# **Distribution Agreement**

In presenting this thesis or dissertation as a partial fulfillment of the requirements for an advanced degree from Emory University, I hereby grant to Emory University and its agents the non-exclusive license to archive, make accessible, and display my thesis or dissertation in whole or in part in all forms of media, now or hereafter known, including display on the world wide web. I understand that I may select some access restrictions as part of the online submission of this thesis or dissertation. I retain all ownership rights to the copyright of the thesis or dissertation. I also retain the right to use in future works (such as articles or books) all or part of this thesis or dissertation.

Signature:

Allison Laura Pilatsky

Date

National Bodies and the New Eugenics: A Public Health Vigilance Model

By Allison Laura Pilatsky Master of Arts

Women's, Gender, and Sexuality Studies

Deboleena Roy Advisor

Michael Moon Committee Member

Elizabeth Wilson Committee Member

Accepted:

Lisa A. Tedesco, Ph.D. Dean of the James T. Laney School of Graduate Studies

Date

National Bodies and the New Eugenics: A Public Health Vigilance Model

By Allison Laura Pilatsky B.A., Smith College, 2012

Advisor: Deboleena Roy, Ph.D.

An abstract of A thesis submitted to the Faculty of the James T. Laney School of Graduate Studies of Emory University in partial fulfillment of the requirements for the degree of Master of Arts in Women's, Gender, and Sexuality Studies 2015

# Abstract

### National Bodies and the New Eugenics: A Public Health Vigilance Model By Allison Laura Pilatsky

The historic roots of eugenic discrimination run deep within American political culture and scientific institutions and during the 20<sup>th</sup> century over 65,000 Americans were coercively sterilized in keeping with scientific understandings of racial fitness. Disabled people and people living in poverty were also swept up as eugenic legislation and informal practices spread. This paper follows up on this history by posing the question, how can we interpret contemporary reproductive health management as a direct descendent of eugenics? By examining the evolution of pregnancy oversight practices and the increasing emphasis placed on prenatal diagnostic, this paper argues that contemporary interventions increasingly depend on a model of public health vigilance. The public health vigilance model places pressure on women to pursue multiple phases of prenatal testing, to terminate pregnancies viewed as unfit, and has resulted in the legal concept of wrongful birth. This framework functions alongside ongoing reproductive abuse in the American prison system, punitive family cap policies for social welfare programs, and a cultural vision of the ideal mother that excludes large sections of the population. Challenging this exclusivity and the deprivation of social goods for the most marginalized demands an approach to reproduction that refuses racist and ableist hierarchies and emphasizes improved social services that enable women to pursue motherhood on their own terms instead of within a narrow maternal ideal.

National Bodies and the New Eugenics: A Public Health Vigilance Model

By

Allison Laura Pilatsky B.A., Smith College, 2012

Advisor: Deboleena Roy, Ph.D.

A thesis submitted to the Faculty of the James T. Laney School of Graduate Studies of Emory University in partial fulfillment of the requirements for the degree of Master of Arts in Women's, Gender, and Sexuality Studies 2015

# **Table Of Contents**

Introduction: A Revealing Plea Bargain	. 1
Eugenics In Development: Galton's Science Crosses the Atlantic	7
Eugenics and Public Health from 'Solutions' to Abuses	11
The New Eugenics: Creating a Public Health Crisis	20
National Bodies, National Policies: How the State Controls Reproductive Freedom	.24
The Cure Ideology: Preventing the Undesirable Body	30
Conclusion: The New Eugenics and Exclusionary Visions of the Maternal	.37
Bibliography	.41

# National Bodies and the New Eugenics: A Public Health Vigilance Model Introduction: A Revealing Plea Bargain

For Jasmine Randers, 2012 ended with a period of internal turmoil much like the past two decades; while formally under state commitment in Minnesota, her paranoia and agitation took control, convincing Randers that she was being watched, that she needed to run. And so she did – first to Nashville, where she spent thirty days in the Middle Tennessee Mental Health Institute, and later, slipping from under the watchful eyes of her mother who had arrived to return her to Minnesota, to Nevada, Utah, Idaho, and Oregon. Randers' anxiety propelled her along, unable to find a safe harbor from her internal firestorm.

Still, the propulsive force of mental illness could not fend off other exigencies. Randers journey ended abruptly when her water broke while on a Greyhound bus and she delivered a healthy baby girl at Crittenden Regional Hospital in West Memphis, Arkansas. The event seemed to calm her. Records show that Randers did not display significant signs of mental illness while at the hospital. On December 19, 2012, two days after her daughter Issabelle was born, Randers and the infant were discharged to a shelter. Within a day they were gone without a trace.

Reemerging in Nashville yet again, Randers sought shelter. A failed attempt to get a room at a Comfort Inn led to a phone call to the police who spoke to Randers, asking about the baby. She confirmed that everything was fine and then hailed a taxi in the cold night, riding over to the Howard Johnson where she and Issabelle would spend the night.

The next morning Issabelle was dead. Randers brought her to Skyline Medical Center. An autopsy was inconclusive – the infant was healthy and fed and she showed no signs of direct harm. Her autopsy report lists her cause of death as "could not be determined."

While there are several hypotheses about why Issabelle may have died, including unintentional suffocation while wrapped in her mothers jacket, sudden infant death syndrome, or being smothered while cosleeping with her mother that night, there is no conclusive answer. There was no clear proof that Jasmine Randers was to blame. This lack of evidence was countered with a charge, however; Randers was accused of aggravated child neglect. She faced fifteen to twenty-five years in prison if convicted.

It is worth pausing here to examine the charge. Tennessee law defines neglect as "occur[ring] when a person 'knowingly abuses or neglects a child... so as to adversely affect the child's health and welfare." This definition fails to correspond with the facts of Randers' case. Other than the possible suffocation of the child while wrapped in her mother's jacket – the taxi driver recalls that the baby stopped screaming at some point during the ride to the Howard Johnson – both Sudden Infant Death Syndrome (SIDS) and accidental suffocation or strangulation in bed, and even sudden death of unknown cause, are all classed as Sudden Unexpected Infant Deaths according to the Centers for Disease Control and Prevention (CDC). As a grouping, these are deaths believed to be unintentional. Yet both the assistant prosecutor on the case as well as Glenn Funk, the district attorney who replaced him, felt the neglect charge was valid. They pointed to the lack of infant bottles found in the hotel and Randers choice to call a cab to transport her dead child rather than an ambulance as proof of this. It was all they had to go on.

The charge of aggravated child neglect in this case can then be considered as specious and the jury agreed. In 2015, Randers was determined to be not guilty by reason

of insanity after spending two years in jail as the legal battle wore on. Case comparisons and an eye on the historic relationship of the state to the disabled, the poor, and people of color in particular, all support the assertion that Randers would not have faced these charges had she been in a different social position relative to the state. Instead, in Randers we have a case of triple jeopardy: she was mentally ill, impoverished, and non-white. All of this combined to situate her as an unfit mother, and as will become clear, any one of these factors alone would have been enough to put her at significant risk of losing parental rights. And yet the case has another twist, one even more heavily determined by the United States' history of reproductive control and abuse of marginalized populations.

When the charges against Randers were filed, the case entered the public defender system, where Randers was assigned to Assistant Public Defender (ADA) Mary Kathryn Harcombe. The case also came to rest on the desk of Assistant District Attorney Brian Holmgren. Harcombe would turn out to be an incredible advocate for Randers, but first she had to overcome the hurdle set out by Holmgren. Before he would discuss any type of plea deal with Harcombe, Holmgren insisted that Randers must agree to be sterilized. Harcombe immediately objected. All negotiations stalled.

Brian Holmgren is a difficult figure to challenge when questions of maternal fitness are at hand. A nationally recognized voice in the field of child abuse, the Tennessee ADA is also on the international advisory board of the National Center on Shaken Baby Syndrome, notably a diagnosis that both medical professionals and courts are now actively calling into question. Framed by his image as a kind of parenting expert, a legal Dr. Spock of sorts, Holmgren's demand that Randers be sterilized as part of a plea bargain was part of defining Randers as an unfit mother who should not have given birth, let only have any more children. There would be no further conversation about a plea without concession to this demand. Perhaps this was a kind of legal filibuster, something Holmgren knew Harcombe and Randers would not agree to, thus stymieing any attempt at a plea bargain. Whatever his intention, it didn't work.

Rather than concede to an obviously discriminatory demand, Harcombe called on Holmgren's boss District Attorney Glenn Funk to intercede in the case. While Funk agreed that Randers should face charges in the death of her daughter Issabelle, he rejected Holmgren's demand that she be sterilized as entirely inappropriate and removed ADA Holmgren from the case. Holmgren was ultimately fired in March 2015, just as the Randers trial came to a close. It was also subsequently revealed that Holmgren had discussed sterilization as potentially part of the conditions for a plea deal (Hale).

Contrary to these recent revelations regarding Holmgren's bargaining tactics, David LaBahn, the president of the Association of Prosecuting Attorneys, says there is little evidence that sterilization has been used as part of plea deals in other cases besides Randers. Still, how is it that a case arising in 2012 and settled in 2015 even posited the idea? And moreover, how did Holmgren's use of such a condition, even if only as a potential route, go unnoticed for as long as it did? As other states begin prosecuting those who participated in coercive sterilization decades ago, why is a Nashville attorney attempting a legal workaround to demand the procedure?

