

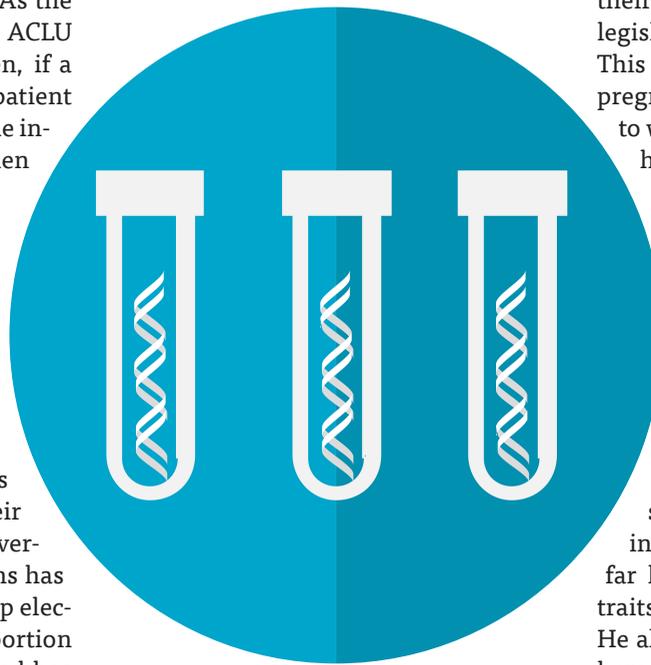
# Prenatal Diagnosis, Reproductive Rights, and the Specter of Eugenics

In 2014, the state of Virginia enacted legislation shielding health care workers who provide genetic counseling from lawsuits if they withhold test results they think might dispose a woman to have an abortion. Although counselors can't lie about results, they no longer have to disclose them. As the executive director of the Virginia ACLU noted, "The way the law is written, if a genetic counselor doesn't think a patient will make 'the right choice' with the information you give them, well, then you don't have to tell them."<sup>1</sup>

Advocacy of such "conscience clauses" is but one element in a recently accelerating campaign to restrict reproductive rights.<sup>2</sup> As Frederick Clarkson has found, a raft of state-level legislative and regulatory restrictions on access to abortion followed the "wave election" of 2010.<sup>3</sup> As Republicans have continued to consolidate their control of state legislatures and governorships, the stream of restrictions has turned into a flood, with the Trump election further emboldening anti-abortion activists. But a closely related trend has gone less noticed: the increasingly successful movement to bar or discourage the practice of *selective* abortion; that is, pregnancy termination based on a determination of fetal sex, race, or—far more commonly—genetic abnormality. Conservative anti-abortion activists have certainly fought to restrict abortion in general, but increasingly their strategies focus on banning abortions sought for specific reasons.<sup>4</sup> In their campaign against selective abortion, conservatives sometimes find *de facto* allies among groups that lean Left politically but share conservatives' unease with the use of

prenatal diagnosis (PND) to avoid the birth of children with disabilities.

On both the political Right and Left, some groups find this use of PND repugnant, and charge that it constitutes "eugenics." Recent changes in medical-practice guidelines and in the technol-



ogy of testing have heralded a major expansion in the use of PND. The sequencing of the human genome in 2003 ushered in "a new generation of prenatal screening tests," as journalist Beth Daley has noted.<sup>5</sup> A particularly significant development has been the advent of noninvasive prenatal testing, which, unlike conventional procedures such as amniocentesis, involves only a simple blood test. Critics of selective abortion are alarmed by these developments; the new tests can make PND easier and cheaper, and eliminate risks to the fetus.

Consequently, they could greatly expand both the uptake and scope of testing, and thus the rate of termination for fetal anomaly. The belief that we are on the cusp of a major expansion of PND has fueled a multi-pronged effort both to regulate what healthcare providers can say to their patients about prenatal tests and to legislatively restrict the use of such tests. This increasing legislative concern with pregnant women's decisions all adds up to what law professor Rachel Rebouché has called a "regulatory moment for prenatal health care."<sup>6</sup>

## WHAT IS EUGENICS ANYWAY?

The word "eugenics" was first coined by Sir Francis Galton, a British polymath and half-cousin of Charles Darwin. Galton believed that differences in heredity explained differences in human intellect, character, and social success, and that the environments in which individuals are raised are far less important than the hereditary traits they inherited from their parents. He also thought that those with the best heredity were being outbred by those with the worst, and that civilization was doomed unless the principle of "breeding from the best" was applied to humans and not just plants and other animals. In 1883, Galton termed this idea "eugenics" (from the Greek *eugenes*, to refer to one born "good in stock, hereditarily endowed with noble qualities").

