience. Fanon offers what is now oft-cited commentary on this production, analyzing the final scene from the film in which the now cured Moss confers with his white veteran counterpart, Mingo, who lost an arm during combat.[55] Fanon describes the scene - "The [white] crippled [sic] veteran of the Pacific War says to my [black] brother, 'Resign yourself to your color the way I got used to my stump; we're both victims'" - before rejecting the moral of the white veteran's advice: "with all my strength I refuse to accept that amputation." Disability studies scholar Rosemarie Garland-Thomson mistakes this instance of film criticism as an actual

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[55] Fanon, Frantz. *Black Skin, White Masks.* 1952. New York: Grove Press, 2008.

exchange between Fanon's sibling and an anonymous disabled man, and misreads Fanon's response as an example of anti-racist "ableism" that seeks to move blackness away from "negative" associations like disability.[56] Garland-Thomson's faux pas is not simply a matter of oversight, however, but rather a structural effect of the additive framework that informs her misreading, one that attempts to retroactively incorporate race into an analysis of disability, and in doing so both ignores the analogy being made and separates an ideology of ableism from complex material conditions of domination and inequality. In the context of this history, it becomes possible to rethink Fanon's refusal, as not simply a rejection of being associated with disability, but as a possible recognition of the ideological and material work that scene is doing - pathologizing blackness and ostracizing and obliterating black people by rendering black suffering and oppression as natural and inevitable, thereby neutralizing any potential threat to the social order. "Resign yourself," the scene commands. Accept the injury as natural and inevitable and do not protest. Perhaps, for Fanon, this is an expression of protest, and of the self-defense denied him by the film.

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[56] Garland-Thomson, *Rosemarie. Staring: How We Look*. New York: Oxford UP, 2009.

Chapter 2: ’A Double Handicap’: The Racial Politics of Special Needs

> “They had gambled by taking an infant into their home with a double handicap: he was a black child in a white home, and his birth mother had been a drug addict” (50).
>
> Seth Margolis, *Losing Isaiah*

I.

In the mid-1980s, at the height of the War on Drugs[57], a series of now discredited medical studies[58] alleged that maternal use of crack cocaine during pregnancy would cause significant and permanent physical, mental, and emotional damage in children that would forever impact their lives. Thus was born the mythical figure of the black “crack baby” who would serve as a kind of logo for the War on Drugs and its criminalization of blackness. The American Enterprise Institute’s Douglas Besharov and political commentator Charles Krauthammer captured the moral panic[59] in a series of revealing editorials. In the 1989 article “‘Brave New World’: Newborns Permanently Damaged By Cocaine,” Krauthammer describes babies born to crack-addicted mothers as “a race of (sub)human drones” who will live “a life of certain suffering, of probable deviance, of permanent inferiority.” He continues, “This is not stuff that Head Start can

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[57] Alexander (2010), p.5, situates the official beginning of the War in Drugs in announcement made by Ronald Reagan in 1992. Alexander debunks the common misconception that the War on Drugs emerged in response to a crack cocaine epidemic, explaining that the spread of crack cocaine in black communities did not begin until several years after the War on Drugs, and that the Reagan administration hired staff to publicize its emergence. Increased funding for the war followed from this manufactured publicity.

[58] Chasnoff’s (1985) study is the most widely cited.

[59] Hall (1978). My use of the phrase “moral panic” is informed by Hall’s analysis and intended to highlight that the hysteria that accompanied the perception that crack cocaine was a threat to society was widely overblown, and motivated by something other than crack itself. Instead, it worked to legitimize racist social and political projects.

fix[60]. This is permanent brain damage," estimating that the condition afflicts between "5 percent or 15 percent of the black community." He concludes, "the dead babies may be the lucky ones." In a *Washington Post* column, Krauthammer builds further on this racist hysteria: "The inner-city crack epidemic is now giving birth to the newest horror: a bio-underclass, a generation of physically damaged cocaine babies whose biological inferiority is stamped at birth." In the national imaginary, the "crack baby" epitomizes the presupposed biological inferiority of black people, representing at once *inherent* black "deviance" and "sub-humanness" and, at the same time, an evil, unnaturally non-maternal, deliberate "choice" on the part of black mothers to harm their babies, a choice that works to negate the absolution of responsibility that inherence might allow.

One week after the publication of Krauthammer's 1989 piece, Besharov elaborates on this "choice" in the *Washington Post* piece, "Crack Babies: The Worst Threat is Mom Herself." The piece first works to demonize black motherhood by invoking another mythical figure of the War on Drugs era, the "welfare queen." The "welfare queen" was invented by Ronald Reagan in a 1976 speech given in a bid for the Republican presidential candidate nomination (Blake 2012). The figure was an "inner-city woman" racially coded as black who "cheated the system" in part by having too many children so that she could "collect welfare checks." Though the "crack baby" had not yet been officially invented, the two quickly became wedded. Besharov's piece relies on the familiarity of the "welfare queen" in such descriptions of the crack baby's mother: "I've never seen mothers like this before. Children aren't being fed. Mothers sell their food

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[60] In other words, as he imagines it, black "permanent inferiority" cannot be rehabilitated. In chapter one of my dissertation, I speak to the ways an analysis of blackness in disability studies undoes the "logic of rehabilitation" that focuses on whether rehabilitation is desirable, rather than for whom it has been available as an option.

stamps. Young women sell their bodies, and that's done in front of the children." "Crack babies," likewise, were imagined to be "the most expensive babies ever born" who would "overwhelm every social service delivery system" (Winerip).

Ultimately, the piece suggests, there can be no redemption for crack-addicted black mothers. They are "hopeless." Their addictions are permanent, as is the supposed damage to their children. Decades later, these original claims have been decidedly debunked as mythical. The harmful effects were overstated, often simply baseless predictions. Adults who were "crack-babies" show no lasting harm. Ramifications that were recorded have since been attributed to other factors, like poverty or even placement in foster care.[61] Yet, on this basis, Besharov echoes proposed changes to federal adoption law, and suggests his own further changes that, eight years after the publication of this piece, went into effect.

> Permeating all child welfare decisions are deeply-felt - but unrealistic - social attitudes about the importance of preserving families… One repeatedly sees admirable - but misplaced - efforts to give parents chance after chance to turn their lives around… If parents cannot care for their children, the children should be removed from their care. This may require the overhaul of federal foster-care and adoption laws which have been wrongly interpreted to preclude early removal of these children. Adoption should be a real option for children whose parents show little prospect for improvement even though this means terminating parental rights. Drug children should not be allowed to get lost in a foster-care limbo, as is now so frequently the case. Courts and agencies are notoriously unwilling to free children for adoption…To make the termination of parental rights easier, the D.C. Mayor's Advisory Board on Maternal and Infant Health has proposed to reduce the "complexities" of the District's adoption procedures. The issue runs deeper, though. Laws and attitudes must also change. No one likes to give up on parents, to label them as "hopeless," especially since many are themselves victims of broader social problems. But their children deserve a chance -- even if we must assume long-term responsibility for their care and upbringing. These are not total solutions -- but they would do more to protect the children of addicts than wishful thinking about drug treatment or arguments about criminal prosecution. Each day

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[61] See also Hurt (2001); Halloway (2016); Winerip (2013); Buckingham (2013)

> that we fail to take decisive action means suffering, even death, for thousands of children.

Besharov alone was not responsible for these changes to adoption law. Rather, as his reference to the D.C. Mayor's Advisory Board suggests, the moral panic over crack babies produced certain discourses about blackness, motherhood, and adoption, that brought about significant changes to the child welfare system and federal adoption law. In this chapter, I offer an analysis of these changes, and in particular the "special needs" designation in adoption law, which in practice categorizes all black children in the foster care system as "special needs," a category that outside of the context of adoption is often used synonymously with "disabled." I read these changes alongside the Seth Margolis's 1993 novel *Losing Isaiah* and its 1995 film adaptation. I argue that the "crack baby" and the "welfare queen" that are so central to the storyline of these two texts also give ideological coherence and function to the "special needs" designation and negatively affect black children in the child welfare system.

It is not a coincidence that Besharov's preoccupation with "crack babies" and their threatening mothers leads him to conclude that adoption policies should shift toward an emphasis on separating black babies from their mothers, nor is it a coincidence that *Losing Isaiah*'s portrayal of this perspective on transracial adoption relies so heavily on the figures of the "crack baby" and the "welfare queen." The shift in adoption policy and the child welfare system comes in the direct aftermath of the War on Drugs as a response to the discourses it produced about criminal black mothers (and the attendant criminally absent or negligent black fathers) and permanently and irreparably damaged black children. As federal adoption policy shifted between 1980 and 1997 toward the separation of children from their birth families, the child welfare system implemented these policies by primarily targeting black families. As part of this shift, federal adoption law extended a subsidy in the form of a tax break to encourage the adoption of children categorized as "special needs," which according to the 1997 law includes race and ethnicity. In practice all black babies, and in some states other non-white babies, became categorized as "special needs."[62]

Never mind that the "crack baby" was a myth, that drug use was proliferated by the war on drugs and its prosecution was racially selective, and that policies designed to separate black children from their birth families have resulted in infinitely more harm to the children and their families. These facts highlight that, as legal scholar Dorothy Roberts' work demonstrates, changes in the foster care system were designed to punish black mothers rather than to protect black children. Similarly, because the number and proportion of white babies who were voluntarily given up for adoption decreased substantially in the aftermath of *Roe v. Wade*, the encouragement of transracial adoption and the increased presence of black babies in the foster care system helped address a new "market" concern for white families, rather than seeking to ensure the general welfare of black children. Such context, in the midst of the War on Drugs, constitutes a "moment of crisis" in which the state reasserted definitions of blackness and "impairment" in relation to one another. The blanket designation of black babies as special needs 1. relies on and comes in the aftermath of a discourse that characterizes black children as inherently "damaged," "deviant," and "subhuman." 2. is designed to incentivize the adoption of black babies who might otherwise not be adopted by mostly middle class white families (in part) because of such characterizations, and 3. thereby functions primarily to *compensate* adoptive

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[62] Because Native adoption is not governed by this set of laws, it is outside the scope of my analysis here. Tribal governments typically have jurisdiction over adoptions of Native children per the 1978 Indian Child Welfare Act.

families for having to "settle" for a "less valuable" child than the white one they would have wanted, rather than, for example, to subsidize additional costs of care, as they do for other special needs babies.

This framing of the crack cocaine epidemic de-emphasized the biochemical processes of addiction and stressed instead moral failings at the level of family and social relations (as opposed to, say economic and political structures), and influenced everything from the development of treatment to policing to, as I argue here, the child welfare system. And this marking of deviance at the level of family and social ties follows in a longstanding pattern identified by Roderick Ferguson in "Nightmares of the Heteronormative." Ferguson explains:

> The black family stands in the background of some of the most talked-about social policy in the United States. Imagined as the products of broken families and neighborhoods, African-Americans have historically diverged from, and therefore violated, the image of the American household. So imagined, African- American culture has always been deemed as contrary to the norms of heterosexuality and patriarchy… African-American existence has always been marked as 'nonheteronormative'. Marking African-Americans as such was a way of disfranchising African-Americans politically and economically. In other words, the material and discursive production of African-American nonheteronormativity provided the interface between African-American racial and sexual formations and the material practices of state and civil society.

I follow from this analysis to argue that this a priori marking of nonnormativity at the level of family and social structures, in relation to the War on Drugs specifically, marks black children as always/already "damaged" and deviant, and black mothers as irresponsible or nonmaternal, in ways that led to the expansion of the foster care system, informed the categorization of black children as "special needs," and justified the punishment of black women for this alleged failure. This is a marking of impairment that is both naturalized and equated with moral failing in a way that works against the recognition and categorization of disability.

II.

Several main laws have historically worked to regulate child welfare in the U.S. The Adoption Assistance and Child Welfare Act of 1980 offered the first federal rules for the regulation of child welfare cases and the foster care system. It mandated that "reasonable efforts" be made to prevent the separation of biological families and provide reunification services when they are separated. It also created Title IV-E of the Social Security Act to offer financial assistance to people who foster children. On November 19, 1997, less than two years after the film release of *Losing Isaiah*, Bill Clinton signed into law the Adoption and Safe Families Act (ASFA). This Act sought to reverse problems attributed to the Adoption Assistance and Child Welfare Act's focus on the unification of biological families, believed to have especially endangered "special needs" children, by requiring the termination of parental rights for children who have been in foster care for 15 of the last 22 months. It amends Title IV-E by providing additional subsidies, in the form of a tax credit, to adoptive parents of "special needs" children. Its definition of special needs includes not only "medical conditions or physical, mental, or emotional handicaps" (section 473C), but also "ethnic background, age, or membership in a minority group" (section 473C). The section breaks special needs into two categories: "handicapped child" and "hard-to-place child," with the vaguely worded "ethnic background" falling into the latter. The specific enforcement of these guidelines is left up to state-by-state discretion, but most states have specified either simply "African American" or "African American or biracial." Some states also include other nonwhite children. Also, under "Title IV: Miscellaneous Provisions" of the ASFA is a section entitled "Coordination of Substance Abuse and Child Protection Services," which required information to be collected from both the

Substance Abuse and Mental Health Services Administration and the Administration for Children and Families regarding the scope and effects of substance abuse in families visited by child welfare agencies, demonstrating the relatedness of the discourse about "protecting" children from their birth families, and War on Drugs discourses about the prevalence of substance abuse. These two laws worked to regulate the foster care system generally, but in between them were laws that focused specifically on race in the foster care system. The Multiethnic Placement Act of 1994 prohibited the delay of adoption placements "*solely* on the basis of race, color, or national origin" and required state agencies to make "diligent efforts" to recruit adoptive parents of the same race as the child. In 1996, this law was amended by the Removal of Barriers to Interethnic Adoption Provisions (IEP), which removed the word "solely" from the original law, and declared any consideration of race in adoption placements, and deliberate efforts to secure race-matching adoptions, a violation of the Civil Rights Act. The trend, in both general adoption law, and adoption law on race, has moved away from same-race families, either as the preservation of birth families or the encouragement of race-matching adoption, and toward "color-blindness" and the encouragement of transracial adoption.

When the Americans and Safe Families Act was passed in 1997, the number of black children in foster care had nearly doubled since the early 1980s. The War on Drugs had led to parental incarceration and the placement of specifically black children in foster care at an unprecedented rate. By then, black children constituted nearly half of all children in foster care.[63] This legislation's focus on speeding the adoption process was a response to one of the disastrous

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[63] 47%, to be precise.
Everett, Joyce, Sandra Stukes Chipungu, and Bogart R. Leashore, eds. *Child Welfare Revisited: An Africentric Perspective*. Rutgers University Press, 2004, 228-229.

effects of the War on Drugs without naming it as a cause. Instead, black families and black mothers in particular were identified as the source of the problem and the bill became yet another punitive measure. Senator John H. Chafee[64], the Rhode Island Republican who was a leading sponsor of the legislation, said on the Senate floor just before the measure passed: "We will not continue the current system of always putting the needs and rights of the biological parents first… It's time we recognize that some families simply cannot and should not be kept together." Speaking just before Bill Clinton made his first public remarks about the measure, Chafee added, "It's certainly not a common event in Washington where we can rightfully claim that we are saving lives, and I think we can say that here. Potentially, we are saving the lives of thousands of abused and neglected children. But we are also giving them hope, hope for the future, hope for a loving, caring family, hope for a permanent, stable, and safe home." Senator Jay Rockefeller echoed the sentiment: "What we have done, I think, is to simply say in public law for the very first time, that the health, and the safety and the security of the child comes absolutely at the top and all other policies emanate from that, and having done that, that gives me reason to hope very strongly for… hundreds and thousands of children all across America. This is a very, very, very important bill." Senator Dave Camp gushed that the law "is about children and their families, and this legislation will help give them that shot, to have a loving home, to have a shot at the American dream." Finally, Bill Clinton promised, "Fundamentally it will improve the well-being of hundreds of thousands of our most vulnerable children." The phrase "safe families" in the name of the act implies danger, harm, and threat, and the language used by the senators who

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[64] These comments are taken from a videotape of the event surrounding the signing of the bill, available for viewing online.
"Adoption and Safe Families Bill Signing," C-Span Video, Nov 19, 1997. Available at https://www.c-span.org/video/?95351-1/adoption-safe-families-bill-signing

introduced the bill and by President Bill Clinton further emphasized this point with the repeated use of words like "health," "vulnerable," "safety," and "well-being."

Also prefacing Clinton's remarks was a short speech by SueAnn Badeau, adopted daughter of Sue and Hector Badeau, who were awarded the 1997 Adoption Excellence Award by the Clintons. SueAnn confirmed, "Being adopted is the best thing that has ever happened to me… And hopefully with this bill, all the foster kids that are here today can get adopted and I pray for them." Her parents, Sue and Hector, were a middle-class white couple with a strong Christian background who had 2 biological and 20 adopted children. Their twenty adopted children included at least ten black children, one child adopted from El Salvador, two adopted from India, and one Chinese-American child. They also fostered numerous children who were refugees from Kosovo and Sudan. When, at one point, the parents were advised by social workers that raising eight black children in Vermont may not be the best decision, Sue responded, "Ours might not be the ideal family for these kids, but isn't it better than nothing?" [65]As this legislation presented the problem, "nothing" was indeed the only alternative, and this bill was to intervene by allowing children to be adopted by families like this one.

However, according to a 2008 report[66] by the Evan B. Donaldson Adoption Institute, not only were the ASFA and the Multiethnic Placement Act completely ineffective at remedying the

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[65] Larissa MacFarquhar. "The Children of Strangers." *The New Yorker*, Aug 3 2015.

[66] Evan B. Donaldson Adoption Institute. "Finding Families for African American Children: The Role of Race & Law in Adoption from Foster Care." Policy and Practice Perspective (2008).

My analysis in this chapter focuses primarily on changes to federal law between the passing of the two federal laws, and up to the publication of this 2008 report. I address the laws as well as the public discourses surrounding them. Since the publication of this 2008 report, some counties across the country have, unevenly, begun to offer multicultural counseling courses to foster parents and prospective adoptive parents. This has raised a different set of problems which are beyond the scope of my analysis here.

racial disparity in foster care, but the federal ban on consideration of race in adoption proceedings has also hurt black children by enforcing an “unyielding color-blindness” that has prevented social welfare institutions from assessing white adopters’ fitness to parent them, assessing their level of “existing or planned connections with the child’s racial/ethnic group,” or even preparing them for the adoption. These laws failed to meet the goal of reducing the number of black children in foster care because they did not address the root cause of the problem, but they were also largely ineffective at motivating a significant increase in the adoption of black children. In fact, according to the Black Adoption Placement and Research Center, which offered a profile for the National Black Caucus of State Legislators[67], the most prevalent myths obstructing the adoption of black children are related to myths about drug use and perceived family background. I elaborate on this below. The Center names these as myths because they are false, but they are nevertheless the primary reasons white families looking to adopt give to explain their reluctance to adopt black children. In other words, these myths - myths of deviance, impairment from drug use, and broader black family and community failures - are, at least in part, the basis of the problem of under-adoption that the designation as “special needs” and the attendant tax credit sought to address.

The novel and film *Losing Isaiah* epitomize this transition in the administration of foster care. Margolis’s 1993 novel tells the story of a custody battle between Selma Richards, a (formerly) crack-addicted black woman and Margaret Lewin, an upper middle-class white woman. Both are seeking custody over Isaiah, Selma’s biological and Margaret’s adoptive son, a

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[67] Schwartz, Sara L., and Michael J. Austin. “Black Adoption Placement and Research Center at 25: Placing African-American Children in Permanent Homes (1983–2008).” *Journal of evidence-based social work* 8, no. 1-2 (2011): 160-178.

"crack baby" who ostensibly still suffers, according to the plot, the effects of his mother's drug use during pregnancy. In the novel, Margaret originally sees Isaiah while volunteering at the hospital and then illegally pays Selma to "adopt" him. After Selma overcomes her drug addiction, she finds Isaiah and successfully sues for custody. In 1995, less than two years before ASFA went into effect, a film adaptation of this novel was released, starring Halle Berre as Khaila Richards (based on Selma's character) and Jessica Lange as Margaret Lewin. In the film, Margaret originally finds Isaiah after Khaila leaves him in a cardboard box by a dumpster to get high, intending to come back. Selma is later arrested for shoplifting and drug possession and Margaret raises him for two years. After overcoming her addiction and becoming religious, as in the novel, Khaila successfully sues for custody of Isaiah, but rather than ending this way, the film ends instead with Khaila's selfless decision to return Isaiah to Margaret after realizing that Isaiah does not consider her his mother and that Margaret is better suited for the role.

The novel was praised by critics for its complexity and its ability to portray both of the main characters, Margaret and Selma, with depth and as favorable to readers, despite that their interests are opposed. For example, the editor's review on the cover explains that the novel "raises one of the most complex and emotional moral questions of our times. Seth Margolis forces you to understand the pain and conflict these two women are feeling, and keeps you rooting for them both." The text moves back and forth between Margaret's and Selma's points of view, which would seem to support this reading. Yet it is titled *Losing Isaiah,* which already gives a sense of its orientation - it is Margaret, in the novel, who loses him. This novel, then, is the story of *her* loss, despite its pretenses to complexity and relativity. The orientation is reinforced by the social stances on race and race mixture attributed to each of the two main maternal characters.

Readers access the racialization of care labor in the novel through Selma, whose problem, per Margolis's portrayal, has more to do with race mixture and non-biological parenting than material inequality. Selma works as a nanny for a white child named Dana. "That's just the way it is in Manhattan, Selma told herself, all these mismatched pairs. Still, you almost never saw a white woman pushing a black kid" (32). Given that Selma herself works as a nanny for an upper middle-class white child, it is difficult to believe that it is mere "mismatched pairs," that would bother her, as opposed to the the racialized material inequality that make it so that black women more frequently serve as nannies for white families than the reverse. This reductive understanding of care labor in the novel allows for a similar reduction of Selma's opposition to transracial adoption, and part of the incentive behind her desire to get Isaiah back, as a reactionary opposition to race mixture, rather than to the material inequality that structures it. The closing line of the novel reiterates this portrayal: "Selma shook her head but had to smile. Trouble with this city is all the kids is with all the wrong people" (374). She wants Isaiah back because "he should be with his own kind; Selma had no doubts on this score" (239). Because the problem is presented so reductively through Selma, Margaret's position is validated as a progressive stance in favor of racial integration (as opposed to the racially segregated world Selma wants) and alternative kinship arrangements that include adoption and non-biological parenting (as opposed to Selma's view that adoptive parents are not "real"). This is how Margaret's position is legitimized and Selma's is undermined in a novel that claims to make both characters equally complex and relatable.

Losing Isaiah portrays the child welfare system and the legal system as, like Selma and for similarly reductive reasons, adamantly opposed to transracial adoption, willing to go to "unreasonable" lengths to avoid placing black children with white families, even against their wishes and to their detriment. This portrayal of the foster care and legal systems coincides with a portrayal of the systems as black. The judge is a black woman with an "intimidating, almost threatening demeanor" (262). The social worker who serves as a witness is also a "tall heavy-set middle-aged black woman" (312). "The social service agencies don't like mixed families. They just don't" (146), proclaims Selma's lawyer. In the narrative voice, the novel explains, "The issue of mixed-race adoption is a particularly thorny one right now. Thousands of black babies languish in hospitals and foster homes waiting for 'suitable' homes. 'Suitable is often a euphemism for racially compatible,' according to Betty Logan. 'There is an unwritten policy among social-service agencies to place babies with parents of their own race'"(215). The novel echoes the rhetoric about foster care spewed by Besharov and others in the midst of the moral panic over crack cocaine, despite that the claim about social service agencies is false. The text (wrongly) attributes the problem of the overrepresentation of black children in foster care to race-matching practices represented by Selma and the legal system that defends her, undermining Selma's legitimacy as Isaiah's mother.

As Dorothy Roberts explains in *Shattered Bonds*, adoption of any kind, including transracial adoption, cannot be the solution to the overrepresentation of black children in the foster care system because even though number of people seeking to adopt is rising, the placement of children in foster care is rising at a faster rate. So, there are not nearly as many people seeking to adopt as there are children in foster care, and there may even be a net increase in children who need to be adopted. Therefore, continued ties with biological families is not the main barrier to having these children adopted and severing them will not solve the problem. Though the legal system in the novel and sides with Selma in an effort to preserve the black family, both the novel and the film on which it is based present this as unjust. The film even goes so far as to "remedy" the legal system's error.

The film is based in Chicago, rather than New York, where the more extreme racial segregation parallels the unambiguous assertion of messages the novel tries, if inadequately, to relay with complexity. Behind the opening credits is an extreme long shot beginning in Chicago's wealthy suburban North Shore, moving through through skyscrapers and well lit-city nights to, finally, the dark and run-down inner-city. Grounding the scene is a non-diegetic piece by composer Mark Isham entitled "Two Cities," and a faint diegetic siren that grows louder as we move toward the inner-city. The entire establishing shot is set in Chicago, one city, but the title of the composition represents the visual introduction of what will be affirmed by the rest of the film: that other (part of the) city, where black people live, is bad and dangerous, and children who are rescued and taken to the wealthy, "safe" (part of the) city where they will be loved by white people are ultimately better off.

Once we get to the inner-city, the camera zooms in on Khaila's (Halle Berry's) body, moving from her legs up to Isaiah breastfeeding. The camera zooms out slightly to show us her pained face, and then zooms in again to where she pulls her finger out of Isaiah's grasp. The shaking, sweating, and pained look on her face - withdrawal symptoms, perhaps? - leave us wondering whether the breastfeeding is nourishing or endangering Isaiah. We later confirm the latter. Isaiah is screaming. Khaila wanders outside with him where we see huge piles of garbage and hear random shouts including "we can trade you some good shit" and "we know what you need, baby," presumably from black men who are not visible on screen. Khaila follows their calls, leaving the screaming baby Isaiah in a cardboard box by the dumpster, where the garbage is overflowing.

The display of negligence here is much more dramatic than in the novel, which involves no dumpster. After being treated for medical problems associated with premature birth, Isaiah comes home to drug-addicted Selma who struggles to care for him after being treated for medical problems associated with premature birth. Margaret pays Selma several unauthorized home visits before offering to buy Isaiah off of her, an offer Selma rejects several times before finally giving in. So, though the novel presents Margaret as well-intentioned, it also leaves open the possibility that her actions are morally questionable, unlike the cinematic representation that paints her as unequivocally "good," even adopting Isaiah "by the book" rather than illegally. Similarly, while Selma makes some effort in the novel and displays at least the intention to care for her child, Khaila is represented cinematically as grossly negligent, almost irritated by Isaiah's existence and unconcerned with his fate. This makes the court's decision to return custody to Selma seem almost absurd, based on *nothing* other than an outdated belief in racial separatism. As the judge explains it, Isaiah should be returned to his "biological mother" because "it is usually in the child's best interest to be with his natural mother especially when there is a racial issue involved." The bond between Isaiah and Margaret and their mutual attachment vindicates Margaret and demonstrates that the justice system is wrong on this score. Margaret never doubts her role as Isaiah's mother.When Khaila decides to return Isaiah to Margaret after seeing how unhappy he is, he greets her by exclaiming excitedly, and repeatedly, "Mommy! Mommy! Mommy!" Isaiah confirms for the audience that his *real* mother is Margaret, and that the judicial system's decision to grant custody to Khaila is a mistake.

Margaret is portrayed as *deserving* of motherhood, unlike both Selma in the novel and Khaila in the film. "Margaret had given up coffee and alcohol a month before she even tried to get pregnant, and she wouldn't let him [Charles] smoke around her once she was pregnant… Selma Richards hadn't concerned herself with what she was doing to her unborn child" (180). Charles's conviction is not as strong as Margaret's, and he sometimes had doubts about whether keeping Isaiah was the best option: "Sometimes… an ugly demon had raised its head inside Charles and whispered that perhaps it would be best for all concerned to simply give up Isaiah without a struggle. It's nothing but trouble down the road, the demon whispered" (281). What makes him want to fight for Isaiah despite these thoughts is that his feeling that Selma is undeserving of motherhood is so strong, stronger than his desire to keep Isaiah: "This woman had no right to their son… No, she'd lost the right when she continued to take drugs after she was pregnant" (281). The antiblackness that motivates his desire to maintain the adoption is even stronger than his "love" for the black child he claims to father.

Though the film's plot explicitly supports Margaret, the subtext betrays an acknowledgement of the violence and antiblackness that structure and make possible these relationships. The morning after Khaila leaves Isaiah by the dumpster, the box - with Isaiah still inside it - is put into the garbage truck where Isaiah is nearly incinerated by a blade. The machine is stopped and Isaiah misses death by less than a second. Elsewhere, Khaila recovers from her trip and finds that Isaiah is gone. She goes to a local market to steal some food and is then violently arrested by two white police officers as she sings incoherently. In the film, Margaret is a social worker, and she documents Isaiah's injuries when he is taken to the hospital. Later that night, she recites her notes on Isaiah's injuries into an audio recorder as she lays in bed with her husband, Charles. As she recites, "…and hairline fractures of the clavicle and cranium. Burns and old scarring…" into the recorder, Charles whispers, "Uh, would you say multiple lacerations to the upper torso one more time please?" He sits up and puts his arms around her waist. "Hairline fracture…?" He begins to caress her arm. "Burns and old scarring?"

She understands, somehow without being disturbed, that he is trying to initiate sex, but she does not respond to his advances because she is busy working. To make up for it, she calls him the next day and whispers seductively(?), "cranial contusion…" He laughs, clearly aware that now she is initiating a sexual encounter, and he initially plays along. She invites him to meet her somewhere, even promising to "show you the x-rays," but he turns her down this time because he is busy at work. Their first two discussions of Isaiah involve descriptions of his injuries that they use to seduce each other. In other words, in their first conversations related to Isaiah, they literally deriving arousal, pleasure, from his pain. This is strangely fitting given that it is black pain, Isaiah's, Khaila's, the pain of the destruction of black families, that makes these unions - and their joy at their newly adopted baby - possible. The suspended consummation of their arousal foretells the possibility that the adoption will fall through.

Roberts explains that "the same set of stereotypes" about black maternal unfitness that work to "degrade Black women's reproductive decisions" also work to "support the removal of Black women's children" (61). "Three prominent images of Black mothers cast them as pathological: the careless Black mother, the matriarch, and the welfare queen." *Losing Isaiah* relies on all three, particularly in the character of Marie, with whom Selma/Khaila stays, but even in Selma/Khaila herself. The texts also rely on the "crack baby" and other racist myths about black children and families that affect black people in the foster care system. As noted, the three most prevalent myths obstructing the adoption of black children are: “1. Black children are more difficult to raise; 2. Black children in the foster care system come from ‘drugged up’ mothers, and; 3. Black families are not adopting children, contributing to the perception of the ‘undesirability’ of Black children.”[68] The first point reveals that white parents think of black children as inherently different from and worse, or “more difficult” than, white children. This characterization is replicated in the novel. The novel’s prologue begins with a description of two year old Isaiah pretending to be a ghostbuster, portraying him as fixated on guns and as using them almost maliciously. He also throws tantrums and is very particular, unlike his white sister Hannah.