Coercive sterilization practices form one arm of this project, along with punitive management of maternal health, forced birth control, and the structural encouragement of selective abortion of disabled fetuses. How do these practices become a tool of biopolitics, of the state "power to foster life or disallow it to the point of death," as Foucault formulates the concept (138)? Because it is important not to be mistaken here – not only does the state as law gain access to the bodies of citizens via biopolitics, but Foucault is clear that this law becomes much more pervasive. It becomes what he terms a norm, and norms invade and reemerge, becoming part and parcel of other arenas such as medicine or the educational system (Foucault 144). Thus it is not just the state that has a vested interest in normatively healthy and productive subjects, but the structurally immersive institutions of the society. All of these play their hand in favor of the creation of ideal citizens. When this happens, whose reproduction is encouraged and whose is discouraged? We can look to Connecticut and California's 1909 laws allowing asylum staff to assess whether those deemed feebleminded or insane should be sterilized, or New Jersey's far broader 1911 law giving state sanction to the sterilization of prisoners, poor children being cared for in charitable institutions, those deemed feebleminded, people with epilepsy, and those placed in the vague category of "other defectives" (Black 67-68). These historic eugenics laws have since transformed; today the state places similar restrictions on reproduction in subtler ways or more frequently relies on the infiltration of social norms into fields such as genetic counseling or social services. For example, Darrin P. Dixon suggests that medical professionals are highly likely to give women accurate prenatal advice regarding a diagnosis of Down syndrome, likely leading to inflated rates of selective abortion under conditions where women have not truly given informed consent (2008). Doctors even fear that failure to advise abortion may land them on the opposite side of wrongful birth charges, a charge fundamentally premised on the idea that some lives, specifically disabled lives, are not worth living (Weil). Family cap policies that exclude children conceived while a family is receiving government aid from

being equally supported also hinge on eugenic attitudes about poverty and the suitability of the poor to raise children (NCSL). Thus we see that through both formal policies and informal practices, maternity and the maternal bond become aspirational relationships that some women and children will never be deemed suitable to fill.<sup>1</sup>

Instead of granting systematically oppressed women with access to the highly politicized role of mother, these women will have their reproductive capacity controlled resulting in several possible outcomes: prevention of reproduction; invasive and unnecessary prenatal testing; revocation of parental rights; or intensive observation and state intervention in home life and parenting practices. Also part of this same biopolitical system are the structural denial of services, including healthcare, nutrition, education, housing, and other necessary resources to families and children viewed as part of a dysgenic legacy.

By exploring the ideological foundations of the United States' coercive sterilization programs and extensive eugenic intellectual infrastructure, this project offers an analysis of contemporary reproductive politics and restrictions as part of public health vigilance. Reproduction by those deemed unfit has historically been viewed as harming population health, straining public resource systems, and restricting national potential. This remains the underlying ideology of the state, now expressed primarily through structural racism, classism, sexism, and ableism, though race and class issues predominate. By looking at policy programs and legal management of reproduction, we can see the transformation of eugenic language into a twenty-first century model. Though

<sup>&</sup>lt;sup>1</sup> Although men were also subject to eugenic practices and were widely sterilized in asylums and prisons, this paper focuses on the ways in which women specifically are included or excluded from contemporary models of motherhood through the eugenic management of their reproductive lives.

the history of eugenics in the United States has not been widely acknowledged, the contemporary practice of it, what many term the "new eugenics," is actively denied; instead it occupies the quiet space of what David S. King refers to as "the presumption of termination" (1999) or lingers under the cover of illegal actions, like the unauthorized sterilization of female inmates (McGreevy and Mason). This project seeks to uncover that denial and make contemporary population control strategy legible, in order that we may move towards a new, inclusive vision of maternity.

#### **Eugenics in Development: Galton's Science Crosses the Atlantic**

From its initial moment of conception in the 1880s, eugenics has been a technology of public health management, and although it is possible to trace some of eugenics' foundational ideas back to such a broad rang of figures as King Henry III, Gregor Mendel, and Thomas Malthus, as Edwin Black does in his critical history of eugenics, War Against The Weak, this accounting will begin with Francis Galton and his associates. Galton was a cousin of Charles Darwin, and like his cousin was an inimitable counter, fascinated with numbers and the accounting of natural phenomenon. Indeed, Galton was known to live by the motto, "Whenever you can, count" (Black 14). And while that counting first resulted in an important text on meteorology in 1863, from there Galton's interests turned to the human, specifically to a consideration of Mendelian genetics and transmission of personal qualities beyond the physical, such as intellectual and emotional capacities. At a time when many others were still committed to Malthusian theories of restrictive breeding, Galton suggested that highly selective but increased breeding was the preferable approach. He became fascinated with biographies and genealogies as he worked to determine how this model of human reproduction would

work. This improved breeding method was intended to improve the physical and intellectual health of the population.

Galton recognized that his ideas about human reproduction were distinct from the emerging field of genetics, but it was not until the publication of *Inquiries into Human* Faculty and Development in 1883 that he devised a name for this new science. Derived from the Greek words for "well" and "born," Galton offered up this new science of eugenics to the world (Black 16). Galton's particular approach would eventually come to be understood as positive eugenics, as it primarily focused on the selective increased reproduction of those with desirable traits, rather than the active restriction and prevention of reproduction by those considered less well born. Things would not remain so comparatively harmless for long, particularly as the idea of eugenics spread to the United States. What in England the population viewed as intellectually tenuous and scientifically mediocre would become the prevailing science explaining supposed racial inferiority as it crossed the Atlantic and encountered American racial activism.<sup>2</sup> Galton and his English followers were convinced only a religious revolution that centered on eugenics would cause the population to ascribe to the pseudoscience (Black 28-29). In America, eugenics already was the religion.

<sup>&</sup>lt;sup>2</sup> This is not to say that Galton didn't support a racist ideological system in his formulation of eugenics, only that this formulation had less bearing on British society than it would have in the United States, where racial diversity had long been a point of contention and a source of violence and oppression. Galton's racist thoughts regarding eugenic selection included negative characterizations of "Mongolians, Jews, Negroes, Gipsies, and American Indians," and of Blacks he offered the following commentary: "The Negro has strong impulsive passions, and neither patience, reticence, nor dignity. He is warm-hearted... eminently gregarious, for he is always jabbering, quarreling, tomtom-ing, or dancing." Galton also deemed Blacks to be "prolific," thus making them challenging to selectively eliminate (*Black Body* 60).

The United States first received the founding ideas of eugenics during the early 1900s, integrating ideas that were struggling to take hold in England with utter rapacity, particularly as the ideas corresponded with existing notions that non-whites were "no more than a hereditary blight in need of eugenic cleansing" (Black Body 29). Eugenic ideas were foundational to United States history, even if the language to name this ideology was newly arrived. After all, while Africans had arrived in the United States by force under slavery, they were understood to be racially inferior and race was understood as clearly genetic, able to be passed down through reproduction.<sup>3</sup> Such a belief explains not only why Africans were considered fit to be enslaved, but also why education, for example, wasn't considered a viable means of improvement; inferiority was built into the bloodline. Similarly, I would argue that pre-eugenic ideas about nominally good blood being diluted by bad or lesser blood can be used to explain other racist formulations, such as blood quanta. No matter how little African blood you had, it had the impact of diminishing any good qualities proffered by white, well-classed blood. Furthermore, even amongst certain members of the scientific community today, this idea of African

<sup>&</sup>lt;sup>3</sup> Today Western culture seems to be of two minds regarding the genetic status of race. Although formal scientific testing has proven that there is actually no genetic basis for race, many trained scientists continue to associate race with geographic ancestry and use race as a category for division in their research. In the same vein, such scientists will often perceive and even interpret genetic samples from African American donors and Caucasian donors as "opposite races" (*Fatal Invention* 68-69). This kind of thinking is replicated in a variety of public ways, including through the marketing of products like 23andMe testing kits that purport to establish racial ancestry or even in the work of the Human Genome Project, specifically the Diversity Project that sought to acquire supposedly rare DNA for research and preservation (Reardon 100-106). These projects create artificial differences that can be exploited within a eugenic framework. The alternative understanding of race is that it is a social construction, very real and yet unable to be pinned down at a particular genetic locus. The former understanding is far more marketable and also more malleable to the forces of racially discriminatory practices.

hereditary inferiority remains; in 2011, genetic pioneer and co-discoverer of the double helix structure James Watson made the news for a speech in which he commented on the inherently flawed nature of Western social policies towards African nations. These policies are unsuccessful, argued the then 79-year-old scientist, because "all our social policies are based on the fact that their intelligence is the same as ours – whereas all the testing says not really" (Milmo). Anachronistic though his remarks may be, it could also be said that Watson was simply forthright in stating what many people think. If eugenics offered a scientific shroud with which America could cloak its racism in those early days, a cloak still generally reliable today, Watson refused the cloak in favor of the spotlight. And though in the early days of eugenics it remained acceptable to be outwardly racist, eugenics altered this directness and instead delivered its racist messages with a kind of social benevolence. Good breeding would make people healthier, decrease poverty, and increase intellectual and cultural achievement. What could possibly be the trouble with that?

