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# Prenatal Genetic Screening, Epistemic Justice, and Reproductive Autonomy

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## Abstract

Noninvasive prenatal testing (NIPT) promises to enhance women's reproductive autonomy by providing genetic information about the fetus, especially in the detection of genetic impairments like Down syndrome (DS). In practice, however, NIPT provides opportunities for intensified manipulation and control over women's reproductive decisions. Applying Miranda Fricker's concept of *epistemic injustice* to prenatal screening, this article analyzes how medical professionals impair reproductive decision-making by perpetuating testimonial injustice. They do so by discrediting positive parental testimony about what it is like to raise a child with DS. We argue that this testimonial injustice constitutes a twofold harm: (1) people with DS and their family members who claim that parenting a child with DS may be a rewarding and joyous experience are harmed when they are systematically silenced, disbelieved, and/or denied epistemic credibility by medical professionals, and (2) pregnant women are harmed since they might make poorly informed choices without access to all relevant information. The broader implication of the analysis is that epistemic justice is a precondition of reproductive autonomy. We conclude by calling for federal oversight of the acquisition and dissemination of information that prospective parents receive following a positive diagnosis of DS to ensure that it is comprehensive and up to date.

Reproductive autonomy is a core component of women's liberation. Women must be able to choose for themselves whether, how, and when they will have children to exercise some measure of control over their lives and freely participate in society as equals. Understandably, then, many feminists (ourselves included) are alarmed by the accelerating campaign to restrict women's reproductive rights. In particular, we are concerned that technologies for prenatal screening, which purport to increase women's options and autonomy, have actually harmed many women by providing opportunities for intensified control over their reproductive decisions.

First introduced for clinical practice in Hong Kong in 2011, noninvasive prenatal testing (NIPT) detects various chromosomal abnormalities like Down syndrome (DS) from cell-free fetal DNA in the mother's bloodstream.<sup>1</sup> The screening procedure is

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remarkably accurate, carries no risk of miscarriage, and has been widely adopted in prenatal care.<sup>2</sup> At first glance, this technology appears to enhance women's reproductive autonomy by providing genetic information about the fetus to prospective parents so that they can make informed decisions about how to move forward with their pregnancies. However, we aim to demonstrate how NIPT provides opportunities for intensified manipulation of women's reproductive decisions in current medical practice.

The primary goal of this analysis is to assess the power relations at play in information and knowledge claims about prenatal screening and diagnosis within medical institutions. Paying particular attention to the case of DS, we argue that women's reproductive autonomy is restricted by what Miranda Fricker and others have described as *epistemic injustice* (Fricker 2007).<sup>3</sup> We argue that medical professionals perpetuate epistemic injustice when they offer their patients distorted information (information that is out-of-date or prejudicial) or limited information (information that fails to convey all of a patient's options following a positive diagnosis, including information about termination, adoption, and what it might be like to raise a child with DS). This epistemic injustice constitutes a twofold harm: (1) people with DS who are content with their lives, as well as parents who claim that raising a child with DS may be a rewarding experience, are harmed when they are systematically silenced, disbelieved, and/or denied epistemic credibility by medical professionals; and (2) pregnant women are harmed since they might make poorly informed choices without access to all relevant information. One of the broader implications of our argument is that epistemic justice should be understood as a precondition of women's reproductive autonomy. Pregnant women cannot make truly informed and voluntary choices about how to move forward with their pregnancies if they are not getting "the whole story" or if the information they are receiving is distorted by ableist ideology or pro-life propaganda.

