Privatization and Punishment in the New Era of Reprogenetics

Dorothy E. Roberts
University of Pennsylvania Carey Law School

Follow this and additional works at: https://scholarship.law.upenn.edu/faculty_scholarship

Part of the Gender and Sexuality Commons, Health Law and Policy Commons, Health Policy Commons, Inequality and Stratification Commons, Law and Gender Commons, Medicine and Health Commons, Obstetrics and Gynecology Commons, Policy Design, Analysis, and Evaluation Commons, Race and Ethnicity Commons, Science and Technology Policy Commons, Social Welfare Commons, and the Social Welfare Law Commons

Repository Citation
https://scholarship.law.upenn.edu/faculty_scholarship/579

This Article is brought to you for free and open access by Penn Law: Legal Scholarship Repository. It has been accepted for inclusion in Faculty Scholarship at Penn Law by an authorized administrator of Penn Law: Legal Scholarship Repository. For more information, please contact PennlawIR@law.upenn.edu.
PRIVATIZATION AND PUNISHMENT IN THE NEW AGE OF REPROGENETICS

Dorothy E. Roberts

INTRODUCTION

My scholarship on reproduction has made me acutely aware of the stratification of childbearing in the United States.¹ In particular, the social value placed on a woman’s reproduction depends on her standing within the hierarchies of race, class, and other inequitable divisions. My research highlights the harsh dichotomy where policies punish poor black women for bearing children but advanced technologies assist mainly affluent white women not only to have genetically-related children, but to have children with preferred genetic qualities.² In this regard, I have worked with organizations opposing a program offering substance-abusing women in minority neighborhoods money to be sterilized³ and attended many fancy conferences where academics debate precisely which traits are acceptable to select for when testing an array of embryos for implantation.⁴ While welfare reform

¹ See Rayna Rapp, Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America (1999) (discussing the stratification of reproduction in the context of prenatal testing); Shellee Colen, “Like a Mother to Them”: Stratified Reproduction and West Indian Childcare Workers and Employers in New York, in CONCEIVING THE NEW WORLD ORDER 78, 78 (Faye D. Ginsburg & Rayna Rapp eds., 1995) (arguing that “physical and social reproductive tasks are accomplished differentially according to inequalities that are based on hierarchies of class, race, ethnicity, gender, place in a global economy, and migration status and that are structured by social, economic, and political forces”).


⁴ See, e.g., Gamal I. Serour, Dir., Int’l Islamic Ctr. for Population Studies and Res., Al-Azhar Univ., Egypt, Ethical Guidelines for Gender Selection: Are They Needed?, Address at the University of Michigan’s
laws aim to deter women receiving public assistance from having even one additional healthy baby, largely unregulated fertility clinics regularly implant privileged women with multiple embryos, knowing the high risk multiple births pose for premature delivery and low birth weight. The public begrudges poor mothers a meager increase in benefits for one more child, but celebrates the birth of high-tech septuplets that require a fortune in publicly-supported hospital care.

At the beginning of the twenty-first century, the race and class dimensions of reproduction, a chief way of creating families, are clear. My prior writing on the stratification of reproduction contrasted policies that penalize the childbearing of poor nonwhite women with policies that promote childbearing by wealthier white women. I take a different tack in this article. Rather than place these two categories of women in opposition, I explore how the privatization and punishment of reproduction links them together to avoid public responsibility for social inequities. Both population control programs and genetic selection technologies reinforce biological explanations for social problems and place reproductive duties on women that shift responsibility for improving social conditions away from the state. Reproductive health policies involving both categories of women play an important role in the neo-liberal state’s transfer of services from the welfare state to the private realm of family and market.


7 See LORI B. ANDREWS, THE CLONE AGE: ADVENTURES IN THE NEW WORLD OF REPRODUCTIVE TECHNOLOGY 55 (1999) (noting that the McCaughey septuplets “required forty health care professionals, divided into seven teams, at an estimated cost of up to $1 million”); id. at 61 (noting that the McCaugheys received numerous expensive gifts, including a six thousand square foot house built with private donations, a Toyota minivan, and a lifetime supply of Pampers); Tucker McQueen, Party of Five: Parents of Quintuplets Give Support, Friendship to Couple about to Experience Similar Difficulties—and Joys, ATLANTA J.-CONST., Nov. 1, 2004, at 1E.