Galton, who knew that opposition from Catholics, Whigs hostile to government intervention, and the organized working class would doom any legislative program in Britain, consistently characterized eugenics as a "science" or "study"—not a state prescription. Had

it remained such, it's unlikely that there would be much interest in the subject today. But around 1910, eugenic aims began to inspire an organized social movement, the changing fortunes and reputation of which have informed what the term has come to mean to us. In the 1910s and '20s, that movement was both international and widely supported. Eugenics attracted adherents across the political spectrum, appealing to social radicals and conservatives, militarists and pacifists, feminists and misogynists, racists and critics of racism. What united these disparate enthusiasts was the conviction that differences in heredity explained why some people were weak in mind and body while others were strong, and that the least fit members of society, including "mental defectives," criminals, and the shiftless were breeding more prolifically than the intelligent, prudent, and industrious.

Ultimately, eugenics fell into dispute. World War II and the revulsion against the Holocaust and specific Nazi programs (such as the murder of mentally ill patients) was long considered a watershed event in eugenics' popular demise. More recently, though, historians have stressed how little actually changed in its immediate aftermath.<sup>7</sup> Although criticism increased after 1945, it was only in the 1960s that eugenic sterilizations began to decline in the U.S.,<sup>8</sup> and elsewhere the practice often continued, with and without legal authorization. What ultimately made eugenics disreputable were not revelations of Nazi atrocities but the social movements of the 1970s, especially second-wave feminism, with its maxim that women had a right to control over their own bodies. By the 1980s, the term "eugenics" had acquired highly pejorative connotations.

Once the term became stigmatizing, it also acquired value as a political resource. To claim that a policy or practice constitutes eugenics became implicitly to condemn it. Critics of birth control and reproductive genetic services such as PND and the selection of embryos created via in vitro fertilization would strive to associate them with eugenics. And the criticisms crossed traditional culture-war divides. Catholic disability-rights

advocate Mark Leach compared the rationales for past eugenics and contemporary prenatal testing, concluding that the latter "is factually eugenic." Pope Benedict XVI repeatedly warned that, "There are appearing in our days troubling manifestations of this hateful practice [of eugenics]," suggesting that practices such as the selection of embryos and prenatal testing would lead to abortion.<sup>9</sup>

Supporters of these practices strenuously reject efforts to link them to eugenics. Ellen Painter Dollar, a pro-choice disability-rights advocate, acknowledged that prenatal testing would lead to "babies with genes defined as 'undesirable' [not being] born." But she denies that such testing constitutes eugenics, writing:

Historically, "eugenics" refers to social movements, supported by *governments, institutions, or influential public figures*, that had a stated goal of purifying the gene pool either positively (by enabling those with traits perceived as positive to reproduce) or negatively (by forcibly sterilizing or otherwise limiting the reproductive capacity of those with traits perceived as negative). In contrast, proactive decisions today... are largely private decisions made by expectant parents primarily concerned with the well-being of their family, not the genetic make-up of society at large.<sup>10</sup>

Historian of technology Ruth Schwartz Cowan would agree. In her view, "Prenatal diagnosis has almost nothing in common with eugenics, neither historically nor technologically."<sup>11</sup>

### **CONFLICTING PERSPECTIVES ON THE EUGENICS AND REPRODUCTIVE GENETICS RELATIONSHIP**

Today, we can broadly distinguish three perspectives on the relation of eugenics to reproductive genetics.<sup>12</sup> The first is that they have little in common. In this perspective, the eugenics movements that flourished in the early decades of the 20th Century are epitomized by Nazi efforts to breed a master race and eliminate those considered undesirable. Contemporary reproductive genetics could hardly be more different, since, according to this view, it doesn't target

racial or ethnic minorities, concerns disease rather than ill-defined traits like "feble-mindedness," and conceives of disability as a personal and not a societal matter. Above all, it lacks the coercive power of the state. Indeed, the oft-stated point of the enterprise is to increase reproductive choices. Science journalist Matt Ridley (as well as Ellen Painter Dollar and Ruth Schwartz Cowan) expresses this perspective when he writes, "The essence of eugenics was compulsion: it was the state deciding who should be allowed to breed, or to survive, for the supposed good of the race. As long as we prevent coercion, we will not have eugenics."<sup>13</sup>