The second point identifies reveals that the conception of black children as “crack babies,” and the demonization of black mothers as “welfare queens” directly affect their treatment in the foster care system and their chances of being adopted. Their designation as “special needs” is intended to incentivize their adoption in this context. The story of *Losing Isaiah* relies heavily on ideas of ability and impairment in these two figures. When we first meet Selma Richards, she is braving the cold of the New York winter to go to a class where she learns how to read. She is working to remedy the effects of her poor black upbringing, the only way readers can be sympathetic to her plight and see *some* legitimacy in her claim to Isaiah. The only way we can sympathize with Selma is by contrast to Marie, who comes to represent the “black welfare queen,” immoral and hypersexual (“men didn’t care so long as the wine and sex were free and clear. They were free and clear with Marie” (25)). She and her two children live only on

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[68] Schwartz and Austin, “Black Adoption Placement and Research Center.”

welfare ("only food stamps and welfare keep the three of them in food and clothing, not to mention beer and wine…" (25)). She is addicted to drugs, entirely neglects her children, and illegally rents a room in her public housing apartment to Selma, forcing her children to sleep in the living room. Her blackness is almost contagious and represented, unsympathetically, as physical illness: "She looked gaunt and unhealthy. And there was something contagious about the way she looked. You didn't want to get too close, let alone touch her" (233). Though she has nothing to do with Isaiah, she is essential to the narrative in that she represents this trope to mitigate the extent to which Selma will represent it, thereby allowing readers to sympathize with Selma. Still, Selma, as a black mother in the white literary imagination, must represent the stereotype to some degree. Born to a heroin-addicted mother as a result of an affair with a married man who left her, Selma grew up neglected by a drug-addicted mother who barely loved her, alternately living off welfare and off the money her mother made from sex work (89). Before and immediately after giving birth to Isaiah, Selma lived entirely off welfare, spending most of the money on her drug habit" (269). Even the $25,000 she was paid by the Lewins for Isaiah she spent entirely on drugs. She also believes welfare is a good source of income.

Isaiah is also a "crack baby." Charles and Margaret argue over the extent to which this has affected Isaiah; while Margaret believes they "don't have to worry" because "Isaiah's completely normal," Charles insists that "our boy's mother use drugs during the first months of her pregnancy. Maybe longer. We'll never know what impact that had." Despite years of white parenting, the "special needs" he develops as a result of his connection to his black mother may never be fully eradicated - after all, we know from Besharov that "crack babies" cannot be rehabilitated. Margaret is disturbed by this argument because "you talk about him like *he* was a junkie"[69] (49), revealing the slippage that imagines "crack babies" and "welfare queens" as having both inherent or birth-related limitations and simultaneously a deviance for which they should be responsible. Charles thinks he is simply being realistic. "They heard stories, all the time now, about crack babies being returned to foster homes because their adoptive parents couldn't hack it. They'd been warned to look for seizures, mood swings, speech problems" (50). After having him tested, the Lewins confirm "only that he was 'normal,' albeit at the low end of the normal range, whatever that meant. Some parents they knew would be devastated to learn that their child was 'just' normal" (50), but this was more than they could expect for Isaiah. They would never know for sure: is he "only" low-average because he is black or because of the drug use? After all, "they had gambled by taking an infant into their home with a double handicap: he was a black child in a white home, and his birth mother had been a drug addict" (50).

So black children's "special needs" in this novel and film, are the result of individual failings - their own and their mothers'. "She and Charles had been warned to look out for developmental problems stemming from his *ghastly birth*" (104, emphasis added). The fact that Margaret feels Charles might be indicating that *Isaiah* was the "junkie" is representative of this slippage. This belief is even attributed to Selma: "she had already handicapped him once, by giving birth to him, and she wasn't going to make matters worse by hanging around" (118). Not only does her blackness produce "handicapped" black babies, it further handicaps them with black mothering. In this war, the novel attributes the responsibility for the overrepresentation of

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[69] Though I ultimately could not include the data here, I collected some data from the California Kids Connection website that shows that black children's profiles are more likely to describe them as needing discipline (and other similar terms) than white children's, and less likely to describe them as needing care. This illustrates the argument I make about the co-existence of ideas about inherent limitations and criminality/ punishment.

black children in foster care to black mothers and babies themselves.

The third point is also statistically false, but remains entrenched because of pervasive narratives about the children's birth families. Black children who are adopted are most likely to be adopted by black relatives and friends. Black people also adopt in the same proportions as white people, and almost always adopt black children. According to a 2002 CDC study of women between the ages of 18-44 years old[70], roughly 35.8 percent of white women and 41.3 percent of black women have considered adoption at some point. Of those who have considered adoption, 16 percent of the white women and 23 percent of the black women took steps to adopt. Of those who took steps to adopt, 27 percent of the white women and 22 percent of the black women ended up adopting. This is to say that while black women are more interested in adoption and more likely to take steps toward it, they are less likely to end up adopting a child, which indicates that they face some barriers to approval at some point in the process. The claim that black people do not want to adopt black children is false. There are simply not enough black people able to adopt, black people permitted to adopt, and white people willing to adopt a black child, to account for the total population of black children in foster care.

And the history of the both the overrepresentation and the under-adoption of black children is uniquely antiblack. The desire for similarity or for children who can phenotypically pass as adoptive parents' biological children, also known as "homophily," cannot fully explain the strong bias by prospective white adoptive parents against black children because no bias can be found against "Hispanic" children. In other words, an element of antiblackness is motivating

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[70] United States Department of Health & Human Services. "Adoption Experiences of Women and Men and Demand for Children to Adopt by Women 18–44 Years of Age." *Vital Health Statistics* 23, no. 27 (2008).

the preferences in excess of homophily or general racism that might otherwise be used to explain it[71], and this antiblackness cannot be separated from broader ideologies about mothering and drug use. Social workers report having to "convince" couples to "consider" adopting black babies. No prospective white adoptive parents (0%) list as their top preference black babies, even though 83% "would accept" them. Again, this is not simply homophily because 17.5% of prospective white adoptive parents list as their top preference "another race" (i.e., "other" than black or white, the third option) (CDC 2002). Those who indicate that they "would accept" black babies typically do so with the knowledge that this selection will speed adoption proceedings. And even those who might want black babies may not be able to parent them adequately, particularly not if one understands adequate parenting to involve black people who serve as loved ones and role models in the child's life, and whose presence might help them cope with institutional and interpersonal racism. In particular, those prospective white adoptive parents who must be "convinced" to adopt black children are likely unqualified to do so. The listing of black children as "special needs" is motivated and rationalized by the same ideological factors that pathologize blackness and black motherhood and the "impairment" that is presumed to be the result, and does little to provide for any particular "special need."

III.

The term "special needs" developed slowly over time, originally used to describe "the special needs of" a particular group, and not as a name for a group in itself. Typically the phrase was used as "the special educational needs" or "the special medical needs" of specific groups in education and healthcare policy recommendations. Still, it has always been more commonly used

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[71] Baccara, Mariagiovanna. "Child-Adoption Matching: Preferences for Gender and Race." *American Economic Journal: Applied Economics*, American Economic Association 6 no. 3, (2014).

to refer children and most commonly used in reference to education and schooling, and conditions that are believed to intervene with the schooling trajectory. Eventually it came to be used interchangeably with "handicapped" and now with "disabled," and was solidified legally as a separate category referring to people in federal adoption law.

The most common phrasing, "special educational needs" was formalized in the American legal system by legislation born out of a series of lawsuits following the *Brown v. Board of Education* decision. These lawsuits sought to have the protections granted by the 1954 Supreme Court ruling extended to other groups. The Elementary and Secondary Education Act of 1965, which extended protection to children born into poverty, recognizes the "special educational needs of children of low-income families." The phrasing here remains incidental, as the children themselves are not described as "special needs." The phrase is further solidified by the Education for All Handicapped Children Act of 1975, also born of lawsuits in the aftermath of *Brown v. Board*, which stipulates that all "handicapped" children had a right to equal education in "the least restrictive environment possible" and also mandates that public education must "emphasize special education and related services to meet their unique needs." Congruent with shifting terminology, the Bureau of the Education of the Handicapped (est. 1967) changed its name in 1990 to the Office of Special Education Programs and changes the name of Education for All Handicapped Children to Individuals with Disabilities Education Act.

It follows a similar trajectory in the medical field. In medical literature, the phrase did not appear at all until a 1949 study on children with cerebral palsy (Giden) and then not until 1959 in a piece on "low-income families" who have children with "special medical needs" (Hailey). Even in the medical literature, "special needs" continued to be used with regards to particular groups of disabled people, and then in the 80s and 90s began to be used interchangeably with "handicapped" and then with "disabled" (Warnock; Hine; Baker). Now the term is often used interchangeably with "disabled," but remains most commonly associated with education and adoption. Many contemporary medical and parenting guides explain special needs as an umbrella term that includes "behavior issues, developmental issues, learning issues, and mental health issues."[72] Organizations designed to provide resources and support for special needs also confirm that it is now typically used as a synonym for disability. The Special Needs Alliance, for example, is designed to serve "individuals with physical and cognitive disabilities," and the Federation for Children with Special Needs "provides information, support, and assistance to parents of children with disabilities."

Though the two following studies from the early twentieth century are consistent with this history in that they use "special needs" incidentally rather than to describe a group of people, they offer a precursor to the contemporary usage of the phrase, in ways relevant to my argument. Published in 1919, Pressey and Teter's "A Comparison of Colored and White Children by Means of a Group Scale of Intelligence" finds that "colored" (black) children "averaged below white children of the same age on all the tests" of intelligence, and recommends therefore that black children's "special needs" in education necessitate a focus on "dealing with concrete and routine problems," at which they do "relatively well," and not "abstraction or mental reconstruction," at which they do "poorly." Southard's and Thom's 1918 piece, "How May We Discover the Children Who Need Special Care," by contrast, argues that "we should strive, alike through the careful study of the individual and through adaptation of educational methods to special needs,

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[72] Terri Mauro, "What Are 'Special Needs'?" (2016).

for prevention, correction and the increasingly satisfactory guidance of development" (163) for particular groups of students. They identify "five classes or groups" to determine who might need such tailored attention: "1. the intellectually superior or supernormal; 2. the intellectually inferior or subnormal; 3. the intellectually dependent; 4. the affectively or instinctively defective; 5. the mentally normal, typical or average." They explain that the importance of their recommendations lies in preventing, especially, the middle three categories from "innocently burden[ing], if not also deteriorat[ing], the race" (164), i.e., the white race.

The first study, even though examining separate groups of children in entirely segregated schools, gives no consideration to the quality of education given to the children, the material resources to which they have access, or the criteria by which intelligence is determined. Instead, it makes a conclusion about their inherently different capacities and recommends schooling to black children that aligns with the abilities it assigns them. And these abilities, incidentally, also correspond with popular beliefs about the forms of labor, low-wage manual labor, performed disproportionately by black people at the time. By contrast, the study of white children is concerned with maximizing their potential, and for the sake of "the race," enhancing the care and attention all white children receive (even if the standards that structure their definition of potential are rooted in unquestioned values like productivity, independence, and even sexual purity[73]). While *some* white children have special needs that require an investment of resources to ensure their (state-defined) growth and well-being, *all* black children have the "special need" to be prepared for low-wage labor at which they do relatively well, and to not be taught to think

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[73] This is actually specified in the article. The second category of persons, according to this classification, is commonly known as "morons" and has a tendency toward "sexual promiscuity," another highly racialized reason to address their "special needs."

abstractly. Whereas in the former case, the marking of an impairment is used to make an argument for *more* sympathy and resources, in the latter it is used to justify the wholesale withholding of resources from black children in schools.

Adoption law represents the first instance in which federal law uses the phrase “special needs” in reference to a category of persons. It also extends the category beyond any of its contemporary or historical social or institutional definitions. The first major federal legislation to use it this way is the 1980 Adoption Assistance and Child Welfare Act. The law created Title IV-E of the Social Security Act to offer financial assistance to people who foster children, but not specifically as an incentive for fostering “special needs” children. The Adoption and Safe Families Act (ASFA) maintains this usage of “special needs” but extends Title IV-E of the Social Security Act with additional subsidies, in the form of a tax credit, used as an incentive for adoptive families of “special needs” children. It defines special needs to include not only a medical definition, described within the act as “medical conditions or physical, mental, or emotional handicaps” (section 473C), but also “ethnic background, age, or membership in a minority group” (section 473C). The section breaks special needs into two categories: “handicapped child” and “hard-to-place child,” with the vaguely worded “ethnic background” falling into the latter. The specific enforcement of these guidelines is left up to state-by-state discretion, but most states have specified either simply “African American” or “African American or biracial.” This is likely the result of overrepresentation in the foster care system. Native Americans are the only other overrepresented group according to national data, and black people are the only group overrepresented in every state in 2007, constituting roughly 37 percent of national membership in the foster care system (Racial Disparities in Foster Care Admissions

Report, 2007).

The first law specifically designed to regulate race and the foster care system, the 1994 Multiethnic Placement Act, moved in roughly the same direction. The law took as its premise that the overrepresentation of black children in foster care could be remedied by the removal of race-matching adoption policies and sought to discourage them. The 1996 amendment to this law, Interethnic Adoption Provisions, outlawed any consideration of race in adoption placement and was prompted by complaints by prospective white adopters that they were being "unfairly kept" from adopting black babies and this was slowing their adoption proceedings (NACAC). As the 2008 Evan B. Donaldson report made clear, these laws were ineffective at remedying the racial disparity in foster care, and hurt black children by enforcing an "unyielding color-blindness." The laws were inspired not by the needs of black children, but by the "needs" of white adopters (faster adoption proceedings and access to transracial adoption). This is particularly so in the aftermath of *Roe v. Wade* and the destigmatization of abortion that led to a sharp drop in the population of white babies, and more generally in the voluntary placement of babies for adoption.

For example, Elizabeth Bartholet describes black families as unfit for parenting and suggests that the solution for "nobody's children," black children, is transracial adoption. If there is any doubt that her argument is motivated primarily by the interests of white people looking to adopt and not the black children themselves, then it is useful to look to where her stance on adoption differs from fellow Harvard Law Professor Randall Kennedy, who is black. Like Bartholet, Kennedy holds that banning "race-matching" preferences in the foster care system will enhance the likelihood that black children will be adopted. He argues further that people seeking to adopt should not be allowed to state a racial preference, either. This is where Bartholet disagrees with him, insisting that prospective parents should have a "right to choose" who to parent. Because the MEPA-IPA laws already prohibit racial considerations on the part of foster care, and this has not significantly reduced the racial disparity in children who are adopted out of foster because white parents usually do not want to adopt black children. So while Kennedy's argument could be disputed on the grounds that being adopted begrudgingly by disappointed white parents may not be best for black children, it certainly would work toward eliminating the racial disparity in adoptions. Bartholet, however, does not dispute the merits of transracial adoption, and therefore it stands to reason that she should, if she were concerned with low adoption rates for black children, support bans on racial preferences by prospective parents. The refusal to support such bans suggests that the concern is in fact with white adoptive parents' access to babies of their choosing, and not the care and well-being of black babies. Such an orientation in the characterization of the problem is revealed in the novel by Margaret's understanding of herself as victimized, comparing herself to "Jewish families in Germany" but also, tellingly, "pioneer families outrunning Indians" (235). Such a fantasy represents a warped, but also very white-centric understanding of victimization that holds white people as entitled to anything they claim, and any challenge to white property claims, whether over indigenous land or black bodies, as oppressive.

Given that the special needs designation has not remedied the needs of black children in the foster care system, even those needs identified by the discourses surrounding the passage of the ASFA (i.e., the need to be adopted), and yet the designation is maintained, what is its actual function? In the absence of a measurable benefit, the special needs designation and the attendant tax credit for black children is based on several interrelated "logics": 1. it draws ideological legitimacy from and reinforces the idea that black children are inherently, always already deviant, an inferior "bio-underclass," and that this deviance, if not biological, can be attributed to a moral failing. It suggests that not only are they "difficult to place" but that they are simply "difficult." 2. The designation has a "market" function, working to fill a demand mostly by middle-class white people looking to adopt (despite that they adopt in the same proportions as black people, and despite that they do not adopt the majority of black children who are adopted - single black women adopt two thirds of the black children who get adopted, white couples remain *the* source of the unmet "demand" because they are the ones requesting white infants who are not available). Thus, encouraging and incentivizing the adoption of black babies is an alternative way to meet the demand in the absence of a socially acceptable means of acquiring the white babies prospective white adopters seek. 3. The incentive once again reinforces a value system in which black babies are worth less and their parents should be "compensated" for choosing to adopt them.

In 2014, a white couple, Jennifer Cramblett and Amanda Zinkon of Ohio, filed a lawsuit against Midwest Sperm Bank LLC for "wrongful birth and breach of warranty" after Cramblett was accidentally inseminated with the sperm of a black donor, rather than the white donor they had selected. According to court records, after speaking to the clinic and confirming the the vials were switched, Cramblett "began to cry uncontrollably. She began to shake and she could not breathe. She could not speak or think straight. Her hands and feet became numb" (5). The clinic refunded them the cost of the vials of sperm Cramblett had used to become pregnant, but they sought even further recompense for their "personal injuries, medical expense, pain, suffering, emotional distress and other economic and non-economic issues," i.e., not just for the sperm but for the child herself. According to their claim, this necessitated "*compensatory damages* in an amount exceeding fifty thousand dollars" (emphasis added, 8). They cited comments from "racially intolerant" friends and relatives, the fact that they had never met black people before college, and having to drive to a "black neighborhood" to find a hair stylist, as part of the damages. Asked how they would later explain the lawsuit to their daughter Payton, Cramblett replied, "She'll know the lawsuit was about a company that had to make changes and give us *compensation* so that we can go through counseling and learn how to love each other even more" [74](emphasis added).

Their claim is based on the logic that they have suffered a traumatizing injury, an injury so great that Cramblett experienced it physically, by receiving something (someone) not only different from, but also clearly less valuable than, what they wanted, despite that Payton is Cramblett's biological child. *Compensation* redresses loss, and they expected to be compensated for what they understood as a personal loss to them, in an amount exceeding $50,000, representing the difference in value between who they wanted (what they expected to have) and who they received (what they "lost" relative to their expectation). As an explicit incentive designed to encourage prospective white adoptive parents to "settle" for black children they would not have otherwise adopted, the tax break granted by Title IV-E and the listing of black children as special needs is based on the same logic, working to compensate white parents for the difference in value between the white children they wanted to adopt and the black children they had to "settle" for because of demand and availability. Unlike tax breaks and stipends for

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[74] Circuit Court of Cook County, Illinois."Jennifer L. Cramblett, Plaintiff vs. Midwest Sperm Bank, LLC c/o Scott J. Bakal, Statutory Agent. Complaint for Wrongful Birth and Breach of Warranty." (2014).

children with medical conditions, which help alleviate the cost of ongoing care, tax breaks are not intended to provide black children with resources or medical care. As an incentive, such a monetary provision has no function but a compensatory one concerned with the desires and the imagined compromise, at best, or injury, at worst, to white parents. It is not concerned primarily with the "needs" of the black children, after all.

Listed as a separate category from "hard-to-place," adoption law acknowledges for "handicapped children"[75] needs beyond simply the need to be adopted. The stipend, for adoptive families of disabled children is designed, at least in part, to help fund resources, therapies, or medical treatment the child may need that a child without a diagnosed medical condition may not need. This is demonstrated by the Child Welfare Information Gateway, which is a government informational resource for child welfare provided by the U.S. Department of Health and Human Services. The page on "Children with Special Needs," listed under the adoption resources, offers a variety of links to organizations that give information or aid to those who have adopted or are looking to adopt a child with special needs. The vast majority of these organizations are either specifically about disability, or equate "special needs" with disability. One of the links provided leads to a military page on "Adopting a Child With Special Needs." The page explains that special needs adoptions involve, in addition to the usual adoption fees, "medical and other costs," and then provides information on how military families who adopt special needs children can get help with these costs, including the Title IV-E adoption tax credit. The logic for disabled babies who qualify for the special needs tax credit is that the tax break will help alleviate these

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[75] Of course, black babies can have conditions that would lead them to be legally classified as disabled, but they are "special needs" regardless of such conditions. Their designation as such is not dependent on other factors.

additional costs. In March 2016, the Association of Administrators of the Interstate Compact on Adoption and Medical Assistance held a national meeting in Oakland, California to discuss ways to improve benefits for families who adopt children who need medical and psychological services.

The state demonstrates an interest in caring for disabled children, beyond simply incentivizing their adoption, but it often does so without accounting for what might be described as "ableist" logics of disability and parenting. Disability studies scholars like Gail Landsman have pointed to some of the problems with state and medical framing of the parenting of disabled children, problems that might be replicated by adoption services for disabled children. Some of these problems include "mother-blame" and its counterpart "maternal-fetal conflict," "diminished personhood" for disabled babies, and the normalizing/rehabilitative objective of medical care. Others have also identified the fact that parental disability is often invoked as a factor to justify the termination of parental rights. Landsman's study is an ethnographic analysis of the experiences of mothers at the Newborn Followup Program of the Children's Hospital of Albany Medical Center in New York in 1995. The program is part of the free Early Intervention services for disabled children mandated by the 1986 Individuals with Disabilities Education Act. Such follow-up programs are often where infants are first diagnosed with disabilities, and the study interviews their mothers to ask how they make sense of changes in their roles and revise the concept of "normal." While they varied in class background, "the vast majority of the mothers were white" (6).

Landsman offers a historical trajectory in the United States that moves from popular conceptions of motherhood as sacred and valued toward the emergence of what has elsewhere been called "maternal-fetal conflict" as a backlash to feminist movements that demanded access to safe abortions: "pregnant women are currently portrayed… as the potential enemies of their developing fetuses" (85). White motherhood acquired its status as sacred and valued only by virtue of its whiteness and its potential to advance the "white race," which is why white women who pushed back against their roles in republican motherhood were often accused of race suicide[76]. The pressure to produce "perfect" babies, then, cannot be separated from the push to perpetuate whiteness and maintain white supremacy. By contrast, for Roberts, the first and most striking manifestation of maternal-fetal conflict begins with enslaved black women, its most powerful image according being the whipping of pregnant slaves in holes that would protect the fetuses. The fetuses were protected as prospective commodities, dead subjects, at the same time that black women were subjected to the direct enactment of power on their bodies. In "Unshackling Black Motherhood," Roberts shows how the "maternal-fetal" conflict is invoked in the "war on drugs" and crackdown against (mostly black) women who use drugs during pregnancy as a way to legitimize the criminalization and warehousing of black women, and not to protect the lives of their children. The rhetoric justifying these forms of genocide implies both that all black children are a "mistake" whose births should be prevented, and that black women are to blame. The rhetoric is familiar enough that it finds its way into the novel, albeit in an attempt at sympathy: "It's a boy, the doctor had said in a flat, critical voice, as if what she'd made was a mistake and not a new human being" (117).

In other words, the regime relies on what Landsman calls "mother blame." Landsman argues that while mother blame has a long history across various cultures, it has tended to

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[76] Patricia Palmieri, "From Republican Motherhood to Race Suicide: Arguments on the Higher Education of Women in the United States, 1820-1920."

decrease in conjunction with increases in genetic testing and reproductive technologies, which have offered alternate sources of “blame” for childhood disability. For example, “pregnant women are viewed as non-relevant to the health of the fetus” in Israel where people are “avid consumers of new reproductive technologies.” By contrast, “even with increasing geneticization, women are held accountable for the birth of disabled children in American culture” (17). Landsman offers some information about what might explain this persistence, including “unequal social burdens” that persist despite “equal material (genetic) donations” and, especially, “public health campaigns.” Campaigns are put on by organizations like the March of Dimes: Preventing Birth Defects, which produced “Mommy… Don’t” posters in the 1980s and 90s with images of pregnant women consuming drugs and alcohol. All of the posters feature black women. What remains unspoken is that this campaign in particular “most closely linked illicit drug use with black women” (Reagan 229), and such campaigns generally were part of the War on Drugs and its reliance on the “welfare queen,” a woman who collects welfare checks to fund her crack cocaine addiction while neglecting her children, racialized as black by Ronald Reagan in a 1976 campaign speech[77]. The (predominantly white) women Landsman interviews, to some degree giving in to mother blame, express surprise that their children were born with disabilities because they “did everything right” in contrast to “people drinking and druggin” (32), suggesting that their own internalization of mother blame is influenced by these racialized campaigns. Thus even the general persistence of mother blame in the United States as it related to dis/ability, I argue, can be attributed to a regime that devalues black children and blames and punishes black

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[77] Demby, Gene. “The Truth Behind the Lies of the Original Welfare Queen.” *National Public Radio* (2013).

mothers.[78] And this mother blame, as a result, does not affect all mothers equally. Roberts explains that whereas white parents with housing problems are more likely to be offered housing services, black families with housing problems are twice as likely to be separated from their children and more likely to be offered "parenting services" (21). The services offered them are "focused on fixing their perceived parenting deficits… [and] offered them few material benefits such as rent subsidies, furniture, food, clothing, and child and respite services" (21). The problem is addressed by the state as an inherent individual failing for which black mothers should be blamed, even when the same exact problem when faced by white people is addressed as external and material.

The devaluation of disabled white babies and blaming of their mothers for their disabilities, cannot be understood outside of the context where black children are always already devalued, black families are always surveilled and torn apart, and black mothers are always blamed. In Bartholet's *Where Do Black Children Belong*, she tells the story of her adoption, on two separate occasions, of Peruvian babies, the second of whom was "unusually white." To deter others from trying to adopt him, and to prevent state officials from hiking the cost of his adoption because of his whiteness, she explains, "When required to take him to the various police and medical examinations and court appearances that are part of the adoption process in Lima, I learned to keep his face covered with a blanket at all times… *I would talk constantly of how frail and ill he had been since birth, hoping thereby to discount his white value*" (1169, emphasis added). In some ways, even white babies' categorization as special needs might move children

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[78] This is not to say that black motherhood is not devalued in places like Israel, which admitted several years ago to forcibly and unknowingly sterilizing Jewish African immigrants, but rather that perhaps Israel's attacks on black motherhood have not taken the American form of characterizing black women as particularly prone to substance abuse and then separating them from their children on these grounds.

up and down an already established and commonly understood racial ranking of desirability. This is why all black babies are automatically classified as special needs, having already been determined to be less desirable regardless of medical or family background. And the ranking may well hold for the international adoption market: "The Latin American countries with significant Indian or mestizo but limited black populations generally fall between Chile and Brazil on the desirability list because the adoption 'market' rates Indian as lower than white but higher than black" (1167). An approach that recognizes the relationship between the racist history of the War on Drugs and the strength of "mother-blame" in the U.S. could help address some of the problems with disability and parenting identified by disability studies.

IV.

At a protest in Oregon held after a grand jury in Missouri failed to indict a Ferguson police officer for the murder of Michael Brown in late 2014, a viral photograph was taken featuring 12-year old Devonte Hart hugging a police officer, Sergeant Bret Barnum, with tears streaming down his face. The photograph was shared more than 150,000 times on Facebook and through numerous media outlets and talk shows. CNN shared the photograph in an article titled "The Hug Shared Around the World."[79] Devonte's adoptive mother Jennifer Hart proudly took credit for this encounter, inadvertently revealing it to be coerced and suggesting that Devonte's tears may have stemmed from terror:

> Last night I encouraged Devonte to face his concerns and fear. It was one of the most emotionally charged experiences I've had as a mother. He trembled holding a Free Hugs sign as he bravely stood alone in front of the police barricade. Tears rushing from his eyes and soaking his sweater, he gazed upon them not knowing how they would react. After a while, one of the officers approached him and

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[79] Grinberg, Emanuella. "The hug shared around the world." *CNN* (Dec 1 2014).

> extended his hand. Their interaction was uncomfortable at first. I kept my distance and allowed him space to truly have his own experience.

More than three years later, on March 25, 2018 Devonte Hart's adoptive parents, Jennifer and Sara Hart, and three of his siblings were found dead in an SUV that drove off the edge of a cliff in Mendocino County, California. Though it was immediately noted that there were no skid marks to indicate that the driver of the vehicle had tried to brake, law enforcement officials and media reports were initially reluctant to ascribe intentionality to the incident, maintaining for up to a week after the event that there was "no evidence" to do so. The bodies of Devonte and two of his other siblings were not inside the vehicle, and one body found near the vehicle has yet to be identified. Police have been unable to identify the body based on dental records because they have not found a dentist who treated the Hart children. All six of the children, however, are now presumed to be dead. On the day of this murder-suicide, Child Protective Service officers were scheduled to make a visit to the Harts' home, after receiving yet another call reporting signs that the children were being abused, including that the children repeatedly pled for assistance from their neighbors.

Transracial adoption is not, of course, always or inevitably harmful, but there are a number of very real harms caused by the foster care system's promotion of transracial adoption as *the* solution to a problem attributed to the moral failings of birth families rather than the political and economic context in which they have and raise children. What this story illustrates is that the foster care system as it currently stands is unable and uninterested in vetting, and indeed *restricts* vetting, prospective white adoptive families to make sure that they are qualified to parent black and other non-white children, and that they maintain ties to black and other non-white people who can serve as a supportive presence in the children's lives. Such a presence could ensure, for example, that the very legitimate fears of the police expressed by Devonte were being recognized and validated, and that he was receiving protection and support from people who understood the situation, rather than being "encouraged" (read: coerced) into "facing" his fears, alone, as though they were unreasonable, and thereby being used to promote a narrative that only provides comfort to other white people who, like his adoptive parents, want to deny the realities that produced his fears in the first place.

Though transracial adoption does not necessary lead to abuse and parents of any race could potentially be abusive, these children were *clearly* and *openly* being abused by their white parents, who continued to be approved for adoption despite a legal record of abuse. The children were small and underweight for their ages even in 2014 at the time of the viral photograph, and even more so in 2018 at the time of their tragic deaths. While children subjected to abuse are often too afraid to report their abusers, the abuse in this case was so bad that the children repeatedly notified their neighbors, the only other adults to whom they had access because they were homeschooled, that they were being denied food, physically assaulted, and subjected to racist verbal abuse. That their parental ties were maintained despite these reports suggests that the welfare of black children, despite the narrative behind the changes to federal law I discussed in this chapter, is *not*, ultimately, the primary concern of the child welfare system. Rather, the punishment of black parents, and specifically black mothers, who often lose their children when the relationship is deemed neglectful by social service workers, before it becomes at all physically abusive, is the real underlying motive. More to the point, the narrative that suggests children in the American child welfare system, particularly black children, are being rescued, comes at the expense of their birth families, and specifically their birth mothers, who often want to keep their children and are working toward this goal. As in the case of Devonte and his siblings, the foster care system severs these ties too quickly, causing trauma for both the children and their birth families, a move that is geared less toward ensuring the welfare of the child and more toward acting as a punitive measure based on a belief that the birth mother has failed her maternal responsibilities.