Viewing new reproductive technologies as a form of private regulation of women’s childbearing decisions complicates the choice-versus-regulation dichotomy that typically frames discussions of these technologies’ costs and benefits. Technologies that enable women to have children and to select those children’s genetic traits are often viewed as entirely freedom-enhancing tools that should therefore be free from state regulation. I argue, however, that like the reproductive regulations imposed on less privileged women, use of these technologies has the potential to restrict women’s control over reproduction while reinforcing social hierarchies that disadvantage women. Thus, it is possible that some state regulation of the technologies will promote rather than hamper women’s reproductive freedom. More importantly, recognizing the restrictive potential of reprogenetics supports greater state investment in eliminating the systemic inequities that make these technologies seem so attractive for addressing disability and illness. Rather than expand public surveillance and regulation of women’s reproductive decisions, we should tackle the social conditions that limit women’s options for bearing and raising healthy children who can flourish in this society.

A. Punishing Reproduction, Privatization, and Social Inequality

The turn of the twenty-first century has ushered in an explosion of rhetoric and policies seeking to punish and regulate poor and minority women’s reproductive decisions. Poor black women are especially vulnerable to proposals that punish childbearing. The view of black women as irresponsible reproducers is deeply embedded in the dominant American culture and reinforced by a disparaging mythology about black mothers.\(^9\) Negative icons of black maternity have included the sexually licentious Jezebel that legitimated white slave masters’ sexual exploitation of their female slaves; the asexual Mammy who, although she cared for her masters’ children, remained under the supervision of her white mistress; the emasculating Matriarch held responsible for the disintegration of the black family; and the sexually irresponsible Welfare Queen who bred children just to fatten her welfare check and then wasted the money recklessly on herself.\(^10\)

The most recent addition to this maternal mythology is the pregnant crack addict who is supposed to lack any maternal instinct. Newspaper articles portray pregnant black women addicted to crack cocaine as careless and selfish women who put their love for crack above their concern for their children.\(^{11}\) Reinforcing the link between black female sexual licentiousness and maternal irresponsibility, reporters often represent them as prostitutes who become pregnant after trading sex for crack.\(^{12}\) Unlike any other drug, the chemical properties of crack cocaine are said to destroy the natural impulse to mother.\(^{13}\) These women’s children are also the subject of gross racial stereotyping. Some reporters claim that so-called “crack babies” not only suffer physical and emotional damage, but are also more likely to become social pariahs.\(^{14}\) Noting the failure of medical research to substantiate any such condition, syndrome, or disorder, a group of researchers wrote that “‘Crack baby’ is not a medical diagnosis but a media stereotype.”\(^{15}\)

These stereotypes of black female sexual and reproductive irresponsibility support welfare reform and law enforcement policies that severely regulate poor black women’s sexual and child bearing decisions.\(^{16}\) Judges and legislators view poor black women as suitable subjects for harsh reproductive penalties because mainstream society does not view them as suitable mothers in the first place.\(^{17}\)

The rush to punish poor, substance-abusing mothers for their reproductive failures can be compared with the more temperate regulation of pregnant middle-class women who use risky pharmaceuticals to treat their mental health problems. For example, I was struck by the sympathy shown to mothers in a recent radio program discussing the dilemma of pregnant women who take Prozac and other SSRI (Selective Serotonin Reuptake Inhibitors), which have not been approved by the FDA for use during pregnancy because there is

\(^{11}\) See, e.g., ROBERTS, supra note 8, at 153–59 (citing articles); ASSATA ZERAI & RAE BANKS, DEHUMANIZING DISCOURSE, ANTI-DRUG LAW, AND POLICY IN AMERICA: A CRACK MOTHER’S NIGHTMARE 53 (2002).

\(^{12}\) ZERAI & BANKS, supra note 11, at 53.

\(^{13}\) See, e.g., Cathy Trost, Born to Lose: Babies of Crack Users Crowd Hospitals, Break Everybody’s Heart, WALL ST. J., July 18, 1989, at A1 (quoting a nurse as stating that “most remarkable and hideous aspect of crack cocaine use seems to be the undermining of the maternal instinct”); see also ZERAI & BANKS, supra note 11, at 50–57 (discussing newspaper articles that supported a “crusade against crack mothers” from 1988 to 1990).


\(^{15}\) Deborah A. Frank et al., Letter to the Editor, “Crack Baby” Syndrome, N.Y. TIMES, Nov. 28, 2003, at A42.