The problem, as it turned out, was that Galton's positive eugenics did not survive long upon its arrival in the United States, particularly as it found leadership and organization under the guidance of Charles Davenport at Cold Spring Harbor and the Carnegie Institute. Davenport was a biologist with strong convictions about racial inferiority. Standing strong against the progressive political notion of the nation as "melting pot," Davenport offered instead a model of race that placed all non-Nordic groups in an inferior position and labeled them with group-specific traits; the Irish, for instance, were deemed to have "considerable mental defectiveness" whereas Germans were "thrifty, intelligent, and honest," and these traits were passed along generationally (Black 35). As such, strategic breeding was of the utmost importance, so important that Davenport sought, with the backing of the Carnegie Institution, to create a national policy of it: negative eugenics, more commonly known as racial hygiene. This theory would publically propel American social policy through World War II, at which point public awareness of Nazi abuses would force eugenics underground. It would later reemerge with a new shape as the genetic revolution took hold, in large part under leadership also based out of the Cold Spring Harbor laboratory; James Watson took over as laboratory director in 1968, leading in this capacity until 1994 when he became president, and in 2004 took the title of chancellor (Watson). In 2007, Watson officially resigned his title after the first major incident in which he made racist remarks about people of African ancestry (Dean). From Davenport to Watson and eugenics to the Human Genome Project and beyond, scientifically unsound attempts to link genetics and race continue and in every case assert unforgiveable conditions for division and government-sanctioned abuse.

#### **Eugenics and Public Health from 'Solutions' to Abuses**

We see the first clear articulations of eugenics as a public health practice beginning around 1910 when Davenport hired Harry Laughlin to join him in leading the Eugenics Record Office (ERO), an undertaking funded by E.H. Harriman, a railroad heiress (*Black Body* 62). Harriman was just one of many high powered American investors and growing corporations that funded eugenics programs, seeing the study of racial difference as supportive of capitalist systems of exploitation. With this additional support, Davenport finally felt he had the resources to undertake extensive studies of the group he deemed the "submerged tenth," those considered to be the most unfit in American society. Prior to Harriman's funding for the ERO, Davenport had felt overwhelmed by what he saw as the increasing need for a change in American reproductive practices, as well as by his own wealth of ideas. Alone he could only do so much, but with the help of Laughlin, many more of those ideas became actionable. They began with studies of those considered to be hereditary criminals and then of epileptics, compiling long genealogies accounting for generations of the feebleminded, immoral, and otherwise inferior and unfit. As a label, feebleminded was applied to subjects with impunity, encompassing a range of mental states, often without any kind of objective assessment.<sup>4</sup> Indeed, the term could be applied to anyone researchers wanted to include within their field of the unfit, and it could be nearly impossible to shed the label once applied.

With the development of an organized government eugenics program, the nature of discrimination in the United States began to change. What before had been largely an informal system emerging out of the slavery era – old masters who controlled the reproduction of slaves, raping women and enslaving the offspring shifting to a greater emphasis on vigilante violence ending in lynchings around the turn of the century –

<sup>&</sup>lt;sup>4</sup> Carrie Buck, the plaintiff named in *Buck v. Bell* was considered to be the second generation of imbeciles in the court's quote. Her mother Emma had previously been committed to an asylum and Carrie was committed to the Virginia Colony for the Epileptic and Feebleminded after giving birth to her illegitimate child, Vivian, at the age of 17 (Buck's pregnancy was the result of being raped by her foster mother's nephew). With no evidence other than a limited understanding of hereditary transmission of traits, the courts not only determined that Carrie could be subjected to compulsory sterilization, but that Vivian was almost certain to share the traits of feeblemindedness and sexual promiscuity ascribed to her mother and grandmother; indeed she was "tested" at seven months and said to have failed the test for a six month old child. Vivian died at age eight, but research into her brief educational history demonstrates that she was a student of average intelligence, something that is also suspected of her mother. We see here the essential meaninglessness of the term feebleminded, and it is arguable that Buck attracted the label because of her supposed promiscuity as well as her poverty. As I will discuss later in this paper, the poor constitute one thread of the national threat facing reproductive health and social welfare, thus meriting coercive sterilization.

would be transformed into precisely executed reproductive abuse streaming forth from laboratories and medical offices, generally in the form of coercively sterilized young people, though in other cases the abuse took the shape of scientific justification; it was not racism that yielded the division between white and Black Americans, but rather the truth of the thing, that Black's were biologically inferior (Black 166). The halls of Congress also worked in harmony with eugenic science as major eugenicists backed the immigration bills meant to supplement sterilization programs, passing bills that restricted immigration from countries outside Western Europe, including the 1917 and 1924 Immigration Acts (Ordover 24). The aura of certainty and accomplishment surrounding scientific advancement also helped to extend the scope of national reproductive control, taking a system honed on the bodies of slaves and impressing it on the poor, the disabled, those thought to be "hereditary criminals," and others generally classed as of inferior stock. Galton endorsed proper marriage for the improvement of society; the United States, reconstructed the system so that all those considered unfit for proper marriage were cut off from reproduction altogether. Racial hygiene, then, was the understood to be the best of both positive and negative eugenics and from the start American scientists perceived themselves as the world leaders in having devised such a program. Imagine their surprise to discover that under the rubric of Hitler's final solution "[t]he Germans [were] beating us at our own game" (Black xvii).

After less than a year of study, Davenport, Laughlin, and others proposed extensive sterilization campaigns meant to improve American racial hygiene, eliminating those deemed mentally, physically, and morally inferior. Ultimately American sterilization programs, so often erased or minimized by a popular linking of racial hygiene with Nazi Germany, would reach over 65,000 total cases in 30 states, a number far below Davenport's 1914 goal of sterilizing 15 million people over the next two generations (*Fatal Invention* 39). However, due to the secrecy surrounding many eugenics programs, their impact on those generally thought unworthy of being accounted for, and the shame faced by victims of sterilization procedures, the 65,000 case figure may in fact be a very conservative estimate.

From the perspective of public health and well being, it was sometimes easiest for scientists to discuss eugenics in a way that veiled some of the racial issues at hand. For example, a 1906 text by Dr. G. Frank Lydston focused on the value of sterilizing "[i]ncurable criminals, epileptics, and the insane" included as its title page illustration an image of the "skull of a Negro murderer" (*Black Body* 67). It was unnecessary to speak in racial terms when the broad application of such an image made clear that anti-Black racism dripped from every word of the text. Eastern and Southern Europeans might be less fit than older Aryan stock, but the greatest social problems, those that should be remedied by compulsory medical interventions, were surely carried by Blacks. The population of the criminal, epileptic, and insane was surely saturated by Black bodies. Still, Lydston's words were still largely hypothetical. There were a few small-scale sterilization operations underway in the United States, but the true explosion was still around the corner.

In addition to the work coming from the Carnegie Institute and the ERO in the early 1900s, the most influential event in the development of American eugenics was the 1927 Supreme Court case *Buck v. Bell* that established compulsory sterilization programs as constitutional. Although the first targeted sterilization law was passed in Indiana in 1907, prior to Laughlin's tenure with the ERO, this law focused on vasectomy as a way to reduce crime, degeneracy, and institutional costs, and while Davenport and Laughlin would champion these same goals, the Indiana law lacked the scope that proponents of eugenics recognized as necessary to social reform (Lombardo 29-30). Thus, it was with the famous edict that "three generations of imbeciles is enough," that *Buck v. Bell* enabled government funded sterilization programs to gain momentum (*Fatal Invention* 41). Prisons, state hospitals, and other similar institutions led the way, offering the expanded scope eugenicists envisioned. Indiana separately expanded its eugenic sterilization law that same year, a success attributed to the broader social recognition of eugenics caused by the progress of *Buck v. Bell* through the courts (Lombardo 33).

North Carolina offers an excellent example of how sterilization laws premised on public health emerged in the period immediately after *Buck v. Bell.* North Carolina passed their initial sterilization law two years after *Buck v. Bell,* in 1929, and followed up by creating the state Eugenics Board in 1933 (Railey 14). Under North Carolina's legislation, sterilization was targeted towards those who were "mentally diseased, feeble-minded, or epileptic," and furthermore these sterilizations were to be performed for the personal good of the patient or for the public welfare. However, it rapidly became clear that the welfare departments that administered the program via groups of social workers had little interest in any personal benefits that might accrue to the patients. Though according to John Railey's work a few individuals requested sterilization with the support of their families, most of those sterilized were pressed into the procedure by family members and social workers (15). Nial Cox Ramirez would be just one of 7,600 people sterilized in North Carolina under their program, which continued until 1974.

The idea of consent within the framework of state sponsored sterilization was a nebulous one, not considered especially important to the procedure, as Ramirez was quick to realize (Railey 15). Instead of an emphasis on autonomy and consent, much as we see in disability community today and as will be discussed later, family members coerced, pressured, guilted, and otherwise spoke over the disabled person, even when the disabled individual had the capacity to understand the implications of their choice. Disability most certainly eliminated the prospect of individual choice.