Finally, the discourse of intrinsic deviance, where black children are framed as being always/already "disabled" by bad parenting, drug use, and other moral failings is used to bolster these narratives and justify these changes. Before Devonte obtained internet fame with the protest photograph, his adoptive mother Jennifer Hart conducted a 2014 Huffington Post interview[80] that featured him, exposing his personal history and describing him in language that echoes statements by Besharov and Krauthammer: "Devonte Hart entered the world 12 years ago with drugs pumping through his tiny newborn body. By the time he was four years old he had smoked, consumed alcohol, handled guns, been shot at and suffered severe abuse and neglect. He knew only a handful of words, including fuck and shit, and he struggled to identify with the names of food, body parts and everyday objects. Devonte was a violent toddler and his health was weighed down by a heavy list of disabilities." After setting up the extent of his "damages," the article praises his adoptive mothers for rescuing him from the situation. "With their unconditional love, nurturing natures, patience and acceptance," journalist Chloe Johnson writes, "Devonte defied all odds and has grown into a young charismatic man with a heart of gold." The feature concludes with a quote from Jennifer Hart, who drove the SUV over the cliff: "for the

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[80] Johnson, Chloe. "Meet Devonte: The Little Boy with a Big Heart." *Huffington Post* (Nov 13 2014).

love of the universe, let’s not categorize abilities by skin tone. Let’s move forward, shall we?” After seeing news reports about the murder, Sherry Davis, an in-home care worker and birth mother of Devonte and his siblings Jeremiah and Sierra, who were also adopted by the Harts, spoke to The Oregonian/OregonLive about her struggle with substance use and how she lost her children. After maintaining sobriety for a year, she relapsed after discovering that the Harts’ had officially adopted the children, despite that their paternal aunt was in the process of trying to secure custody. She has now been sober for over eight years, and never lost hope that she would one day regain custody. “They're so quick to snatch [children] from people like us, but once they're adopted, they don't even check on them,” Davis said in the interview. “[They] gave them to monsters.”

Chapter 3: Companionship Servitude

> "Driss becomes my body in a way. When he dances, it's a little as if I were dancing. When he tells a joke, it's a little as if I were joking… We mustn't always want things to pass through us. It's an opportunity when they pass through a partner. It's fascinating on a human level."
>
> Francois Cluzet, on playing Philippe in *The Intouchables* (2011)

I.

In May 2017, fearing that the Trump Administration was considering the termination of Temporary Protected Status for tens of thousands of Haitian immigrants to the United States, Massachusetts State Attorney General Maura Healey and Massachusetts State Senator Linda Dorcena Forry wrote a letter[81] to U.S. Secretary of Homeland Security John Kelley urging him to extend TPS status. They made this recommendation on the basis that Haitian immigrants covered by TPS have enjoyed "economic opportunity through employment and business development, all the while continuing to pay taxes." More importantly, they argued, "Haiti does not have the infrastructure or resources to absorb or support the returning population." The little progress that was made toward redevelopment in the aftermath of the 2010 earthquake, they argued, was subsequently undone by one of "the largest cholera epidemics ever recorded," Hurricane Matthew in late 2016, and the emergence of microcephaly, linked to the Zika virus. "Haiti's medical system," they said, "remains unable to adequately address the nation's public health crises."

The Massachusetts Senior Care Association, too, has been vocal in urging the extension of Temporary Protected Status (TSP) for Haitian immigrants, noting that the majority of TPS

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[81] Healy, Maury and Senator Linda Dorcena Forry. "Re: Extending Temporary Protected Status for Haitian Nationals, May 16, 2017." From The Commonwealth of Massachusetts Office of the Attorney General. Available at http://www.mass.gov/ago/docs/press/2017/extending-temporary-protected-status-for-haitian-nationals-letter-to-dhs.pdf .

Haitian immigrants in the state serve as home aide and other healthcare workers and with the rise of baby boomers, the loss of their labor is a real threat to the national economy. On December 4, 2017, President of the Massachusetts Senior Care Association Tara Gregorio and President of the Massachusetts Senior Care Foundation Marva Serotkin published an open letter to the Trump Administration in the *Boston Globe*, once again urging the administration to maintain the Temporary Protected Status of Haitian immigrants. They explained that a decision to end TPS for Haitian immigrants "will have a devastating impact on the ability of skilled nursing facilities to provide quality care to frail and disabled residents." The letter notes that "4,300 Haitians provide care and companionship to our residents" and that their deportation would undoubtedly harm the "150,000 people who live in the state's nursing home each year." Despite protest, in November 2017, the Trump administration terminated TPS for Haitian immigrants, effective July 2019. The administration has also terminated TPS for 200,000 Salavdorans who have been in the United States for nearly two decades, as well as thousands of immigrants from Nicaragua and Sudan. A decision has not been reached regarding the status of 57,000 immigrants from Honduras. Concluding the letter, the MSCA implored, "We urge the Trump administration to reconsider its decision."[82] Trump followed these pleas by famously asking in a 2018 meeting with lawmakers, "Why are we having all these people from shithole countries come here?" He followed more pointedly: "Why do we need more Haitians? Take them out." As of now, there is no indication that the administration is reconsidering the termination.

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[82] Tara Gregorio (MA Senior Care Association) and Marva Serotkin (MA Senior Care Foundation). "Letters: Nursing facilities, and their residents, will feel impact if Haitians' status ends." The Boston Globe, Dec 04, 2017.

News coverage about this development narrativized the situation by characterizing the relationships between in-home caregivers and those being cared for as “friendships,” eliding the exhausting realities of caregiving labor. Published in *Kaiser Health News*, and reprinted in *Aging Edge*, Melissa Bailey’s “As Trump targets immigrants, elderly brace to lose caregivers,” begins with the story of 96-year old Italian-American Isolina Dicensio and her caregiver, a 46-year old Haitian woman whom we know only as Nirva. The article begins, “After back-to-back, eight-hour shifts at a chiropractor’s office and a rehab center, Nirva arrived outside an elderly woman’s house just in time to help her up the front steps.” Readers are expected to gloss over the detail about the back-to-back eight hour shifts, and instead focus on the beauty of the relationship between the two women. They greet each other with pet names. Nirva takes Isolina’s arm to help her up the stairs. They stop for a hug at the top of the staircase.[83]

Likewise, letters calling for extension of TSP status for Haitian immigrants romanticize their labor and their “contribution” but give little attention to the extreme levels of abuse and exploitation they face as workers. Temporary Protected Status is a particularly contentious immigration status. Ostensibly created for people fleeing war or natural disasters in their homeland, it does not include a route for permanent citizenship. However, in practice it is extended for so long that immigrants often spend decades in the United States and have family members who are citizens. Still, the immigration status can be terminated at any time, which has left TPS immigrants vulnerable not only to abuse and exploitation in the workplace, but also to sudden forced estrangement from their families and communities. Instead of focusing on this

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[83] Melissa Bailey. “As Trump targets immigrants, elderly brace to lose caregivers.” *Kaiser Health News*. March 2018. http://www.post-gazette.com/aging-edge/aging-edge-reports/2018/03/28/As-Trump-targets-immigrants-elderly-brace-to-lose-caregivers/stories/201803280102

U.S.-based abuse, the letters paint Haiti as the site of suffering for Haitian immigrants, without context, and list as reasons why the extension is necessary a variety of illnesses supposedly rampant in Haiti and to which Haitian immigrants would be put at risk if they were sent back. The invocation of risk and danger is used strategically by the MSCA to advocate for the maintenance of TPS because that is the criteria on which it is based. What must be overlooked is the risk posed by working conditions in the U.S., and specifically that the caregiving labor being characterized as affectionate is difficult and *highly* exploitative, with most workers so underpaid that they often leave when they find better opportunities in the fast food industry. Moreover, the labor does not come with benefits like health insurance[84] and laborers often do not have enough income to purchase their own. Living in poverty and without health insurance, of course, is a threat to the health and well-being of TSP immigrant care laborers.

I contend that any argument about disability care and caregiving cannot be divorced from broader political and social relations already organized along lines of race and gender. Care can be understood as a relation in which the body or being of one person is used to improve the well-being or comfort of another, enhanced in quality when the person providing care is personally invested in the well-being of the one who receives it. Many theorists have also noted that care labor is a particularly significant part of global labor systems in contemporary neoliberalism. I argue that an understanding of care as simply a natural or inevitable form of human relation, which everyone needs, provides mutually and is understood to deserve, relies on apolitical ideas

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[84] In Massachusetts specifically, the Health Safety Net was created in 2007 to provide emergency medical services to particular residents of the state who meet income requirements, including many TSP immigrants. However, the services covered by this program are limited and they do not fund or subsidize preventative care services or many other forms of non-emergency medical care. "Healthy Safety Net Overview" Nov 2011. https://www.mass.gov/orgs/health-safety-net

of humanity and on an imagined social equality that cannot be willed into existence simply by being proclaimed. Moreover, care labor is not a new form of labor, or even unique to today's world, but institutionalized care provision, as a mass, globalized system has its roots in slavery, and the ideologies that determine who deserves to receive it and who should provide it are inseparable from "enslavability" and the several centuries' long process by which it has been connected to blackness in many parts of the world.

Understanding the care provided to the disabled subject, no matter the background of the caregiver and cared-for, cannot be separated from care labor's origins as a system in racialized slavery and its continued manifestation as antiblackness, or from existing material and ideological realities of race, gender, and class that allow care to cohere and be legible for different subjects in different ways. Thus, "we all need care," a disability studies claim that counters the myth of independence, is true but socially and politically irrelevant in the larger context of racist ideologies about whose bodies are available to be used in service of others; who deserves and does not deserve to be well and comfortable; whose ailments warrant response; the material conditions according to which care is distributed; whose kinship relations are to be recognized and respected; and for whom it is even possible, in social and legal terms, to be considered an independent social and political agent, in spite or because of these care relations. In this chapter, I read the 2011 French film *Intouchables*, and two memoirs associated with it, and the context of its American remake, *The Upside*, which was scheduled for release in 2018. I focus on this story because it gestures, in its subtext, to that disavowed or repressed history, even as it seeks to tell an entirely different story about care. It serves as an opportunity to reconsider what a properly contextualized analysis of care might look like, as well as the global and local ways in which ideas that structure care and care labor emerge and circulate.

II.

The extreme level of exploitation many caregivers face is made possible and exacerbated by what is known as the "companionship exemption" and the racist history of labor and legislation from which it follows. The 1938 Fair Labor Standards Act[85] was enacted as part of the New Deal to address "labor conditions detrimental to the maintenance of the minimum standard of living necessary for the health, efficiency and general well-being of workers" by mandating minimum wage and overtime pay. Several professions were left unprotected by this law, including domestic labor, restaurants, and agricultural labor. Coverage was extended to the latter two forms of labor in 1961[86] and 1966[87], but domestic labor was left unprotected until 1974[88]. The extension of protections to domestic labor came with a key caveat known as The Home Health Care and Companionship Services Exemption, or the "companionship exemption" for short. "Companionship services" exempt from protection were defined as "those services which provide fellowship, care, and protection for a person who, because of advanced age or physical or mental infirmity, cannot care for his or her own needs. Such services may include household work related to the care of the aged or infirm person such as meal preparation, bed making, washing of clothes, and other similar services."

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[85] Fair Labor Standards Act of 1938, ch. 676

[86] Fair Labor Standards Amendments of 1961, Pub. L. No. 87-30, 75 Stat. 65

[87] Fair Labor Standards Amendments of 1966, Pub. L. No. 89-601, 80 Stat. 830

[88] Fair Labor Standards Amendments of 1974, Pub. L. No. 93-259, 88 Stat. 55

The 1938 Act excluded domestic labor and a number of other professions[89], including agricultural labor, which were historically performed by slaves in the United States. Legal scholar Molly Biklen attributes the exclusion to "the ideological separation of the private home and workplace, and the 'special' place of domestic labor within the family"[90]. Legal scholar Sheila Bapat extends this analysis in tracing the original exclusion of all domestic workers from the 1938 Act and the later 1974 exemption to the history of slavery in the United States, which characterized slaves, particularly those who performed domestic labor, euphemistically as "part of the family," delegitimizing and devaluing the labor on that basis. At the time of the 1938 law's passing, the vast majority of domestic workers in the United States were black women. And a highly disproportionate number of care laborers, still, are African American women, and many more are immigrants from various parts of Latin America and the Caribbean. The vast majority of laborers in home aide and related caregiving positions are women, comprising 85% of the total workforce. Nearly a million immigrants work as certified nursing assistants, home health aides, or personal care attendants, making up a fourth of the total workforce for these positions. Roughly 35% of care laborers in the United States are "black, non-Hispanic."[91] Similar patterns can be found for non-paid care labor of friends and relatives, which falls most frequently to black

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[89] In effect, this exemption acted as a counterpart to the criminal conviction exemption to the thirteenth amendment, leaving laborers in particular employment sectors, still mostly black, open to extreme levels of exploitation and abuse even without a criminal record.

[90] Biklen, Molly. "Healthcare in the Home: Reexamining the Companionship Services Exemption to the Fair Labor Standards Act." *Columbia Human Rights Law Review* 35, 2003, p. 114.

[91] Anita Bercovitz, Abigail J. Moss, Manisha Sengupta, Eunice Y. Park-Lee, Adrienne Jones, Lauren D. Harris-Kojetin, and Marie R. Squillace. "An Overview of Home Health Aides: United States." U.S. Department go Health and Human Services - Centers for Disease Control and Prevention. National Health Statistics Reports, Number 34. May 19, 2011. https://www.cdc.gov/nchs/data/nhsr/nhsr034.pdf

and Latina women, and is especially time-consuming for them because they are least likely of all non-paid care laborers to get help from paid workers.

While campaigning for presidency in 2007, Barack Obama vowed to extend labor protections to all domestic workers, and worked as president to narrow the terms of the "companionship exemption." The exemption was narrowed in 2015 to apply only to individuals and families who employ domestic workers privately; it no longer applied to third party home care worker agencies who sent employees to private residences to perform this labor. Additionally, the exemption was restricted to home aide and companionship services provided to elderly and disabled people who require them; if additional labor is performed for other family members, the exemption is negated. The revision also establishes guidelines according to which employers are required to document the relationship. Following these changes, the Obama Administration was sued by the Home Care Workers Association, which attempted to block the amendment, but it was nevertheless upheld. Still, these more narrowly defined forms of "companionship services" remain the only category of labor for which there is no nationwide minimum wage requirement.

In 2010, New York was the first state to pass a Domestic Workers' Bill of Rights, and since then only two other states, Hawaii and California, have followed suit. The bills mandate overtime pay and protection from harassment and discrimination but only the New York bill includes a minimum wage requirement, in the amount of $7.25. So, in nearly every state, there is no minimum wage requirement for "companionship" labor; workers instead reach an "agreement" privately with their employers. They are severely underpaid and extremely vulnerable to abuse and harassment. And even the changes mandated when the exception was narrowed are not always enforced. In 2016, the Massachusetts Fair Labor Division received an anonymous tip noting that a Massachusetts-based home care company, Maestro-Connections Home Health Systems, LLC[92], was falsifying payroll records and refusing to pay overtime to its 600 skilled nursing and home aide employees. In November 2017, the company reached a settlement with the Attorney General, agreeing to pay over $1 million in penalties and restitution. It is impossible to know how many other companies are doing the same, without anonymous complaints to expose them.

Moreover, like many small Obama-era legislative reforms, these changes are under threat under the new administration. With the election of Donald Trump in 2016, many such home care agencies held out hope that Trump, campaigning under a "pro-business" platform, would reverse these Obama-era changes. In "Trump as an advocate for the disabled, elderly,"[93] an opinion piece published in January 2017 in the *Orlando Sentinel*, president of Evergreen Home Care Joseph "J.B." Bensmihen expresses this hope. He frames the issue as a "disability rights" issue on which Obama ostensibly came down on the wrong side, a mistake he hopes Trump will remedy. With this opposition between "disability rights" and care laborers in mind, I focus on several key aspects of the "companionship exemption" that are relevant to my analysis here, including its original form, the revised version, and the legislative debate surrounding its inclusion in the 1974 changes to the FSLA. As Saidiya Hartman has argued, "domestic work carried the taint of

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[92] Gainey, Emalie. "Press Release - Home Health Company Agrees to Pay More Than $1 Million for Not Providing Overtime Wages to Aides." *Massachusetts Government Office of Attorney General Maura Healey and the Attorney General's Fair Labor Division* (Nov 21 2017).

[93] Bensmihen, Joseph "J.B." "Trump as an advocate for the disabled, elderly." *Orlando Sentinel* (Jan 2017).

slavery,”[94] and I read the ways that this “taint” informs the exemption and the larger discourses about care labor for the disabled in media and scholarship that provide the context for it.

First, explicit connections to slavery were made as part of the debate surrounding the inclusion of the exemption. Specifically, it was identified by opponents of the exemption as central to how domestic labor continues to be understood and why many are reluctant to include it in the FSLA. Senator Harrison Williams stated, “Many domestics are treated just as they were 150 years ago-that is, as slaves.... They are called ‘girl’ and by their first names while they, themselves, must still address their employers and their employer’s children as ‘ma’am’ or ‘sir' or ‘Miss Jane.’” In his own statement, Senator Jacob Javits added that, “there is still some kind of lingering question about whether [domestic workers] are ‘servants’ in the old sense, so that you can have kind of a chattel mortgage on them, rather than being workers like anybody else” (124). Biklen reads these statements as attempts to push for an understanding of domestic labor as a “modern, arms-length employment relationship,” as opposed to an “informal” family arrangement (124). However, in this reading of statements that explicitly invoke *slavery* and *chattel* (as opposed to white middle class housewifery), Biklen elides the status of domestic labor under slavery as modern, as both formal and a form of what Christina Sharpe calls “monstrous intimacy,” as unidirectionally “arms-length.”

Second, the wording of the revised exemption characterizes care labor for the disabled and elderly as labor that allows people to live “independently,” rather than inherently signifying *dependence*. The revised exemption clause includes under its definition of “care”: “tasks that enable a person to live *independently* at home” (emphasis added). My analysis in this chapter

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[94] Saidiya Hartman. “The Belly of the World: A Note on Black Women’s Labors.” *Souls* 18.1, 2016.

asks how racial logics of personhood, agency, (in)dependence, and objecthood, informed by the "taint of slavery," maintain this framing in the social sphere, and how this framing supports and perpetuates the opposition between "disability rights" and a caregiving workforce predominantly made up of black women and other women of color in service of asserting the former at the expense of the latter.

Finally, I want to focus on how the characterization of affection, care, or love as inherent and "freely given" is used to negate the extent to which the labor is imagined as "real" as well as the injury of its extraction. Biklen explains that "the home has been, and often continues to be, seen as a separate sphere from the market, where individuals are bound by relationships, affection, and love, rather than economic transactions. This view of home economics has made courts resistant to enforcing contracts between family members for care and service" (118). Yet, as literary theorist Hortense Spillers has argued, this gendered division between the home (or the domestic or the private realm) and the market (or the public realm), cannot be maintained in the context of captivity: "female gender for captive women's community is the tale writ between the lines and in the not-quite spaces of an American domesticity" and this continues to pose "an implicit and unresolved puzzle… within current feminist discourse"[95]. In the legislative debate about the exemption, what is being debated is not domestic labor given by family members; instead, what the legislators are arguing over, explicitly, are those forms of domestic labor which are not expected as a result of kinship ties. Biklen adds that "in the view of the opponents to the committee bill, the occupation of "companion" was synonymous with 'social companion,' and the understanding was that workers in this occupational sub-group were more like intimates than

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[95] Hortense Spillers, "Mama's Baby, Papa's Maybe: An American Grammar Book." Diacritics, Vol. 17, No. 2 . 1987, p 77- 78.

employees" (122). Bilken is right to argue for a reconceptualization of "home" that does not equate it with intimacy and affection. However, at stake here is that the framing of the debate imposes "the home," the private realm, with its connotations of "relationships, affect and love" on laborers for whom these homes are a public marketplace. In this chapter, I explore the commitment to this fantasy in academic and popular culture discourses about care labor and disability.

III.

Olivier Nakache's and Éric Toledano's 2011 French film *The Intouchables* has gained enormous popularity in Europe, the U.S. and parts of Asia, becoming the second highest-grossing French film ever and the highest-grossing film in any language other than English in 2012. It tells the story of Philippe (played by Francois Cluzet), a wealthy white man who was paralyzed in a skydiving accident and is searching for a live-in caregiver. Driss Bassary (played by Omar Sy) is a Senegal-born black man from "the projects" who applies for the position hoping to be rejected so that he can continue to receive unemployment benefits. Philippe hires him and the two eventually become close, their friendship bridging the distance between their social worlds and helping Philippe recover emotionally from the trauma of his disablement. As the tagline puts it, "sometimes you have to reach into someone else's world… to find what's missing from your own." The film is based on the true story of Philippe Pozzo di Borgo and his French Algerian-Moroccan caretaker Abdel Sellou. In fact, it borrows heavily from Pozzo's 2001 autobiography, *A Second Wind*, and a brief French television documentary based on the same story. Following the release of the feature film, Sellou reluctantly agreed to publish his own memoir, *You Changed My Life*, about his relationship with Pozzo[96]. These texts, taken together, reveal the marking of blackness, especially, in an antiblack world as always already impaired through particular character traits - inherent immorality, impulsivity, unintelligence, criminality, laziness, sexual excess. As I have argued, this marking both leaves blackness as an impossible proper subject of disability, and makes possible analogies between blackness and disability. This racialization is also part of an economy of care, necessary to any understanding of disability, that determines who should and should not provide and receive care, and who does and does not deserve care.

The film opens with the scene in which Driss speeds, leads police on a car chase, and then bets Philippe that he can get the police to give them an escort to the hospital if Philippe pretends he is suffering. The scene establishes some of what the producers wished to convey about the characters and their relationship. Driss's character is wild and chaotic, impatient and rude (his opening line is "outta my way"), with little respect for law and order. The scene also gives audiences a glimpse into why Philippe derives so much enjoyment from their relationship. Also, importantly, as Pozzo has repeatedly expressed to the producers, he wants the film to be fun and humorous so as not to elicit the audience's pity for his condition - the scene helps establish that by allowing Driss and Philippe to use Philippe's suffering as a tool with which to play a prank on police officers and convey humor to the audience. Inadvertently, the subtext of this scene also reveals the logic by which suffering is rendered as visible to the state and care (like surveillance and punishment) is understood as deserved and necessary. Driss, a black man dressed in white sneakers, sweat pants, a grey hoodie and an oversized black leather jacket (i.e.,

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[96] For the sake of clarity, I will refer to the two characters by their first names, Philippe and Driss, and the characters on which they are based by their last names, Pozzo and Sellou.

as I argue below, in what the French understand as black American fashion, situating him as "from the projects") is driving an expensive sports car and speeding, drawing a crowd of police officers in multiple police cars on a chase. They order him out of the car and four guns are pointed at his face. One of the officers slams his body against the hood of the car. He yells about Philippe's condition, allowing them to pause long enough to confirm his story. Philippe's suffering, even when feigned, is legible to the officers (and the state) and is understood to deserve a response of care, whereas the suffering that being slammed against the car causes Driss is deserved because of his poor character. Having established the film as pleasurable, the scene concludes with Driss marking a "change of mood" with the Earth, Wind, and Fire song "September" and the opening credits. Philippe's feigned emergency interrupts Driss's subjection to state violence and subsumes it in the storyline by momentarily redirecting the state's attention to providing Philippe the care he needs, but it does not address it as a problem in itself, thereby naturalizing it. I show that not only does this subtext need to remain unaddressed, its presence is actually necessary to such "care-ethical approach" based in empathy.

Much of disability studies care theory builds off of Carol Gilligan's seminal intervention into developmental theory and moral philosophy, the 1982 *In a Different Voice: Psychological Theory and Women's Development*, which argues that developmental theory is limited by its male-centric approach to moral problems in that it centers justice, as opposed to values that are more important to women, like care and connection. Annette Baier, for example, imagines that "justice" has already been achieved by groups like "blacks and women," but this has not solved their social problems because what remains missing are care and human relationships that would help bring about real social change.[97] Michael Slote builds on Gilligan's premise by extending the argument further than other care theorists to say that "a care-ethical approach can be used to understand *all* of individual and political morality" (2, emphasis added), as opposed to be being a single one ethical virtue among many or being applicable only in situations where people can directly connect with one another. A care-ethical approach can advance "respect, autonomy, social justice, and deontology." He supports his argument by an understanding of care "based in and sustained by our human capacity for empathy with others" (4). In other words, justice and other values can be subsumed under, or viewed from the perspective of care, and distance between people can be bridged by empathy.

Nel Noddings takes a similar approach, where care is not a "virtue belonging to the carer," but should rather be understood as a reciprocal "human relation." "The desire to be cared for," he explains, is "almost certainly a universal human characteristic" (17). "A *caring relation* is, in its most basic form, a connection or encounter between two human beings" (15). The plot and popularity of *Intouchables* rely on such understandings of care and empathy as both a basic, reciprocal human relation and a solution to social and political problems. The "distance" between the worlds from which Driss and Philippe come is bridged by a genuine human connection based

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[97] She interviews "women in and around a university" (2) - i.e., likely middle-class white women - and finds that "the feminine voice" understands morality to include "winning approval, love, and friendship," the "wish not to hurt others," and "a way of solving conflicts" so that relationships with other people will be harmonious, based on mutual understanding and connection. This, she argues, as opposed to the masculine value of justice is how women problem-solve and build their moral codes. Annette Baier elaborates in "The Need for More than Justice" that the people "challenging the supremacy of justice include "surprising" groups like "blacks and women" (41) - though, notably, of the ten people she mentions who do this work, none are black - who used "the language of rights and justice" to "change their own social position" but found limitations in the outcome of this strategy. She attributes these limitations to the fact that though organizing for justice can successfully help these groups achieve "equal opportunity" and "basic liberties of free speech, free association and assembly," etc., this does nothing "to ensure that the people who have and mutually respect such rights will have any other relationships to one another" (47).

in care, empathy, and mutual respect. They win each other's "approval, love, and friendship" and through that, they both benefit. The subtext gestures to a different story about care that is also missing from the accounts of care offered by these care theorists, including the limits of empathy and the imaginary social equality that serves as the precondition for human relationally and a "care-ethical approach" to social and political problems.

Some have taken a more critical stance toward care the care-ethical approach. Such scholars include Carol Bacchi and Chris Beasley, who argue that proponents of care as an organizer of politics offer an argument that it simultaneously too "normatively prescriptive" in its understanding of individual behavior and too vague, or capable of being used to support any stance, in terms of larger political goals. For example, some have used a "care-ethical" argument to argue against the welfare state on the grounds that care will be of higher quality if people provide it directly to others in their social networks. Others, like Nel Noddings and Eva Feder Kittay have used the care-ethical approach to argue in favor of a stronger welfare state. Similarly opposed stances have been taken for and against abortion, for example, using this approach. Historian and theorist Saidiya Hartman's *Scenes of Subjection* can further illuminate the limits of this approach, given the concerns at hand. Hartman questions the limits of white abolitionist empathy for enslaved black people by asking whether it requires that the slave be replaced with the empathizer, thereby negating the empathy.

Kittay, one of the foremost disability studies care theorists, does not in her analysis claim a care relation based on social and legal contexts of formal equality. On the contrary, she claims, that care is particularly necessary for those who defy the "conception of a person as independent, rational, and capable of self-sufficiency" (559). The "inclusion of people with mental retardation may well be liberalism's limit case" because all other movements involved a "blueprint developed by persons of color, women, and gays and lesbians" that can be summed up as "attempts by the marginalized to be recognized and fully enfranchised demanded that the practice of liberalism be consistent with its tenets of universal equality and freedom" (558). The problem with this argument is not only that it offers an inaccurate summary of the demands of a wide variety of often conflicting movements, but also that it presumes that all people are indeed socially and politically equal except for those whose physical differences limit their capacity for capitalist productivity and civic participation.[98] In fact, "equality" is not universally realized, and and the ideals of freedom and equality are imagined and realized for some against others, even in the absence of physical differences that limit the potential for productivity and other liberal ideals. In other words, Kittay nevertheless relies on an imagined social and political equality, except for those for whom it is not physically possible. Hartman would here too be useful for her argument that post-1865, black "subjectivity" was only legible to the state as criminality, to legitimize punishment. Black people were "granted" burdens and "responsibilities" of citizenship, but not the benefits. They certainly were not imagined to deserve care, protection, or resources from the state.

Her prescription for care, therefore, cannot account for racial inequality. For Kittay, care is "a labor, an attitude, and a virtue." Though the labor can exist without the attitude, the quality

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[98] It should be noted that in making this argument Kittay breaks from the social model of disability, arguing against it on the grounds that some physical differences would restrict the capacity for productivity or independence in *any* environment. It could be argued, against Kittay, that social or discursive models of disability do not argue simply that physical differences do not exist in themselves, nor that all persons have the capacity for independence with changes in the environment, but that no form of physical difference is a *disability* in itself; it may not, for example, be a problem in a context that did not require or expect independence or productivity. This could then prompt a conversation about how one would need to define disability to make this claim - but this is all outside the scope of this chapter.

of the labor suffers and the human relationality made possible by a caring attitude cannot be present. A caring attitude "denotes a positive, affective bond and investment in another's well-being" and care as a virtue, the ultimate kind, requires "consistency of care, maintaining care even when it is difficult and disadvantageous to us, requires the cultivation of the virtue. Care as a virtue is a disposition manifested in caring behavior (the labor and attitude) in which 'a shift takes place from the interest in our life situation to the situation of the other, the one in need of care' (Gastmans…)" (560). This is the plot of *The Intouchables*, in which caring for Philippe becomes so genuinely important to Driss that he is allowed no plot of his own. He briefly considers leaving to care for his family, only to return as Philippe's caretaker when he realizes Philippe needs him. When the film ends, he still holds the position, in contrast to Sellou, who eventually terminates his position as Pozzo's caretaker. What must be ignored for this to be held as a virtue are the socioeconomic conditions that make it possible for Driss to care for Philippe, including the fact that he is literally forced to do so - Pozzo refused to sign a paper that would allow him to continue receiving unemployment benefits - as part of a bid to prevent him from receiving care from the state (since he does not deserve such care because he is "lazy," a moral failure that can only be cured by his service to Philippe). What must also be ignored is the fact that his position as Philippe's full-time live-in caretaker is interfering with his ability to care for his own family, who themselves receive little care, and this dilemma is not one that the film bothers to resolve; the film does not provide an explanation for why Driss chooses to return to the position despite pressing problems in his own family home. Only in the complete absence of an acknowledgement of an economy of care that determines its distribution can it be considered a virtue for a caretaker to place someone else's needs above one's own.