\(^{16}\) See ROBERTS, supra note 8, at 159–62; ZERAI & BANKS, supra note 11, at 142–43.

\(^{17}\) See ROBERTS, supra note 8, at 159–67.
evidence they may cause subtle neurological problems in newborns. A psychiatrist interviewed for the program explained that she tries to put the FDA warning in context: “Ultimately, when you are face-to-face with a woman struggling with depression or anxiety during or after her pregnancy, her experience of illness is, I think, the most important determinant of the right thing to do.” This attention to the depressed mother’s perspective contrasts starkly with the typical disregard of the needs and humanity of poor black women who self-medicate with crack cocaine.

By identifying procreation as the cause of deplorable social conditions, reproductive punishments divert attention away from the need for social change. Black mothers’ crack use, for example, became a primary explanation for high rates of black infant mortality, a trend long predating the crack epidemic. A recent exchange in the editorial pages of the New York Times iterated the tension between attributing worsening rates of infant death to the deficiencies of the U.S. health care system and to maternal substance abuse. Columnist Nicholas D. Kristof wrote that in 2002 the already abysmal infant mortality rate rose in this country to seven deaths for each thousand live births, placing the United States behind forty-one other countries, including Cuba. Kristof noted that by slashing entitlements, especially those giving children access to health care, the government is likely to exacerbate poor maternal and infant health.

In direct response to Kristof’s article, Barry S. Levy, an adjunct professor at Tufts Medical School and a past president of the American Public Health Association, endorsed Kristof’s diagnosis: “America’s world ranking of 42nd in infant mortality, like the obesity and smoking epidemics and the recent shortage of flu vaccine, reflects the overall decline in government support for public health.” But Betsy McCaughey, an adjunct senior fellow at the Hudson Institute, disagreed with Kristof’s focus on “the shortcomings of our health system,” arguing instead that “the high infant mortality rate reflects a

---

19 Id.
20 See ROBERTS, supra note 8, at 154–59.
22 Id.
society where young girls and women take drugs while pregnant and give birth to low-weight, drug addicted infants.\textsuperscript{24}

Neither Kristof nor his respondents mentioned the contribution of reproduction-assisting technologies to the rising rate of infant deaths. The numbers of babies born with low birth weight has increased in recent years in part because of high risk multiple births to women who implant several embryos created with high-tech procedures.\textsuperscript{25} Affluent women who decide to take the risk of bearing unhealthy babies have not suffered the official sanctions or public vilification directed to poor women with substance abuse problems who often take steps to minimize any harm to their babies.\textsuperscript{26}

This diversion of attention from social causes and solutions reinforces privatization, the hallmark of the neo-liberal state that pervades every aspect of public policy. In the wake of globalization, industrialized and developing states have sought to reduce the financial burden of social welfare programs while promoting the free market conditions conducive to capital accumulation.\textsuperscript{27} Observing this phenomenon, Canadian legal scholar Roxanne Mykitiuk writes that “the public sphere embraces as its governing logic market rationales and practices.”\textsuperscript{28} Critical to this process of state restructuring is the

\textsuperscript{24} Betsy McCaughey, Letter to the Editor, Why are Infants at Risk in America?, N.Y. TIMES, Jan. 14, 2005, at A22.
\textsuperscript{25} See Marian F. MacDorman et al., Explaining the 2001–2002 Infant Mortality Increase: Data from the Linked Birth/Infant Death Data Set, 53 NAT'L VITAL STAT. REP. 1, 5 (2005), available at http://www.cdc.gov/nchs/data/nvsr/nvsr53/nvsr53_12.pdf (“Increases in the number and percentage of multiple births over the past two decades have contributed to increases in the percentage of preterm and low birthweight births,” and account for twenty-five percent of the increase in infant mortality between 2001 and 2002); see also Seth Borenstein, U.S. Infant Mortality Rate Increases: Cause Attributed to Older Mothers Giving Birth, Multiple Births, MILWAUKEE J. SENTINEL, Feb. 12, 2004, at 10A; Rob Stein, U.S. Infant Mortality Rate Rises 3%: First Increase Since ’58 Surprises Officials as Other Health Indicators Keep Improving, WASH. POST, Feb. 12, 2004, at A11.
\textsuperscript{26} See, e.g., ROBERTS, supra note 8, at 191–92 (discussing Jennifer Johnson’s efforts to get treatment for her crack cocaine addiction while pregnant); see also Margaret H. Kearney et al., Mothering on Crack Cocaine: A Grounded Theory Analysis, 38 SOC. SCI. & MED. 351, 355 (1994) (describing “defensive compensation” by substance abusing mothers to protect their children from the negative effects of the mothers’ drug use). My point is not to judge the culpability of either group of women, but to highlight and contest the disparities in societal and state judgments about their reproductive decisions.
transfer of services from the welfare state to the private realm of the market and family. At the same time, the state deliberately transforms its institutions to advance private sector interests in the market economy.