Although family was a dominating factor in North Carolina's sterilization program, it was not the controlling force for Ramirez or many like her; rather, issues of consent fell more heavily upon local welfare officials. So when Ramirez found herself pregnant at seventeen year old in 1964 while working as a housekeeper as well as in the tobacco fields of small town Plymouth, North Carolina, pregnant without the possibility of legal abortion and with the knowledge that her mother had already had children by her age, Nial steadied herself, ready to take on the responsibility, to become a mother. That is, she was prepared until Anne Smith, a white woman from the neighborhood and a county welfare department employee came to talk. Under pressure from her supervisor, Smith was sent to encourage Ramirez to be sterilized after the birth of her child. Smith was unsure about whether or not this was an appropriate undertaking, but her supervisor was certain and so she pressed the message, going so far as to make threats that the family's welfare checks would be taken away for not complying with the state. Yet in all of these conversations, something was conspicuously absent: As Railey points out, the department was not concerned that Nial Ramirez was mentally handicapped and likely to produce mentally handicapped children. Although that was the initial function of the

state's program, it was not integral to the case here. No, Ramirez was subject of such scrutiny precisely because she was Black and on welfare. That was all the reason the department felt they needed to deem her unfit. In every conversation, however, Nial resisted. "I do not want this," she told Smith (Railey 26). To Ramirez, that should have been the end of the conversation.

Nial Cox Ramirez gave birth to her daughter Deborah on November 24, 1964. She was overjoyed, determined to give her daughter a better life as well as siblings in the coming years (Railey 27). Daughter in her arms, she hoped that the worst of the state's incursions on her body were in the past now that her pregnancy was over. It was time to start fresh. But as Nial savored these first few days and weeks with Deborah, Smith was quietly at work. In accordance with North Carolina's formal procedures, Smith drew up a sterilization petition, describing Ramirez and why she ought to be sterilized. Although never before mentioned, Ramirez (as well as her mother) was described as having a low IQ and as having completed school up until the eighth grade only by social promotion. Smith also claimed that Ramirez and her mother, though essentially unable to understand the sterilization procedure, had given some form of consent to having the procedure performed (Railey 31). Furthermore, because the legal construction of North Carolina's sterilization program was such that it applied to those deemed "mentally ill, feebleminded, or mentally retarded, and the epileptic," Nial would need a diagnosis. Dr. Claudius McGowan, the doctor employed by the county health department, attested to having known Nial since childhood and filled in the paperwork describing her as "Mental [*sic*] Retarded." McGowan was not a psychologist or psychiatrist and not formally positioned to make such a diagnosis, but this did not seem to matter (Railey 33). The

petition was ready. All that was left was Ramirez's signature and the approval of the state Eugenics Board.

In North Carolina, the procedure was for sterilization petitions to be mailed to the Eugenics Board where they would be reviewed and approved by the five member group, formally consisting of the commissioner of publish welfare, the state health director, that attorney general, and state mental hospital heads, but more often run by low-level staff members; the actual committee members saw the job as minor, not worth their effort to oversee (Railey 39). Importantly, those who were to be sterilized rarely if ever came before the board to make their case. This failure to individually assess potential victims of sterilization increased the likelihood that families claiming a disabled person under their guardianship desired to be sterilized were in fact articulating their own desires, needs, and prejudices while ignoring any potential input from the individual in question. This was similarly true for those whose petitions were issued by social service officials, as was Ramirez's. In this way, a paradox emerged: disabled and marginalized people were invisible in a process that kept them under a microscope.

The next time that Anne Smith came to see Nial was just before New Years, this time with the petition in hand. Ramirez was greatly displeased to see her, and furious to be confronted with the petition for her sterilization. Had she not made clear that this was not at all what she wanted? It didn't seem to matter. But before Nial could tell Smith to go to hell and leave her alone, she was wracked with guilt. Although Smith's threat of refusing Ramirez's family their welfare check was not an actionable one, Ramirez had no way to know that. She worried about her mother and her siblings and her own infant child. She could not be the one to deny them the help they needed. Ramirez signed the

papers before her in neat script. Still a minor under North Carolina law, her mother followed suit (Railey 35). Ramirez's case would come up for review on January 28, 1965, yet another case of a Black woman on welfare. Approval was certain.

A closer look at the attitude the Eugenics Board and most government representatives held towards North Carolina's eugenic sterilization program was generally casual, with a simple goal – eliminate the morons. But later in the 1960s, by the time Ramirez's case found itself in front of the board and as the Eugenics Board came under the purview of Governor Terry Sanford, this center of action shifted; the board, a body of white men, were clearly pressing an agenda emphasizing the sterilization of Black women and girls (Railey 17, 39). North Carolina, like most states, had always performed a high number of sterilizations on Black women, but the intensity present in this case came in the form of whispers. The panel knew what they were doing, but they were cautious not to speak of it.

Nial Cox Ramirez was sterilized on February 10, 1965 in an irreversible procedure, though she was told it could be undone. She cried as she was wheeled into surgery. The tears were not just about her, but about the children she wanted that she could not have, about the decisions stolen from her, made permanent with only a mockery of consent. But this would not be the end for Ramirez. She moved with her daughter to New York, trying to start anew. It was there that a doctor referred her to the ACLU, where she connected with Brenda Feign. Feign listened to Ramirez's story, and recognized it as just one of many (Railey 54). This was a new revelation in the early 1970s, but with Feign's help and Ramirez's frightened but determined voice, it would soon become national news. In July 1973, Ramirez became the face of an ACLU class action suit filed in a North Carolina federal court (Railey 56).

Ramirez had her first encounter with the press on the same day that the suit was filed, an intimidating event. When asked about her concession to the procedure, Ramirez told the press, "When you're black and poor, you have to forget what you want and do what the rich, white people say" (Railey 57). Regardless of what doctors and welfare agencies said about Ramirez, she understood viscerally what compulsory sterilization was about. The surgical mechanisms didn't matter. What mattered were the racist foundations of these surgical interventions. What mattered was the absence of choice. Somehow the idea that reproductive health was a public health concern had been distorted to mean that reproductive health decisions were in the hands of public leadership – white, wealthy leadership – and not left to the discretion of those whose bodies and reproductive lives were in question. As human rights activist Eleanor Holmes Norton said of Ramirez's case, "It is the essence of racism for people to believe that sterilization is in the interest of blacks" (Railey 57). These forceful words spoken on that July day would be the first in a long saga to find justice for Nial Cox Ramirez and others like her.

#### The New Eugenics: Creating a Public Health Crisis

Cases like the ACLU class action suit that challenged the North Carolina program should have been the end of eugenics. No longer hidden by the workings of state subterfuge, so common as to be known as "Mississippi appendectomies" and yet never publically discussed, coming before the courts should have been the moment of resolution. Instead, eugenics plunged further underground to reinvent itself. What would emerge, however, would be a scientifically more complex and empowered set of practices, what Nancy Ordover deems "New Technologies, Old Politics" (179). The targets of this new eugenics would also be broader; research into human genetics and improved prenatal testing technologies had proven that even those considered to be prime candidates for reproduction – white, middle class, well educated – could be subject to errors of conception, resulting in abnormalities and disabilities. Thus, the new eugenics not only continued to actively limit reproduction by women of color, disabled women, and poor women, this new field also encouraged increased testing among those otherwise seen as fit. More tests meant a greater certainty that only pregnancies resulting in "fit" or healthy children would be carried to term. The vigilance that before pursued specifically the bodies of women now also concerned itself with the fetus, a kind of body of its own. Prevention now included keeping "at risk" women from reproducing while monitoring those appropriate mothers and families for any wayward cells.

At this juncture, I turn to this term vigilance specifically as it has been reframed in recent years within the context of "global public health vigilance." This concept acquires much of its definitional force from Lorna Weir and Eric Mykhalovskiy's 2010 text *Global Public Health Vigilance: Creating a World on Alert.* As the text describes in its opening, global public health vigilance derives from an increasing interest in and effort to prevent the spread of infectious diseases, such as SARS and swine flu (Weir and Mykhalovskiy 1). More recently we have seen an emphasis on the term in the face of Ebola and the global effort to treat and prevent the spread of this life threatening infectious disease, I argue that the nature of reproduction in the United States under the

contemporary eugenic regime constitutes a form of national public health vigilance. The overlap between the global framework and the nature of national reproductive concerns becomes clear when we look at the three key features of global public health vigilance according to Weir and Mykhalovskiy: "(1) the impact of a new disease concept called 'emerging infectious diseases' (EID), (2) the invention of a monitoring/surveillance technique called 'online early warning outbreak detection,' and (3) the formation of a politico-juridical regime dealing with international public health emergencies" (1). These three factors can be reassessed in light of national reproductive politics and practices.

First, Weir and Mykhalovskiy identify the idea of emerging infectious disease, which for their model is essentially the site of vigilance. Indeed, when it comes to global public health vigilance, the key is to identify new epidemics as they first surface, while they are still emergent, raising the question of where to position emergent risk within national public health vigilance as applied to women's reproductive lives. Rather than locate emergent risk at a particular phase of women's lives, I would position it at an historical juncture; when it comes to the kind of national public health vigilance addressed here, the risk or moment of emergence is not located within the body. But with a long national history of reproductive control and intervention, where should the pin or emergence be dropped? Although there are several contenders for the date in this case, with the goal of encompassing a specific kind of modern genetic vigilance, I have selected 1967, the first year in which an American lab reported the detection of a fetal chromosome abnormality via amniocentesis. (Rapp 27). Although there were obviously many other modes of vigilance at work prior to this date - consider hundreds of years of manipulation of reproduction by slaves, for example – the new ability to make diagnostic judgments in the womb caused a dramatic shift in how pregnancies was understood. The development of amniocentesis allowed for a kind of new prenatal vigilance focused on the fetus and the potential flaws of the fetus, rather than the exclusive emphasis on the flaws of the mother and extended family that we saw prior to this point.