To make our case, section I begins with a brief sketch of the current political landscape surrounding prenatal screening in order to establish the relevance of our bioethical and epistemological analysis for feminists concerned with women's reproductive rights. Section II discusses how autonomy has been defined in legal doctrine and conceptualized by mainstream bioethics, placing particular emphasis on informed consent and nondirectiveness as necessary but insufficient conditions for supporting women's reproductive autonomy. Embracing a feminist relational autonomy framework, we argue that an adequate theory of patient autonomy must also attend to the ways in which wider social forces—like ableism—influence medical decision-making. Section III examines the challenge of prenatal screening in DS cases, arguing that current medical screening and informational practices fall short of even the baseline requirements of informed consent and nondirectiveness. We demonstrate how medical professionals can intentionally and unintentionally promote ableist assumptions about quality of life that implicitly, and sometimes explicitly, dissuade women from carrying pregnancies to term. Section IV applies Fricker's theory of epistemic injustice to the patient-physician relationship. Here we observe that women who receive prenatal diagnoses of DS are rarely exposed to accounts from the lived experiences of individuals with DS, or those of their family members. Their stories are important because they not only constitute a counternarrative to the ableist assumptions prevalent in the health services community, but they also enrich prospective parents' expectations about raising a child with DS. We argue that marginalizing these narratives constitutes a testimonial injustice against individuals with DS and their family members, while simultaneously constraining the reproductive autonomy of pregnant women. Finally, in section V we conclude that this epistemic injustice ultimately warrants federal regulation over the

type of information that physicians must make accessible to their patients in prenatal screening and diagnosis sessions.

### I. The Politics of Prenatal Screening

Disability rights organizations and pro-life groups in North America and Europe have objected to prenatal screening practices out of fear that the routinization of NIPT will increase rates of selective termination.<sup>4</sup> In the United States, various pieces of legislation have been put in place at both federal and state levels to reduce the likelihood of termination after the positive diagnosis of a fetal genetic condition.<sup>5</sup> These laws can be divided into two types: (1) prenatal nondiscrimination acts, which criminalize abortion in cases of fetal genetic impairment, and (2) information acts, which specify how information about prenatal testing and diagnosis will be delivered to patients.

Regarding the first type of legislation, prenatal nondiscrimination acts undeniably and unjustifiably restrict women's reproductive choices. Quite simply, a woman cannot freely exercise reproductive decision-making when the state coercively prohibits her option to pursue an abortion. In 2013, one year before NIPT was introduced in the United States, North Dakota became the first state to prohibit abortion based on a "genetic abnormality or a potential for a genetic abnormality."<sup>6</sup> Louisiana and Indiana enacted prenatal disability nondiscrimination acts in 2016. In 2017, Ohio passed its version banning abortion if a "pregnant woman is seeking the abortion, in whole or in part, because of . . . a test result indicating Down syndrome in an unborn child."<sup>7</sup> Kentucky's legislation was enacted in 2019, followed by similar bills in Missouri and Pennsylvania later that year. The exact terms of these bills differ, but all prohibit abortions in cases of potential fetal impairment. Although these pieces of legislation claim to be in service of individuals with disabilities and their families, critics have persuasively argued that their primary goal is to prohibit abortion and eventually overturn *Roe* (Piepmeier 2013; Giric 2016; Denbow forthcoming). If the primary goal had been to promote disability rights, these measures would have been accompanied by public policies to expand resources that improve the social situation of people living with disabilities, including increased funding for Medicaid, improvements to special education, community-based living initiatives, and the implementation of family support services. Prenatal nondiscrimination acts should instead be understood as pro-life Trojan horses: their proponents take up the rhetoric of disability rights to advance an anti-abortion agenda.

Unlike prenatal nondiscrimination acts, information acts can enhance women's reproductive autonomy in certain cases. Information acts grew out of the pro-information movement of the disability rights campaign over a decade ago. The pro-information movement developed in response to the fact that medical professionals—the very people on whom many pregnant women rely as their primary source of information and counseling as they make reproductive decisions—often exhibit ableist attitudes and provide misinformation to patients. As we illustrate in more detail later, many medical professionals discuss the prospect of having a child with a genetic impairment as a tragedy for the child or burden for the family that inevitably diminishes quality of life. To counterbalance this skewed perspective, members of the pro-information movement want prospective parents to be given more balanced and up-to-date information about the lived experience of conditions like DS so that pregnant women have a fuller and more nuanced idea of what it might mean to birth and raise a genetically impaired child.

At the federal level, the "Kennedy-Brownback Act" (2008), named after co-sponsors Edward Kennedy (D-MA) and Sam Brownback (R-KS), was passed to strengthen

patient support networks, increase referrals to support services for women who receive a positive diagnosis of DS and similar conditions, and guarantee that patients have access to up-to-date and accurate information about test results and the range of outcomes associated with the diagnosed conditions.<sup>8</sup> The Act authorizes federal public health agencies to award grants and contracts related to the collection and distribution of information, but no specific funds were appropriated for the law. It also lacks enforcement provisions. Disability rights organizations began to mobilize at the state level as they realized that the federal statute would have little impact. To date, at least nineteen states have passed laws with the stated goal of ensuring that pregnant women are better informed about the implications of a positive result.