In his second term, President George W. Bush’s domestic agenda explicitly revolved around promoting these neo-liberal values. He called for privatization of programs traditionally provided by government as the means of establishing an “ownership society” in the United States that would replace the prevailing New Deal approach. The Cato Institute, a libertarian think tank that champions the ownership society, describes the concept as follows:

An ownership society values responsibility, liberty and property. Individuals are empowered by freeing them from dependence on government handouts and making them owners instead, in control of their own lives and destinies. In the ownership society, patients control their own health care, parents control their own children’s education, and workers control their retirement savings.

President Bush’s most controversial step in creating an ownership society is the restructuring of Social Security to allow younger workers to divert a portion of their social security taxes into private accounts that could be invested in stocks and bonds. President Bush’s plans for an ownership society also include eliminating tax laws that penalize wealth accumulation and transfer, and changing class action laws to shield corporations from large tort damages awards. The ownership society and the privatization philosophy it reflects demand that individuals rely on their own wealth to meet their needs and discourage government aid for poor mothers who face systemic hardships in caring for their children.

At the same time that the government has reduced support for families, there has been a parallel increase in state intervention in poor women’s lives.

29 Id.
32 See Judy Keen, Bush’s Choice of Words Is Telling, USA TODAY, Mar. 11, 2005, at 6A.
Over the last two decades, the welfare system, prison system, and foster care system have clamped down on poor minority communities, especially inner-city black neighborhoods, thereby increasing many families’ experience of insecurity and surveillance. Welfare is no longer a system of aid, but rather a system of behavior modification that attempts to regulate the sexual, marital, and childbearing decisions of poor unmarried mothers by placing conditions on the receipt of state assistance. The federal government encourages states to implement financial incentives that deter welfare recipients from having children and pressure them to get married.

The contraction of the U.S. welfare state, culminating in the 1996 federal welfare reform legislation, paralleled the expansion of prisons that stigmatizes inner-city communities and isolates them further from the privileges of mainstream society. Radical changes in crime control and sentencing policies led to an unprecedented buildup of the U.S. prison population over the last thirty years. By the end of 2002, the number of inmates in the nation’s jails and prisons exceeded two million. Today’s imprisonment rate is five times as high as in 1972 and surpasses that of all other nations. The sheer scale and acceleration of U.S. prison growth has no parallel in western societies. African Americans experience a uniquely astronomical rate of imprisonment, and the social effects of imprisonment are concentrated in their communities.

Mounting social science studies on the community-level impact of mass incarceration reveal that prison has become a systemic aspect of community members’ family affairs, economic prospects, political engagement, social

34 See infra notes 36–49 and accompanying text.
39 Garland, supra note 38, at 1.
40 See id. at 1–2 (describing the defining features of mass imprisonment).
norms, and childhood expectations for the future. This social dynamic aggravates and augments the negative consequences to individual inmates when they come from and return to particular neighborhoods in concentrated numbers. Prisons break down social networks and norms needed for political solidarity and activism. Mass incarceration also destroys social citizenship at the community level through felon disenfranchisement laws that dilute neighborhood voting strength, through labor market exclusion, and by marking entire communities as criminal and undeserving of public resources.

The racial disparity in the child welfare system mirrors that of the prison system. Because child welfare policy relies heavily on the punitive removal of children from their homes, the largest group of the children awaiting adoption in the nation’s public child welfare agencies is African-American. One year after Congress passed the welfare reform law, it enacted the Adoption and Safe Families Act of 1997 (ASFA). ASFA amended federal child welfare policy by prioritizing protection of children over the support of families and by promoting adoption as a means to fix the overloaded foster care system. As Mark Courtney notes, this marks the first time in U.S. history that states have a federal mandate to protect children from abuse and neglect but no corresponding mandate to provide basic economic support to poor families. Like welfare reform, ASFA looks to a private remedy—in this case, adoption—rather than curtailing the flow of poor, minority children into foster care by providing needed resources to their families. Not only is there no guarantee that all the children awaiting adoption will be placed in adoptive homes, but adoption does nothing to address the needs of poor families who are most at risk of involvement in the child welfare system.