In framing the debate this way, disability studies care theorists like Kittay and Noddings suggest that there are two primary sources of care. The first is kin, usually women, who provide uncompensated reproductive labor. Proposed solutions to this problem typically include suggestions that men should share more in reproductive labor, that reproductive labor should be properly recognized and compensated, or that the state should provide adequate care to offset the care labor kin must provide. The other recognized source is paid care laborers who are compensated, albeit poorly. The solution here is to better compensate care laborers, which is important because it would create the conditions for a strengthened caring attitude/virtue and thereby improve the quality of care provided to the cared-for. Overlooked by this account is a long history of care and other reproductive labor provided by enslaved black people, neither as waged laborers nor as kin, and relatedly the degree to which, in the United States and elsewhere, black women have been made to provide this care for white families. Even up to the early twentieth century, 75% of employed black women in the US worked either in domestic service or agriculture[99].

Also overlooked is the long history of state and social attacks on black people's, particularly women's, attempts to care for their own families. As Toni Morrison notes in "The Family Came First," when "black women stayed at home to care for their children (a duty and virtue for white women), they were said to be 'doing nothing' and to have 'played the lady' by demanding that their husbands 'support them in idleness'."[100] It was not a virtue for black women, who because of material conditions, were often prevented from staying home to care for

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[99] Duffy, Mignon. "Reproducing Labor Inequalities: Challenges for Feminists Conceptualizing Care at the Intersections of Gender, Race, and Class." *Gender and Society* 19 no. 1 (2005).

[100] Morrison, Toni. "The Family Came First." *The New York Times* (1985).

their families in the first place. Pamphlets like *Friendly Counsels for Freedmen*, Hartman explains, portrayed slavery as an institution that provided care for black people, and instructed newly freed black people that it was now their "responsibility" to provide care for themselves (136). They were therefore denied state care and resources - that they had produced - and their "inability" to care for themselves was characterized as a moral failing that further legitimized this practice. In "Poverty, Race, and the Distortion of Dependency: The Case of Kinship Care,"[101]Dorothy Roberts sheds light on the ways that contemporary U.S. child welfare system devalues the relationships between poor black mothers and their children, often providing necessary financial assistance only on the condition that the children become wards of the state (even when they live with relatives), causing the relatives to lose the legal authority to make decisions about the children's lives. This cost is read by the state as a "necessary" response to perceived failures of black families to fulfill their care taking roles.

This characterization is echoed by stereotypes like the "welfare queen," on which *The Intouchables* relies. This is visible in that Driss is only interviewing for the job to be rejected and receive his employment check, but another telling scene reiterates this trope. Driss goes back to Fatou, his aunt/ adoptive mother's apartment, trying to gift her a ceramic egg he stole from Philippe during his interview, and stay with her. She calls him an idiot, tells him that his scams will not pay the rent, and orders him to "pack your things and get the hell out." Even his own mother thinks he does not deserve to be cared for, and this helps leave Driss with no other option but to take the position with Philippe. In the background, we see one teenage child taking care of a toddler. There are too many children to count; they run through the halls and crowd the tiny

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[101] Roberts, Dorothy E., and Feder Kittay. "Poverty, Race and the Distortion of Dependency." *The Subject of Care: Feminist Perspectives on Dependency*, 2002.

bathroom as Driss tries to bathe. There are so many children that Fatou cannot possibly be fulfilling her role as a caretaker; there appears to be no father. For reference, Sellou only had one brother. Clearly, Fatou, too, is “taking advantage” of “the system” and does not deserve those welfare checks by which the state cares for her family.

Women of color scholars of reproductive labor, in texts like Rhacel Parrenas’s *The Force of Domesticity,* Grace Chang’s *Disposable Domestics,* and Kalindi Vora’s *Life Support* acknowledge the colonial histories and contemporary globalized race and gender inequality that works to distribute contemporary care labor and compel some (mostly) women of color to provide wealthier white families with care labor at the cost of attending to their own families. They situate their analyses primarily in contemporary neoliberal globalization, which they argue has heightened the importance of care labor, and increased the ways it could be provided, to degrees never before seen. But despite the long history of black care labor in the US and elsewhere and the heavy reliance in both historical and contemporary Europe and the Middle East on black domestic labor - sometimes unfree and/or unpaid - black women remain for the most part excluded from scholarship on affective labor in globalized economies, except in side notes, references, and analogies (usually to slavery) that are typically not the primary subjects of the argument. Perhaps this inclusion would disrupt some key arguments of these texts, including one that opens Eileen Boris’s *Intimate Labors*: “One of the most striking features of contemporary global capitalism is the heightened commodification of intimacy that pervades social life.” Whether the argument is about intimacy, the commodification of bodily functions, affective labor, or transnational displacement of people who provide care and service, it is difficult to sustain the case that there has been an *intensification*, in terms of number, scale, or global reach of any of these things except by ignoring and denying centuries of forced and unpaid provisions of care by enslaved black people across the Americas, in Europe, and in the Middle East, a history that continues to have effects today.

A number of black feminist scholars have taken a different approach to theorizing domestic and caregiving labor, which continues to be performed disproportionately by black women and other women of color, to the history of slavery and in particular the figure of the "mammy" that emerged through this history. For these scholars, the problem is not *only* that these laborers are not properly compensated. They also locate the problem in the ongoing *desire* and even *demand* for a black caregiver who gives of (usually) herself, lovingly, willingly, affectionately, to white families. Micki McEyla explains in *Clinging to Mammy* that "we must confront the terrible depths of desire for the black mammy and the way it still drags at struggles for real democracy and social justice" (14). They also note that this giving typically comes *at the expense of herself and her kin*. As Saidiya Hartman writes in "The Belly of the World," "As domestic workers, black women were conscripted to a role that required them to care for and replenish the needs of the white household, and tend to the daily activities necessary for its maintenance… The care extracted from her to tend the white household is taken at the cost of her own." The demand for more highly paid caregivers who can be more loving does not properly account for this history. The extraction of the labor, the demand for it and the expectation of it, by this account, constitute an ongoing form of racist violence. As Joy James notes in "The Womb of Western Theory," "has undertheorized violence against Captive Maternals' reproductive labor, commodified emotional affect, sexual consumption, connectivity, and longevity for the enrichment of the lives of others" (263). Of course, a world in which caregivers are *properly* (not just better) compensated may very improve the quality of the labor, but that world does not exist and if it did, it would not exist in a vacuum divorced from this history. Thus it is pertinent to this chapter to remember Christina's Sharpe's analysis of the mammy figure, who "shores up racial divides and intimate intra- and interracial familial dynamics, at the same time that she, in her place, *secures all other subjects in their positions in the social fabric*" (emphasis added, 25). Following this analysis, I examine how this is the case in relation to the various subjects invoked and represented in the popular culture depictions I discuss here.

IV.

The global history of the slave trade(s) evidences a pattern whereby several groups of people, including perhaps most prominently Arabs/Muslims and Europeans/Christians helped to establish, over time, a connection between blackness and "enslavability." This is not to say that every black person everywhere was enslaved, but a logic that justified the enslavement of black people as "natural" and un-objectionable. As Sylvia Wynter explains, "The medieval Islamic accounts of the lands and people of non-Islamic black Africa" relied on a binary opposition between (as the extreme ends of a triadic model) people who traded like Muslims and peoples who - unlike either the Muslims or the intermediate category of other peoples who traded in a rudimentary manner - did not trade at all and necessarily lived like 'beasts,' that is, conceptually other peoples like the *Zanj*, the *Habasha*" (21). These were the "then current names of the indigenous peoples of black Africa" (22). Though the world, in early Muslim colonial and imperial ventures, was divided primarily by religious terms, classifications nevertheless came to assume elements of what might be called race, specifically anti-blackness. For example, in the seventeenth century “Sultan Mawlay Is’mail [made the] decision to enslave all blacks in Morocco including free black Muslims, [a decision that was] supported by many ‘ulama’ (or religious scholars)” (El Hamel 105), and in the eighteenth century Muhammad az-Zabidi wrote a voluminous Arabic dictionary in which he explained “the master (as-sayyid) is generally white and the slave (al-‘abd) is usually black” (105). Winter explains that these classifications were then “paralleled in the geographic account of the earth by feudal-Christian geography” and its division between “habitable” and “uninhabitable” zones of the earth and they, coupled with “the Portuguese landing on the shores of today’s Senegal and their drawing of areas of West Africa into a mercantile network and trading system, on the basis of the exchange of their goods for gold or slaves*, were the necessary and indispensible prelude*, not only to Columbus’s own voyage but also to the specific pattern of relations… between Christian Europe and the non-Christian peoples of the world” (10-11). The French later marked their own presence on the territory of present-day Senegal by establishing slave-trading posts and later a formal colonial system. It could on this basis be said that Arab/Muslim imperialist ventures and enslavement of black people played a part in propelling and solidifying a linkage between blackness and enslavability that developed slowly over centuries. It also, ironically, served as a prelude for some of the logics by which Europeans would later justify colonial ventures in the Middle East, like “progress,” “humanness,” and economic “development” (what was formerly described as trading patterns) - but these colonial ventures did not involve the large-scale enslavement of Arab populations, nor did they lead to a linkage between “Arabness” and enslavability.

The result of this long process, as Orlando Patterson explains, was that “a black skin in almost all the Islamic societies, including parts of the Sudan, was and still is associated with slavery" (58). This is evidenced in the fact that "at least since the seventeenth century, the Arabic term for black (aswad) became interchangeable with slave ('abd)" (El Hamel 105). And clearly this was also the case in the Americas. The enslavement of non-black people and the fact that some black people had high status "did not mean that blackness was not associated with slavery" (Patterson 58). The concept of enslavability is important in the context of a discussion of care because its association with blackness remains regardless of changes in the practice of or laws around slavery. As noted the association can be seen linguistically. It is also evident materially and ideologically - as cultural critic and novelist Toni Morrison notes, "in that construction of blackness *and* enslavement could be found not only the not-free but also, with the dramatic polarity created by skin color, the projection of the not-me. The result was a playground for the imagination. What rose up out of the collective needs to allay internal fears and to rationalize external exploitation was an American Africanism - a fabricated brew of darkness, otherness, alarm, and desire." And enslavability - as availability to be used in service of others - helps to structure and naturalize the economies that govern whose bodies and lives are available to be used to improve the lives of others - to *care for* others - and who deserves to be cared for, in ways that overdetermine care as a simple human relation, and structure the details of any particular relationship between two people.

In rehearsing this history, I argue that many of the logics that structured and racialized chattel slavery in the United States and elsewhere in the world by fixing blackness to enslavability/servitude continue to exist in various forms, including ideologies and material realities of the economy of care as it exists today. Something that developed over several centuries across the world does not simply disappear with a law. In other words, though I would not agree that slavery simply ended in 1865, what I am trying to highlight here are the ways that contemporary ideologies of care, servitude, slavery/enslavability - are produced out of long histories of slavery and continue to to influence economies and ideologies of care in ways that should be accounted for by care theorists. Moreover, these ideologies travel widely, both because of the global reach of US-media and technologies that allow for the exchange of cultural forms, but also because of the wide reach and interconnectedness of the systems out of which these ideologies emerge. These histories of slavery and colonialism cannot be separated from contemporary material realities of race and class - anywhere in the world - that give particular resonance to certain cultural symbols - like, say, the black servant - that resonate and enjoy immense popularity internationally.

The importance of the relationship between slavery and blackness in American popular culture is as old as most media forms, and can be seen in early literature (as elaborated by Morrison), performance like minstrelsy, the earliest radio and television shows like *Amos n Andy*, the earliest feature films like *Birth of a Nation* (1915)[102]. What most of these have in common is the suggestion that black people are better fit to be enslaved, both because they are happy to serve, and better people while serving, white people or because of the inevitable dangers that result from their freedom - epitomized by particular stereotypes like criminality, greed, laziness, and pathological embodiment of gender and sexuality. *The Intouchables*, though released in France in 2011, relies on many of these same popular culture representations of blackness, and its international popularity relies on their familiarity. In many ways, these representations actually intensified *after* 1865. Kenneth Goings, for example, situates the establishment of

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[102] See, for example, Herman Gray (1993), Jane Rhodes (1993), Darnell Hunt (2005).

figures of black servitude, like Aunt Jemima and Uncle Mose, in the "Reconstruction" and "Redemption" periods immediately following the formal end of chattel slavery. These figures, which circulated on postcards, food products and other commodities, as figurines, and as characters in popular culture, were central to the "mythologizing" that sought to defend and re-establish Southern racial hierarchies. They helped to alleviate white anxieties about the end of racial slavery, and ultimately helped bring about the end of Reconstruction and, with that, the reversal of what little gains the black community had made in political representation[103]. Such figures of servitude continue to appear on food products and other commodities - albeit with post-Civil Rights "makeovers" (Rhodes) - and they also have international counterparts, like the French *Banania* brand hot chocolate image of a grinning black man. Frantz Fanon writes satirically of the image in *Black Skin, White Masks*: "Always at your service/ Always deferential and smiling/ Me never steal, me never lie/ Eternally grinning *y a bon Banania*." Such images, he explains, work to fix "black essence" and "black 'nature'" "on-screen" (163).

Hollywood representations of happy black servants whose servitude to white people enables their character growth have persisted with impressive recalcitrance, appearing in *Gone With the Wind* (1939), *Imitation of Life* (1959), *Driving Miss Daisy* (1989), *The Help* (2011), and *The Butler* (2013), to name just a few of the more popular titles in Hollywood film history. The latter two are part of a broader resurgence of such films, and other films about slavery, that emerged in the context of newfound anxieties about black political leadership that have characterized Barack Obama's presidency. *The Butler* offers a particularly remarkable resolution to these anxieties by having the black servant work for the U.S. president in the White House.

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[103] Goings, Kenneth. *Mammy and Uncle Mose: Black Collectibles and American Stereotyping*. Bloomington: Indiana University Press, 1994.

While British film critic Anthony Quinn[104] compares *The Intouchables* (2011) to *Driving Miss Daisy* (1989), situating it a racist American past supposedly long gone and making its racism all the more disgraceful, it might be more interesting to situate the film in a French context that is more similar to and intertwined with the American context in which these last two films emerge. The election of Obama as U.S. president brought with it a resurgence of black political consciousness and activism amongst French youth that have been met with anxiety by the white French public[105]. Additionally, the appointment of black French Justice Minister Christiane Taubira in 2013 was met with anxiety and impassioned anti-black racism including several publications that compared her to a monkey. Taubira had long been involved in French politics, had run for president as part of the Left Radical Party (PRG) in 2002, and drafted and fought actively for what came to be known as Taubira Law, a 2001 French law that recognized the transatlantic slave trade as a "crime against humanity."[106] Though perhaps it was not a direct, conscious response to these events, *The Intouchables* can be read as emerging in the midst of national anxieties and conversations about race and blackness that respond to and negotiate these (inter)national circumstances.

Black political demands in France and elsewhere have been met with an insistent colorblindness and a general refusal to acknowledge racist contexts, past and present, out of which these demands emerge. This colorblindness, mirrored in *The Intouchables*, which recycles racist tropes even as it relies on a denial of racism, is illustrated most prominently by the French

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[104] Quinn, Anthony. "Untouchable (15)." *The Independent: Film Reviews*. (Sep 21 2012).

[105] Kimmelman, Michael. "For Blacks in France, Obama's rise is reason to rejoice, and to hope." *New York Times* 17 (2008).

[106] Keaton, Trica Danielle. *Black France / France Noire: The History and Politics of Blackness*. Durham: Duke U.P., 2012.

government's refusal to collect official national statistics on racial discrimination and disparities that are demanded by its black and Arab populations. Interestingly, Algeria has also refused to do so, despite the demands of its black citizens and residents, on the same grounds, citing rules about color-blindness in Islamic religious teachings. Existing non-official data substantiates claims of racism and poor living standards for black and Arab populations, with Arabs generally occupying an intermediary material status between black and white. The three texts together, *The Intouchables* and the two associated memoirs reflects this social and material inequality, even as the film's plot denies it, and recycles ideologies that have long legitimized the histories out of which these material realities emerged. They thereby both recycle racist ideologies about care and servitude, and simultaneously reveal a different story about race and servitude.

V.

The texts, taken together, reveal the marking of blackness, especially, in an antiblack world as always already impaired through particular character traits - inherent immorality, impulsivity, unintelligence, criminality, laziness, sexual excess. As I have argued elsewhere, this marking both leaves blackness as an impossible proper subject of disability, and makes possible analogies between blackness and disability. This racialization is also part of an economy of care, necessary to any understanding of disability, that determines who should and should not provide and receive care, and who does and does not deserve care. Arabs in France and in the three texts, though "socioeconomically disadvantaged," as producer Omar Toledano phrased it, have much more room to move up and down social and racial hierarchies.

Unlike Pozzo's memoir, written primarily in past tense, reflective, interspersed with poetry and passages of old letters, Sellou's text relies more heavily on present tense, with an impulsive, descriptive, decidedly unreflective feel until the last several chapters and the prelude.

> The other day, I was walking on the Pont Neuf - it was just about that same kind of day as it had been back when I had that chase with the cops… As a kid, I didn't realize that even an expert swimmer would have trouble making it out. I also didn't realize that exactly ten years before I was born, the French had tossed dozens of Algerians into these waters. And they did it knowing full well how dangerous the river was. I looked at the stone ledge where I had hidden from the cops and shuddered at my former audacity. I thought that, now, I'd never dare to climb over the edge. I thought that above all that now, I had no reason to hide or to run (Sellou xv-xvi).

This is how the prelude ends. Though Sellou invokes and makes critical references to French colonialism and contemporary French social structures, the text alongside Pozzo's memoir ultimately celebrates his reformation, thanks to Pozzo, from rowdy, rebellious, "uncivilized," inexplicably angry and immoral child to responsible adult who acquiesces to white French authority, adopts white French morals and norms of propriety, and recognizes of the "humanity" of all, including wealthy whites. French colonialism and racism are thus figured as problems that it is his individual responsibility to overcome. His ignorance - "I didn't realize that even an expert swimmer would have trouble making it out" - and his foolish arrogance are positioned immediately alongside French racist violence - "the French had tossed dozens of Algerians into these waters" - in the passage that situates Sellou's transition for the reader at the very end of the prelude. He overcomes both problems by becoming more moral and responsible (read: white): he now has the wisdom to "shudder at my former audacity" - and the good sense to relinquish his rebelliousness to French authority - "now, I had no reason to hide or to run" from the police. What he gives to Philippe in care he is repaid in whiteness.

This potential for movement is perhaps what makes it necessary for Sellou to become a black character named Driss in the film. While Sellou is a non-black Arab man of Algerian and Moroccan descent, Driss, a character of Senegalese descent, was played by Omar Sy, who, for this role, became the first black French actor to receive a Cesar Award (the French equivalent of an Academy Award). This is notable in a country where Arabs comprise the second largest ethnic group after (white) French and participate actively in the entertainment industry, with several well-known French Arab actors, around the same age as Sy, including Selim Kechiouche and Jamel Debbouze having previously starred in box-office hits, and several others having won Cesar Awards, like Hafsia Herzi, Kad Merad, and Tahar Rahim. Indeed, film critic Jay Weissberg calls the casting of a black actor "telling" in a review for *Variety*[107], in which he also states that "it is painful to see Sy, a joyfully charismatic performer, in a role barely removed from the jolly house slave of yore, entertaining the master while embodying all the usual stereotypes about class and race." Weissberg is not alone. A similar critique was made by several others, including Quinn, who wrote a review in *The Independent* describing the film as a "third-rate buddy film that hardly understands its own condescension" and speculates that its popularity rests on "the fantasy it spins on racial/social/cultural mores, much as *Driving Miss Daisy* did 20-odd years ago – uptight rich white employer learns to love through black employee's life-force." But, he asks, "That was set in the segregationist America of the 1940s. What's this film's excuse?"

Several French reviewers rejected such critiques, calling them U.S.-centric. In the *Slate*'s "Is *The Intouchables* Racist," Daphnee Denis states that "like many French people, I disagree with this analysis," explaining that "from a French perspective, the movie isn't outrageous at all."

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[107] Weissberg, Jay. "Intouchable." *Variety* (2011).

Alan Mattli authored a piece called "Playing the Race Card on 'Intouchables', or: The American Misunderstanding,"[108] in which he argues that even if he did agree with critiques about the "sociopolitical implications," which he does not, the film would still "work as a thoroughly enjoyable, hilarious, bittersweet comedy about how two lost souls find solace in each other." Furthermore, it is "clear" to him that "critics like Weissberg… come from a different background than European, and particularly French, reviewers and audiences when it comes to the subject of race relations." The irony here is not only that Weissberg is living in Italy and Quinn is from the United Kingdom, but also that Mattli uses a reactionary American tool, the expression "playing the race card," to dismiss concerns about antiblack racism. The decision to cast a black actor and make the character black was central to the production of this film and to the meanings the producers intended to convey. The decision serves as a good opportunity to consider the racialization of Arabs in relation to whiteness and blackness, the specificity of the relationship between blackness and disability/care/servitude, and the ways that ideologies material realities of blackness circulate globally.

Though Sellou had initially hoped his character might be played by someone like the French-Moroccan actor Jamel Debbouze, to whom he "felt close," he explains that he understood the decision to cast Omar Sy instead once he realized he shared some similarities with Sy, including having grown up "in the projects at Mantes-la-Jolie" (174). Though Sellou chooses to settle the question on these grounds, it is worth noting that Debbouze also grew up in the same neighborhood as Sy, so this alone cannot explain the casting decision. What explains it? An interviewer asks the directors about their decision to change "Algeria-born Abdel" to "Senegal-

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[108] Mattli, Allan. "Playing the Race Card on 'Intouchables', or: The American Misunderstanding." *The Zurich English Student* (July 19 2012).

born Driss," saying he "presumes… the change is rooted in your feeling that Omar is the right person to play the character." Toledo explains that they were trying to capture "a cultural type in France, a young person who's grown up in the projects around Paris," and that "for the *realism* of the project, *for the most impact, Omar's involvement was essential,*" so much so that they would not have attempted the film without it (4, emphasis added). Toledano elaborates that the characteristics of the "cultural type" or "social type" he references include "a way of speaking, walking, a sense of humor and vitality that belongs only to a certain social type." They did not want to make a caricature of this "type" so casting Sy was essential because he "was [their] guarantee of authenticity from the clothing down to the most subtle slang" (6), and therefore also necessary for the "authenticity of the story."

In *Immigration, 'Race,' and Ethnicity in Contemporary France*, Alec Hargreaves argues that for first- and second-generation immigrant youth in France, particularly "North African" and "sub-Saharan African," there is a "strong interest in international youth culture, especially marked by American and/or black influences" (105). This is because many of their parents participated in anti-colonial struggles against France and the conditions under which they live there are often difficult. Thus, though they typically know little about the cultural and religious practices of their parents' home countries, they also want to refuse, on political grounds, easy identification with French nationalism. Hargreaves explains that "the transnational cultural codes on which these gangs draw most heavily originate in what Gilroy (1993) has called the Black Atlantic, a cultural archipelago stretching from sub-Saharan Africa through the Caribbean and into the black ghettos of the United States; the Maghreb [or, Arab North Africa] (where most young people of Third World origin in France have their ancestral roots) offers certain parallels but is not directly part of this space" (138). Assuming Afro-diasporic cultural patterns and behaviors, then, helps to establish oppositional identities, especially for activists. For example, "Third World" youth first began to organize in the 1980s under the title "Rock Against the Police," borrowed from the "Rock Against Racism" concerts put on by British Afro-Caribbean youth, who were themselves influenced by black American organizing. Another example is that French youth refer to their "gangs" as Zulus, named after black American activist Afrika Bambaata's Zulu Nation, founded in New York in 1975. The names of these Zulus are often English names, like Black Dragon or Criminal Action Force, and the members "dress in the stylized fashion of young black Americans, incorporate liberal doses of American English into their linguistic codes, and have adapted the rhythms of rap into newly inflected forms of French" (139). They access and assimilate elements of black American culture primarily through US-dominated mass media, which, as is clear, is also influential in transmitting racist tropes and anti-blackness.

Once taken on as oppositional identities, ideas of racial blackness become the prism through which black people and Arabs are racialized in France, and also the symbol to which Arabs selectively lay claim to express resistance to French whiteness and build their oppositional identities. Consider, for example, the following Charlie Hebdo cartoon, recently published on the subject of Syrian refugee toddler Aylan Kurdi, whose body washed up on the shore of a Turkish beach. The image relies on racist tropes long used by media representations, from the the earliest inceptions of most media forms, to mark blackness - including representations of black people as non-human primates, and representations of the imaginary "black male rapist" who lusts after white women. Such representations continue to be used against black people, like politicians and athletes, in France as well. That blackness is used for both, and not, say, “Arabness” that is used to racialize Arab and black immigrants, speaks to the relative positioning, socially and ideologically, of the two categories. That is, Arabs *sometimes* become *like* black people, when they have it particularly bad, but to say the opposite - black people are being treated like Arabs - does not carry the same signification and its social meaning would not be easily recognizable, even in France. This is why a particular “cultural type,” as the directors put it, might be invoked by the figure of Sellou and the French media’s interpretation of his relationship to Pozzo, but epitomized and properly signified by Omar Sy/Driss, who then becomes “essential” to the “authenticity” and international appeal of the film. The meanings evoked by Driss and his relationship with Philippe resonate and arouse familiarity internationally, thanks both to the global reach of US media and to local variations of antiblackness that give significance to racist American representations.

Figure 3.1 Charlie Hebdo Cartoon (Translation: “What would little Aylan have become? Ass groper in Germany.”)

Arabs in France have a very different socioeconomic position than Arabs in the United States. They are the second largest "ethnic group" after white French, so they are more visible as a minority group. They tend to be less wealthy, live in segregated "projects" often alongside poor black people in suburbs, where French ghettoes are located, and their presence there has direct ties to French colonialism in places like Algeria and Morocco. Still, their social position, even in France, tends to be more fluid than the social position of black immigrant counterparts, whose presence also has direct ties to French colonialism in places like Senegal and the Caribbean. This in part due to a very different history of racialization for the two groups in relation to French slaveholding and colonialism, and also in part because their racialization depends on recognizability as Arab. Immediately upon arrival to France as a young child, Sellou was quiet and courteous. "I was very nice and well behaved. No different, in appearances, from the little French kids in velvet shorts and suspenders" (9). The "no different, in appearances" is important because many available race-based statistics in France, like the statistics on police stops, are based on recognizability as black or Arab. For light-skinned non-black Arabs, often this recognizability is based on behavior: his niceness and good behavior as a child allow him to "appear" as white French, whereas later his dress and behavior render him recognizable as Arab, and later still, back to white French if and when he chooses. Often that recognizability is also a deliberate choice, one that entails donning markers of American blackness, as a symbol of opposition to material realities that are products of French colonialism and racism. But this choice also means that markers of poverty and racialization can be selectively removed, if the person donning them is sufficiently light-skinned, fluent in French, etc., allowing them, potentially, to climb the social ladder. In other words, non-black French Arabs have more room to pass as white and thus more mobility along racial hierarchies, their racialization generally being tied more directly to material circumstances in specific times and places.

Available data on racism in France reflects French Arabs' status as intermediary between black and white. For example, black people in France are 40 percent more likely to describe themselves as targets of racial discrimination than other *visible* minority groups[109], an already murky category for Arabs in France, the other main "minority group." According to a 2009 study called "Profiling Minorities" that examines racial discrimination in stop-and-search encounters with police, both black and "*visibly* Arab" (emphasis added) youth, already a smaller subset of the total Arab population, are stopped significantly more frequently than French whites, with the most stark disparities for black people. Such police practices are influenced, as sociologist Loic Wacquant explains[110], by mass incarceration-era police practices in the United States that most heavily targeted young black people. Specifically, French politicians looked to New York for solutions to what they described in the late twentieth century, despite statistics that showed otherwise, as a new "crisis" in crime and social disorder. The "crisis" was imagined and described in thinly racialized terms, and the solution - to look to New York - was yet another example of the ways blackness in the United States influences racist French policies and representations. The siren that begins the police chase in the opening scene of *Intouchables* is an American sound and not the sound of the French police siren, according to the film notes, which characterize this as a "goof" and a "factual error." The French police siren is different and was not included in the film. The producers are French, and so are the actors; surely they have some

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[109] Zick, Andreas. "Intolerance, Prejudice, and Discrimination: A European Report." *Friedrich Ebert Stiftung Forum: Berlin* (2011).

[110] Wacquant, Loïc. "The penalisation of poverty and the rise of neo-liberalism." *European Journal on Criminal Policy and Research* 9, no. 4 (2001).

familiarity with the sound of the French police siren. It would appear this is not a simple error, but perhaps reflects the influence of Hollywood film and American policing on French ideologies - and practice - of policing and race.

The intermediary status of Arabs is also visible in labor statistics showing that 4.3% of Algerians are unemployed, 4.4% of Moroccans, and 3.7% of Tunisians, compared to 6.6% "other Africans." By contrast, between 5.8-7% of Maghrebis are "artisans, tradespeople, or company heads" compared to 3.8% of "other Africans." And, relevant to the theme of this chapter, between 5-6% of Algerians, Moroccans, and Tunisians are "personal service" workers, compared to 8.3% of "other Africans."[111] The racialization and socioeconomic status of Arabs in France is also more limited to France than it is for black people. For example, Sellou recalls a moment in which he visits Canada with Philippe and, while there, accidentally gets into the car of "an enormous black woman" (163). He apologizes and explains he did not mean to scare her, to which she replies "'I'm not scared of you at all, little white man!'." Abdel is surprised: "White man! She called me white man! It took crossing the Atlantic for me to get called white man!" (164). For Abdel, his racialization is geographically and temporally situated. He can grow more white over time and become white instantly by going elsewhere.

Ironically, Sellou distances himself from the black American behavior patterns of the "cultural type" the film producers insisted had to portray Driss, based on Sellou, in the film. He notes dismissively of the "Blacks and Arabs," "Some of them think they're American. They stuff themselves to have the same build as breakdancers. You can hear them coming a mile away, ghetto blasters booming on their shoulders. A baseball cap slapped on their head, but turned

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[111] "Trajectories and Origins Survey." *Institut National D'Etudes Demographiques*. 2009.

backward, and they wear pants as big as they can find… They put on their show and the volume covers the sound of negotiations" (35). The "American" here is clearly "black American," characterized by the same markers of American blackness that Hargreaves argues is characteristic of black and Arab French resistance. This description, however, is marked by a more general distancing from blackness that helps position Sellou and allows to render legible his transformation into more responsible, mature, productive adult citizen (white man). He comments casually on encountering a dead black man in the street and "the white rice that's coming out of the dead guy's throat, black. Dead for sure" (37).