As with antidiscrimination legislation, pro-life organizations have hijacked information acts to advance their anti-abortion agendas. For example, Indiana's information act prohibits the state from recognizing materials that "implicitly or explicitly reference pregnancy termination," and Louisiana's and Texas's laws also prohibit medical professionals from recognizing termination as an option following a positive test result.<sup>9</sup> Moreover, "conscience clauses" in Virginia and Nebraska laws allow genetic counselors to refuse to share any information that conflicts with their moral or religious beliefs, even allowing them to withhold results for fear that prospective parents will seek termination. As we argue later in the article, these clauses threaten to undermine practices of informed consent that buttress even the thinnest conceptions of patient autonomy and limit reproductive autonomy more broadly.

These ongoing political battles about prenatal testing and state regulation raise various concerns pertinent to feminist philosophers. We are concerned with the epistemic dimensions of these political struggles and grapple with several questions throughout the remainder of our analysis, including: What types of information should be included in physician–patient discussions about prenatal testing and diagnosis, and what constitutes a legitimate knowledge claim within this context? Who has epistemic authority in these discussions, and whose views are discredited? And, as a matter of social justice, which normative political obligations need to be fulfilled so that information about prenatal testing and diagnosis can simultaneously promote women's reproductive autonomy and also value people with disabilities? The answer to these questions depends in part on how one envisions the patient–physician relationship, a subject we explore in more depth in the following section.

## II. Patient Autonomy and Physician Authority

As its etymology suggests, autonomy refers to one's capacity to self-govern (autonomy is derived from the Greek *auto*—"self"—and *nomos*—"rule" or "law"). Autonomous persons make choices to shape the directions of their lives, free from excessive control by outside forces. The ideal of autonomy takes pride of place within liberal political thought. Positing individuals as the best judges of their own needs and interests, liberalism asserts that individuals have the right to pursue their life paths free from unwarranted paternalistic interference. Individuals each ought to enjoy a right to self-governance, provided they do no harm others. Liberals generally stylize the right to autonomy as noninterference since it enables citizens to make personal decisions without having to justify themselves to others or the state: self-determination thrives as external forces, like majority opinion and governmental authority, abate. As John Stuart Mill declared, "Over himself, over his body and mind, the individual is sovereign" (Mill 1858/2008, 14).

Contemporary bioethics is deeply indebted to this liberal tradition, and patient autonomy has become a cornerstone of the discipline. That said, the ideal of patient autonomy emerged only recently. Medical paternalism was the prevailing norm throughout North America and Western Europe until the middle of the twentieth century. Medical paternalism allowed physicians to unilaterally provide treatment—without their patient’s specific authorization—under the premise that, as high-minded experts, they knew what was best for the patients under their care (Kultgen 1995, 62). Prior to World War II, paternalistic medicine was practiced and taught largely at the bedside: physicians prescribed treatment to patients with whom they had sustained relationships built upon the presumption of implicit trust. These relationships began to change in the 1950s. Horrified by Nazi medical war crimes recounted in the Nuremberg Trials, the American public initially turned its attention to reports of unethical research practices at home before eventually scrutinizing the heretofore unchallenged authority of personal physicians. Coupled with increased professional specialization—in which teams of experts displaced the familiar family doctor—and falling levels of public trust, larger segments of the American public grew wary of healthcare providers. As David Rothman explains, “the doctor turned into a stranger, and the hospital became a strange institution” (Rothman 2003, 108). A distinctly liberal conception of patient autonomy grew from this malaise, and it is now widely accepted that patients have a right to make their own decisions about their medical care and treatment.