43 Id. at 1281–97.
47 ROBERTS, supra note 44, at 173.
49 ROBERTS, supra note 44, at 149–72.
At times, policy regimes have emphasized the social causes of marginality and attempted to use welfare and prisons to reform and integrate socially dispossessed groups. Exclusionary regimes, such as the one we are witnessing in the United States today, paint marginalized people as undeserving and unreformable deviants to be separated from the rest of society; this is reflected in stingy public assistance and punitive anticrime policies.

There is a correlation between punishment and privatization. The decrease in state responsibility for addressing poverty and social inequality has accompanied an increase in state intervention in the lives of poor- and low-income mothers, especially women of color. In other words, economic insecurity is increasing among the most disadvantaged communities not only because of state inaction, but also because of policies that affirmatively sustain, replicate, and intensify systemic political and economic subordination. And these two trends are mutually reinforcing.

Private remedies for systemic inequality and punitive state regulation of the most disadvantaged communities are two sides of the same coin. Deliberate state policies and practices work affirmatively to increase economic insecurity of these communities while obscuring the state’s responsibility for causing it or government’s obligation to address it. Attributing social inequities to the childbearing of poor minority women and then using this attribution to justify the regulation of reproduction is a critical component of this punitive trend away from state support for families and communities.

B. Reproductive Genetics, Privatization, and Social Inequality

At the other end of reproductive caste system, new genetic technologies have generated greater surveillance of women, the ones primarily responsible for making the “right” genetic decisions. For decades, prenatal testing has provided the capacity to avoid bearing children with genetic disorders. Advances in reproduction-assisting technologies that create embryos in a

---


laboratory have converged with advances in genetic testing to produce increasingly sophisticated methods to select for preferred genetic traits. Reproductive technologies like \textit{in vitro} fertilization assist couples to have children who not only are genetically related to them but who are genetically advantaged. With preimplantation genetic diagnosis clinicians can diagnose early embryos for their chance of having over four hundred genetic conditions and implant only the ones that probably do not have these conditions. Sperm sorting allows couples to select the sex of their children with eighty-five percent accuracy.\textsuperscript{52} Some scientists predict that reproductive cloning and genetic engineering—actually enhancing the embryo’s genetic makeup—will be developed in the near future.\textsuperscript{53} These cutting edge procedures that enable selection of embryos for their genetic traits are part of a new kind of reproduction-assisting science called “reprogenetics.”\textsuperscript{54}

It is important to distinguish between the ways in which genetic testing is actually implemented. On the one hand, mass carrier screening programs, especially those mandated by the government and aimed at reducing the incidence of a disease in a population, have led to widespread discrimination and coercion.\textsuperscript{55} On the other hand, providing nondirective genetic counseling with informed consent to individuals who request it is unlikely to exploit women and members of minority groups. Yet genetic screening programs, even if they are supposed to be voluntary, create the expectation that women will act on the results. Communities can put pressure on parents, especially mothers, to produce perfect babies for the sake of the whole.

Ashkenazi Jews in the United States have developed perhaps the most sophisticated defense and successful implementation of a community-based program of genetic screening, largely responsible for a ninety percent reduction in the incidence of Tay-Sachs disease from 1970 to 1993.\textsuperscript{56} An authority on Jewish medical ethics defends the program as a “legitimate


\textsuperscript{53} ANDREWS, \textit{supra} note 7, at 237–39; GREGORY STOCK, \textit{REDESIGNING HUMANS: OUR INEVITABLE GENETIC FUTURE} 1–2 (2002) (predicting that within a decade cloning and human genetic modification “will be the cutting edge of human biological change”).

\textsuperscript{54} Parens & Knowles, \textit{supra} note 52, at S4. The authors define reprogenetics, broadly, as “the field of research and application that involves the creation, use, manipulation, or storage of gametes or embryos.” \textit{Id}.