Moving to Weir and Mykhalovskiy's second component in the global public health vigilance framework, they highlight the creation of an early warning surveillance technique. In the contemporary age of advanced reproductive technology, the concept of early detection has been taken to extremes, such that in cases of in vitro fertilization, embryos can be screened for abnormalities before they are even implanted. Preimplantation genetic diagnosis, then, is something of a work around because it prevents the often more complicated ethical concerns of terminating a fetus.

The third component of Weird and Mykhalovskiy's model complements and completes the early detection system by outlining the general provision of a "politicojuridical regime" that manages public health emergencies. Since the original research programs at Cold Spring Harbor, run by Charles Davenport to the North Carolina Eugenics Board and the contemporary management of women's reproduction through welfare programs and the criminal justice system, reproduction by women of color, disabled women, and poor women have all been managed by a system that views them as specters of a public health emergency. Women whose reproductive lives fall within this mode of management also exist outside of contemporary models of the maternal, making the systematic curtailing of their reproductive lives of no consequence.

Taken together, the three components of Weir and Mykhalovskiy's global public health vigilance model can thus be effectively translated to describe both the historical narrative arch and the current public health management of women's reproductive lives. Through increased knowledge and improved reproductive technologies, along with the refining and expanding of the politico-juridical state, the United States has systematically created a new eugenics. Indeed, as Theodore M. Porter points out, as discourses of eugenics seemingly disappeared, the language of genomics appeared; this especially happened beginning around the 1980s after a brief period of time during which eugenic ideologies retreated underground, reinventing themselves (Porter 2014). It reappeared with a new public face, but the same fundamental goals.

Genomics transformed Davenport's eugenic language about feeblemindedness or hereditary criminality and replaced it with the search for the gay gene, the gene for schizophrenia, even the genes for religious belief. The rise of genomics did not change the nature of the science, but only refined the tools of the search, continuing to marginalize certain human genetic subsets (Porter 2014). Genomics has endorsed the continued public health project of restricted reproduction by the unfit. Where global public health vigilance views the spread of infectious disease as constituting an emergency, national public health vigilance concerns itself with the decline of the national body, the reproduction of unfit citizens who are seen as failing to contribute to the image of the ideal citizen: white, healthy, and upper-middle class. Reproduction by anyone else constitutes a public health emergency.

#### National Bodies, National Policies: How the State Controls Reproductive Freedom

How is this concept of the proper national body enforced in a society increasingly aware of our eugenic past? After all, Nial Cox Ramirez stands as an example that states can and will, when pressed, respond to the harms of their past eugenic practices. But such recognition can take decades – although the ACLU suit that encompassed the harms done to Ramirez was announced in 1973,<sup>5</sup> a committee to discuss reparations for victims of North Carolina's eugenic policies first met in 2003 (Railey xv). And although a reparations law was finally passed in 2013, NPR reported in 2014 that many of those sterilized during the period may not qualify because they were sterilized through means other than the official Eugenics Board of North Carolina (Mennel). Certainly there is room for acknowledgment of past wrongs, but that does not preclude the creation of new eugenic programming. The new eugenics could not afford to take a step back from what it then viewed and continues to view as a public health emergency.

In the early 1990s, a new approach to the national public health emergency of undesirable births began to emerge: the coercive use of Norplant, a long term, implantable birth control method. Similar to the insertion of sterilization as a critical aspect of Jasmine Randers' plea deal negotiations, judges in the early 1990s were known to give women the choice between jail time and the use of Norplant (ACLU, "Norplant"). In other cases during this time period, state legislators introduced measures to incentivize the use of Norplant by women receiving government aid (Gold 2014). Though none of the twenty proposed laws passed their respective legislative bodies, some came close; replacing them, as Nancy Ordover explains, was a kind of voluntary eugenics. It may not have been possible to demand contraceptive use through legal pathway; instead a child exclusion of "family cap" legislation allowed states to refuse welfare benefits to children born under certain conditions, typically within 10 months or more of an application to the

<sup>&</sup>lt;sup>5</sup> The original ACLU suit sought \$1 million in damages for Nial Cox Ramirez. She ultimately lost, though one of the defendant parties (there were several) awarded Ramirez a few thousand dollars to avoid an appeal (Railey xiii).

state welfare program (Ordover 191). By refusing public assistance benefits to children born while their mother or families are on welfare, state governments create incentives for the use of long acting birth control options, like Norplant and Depo Provera, although they cannot legally require it.

Still, while the plea deal and sentencing procedures of the legal system may require a level of transparency that prevents the ongoing use of birth control and/or sterilization as conditions of legal leniency, once women are filtered into the prison system the protection that transparency offers tends to disappear. This is how nearly 150 female inmates were sterilized in the California prison system between 2006 and 2010 according to The Center for Investigative Reporting (Johnson). In light of this revelation, California has since taken steps to prevent this from happening again, signing into law a piece of legislation protecting the reproductive rights of inmates (McGreevy and Mason), but this is just one of fifty states and, more importantly, the original actions were an abuse of power. Abuses of power do not necessarily abide by legal restrictions.

The management of reproduction among women with disabilities is similar in many ways to what women of color and poor women experience, but what is remarkable is that, whereas for most other women sterilization abuse has lost its place of prominence to other restrictive practices, disabled women are more likely to still be subject to coercive sterilization. Indeed, while *Buck v. Bell* has never been overturned, virtually the opposite has happened since the 1980s. There are two cases worth highlighting in this regard. One case, referred to as *In re Valerie N.*, arose in California and was adjudicated in 1985. At that time in California, there was in fact a law banning the sterilization of the mentally disabled, a law which was challenged by the parents of the woman in question

as they were her legal conservators. The court ultimately ruled that the general ban on sterilization was impermissible and in fact in violation of the privacy and liberty granted by the Fourteenth Amendment (Cepko 1993).

The second case, *in re Moe*, a Massachusetts case that came before the court in 1982, the question was positioned differently as Massachusetts had no legislation equivalent to the California sterilization ban. Rather, in this case, the court approved a sterilization request using language carefully meant to establish a kind of eugenics-oriented permission without overstepping what by then was a clear boundary of contemporary consciousness. In order to do this, the court asserted that the sterilization of the woman in question was not compulsory, and therefore permissible (Cepko 1993). This established a low standard for bodily interventions and one that was in line with historical abuses of power over the disabled. Courts have continued to approve such sterilizations in the years since these cases, including in *In re Wirsing*, a 1998 Michigan case (Cantor 233); there have also been controversial cases outside the courts, particularly regarding the use of growth attenuation, of which sterilization is one component (Coombes 2007).

For those women whose bodies do not fall within the catchment of reproductive exclusion, the state offers a gentler set of interventions. One example of this is the CDC's "Show Your Love" campaign. "Show Your Love" is a campaign targeted at helping women manage their reproductive health, whether or not they wish to have a child, and there are different sets of talking points for women who hope to become pregnant in the near future and those who hope to prevent a pregnancy. The complete slogan for the campaign, however, is "Show your love. Your baby will thank you for it" and the ultimate target found on the CDC website is on preconception health (CDC,

"Preconception Care and Health Care"). The goals are noble and read as clearly in line with most prenatal care advice, and yet the reality is that many individuals targeted by these campaigns will struggle to fulfill the complete array of aims. Here I will take poverty as an example of how the idealized pregnant body peremptorily excludes certain groups that have been considered unfit over the long term, such as women of color, disabled women, or impoverished women, or, because these conditions tend to be linked, some combination thereof.

The CDC offers a number of resources to support the Show Your Love campaign, including images to link to your website, pamphlets, buttons, talking points, and posters (CDC, "Preconception Care and Health Care"), but here I will focus specifically on the contents of the complete Show Your Love checklist for women who hope to become pregnant, entitled "Show Your Love! Steps to a Healthier me and baby-to-be!" This checklist is meant to be used for long-term planning that, by setting two or three goals a year, should prepare a woman to be in optimal health when she becomes pregnant. This goal-oriented health strategy may also be misleading in that it plays into notions about the level of control we can exert over our reproductive lives and the health of any children that are conceived (Willingham). Still, good maternal health is a powerful predictor of good fetal and infant health, and as such the CDC's intentions make sense even as they erase the factors that can prevent women from accomplishing the presented health goals.

The CDC's Show Your Love checklist asks women to first do some planning: how many children would they like to have, how old would they like to be when they become pregnant, how far apart would they like to have their children. Already this leaves out complicating factors like conceiving multiples, fertility issues that prolong the conception process, or failing birth control, but this is a plan and so here we function in ideals. Another part of the checklist suggests "avoid[ing] harmful chemicals, metals, and other toxic substances around the home and in the workplace." This is a far more difficult task for women living in poverty, as they are more likely to work in environments that contain more toxic substances, such as in factories, and are also more likely to live in areas with greater pollution. Formulations like this make it clear that the Show Your Love campaign is constructed around a population subset with greater racial and economic security. The campaign feeds into contemporary constructions of maternity without actually intervening in individual lives. It is simple enough to describe your ideal population demographics without being direct about who is excluded.