Sellou tellingly locates the beginning of his antagonistic encounters with the criminal justice system through the figure of a "big black guy" murderer "in a coat and tennis shoes." "What could be more generic," he asks, once again naturalizing the idea of black criminality. Though he was not involved in the murder, he was caught on tape as a witness. "There was a fight, a stabbing, the guy dropped dead on the ground, the end. But the beginning of my judicial career." The next few chapters detail his encounters in and out of court and prison. This is a curious origin story for his "judicial career," given that he has already been called in to police stations many times as a child for shoplifting. But this origin story, alongside his remark about the "genericness" of big black men murdering, serves to establish blackness as the site of "real," inherent, dangerous criminality, and also to identify his own proximity to blackness (literally, for being too close to the site of black "criminality" but also figuratively or socially) as the *cause* of his own form of criminality (albeit more "petty," as Pozzo describes it), a behavior pattern he is later able to overcome.

In addition to being murderers, in this text, black men also “like to” rape. He sees that in “the Mendy, those groups of Senegalese - like Driss - who like to have their fun with girls. They go down regularly for a gang rape. They get six months, tops, come out a bit thicker around the waist, a fresh new haircut, then they get straight back to business, treat themselves to new, young meat. Only once, one of them got three years because he put the girl’s eye out with a crowbar” (59). Having earlier distanced himself from “degenerates” who engage in “that kind of violence [that] isn’t for me,” Sellou reifies this “degeneracy” as black. He characterizes “Senegalese rapists” as accustomed to imprisonment and fixes them there, destined as they are by their natural tendencies to return again and again. By producing a narrative of blackness as inherently violent, criminal, irrational, Abdel endorses both the discourses that produce blackness as a kind of “disability,” and simultaneously discourses that characterize black people as undeserving of care, perhaps even receiving too much of it already from a criminal justice system that hands them prison terms that are too short for their crimes, enabling their recidivism.

Arabs like him, by contrast, mostly engage in “petty crime,” crimes that can be explained by their circumstances, even if Sellou prefers explanations of failed families and personal responsibility. When he first goes to prison, he encounters two Arabs whom he calls “the Laurel and Hardy of petty crime” (65) and describes as fearful of and unfamiliar with the criminal justice system. He finds himself having to “teach lessons” to naive “pre-retirement age Mohammeds who steal wallets” (67). They are not “real” criminals and imprisonment is not as routine for them as for “Senegalese rapists.” Before he is reformed, Abdel has no respect for the law. “What is law, exactly? The law, my law, is whatever I decide for myself… I pick up girls easily at the parties I crash, I steal one of their daddies’ Volvos, go eat seafood in Normandy, leave the car on the side of the road when the gas runs out and hitch back to Paris" (67). His criminal behavior in this text, while "immoral," is not inherently dangerous, violent or irrational. It might even be read as clever. By participating in the reproduction of ideologies about blackness and distancing themselves from it, Arabs - like Abdel Sellou and Eric Toledano, who is of Moroccan descent - are able to enhance their own potential for social mobility. All of these factors allow French Arabs, in certain places, at certain times or points in their lives, to move up, distance themselves from blackness and from their own subjection to racist violence. This also explains why a story about a wealthy white man and a poor Arab man in France can signify something, for these producers, that they feel is best epitomized by the same white man and his relationship with a poor black man.

VI.

Following a conversation with Pozzo, the directors note two "lines of thought"[112] that emerged regarding what makes this story work for audiences. The first is that "two levels of French society" represented by the characters "create new relationships and feelings when they come into collision." And the second is that because each of the two men has a "disadvantage," one "physical" and one "socioeconomic," "a sort of strange and unexpected symmetry" is produced that "makes a deep connection possible" (5). In both thoughts, the directors reproduce the analogy between blackness and disability. The thought emerges from a conversation between Pozzo, a wealthy white man who has become disabled, and the directors, and betrays an understanding of blackness that situates it as the always/already for what befalls disabled (white) people. Thus, the "deep connection" that is made possible is the wealthy white man's newfound

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[112] The Weinstein Company. "The Intouchables Production Notes." Secured from www.twcpublicity.com in Nov 2015.

ability, in his mind, to understand what people marked by blackness have always known. And this analogy has a long history of being made in popular culture between blackness and, specifically, disability, which might have influenced the directors' belief that Omar Sy (and not Debbouze) was "essential" to the project, appearing in *Home of the Brave*, which as we know from Frantz Fanon, was screened in France.

Notably, one of the main reasons Philippe is drawn to and hires Driss is his impression that, unlike the other applicants, Driss does not pity him. In *The Ugly Laws: Disability in Public*, Susan Schweik describes pity as, at least potentially, dangerous for disabled subjects, explaining that "'no pity' has been the crucial rallying cry of the disability rights movement" (58). In *On Revolution*, political theorist Hannah Arendt coins the term "politics of pity" in reference to a relationship between "those who suffer" (the unfortunate) and those who do not (the fortunate spectators). The capacity to pity is only possible in one direction (directed by the fortunate spectators at the unfortunate who suffer). Pozzo, in his own memoir, notes that one of factors that most drew him to Sellou was that Sellou did not look at him with the same pity as other caretakers. He later moves to Morocco and marries an Arab woman, citing the same reason for both. Given that it is one of his demands for the film's production that he not be characterized as pitiful, this is clearly very important to him. I find that the social positionality between him and his character is a more powerful determinant of whether Pozzo feels he is being pitied by caregivers than any objective interpretation of their behavior. For example, "for some reason," Sellou finds it necessary to show Pozzo a respect he has never shown authority before, and he felt this way upon seeing him. "Despite his insisting otherwise, I still use the term *vous* - the formal term for 'you' - when talking to my 'friend.' I called him *monsieur*. For some reason I can't determine, I was incapable of calling him by his first name. It's still the case today, by the way" (173). This behavior is not interpreted by Pozzo as pity. What might be pity in some cases can be kindness or reverence in others and this depends on the social position of the actors.

This relation is also central to the ways that Philippe/Pozzo is imagined as "independent" (by himself, by Sellou, by Cluzet, and by the producers) despite the multitude of ways he *depends* on the labor of his caretakers, and has depended on them - as a wealthy white man - even prior to his disability. These labors are what help to establish his subjectivity as a wealthy white man and, once he becomes disabled, to constitute him as a properly disabled subject - one who can continue to live because of the care provided to him, who thinks and is productive. The ability for his caretakers to disappear in relation to him, except as prosthetics/objects, and not as subjects who can look upon him with pity, is part of what helps to produce him as an independent subject and produce them as objects to that end. This relation is best exemplified by a poor black man and a wealthy white man, and it precedes and overdetermines the care relations related to Philippe/Pozzo's disablement.

This availability to be taken on as an object is best exemplified by one particular scene, worth examining for its centrality to the producers' conceptualization of the film. None of the material behind this scene is in either of the memoirs because Abdel has no interest in music, but both the song and the scene were central to the film's development. In the scene, Philippe unenthusiastically holds his annual birthday party, resentful of the many friends and relatives who only ever visit him on this occasion. To entertain himself, he requests that the band play Vivaldi's "Four Seasons." Antonio Vivaldi wrote each of the four tracks with a phrase meant to serve as "instructions," and for "Summer," the one being played in this scene, the instructions read “languor in the summer heat” - perhaps representing Philippe’s demeanor before Driss changes his life.

Philippe: “You can’t tell me you feel nothing.”

Driss: “It doesn't do anything for me. Music’s something you dance to.”

Obviously Philippe cannot.

He requests a series of songs that Driss ridicules, imagining where they would play: in an advertisement for coffee, in a palace, and on the phone line when the Paris benefits office puts him on hold: “waiting time: two years.” All are boring and slow-moving places where decorum, propriety, or “good behavior” are expected.

Driss: “After your classics, let’s listen to mine. Earth, Wind, and Fire. It’s a killer.”

Philippe: “It’s definitely something else.”

He watches Driss’s body move. The film closes up on Driss’s legs. Philippe smiles. “Dance,” the song instructs in the background, and Driss calls to the crowd, “Let’s dance. Come on, *move*! It’s his birthday.” Other guests, all white, try to join him but they are exaggeratedly clumsy and awkward. One of them falls and Driss helps him up. They appear not to have Driss’s “rhythm.” And this marking of Driss as naturally rhythmic is emblematic of a long history of this association between blackness and rhythm. It is an important part of what symbolizes, for Frantz Fanon, the racialization of black people as “backward, simple, free in our behavior,” locates “emotion [as] completely Negro as reason is Greek” and positions black people as “humanity at its lowest” (126), all characteristics of the racialization of blackness that have rendered it as available for analogies with disability Driss is, per this characterization, in tune with his body and moves with ease, in contrast with the rigid, proper, well-behaved white bodies, but in especially stark contrast with Philippe, whose body cannot move. Philippe is pure intellect, or as Sellou puts it, “the great, immobile sage, soul floating above his miserable carnal envelope, superior being delivered from flesh and earthly needs” (169). The scene ends with Philippe’s eyes moving up and down, scanning Driss’s body. “I find romance when I start to dance in Boogey Wonderland.” The film cuts to a scene in which Driss tucks now tired Philippe into bed at the end of his birthday party. He shows Philippe a letter that came from a love interest with whom he has been corresponding by mail, in response to a Philippe’s request, at the behest of Driss, for a picture. They are relieved to discover she is attractive, and she is extending an invitation for a date.

Philippe dances at his birthday party by watching Driss. He lives vicariously through Driss. He acquires a body that helps him be where he needs to be, do what he needs to do, care for himself, dance, have fun, and even recover a capacity for sex and romance he thought was lost. And this is how the actor playing Philippe, Francois Cluzet, understands his character’s relationship to Driss as well: “Driss becomes my body in a way. When he dances, it’s a little as if I were dancing. When he tells a joke, it’s a little as if I were joking… We mustn’t always want things to pass through us. It’s an opportunity when they pass through a partner. It’s fascinating on a human level.” In this, *The Intouchables* recalls Lee Frost’s 1972 science-fiction film *The Thing With Two Heads*, in which the dying, paraplegic Dr. Maxwell Krishner (Ray Milland) demands that his head be transplanted onto a new body. The experimental procedure had previously only been performed on gorillas, but his head is successfully transplanted onto the “very big” body of a still-living black man on death row named Jack Moss (Roosevelt Gier). The two films rely on the same logics regarding racial distributions of intellect and brawn, entitlement to treatment and care, bodily fungibility and the availability to be used, literally, in service of other people. And because markers of American blackness are so central to the racialization of blackness in France, black American music is so important to setting up Driss's character, and to establishing a bodily site of pleasure and rebelliousness to which Philippe - ever critical of his fellow wealthy white Frenchmen and now feeling personally oppressed by them - can lay claim and through which he can live vicariously.

VII.

The Intouchables received so much international acclaim that it was picked up by the Weinstein Company for an American remake. The American version was renamed *The Upside* and stars Kevin Hart (as Driss, based on Abdel Sellou, now known as Dell) and Bryan Cranston (as Philippe, based on Philippe Pozzo, now known as Phil). The film was originally scheduled to be released in theaters on March 9, 2018. However, because the Weinstein Company declared bankruptcy in the aftermath of Harvey Weinstein's sexual assault scandal, the release of this and many of the company's other films was placed on an indefinite hold. Still, the film premiered at the Toronto Film Festival in 2017, and between September and November 2017, at several film festivals across the United States.

On January 30 2017, Kevin Hart posted a photograph to Instagram to announce that filming for *The Upside* had begun, paying tribute to Omar Sy and expressing his appreciation for the character in the caption: "I am so excited to play this character. He is a character that is in the prison of his own making. He feels that the system is not only holding him back but that it refuses to give him a fair shot. Learning to care for others and other people's needs is what ultimately changes him. I can't wait for you guys to meet 'Dell'… Major shoutout to Omar Sy who was absolutely amazing in the original. I'm going to make you proud man!!!!! I'm a fan."" In line with the storyline of *The Intouchables* and the legacy of films in which it follows, Hart's tribute identifies the character's belief that "the system" is "holding him back [and] refuses to give him a fair shot" as not only false but a character flaw. Though, as an ex-convict, he was literally imprisoned, his prison is "of his own making." What allows him to overcome this character flaw is "learning to care for others and other people's needs." The care labor, once again, is portrayed as a gift for the black laborer. The problem, his anger and his "skewed" perception of the world, is solved and an "even" relationship is made possible once he learns to *love* giving of himself to the wealthy, white character.

The Intouchables, despite its popularity, was met with criticism for recycling racial tropes common to American films about slavery and servitude, particularly the trope of the "happy servant." Familiar with this criticism and having no recourse to the excuse that such problems are specific to the United States and inapplicable to France, the producers of *The Upside* attempted to avoid the dynamic that produced this criticism. Film critic Eric Kohn[113] argued that they were somewhat successful in this goal by playing up, further, the lighter and more humorous elements Philippe requested in the original film, and downplaying the extent to which the bond between the two characters allows them to "overcome" their differences. As the film is not yet available for public viewing, I cannot comment specifically on this assessment. However, though Kohn argues that "most of the humor in *The Upside* is too superficial for any kind of deeper cultural reading" and that it is characterized primarily by "prolonged gags about catheters and smoking

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[113] Eric Kohn. "'The Upside' Review: Kevin Hart and Bryan Cranston Make an Odd Couple in English-Language Remake of 'The Intouchables'." *IndieWire* (Sep 9, 2017).

pot," he identifies a key "poke at Phil's wealth" made by Dell: "Your *plantation* is bananas" (emphasis added). In this remake, Phil is wealthy because he is a renowned author and the filming took place in Philadelphia; the house is not located on a literal plantation. The scene could have "poked at Phil's wealth" by describing the house as a "mansion" or a "palace." Fraught with anxiety about distancing itself from connotations of slavery and servitude, the film is apparently unable to escape them.

Like the original, the comedic effect of this version of *The Intouchables* relies on the supposed mismatch between the caregiver and caregiving role. Because Sellou/Driss/Dell was selected on the basis that he was *not* qualified and "from the streets" and therefore both untrained and uninterested in performing overt displays of concern, care, and deference (gestures read by Pozzo/ Philippe as pity), it was specifically on the basis of his masculinity that he was chosen. Women are often socialized to perform gestures of care and affection that Pozzo as well as the characters based on him (Philippe and Phil) reject as infantilizing. And in the films, Pozzo had specifically requested that his story be presented as a comedy to work against the element of pity. The clash between the "feminine" nature of the labor and the masculinity of a male caregiver, and even more so, the "hypermasculinity" of a *black* male caregiver (unlike Sellou) who, according to the original directors, best represented Sellou's actual background, is a big part of what produces the clash, and therefore the comedy. The joke is that the labor does *not* come naturally to him, that he is a caregiver who does not appear obviously to *care.* At the same time, it is his blackness that sells the "meaningfulness," allowing the relationship to read convincingly as beneficial for both parties. After all, coming from "the streets," he had *nothing* before this wealthy white man taught him how to become a *social* being, to care about something other than himself and thereby to escape the “prison of his own making.” In this section, I tie *The Intouchables* to another recent representation of a disabled white character and his black caregiver, the 2016 TV series *Speechless*, which mirrors the film in a number of ways that speak to the utility of the black male caregiver character in stories about disability. I briefly contextualize these representations with an analysis some of the tropes they borrow from American popular culture representations of servitude.

The 2016 ABC comedy sitcom *Speechless* breaks ground as the first TV show to center a disabled character (JJ DiMeo) played by an actor who is himself disabled (Micah Fowler, who has cerebral palsy). Both the character and the actor have cerebral palsy. JJ is nonverbal, though Fowler is not, and communicates using augmentative/ alternative communication (AAC) with a laser-pointer and a letterboard. Letters and frequently used words are printed on a keyboard at which JJ points a laser, and a caregiver reads aloud the words and sentences JJ spells out. The creator of the show, Scott Silveri, reported that he has waited twenty years to tell this story on-screen. Silveri grew up with a brother who has cerebral palsy and is nonverbal, so the story is personal for him. By his account, he did not want to tell a story “about disability” per se, but to tell the story of a family in which one member, the central character, lives with a disability. He sought to move away from stigmatized representations of disability as a problem, and disabled people as either pitiable or inspiring, always overcoming. Instead, he endeavored to “demystify life with a disability a little bit – to make it feel less foreign – that would be fantastic. Entertainment has the power to do that, yes, probably more than other avenues.” JJ is therefore portrayed as happy, intelligent, and witty, funny without caricature. The show has been very well received, and nearly all critics praised it for doing just what Silveri intended in such articles as

"*Speechless* Is Breaking New Ground on Television*,*"[114] "'Speechless' Big Winner as Media Access Awards Salute People With Disabilities,"[115] "7 Things Speechless Gets Rights About Special Needs Families,"[116] and "ABC's *Speechless* does a radical thing for families of characters with disabilities: it lets them have fun."[117]

Like *The Intouchables* and *Speechless*, many popular culture stories of caregiving are based on nonfictional accounts of the main white character's life from their own perspective or that of a relative. For example, Kathryn Stockett's 2009 novel, *The Help*, adapted into a film in 2011, focuses on the story of a young white woman named Eugenia "Skeeter" Phelan, who aspires to be a journalist, and her relationship with two black maids, Aibileen Clark and Minny Jackson. In the novel, a secondary protagonist white woman named Lou Ann, who is dropped from the cinematic adaptation, is suffering from depression. The only person who can help her overcome the depression is her maid, Louvenia Brown, who speaks lovingly of her employer to Skeeter, the journalist whose character makes it into the film. Ablene Cooper works as a domestic worker for Kathryn Stockett's brother and his family. Occasionally, she babysat Kathryn Stockett's children. Cooper sued Stockett on the basis that the central character "Aibileen" was modeled after her, with many biographical details taken directly from her life. The lawsuit was dropped by the court because it was filed past the one-year statute of limitations. Cooper explained that the text and Stockett's conduct left her feeling "violated, outraged, and

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[114] Perry, David. "*Speechless* Is Breaking New Ground on Television." *The Atlantic* (Sep 21 2016).

[115] Gray, Tim. "Speechless' Big Winner as Media Access Awards Salute People With Disabilities." *Variety* (Nov 18 2016).

[116] Seidman, Eileen. "7 Things Speechless Gets Rights About Special Needs Families." *Babble, Courtesy of Disney* (2016).

[117] Framke, Caroline. "ABC's Speechless does a radical thing for families of characters with disabilities: it lets them have fun." *Vox* (Feb 26 2017).

revulsed." She also described the caricature produced by Stockett as "embarrassing" and "humiliating." Stockett countered that though the character shared a "similar" name, she hardly knew Stockett and that the character was actually based on her childhood caregiver, Demetrie McLorn, who passed away when she was 18. In the acknowledgements section of the novel, Stockett writes "my belated thanks to Demetrie McLorn, who carried us all out of the hospital wrapped in our baby blankets and spent her life feeding us, picking up after us, loving us, and thank God, forgiving us" (524). Conveniently for Stockett, McLorn is no longer around to say whether she feels similarly violated and outraged by the portrayal. *Driving Miss Daisy* (1989), too, was first a 1987 play written by Alfred Uhry, based on his grandmother Lena Fox and her black chauffeur William Coleman. This begs a question posed by Kimberly Wallace-Sanders in *Mammy: A Century of Race, Gender, and Southern Memory*, "We know that African American women tended white children during slavery, but how do we assess the marginal appearance of this relationship in slave narratives and former slave biographies when compared with the number of white authors who emphasize this relationship" (133)?

A key focus of the show is the relationship between JJ and Kenneth (Cedric Yarbrough), who becomes his caregiver full-time at school and, it seems, most of the time in his private residence as well. The show, while deliberately and self-consciously steering clear of a portrayal of disability as tragedy, nevertheless offers a realistic portrayal of some struggles a special needs family might face. In the pilot episode, the family moves, for the sixth time in two years, to a new school district in an attempt to find a school environment that is accommodating for JJ. They move to perhaps the only run-down home in Newport Beach, California, a city where JJ might find the resources he needs but where neighboring families are conspicuously more wealthy than the DiMeos. The new school provides a communication aide for JJ, a white woman whose excessive enthusiasm JJ finds off-putting and potentially damaging to his reputation. Instead, he takes to the school groundskeeper, a black man with no training as a special needs aide whom we know only as "Kenneth," until one episode reveals to the DiMeo's surprise that his last name is Clements. Luckily, Kenneth manages immediately to drop all of his personal and professional responsibilities to become JJ's full-time aide, and is taken in as the "sixth member" of the DiMeo family.

The sense of "cool" to which JJ is drawn mirrors the relationship between Philippe and Driss. "Cool" does not pity because it does not care (too much). This is the basis for JJ's insistence that Kenneth become his caregiver in *Speechless*, despite that Kenneth (like Driss) is not formally trained for the position. The white woman with formal training apparently lacks "cool" and is too eager to please JJ, who finds her embarrassing. Black masculinity has long been associated with what Richard Majors terms a "cool pose," including "poise under pressure and the ability to maintain detachment, even under tense encounters," as well as a brand of masculinity that "epitomizes control, strength, and pride," "a mysterious challenge," and is embodied by someone who is "charismatic, suave, debonair, entertaining".[118] Majors examines why black men, particularly youth in the inner-city, project this form of masculinity, and its consequences; I am interested here in the persistence of this association between black men and the "cool pose" in popular culture representations and particularly in these representations of disability and caregiving. The "cool pose," because it keeps in check overt expressions of compassion and sympathy, allows the disabled character, and also Pozzo in real life, to receive

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[118] Richard Majors and Janet Mancini Billson. *Cool Pose: The Dilemmas of Black Manhood in America*. Touchstone, 1993, 2.

care without the excess inherent in pity. At the same time, the character embodies a “cool” form of masculinity vicariously through their caregiver, counteracting any pity the character might receive from other characters or the audience, and instead inspiring awe or jealousy. Rather than going to school with an overbearing mother figure (the trained white woman aide), JJ can go with a cool black sidekick who understands youth culture even as an adult, has the physical prowess to intimidate others in JJ’s defense, and nurtures him as needed, but knows how and when to do so without compromising his social status.

The dynamic between the DiMeos and Kenneth becomes even more disturbing through the show’s running joke that the DiMeos do not pay him. The joke is ostensibly intended to be read as a charming, humorous comment on the family’s financial struggles, but perhaps does not to achieve this delivery in light of the long history of black “almost-family members” who perform care labor in white families for no pay. Consider this exchange from the eighteenth episode of the first season, where we discover Kenneth has a second job as a grocery store employee:

> Kenneth: They’re my day job… I like the kid but the pay’s not that great so I work here on weekends to make ends meet.
>
> Co-worker: So you don’t want them to know because you don’t want them to feel guilty?
>
> Kenneth: They don’t work on that level. I don’t want them hitting me up for expired free stuff.

And, later in the episode, when they find him working at the grocery store:

> Kenneth: Now I have to come clean. I love working with the family but it doesn’t exactly keep the hot tub warm.
>
> JJ: You work extra so you can stay with me?
>
> Kenneth: That’s right, buddy.
>
> Maya, JJ’s mother: That is *so* selfless of you Kenneth. So, what’s the friends and family discount on the old bread?

The same joke is repeated throughout *Driving Miss Daisy*, including as part of the “touching” final scene in which Daisy and Hoke share a meal.

> Daisy: Boolie paying you still? (Boolie is Daisy’s son.)
>
> Hoke: Every week.
>
> Daisy: How much?
>
> Hoke: Now that's between him and me.
>
> Daisy: Highway robbery!
>
> Hoke: It sure is.
>
> Daisy: It sure is.

Moments later, the film ends as Hoke spoon-feeds Daisy a bite of pie. Particularly in these scenes, the joke is, seemingly, meant to convey that the affection between the two characters renders monetary compensation unnecessary. In the case of the former show, the joke is also a comment on the DiMeo’s own financial struggles. And yet, the caregivers’ living wage is what must be sacrificed for the relationship, to say nothing of their ability to care for their own needs and nurture their own family relationships. What supersedes these concerns is that the relationship is so meaningful for the black caregivers, who had apparently been imprisoning themselves until they learned to *love* giving of themselves.

In one episode, JJ decides to join choir because he finds the new choir instructor attractive, much to the frustration of his brother Ray, who is genuinely interested in pursuing it as an extracurricular activity. The two compete for the lead spot in an upcoming performance, which Ray is confident will be given to him because his brother is nonverbal. When it is JJ's turn to audition, he points to the words on his keyboard and Kenneth sings for him. JJ receives a standing ovation for "his" performance and is given the lead spot. Rather than signifying a form of *dependence*, the presence of black caregivers in these popular culture depictions is characterized, paradoxically, as making independence possible. As the *Kaiser Health News* piece characterizes the relationship between Nirva and Isolina: "Over the years, Nirva, 46, has helped her live independently, giving her showers, changing her clothes, washing her windows, taking her to her favorite parks and discount grocery stores." This "independence" is made possible when the black caregiver is disregarded as a person, and represented instead as a vessel through which abilities and bodily functions are made available for the use of the disabled character. The black caregiver's labor, time, and body are sacrificed to make possible another's "independence," experience of life, and recovery. It is portrayed as the basis of a deep, affectionate connection between two people, where the sacrifice is made more meaningful by the black character's willingness to provide it in the name of love, seeking nothing in return, sometimes not even payment.

What reads to some audience members as an obvious imbalance in the relationship, one that renders it as exploitative, patronizing, or dehumanizing, goes unnoticed by other audience members, ostensibly because merely being accepted by a white person is an honor so great that it negates the imbalance. The relationship, by these accounts, is even "instructive" for the black caregivers, following, per Hartman, in the legacy of "social reformers and Progressive intellectuals [who] encouraged domestic work as a form of moral tutelage and training [for] black women."[119] Yet the "independence" relies on the presence of a person to perform for them tasks they are no longer able to perform alone. The independence is, after all, dependence. Rather than acknowledging that and using it generatively, for example, to question the very concept of independence, to expose the ways "independence" always relies on hidden and uncompensated labor, and is something that can be purchased or acquired by those with the means and the power, these representations, like the "companionship exemption" and surrounding discourses, unfortunately valorize "independence" as a form of empowerment for the disabled character, thus dehumanizing the characters whose unacknowledged labor makes it possible. One can only praise and admire JJ's performance in choir by, literally, refusing to see that it is actually Kenneth who is singing for him. Though this particular scene borders on the absurd for comedic effect, it exaggerates what is essentially the core of JJ and Kenneth's, and Philippe and Driss's, and Phil and Dell's, and Daisy and Hoke's relationships.

VIII.

In "The Fault Line in Haiti Runs Straight to France,"[120] British historian and columnist Ben MacIntyre ties the devastation of the 2010 earthquake in Haiti to the history of French slavery in Haiti, and to France's collection of debt payments from Haiti well into the twentieth

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[119] Saidiya Hartman. "The Belly of the World: A Note on Black Women's Labors." Souls 18.1, 2016.

[120] Macintyre, Ben. "The fault line in Haiti runs straight to France." *The Sunday Times* 21 (2010).

century: “if France had not saddled the country with debt almost from its inception, Haiti would have been far better equipped to cope with natures spite.” After Haiti won its independence from France in the early nineteenth century, it was cut off from trade relations by a number of key slaveholding powers around the world. In 1806, the United States instituted a trade embargo against Haitian “ex-slaves” in support of France[121]. “In 1825, in return for recognizing Haitian independence, France demanded indemnity on a staggering scale: 150 million gold francs, five times the country’s annual export revenue. The Royal Ordinance was backed up by 12 French warships with 150 cannon. The terms were non-negotiable. The fledgeling nation acceded, since it had little choice. Haiti must pay for its freedom, and pay it did, through the nose, for the next 122 years.”[122] In 1915, the US initiated a military occupation in Haiti on the basis of “anarchy” and a “threat to order,” and followed the occupation with US-backed dictators in the 1950s that accumulated the new “debt” that, beginning in 2000, Haiti paid “back” to the IMF, whose largest member was the United States. Given that this joint effort by France and the United States directly produced the infrastructural problems in the aftermath of the 2010 earthquake, the presence of Haitian TSP immigrants in the US is a direct result of this history.

Though the US (and France) directly owe them (and other Haitians) a moral debt, their presence in the US is framed as a gift to Haitian immigrants, and their exploitation is framed as a courtesy. That the debt Haiti paid to France was called an “independence debt” is emblematic of the way that white subjects and nation-states position themselves as *entitled* to *demand* the lives and labor of black people, whose refusal to give is interpreted as an injury that must be restituted.

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[121] Hickey, Donald. “America's Response to the Slave Revolt in Haiti, 1791-1806.” Journal of the Early Republic, Vol 2, No 4. 1982.

[122] Ben MacIntyre. “The Fault Line in Haiti Runs Straight to France.” The Times UK. 2010.

Here, I have positioned care labor within this history to examine how these demands continue in US, and also in French, popular culture representations of caregiving, and to ask why representations of white disability are often accompanied, specifically, by the figure of a black caregiver. Haiti is important for this discussion of in/dependence for the fact that the lives and labors of Haitians literally produced France's wealth but its own assertion of independence was taken as a transgression against France that demanded "repayment" for an incurred "debt," a debt which was later collected by the United States in various forms. The continued centrality of Haitian and other black care labor to both France and the United States replicates this framing, where the "debt" is owed to white people in the form of care, on which basis (and through which elision) a form of personal "independence" can be claimed.

Chapter 4: The Fantasy of the Able Body

> "Sooner or later, if we live long enough (so we say), we will all become disabled. I don't want to dispute these foundational disability studies points… but I do want to invert them: sooner or later, if we live long enough, we will all become normate. And if the established disability studies point is worth repeating, again and again, the queer disability studies point I'm excavating is worth resisting" (198).
>
> Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (2006)

I.

In many disability studies texts, the stakes of the field are explained through the project's universalism: "someday we will all be disabled," we are told, through physical experiences related to aging, accidents, or other medical conditions. Robert McRuer, critical of rehabilitation as a normalizing project that governs disability, revises this argument about the stakes of the field. As McRuer correctly notes, this warning figures disability as a medical condition even in texts that argue otherwise. Thus he revises the warning/prediction in light of his critique of rehabilitation and the social model's critique of the medical model of disability: "if we're not careful, someday we might all be able." In other words, rehabilitative technology might advance to such a degree that all disability will be rehabilitated and eradicated and all people will be incorporated. For McRuer, this is a warning because disabled people offer an important and generative form of social diversity, and a variety of perspectives through which to experience the world. The elimination of disability also eliminates this diversity. Although this is an important revision of earlier articulations of the field's stakes, it nevertheless lays claim to the same kind of false universalism presumed by the argument it refutes. If impairment, for some, is presumed and the occupation of a disabled subject position therefore obscured, then it may not be true that we might all "someday" become disabled. Similarly, if rehabilitative technologies are not equally available to *all* and are developed at the expense of some, then it may not be true that we might *all* someday be “able.” Both arguments obscure the racial hierarchies that underlie this false universalism.