Much of the bioethics literature of the past forty years has refined liberal accounts of patient autonomy. The debt to liberalism is especially apparent in early feminist considerations of medical decision-making in the terrain of reproductive health. In order to take decision-making power out of the hands of men, doctors, and the state, mainstream prochoice feminist discourse emphasized the importance of defending a woman’s right to choose by elevating her voice in matters pertaining her own reproductive health while protecting her right to privacy in a medical setting. As Onora O’Neill observes, “Appeals to the right to choose were extended to express not only the idea that reproduction is in very many respects an area of life in which persons have a right to make their own choices, but the thought that it is a domain in which nobody else has any right to determine what they shall do in any respect” (O’Neill 2002, 253). As such, antipaternalist demands for autonomy employed the liberal language of rights to both choice and privacy in the medical domain. Framing abortion as a medical procedure, and positioning pregnant women as patients with rights to make autonomous decisions about their medical care, reproductive rights were thus conceived largely as negative rights to noninterference.<sup>10</sup> Thus construed, feminist demands for noninterference were consistent with mainstream bioethical principles of informed consent, whereby patients grant physicians explicit permission to deliver treatment after weighing the procedure’s benefits and risks against alternative treatment plans.

We find a similar view of patient autonomy described in American jurisprudence in the foundational case for informed consent, *Canterbury v. Spence* (1972). Recognizing the harms of withholding information about the risks associated with prescribed treatment plans, the court widened the physician’s scope of due care to include disclosure of relevant information about a given treatment’s risks and alternatives. The court framed this fiduciary duty to disclose as part of a broader effort to enhance patient autonomy:

The context in which the duty of risk-disclosure arises is invariably the occasion for decision as to whether a particular treatment procedure is to be undertaken. To the physician, whose training enables a self-satisfying evaluation, the answer may

seem clear, but it is the prerogative of the patient, not the physician, to determine for himself the direction in which his interests seem to lie. To enable the patient to chart his course understandably, some familiarity with the therapeutic alternatives and their hazards becomes essential.<sup>11</sup>

The Court thus tasked medical professionals with a duty to guide and counsel patients as they make their own medical decisions, expecting physicians to do so by obtaining informed consent after presenting relevant information and treatment options in a nondirective manner.

The Court's decision in *Canterbury* also highlighted how informational asymmetries translate into power dynamics between patients and their healthcare providers, and how this inherent power imbalance in the patient–physician relationship makes the exercise of patient autonomy challenging in practice. As the Court observes, “The patient’s . . . dependence upon the physician for information affecting his well-being, in terms of contemplated treatment, is well-nigh abject.”<sup>12</sup> Even in the current age of internet research and WebMD, patients often trust the goodwill and expertise of medical professionals over other sources, relying on them as primary providers of authoritative and reliable medical information.<sup>13</sup> After all, medical professionals have extensive medical training and requisite credentials that most patients do not, so specialization creates an asymmetry of knowledge and skill between patient and medical provider. Physicians therefore serve as gatekeepers with the power to determine what information is deemed relevant to patient decision-making. This status grants them the opportunity to empower patients with information to enhance free decision-making, but it also affords them the capacity to silence and manipulate.

In their influential *Principles of Biomedical Ethics*, Tom Beauchamp and James Childress draw our attention to the ways in which manipulation and framing effects may filter or distort information and, by extension, abridge patient autonomy. Often, physicians and other healthcare professionals are biased concerning what qualifies as fact or legitimate knowledge, and may therefore omit some sources of information from consideration:

In health care, the most likely form of manipulation is informational manipulation, a deliberate act of managing information that alters a person's understanding of a situation and motivates him or her to do what the agent of influence intends. Many forms of informational manipulation are incompatible with autonomous decision-making. For example, lying, withholding information, and misleading by exaggeration with the intent to lead persons to believe what is false all compromise autonomous choice. The manner in which a healthcare professional presents information . . . can also manipulate a patient's perception and response. (Beauchamp and Childress 2013, 139)

Even well-intentioned physicians cannot know all facets of how their patients will make decisions about their health, decisions that are, as Beauchamp and Childress acknowledge, only partially medical to begin with (126). Physicians' training may enable them to evaluate credible medical information or assess the risks and benefits associated with a given intervention. But women's reproductive decisions are also choices about how they will structure their broader lives, and there is nothing in physicians' training that equips them to make such an evaluation.