\textsuperscript{55} See generally TROY DUSTER, \textit{BACKDOOR TO EUGENICS} (1990).

implementation of the biblical mandate to heal."57 Premarital genetic testing for Tay-Sachs has become the standard of care in some Orthodox Jewish communities where marriages are arranged.58 “It’s now a duty, not a choice,” says legal scholar Karen Rothenberg.59

More generally, it is increasingly routine for pregnant woman to get prenatal diagnoses for certain genetic conditions such as Down syndrome or dwarfism.60 Many obstetricians provide these tests without much explanation or deliberation because they consider these screenings to be a normal part of treating their pregnant patients. The director of reproductive genetics at a large Detroit hospital reported that at least half of the women referred there with an abnormal amniocentesis result were “uncertain about why they even had the test.”61 A genetic counselor similarly notes, “Patients will come in and say, ‘I am having the amniocentesis because my doctor told me to,’ but really in their hearts they are not so sure that’s right for them. Some people are relieved to find that they have a choice about having the test.”62 Still, many pregnant women now view genetic testing as a requirement of responsible mothering.

I experienced this type of shallow ethical evaluation of prenatal testing in 2000 when I was pregnant with my fourth child at age forty-four. My obstetrician recommended that I participate in a clinical trial by Northwestern University Medical School researchers investigating the potential for ultrasound to help detect genetic anomalies in the first trimester of pregnancy.63 “It’s a way to get a free ultrasound,” he told me. Although the researchers had an ethical obligation to reveal any significant risks entailed in the procedure, neither they nor my obstetrician discussed with me the decision I would have to make if the test results predicted that the fetus I was carrying had a high risk of Down syndrome.64 Instead, everyone seemed to assume that

57 Rosen, supra note 56, at 81.
60 See Carol Smith, Q-and-A on Genetic Testing, SEATTLE POST-INTELLIGENCER, July 2, 2004, at B3.
63 See generally Ronald Wapner et al., First-Trimester Screening for Trisomies 21 and 18, 349 NEW ENG. J. MED. 1405 (2003) (describing the study).
64 It is likely that the consent form I was given stated the possible test outcomes and the risks and benefits of my participation in the clinical trial.
the information could only make me better off and that there was no need for serious deliberation about what I would do with it.65

Like the punishment of minority women’s childbearing, reprogenetics is linked to the elimination of the welfare state and support for private remedies for illness and disease. Placing responsibility for ending health disparities on individual reproductive decisions can reduce the sense of societal obligation to address systemic inequities. Reliance on eradicating illness through genetics can divert attention and resources away from the social causes of disability and disease, as well as social norms that impair social participation by sick and disabled people. Some disability rights activists argue that genetic testing may privatize disability in the sense that availability of prenatal diagnosis for a disorder may discourage government funding for research and social services for people who have the disorder.66

Genetic biotechnologies also shift responsibility for addressing disease from the government to the individual by suggesting that health disparities are a result of genetic variation rather than inequitable social structures and access to health care. The FDA recently approved BiDil, the first race-based drug, to treat heart failure specifically in African Americans.67 One theory supporting BiDil is that the reason for higher mortality rates among black heart patients lies in genetic differences among the races, either in the reason for getting heart disease or the reason for responding differently to various medications for it.68 BiDil’s manufacturer discounts the importance of environmental factors in explaining differences in black and white patients’ experience of heart disease to market a technological cure based on an asserted genetic difference.69 As law professor Jonathan Kahn has chronicled, the FDA’s initial denial of approval to BiDil as a race-less drug led its creators to re-conceptualize it as a drug for blacks, enabling them not only to obtain the

65 The Genetics and Public Policy Center at Johns Hopkins University recommends considerably greater deliberation prior to prenatal genetic testing: “The decision to undergo prenatal diagnostic testing should be carefully considered. The testing should usually be done in concert with a process of education and values clarification.” GENETICS & PUB. POL’Y CTR., PRENATAL GENETIC TESTING 5 (2003), available at http://tools-content.labvelocity.com/pdfs/3/62763.pdf.

66 See LORI B. ANDREWS, FUTURE PERFECT: CONFRONTING DECISIONS ABOUT GENETICS 101 (2001); see also Amy Harmon, The Problem With an Almost-Perfect Genetic World, N.Y. TIMES, Nov. 20, 2005, at 1 (Week in Review sec.)