The proposition that we might all someday be able-bodied reaches its logical extreme in a project called transhumanism. According to the 2009 Transhumanist Statement put forth by the World Transhumanist Association, the project seeks to use and produce technologies that will broaden “human potential by overcoming aging, cognitive shortcomings, involuntary suffering, and our confinement to planet Earth.” The project also aims for the “reduction of existential risks, and the development of the means for the preservation of life and health.” “Overcoming aging” involves overcoming the health conditions that, for many disability studies scholars, would potentially disable anyone, so much so that many adherents of transhumanism hope to overcome death itself and “achieve” immortality. This utopian vision collapses the conditions that comprise disability with “suffering” and thereby justifies the quest to eliminate them. The movement emerged in the 1990s, and has become increasingly more popular over the last two decades with many billionaires, primarily white men, investing huge sums of money into the development of scientific technology that could make this vision, the entirely able-bodied future of which McRuer warns, reality.

Transhumanism has been criticized by some disability studies scholars as a project that seeks to eliminate disability. In response, proponents of transhumanism argue that such scholars and activists are in the minority, that most people do in fact wish to eliminate health conditions, aging, and mortality, and that an all able-bodied future is one that most people do and should want. This chapter makes the argument that transhumanism, in its suggestion that “we might all be able-bodied" and the social model of disability that opposes it, in both its suggestion that "we could all potentially be disabled" and its *warning* that "we might all be able-bodied," share a false universalism that relies on racist rhetoric even as it obscures the role of naturalized racism in producing the illusion of a "universal" subject position that anyone could embody. Through its dystopian storyline, *Gattaca* (1997) uses the principles proposed by the social model of disability to critically reveal the dangers of the imagined able-bodied utopia put forth by the project of transhumanism. However, in relying on tropes of and metaphors to race and racism to make this argument, it reinforces the legitimacy of racial hierarchies in a move shared by the universalism of both projects.

The 1997 science fiction film, *Gattaca*, directed by Andrew Niccol, offers a dystopian take on a moment in the "not-so-distant future" when reproductive technologies and genetic engineering have become so common that nearly everyone is conceived through a eugenics program. The film focuses primarily on the story of one character, Vincent Freeman (played by Ethan Hawke), who was conceived outside of this program and therefore born with a 90% chance of developing a heart condition that would cause him to die by the age of thirty, as well as other physical "shortcomings" like myopia, or nearsightedness. Despite his destiny and the rampant genetic discrimination, or "genelism," that has superseded every other form of social discrimination, Freeman overcomes his genetic flaws to live out his dream of traveling to space through a program called the Gattaca Aerospace Corporation. Though the film did not initially perform well in the box office, it received very positive reviews from critics, has since gained a cult following, and is now one of the most widely referenced dystopian films, especially in texts that warn about the dangers of genetic engineering and other technologies that allow people to "play god."

"Playing god" is, explicitly, part of the project of transhumanism, which hopes not only to allow people to play god but to allow them to become god. The transhumanist scale of beings moves from animal to human to deity. Disability and mortality make (white) people "human" and their transcendence can make "humans" gods. The 1997 film emerged in the midst of increased discussion and debate that followed the formal 1990 launching of the Human Genome Project, an international and collaborative biological project that worked to identify and map every gene on the human genome, a project that was declared complete in 2003. Also in 1990, by the earliest estimates, "transhumanism" was first coined and the project was written into existence. Because the field emerged, by these estimates,[123] with a publication by Max More in 1990, much of what has been published comes in the form of statements, proposals, and "manifestos" that outline the project's goals and vision.

In this chapter, I read key texts, manifestos and declarations of the project of transhumanism in conjunction with the now widely-cited film *Gattaca* that offers a dystopian take on that project. This chapter argues that the fantasy of transhumanism is already a reality to some degree, and that *Gattaca*'s dystopian take on the project reflects a fear that white people will have to live as the project's current victims already do. The future of transhumanist technology, whether viewed through a utopian or dystopian lens, cannot be separated from existing social divisions, especially around race which has historically been used as a proxy for genetic fitness. Both versions of the fantasy reveal the extent to which disability in both identity and government is structured by the presumed superiority of whiteness and a fear that disability

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[123] More, Max, and Natasha Vita-More (eds.). *The Transhumanist Reader: Classical and Contemporary Essays on the Science, Technology, and Philosophy of the Human Future*. John Wiley & Sons, 2013.

brings white people closer to blackness, holding back white people's presumed godlike potential. Transhumanism, the extreme of "we will all be able-bodied" and the social model of disability, "we could all be disabled," share a false universalism that relies on racist rhetoric even as it obscures the role of racism in producing the illusion of a "universal" subject position.

II.

Andrew Niccol is a screenwriter, producer, and director from New Zealand who specializes in dystopic, futuristic, and social commentary films. Some of his most famous works include *Gattaca* (1997), *The Truman Show* (1998), which he wrote and co-produced, *Lord of War* (2005) which takes on the issue of arms trafficking, and *In Time* (2011) which follows from many of the same themes presented in *Gattaca*. In *In Time*, everyone has been genetically altered to stop aging by 25, and money has been replaced by time as a form of currency. As a result, the wealthiest people have the most "time" and live longest; the film's plot line is another indirect critique of aspects of transhumanism. As philosophical social commentary infused with "Catholic sensibility,"[124] Niccol's films often blend objections to inequality characteristic of the political left-wing with the religious moralizing of the right. The moralistic tone that sometimes permeates his work, at the same time that it chastises social injustice, at once mourns the "loss" of religious faith and traditional family. In other words, by resting the critique on morality, the films sometimes uphold "moral" tenets indiscriminately, such that the radical elements of the film that call for social justice can be subsumed by religious beliefs and a conservative longing for the past that work against the former impulse and stifle the films' potential. Accordingly, when *Gattaca* rescues "the human spirit" from a dystopian, thoroughly eugenicist, and unjust

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[124] Foley, Michael. "Plato, Christianity, and the Cinematic Craft of Andrew Niccol." *Logos: A Journal of Catholic Thought and Culture* 9, no. 2 (2006): 43-67.

universe that seeks "perfection" through a belief in genetic determinism, it also rescues white masculinity; a belief in the fetus as a person; white heteronormative couplings based in love, where a white woman represents peace, support, and a nurturing spirit to help uplift a heroic white man who defies all odds; religious tenets that oppose "nature" (i.e., god) to science and value the former over the latter; and the bootstraps myth of social advancement. Both for the presentation of the story as dystopian fiction, and to highlight these forms of "moral corruption" that exceed social injustice, then, the film can only cohere with a white male lead and a secondary white female character.

In this vein, *Gattaca*'s critique of strict control over reproduction does not offer an alternative vision for reproductive justice. Disability studies scholars of reproduction often highlight the tension between pro-choice advocates of reproductive rights who believe pregnant women should have the right to decide whether to terminate a pregnancy and disability rights advocates who believe people should not be allowed to terminate a pregnancy based upon disability status. The tension is exacerbated by the fact that the latter activists often personify fetuses with disabilities by, for example, referring to disability-based abortions as "genocide against my people."[125] This works against the former activists' long-standing insistence that the fetus is not a person, and that women should be allowed to decide what happens with their bodies. *Gattaca* alleviates this tension by presenting a universe where abortion is prevalent and routine, but the vast majority of it does not take place in women's bodies. Rather, zygotes are produced and tested in a laboratory, and the vast majority of them are disposed before the "perfect" embryo is used to impregnate a prospective mother. By rejecting the entire process as

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[125] Saxton, Marsha. "Disability Rights and Selective Abortion."

oppressive, fetuses are rescued as people and abortion is denounced without the necessity of engagement with the conflict posed by the insistence on female self-possession. Transhumanism promises to resolve the tension entirely by seeking to produce artificial wombs where gestation can become independent of non-fetal bodies.

However, both *Gattaca*'s denouncement of this form of abortion and transhumanism's promotion of it precede the imagined universe where this tension is resolved. The respective positions taken proceed with no consideration of how the existence of bodies with wombs, for now necessary to the process, and the people whose bodies they are, complicate either position. The urgent critiques of black and women of color activists for reproductive justice[126] who have highlighted the ways black women and other women of color have historically been discouraged or altogether prevented from having children also fall out of this debate. The terms are restricted to whether, on the one hand, abortion based on dis/ability status should be outlawed and/or considered unethical, or, on the other hand, it should be encouraged for the alleged benefit of the group. Left out of this debate is a discussion of the context that has and will continue to shape such decisions, and render any "debate" about the acceptability of abortion for various fetal conditions largely inapplicable to many women, including the cost of fetal screening, the material and psychic costs of raising *any* child without considering the additional cost associated with some medical conditions, and the kinds of attacks on black motherhood outlined in the second chapter. Such impediments make the process of determining whether and when to carry a pregnancy to term a profoundly different decision for different groups of women. Both positions of this debate fail to account for what has long been central to eugenics: while black and other

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[126] Ross, Loretta, and Rickie Solinger. *Reproductive Justice: An Introduction*. University of California Press, 2017.

nonwhite people were written out of the project wholesale, the inclusion of white people was selective based on different conceptions of dis/ability status.

In “Disability, Democracy, and the New Genetics,” disability studies scholar Michael Berube reads *Gattaca* to argue that a society like that presented in the film would call for a democratic debate involving a variety of participants that both recognizes individual choice and at the same time insisting that “democracy does not have to honor all the preferences and desires of every person participant therein.” This framing, based in individual choice and democracy, betrays the same oversight outlined above. According to Berube, such a debate, ideally, would work against equating disability with disease, and focus on “extending the protection of the social welfare state to stigmatized populations while working also to de-stigmatize previously stigmatized identities (as had been done, evidently, with regard to people of African descent in the world of *Gattaca*).” As noted, arguments that rest on or promote “democracy” and individual support presume a false universality and egalitarianism. Beyond that, does this analysis in fact describe what has been done “with regard to people of African descent” in the world of *Gattaca*, let alone in existing applications of eugenics?

Berube acknowledges, following Roberts in *Killing the Black Body*, that “the discourse of eugenics is not really ‘history’ at all, and certainly not ancient history” but he qualifies,

> yet the new genetics is not precisely the same as the old. Our era differs from the era of the Kansas State Fair in critically important wars: one might call these ‘public’ and ‘private’ eugenics, or one might call them macro and micro eugenics, as Barbara Katz has done in *Genetic Maps and Human Imaginations*, or one might say (as I will proceed to) that the old eugenics saw the human population as an aggregate of various ethnic and racial traits some of which were not beneficial to the enlightened propagation of the species, whereas the new eugenics sees individuals as aggregates of biochemical traits some of which are not beneficial to the families or populations in which they occur. I believe that this molecular view of the human is inadequate

> and incomplete, partly because genetics is an inexact science, a science of probabilities in which we cannot be sure how a biochemical predisposition may express itself, and partly because we have limited but conscious, self-reflexive control over how we express some of the traits with which we are born. (This too is one of the lessons of *Gattaca*…).

Here, Berube finds value in *Gattaca's* critique of eugenics, but, like the film, he overestimates the extent to which the present-day application of eugenics has moved away from a view of the human population as "an aggregate of various racial and ethnic traits" and underestimates the centrality of race both to transhumanist eugenicists' own descriptions of their project, and to the more unconscious ways that race informs which traits and abilities are understood to be desirable in the more general application of eugenics. I read *Gattaca* alongside transhumanist texts to illustrate this point. I am suggesting that a time will not come, in the future, where the deliberations proposed by Berube will take place once the technology is available; rather the technology develops slowly and the "democratic consensus" unfolds slowly and subtly with it, carrying along ingrained racism and reshaping it to the new applications that are perpetually being made possible.

While Berube takes a positive view of the film, other disability studies scholars have critiqued it. According to Berube, Anne Finger's 1998 review[127] of the film set the stage for its reading within the field. According to Finger, the film promotes an identification with Vincent, the main character. Vincent represents, in many ways, the disabled character in the film. So, Finger argues, "rather than leave the audience members in the uncomfortable position of thinking of themselves as disabled, the film had to create a 'really disabled' person, someone who fits our

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[127] Finger, Anne. "Invalids, De-generates, High-Tech Zombies and Old-Fashioned Hollywood Cripples." *Electric Edge: Web Edition of the Ragged Edge* (Jan/Feb 1998). http://www.ragged-edge-mag.com/jan98/movie01.htm .

stereotype of what crip is. In the end, despite its possibilities, *Gattaca* doesn't really challenge the terms of the debate. It tells us that with hard work and 'spirit' we can overcome, but it still leaves intact a division between 'us' and 'them,' whose bodies succeed and whose fail." Disability studies scholar Kathleen Ellis adds to this critique that the film promotes a negative view of people with disabilities in that "Jerome is presented as a weak, contemptible character, wallowing in vodka and self-pity." Berube challenges these critiques by noting that "Jerome is not bitter and suicidal because he is disabled; he tried to commit suicide before he was disabled, solely because he had to settle for a silver medal, and he is bitter because his attempt failed." Instead of attributing Jerome's disposition to his disability, the film instead attributes it to the combination of a fallacious belief in genetic determinism and what political philosopher Michael Sandel calls the "burden of perfection."

Though Berube does not include it in his analysis, *Gattaca*'s original epilogue, included only in the "deleted scenes," seems to confirm his assessment of the film's analysis of disability against some of the more predominant readings in disability studies. The epilogue begins "In a few short years, scientists will have completed the Human Genome Project, the mapping the genes that make up a human being. We have now evolved to the point where we can direct our own evolution. Had we acquired this knowledge sooner, the following people may never have been born:" The list includes a variety of famous figures, all but two of whom are white, including Abraham Lincoln, Emily Dickinson, John F. Kennedy, Albert Einstein, and Ray Charles, and the disabilities with which they lived, including Marfan Syndrome, manic depression, epilepsy, dyslexia, and primary glaucoma. The scene then explicitly compels identification between disability and the average audience member, an identification Finger argues the film denies, by ending the epilogue with "Of course, the other birth that may never have taken place is your own." In this way, the film's premise cosigns both the truism, "someday we will all be disabled," or put differently, none of us is entirely "able," and McRuer's rebuttal in the form of the warning "someday we might all be able."

III.

In the 2013 text, *The Transhumanist Reader: Classical and Contemporary Essays on the Science, Technology, and Philosophy of the Human Future*[128], More and Natasha Vita-More outline the key goal of the project: to "seek the continued evolution of human life beyond its current human form as a result of science and technology guided by life-promoting principles and values." In "The Philosophy of Transhumanism," More explains that this entails the elimination of disease and illness, the colonization of other parts of the universe, and the re-organization of people around the globe:

> Posthuman beings would no longer suffer from disease, aging, and inevitable death (but they are likely to face other challenges). They would have vastly greater physical capability and freedom of form – often referred to as "morphological freedom" (More 1993; Sandberg 2001). Posthumans would also have much greater cognitive capabilities, and more refined emotions (more joy, less anger, or whatever changes each individual prefers). Transhumanists typically look to expand the range of possible future environments for posthuman life, including space colonization and the creation of rich virtual worlds. When transhumanists refer to "technology" as the primary means of effecting changes to the human condition, this should be understood broadly to include the design of organizations, economies, polities, and the use of psychological methods and tools (4).

Such sentiments are echoed in other introductory texts[129]. Most of the scholars frame

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[128] *The Transhumanist Reader: Classical and Contemporary Essays on the Science, Technology, and Philosophy of the Human Future* Chichester, West Sussex, UK : Wiley-Blackwell, 2013

[129] H+/-: Transhumanism and Its Critics, eds, Gregory R. Hansell and William Grassie, 2011.

transhumanism as a "project of optimism," with a 2006 text by Simon Young[130] arguing that opponents of the project are necessarily nihilistic or pessimistic about the human condition. Most also agree that eugenics is central to this project, but Young argues that the project does not advocate eugenics, per se, but rather the belief that "ordinary men and women" can use technology to enhance their and their children's lives, and that the risks are worth taking because there is too much to be gained from such an experiment. Such definitions, particularly the use of genetic engineering and reproductive technologies to eliminate disease and sometimes mortality, imagine the utopian version of *Gattaca*'s dystopian world.

Beyond promoting the "end" of illness or mortality, most of the texts are vague about what such an improvement, or such experiments, or support for eugenics would entail, but one of the less ambiguous texts, and one that explicitly espouses eugenics as necessary to the project of transhumanism, is Steve Fuller and Veronika Lipinska's 2014 *The Proactionary Imperative: A Foundation for Transhumanism.* This text advocates for a "proactionary" stance toward the development of new technologies and scientific research that will allow "humans" to reach their full god-like potential. The title comes from cryonics executive Max More's 2004 declaration "The Proactionary Principle," which rejects the "precautionary principle." The precautionary principle posits that in technological development or scientific research with the potential to cause harm to individuals, the public, or the environment, the burden of proof falls on those advocating for that research to show that the undertaking is not harmful, or is less harmful than alternatives and therefore warranted. The proactionary principle counters that the former principle assumes the worst case scenario, inhibits scientists' "freedom to innovate" and places

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[130] Simon Young, *Designer Evolution: A Transhumanist Manifesto*, 2006.

more weight on technological risks, which are often hypothetical, as opposed to natural risks, which are often existing or proven. On this basis, the declaration describes the precautionary principle as a "principle against progress" and posits that the effects of risky research and development should be addressed "through compensation and remediation instead of prohibition." They describe their alternative as follows:

> With the advance of scientific research, the choice in favour of a pro-human position has been made more difficult, since the empirical findings appear to support the Darwinian view that there is nothing special about Homo sapiens understood in strict biological terms that might permit it to control its own destiny any more successfully than the other organisms with which we cohabit the planet. Love it or loathe it, eugenics stepped into the breach to address this problem, precisely in a manner that was designed to be *favourable to humans*. However, to be true to itself, *eugenics requires mass surveillance and experimentation*, with the understanding that *many in retrospect may turn out to have been used or sacrificed for science*, given what may be an irreducible uncertainty about how particular genetic combinations function in particular environments (63, emphasis added).

The precautionary principle guides some of the most significant research ethics regulations regarding human experimentation and climate change. Most of the former, including the Nuremberg Codes, the U.S. 1974 National Research Act, the 1979 Belmont Report, and the 1991 Federal Policy for the Protection of Human Subjects (also known as The Common Rule), were developed in response to the most well-known and widely-cited examples of research ethics violations, the Nazi experiments on Jewish prisoners, and the forty-year Tuskegee Syphilis Experiment. Fuller's and Lipinska's text borrows the name of this declaration because it posits such an approach to scientific research and development to be the basis of the fulfillment of god-like human potential they foresee, and the aforementioned research regulations as barriers to this fulfillment.

The authors identify a variety of "barriers" to the fulfillment of their project, including these research guidelines and a focus on more equitable distribution of resources.

> Proactionaries are not primarily interested in ensuring that every kind of being currently on the planet survives or enjoys the same standard of existence, a state that postmodern philosophers often portray as a leveled ontological playing field (e.g. Latour 2004). To the proactionary, there is nothing intrinsically valuable in this sense of 'equality', despite its reputation as a posthumanist utopia. On the contrary, it looks like the enforcement of what the former Wall Street trader and self-styled 'risk engineer' Nicholas Taleb (2012) would call a 'fragile' approach to the ecology that fails to recognize the creative power of destruction in both natural and human history… The classic welfare state concern – nowadays increasingly extended to environment – about 'quality of life' may function as a secondary constraint on the pursuit of what really matters to the proactionary, namely, the full realization of human potential (3-4).

Accordingly, in addition to ethics guidelines on research in the form of the precautionary principle, this project names concerns about social equality, environmental protections, and the welfare of other "kinds of being" as "constraints on the pursuit of what really matters to the proactionary," or barriers to be broken so that this project can be realized. In accepting mass surveillance and harmful scientific experimentation as necessary, and in their willingness to set aside concerns about material and social inequality, the authors reveal whose interests drive the project of trasnshumanism, including who stands to benefit and who must be sacrificed in the project.

By asserting a universal "human" subject position that allegedly stands to benefit from such a project, the authors rest their premise on a presumed, but false, universalism and commonality, thereby circumventing the more important questions: at whose expense are these risks expected to be taken, and for whose benefit? At whose expense have they historically and presently been taken? Precisely, to which "humans" was eugenics designed to be favorable? It is the security of the inevitability of their position as people who will *not* have to be sacrificed in scientific experiments, will *not* have to be moved to environments allegedly better-suited to their genetic composition, will *not* have to be prevented from procreating that they can imagine themselves to be more like gods than the other animals and imagine that the future they propose is not an existing reality that has already produced the position they occupy.

IV.

The transhumanist movement has risen to a particularly high level of prominence since the Transhumanist Party candidate Zoltan Istvan ran for president in the 2016 U.S. presidential election and lost. He subsequently explained that "I never ran to win the presidency, but rather to spread word about the transhumanist movement and its goal to conquer death with science and technology." Not surprisingly, he then moved on to support Donald Trump in his bid for the presidency. He explained that "unlike many others," he looked forward to Trump's presidency because "My main thing is science — and Trump will be good for science, since if he really wants to Make America Great Again, then he'll have to beat China in it. And China is doing amazing science and tech, and so Trump will be forced to help technology and science move forward in America to keep up."[131] The "many others" unhappy with Trump for his promised racist, discriminatory and genocidal, policies, were clearly not imagined, then, to be included in Istvan's vision of technology-enabled immortality and bliss.

Since then, Trump has met with a variety of billionaire white men who espouse transhumanism and seek to invest millions of dollars in promoting it. One of the most prominent is venture capitalist Peter Thiel, who donated 1.25 million dollars to Trump's presidential

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[131] Brown, Mike. "Transhumanist Zoltan Istvan: "Trump Will Be Good for Science." *Inverse* (Nov 11, 2016).

campaign and was later appointed to his transition team. Thiel came under fire after some of his old college friends revealed that at the height of the South African apartheid regime, he was a staunch defender, arguing that it represented a “sound economic system” and criticisms of its racism were “based in emotion.” In light of this criticism and his support for Trump’s campaign, with all its racist, genocidal rhetoric and policy and a healthcare plan that would leave millions uninsured, Thiel and others like him reveal that there is no contradiction between seeking immortality for “all of humanity” and implementing policies of racist colonialism, labor exploitation, and genocide because, it is clear, not everyone is part of the “all” who should be immortal. As Kansas representative Roger Marshall phrased his defense of Trump’s healthcare plan, “I think just morally, spiritually, socially, [some people] just don’t want health care.” Many of “such people” are “homeless,” he explained in a racially coded rant.

Peter Thiel’s German father, a chemical engineer named Klaus, lived for awhile in Swakopmund, a city in Namibia that served as the central location for German colonialism in Southwest Africa from the late nineteenth century onward. Most German-descended Namibians still live in this city, and their children attend expensive private schools in which they are taught to glorify the colonial past and defend its monuments, monuments opposed by most Namibians because, as German-Namibian Andreas Vogt explains, “the people of Africa, the majority, are of simple mind” (Onishi 2017).[132] Thiel was schooled at such an institution, developing alongside such racist sentiments a strong training in math and science and a distaste for authority that would later inform his libertarian conservatism. Meanwhile, his father worked as a chemical engineer for the Rossum uranium mining company, initially German-funded and now owned by

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[132] Onishi, Norimitsu. “A Colonial-Era Wound Opens in Namibia.” *The New York Times*. Jan 21 2017.

a British-Australian multinational mining corporation called Rio Tinto. Namibia's uranium mining companies continue to generate enormous amounts of wealth and nuclear power for mostly European former colonists, with a recent increase in investments from Iran and China, even as Namibian workers continue to suffer the adverse health effects of working in the mines. Workers report being unaware of the impact of uranium mining on their wellbeing until after they are diagnosed with cancers or unexplained illnesses, at which point they are often denied healthcare and treatment for which they are otherwise unable to pay[133]. As a chemical engineer, Klaus Thiel participated in the processing and management of uranium at this plant. He also worked in South Africa so, having spent some time there himself as child in the midst of apartheid, Peter Thiel's defense of apartheid as a "sound economic system" comes from the first-hand experience of materially benefitting from it.

Like South Africa's "sound economic system," *Gattaca*'s universe is characterized by a system of segregation and labor discrimination based in assumptions about biological difference, but the film is more critical of such a system than is Thiel. The film debunks ideas of genetic determinism that suggests genes are destiny, that they can reveal everything about a person's being and potential. For one thing, Vincent outlives his predicted thirty year lifespan. He also gains the confidence to pursue his dreams after finally beating his genetically engineered brother in a swimming race in the ocean and having to save him. Finally, he is suspected of having murdered an administrator at Gattaca Aerospace Corporation because he is a "degenerate" (pronounced de-gene-erate) or an "invalid" and therefore has a propensity for violence wired into his genes. However, it turns out this administrator was in fact murdered by

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[133] Shindondola-Mote, H. "Uranium Mining in Namibia - The Mystery Behind 'Low Level Radiation'." Labour Resource & Research Institute, Feb 1 2009.

the genetically engineered director of the program, a "valid" whose DNA suggests he does not have "a violent bone in my body." Thus, the film suggests, DNA, chance, and biological propensities cannot explain personhood; personal choices and "hard work" are still more reasons why discrimination should not be based on DNA.

Although the film suggests genetic profiling is not a good basis for social discrimination, it nevertheless, like Thiel, *laments* the elimination of "previous" forms of social discrimination, particularly racial/ class discrimination. Vincent, narrating the film, explains "I belonged to a new underclass, no longer determined by social status or the color of your skin. No. We now have discrimination down to a science." The sad, slow music that plays as Vincent relays this tragic tidbit reinforces the grieving tone. This is part of what makes the film dystopian. While discrimination determined by "social status or the color of your skin" is simply business as usual, discrimination based on genetic profiling is a future we *cannot allow*, especially when it targets "hard-working" white men who, by standards not too highly technical, are able-bodied.

And this discourse of "hard work" is central to *Gattaca*'s rebuttal to transhumanism, which seeks to make people so biologically superior that they do not need hard work. Having been born with a variety of disabling physical conditions, Vincent represents the congenitally disabled character in this film. This is epitomized by the classification of Vincent and other non-engineered people as "invalid," a derogatory term for people who are ill, particularly with severely disabling conditions. To access a position at Gattaca and eventually be selected to fulfill his dream of space travel, Vincent chooses to become what is called a "social ladder," a particularly disliked segment of people who assume the identity of a "valid" person, if that person no longer participates in the society for whatever reason. The person whose identity is

Jerome Morrow, a "perfect" swimming champion who went into hiding after becoming paralyzed by a car accident. Once Vincent assumes his identity, Vincent becomes Jerome and Jerome goes by "Eugene," his middle name, instead. In order to pass, Vincent must have access to a nearly-constant supply of Jeerome's biological information in the form of blood samples, urine samples, hair, and even a recording of Jerome's heart rate.

It is important to note that Jerome, the character whose identity Vincent assumes, has an acquired (rather than an innate) disability. Vincent/Jerome passes for able-bodied by becoming Jerome and assuming Jerome/Eugene's previously able-bodied persona, as Jerome/Eugene moves from able-bodied to disabled. Passing allows Vincent/Jerome the opportunity to prove that his disablement is socially imposed, not inevitably linked to his genetic makeup nor a natural physical impairment, but resulting from the assumptions made and barriers imposed on people with his genetic makeup. In this way, the film ascribes to the "social model" of disability and refutes the "medical model" of disability. In this vein, the film portrays Vincent/Jerome's process of becoming "able" (or passing as such) as an intrusive, uncomfortable, and even violent process of "normalization." For example, to become Jerome, Vincent cannot reveal his myopia, and therefore cannot wear glasses or other contact lenses. This is generally uncomfortable for him, and even potentially dangerous, as represented by a scene in which Irene takes him to a secluded area to enjoy some romantic scenery. Not only is he unable to enjoy the scenery because it appears blurry to him, but to get there he must cross a street of fast-moving cars; while Irene is able to do so because of her perfect vision, Vincent/Jerome struggles to cross and puts himself in danger in the process. Though "corrective" lenses are also examples of rehabilitative technology, the movie does not present Vincent/Jerome's myopia itself as the problem for him; instead, the problem is that he is forced to hide it in a different act of normalization. More revealingly, Vincent initially resists but is forced to undergo a difficult and painful surgery on his legs to add a few inches to his height so that he is able pass as the much-taller Jerome. The discourse of “passing” on which the film relies is itself highly racialized.

The film further defends the social model of disability by portraying the eugenic process of genetic engineering through reproductive technologies, rightly, as an ableist one. The doctor who works with Vincent’s parents to conceive their second child explains that he has “taken the liberty” of eliminating any “conditions.” The parents, being religious, wonder whether they “might leave some things up to chance,” but “not diseases of course.” The film takes a critical stance on this tight regulation of acceptable embodiment, and the limits it imposes on physical and neuro-diversity. The uniformity is characterized as both limiting diversity, and failing to deliver on the “perfection” it promises because people born “perfect” have less incentive to push themselves, and those born “invalid,” through hard work and chance, are often able to transcend expectations about their capacities.

Jerome/Eugene, dissatisfied with coming in second in a swimming match, is revealed to be the source of his own disablement, after throwing himself in front of a car in a failed attempt at suicide. While Vincent/Jerome’s dangerous encounter with moving cars is socially imposed by the compulsion to pass as able-bodied, Jerome’s is the result of social pressure to live up to the “perfection” he is thought to embody, and his feeling that he has failed to do so. At the end of the film, it is implied, he follows through with his suicide by pulling himself into an incinerator after leaving a refrigerator full of his DNA for Vincent/Jerome to use upon his return. In this way, the film presents mental illness as something anyone can struggle with, even if their DNA suggests they should be "perfect," exposing the fallacy of the transhumanist suggestion that new technologies and an improved gene pool will ensure that everyone will live happily. On the other hand, it also represents the film's moment of possible betrayal of the social model it otherwise espouses, by representing disablement as something *either* socially imposed or self-selected, and in its somewhat unsympathetic portrayal of Jerome/Eugene's struggles with mental illness (despite being dealt "a good hand") as juxtaposed to Vincent/Jerome's "self-determination" in the face of his social struggles. Social barriers can be overcome with such determination but the only "true" physical limitations, the film suggests, are those one imposes on oneself, yet another example of popular racist discourse, otherwise known as "pulling yourself up by your bootstraps." This discourse suggests that despite physical "limitations" and social circumstances, it is an individual's responsibility to overcome them through hard work and determination. In using discourses of "hard work" and determination to illustrate the fallacy of genetic determinism, the film obscures the way both discourses have historically been used to justify racial oppression. They alternate and interweave conveniently so that, regardless of which discourse is used to explain people's behavior and social circumstances, racial oppression remains "justified." At the same time that it relies on these racialized discourses, *Gattaca* presents a world in which race is ostensibly no longer relevant.

Transhumanists Lipinska and Fuller seek similarly to rescue to the racist ideas of Nazi eugenics from their association with racism. After abandoning concern for social inequality and advocating for more lax human experimentation policies, the authors explicitly advocate the revival of eugenics as the "science of progress," a science that suffers "unfairly" from its association with Nazi genocide, which they understand as not necessarily its inevitable outcome.