The central problem of the Show Your Love campaign is that, although this may be a list of ideal conditions for pregnancy, it remains that by presenting goals that are inaccessible to certain population groups, those goals that remain accessible are joined in the alienation. Rather than targeting women based on their access needs and offering resources or ideas for coping with those things that may be out of their control, such as toxic workplace exposures, the Show Your Love campaign leaves women to wonder what the implications of non-compliance will be. If your baby will thank you for actions that improve your health, will you be found unfit if you cannot perform those actions? The unspoken answer is yes, you very well might be. And when you are found unfit, you will be inserted into the new framing of national public health vigilance; yours is the body this vigilance hopes will not reproduce.

#### The Cure Ideology: Preventing the Undesirable Body

If one factor can be said to have most changed the face of the new eugenics and conditioned us to understand disability as a public health crisis, that single thing is decidedly the development, refinement, and increased use of prenatal diagnostic technologies. Prenatal diagnosis is now a pervasive part of obstetrics in the United States and allows for significant insight into the biological particularities of a pregnancy early on, specifically early enough for the pregnancy to be legally terminated. There are many different forms of prenatal diagnostic technology, ranging from basic sonograms that can detect structural development issues, to blood tests that allow doctors to detect genetic abnormalities, and even preimplantation diagnostic technologies that allow parents and doctors to deselect specific embryos before they are implanted into a woman. The complexity of contemporary prenatal diagnostics has also given way to a legal framework known as wrongful birth, a concept that I will return to. In all of these cases, however, the overall force of their existence is oriented towards the elimination of disabled individuals before birth, or, in the case of wrongful birth, the straightforward statement that this person should not have been born. Disability is to be prevented; this simple statement in large part constitutes the fullness of contemporary cure ideology. We can cure disabilities by preventing people with them from being born at all. Somewhere the emergency bell has sounded.

From a feminist perspective, we immediately encounter a problem with part of this line of thinking, specifically the part that says that we are preventing people with disabilities from being born. How does this statement fit within a feminist choice framework that typically works to divest itself from the language of personhood in
reference to fetuses? Can we acknowledge the human potential of the fetus and the characteristics of that future human and still stake a complete ethical claim for abortion? There are certainly conflicting answers to this, but for my purposes here I will let the noted feminist bioethicist Adrienne Asch set the terms. Asch offers us two key means of assessing the use of selective abortion in cases of a prenatal diagnosis of disability: the any/particular distinction and the expressivist argument.

Beginning with the any/particular distinction, Asch's argument states that there is a distinction between choosing abortion based on the particular trait possessed by a fetus and choosing abortion on the premise that you do not wish to bear/parent any child at this time (Parens and Asch 15). To select based on a particular trait is to enact a variety of prejudice against an otherwise wanted child. More specifically, to select based on disability has pernicious effects in that it also has an expressive component; to individuals with disabilities this choice suggests that their lives are less valuable or less worth living than the lives of able-bodied/able-minded individuals. To other children, this choice can express the idea that they would not be loved if something happened to them resulting in a disability, or that if they fail to live up to a particular standard they may fall out of the good graces of their family or society (Parens and Asch 13).

Asch's argument sets forth valuable concerns, but the argument falls short in several regards, including from the feminist perspective that emphasizes the empowerment of women to make independent reproductive choices. Eva Feder Kittay and James Lindemann Nelson raise the important point that the use of prenatal testing and the decisions made because of these tests rarely send a singular message, but rather are fully invested in a range of complex life realities, such as available resources (financial, physical, or emotional) for raising a disabled child, among other issues (Parens and Asch 14-15). Expressivity has its, but in social conditions that are heavily influenced by the historic and ongoing use of eugenic practices, it is an argument worth acknowledging. Just as women are too often left out of conversations about our own reproductive lives, disabled people are commonly excluded from conversations about not only our rights, but our existence at all. Both of these disadvantaged groups, then, require a hearing in the face of the new eugenics.

Although women are commonly left out of the large-scale discussions about our reproductive lives, when it comes to the individual decisions that help to construct the new eugenics, women in fact have a significant amount of power. They sit in the doctor's office, consent to tests, and often make the ultimate decisions about termination, though these decisions are heavily informed by cultural messages, partner pressures, and material resources. With this in mind, Rayna Rapp expands on Adrienne Asch's understanding of selective abortion by situating the pregnant woman as moral philosopher and even the gatekeeper who decides who may enter the human community. This level of responsibility holds women to a high moral standard, suggesting that a significant component of community prejudice is rooted in women's reproductive choices. Here, women are given not just the responsibility of choosing between life and death (if it is believed that those terms apply to the particular point in pregnancy), but also of negotiating what makes a life valuable. Is a life lived with a disability a life worth living? And additionally, is a life spent raising a child with a disability a life worth living? The question circulates in both ways; to opt for selective abortion is to speak to both of these concerns. The first question concerns itself largely with questions of intrinsic worth, as

well as issues of pain, suffering, and exclusion, while the second question pushes up against problems of community/social support and resources, both material and emotional. When we speak of lives worth living in these scenarios, then, we speak not just of the life of the disabled individual, but also of their primary caretakers, typically mothers. The gendered distribution of labor and lack of social support for things like respite care cannot be overlooked when interrogating the ethics of selective abortion.

This is the ethical crossroads that the use of prenatal diagnostic technologies occupies and it needs to be acknowledged. The new eugenics has made itself pervasive, offering those women with access to good prenatal care the ability to test their way to assurance, the dream of the perfect child. It also penalizes those who are poor, women of color, or already living with a disability themselves. Even if they have access to good prenatal care, if forces outside their control do not sterilize them before they reach adulthood, these are the women who live on the radar of social services, whose children can be snatched away from mothers who were never seen as truly maternal. The maternal is a narrow field, shaped by images of purity, of the perfect mother and her perfect child. Anything less will not do.

What statistics we have about prenatal testing and selective abortion show clearly this adherence to the maternal dream. In 2013, Amy Julia Becker reported for *The Atlantic* that between 70 and 85% of women who receive a prenatal diagnosis of Down syndrome choose to abort. Interestingly, Becker also notes that these numbers are down, even though availability and accuracy of testing are both up. Rather, it seems that to some extent testing is used in the service of preparation for having a disabled child, instead of only for terminating. Yet 70-85% of pregnancies is a high rate of termination for a condition that is generally not life threatening and while Down syndrome is highly variable in severity, the severity cannot be determined prenatally. In this case, Becker's assertion that more prenatal testing does not lead to more abortions is an unremarkable assertion; the number of diagnoses that do end in termination remains large. If looked at from the angle of Asch's expressivity argument, the cultural message is clear: we are better off without so many disabled children, without future disabled adults who will weigh on families and government support systems.

Importantly, the prevalence of termination does not end with this single diagnostic category. A 2005 study showed that given availability of screening, 87% of women carrying a fetus with fragile X syndrome would terminate a pregnancy (Musci and Caughey), while a 2012 study of prenatal diagnosis of spina bifida, a condition with high survival rates as well as one that has benefited from significant treatment advancements allowing for independent living, showed a 56% termination rate (Trudell and Odibo). In cases of hypoplastic left heart syndrome, a condition that used to be considered fatal, but which is not frequently correctable through surgery, 63% of parents chose to either terminate the pregnancy after diagnosis or declined post-natal interventions in favor of palliative care (Fruitman 2000). Whether or not we take these terminations in the nature of the expressivist argument, the signs are clear: we are not individually or socially equipped to accept disabled lives among the general population. How do we understand this new mode of eugenics that places individuals in the position of power? In a society that offers little in the way of social supports, can termination be considered an individual choice, or is it conditioned by the lack of safety nets? It is difficult to determine what is at work here, but a eugenic perspective continues to be spoken from positions of power, by

such figures as the Princeton-based ethicist Peter Singer, in the language of wrongful birth suits and their media coverage, and in the sympathy often extended to parents who kill their disabled children. We endorse the new eugenics when we extend a hand of welcome to those whose rhetoric and actions work to eliminate people with disabilities or who debase and discredit their humanity. Unfortunately, that welcome is extended far too frequently.

Wrongful birth suits are a compelling area of inquiry when thinking about the eugenic structuring of our society. In most cases, the goal of a wrongful birth suit is to make life less difficult for the family involved; their child typically has a severe disability and they are not equipped with the necessary material resources to facilitate raising this child. Thus, the charge says that the doctor has failed in their job because, had they been properly vigilant, the family could have terminated the pregnancy. The statement is one about resources, but it is easily interpreted as one about disabled people. How can parents sue for wrongful birth without inherently appealing to the idea that this is not a life worth living? A 2006 article by Elizabeth Weil puts the question into a common perspective. Reporting on the difficult issue of wrongful birth in both historic and contemporary perspectives, Weil unfolds the significant diagnostic technologies now at our disposal. The result of these, she explains, is that we may not have unreasonable expectations about childbearing. We assume that " if we choose to take advantage of contemporary technology, major flaws in our fetus's health will be detected before birth" and that "we will be able to do something — namely, end the pregnancy — if those flaws suggest a parenting project we would rather not undertake" (Weil). This isn't always the case, as it was not for Donna Branca whose son was born with Wolf-Hirschhorn syndrome in 1999.