The information that medical professionals choose to disclose often carries significant weight. Patients who lack medical training or access to higher education may be inclined to weigh the information presented by healthcare providers so heavily that they defer to them without question (Trachtenberg, Dugan, and Hall 2005, 348). As Rayna Rapp explains, “Science speaks a language of universal authority” (Rapp 1988, 133), making physicians’ biomedical knowledge—which is presumed to be well-tested, objective, and trustworthy—difficult to challenge or refute. Moreover, physicians are experts with a privileged status in modern social life beyond the strict boundaries of the medical field. Being a doctor is socially respectable, and physicians are generally held in high esteem. Despite efforts to shift professional norms away from paternalism and toward a more cooperative engagement between physicians and their patients, medicine maintains a hallowed social position that resists change.

In sum, scholars generally agree that obtaining informed consent through nondirective counseling promotes patient autonomy and helps minimize the power imbalance inherent in the patient–physician relationship. However, feminist proponents of relational autonomy have challenged bioethicists’ and medical professionals’ limited focus to date, arguing that the myopic concern with informed consent is too narrow to capture the myriad ways in which wider social structures and institutional frameworks constrain or facilitate the choices of members of oppressed groups (Sherwin 1998; Ho 2008; Nelson 2013). For instance, Anita Ho rightly argues that traditional bioethics understands patient autonomy in narrowly dyadic terms: autonomy is understood to have been respected as long as physicians (the dominant actors) obtain informed consent and refrain from unduly influencing the choices of those in their care (the potentially vulnerable actors) (Ho 2008). However, as proponents of relational autonomy have long argued, medical professionals are not immune from the effects of socialization, nor do patients make choices in a social vacuum, so the dyad cannot remain the primary unit of analysis.

Any adequate theory of patient autonomy must therefore take stock of the socially embedded nature of the self. Catriona Mackenzie explains how relational autonomy theory does so by diagnosing “how social domination, oppression, stigmatization, and injustice can thwart individual autonomy” and then hypothesizing “possible solutions, in the form of proposing how specific social relations, practices, and institutions might be reformed in such a way as to protect and foster individuals’ autonomy” (Mackenzie 2014, 23). The relational autonomy framework thus envisions how social scaffolding—our political and economic institutions, kinship networks, social relations, and cultural norms—can be redesigned to better facilitate self-governance in various realms of our lives. This framework raises the possibility that respect for autonomy requires more than merely letting individuals be. It may also mandate positive action to form the conditions (that is, care, economic security, nonsubordination) necessary for autonomous choice. A paradigm shift follows: rather than looking for the absence of certain factors in determining an agent’s degree of autonomy, we turn our attention to the presence of conditions that facilitate people’s decision-making capacities.

This shift has implications for the role of the state in citizens’ lives. As Linda McClain persuasively argues in *The Place of Families*, relational autonomy theory sees governmental restraint and action as complementary dimensions of how the state can protect and promote its citizens’ capacities for self-determination. In McClain’s view, governmental noninterference is often necessary but insufficient (McClain 2006, 42). It is necessary, because excessive governmental power in the private realm may pose a significant threat to an individual’s pursuit of a self-governing life.

The state, for example, should refrain altogether from usurping women's decision-making power in matters concerning their own reproductive health. Laws limiting access to contraception and abortion are, therefore, illegitimate forms of state control. Yet restraint is also insufficient because the government must often take proactive measures to create the social conditions that foster citizens' opportunities to make autonomous decisions. For instance, the state may need to fund public health campaigns that facilitate informed choice and empower women to take control over their reproductive fates. Respecting a protected sphere of private decision-making does not necessarily entail abdicating a positive governmental responsibility to affirmatively secure the social conditions necessary for autonomous decision-making. Sometimes the state must refrain from acting, and sometimes it is required to act.

The following section adopts a relational and contextualized approach to autonomy to examine how ableism affects a woman's capacity to make reproductive decisions following prenatal genetic screening. Often using the language of tragic pathology, physicians and genetic counselors sometimes presuppose termination when delivering fetal diagnoses of DS to prospective mothers. In other cases, conscience clauses empower healthcare professionals who personally oppose abortion to limit what information about fetal health they choose to share. Whether healthcare professionals regard termination as a given or off the table, we argue that their attitudes can color the information they provide, restricting women's reproductive autonomy in the process.