68 Kahn, supra note 67, at 11.

69 Id.
FDA’s blessing, but also raise venture capital, receive a lucrative patent, and launch a successful marketing campaign.\footnote{Id. at 46.}

At the same time, the neo-liberal support for capital accumulation increasingly pervades the biotechnology industry. The initiative approved by California voters in November 2004, allocating $3 billion in tax-supported bonds to the biotechnology industry for stem cell research, illustrates the state’s promotion of private investment in genetic technologies.\footnote{See Cal. Const. art. XXXV; Cal. Prop. 71, Stem Cell Research, Funding Bonds, Initiative Constitutional Amendment and Statute (2004).} The state-supported biotechnology industry creates a market for its genetic testing and selection products by making consumers feel obligated to use them to ensure the genetic fitness of their children.\footnote{See Myktiuk, supra note 28, at 109–10.}

Reprogenetics serves as a form of privatization that makes the individual the site of governance through the self-regulation of genetic risk.\footnote{Id. at 108.} As Professor Myktiuk writes, “Is there a sense in which the new genetic technologies are being used, or are capable of being used, as a means of literally creating the responsible, autonomous, citizen of neo-liberalism—that citizen who makes no legitimate claims on the state but rather, who freely exercises their capacity for choice and manages their own self care?”\footnote{Id.} The logic of reprogenetics could support the view that childhood illness and disability is the fault of mothers for not making the right genetic choices. Making the wrong genetic choices in turn disqualifies citizens from claiming public support. These women are, in effect, punished for their reproductive decision to have an ill or disabled child because they are denied the support they need to raise their child. In her book exploring the public consequences of private decisions about reproductive technologies, Lynda Beck Fenwick asks readers to ask themselves, “Are you willing to pay higher taxes to cover costs of government benefits for babies born with genetic defects, even when the parents knew of the high likelihood or certainty such defects would occur?”\footnote{Fenwick, supra note 62, at 113.} As a result, the proliferation and promotion of new genetic technologies is inversely related to access to general health care.

Women bear the brunt of reprogenetics’ contribution to the neo-liberal restructuring of health care. Genetic technology introduces a new gendered
division of reproductive labor and surveillance as women become “gatekeepers of new social order.”

Professor Mykitiuk points out that, contrary to the deregulation that typically occurs in the service of big business, the new duties imposed on women constitute a “re-regulation intended to make possible the greater appropriation of intellectual property and its capitalization.”

Reprogenetics also makes eugenic thinking seem more acceptable. Sociologist Barbara Katz Rothman calls the marketing of prenatal diagnostic technologies a form of “micro-eugenics,” eugenics focused on the individual (in contrast to macro-eugenics’ focus on populations), that values or disvalues specific characteristics believed to be inherited. Some disabilities rights advocates object to preimplantation or fetal diagnoses that lead to discarding embryos and fetuses predicted to have disabilities because they devalue people who have these disabilities, implying that they should never have been born. The quality of many disabled people’s lives depends as much on social acceptance, access, and accommodation as on their physical capacities. Apart from avoiding certain fatal or severely disabling diseases, such as anencephaly or Tay-Sachs disease, reprogenetics inscribes the perceived social advantage of having or not having certain abilities or traits associated with genes. Selecting children’s abilities or sex reflects the social advantages and disadvantages connected to these categories and may reinforce an unjust value system that privileges some over others. Unable to count on societal acceptance or support for children with disabilities, however, many women feel compelled to turn to genetic testing to ensure their children’s welfare.

The role privileged women play in this integrated system of privatization and punishment is obscured by liberal notions of reproductive choice. Despite the potential for reprogenetics to diminish public health care and intensify regulation of women’s reproductive decisions, its sponsors often defend the

76 Mykitiuk, supra note 28, at 112; see also Abby Lippman, Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities, 17 Am. J.L. & Med. 15, 39 (1991) (“[B]ecause a child’s disability is viewed as a private problem for the family, the gendered attribution of responsibilities for family health to women obligates them to deal with it alone whether by avoiding, reducing or managing disability.”).
77 Mykitiuk, supra note 28, at 112.
79 See FENWICK, supra note 62, at 90.
80 See Lippman, supra note 76, at 32.
industry’s immunity from state regulation in the name of women’s reproductive freedom. Marsha Tyson Darling of the Center for African-American and Ethnic Studies at Adelphi University notes that “eugenic advocates have undertaken to infuse eugenics imperatives into the women’s reproductive rights movement.”

They see women’s ability to select the traits of their children, including sex and other qualities unrelated to health, as an aspect of reproductive choice. Concerns about the implications for women, the disabled, racial minorities, and other disadvantaged groups are dismissed as threats to reproductive freedom.