For them, the problem with Nazi "national socialism" was not in the ideas nor even the application, but the "scale" - they simply took their good ideas too far. They suggest treating the genocidal outcome not as an inevitability, but instead considering the "original" ideas on their own terms. "Against this backdrop, the phrase 'National Socialism' should not be seen as either a sham or an oxymoron. A perversion of an adventurous scientific impulse – however heinous – should not obscure the overriding value of nurturing such an impulse." They are right to conclude that it is not an oxymoron but wrong to suggest that the politics are therefore genuinely progressive and that the original ideas are valuable on their own terms. Nazi national socialism, like all forms of socialist white supremacy, defends the restriction of resources and benefits to white populations at the expense of others, who must leave or die. Thus the genocidal outcome was not a "perversion of an adventurous scientific impulse" but a necessary component of the project, a logical implementation of an already perverse impulse. Here as in transhumanist eugenics, one group decides who is included and others deal with the violence of exclusion. One group decides what defines fitness, progress, and well-being, and others, unfit, are sacrificed to make progress possible. Some groups suffer in the process of extraction of resources that will be shared (e.g., Namibians and others colonized by Germany) as others share the resources amongst themselves. Some are used as the fodder for scientific discovery (e.g., Namibians whose skulls and other body parts were extracted, experimented on, and exhibited in the 1904-1908 Shark Island concentration camps and after the genocide that followed, Jews in Nazi concentration camps, etc.) as others benefit from the same scientific discovery. The project is, by its own description, a nationalist one, intended to benefit members of a particular "nation" at the expense of others, not intended to benefit everyone no matter the scale at which it is pursued. The difference between early Nazi euegenics, racist Americans eugenics that inspired Nazi eugenics[134], and the transhumanist eugenics advocated here is not "scale," but that the latter refuses to name explicitly (and perhaps is not consciously aware of) those who will benefit and those who will be sacrificed, masking this unavoidable component of the project with an imagined universal humanness.

Their transhumanist eugenicist vision, Fuller and Lipinska argue, is not racist in that it follows from Jose Vasconcelos's promotion of a "cosmic race," which they understand to be a "radicalization of the US self-understanding as a 'melting pot' (which had been de facto only of European races)" (98). Vasconcelos's eugenicist ideas are genocidal and antiblack on their own terms. But they contradict themselves even on this point when they postulate both Vasconcelos's eugenicist theories in their transhumanist vision and Nazi Germany's original "peaceful" version of national socialism, particularly in its proposal that human subpopulations be relocated to "homelands" where they are surrounded with members of their own population in pursuit of "genetic equilibrium." They express optimism about the supposed likelihood of such a prospect, suggested by renewed interest in DNA ancestry testing that has revived the significance of racial categorization and connected it to geography. Their slippage here, between homelands organized by racial categories and those organized by "genetic equilibrium," reproduces the more long-standing slippage between race and genetic similarity in the presumption of racial categories as biological. Because race has been used as such a powerful proxy for biological and genetic difference for the past few centuries, to imagine that genetic advances would render it irrelevant,

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[134] American and German eugenics, even before the rise of Hitler and the National Socialist Party, were closely intertwined. Ideas between the two were exchanged through the International Society for Racial Hygiene (Harriet Washington 193).

no matter how imprecise or illogical they expose racial categorization to be, is ill-founded. Indeed, racial difference has continued to be essential to short-handing the categorization of genetic fitness, nearly seven decades after it was declared by the United Nations in 1950 to be socially constructed. This is why Fuller and Lipinska end up falling back on racial categorization as a useful way to reveal genetic patterns that would call for a re-organization of bodies and the tailoring of new technologies, even as they call for a more fluid eugenics based in race mixture.

It is worth noting that this variety of "socialism," and the transhumanist vision espoused here, fits perfectly with contemporary white nationalist socialist ideologies that point to the policies of Scandinavia as examples of socialist governments that are effective only because they cater to a nearly exclusively white population. If this is true, it is less because black and nonwhite people are unsuited to live among white people and benefit from the same socialist resources and policies and more because the mere presence of black and nonwhite people who might benefit from social services turns much of the white population against those services, enabling their elimination. There is much evidence to support that this is the case[135]. By contrast Fuller and Lipinska provide no evidence for their claim that different groups of people are genetically better suited to live exclusively amongst each other, nor do they provide even an *explanation* for why some people's genetic composition should prevent them from benefitting from socialist policies and services, or living well amongst people with alleged genetic differences from them. Yet without evidence or explanation, Fuller and Lipinska are willing to align themselves with a white nationalist project in calling for experimental practices that would violently destroy the lives of black and nonwhite people by forcibly shuffling them around the

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[135] Gilens, Martin. *Why Americans Hate Welfare*. Chicago: University of Chicago Press, 1999.

world, or worse, to *see* whether such policies would improve the lives of white people. And if they did improve the lives of white people who would measure such an improvement in racist terms, they would use this fact as evidence for their original claims. Such unsubstantiated assumptions, steeped in racist "common sense," undergird not only calls for transhumanism but the actual research and development that would and does constitute it, which is precisely what makes it such a dangerous project.

In the film's end scene, the camera rotates around the space shuttle on which Vincent/ Jerome has finally made his way, resting on his face and then quickly gleaning the other passengers, including a black man and an Asian man. This scene, one of the few to include nonwhite people, makes a superficial nod to multiculturalism. Still, the film's universe links genetic superiority to whiteness. In one scene, Vincent, then a toddler, and his parents visit a clinic with the intention to "properly" conceive their second child and avoid the tragic fate they suffered with their first pregnancy. The doctor working at this clinic is a black man. As they run through the list of characteristics they have chosen for their second child, the doctor says "I see you've specified brown hair, hazel eyes and…" and then he pauses before saying "fair skin." The pause is a knowing one. There is a shared understanding that the parents, and presumably other white parents, consider this characteristic to be genetically superior. Moreover, the most prominent "valid" characters in the film are all white, including all of the people who work at Gattaca with Vincent/Jerome. Irene, the protagonist love interest played by Uma Thurman, is particularly fair skinned and blonde, and a key scene focuses in on a single strand of her blonde hair. However, whiteness is also represented by Vincent, the protagonist "invalid." The film's lighting accentuates the blue color of both their eyes. The film, then, at once links whiteness to presumed genetic superiority and rescues whiteness from the possibility of genetic discrimination, reasserting the “right” of white people, particularly, to be protected from any form of social discrimination based on the particularities of their corporeality. By making this assertion through metaphors to racial discrimination and by lamenting its absence, the film reinforces the naturalness and legitimacy of racial discrimination.

It would stand to reason that in a fantastic dystopia about genetic technology, race would “not matter,” which might explain the superficial nod the film makes to multiculturalism. It stands to reason because whatever biological characteristics are imagined to be inferior and connected to members of particular racial groups could be tested for in themselves. Even if one were to presume that some races are more likely to be “intelligent” or “criminal” than others, and “human advancement” needs more intelligent, less criminal people, then why not use DNA testing to determine, precisely, the individuals whose intelligence and criminal tendencies would allow them to make the cut rather than relying on the probabilities suggested by racial categorization? This is the fear reflected in the film: that the characteristics alleged to reflect, primarily, black people, could now be confirmed to exist in white people, and at their expense in similar ways. But this belief relies on a fallacy because it takes the justification for racial inequality as its explanation. It imagines that the excuses used to justify racism define the actual concerns of the people making the excuses. But as Stuart Hall argues, demonstrating to someone that their racist argument that is not supported by evidence does not lead that person to recant their argument, but rather to find another excuse for it. Black people are not criminalized because they are or are thought to be “more criminal”; they are thought to be more criminal because they are criminalized. This is why the prototypes of technologies of both rehabilitation and criminalization are already racialized before the technology is built. It also explains why the advancement of DNA testing has brought a significant spike in race-based rather than race-neutral studies of the alleged genetics of criminality, studies that have worked to re-establish race as both a biological fact and connected to inherent criminality in the late-twentieth and early twenty-first centuries. Technology has not brought about significantly new systems of social classification and discrimination but rather has been used to establish the legitimacy of existing racial hierarchies. In other words, "genelism" as *Gattaca* names it, already exists, as a manifestation of racism, and not as an "objective" evidence-based social system that would refute and replace it with a hierarchy that reflects a "more accurate" assessment of people's capacities. This explains the contradictory elevation of whiteness and nod to multiculturalism reflected in both *Gattaca* and Fuller and Lipinska's text.

The production of technology itself is inherently racialized. When technologies are designed, tested, and developed on particular bodies, they are best suited to and most effective for that population of people. Technologies of health, service, and recreation have typically been designed for use by white people. In vitro fertilization (IVF) reproductive treatments have a significantly higher success rate for white women, even when controlling for other factors, though doctors are, still, "unsure" why. The explanation may be related to selection of test subjects for whom the technologies are designed, or it may be related to differences in the reasons why women of different racial backgrounds choose to use IVF treatments. It may be, for example, that IVF treatment is more available as an option to white women, who therefore consider using it earlier in the process of attempting to conceive than non-white women. Other technologies, technologies of service and recreation, are also tailored to white bodies. For example, because LED-based sensory technology is often tested on light skin, it also often does not work for dark-skinned people. Documented cases of this problem include Apple's iWatch, health and activity trackers worn on the wrist, and sensory soap dispensers. While it is not impossible to for this technology to perceive dark skin, it is often designed based on the amount of light reflected off of light skin, and only adjusted after the negative publicity that follows the discovery that it is ineffective for dark-skinned people.

Whereas technologies of service, comfort, and rehabilitation are designed for a white prototype, policing technologies are designed to establish white innocence and black guilt. Technologies of criminalization are designed to identify a suspect to the extent to which the suspect's whiteness can be ruled out. For example, in the highly controversial DNAWitness technology, used only twice ever to identify black suspects in London, England, and in Baton Rouge, Louisiana, USA, there are only four possible racial categories: European, African, Asian, and Native American. Of the categories, the "'European American' face was the only one revealed to be '100 percent,' in this case, of course, pure 'European'"[136]. Many scientific studies since the emergence of this technology in 2006 have confirmed that the technology is ineffective and does not meet standards of reliability for evidence, and should therefore not be admissible in a court of law[137]. But notable, too, is that the technology, having only one "pure" type, and only one other "nearly pure" type, the "African," works first to rule out whiteness and then to "quantify" blackness in its process of racial identification. If the DNA sample contains alleles outside of the imagined "purity" of the European type, it is immediately confirmed to be

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[136] Krimsky, Sheldon, and Kathleen Sloan, eds. *Race and the Genetic Revolution: Science, Myth, and Culture*. Columbia University Press, 2011.

[137] Fullwiley, Duana. "Can DNA 'witness' race?: Forensic uses of an imperfect ancestry testing technology." *Genewatch* 21 no. 3-4. (2008).

something else, and the percentage of "African" helps confirm what that is. Because all of the other "types" contain alleles from the European sample, the presence of alleles from the European sample does not confirm that the suspect is white. This means that by the available criteria, it is most difficult to establish that a particular suspect is white. While the unreliability of the technology is important, the logic behind its design suggests that its priority is to establish white innocence, not white guilt, first by identifying the presence of "contaminating" nonwhite alleles, and its next immediate function is to establish black guilt.

As noted, Vincent's experiences of discrimination are highly racialized. For example, the primary manifestation of "genelism" is that "invalids" are forced to perform low-wage "unskilled" labor. Vincent initially works as a janitor with other "invalids." All who work at Gattaca, Vincent's dream job, are scrupulously tested to ensure their genetic superiority. Most telling, however, is that "invalids" are automatically presumed criminal and guilty in the universe of this film, a reality for black and some other non-white people in the present-day United States, but not for white men who look like Ethan Hawke. This is so much the case that the detectives use DNA testing simply to search for the presence of an "invalid" in the building at the time of the murder, and not necessarily for evidence that would reliably link the person to the crime scene. The motive is presumed, not determined based on evidence: the "invalid" was likely discovered to be a "borrowed ladder" by the administrator and therefore committed the murder as a way to cover their tracks.

Gattaca is set in San Rafael, California, just across the Golden Gate Bridge from Silicon Valley and San Francisco. More specifically, the film was filmed in the Marin County Civic Center. Built in 1960, the Civic Center is a popular site for the filming of science fiction films, including particular scenes in the *Star Wars* films. The Center is also home to the Marin County Courthouse, the site of the attempted jailbreak of the Soledad Brothers of the Black Panther Party and the notorious murder of one of the three "brothers," George Jackson.[138] The attempted escape came in the aftermath of the murder of three black prisoners in the Soledad Prison, where the Soledad Brothers were also being held, by prison guards. The prison is located in Salinas Valley, CA, which neighbors the Silicon Valley. After Jackson's death, the two surviving Soledad Brothers - John Clutchette and Fleeta Drumgo - were charged with the murder of a prison guard but were later acquitted of the charges when the state failed to provide sufficient evidence. In the literal backdrop of this history of racist murder, state repression, and false accusations of murder against black people who were presumed criminal, *Gattaca* presents a story of a white man who is falsely accused of committing a murder because he is characterized as genetically inferior and therefore presumed criminal. By contrast to the original, this version is presented as tragic, dystopian, and, significantly, fictional.

The "Silicon Valley," the southern half of California's Bay Area, is home to some of the most powerful tech corporations in the world, and the highest number of start-up tech companies. It is also the breeding ground for transhumanist organizations like Thiel's Humanity+. White supremacists like Richard Spencer have long insisted that the Silicon Valley is home to a surprisingly large number of closeted white supremacists. Others have disagreed, noting data that shows professional workers in the Silicon Valley tend to hold more socially progressive views than the rest of the country, on average. While that may be true, the Silicon Valley is certainly home to some of the most wealthy white supremacists, and some of the most directly involved in

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[138] Davis, Angela. "Reflections on the Black Woman's Role in the Community of Slaves." *The Black Scholar* 12, no. 6 (1981): 2-15.

the tech industry and the production of new technologies. Through the Thiel Foundation, Thiel funds research and start-up companies that seek to "extend life." His analytic company Palantir Technologies, has been sued by the Department of Labor for racial discrimination, based on data that found there was a one in one billion chance that the company's pattern of racial discrimination was due to chance.[139]

The Silicon Valley itself was developed through a series of racist and specifically anti-black practices. Black Korean War veteran Bob Hoover recalls arriving to the Silicon Valley in 1959 and being repeatedly turned down in his attempts to rent or buy a home. In 1954, William A. Bailey and his family became the first black residents of a subdivision of the Silicon Valley called the Palo Alto Gardens. This drew outrage and protests from hundreds of nearby white residents, prompting the Palo Alto Gardens Improvement Association to oust a president who was calling for "tolerance" and draft a "gentlemen's agreement" stating that all future residents must be approved by the association. Bailey's refusal to leave in the face of this pressure, with support from the NAACP, resulted in "white flight" where at least twenty percent of neighboring white residents left immediately from this neighborhood, and left East Palo Alto as the only predominantly black community in the Silicon Valley (Michelson, City of East Palo Alto Historic Resources Inventory Report, 70).

Though non-black people of color were met with some discrimination, it was typically on a much smaller scale. Suburban developer Joseph Eichler recounts selling a home to an Asian American family in Palo Alto, also in 1954, and being met with five angry white homeowners (as opposed to the 125 who demanded that the Baileys be forced to leave). Because the scale was

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[139] Dickey, Megan R. "Palantir settles racial discrimination lawsuit with the Department of Labor." *TechCrunch* (Apr 25, 2017).

much smaller, Eichler and his business partner were able to tell the five objecting white homeowners to leave[140] without producing the same kind of white flight that followed the Baileys, making at least some Asian American settlement in the Silicon Valley possible. Thus the "modernist" progressive California region that would become the heart of technological development only one or two decades later emerged as a begrudgingly and selectively inclusive white place, "tolerating" Asian residents but drawing the line at black people. Ten years later in 1964, the Romic Waste Management Facility, developed to process chemical waste from hardware production in the Silicon Valley, was constructed in East Palo Alto, the region's predominantly black area, even as black people were adamantly kept out of the parts of the Silicon Valley where the technological development took place. The facility, not surprisingly, had several "accidents" that sprayed poisons into the air and leaked cyanide and other chemicals into sewage water[141]. This history shaped the region's composition in a way that continues to have a major impact on the Silicon Valley's technological industry by determining who runs it, and thus it has an impact on the future of technology by shaping in racialized ways the kinds of technologies that will be conceptualized, prioritized, funded, and produced.

Thiel founded the *Stanford Review*, a conservative college newspaper, while he was a student at Stanford University.[142] The founder of Stanford University, Leland Stanford, was a notorious eugenicist, who for fifty years was adamantly opposed to non-white enrollment at the

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[140] Adamson, Paul, and Marty Arbunich. *Eichler: Modernism Rebuilds the American Dream*. Gibbs Smith, 2002.

[141] Cyanide Incident, November 1995, City of Palo Alto http://www.cityofpaloalto.org/civicax/filebank/documents/3695

[142] Tech entrepreneur Jeff Giesea has worked for Peter Thiel and written for the *Stanford Review*. Both Giesea and Thiel attended the pro-Trump "DeploraBall" in Washington, D.C. before the November 2016 election.

University, and non-white immigration to the region. Decades later, Peter Thiel and co-transhumanist billionaire David Sacks co-authored a piece in the *Stanford Review* called "The Case Against Affirmative Action" in which they explained that they "see very little racism" in Stanford and that affirmative action-informed admission practices are therefore unnecessary and unfair to white students. The two later co-authored a text called *The Diversity Myth: Multiculturalism and Political Intolerance on Campus*[143] in which they continue railing against affirmative action as "dumbed down admissions criteria" and assert that the "liberal multicultural agenda," rather than teaching students more, actually teaches them less by restricting their expression and enforces anti-Western "zealotry" within campus curricula. He describes an incident in which two white freshmen, Gus Heldt and Ben Dugan, harassed a black sophomore, B.J. Kerr, following a conversation in which Kerr suggested Beethoven might have been black. The two freshmen made a blackface caricature out of an illustration of Beethoven and posted it on Kerr's door, and then proceeded to attend several events by Ujamaa (the black dormitory) in which they derided black students and offered an "explanation": they were trying to offer an "educational" moment for black students who, they were "disturbed to find," cared too much about race. Students demanded that they be removed from the dormitory and they were. As Thiel and Sacks describe the incident, this is an example of a "witch hunt" involving "housing discrimination" that favored a "privileged multicultural group" that had simply "overreacted" (43). Another incident involved a student who was "forced" to remove a Confederate flag or be kicked out of housing. On this basis, the two conclude that "hapless innocents get thrown out of housing, lose their jobs because of 'insensitivity'" (186).

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[143] Thiel, Peter and David Sacks. *The Diversity Myth: Multiculturalism and Political Intolerance on Campus. Independent Institute*, 1998.

The irony of portraying black people as the agents of housing discrimination against "innocent" white victims in the Silicon Valley is lost on the two billionaire authors, products of this long-standing affirmative action for the region's white residents. After a lifetime of benefitting from legacies of colonialism and antiblackness, everywhere from Germany to Namibia to Stanford, Thiel rejects policies that might level the playing field as unfair to him (and other white men), continuing to push for the long-standing practice of deliberately excluding black people from Stanford, the Silicon Valley, and the tech industry. In her forward to their text, "feminist" historian turned-conservative Elizabeth Fox-Genovese writes that "at Stanford and beyond, the campaign to impose 'multiculturalism' amounts to nothing less than a war on Western civilization and, beyond it, a war on the very idea of civilization." She concludes that, "This engaging saga of Stanford's experiment in multiculturalism compellingly draws readers into the nightmare world of *social engineering* in practice" (emphasis added). The "nightmare world" presented by the transhumanist billionaires, it turns out, is not all that different from *Gattaca*'s nightmare world of social engineering qua genetic engineering, the shared nightmare being the displacement of white supremacy. The fantasy, however little basis it has in reality, is that white people might one day have to live or are in the process of being forced to live as black people already do.

V.

Bestselling Israeli author Yuval Noah Harari's 2015 novel *Homo Deus: A Brief History of Tomorrow* offers a more ambivalent take on transhumanism, glorifying the search for immortality, happiness, and power while nonetheless predicting and warning of the perils of a technologically enhanced Homo Deus (or Human God) that might render "ordinary" humanity meaningless. An interview-based editorial about Harari and his novel, "Upgrading humans into GODS will be the next 'billion dollar industry' expert claims," appeared in the UK's *Daily Mail*. Based on Harari's comments, the piece argues, much like *Gattaca*, that new technologies will allow people to "upgrade" themselves into gods and that "because not everyone will be able to experience the upgrade, due to costs, there will be a divide that could spark 'old racist ideologies' - but this time, differences will be 'engineered and manufactured'." Harari explains what the transformation into divinity will entail as follows: "humans will acquire abilities that in the past were considered divine, such as eternal youth, mind reading, and the ability to engineer life." Because these changes will be available only to some and will be accompanied by technological changes that render many of today's current professions obsolete, the world will also, he predicts, see the rise of a "useless class."

Projections that people will "one day" (and not already) possess characteristics previously thought possible only for gods necessarily ignore the technologies that have made it possible, for example, to "bring people back from the dead" by resuscitating them, to "be in two places at the same time" via Skype, to "read people's minds" with brain imaging technology thought to reveal information about psychological states, to alter minds through drugs or surgery, to control human conception through fertility treatments, or to create life itself by cloning a sheep. Projections that new technologies will render portions of humanity as "useless" necessarily ignore the technological developments that have already rendered portions of the population - disproportionately poor and black - as "surplus" populations in the present labor market, leading to their warehousing in prisons en masse[144]. The assumption that racist divides

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[144] Gilmore, Ruth Wilson. *Golden Gulag: Prisons, Surplus, Crisis, and Opposition in Globalizing California*. Vol. 21. Univ of California Press, 2007.

are “old” and somehow gone and that the new divide will be unrelated ignores the extent to which all of these technologies have been and continue to be racialized and their costs and benefits have been distributed accordingly. A new study published in the *Journal of the American Medical Association*[145] finds that the “top one percent” wealthiest people live on average 10-15 years longer than everyone else. Duke University Professor William Darity[146] found that “*nearly all”* or more than 96% of families that fall within the category of “top one percent” wealthiest families in the U.S. are white, while just over one percent of families in this category are black. Earlier studies have found extreme race-based disparities in life expectancy, with the starkest disparity between white and black people, a disparity that has increased since the 1980s (CDC 2013). This disparity is compounded by education levels such that the most highly educated white people live 10-15 years longer than the least-educated black people. Wealth disparities further compound this disparity, particularly since the life expectancy of the top one percent has increased by 2-3 years since just 2001 while it has remained steady for everyone else. Finance analyst Yves Smith explains that “a three-year gain in average lifespan might not, at first glance, seem earth-shakingly significant. But consider this: If doctors could by some miracle suddenly cure all cancer, federal health officials tell us the average overall American life expectancy would increase by just three years. In other words, as MIT’s Michael Stepner puts it, the changes in life expectancy we’ve witnessed over the last 15 years rank as ‘the equivalent of the richest

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[145] Chetty, Raj, Michael Stepner, Sarah Abraham, Shelby Lin, Benjamin Scuderi, Nicholas Turner, Augustin Bergeron, and David Cutler. “The association between income and life expectancy in the United States, 2001-2014.” *JAMA* 315, no. 16 (2016): 1750-1766.

[146] Darity Jr, William, Darrick Hamilton, Mark Paul, Alan Aja, Anne Price, Antonio Moore, and Caterina Chiopris. “What We Get Wrong About Closing the Racial Wealth Gap.” *Samuel DuBois Cook Center on Social Equity* (2018).

Americans winning the war on cancer'."[147] Wealthy white people are already living longer, more comfortable, more technologically-enhanced lives than most other people, at the particular expense of poor, black people, in the present and throughout the recent past.

Though Harari's novel predicts a future that has, ostensibly, yet to arrive, it uses ethical dilemmas of the past as the basis for its bleaker predictions. Like any science fiction novel, its portrait of the future has meaning and resonates with an audience only in light of the elements of that future that have already arrived. And transhumanists themselves sell their project as a revised version of earlier ideas and experiences: "humanity 2.0,"[148] "human 2.0,"[149] or "eugenics 2.0" (Fuller, Lipinska). They seek a *return* to the original "peaceful" potentially-progressive (by their account) ideas of Nazi national socialism, and to moments in scientific discovery *prior* to what they understand as too-restrictive ethics guidelines. This proposal for technological development falls in line with Richard Grusin's[150] observation that digital "media were new precisely because of the ways in which they refashioned older media" and, on this basis, coin the term "'remediation' as the double logic according to which media (particularly but not exclusively digital media) refashion prior media forms" (17). Because technological development takes place gradually, based on revised versions of earlier forms of technology and not on complete and absolute breaks from past models or unprecedented discoveries, any technology-enabled future would necessarily entail elements of the current world, and related

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[147] Yves Smith, "Inequality Kills: Top 1% Lives 15 Years Longer Than the Poorest." *Naked Capitalism* May 3, 2016.

[148] Fuller, Steve. *Humanity 2.0: What it Means to be Human Past, Present and Future*. Springer, 2011.

[149] Eppinette, Matthew. "Human 2.0: Transhumanism as a cultural trend." *Everyday Theology: How to Read Cultural Texts and Interpret Trends* (2007): 191-207.

[150] Grusin, Richard A. "Premediation." *Criticism* 46, No. 1, Winter 2004: 17-39.

divisions would reflect those that already exist and are structured along technological lines. Indeed, existing hierarchies structure and make possible the technological development itself. This projection of the future would fall in line with Grusin's revision of the concept of remediation in the form of "another logic, a logic of premediation in which the future has always already been premediated." As Grusin explains, "Although futuristic technologies might promise to bypass mediation, they don't" (18). There will be no clear point at which such technology will definitively exist in ways in previously did not, an absolute break from all previous technology. Therefore the best, and only, way to understand what the future of technology will entail is to understand what it has entailed and currently entails. This is true not just of the technology itself, but the social environments that structure everything from the conceptualization, funding, production, access, and outcomes of that technology. Accordingly, in contrast to both its enthusiastic proponents and its panicked detractors, I understand transhumanism as an advancement and continuation of an existing project that has, for centuries, extended and enhanced the lives, disproportionately, of wealthy, white people at the expense of, disproportionately, poor, black people. The project looks, perhaps, to expedite this process and make it more efficient, in part by *returning* to moments when it faced less resistance. Yet transhumanism will not suddenly and profoundly reorganize the world such that it is unrecognizable. *That* might be its true horror.

The real debate here is about whether, how, and to what extent whiteness should be expansive in its relationship to disability. Does "eliminating" or forcefully rehabilitating all disability guarantee the strongest (white) race (transhumanism)? Or does doing so rob the (white) race of the diversity of embodiment and experience, and thus perspective, that disability provides, unfairly depriving some white people of the opportunity to realize their full potential through strict social limitations and self-fulfilling assumptions about their capacities (as in *Gattaca*)? Blackness figures in both fantasies only to highlight such a nightmare, as the naturally and unproblematically excluded, subjugated, and "inferior" position that illustrates what whiteness should not, cannot be, and must be prevented from becoming at all costs (i.e., socially and physically "inferior" for the transhumanists, or socially and politically subjugated for its critics). The fantasy that everyone will be "rehabilitated," able-bodied, or immortal, whether one aspires to it or warns of it and fears it, necessarily excludes some people, those who do not have access to the resources and technology to realize it and those at whose expense the technologies are developed. The hope of transhumanism is that it will rescue whiteness (read: the human race) from association with biological vulnerability and inferiority natural to people who do not unquestioningly belong in the human race. The horror of transhumanism, for some, is that disability would be characterized as rendering certain people more proximal to this naturalized and racialized inferiority and thus have to be eliminated (and/or subjugated) in pursuit of this project.

The film represents a dystopian fantasy through the eyes of a "disabled" hero who exposes the horrific possibility, essentially, that transhumanism will force disabled people to live like black people already do. The loosely defined group of white people, diverse in physical ability, who are represented by Vincent/Jerome should not, the film argues, be banned from their desired professions, unable to realize their dreams, restricted in their employment opportunities or forced to perform menial labor. They should not be more likely to have a heart condition and suffer from premature death. They should not be presumed criminal. They should not be kept from participating in the production of scientific inquiry because of assumptions about their intellectual capacity. They should not be told that they are genetically inferior. And they should not be subjected to any of this because someone else should. So the fear of the transhumanist project is that, viewed dystopically, it will extend this lived reality to deserving white disabled people. And this fantasy is what exposes the lie of the universalism of both projects.

Epilogue: ‘This Isn’t the South Bronx’

> “If a society permits one portion of its citizenry to be menaced or destroyed, then, very soon, no one in that society is safe. The forces thus released in the people can never be held in check, but run their devouring course, destroying the very foundations which it was imagined they would save.”
>
> James Baldwin, “Nothing Personal” (1964)

I.

By way of this epilogue, I conclude the dissertation with a meditation on the pressing issue of the contemporary opioid epidemic, contrasting the discourses and legal and political responses surrounding it to the cocaine epidemic of the 1980s. I use this case study to tie together several main themes from my dissertation: that the recognition of disability is not based incontrovertibly on particular conditions or their symptoms, but on the subjects who live with them; that the rehabilitation of white disability is based on a presumption of normativity and ability; that corporate investment in technological and pharmocological forms of rehabilitation that promise to eliminate disability in the future are structured by racist discourses and material realities; and finally, that the legal and medical recognition of disability is not *only* a form of coercive government, but also allows the provision of care, resources, and protection to which not all people have access, regardless of whether they live with conditions that might be characterized as disabilities.

Throughout this dissertation I have dwelled with the ways that racism, defined by geographer Ruth Wilson Gilmore as “state-sanctioned and/or extra-legal production and exploitation of group-differentiated vulnerabilities to premature death” (261), disrupts the social legibility and legal and medical recognition of disability, as well as the “return” to normativity that surrounds its government. In the first chapter, I showed that in the aftermath of World War II, the "rehabilitative turn" took two different trajectories for white and black populations: where for the former there was a compulsion toward able-bodied normativity, for the latter this compulsion quickly became a state-sanctioned medical experiment that quite directly and openly exploited "group-differentiated vulnerabilities to premature death." In the second chapter, I turned to the War on Drugs of the 1980s to examine how its racist discourses of intrinsic deviance pathologized black mothers and black children, and informed the categorization of black children as "special needs" in the foster care system to promote transracial adoption as a supposed solution to these failures. Rather than characterizing the problem as related to sociopolitical conditions, or even a personal disability or medical condition (drug use) that might be rehabilitated, the discourses surrounding changes to the foster care system instead characterized the problem as a personal moral failing and justified punitive measures on this basis. In the third chapter, I asked, once a white subject has been properly marked as disabled, whose lives and labor are presumed available to be sacrificed in service of rehabilitation? To address this question, I contextualized popular representations of disability that rely on the character of a black caretaker within the "companionship services" exemption to the Federal Labor Standards Act. Finally, in the fourth chapter, I turned my attention to the transhumanist movement to address how the presumption of naturalized black suffering and intrinsic deviance (will) continue to influence efforts to eliminate disability, as well as disability rights opposition to these efforts. Despite the rhetoric of universalism on both sides of the issue, the costs and benefits of the development of rehabilitative technologies has and will continue to be distributed unevenly.