### III. (Mis)Informed Choice: Biased and/or Limited Information

In the previous section, we argued that medical professionals have considerable epistemic power. This power translates into an attendant responsibility to deliver accurate and comprehensive medical information—in a clear and nondirective manner—so that patients themselves can make autonomous decisions about their medical care. In the case of prenatal genetic screening, many physicians attempt to fulfill this responsibility. However, several studies have demonstrated that a substantial portion of them do not. Some medical professionals draw significantly upon their own values when discussing patients' options, which is especially problematic given that studies have also shown that many harbor ableist biases by assuming that disability is inevitably undesirable, tragic, and/or necessarily leads to a diminished quality of life (Kothari 2004; Klein 2011; Reynolds 2017; 2018). Medical professionals are disproportionately able-bodied and are socialized within a wider ableist culture, so it should come as little surprise that many are likely to misunderstand, misjudge, and mischaracterize the lived experience of DS. Not only do many physicians lack first-hand experience with cognitive disability in their personal lives, but research suggests that few obstetricians and genetic counselors have access to disability-sensitive course curricula or direct contact with individuals with developmental and intellectual impairments during their medical training (Sanborn and Patterson 2014).

What is important to consider is how wider ableist biases enter into patient–physician exchanges. In practice, some medical professionals have tried to explicitly alter prospective parents' decisions by offering biased counseling. Others have less perceptibly (and perhaps even subconsciously) exerted undue influence over reproductive decisions by framing and presenting information in such a way that certain choices appear mandatory whereas some options are not considered worth pursuing.<sup>14</sup> To begin, many physicians expect that all pregnant women will undergo prenatal testing. Genetic screening and testing are often framed as a responsible choice or a routine part of

prenatal care (Farrell et al. 2011). The expectation that responsible parents automatically undertake prenatal screening hinders reproductive autonomy by reinforcing an environment in which women come to believe that it is the only course of action to take. Some patients have even reported feeling pressured into testing when they have deliberately opted out.

Consider the experience of Valle Dwight. When Valle and her husband decided that they would not want to terminate their pregnancy even if an amniocentesis came back with a positive result for DS, they shared their decision to forego testing with their physician. The following excerpt from Valle's conversation with her doctor demonstrates how her physician second-guessed her decision:

"Even if the baby has Down syndrome," I told the doctor, "I won't terminate the pregnancy, so what difference does it [the test] make?"  
 "Well, that's what everyone says," she told me. "But they change their minds when they get the test results." (quoted in Soper 2007, 5)

In these types of interactions, physicians who dismiss their patients' preferences or express disapproval when their patients choose a course of action that they would not have chosen for themselves violate their commitment to nondirective counseling.

Scholars have also documented how diagnostic discussions often draw on negative stereotypes and unsubstantiated assumptions about what it is like to live with DS or raise a child with the condition (Lalvani 2011). Some medical professionals underestimate what people with DS can do by offering empirically inaccurate and gloomy predictions, telling prospective parents that their future child may never walk, talk, or read, and/or that he or she will remain dependent for the entirety of his or her life with no potential for success or fulfillment (Soper 2007). Even the language used to convey a diagnosis of DS is overwhelmingly negative. Studies have shown that physicians often rely on the discourse of "tragedy," "burden," "grief," and "loss" when delivering positive diagnoses (Bridle 2000). However, the medical conditions, traits, and abilities of people with DS vary widely and cannot be predicted before distinct individuals are born. Diagnostic tests tell pregnant women only if the fetus does or does not have the specific chromosomal marker, but they cannot predict the severity of medical symptoms in cases of DS, let alone estimate the degree or longevity of care that the child may need.