A second perspective is that reproductive genetics is indeed eugenics, but that fact does not condemn it. Thus, Oxford philosopher Julian Savulescu writes, "in point of fact, we practice eugenics when we screen for Down's syndrome, and other chromosomal or genetic abnormalities."<sup>14</sup> In the view of Savulescu and several other philosophers, scientists, and science journalists, PND may be eugenics—but not the worrying kind. In their view, eugenics can be good or bad depending on the specific form it takes, and PND is benign.<sup>15</sup>

In the third perspective—more common than Savulescu's argument—reproductive genetics is also assumed to be eugenics, and as such, unreservedly bad. This attitude is shared by many politically Left and feminist critics of biotechnology as well as Catholics and disability-rights advocates. Like Savulescu, these critics define eugenics broadly. In their view, it need not involve government coercion (as with the sterilization laws adopted at earlier points by 33 American states and many countries). It can instead come through the "back door," to use a phrase popularized by sociologist Troy Duster, chosen by women and their partners responding to social norms of health, attractiveness, and so forth.

For these critics, eugenics is fundamentally about attitudes, not state intervention. In their view, PND involves judgments about which traits are desirable or undesirable that reflect socially prejudicial assumptions, with some lives viewed as inherently defective. On the feminist Left, political scientist and

historian of technology Joan Rothschild exemplifies this perspective when she writes:

Science and technology, medical professionals, and parents meet in the doctor's office. This privatized setting is the site for individual decisions... whether to keep a pregnancy or terminate it, and for which diagnosed "defect." Each decision becomes another judgment as to which conditions, and which children, are acceptable or not. As they aggregate over time, individual decisions add up to a selection process, marking the imperfect, those who may be dispensed with, while certifying those worthy to be born.<sup>16</sup>

A similar viewpoint is expressed by Mark Leach when he asks:

Why is the existence of a governmental policy the critical element for raising moral concerns about the eugenic implications of prenatal genetic testing? Is the lesson of the previous eugenics atrocities that viewing others as burdensome defectives ripe for elimination is wrong *only* when a governmental policy says so? Or, is not the lesson that it is wrong to view another human life as defective, as a burden, regardless of whether there is a governmental policy or not?<sup>17</sup>

### THE EXPANSION OF PRENATAL TESTING: NEW PRACTICE GUIDELINES AND NEW TECHNOLOGIES

The last decade has witnessed a rapid expansion of prenatal genetic testing. One factor has been a recommendation by professional societies to eliminate maternal age as a criterion for amniocentesis and another less-common test, chorionic villus sampling (CVS). In 2007, the American College of Obstetricians and Gynecologists published a new Practice Bulletin recommending that PND for aneuploidy (the gain or loss of a chromosome) be made available to all women, regardless of maternal age, who were less than 20 weeks pregnant at the time of their first prenatal visit. The American College of Medical Genetics soon followed suit.<sup>18</sup> To opponents of selective abortion, these new guidelines seemed to presage an imminent expansion of prenatal testing and hence increase in

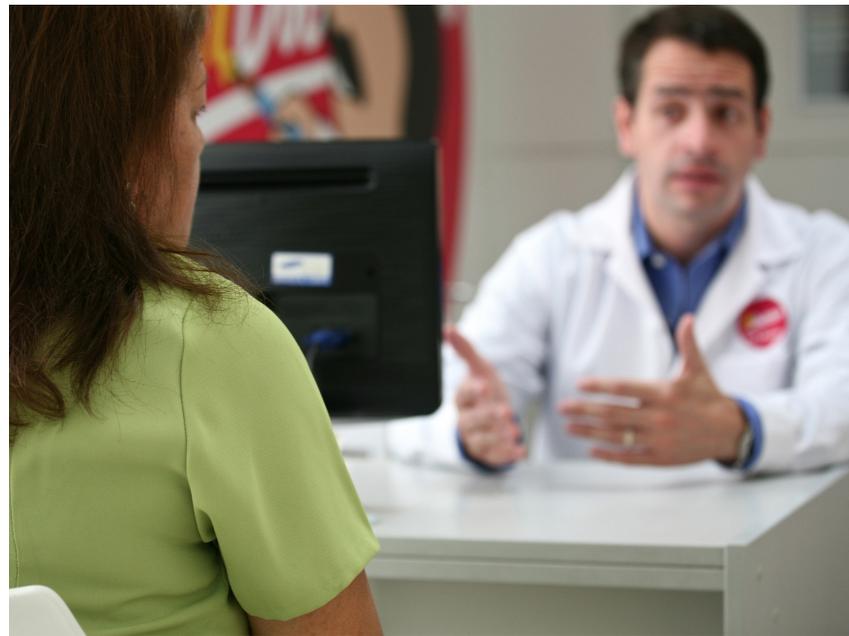
terminations for fetal anomaly.