Rather than using the epilogue to restate or summarize these disparate but related case studies, I would instead like to close by briefly considering a moment of contemporary immediacy that has presented itself for an analysis on the terms of my argument. This case study underscores how substance use disorder as an emergent and increasingly recognized disability achieves its recognition against a history (and present) that characterizes drug use amongst poor black people as a form of intrinsic deviance that should garner contempt and punishment. It illustrates that the punitive War on Drugs in the 1980s, which targeted inner-city black communities in particular, ostensibly as a response to the crack cocaine epidemic, was not the inevitable response to the social problems it claimed to address; rather, the epidemic was a justification for the punitive measures that supposedly stemmed from it. Though the study does not restate the arguments of my chapters, it does combine a number of their key claims. It shows that the legal and medical responses to substance use disorder among black and white people have taken and continue to take very different trajectories. It shows that where substance use disorder is understood, legally, medically, and socially as a moral failing and a form of intrinsic deviance when it befalls black communities, it is understood increasingly as a tragic physiological condition that warrants sympathy and rehabilitation when it targets white communities. It illustrates that the punitive measures that have been levied at black communities on this basis are figured as a form of necessary sacrifice from which we can now learn, eliding the ways these punitive measures continue into the present. Finally, it demonstrates that the development of rehabilitative technologies is shaped by these narratives. I turn to this example so as to demonstrate the potential forward motion of this dissertation and my own eagerness to use these arguments as a way critically to engage with representational and policy-based issues that are of dire consequence.

II.

"Shootings in broad daylight, drug deals in abandoned buildings, mothers overdosing on heroin: This isn't the South Bronx in the 1980s; it's Trumbull County, Ohio in 2017. This area was ground zero of Trump's Rust Belt Rebellion and it's easy to see why. The American Heartland is becoming the new inner city." CNN journalist Fareed Zakaria offers this commentary in the 2017 documentary film, *Why Trump Won*. It is the central component of his account of billionaire real estate mogul Donald Trump's popularity with white working class voters, including many who previously voted as Democrats for President Barack Obama in 2008 and 2012. With the ominous words "ground zero," the documentary cuts to a scene from Trump's 2016 campaign speech in Columbus, Ohio in which he declares: "The American dream is dead…. We're losing our jobs. We're losing our factories." What remains implicit in Zakaria's voiceover is made explicit in a follow-up comment by writer George Packer of *The New Yorker*, who states plainly, "You began to see two generations on public assistance, fathers missing, the things I was used to hearing about the black inner city were true of the white small town in rural areas." This narrative is interspersed with visual imagery of overgrown greenery, aging houses flying American flags, idle railroad tracks and abandoned factories, and a billboard about drug overdose featuring a prostrate white male victim. In the background of the audio track are recordings of 9-1-1 calls from panicked relatives of overdose victims. One poignant call reporting a murder concludes with a woman's voice crying out, "Please! I have kids!"

This popular rhetorical strategy is especially glaring to anyone familiar with Kimberle Crenshaw's well known theorization of intersectionality. Crenshaw (1991) points out that domestic violence awareness campaigns often begin by citing, and then refuting, the assumption that it is a problem exclusive to black women and other women of color (which is also to say a crime committed by black men and other men of color). This move is used to add shock value to the campaign and to inspire support for organizing efforts, but it achieves these goals by relying on, and reinforcing, commonsense understandings of where and for whom violence and suffering is, and is not, commonplace and acceptable, and then using these assumptions to stress the novelty and magnitude of the problem. When Trump says "we are losing...," he is not, of course, implying that he personally has lost his job. The predominantly white audience nevertheless understands him to be invoking a presumptively white collectivity whose jobs are, through immigration and affirmative action policy, being wrongfully taken by non-white people within the United States and, through business outsourcing prompted by taxation and regulation, in other parts of the world as well. "We" should not have problems with substance use and street violence, runs the logic, because "we" should have jobs that pay the bills and keep our communities safe.

This conclusion takes up the issue of "substance use disorder"[151] and argues that the discourse surrounding the 1980s crack cocaine epidemic and the present-day opioid epidemic rely on similarly racialized rhetoric, and its implications regarding pain and suffering, safety and employment to establish substance use disorder as a (white) disability and not a (black) criminal liability as it was understood throughout the Reagan-Bush era War on Drugs. These racially disparate characterizations of substance use disorder help to shape and, in turn, are perpetuated by the respective technologies of rehabilitation and criminalization developed in response. The relationship between disability and substance use disorder is worth considering, in part, because disabled people who suffer from chronic pain or who have co-occurring physical or psychological disabilities are, according to the US Department of Health and Human Services, two to four more times likely to develop addictions to a variety of substances than the general population. More to the point, the debate surrounding the categorization of substance use disorder is a prominent case study in how state and civil society understand and relate to an emergent disability through the deployment of law and technology.

III.

A sizable number of people struggling with substance use disorder have sought legal protection, with varying degrees of success, under the 1990 Americans with Disabilities Act

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[151] The 2013 fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V) lists "substance use disorder," as a mental disorder. In contrast to the fourth edition published in 2000, it combines what were previously two disorders - "substance abuse" and "substance dependence" - and eliminates "recurrent legal problems" from the diagnostic criteria. The single disorder now ranges in severity from "mild" to "severe." The terms "dependence" and "abuse" are contested because of disagreements over their precise definitions, but dependence is generally defined in relation to tolerance and withdrawal, and addiction is generally taken to be the most extreme form of substance use disorder, the form that constitutes a medical disease (which is increasingly conceptualized as chronic). By these definitions, "use," "dependence," and "addiction" are not synonymous because not all users are dependent, and not all who are dependent are addicted. My use of these terms in this essay reflects my attempt to be precise about the population at whom legal or medical intervention is directed.

(ADA). The text of the ADA, drafted not coincidentally during the height of the War on Drugs, states that protected disability status does not extend to "any employee or applicant who is currently engaging in the illegal use of drugs," but does extend to any former user who "has successfully completed a supervised drug rehabilitation program and is no longer engaging in the illegal use of drugs, or has otherwise been rehabilitated successfully and is no longer engaging in such use." It also maintains an employer's right to enforce the prior Drug-Free Workplace Act of 1988, and to prohibit the use of all illicit drugs and alcohol at the workplace (Sec. 12114). Thus, criminal activity would seem to stand in direct opposition to disability status in cases involving substance use disorder, and vice versa. Herein we see some of the impetus to establish disability status in contradistinction to criminal standing. Given the notorious racial politics of the drug warriors, we can infer, rather soundly, that the institutionalization of protections under ADA here is shot through with anxiety about establishing sufficient distance from an image and idea of racial blackness always already associated with criminality.

While alcohol use disorder is recognized as a protected disability as long as all other ADA enforcement criteria are met, the "protected disability" status of a person with substance use disorder relating to the use of any illegal substances hinges on whether that person has been successfully rehabilitated, and is shaped by the relationship between the substance and the criminalization of its imagined users. As lawsuits involving such cases have shown, "successful rehabilitation" does not follow simply from the completion of a rehabilitation treatment program. Even if such a program has been completed, the person may still be considered a "current user" if it is believed that they still suffer from dependence and/or are likely to relapse (Foreman 2000). Such determination is significantly more discretionary on the part of the court and thus vulnerable to racial and other bias. To my knowledge, there is no comprehensive data on the role of race in determining success in these cases, but available data shows that in 1999, about 3.5 percent of all claims filed to the U.S. Equal Employment Opportunity Commission regarding ADA violations involved addictions to alcohol or other drugs. While both the number of people whose claims were successful and the amount of monetary compensation they were awarded has remained steady for alcohol use disorder since that time, both the number of successful lawsuits involving "drug addiction" and the awarded monetary compensation have gone up considerably during the period since 2008 when the opioid crisis first gained publicity and drug policy, in turn, became more forgiving (EEOC 2016). This suggests that as illegal drug use becomes less associated with blackness, and by extension with criminality, claims for protection and relief become more successful.

In 2014, Theodore Cicero, Professor of Psychiatry at Washington University in St. Louis, led a study entitled "The Changing Face of Heroin Use in the United States," which surveyed patients undergoing treatment for opioid dependence at one of the 150 substance use treatment facilities connected to the Survey of Key Informants' Patients (SKIP) Program. Patients were approached by treatment center staff for participation in the study. The study found that "whites and nonwhites were equally represented in those initiating use prior to the 1980s, but nearly 90% of respondents who began use in the last decade were white" (Cicero). Based on this finding they confirm "a number of mainstream media reports that the abuse of heroin has migrated from low-income urban areas with large minority populations to more affluent suburban and rural areas with primarily white populations." They offer a number of explanations for this trend, including its relationship to prescription opioids. People who develop addictions to prescription opioids, they note, will often drift into the use of heroin and other illegal opioids because they are cheaper and more accessible.

Cicero concedes that the study leaves unanswered questions about the extent to which this sample is representative of those who use heroin "recreationally," and that the population may be selective because "many factors influence the decision to enter treatment, such as family or court pressures and financial ability." The study further fueled the kinds of "mainstream media reports" that were alleged to have been confirmed by these findings, with headlines like "Heroin Kills More White People Than Anyone Else" (Owen 2016). While the 2014 study does suggest that the opioid epidemic has disproportionately affected white users, it does not address the possibility that the findings may have been skewed not only by barriers to *seeking* treatment but by the other outcome that frequently befalls people with substance use disorder: incarceration. The U.S. Sentencing Commission's 2016 *Sourcebook of Federal Sentencing Statistics* shows that although white people are slightly more likely to use drugs than black people or Latinos and that all groups deal drugs at about the same rate, blacks and Latinos are still significantly more likely to be prosecuted for nearly every type of drug crime. Specifically, for heroin cases, 40% of known offenders were black and 42% were "non-black Hispanic," with only 16% white.[152] A 2016 American Civil Liberties Union report shows that even at the level of drug *possession*, black people are arrested at higher rates in every state, on average 2.5 times more often than their white counterparts. Such patterns might be skewing data on opioid use too, particularly if that data is based in treatment centers.

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[152] For reference, these groups constitute 13, 17, and 77 percent of the U.S. population, respectively.

While general drug use rates have been roughly even across racial groups, crack cocaine use in particular affected black working-class communities disproportionately for a variety of reasons, including its greater affordability and accessibility relative to powder cocaine. At the height of the crack cocaine epidemic, 37 percent of users were black against 13 percent of the general population. However, one 1995 study (Burston) found that when asked to picture a drug addict, without specifying a substance, 95 percent of people from all racial backgrounds pictured a black person. So while the crack cocaine epidemic did affect black communities disproportionately and the opioid epidemic has so far disproportionately affected white communities, the public *perception* of each epidemic is highly biased, at levels far exceeding any disproportion. Thus, the racially disparate discourse about the two drug epidemics are based not in an analysis of the typical user of each substance, but in stereotypical public perceptions of the relationship between race and drug use. Likewise, the *general* political and medical responses to the epidemics target the imagined typical user, which in the former case is black and in the latter case is white. And within both epidemics, black and other non-white people are significantly more likely to be incarcerated whereas white people are more likely to be offered or ordered to treatment.

Researchers have suggested that the disparity in the prescription of pain medication might account for some of the "disproportionate burden of opioid abuse among whites." Studies have long shown that black patients are about half as likely to receive pain medication as whites for the same ailments (Singhal 2016) and that about half of medical students still believe black people feel less pain than white people (Hoffman 2015). This deliberate failure to recognize black pain and the withholding of treatment and medical services from black people may have, ironically, insulated black communities from the *initial* manifestations of the opioid crisis associated with prescription painkillers. However, now that the epidemic has shifted to heroin and synthetic opioids, like the more potent and lethal fentanyl, overdose deaths are rising in similar rates among both black and white users (CDC). And, if history is any guide, the same factors that provided for the short-term insulation of black communities from the current epidemic will likely result in relatively lower treatment rates and higher incarceration rates among black people with opioid dependence in the middle and long terms.

IV.

The 1981 Military Cooperation with Civilian Law Enforcement Agencies Act initiated the militarization of state and local police forces across the US, granting them access to weapons, equipment, and surveillance technologies that would be heavily utilized in the War on Drugs. The 1986 Anti-Drug Abuse Act, signed into law by President Reagan during his second term of office, focused squarely on greater criminalization, instituting the first mandatory minimum sentences for drug-related criminal charges. The sentencing guidelines were much harsher for crack cocaine than for powder cocaine, the latter more popular in white communities: the distribution of 5 grams of the former carried the same mandatory minimum sentence as the distribution of 500 grams of the latter. The 1986 Drug-Free Workplace Act further mandated that workplaces enforce drug laws and encouraged drug testing for employees. Together these laws fueled unprecedented mass incarceration, the wholesale criminalization of black communities, and the development of technologies of policing and confinement, rather than treatment, in response to the cocaine epidemic.

While the development of technologies of criminalization was thriving, the development of treatment options for cocaine addiction was sorely lacking. The limited availability of pharmacological options to address cocaine addiction was shaped by the political climate. One 1995 Institute of Medicine study sought to identify barriers to the development of medication to treat cocaine addiction (Goodman 1997). Among the key market barriers this study confirmed were "patient population perceived as difficult to study," "varied state or local regulations," "limited number of narcotic treatment programs," "stigma of drug-abuse," "bias by some treatment providers against pharmacologic options," and "uncertain treatment financing." All of these barriers relate to racist ideology equating drug addiction with criminality, lax morality, and bad behavior in a population uninterested in its own well-being, as well as to a state response that, informed by such ideology, prioritized containment and incapacitation over treatment. Representatives from several pharmaceutical companies stressed "potential patient compliance problems and limited access to patients" and others noted that treatment centers were staffed by people who "tended to oppose the use of drugs to treat substance abuse, which such staff regarded as 'behavioral' conditions, thereby further restricting the potential sale of these drugs." In line with this thinking, the predominant therapies developed to treat cocaine addiction are cognitive-behavioral therapies.

The 1989 *New York Times* editorial, "Experts Finding New Hope on Treating Crack Addicts," begins with this declaration: "Drug experts now believe that the extreme difficulties they face in treating crack addiction stem far more from the setting and circumstances of the users than the biochemical reaction the drug produces" (Kolata). The *Times* interviewed Dr. Herbert Kleber, a Yale University Professor of Psychiatry and Deputy Director at the Office of

National Drug Control Policy, who noted that "addiction can be treated," but, he stressed, "the key is that the addict must be given a place in family and social structures *where they may never have been before*" (emphasis added). As Kleber put it more succinctly, "habilitation more than rehabilitation." The difference between habilitation and rehabilitation is that the former does not assume a prior normalcy. In other words, habilitation claims to teach fundamental skills that the patient never enjoyed, rather than restoring a former capability that was lost when the disability was acquired. Because this absence of prior skills is imagined to take place at the level of "social and family structures," habilitation here assumes something more like a state prior to culture or civilization as such. And because this absence is located in an entire population, it troubles the concept of "norm" upon which Foucault's theories are based, premised as it is on statistical group measures. Accordingly, the *population* is marked as deviant, not individuals within it. Given this alleged absence of family and social structures, a vacuum in which black people are not born and raised by kith and kin but simply emerge anonymous and anomic, to where can the patient who has completed treatment be expected to return?

The predominant forms of treatment for cocaine addiction have followed from this theoretical basis. They have tended to de-emphasize any biochemical processes of addiction and stress behavioral change. While research is now underway to develop pharmacological treatments for cocaine use, and medical treatments for other ailments are now sometimes used as part of the treatment for cocaine addiction, no medication has been developed specifically for that purpose, much less received approval by the FDA[153]. The most common therapies for cocaine addiction are contingency management, which provides incentives for abstinence in the

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[153] Medications developed to treat opioid addiction or other ailments have sometimes been shown to be effective for cocaine addiction and subsequently used for this purpose (see, for example, Shen 2017).

form of points, vouchers, or prizes; and cognitive behavioral therapy (CBT), which teaches patients to recognize triggers and situations that lead to relapse and thereby to avoid them. A computerized version of CBT, called CBT4CBT, is even used in some treatment facilities to implement treatment with games, quizzes, and activities.

Rather than assuming behavioral treatment of this sort departs from the violence of criminalization in pursuit of biopolitical normalization, I suggest that these therapies reenact what Saidiya Hartman terms "the burdened individuality of freedom" in her analysis of post-emancipation "practical handbooks written for the emancipated in order to assist them in the transition from slavery to freedom" (128). Here, the presumptively black individual bears the impossible responsibility of "proving" fitness for freedom, even as the state-sanctioned racist violence of segregation and inequality, policing and imprisonment bears down upon them. With neither substantive socio-economic restructuring nor even significant medical intervention, "habilitation" measures operate similarly to Reconstruction era handbooks. They do not negate the structural violence of racial domination but rather recite the terms of a program of self-discipline that is designed to fail, all while shifting responsibility for that failure, and the series of failures for which it is a proxy, away from state and civil society and onto its principal victims. Thus the punitive strategy of "policing the crisis" in black communities becomes justified as the fateful result of failed self-discipline, as though punishment were somehow both inevitable and elective. By this account, CBT4CBT, random drug tests, surveillance drones, and assault rifles all function as tools for different aspects of the same project: enacting the spectacular racial violence of old-school sovereign power supplemented by the precision and pervasiveness of modern disciplinary power.

V.

In October 2017, Donald Trump gave a brief speech declaring the opioid crisis a public health crisis, describing it, with characteristic hyperbole, as "the worst drug crisis in American history and even, if you really think about it, world history." But Trump is far from the only politician to address the issue head on. Indeed, the Obama Administration had already signed into law the first major federal legislation addressing the opioid crisis in July 2016, an outgrowth of the fact that both Democrats and Republicans have agreed in recent years (if for different reasons) on the need to promote treatment initiatives and decriminalization of low-level drug use. And presidential hopefuls addressed the crisis throughout the 2016 election year, often referencing friends and family who have struggled with addiction. In contrast to the portrayal of crack addicts as isolated and kinless, public discourse about opioid addicts have stressed the centrality of social ties. Stories of close personal experience have been invoked by politicians in both major political parties to motivate support for the decriminalization of drug use and the treatment of drug addiction as a public health problem.

Nearly half a dozen candidates from the 2016 Republican primaries, for instance, relayed personal stories about kin or colleagues: Donald Trump talked about his brother's struggle with alcoholism; Carly Fiorina spoke of her step-daughter struggling with addiction before passing away in 2009; Jeb Bush mentioned his daughter's addiction to a variety of substances; Chris Christie shared a tale about a law school colleague; and Ted Cruz revealed that his sister died of a drug overdose in 2011. These stories all sought to legitimize the pain and suffering of drug use as reported by healthy white (usually male) authority figures who have the social standing to bear witness. They also attempt to make the candidates appear relatable and trustworthy to a voter base for whom such problems have become a central concern. Through these stories, candidates attest that drug addiction is a disabling condition that should be treated with compassion and support, not a criminal liability that should be prosecuted to the fullest extent of the law.

Other candidates with less direct personal experience, like Rick Perry, concurred. In a January 2015 speech Perry stated, “Over the years, I came to see our approach to nonviolent drug offenders as flawed,” praising the bipartisan “leadership of Democrats and Republicans” for prompting local drug courts to act as “diversion programs that treat alcoholism and drug addiction as a disease and not a moral failing.” In March 2016, Bernie Sanders said during a CNN town hall that “all over this country, a massive crisis in heroin addiction and overdosing, and opiate addiction as well” was forcing lawmakers “to rethink the so-called War on Drugs which has been a failure” and “to look at substance abuse and addiction as a health issue, not a criminal issue.” In a Ohio campaign speech in October 2016, Hillary Clinton suggested she would be the best candidate for anyone who believes “we should do more to stop the opioid epidemic that is destroying lives and communities [and] that we should do more to help with mental health and make sure that people get the treatment that they deserve.”

In this light, it seems unlikely that the success of Trump’s campaign could have depended, as Zakaria suggested, on the fact that he was the only candidate, much less the most credible one, addressing these critical issues. Rather, his success among audiences most affected by the opioid crisis to date may have had more to do with the fact that he played up, more explicitly than anyone else, the feelings of white racial resentment and hostility implied in the rhetorical strategy of *Why Trump Won* - namely, that *we* are not supposed to have *their* problems, white communities are not supposed to be afflicted by problems assumed to be endemic to black communities. "This isn't the South Bronx in the 1980s." This sense that the crisis is unexpected and undeserved for *us*, that it should not have happened *here*, establishes an *a priori* normalcy for white communities (starkly contrasted with an a priori abnormalcy for black communities), adding legitimacy to the push to label opioid dependence as a disability (rather than a liability) and the epidemic as a public health (rather than a public safety) crisis.

Please! I have kids! The mother-child bond is used centrally in the CNN documentary, and no less elsewhere in the discourse surrounding the opioid epidemic, to establish the fact that the afflicted have relations of kinship, not just within their immediate families but within their broader communities as well. This connectedness renders those ravaged by the epidemic familiar and sympathetic, even to audiences that may not be personally affected. "These are beautiful babies," said President Trump about children born to opioid addicted mothers in his 2017 speech, presumably nothing like the "race of subhuman drones"[154] born during the crack cocaine epidemic. Current federal guidelines suggest that women who use opioids be given treatment while they are pregnant rather than being arrested, as Dorothy Roberts (1997) shows black women generally were for crack cocaine use in previous decades. Federal guidelines also recommend that infants and toddlers especially not be separated from opioid dependent mothers, because treatment is more likely to be completed and relapse less likely when mothers are allowed to remain with their children (SAMHSA 2016). This recommendation breaks sharply

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[154] In a 1989 article for *The New Republic* entitled, "'Brave New World': Newborns Permanently Damaged By Cocaine," psychiatrist and conservative commentator Charles Krauthammer describes babies born to crack-addicted mothers as "a race of (sub)human drones" who will live "a life of certain suffering, of probable deviance, of permanent inferiority." He continues, "This is not stuff that Head Start can fix. This is permanent brain damage," he asserted, inaccurately, estimating that the condition afflicts between "5 percent or 15 percent of the black community." He concludes, morbidly, "the dead babies may be the lucky ones."

from decades of social policy aimed specifically at the separation of black mothers from their children, motivated and justified by the policing of crack cocaine use (Roberts 2011). Metaphors of other disabilities are often used to stress the medical status of the new substance use disorder as a health condition and to highlight the importance of using caution before separating families. As one publication posed the problem, "When is an overdosing parent a danger to his or her children? The answer is rife with complexities, complications—and most of all—severe second-guessing should the agency's call turn out to be wrong and a child suffers harm. For starters, opioid addiction is treated as a disease. Would one remove a child from a diabetic parent who collapses from insulin shock, for example" (Luciew 2017)? The issue of maternal drug use has suddenly become complicated, and the question is posed as though there is no available historical reference.

In 2014, the United States Sentencing Commission voted unanimously to reduce federal drug sentencing guidelines. The vote was supported by all members of Congress, Republicans and Democrats alike. Since then more than thirty states have moved to loosen drug sentencing laws too, classifying low-level drug possession as a misdemeanor rather than a felony and relaxing or removing mandatory minimum sentences.[155] Many states have instituted "drug courts" to oversee treatment efforts as an alternative to incarceration for those charged with such misdemeanors. In 2016, President Obama signed the Comprehensive Addiction and Recovery Act (CARA) into law, "the first major federal addiction legislation in 40 years and the most comprehensive effort undertaken to address the opioid epidemic" to that point (Public Law

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[155] Though a few states like Florida and West Virginia have passed tougher drug sentencing laws since this time and Attorney General Jeff Sessions continues to push for "tough on crime" policies from the War on Drugs era, this has not stemmed the general tide of decriminalization, which continues to enjoy support from the majority of political representatives across party lines.

114-198). It identified “six pillars” for a “coordinated response”: prevention, treatment, recovery, law enforcement, criminal justice reform, and overdose reversal. It provided funding for more “medication-assisted treatment” and for the development of new “evidence-based” rehabilitation programs. By pushing for criminal justice reform alongside more general collaboration with treatment centers and first responders trained to use naloxone (a drug that rapidly reverses opioid overdose), the new law effectively decriminalizes low-level drug use and addiction. The only reference the legislation makes to policing that is not pegged to these ameliorative goals involves “enhancing law enforcement efforts to combat illegal distribution of opioids,” which, as the 2016 data reveals, involves extreme racial disparities rivaling those that have characterized the entire history of the War on Drugs.

One program in particular has led the way in implementing treatment through law enforcement. Under the “Angel Program,” launched in the small coastal town of Gloucester, MA in 2015, police do not arrest people who are caught in possession of drugs, but instead take them to local hospitals where volunteers, the titular “angels,” facilitate access to treatment programs. A 2016 *New England Journal of Medicine* report on the program finds that despite some barriers, the hundreds of self-referrals to police in the first year of the program suggest that people are willing to seek treatment through police departments if they do not fear prosecution. Additionally, 153 police departments in twenty-eight states have since adopted the model (Schiff 2016). As in Trumbull County, Ohio, more than 90 percent of the population of Gloucester is white. After Trump declared the opioid epidemic a public health crisis, National Dislocated Worker Grants were approved to be issued through the Department of Labor to victims of the crisis, “subject to available funding” (Hodge 2017). Though the latter qualification casts doubt on the policy's ultimate viability, the move works to protect against one key area of discrimination against disabled people. It also casts the unemployment status of people with opioid addictions as an outcome of their disability, rather than a personal failing, and helps, at least in theory, to reintegrate them into the workforce and social life of their local communities. In other words, it rehabilitates them by "restoring" their status as "productive" members of society.

Unlike the crack cocaine epidemic and even present-day options for the treatment of cocaine addiction, pharmacological options are central to treatment and rehabilitation efforts in the opioid epidemic. CARA, as noted, focuses on "medication-assisted treatment programs" and extends the permissible use of naloxone by incorporating it into the training and resources of first responders. In many states, Walgreens and other leading pharmacies already keep naloxone in stock and make it available without a prescription. Activists are pushing to further increase its prescription-free availability everywhere, so that friends and family members of overdose victims could rapidly reverse their condition as needed. Since the 2009 launch of the Safe Use Initiative for pain medication, the FDA has been heavily involved in the opioid epidemic. In 2014, the FDA approved naloxone injections for opioid reversal; in 2015, it approved a nasal spray version of naloxone. Following the passage of CARA, the FDA also approved the use of Probuphine, a buprenorphine implant which can be left under the skin for six months to release a constant low-level dose. Buprenorphine is an opioid, but it can help minimize symptoms of withdrawal as patients detox from opioid addictions. This option eliminates concerns about "patient compliance" with treatment, which hindered efforts to develop pharmacotherapies to treat cocaine addiction in the past. Methadone, which blocks the "high" of opioids to reduce patient dependence, has long been approved by the FDA for this purpose.

In 2017, at the National Rx Drug Abuse and Heroin Summit, lawmakers, healthcare providers, and law enforcement officials came together to discuss the necessity of formulating solutions to the opioid epidemic. Following this conference, a summary was published in the *New England Journal of Medicine* detailing a three-pronged scientific approach to tackling the crisis (Volkow 2017). The first focus is on the further development of opioid reversal medications. Though naloxone is highly effective with heroine, it is not powerful enough to treat fentanyl-related overdose, particularly if it does not reach the patient in short order. Technologies that could detect a the onset of an overdose and signal for early intervention were also proposed in this vein. The second focus was opioid addiction treatment options, including preventative vaccines. Finally, the third focus was non-addictive treatments for pain management, including brain stimulation and gene therapy. Researchers at the Justice Center for Research at Penn State University, among others, have already taken up these proposals (Auman-Bauer 2017).

It is clear that pharmacological options have been centered in the response to the opioid crisis at all levels, from federal to state to local jurisdictions, and potentially, for use in private residences as well. Because these options address the problem at a physiological level, they sidestep altogether questions of self-discipline, will power, and moral responsibility, rendering such questions irrelevant to the recognition of pain and suffering taken to be at the heart of the matter. Of course, with the reduction of substance use disorder to its physiological symptoms, the condition is effectively medicalized and individualized, and any broader questions of government and corporate responsibility for the socioeconomic conditions that produced the epidemic are also elided. Yet and still, the presumptively white individual within whom, in the medical model, the disorder manifests is not made to take responsibility for these broader problems, as have their black counterparts for the last five or six generations since emancipation.

VI.

"Treating" the body based upon a belief in claims to pain and suffering is not a progressive political move per se. After all, people who develop addictions to alcohol, opioids, or stimulants are often using them, legally or not, to self-medicate for ailments that testify to pressing socio-political problems in their own right. The harm that can result when a medical treatment, like the use of prescription painkillers, goes awry highlights the fact that no absolute distinction can be drawn between licit and illicit forms of rehabilitation. What remains pressing here is a broader social change agenda that would address itself to entrenched structural problems of gross inequality. Still, as seemingly more sympathetic public policy is now pursued by the one of the most conservative governments in recent times, we have to think about how racialized assumptions about pain and suffering continue to shape developments in law and technology.

The violence with which the crack cocaine epidemic in black communities was met in the 1980s, spawning forms of militarized policing that have only expanded in the intervening decades, has already produced collateral damage in white communities racked by the opioid crisis today. Had a public health infrastructure aimed at treatment and recovery been instituted in response to the earlier epidemic, the present crisis would have certainly claimed less lives to date. As James Baldwin put it in, "Nothing Personal," a powerful 1964 essay on the paradoxical formation of American identity (for a multimedia collaboration with the noted photographer

Richard Avedon): “If a society permits one portion of its citizenry to be menaced or destroyed, then, very soon, no one in that society is safe. The forces thus released in the people can never be held in check, but run their devouring course, destroying the very foundations which it was imagined they would save.”

So rather than “realizing the mistakes of our past,” as most politicians have framed the issue thus far, and working belatedly to address the effects of structural violence as it now comes to devastate rural and suburban white communities, the more effective and more ethical approach involves centering our political efforts about that portion of the citizenry that has, for so long, been “menaced and destroyed,” and thus combating the ways this destruction continues into the present. From “the South Bronx of the 1980s” to all related communities today. Such praxis might focus public attention upon the racial inequality of the official responses to the present opioid crisis and inform new initiatives for restorative justice. It would also be important for an analysis of disability more generally because such cases can, I think, illuminate how the proper subject of disability is situated at once by the coercive, normalizing biopolitics of citizenship under global neoliberalism *and* the myriad resources that accrue to whiteness in a racially stratified state and civil society. Going forward, and given this duality, how might we reframe our understanding of disability as not simply another identity to add to a list of “multiple identities,” as Kimberle Crenshaw framed the misuse of intersectionality in a 2016 keynote lecture at the Southbank Centre’s Women of the World Festival, but rather an effect of the “policies and the institutional structures” that “make certain identities the consequence of the vehicle for vulnerability”?

Acknowledgments: This epilogue, in part, has been submitted for publication in the journal *Catalyst: Feminism, Theory, Technoscience*, 2018. The dissertation author, Maisam Alomar, is the primary investigator and author of this article.

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