While she loves her son, Branca was unprepared for his birth, unprepared for this parenting project, as Weil phrases it. Is this really a wrongful birth?

Wrongful birth as a construction hinges on a feminist, post-*Roe v. Wade* mentality, wherein abortion is seen as accessible and always a valid choice. This alone is not a problem, and yet Adrienne Asch's framings of the any/particular distinction and the expressivist argument still stand. What does it mean that we hurry towards these interventions, towards termination of lives and bodies seen as less than perfect? The new eugenics thrills at this possibility, that we can steadily intervene towards a healthier and more perfect society, while disability activists shudder to think that being disabled is an endangered state. Both sides would argue for a national public health crisis, to demand that we use these technologies more rigorously or more sparingly, respectively. The public health vigilance perspective, the perspective that has sought to alert populations to health threats and then systematically eliminate those health threats, would find itself aligned with the former perspective. Eliminate, abort, terminate; this is the language of vigilance, of the new eugenics.

Finally, it is vital to look at the language used in media reports of parents who kill their disabled children. These are the parents who could not sue for wrongful birth, but who felt it deeply, so deeply that they would reach for any justification to kill their disabled child. Often these are children with autism, a condition constantly spoken of as having reached epidemic levels (Eyal 2013). Autism coverage is almost universally framed in terms of public health vigilance, perhaps more than any other condition in the last several decades. Vigilance has led us down false paths. And when nothing has turned up answers, we find ourselves watching two sets of numbers steadily grow: the number of people diagnosed with autism and the number of autistic people killed by their parents or caregivers.

In response to the second column, Emily Willingham wrote an article for *Forbes* in 2013, posing the titular question, "If A Parent Murders An Autistic Child, Who Is To Blame?" No matter how complex the ethics posed by things like the any/particular distinction and the expressivist argument, here it seems that the ethics should not be nearly so complicated. Why even ask the question? Willingham asks the question precisely because, as she puts it, "It's become typical, again and again, for parents who murder their autistic children to get some kind of a 'pass' from the commentariat and the news media because, well, autism is 'such a challenge." Willingham recognizes that this is unacceptable, that sympathy belongs solely with the person killed, and yet mainstream news media has crafted a second set of standards, standards for dealing with this public health emergency. The ideology of cure and the ideal concept of the able national body make it permissible to murder when that murder upholds the model of disease eradication being promulgated by medical, intellectual, and popular sources.

## **Conclusion: The New Eugenics and Exclusionary Visions of the Maternal**

After two years in prison while her trial made its way through the Tennessee courts, Jasmine Randers' mental health is in a worse condition than when the saga began. Although she was placed in a mental health facility to be stabilized after the trial ended, two months later her mother was not hopeful. Instead she is concerned that the time in jail may have sent her daughter away, too far to reach. "I worry about that, that we'll never really get her back again," Randers mother told reporter Stacey Barchenger. If the death of her child was not trauma enough, two years in jails without the necessary mental health services certainly served as a compounding factor. This is the state of mental health care in the United States today, however. Jails stand in for the former asylum and, as see with the sterilization cases in California, jails are not exempt from perpetrating the same crimes against inmates that asylums once subjected patients to. This is not an accident, an uncanny resemblance. It is the workings of the new eugenics.

Since 1980, women's incarceration rates have increased 646 percent (Moshenberg). This timeline coincides with President Jimmy Carter passing the Mental Health Systems Act in 1980 and its subsequent dismantling in 1981 under President Reagan. Reagan's cuts decreased federal mental health spending by 30 percent (Pan). Prisons now house a large number of those who otherwise would be better served by nonexistent community mental health programs, but they rarely provide the necessary mental health services that inmates require while simultaneously compounding the trauma (whether from domestic violence, sexual assault and rape, or other sources) most incarcerated women have experienced. But what the prison system does accomplish is at least a temporary hold on reproduction by those who would be considered unfit and a means of increasing institutional observation and intervention into their families by removing children for placement in the foster care system, for example. Additionally, about 4 percent of women are pregnant when they enter the prison system (Quinn); these mothers are almost always separated from their children immediately. Although most children of incarcerated parents remain in the care of relatives, as of 2004 10.9% of children with mothers in prison are in foster care, compared to only 2.2% of those children with an incarcerated father (Glaze and Maruschak 2010). Where children cannot be prevented, re-homing them with foster parents who may be viewed as more "fit" can

fulfill some of the goals of the new eugenics. Mothers in prison are not part of how either the state or the larger culture envision the maternal.

But what is the maternal today? The ideal contemporary figure of the maternal is constituted through a number of features, most importantly as white, nondisabled, and middle class. They are married and have a social support structure outside the state. They use birth control responsibly and have children with proper prenatal care. Very little makes this figure of the maternal any different from the maternal at other times in history. It is an exclusive club, much as it has always been, but perhaps with even more rules now than ever before. Before, a mother who had a child with Down syndrome could not be blamed, but now it is not uncommon for women to be asked of their child, "weren't you tested?" If knowledge brings with it an equal measure of responsibility, than the advances in prenatal diagnosis have placed a heavy burden on mother today.

The new eugenics understands the contemporary desire for control, and in mastering that desiring it has shifted the locus of responsibility in the direction of the individual. It is no longer the state that coercively sterilizes disabled people, but rather their families that elect to have them sterilized. And by failing to provide significant social supports for birthing and raising disabled children, the state creates an environment more conducive to pregnancy termination. The new eugenics does not rely on actions on the part of the state. Instead, the new eugenics refuses to act; specifically, it refuses to act in such a way as to make what it considers an undesirable outcome not just inconvenient but sometimes impossible relative to the available resources. If the state does not provide, will those deprived of reasonable social goods fall into line? This is the hope of the new eugenics. The new eugenics speaks the language of national public health vigilance, of the idealized national body, and that body is made manifest in the culture. We act in the manner of this vigilance without being told because we are accustomed to fostering the best possible version of the national body; nearly a century of eugenics has trained us well. And as for the rest? Those who fall outside of those parameters can only hope for the scraps that fall from the table. That is what they have always survived on.

## Bibliography

- ACLU. "Child Exclusion Policies in Welfare." American Civil Liberties Union. <a href="https://www.aclu.org/child-exclusion-policies-welfare-reform">https://www.aclu.org/child-exclusion-policies-welfare-reform</a>. Undated. Accessed 31 October 2015.
- -- "Norplant: A New Contraceptive with the Potential for Abuse." American Civil Liberties Union. <a href="https://www.aclu.org/norplant-new-contraceptive-potential-abuse">https://www.aclu.org/norplant-new-contraceptive-potential-abuse</a>>. Undated. Accessed 31 October 2015.
- "Aggravated Child Abuse and Neglect." Office of the Attorney General, State of Tenneesee. 24 October 2008.
- Barchenger, Stacey. "A dead baby, an ill mother and a DA's intervention: Sterilization as bargaining chip in child neglect case prompts district attorney to take notice." *The Tennessean.* 17 March 2015.
- Becker, Amy Julia. "Better Prenatal Testing Does Not Mean More Abortion." *The Atlantic*. <http://www.theatlantic.com/health/archive/2013/02/better-prenataltesting-does-not-mean-more-abortion/273053/>. 21 February 2013. Accessed 31 October 2015.
- Black, Edwin. War Against The Weak: Eugenics and America's Campaign to Create a Master Race. New York: Four Walls Eight Windows, 2003.
- Burlingame, Phyllida. "Stop Sterilization Abuse in California Prisons." American Civil Liberties Union of Northern California. <a href="https://www.aclunc.org/blog/stop-sterilization-abuse-california-prisons">https://www.aclunc.org/blog/stopsterilization-abuse-california-prisons</a>>. 1 August 2014. Accessed 31 October 2015.
- Cantor, Norman L. *Making Medical Decisions for the Profoundly Mentally Disabled*. Cambridge, MA; The MIT Press, 2005.
- CDC. "Preconception Care and Health Care." Centers for Disease Control and Prevention. <a href="http://www.cdc.gov/preconception/showyourlove/">http://www.cdc.gov/preconception/showyourlove/</a>. 1 February 2013. Accessed 31 October 2015.
- -- "Show Your Love! Steps to a Healthier me and baby-to-be!" Centers for Disease Control and Prevention. <http://www.cdc.gov/preconception/showyourlove/documents/healthier\_baby\_me
  - <a href="http://www.cdc.gov/preconception/showyourlove/documents/healthier\_baby\_meg\_plan.pdf">http://www.cdc.gov/preconception/showyourlove/documents/healthier\_baby\_meg\_plan.pdf</a>>. Undated. Accessed 31 October 2015.
- -- "Sudden Unexpected Infant Death and Sudden Infant Death Syndrome." Centers for Disease Control and Prevention. 22 October 2015.
- Cenziper, Debbie. "A disputed diagnosis imprisons parents." The Washington Post. <http://www.washingtonpost.com/graphics/investigations/shaken-babysyndrome/The-unsettled-science-of-Shaken-Baby-Syndrome.html>. 20 March 2015. Accessed 24 October 2015.
- Cepko, Roberta. "Involunetary Sterilization of Mentally Disabled Women." 8 *Berkeley Women's Law Journal* 122 (1993).
- Collins, Sam P.K. "Tennessee Prosecutor Insisted Woman Undergo Sterilization As Part Of Plea Deal." Think Progess.