Some prospective parents have even reported that physicians have openly promoted the termination of the pregnancy (Bridle 2000). In 2016, Courtney Baker posted an open letter to her physician on the internet after he tried to convince her to abort following a positive diagnosis. She explains the harm he caused her, writing,

I came to you during the most difficult time in my life. I was terrified, anxious and in complete despair. . . . But instead of support and encouragement, you suggested we terminate our child. I told you her name, and you asked us again if we understood how low our quality of life would be with a child with Down syndrome. You suggested we reconsider our decision to continue the pregnancy. From that first visit, we dreaded our appointments. (quoted in Brown 2016)

Rather than allowing pregnant women to arrive at their own fully informed decisions, some doctors overtly counsel from their own point of view to pressure patients into termination.<sup>15</sup> Doing so harms women by violating principles of nondirectiveness that betray the trust underpinning the patient-physician relationship. Like Martha

Swartz, we argue that physicians *qua* physicians have overriding fiduciary commitments to treating patients in ways that honor patients' interests, not their own. As she writes, "The patient's autonomous expression of her interests should set the course for medical decision-making, guided by the healthcare professional's advice" (Swartz 2006, 278). The physician's advice should derive from clinical evidence, but personal and unsubstantiated beliefs should play no part in their counsel.

Even when patient–physician exchanges are not directly tainted by personal bias, the information that medical professionals provide is frequently incomplete. Physicians, by the very nature of their work, focus primarily on the medical complications and health risks associated with DS (Skotko 2005; Skotko, Capone, and Kishnani 2009; Sheets et al. 2011a). DS is a genetic condition that is caused by an extra copy of the twenty-first chromosome. People with DS generally have mild to moderate cognitive delays, low muscle tone, and higher chances for a variety of other health issues over their lifespan. Approximately half of those with DS are born with cardiovascular problems that often require surgery in early infancy. Individuals with DS are also at an increased risk of leukemia, thyroid problems, sleep apnea, gastrointestinal blockages, hearing loss, seizures, poor vision, and skeletal problems. Medical prognoses are undeniably important sources of information for reproductive decision-making. However, a long list of potential health problems is not enough to go on when a pregnant woman is considering all of her reproductive options; it is just one piece of the puzzle. Moreover, by discussing DS solely as a medical condition—and failing to recognize that it is also a lived social experience—physicians reinforce the medical model of disability and the notion that "disability itself, not societal discrimination against people with disabilities, is the problem to be solved" (Parens and Asch 1999, 2).

Hence, expectant parents also need access to information on what day-to-day life is like for people living with or raising a child with DS in order to make a fully informed decision in accordance with their own values and life plans. Yet studies show that physicians rarely mention how prospective parents can access information about the lived experience of DS, nor do they sufficiently discuss public services that are available to support families who choose to continue their pregnancies (Sheets et al. 2011a). Reflecting on his experience raising his son Jamie, who has DS, Michael Bérubé explains how testimonies are sources of information that should be more frequently used to supplement clinical information:

Alongside the information about possible health risks, I'd offer prospective parents the testimony of various families—parents and siblings—of people with Down syndrome, as well as the testimonies of people with Down's themselves. The message: if you choose to have this child, your life may become richer and more wonderful than you can imagine, and the child will grow to be a loving, self-aware, irreplaceable member of the human family. *And* if you choose to have this child, your life may become more arduous and complicated than you can imagine. . . . (Bérubé 1998, 82–83)

Bérubé concedes that testimonial information can go only so far. The experience of a few people or families cannot stand in for all members of the DS community, and it may be difficult to predict what one's own experience will be based on those of others. Nevertheless, he makes a convincing case that personal testimonies are important sources of information for prospective parents considering their options because they have the potential to dispel the widespread belief that DS necessarily entails relentless

agony, stress, and low quality of life for the child and family. Testimonies can therefore facilitate informed decision-making by creating balance in the information provided.

In sum, the information provided by healthcare professionals leaves much to be desired. It is often biased or incomplete to the detriment of women's reproductive autonomy since pregnant women cannot freely make decisions about their reproductive lives—without excessive influence or manipulation—when information is misleading or omitted from discussion. The paradox is obvious: even though prenatal screening is touted as a means of enhancing choice in theory, it can actually undermine autonomy in practice. To be clear, we understand that medical expertise and clinical information about DS are essential ingredients of informed choice. Moreover, it is often the case that patients are unable to interpret the results of genetic screenings, so they must put their trust in medical professionals who have undergone extensive medical training. Physicians' exercise of epistemic authority is not always or necessarily harmful. Our primary concern is with instances wherein information is misleading, incomplete, tainted by bias, or provided in a directive manner.