An even more important cause has been the advent of noninvasive prenatal testing, a technique that analyzes fragments of cell-free fetal DNA found in pregnant women's blood. First introduced in Hong Kong in 2011, the technology has spread across the globe, and is now available in more than 90 countries.<sup>19</sup> Until quite recently, its dissemination occurred almost exclusively through the commercial sector. (Six companies, four based in the U.S. and two in China, own most of the relevant patents and other intellectual property.) The vast potential market for noninvasive tests provided correspondingly huge incentives to market directly to consumers and to continuously expand the tests' scope in order to obtain an edge over the competition.<sup>20</sup> With demand driven by aggressive consumer advertising, the uptake of such tests occurred prior to their clinical validation and in advance of their endorsement by relevant professional societies or a regulatory framework for their use. However, in response to consumer demand, such testing is increasingly reimbursed by health insurance in the U.S., and several countries now include it in their national prenatal screening programs.<sup>21</sup>

Although professional societies currently recommend that noninvasive tests only be used for screening, not diagnosis, both the excitement and anxiety the technology has generated arises from its potential to replace amniocentesis and CVS. Noninvasive testing can be offered earlier in pregnancy than amniocentesis, creating less anxiety and potentially allowing abortions to be medical rather

than surgical. Noninvasive testing is also cheaper than conventional PND, and it removes the roughly 0.5-1 percent risk to the fetus.

Due to the risk of miscarriage associated with invasive procedures, their cost, and the stage of gestation at which decisions are made, PND is not now universally offered. Instead, maternal serum tests and ultrasound are employed as screening tests to limit invasive procedures to those pregnancies considered "at risk." But with noninvasive testing, all the factors that have constrained the offer of testing are removed. In the fu-



*Federal and state regulatory efforts to bar or discourage selective abortion have included attempts to regulate the kinds of information that health-care providers give to pregnant women. Photo: Alex Proimos via Flickr.*

ture, it will likely be possible to combine noninvasive testing with full genome-wide analysis, enabling the detection of any genetic condition, predisposition, or even non-medical trait.<sup>22</sup>

The rapid dissemination of noninvasive testing has understandably alarmed those opposed to selective abortion. Although some of their concerns, especially around the commercial sector's dominance of this field, are shared by other groups, Catholics and social conservatives have been particularly vocal. Writing in the *National Catholic Register*, journalist Celeste McGovern summarizes, "Rather than saving lives, pro-lifers

see this test as an enhanced ‘search and destroy’ diagnostic tool that exponentially expands the genetic information available on unborn babies—so that parents may have up to 3,500 genetic possibilities to weigh into a decision about whether or not to have an abortion.” David Prentice, a senior fellow at the Family Research Council, similarly argues, “For the most part, this is just a further slide down the eugenics slope.” Cardinal Christoph Schönborn, Archbishop of Vienna, sees the PrenaTest as “eugenics, pure and simple,” and asks, “Is the infernal term ‘life unworthy of life’ going to become reality again?”<sup>23</sup>

#### **A “REGULATORY MOMENT” FOR PRENATAL DIAGNOSIS**

Concerns related to the expansion of noninvasive testing are international—as is the backlash.<sup>24</sup> In the U.S., these concerns have spurred a variety of federal and state regulatory efforts to bar or discourage selective abortion. One form such efforts have taken is regulation of the kinds of information that health care providers provide to pregnant women. Recent laws in Virginia and Nebraska allow genetic counselors to refuse to share any information that conflicts with their

from health care providers is biased. On this view, obstetricians and gynecologists, genetic counselors, and other providers all believe that life with Down syndrome—the near-exclusive focus of the movement—is exceedingly burdensome to the individual and family. Disability-rights and anti-abortion activists say that assumption is wrong. (These two very different groups of activists sometimes overlap, but their positions aren’t identical, since the latter oppose abortion *per se*, whereas many disability-rights activists are only critical of selective abortion, which they would discourage but not necessarily ban.) They point to statistics indicating that people with Down syndrome and their families are satisfied with their lives. They want prospective parents to be given literature they have produced or vetted and to be referred to their organizations for further information and support.