<http://thinkprogress.org/health/2015/03/30/3640543/mentally-ill-womansterilization- case/>. 30 March 2015. Accessed 23 October 2015.

Coombes, Rebecca. "The Week in Medicine: Ashley X: A Difficult Moral Choice." *BMJ: British Medical Journal* 334:7584 (January 13, 2007), 72-73.

- Dean, Cornelia. "James Watson Retires After Racial Remarks." <http://www.nytimes.com/2007/10/25/science/25cnd-watson.html?\_r=0>. *The New York Times.* 25 October 2007. Accessed 12 November 2015.
- Dixon, Darrin P. "Informed Consent or Institutionalized Eugenics? How the Medical Profession Encourages Abortion of Fetuses with Down Syndrome." *Issues in Law* & *Medicine*, 24:1 (2008), 3-59.
- Eyal, Gil. "For a Sociology of Expertise: The Social Origins of the Autism Epidemic." *American Journal of Sociology*, 118:4 (January 2013), 863-907.
- Foucault, Michel. *The History of Sexuality: An Introduction, vol. 1.* New York: Vintage Books, 1990.
- Fruitman, Deborah S. "Hypoplastic left heart syndrome: Prognosis and management options." *Pediatrics & Child Health*, 5:4(May-June 2000), 219-225.
- Glaze, Lauren E. and Laura M. Maruschak. "Bureau of Justice Statistics Special Report: Parents in Prison and Their Minor Children." U.S. Department of Justice. 30 March 2010.
- Gold, Rachel Benson. "Guarding Against Coercion While Ensuring Access: A Delicate Balance." *Guttmacher Policy Review* 17: 3 (Summer 2014). Accessed 31 October 2015.
- Hale, Steven. "Controversial (and recently fired) ADA Brian Holmgren defends plea bargaining tactics." Nashville Scene. 26 March 2015. Accessed 28 October 2015.
- Johnson, Corey G. "Female inmates sterilized in California prisons without approval." The Center for Investigative Reporting. <a href="http://cironline.org/reports/female-inmates-sterilized-california-prisons-without-approval-4917">http://cironline.org/reports/female-inmates-sterilized-california-prisons-without-approval-4917</a>>. 7 July 2013. Accessed 31 October 2015.
- King, David S. "Preimplantation Genetic Diagnosis and the 'New' Eugenics." *Journal of Medical Ethics*, 25:2 (April 1999), 176-182.
- Lantos, John. "It's Not the Growth Attenuation, It's the Sterilization!" *The American Journal of Bioethics*, 10:1 (2010), 45–60.
- Lohr, Kathy. "Should Parents Be Able To Sue For 'Wrongful Birth'?" NPR. <http://www.npr.org/sections/health-shots/2012/05/15/152687638/shouldparents-be-able-to-sue-for-wrongful-birth>. 15 May 2012. Accessed 31 October 2015.
- Lombardo, Paul A. ed. A Century of Eugenics in America: From the Indiana Experiment to the Human Genome Era. Bloomington & Indianapolis: Indiana University Press, 2011.
- McGreevy, Patrick and Melanie Mason. "Gov. Brown signs bills on birth control, inmate rights." *Los Angeles Times*. <http://www.latimes.com/local/politics/la-me-polbrown-bills-20140926-story.html>. 25 September 2014. Accessed 31 October 2015.
- Mennel, Eric. "Payments Start for N.C. Eugenics Victims, But Many Won't Qualify." NPR.

<http://www.npr.org/sections/healthshots/2014/10/31/360355784/paymentsstart-for-n-c-eugenics-victims-but-many-wont-qualify>. 31 October 2014. Accessed 31 October 2015.

Milmo, Cahal. "Fury at DNA pioneer's theory: Africans are less intelligent than Westerners." <a href="http://www.independent.co.uk/news/science/fury-at-dna-pioneers-">http://www.independent.co.uk/news/science/fury-at-dna-pioneers-</a> theory-africans-are-less-intelligent-than-westerners-394898.html>. *Independent*. 18 September 2011. Accessed 12 November 2015.

- "More Doctors Questioning 'Shaken-Baby Syndrome." NPR. <a href="http://www.npr.org/2011/02/09/133625794/More-Doctors-Questioning-Shaken-Baby-Syndrome">http://www.npr.org/2011/02/09/133625794/More-Doctors-Questioning-Shaken-Baby-Syndrome</a>>. 9 February 2011. Accessed 24 October 2015.
- Moshenberg, Dan. "The growth of women's incarceration in the United States." Women in and Beyond the Global. <a href="http://www.womeninandbeyond.org/?p=13371">http://www.womeninandbeyond.org/?p=13371</a>. 1 May 2014. Accessed 31 October 2015.
- Musci, Thomas J. and Aaron B. Caughey. "Cost-effectiveness analysis of prenatal population-based fragile X carrier screening." *American Journal of Obstetrics and Gynecology*, 192:6(June 2005), 1905-1912.
- NCSL. "Family Cap Policies." National Conference of State Legislatures. <a href="http://www.ncsl.org/research/human-services/welfare-reform-family-cap-policies.aspx">http://www.ncsl.org/research/human-services/welfare-reform-family-cap-policies.aspx</a>. July 2009. Accessed 31 October 2015.
- Ordover, Nancy. American Eugenics: Race, Queer Anatomy, and the Science of Nationalism. Minneapolis: University of Minnesota Press, 2003.
- Ouellette, Alicia. *Bioethics and Disability: Toward a Disability-Conscious Bioethics*. New York: Cambridge University Press, 2011.
- Pan, Deanna. "TIMELINE: Deinstitutionalization And Its Consequences." *Mother Jones*. 29 April 2013. Accessed 31 October 2015.
- Parens, Erik and Adrienne Asch eds. *Prenatal Testing and Disability Rights*. Washington, D.C.: Georgetown University Press, 2000.
- Porter, Theodore M. "In Whose Name? Eugenicists and Geneticists." *Historical Studies in the Natural Sciences* 44:5 (November 2014), 509-513.
- Quinn, Audrey. "On Prison and Pregnancy." Life of the Law. <a href="http://www.lifeofthelaw.org/2013/12/on-prison-and-pregnancy/">http://www.lifeofthelaw.org/2013/12/on-prison-and-pregnancy/</a>>. 17 December 2013. Accessed 31 October 2015.
- Railey, John. Rage and Redemption in the Sterilization Age: A Confrontation with American Genocide. Eugene, Oregon: Cascade Books, 2015.
- Rapp, Rayna. Testing Women, Testing the fetus: The Social Impact of Amniocentesis in America. New York: Routledge, 1999.
- Reardon, Jenny. *Race to the Finish: Identity and Governance in an Age of Genomics*. Princeton: Princeton University Press, 2005.
- Roberts, Dorothy. *Fatal Invention: How Science, Politics, and Big Business Re-Create Race in the Twenty-First Century.* New York: The New Press, 2011.
- -- *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty.* New York: Pantheon Books, 1997.
- -- "Race, Gender, and Genetic Technologies: A New Reproductive Dystopia?" *Signs* 34:4(Summer 2009), 783-804.
- Trudell, Amanda S. and Anthony O. Odibo. "Diagnosis of spina bifida on ultrasound: Always termination?" *American Journal of Obstetrics and Gynecology*, 28:3(April 2014), 367-377.
- Volokh, Eugene. "Sterilization of the 'intellectually disabled." *The Washington Post.* <<u>https://www.washingtonpost.com/news/volokh-</u>conspiracy/wp/2014/04/18/sterilization-of-the-intellectually-disabled/>. 18 April 2014. Accessed 31 October 2015.

- Watson, James D. "James D. Watson: Chancellor Emeritus." <https://www.cshl.edu/gradschool/james-d-watson.html>. Cold Spring Harbor Laboratory. 2015. Accessed 12 November 2015.
- Weil, Elizabeth. "Wrongful Birth?" *The New York Times Magazine*. <a href="http://www.nytimes.com/2006/03/12/magazine/312wrongful.1.html?pagewanted">http://www.nytimes.com/2006/03/12/magazine/312wrongful.1.html?pagewanted</a> =all& r=0>. 12 March 2006. Accessed 31 October 2015.
- Weir, Lorna and Eric Mykhalovskiy. *Global Public Health Vigilance: Creating a World on Alert.* New York: Routledge, 2010.
- Willingham, Emily. "If A Parent Murders An Autistic Child, Who Is To Blame?" Forbes. <a href="http://www.forbes.com/sites/emilywillingham/2013/09/05/if-a-parent-murders-an-autistic-child-who-is-to-blame/">http://www.forbes.com/sites/emilywillingham/2013/09/05/if-a-parent-murders-an-autistic-child-who-is-to-blame/</a>. 5 September 2013. Accessed 31 October 2015.