As I argued above, however, creating duties to use reprogenetic technologies in prescribed ways would limit women’s choices. Just as important, the promotion of these technologies in the context of systemic inequalities and inadequate support for caregiving steers women to make reproductive decisions that reinforce social inequality. Thomas H. Murray faults procreative liberty as the ethical framework for evaluating reproductive technology for its “difficulty summoning the ethical will to curb the indulgence of almost any parental whim.”

One important ethical curb, on public policy as well as parental decisions, that is elided by the singular focus on reproductive choice is the social harm risked by eugenic thinking.

Indeed, some clients of reprogenetics have even claimed moral superiority over women who have abortions for nonselective reasons. In a July 22, 2004, op-ed piece in the New York Times, Barbara Ehrenreich called on women who aborted fetuses based on prenatal diagnosis to support the general right to abortion. She noted that these women sometimes distinguish themselves from women who have “ordinary” abortions. One woman who aborted a fetus with Down syndrome stated, “I don’t look at it as though I had an abortion, even though that is technically what it is. There’s a difference. I wanted this baby.” On a website for a support group called “A Heart Breaking Choice” a mother who went to an abortion clinic complains, “I resented the fact that I had

---

84 Id.
to be there with all these girls that did not want their babies.” This perverse moral distinction between ordinary and so-called “medical abortion” reinforces the reproductive stratification that separates women whose childbearing is punished from those whose childbearing is technologically promoted by distinguishing even between the kinds of abortions they have.

This classification of abortions is reminiscent of the historical distinction that states made between therapeutic or eugenic abortion and elective abortion. When abortion was criminalized in the United States during the second half of the nineteenth century, state laws made exceptions for cases in which pregnancy or childbirth threatened a woman’s life or health. While abortions based on women’s own decision not to have a child (“elective” abortions) were illegal, abortions based on physicians’ judgments about the medical or social ills of pregnancy (“therapeutic” or “eugenic” abortions) were approved. Physicians’ proposals for legislative reform prior to Roe v. Wade centered on the need for abortion to reduce either births of defective babies or births to women with psychiatric disorders. As historian Johanna Schoen observes, “the debates surrounding abortion focused on specific medical conditions that might justify a therapeutic or eugenic abortion but remained hostile to elective abortion, which could extend reproductive control to women.” The existence of a physical or mental impairment was more critical to the medical profession’s defense of abortion than enhancing women’s reproductive freedom.

States classified abortions as eugenic, therapeutic, or elective as a means of regulating women’s access to them and limiting the potential of abortion to further women’s emancipation. A contemporary woman who valorizes eugenic abortion while disparaging elective abortion resuscitates the nineteenth century abortion hierarchy, a hierarchy that impedes women’s reproductive self-determination. Barbara Katz Rothman distinguishes arguments for legal abortion based on “fetal defect” from feminist prochoice claims because they focus on the fetus and not on the woman. Because eugenic thinking can pressure women to abort a fetus deemed to be genetically inferior, Marsha

---

85 Id.
87 Id. at 143.
88 Id. at 142.
89 See ROTHMAN, supra note 81, at 115–16; see also Lippman, supra note 76, at 34 (noting that “prenatal diagnosis has (re)defined the grounds for abortion,” giving geneticists and obstetricians power over abortion decisions).
Saxton notes that the goal of the disability rights movement concerning abortion is “the right not to have to have an abortion.” The incorporation of eugenic values in arguments for women’s reproductive freedom neglects the history of abortion regulation as well as the potential for reprodogenetics to impose restrictive expectations on women to serve as genetic screeners of children.

CONCLUSION

The women at opposite ends of the reproductive hierarchy are part of an interlocking system of privatization and punishment. Both the punishment of marginalized women’s childbearing and the promotion of reprodogenetics for privileged women place reproductive duties on women that help to privatize remedies for illness and social inequities. Instead of joining together to contest the social forces that limit their reproductive freedom, including inadequate health care and the gendered division of household labor, these women are further separated by the exclusive genetic technology industry. Affluent women’s access to high tech solutions to infertility, disability, and illness can impede their motivation to pursue collective action against social inequities, including their own subordinated position in relation to men. The most privileged women’s increasing reliance on high-tech reproductive remedies for socially-caused problems thus obscures the role they share with the most disadvantaged women in the neo-liberal shift from social welfare to privatization and capital accumulation. Both groups of women have an interest in halting this shift and in advocating for greater public investment in improving the social conditions that determine children’s welfare.