This campaign resulted in a 2008 federal law, the “Prenatally and Postnatally Diagnosed Conditions Awareness Act,” cosponsored by Senators Edward Kennedy (D-MA) and Sam Brownback (R-KS), which aimed to strengthen patient support networks, increase referrals to support services for women who receive

emphasize that the movement is merely pro-information, not anti-abortion. However, to the frustration of many Down syndrome associations, this effort to bridge the abortion divide has increasingly been hijacked by right-to-life organizations. Thus, Louisiana’s law prohibits the state from recognizing materials that “explicitly or implicitly present termination as a neutral or acceptable choice,” and recently, Indiana and Texas have followed suit.<sup>28</sup> David Perry, an influential disability-rights activist who is also pro-choice, has written that right-wing legislators’ efforts to use the pro-information movement to restrict reproductive choice has forced him to question whether he can continue to advocate for pro-information laws. “In general, conservative legislatures pass anti-choice bills while simultaneously removing social supports for poor families,” he said. “Even when the bills explicitly deal with disability-selection abortions...they are not disability rights legislation. They are attempts to divide and conquer.”<sup>29</sup>

A more direct effort to limit abortion would ban providers from performing the procedure if they knew it was sought for specified reasons. This strategy is congruent with the incremental restrictions on abortion that have largely supplanted attempts to overturn *Roe v. Wade*. At the federal level, Prenatal Non-discrimination Acts (PRENDAs) to bar abortion based on the sex (or in most versions, both sex and race) of the fetus have been proposed nearly every year since 2008. The 2012 bill passed the House by a vote of 246 to 168, with only seven Republicans opposed (and 20 Democrats voting in favor), but as it was brought up under a rule suspension that limited debate, it required a two-thirds majority to pass.<sup>30</sup> At the time of this writing, the 2017 PRENDA has 64 cosponsors, 63 of whom are Republicans. Should it be enacted, medical professionals could be sentenced to up to five years imprisonment for performing an abortion sought because of fetal sex or race.<sup>31</sup>

#### **PRENDA, FEMINISM, AND RACIAL JUSTICE**

The language of feminism, civil rights, and racial justice suffuses these bills; indeed, they were originally titled the Susan B. Anthony and Frederick Douglass

**“Even when the bills explicitly deal with disability-selection abortions... they are not disability rights legislation. They are attempts to divide and conquer.”**

moral or religious beliefs, while laws in Arizona and Oklahoma protect physicians who fail to disclose fetal abnormalities.<sup>25</sup> These laws are part of a more general movement over the past two decades to expand so-called conscience clauses that allow health care workers to opt out of providing services they disagree with, and to enact regulations that claim to protect women from themselves.

A less controversial effort aims to require objectivity in the information provided to pregnant women. This “pro-information” movement, which began about a decade ago, assumes that many women choose pregnancy termination because the information they receive

a positive diagnosis, and guarantee that they’re given accurate information about test results and the range of outcomes associated with the diagnosed conditions.<sup>26</sup> But no funds were appropriated for the law, which also lacked any enforcement provision. As individuals and organizations realized that the statute would have little if any impact, they began to mobilize at the state level. To date, 17 U.S. states have enacted pro-information statutes.<sup>27</sup> Given that it’s difficult to argue against “information,” which is often taken to be an unqualified good, such proposals are often passed unanimously or by overwhelming majorities.

Those who support such laws often

Prenatal Nondiscrimination Acts. But it's obvious from the records of their sponsors that these bills have nothing to do with either feminism or racial justice. All the PRENDA bills have been introduced in the House by Rep. Trent Franks (R-AZ), a "Freedom Caucus" member and the driving force behind other anti-abortion legislation, including a bill to ban all abortions after 20 weeks even in cases of rape and incest. In Franks' own words: "I've introduced every pro-life effort you can think of."<sup>32</sup> As journalist Kate Shepard remarked of the 2012 version, "The lawmakers behind it haven't been particularly interested in women or people of color after they exit the womb in the past, opposing measures to require equal pay for women and to renew the Voting Rights Act, and most recently gutting the Violence Against Women Act."<sup>33</sup> The real agenda is also evident in the fact that the bills only target abortion and not any other means for practicing sex- or race-selection, such as the choice of which embryos to implant as the result of pre-implantation genetic diagnosis. At the state level, race-selective abortion bans have been approved by legislatures and governors in two states, while sex-selective abortion bans have been introduced in over 20 and approved in nine.<sup>34</sup>

Laws barring race-selective abortion are part of an effort to link relatively high rates of abortion in the African-American community to eugenics. As noted in PRA's *Defending Reproductive Justice: An Activist Resource Kit*, a key event in this effort was the 2010 "Too Many Aborted" billboard campaign sponsored by the Radiance Foundation. A parallel campaign, sponsored by a different group, erected billboards with images of Barack Obama and the legend, "Every 21 minutes, our next possible LEADER is ABORTED." Recently, anti-abortion activists have taken up the language of "Black Lives Matter." Trading on the emotional resonance of that phrase, Americans United for Life (AUL) has sponsored a "#BlackWomenMatter" campaign.<sup>35</sup> (Such efforts often reference Margaret Sanger's frequently-misrepresented "Negro Project." See additional discussion online at PRA's website.<sup>36</sup>) But implicit in PRENDA laws is the assumption that women of color practice

racial discrimination against their own fetuses, an assumption that, as Rep. John Conyers commented, "is absurd on its face."<sup>37</sup> Race- and sex-selective abortion are rarities in the U.S. The legal prohibitions against them are introduced not to counter actual practices but to make liberals and leftists look like hypocrites.

Abortion for fetal anomalies, on the other hand, is widespread. Indeed, in at least 11 states, a diagnosis of serious fe-

fetal tissue be buried or cremated by a funeral home. That Pence was responsible for making Indiana a leader in curbing access to abortion explains why, according to reporter Todd Zwillich, at least some conservative evangelicals believe that "God is using Trump to deliver Pence to the WH, & that Trump will be eliminated."<sup>40</sup> At least in respect to reproductive rights, there could be even worse fates than continuing the Trumpian sta-

### **The legal prohibitions against race- and sex-selective abortion don't counter actual practices but serve to make liberals and leftists look like hypocrites.**

tal defect was a recognized exception to pre-*Roe v. Wade* laws barring abortion. And in the post-*Roe* era, at least six states explicitly allowed late abortions for fetal anomaly.<sup>38</sup> Thus, efforts to legislatively discourage the practice by requiring special counseling when an abortion is sought for that reason or banning it outright are far more controversial. Nevertheless, as part of its "Infants' Protection Project," the AUL proposed model legislation "protecting unborn infants from eugenics" by banning abortions performed because of genetic abnormalities.<sup>39</sup> In 2013, North Dakota became the first state to approve such a statute. Louisiana and Indiana followed in 2016, although implementation of the law in those states has been temporarily enjoined by court order.

#### **A CONCLUDING CAUTION**

This history holds a warning for those who would like to see Donald Trump removed from office and replaced by his VP. It was, after all, then-Governor Mike Pence who signed Indiana's uniquely expansive PRENDA bill—the first to bar abortion based on all three criteria of race, sex, and suspected genetic abnormalities, and to penalize doctors who performed an abortion motivated by these reasons—as well as a host of other restrictive provisions and laws, including requirements that women receive an ultrasound before an abortion and that

tus quo.

Of course, many who would like to see Trump removed from office recognize that Pence would likely be even more destructive to the cause of reproductive rights. But given the nature and extent of Trump's other flaws, they are willing to accept the trade-off. The moral to be drawn from the history of efforts to discourage prenatal diagnosis is not that progressives should prefer Trump to Pence, but that they should be exceedingly wary of engaging in de facto alliances with the Right. The history of PRENDA laws, whose advocates have managed to wrap their anti-choice agenda in the mantle of feminism and racial justice, and the sad fate of the "pro-information" movement, illustrates how easily the efforts of feminists, disability, and civil-rights activists can be co-opted for ends they would find repugnant. As a 14th Century proverb has it: "He who would sup with the devil had better have a long spoon."<sup>41</sup>

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