In the following section, we further examine the ways in which physicians can trump, discredit, and invalidate the legitimacy of testimonial knowledge on the lived experience of DS. We show how medical professionals' tendency to dismiss and overlook testimony constitutes an epistemic injustice, one that violates the dignity of people with DS and also translates into diminished reproductive autonomy for prospective parents.

#### IV. Testimonial Injustice and Its Harm

Social scientists have identified and analyzed what has been dubbed the “disability paradox,” which refers to the persistent finding that people with disabilities report having a good or excellent quality of life in contrast to the widespread ableist expectation that disabled lives are inevitably so bad that they might not be worth living at all (Albrecht and Devlieger 1999; Wasserman, Bickenbock, and Wachbroit 2005). For example, in a survey of 284 people with DS who were asked to rate their quality of life, the vast majority of respondents reported being happy and fulfilled (Skotko, Levine, and Goldstein 2011). Specifically, 99 percent reported that they were happy with their lives, 96 percent liked how they look, and 97 percent liked who they are. Only a very small percentage (roughly 4 percent) expressed sadness or strong dissatisfaction with their quality of life. Relatedly, a survey of roughly 2,500 family members, parents, and siblings of individuals with DS also resulted in reports of happiness and satisfaction with their lives, despite acknowledging the challenges that sometimes accompany living with and/or caring for someone with the genetic condition. Nearly all parents reported loving and being proud of their child with DS, and about 79 percent said their outlook on life was actually *more* positive because of their son or daughter. Brothers and sisters also reported a favorable perspective (Skotko et al. 2015). Beyond surveys, qualitative analyses (Green 2007; Lalvani 2008; 2011; Piepmeier 2013) and memoirs from parents (Bérubé 1998; Soper 2007; Adams 2013) discuss how raising a child with DS can be an enriching experience.

In contrast, medical professionals tend to have more negative quality of life assessments of DS than individuals whose lives are directly affected by the condition (Wasserman, Bickenbock, and Wachbroit 2005; Saxton 2010). Most healthcare professionals focus on the medical or functional aspects of impairment when assessing quality of life, viewing disability as intrinsically negative and equated with suffering. As Eric

Parens and Adrienne Asch have pointed out, health professionals tend to focus inordinately on the negative aspects of an individual's impairment instead of viewing impairment as simply one factor in the context of multiple elements that influence the quality of a person's life (Parens and Asch 1999). This medicalized assessment is clearly at odds with the broader notion of quality of life embraced by disability studies scholars and many people with disabilities themselves, which encapsulates biomedical and social variables such as control over one's life choices, social acceptance, and support.

The problem is not simply that there are conflicting criteria for, and assessments of, quality of life. There is also evidence that medical professionals often disregard the experiential knowledge created by individuals with DS and their family members when personal testimony conflicts with their preexisting assumptions and expectations.<sup>16</sup> Skeptics of positive parental testimony dismiss it as unreliable for various reasons: the parents are clearly in denial and find it easier to unrealistically "sugar-coat" the situation than come to terms with their "tragic" circumstances; parents are afraid to admit that they are disappointed and would have preferred an able-bodied child because they might be viewed as bad parents if they do not appear to love their child unconditionally; they are expressing an adaptive preference because they have never raised a "normal" child so they do not know what they are missing out on; and/or, their emotional investment in their child with DS distorts their rational and "objective" judgment. In sum, medical professionals offer various rationales to justify their incredulous reception of positive parental testimony. Of course, personal testimony (like other types of information) is always fallible and open to critique. However, discounting testimony after careful consideration is a very different thing from saying it is simply obvious or common sense that parents of children with DS who have a positive outlook on their lives are kidding themselves.

We argue that this type of dismissal constitutes what has come to be referred to as epistemic injustice, specifically a form of testimonial injustice. According to Fricker, epistemic injustice is "a wrong done to someone specifically in their capacity as a knower" (Fricker 2007, 1). Fricker further distinguishes two types of epistemic injustice: testimonial injustice and hermeneutical injustice. Testimonial injustice occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word, such as when a white police officer does not believe someone just because he is a person of color. Hermeneutical injustice occurs when collective interpretive resources put someone at an unfair disadvantage when it comes to making sense of their social experience, such as when a woman cannot portray her experience of sexual harassment because she lives in a cultural context that lacks the concept (1). Fricker argues that the social practice of giving information to others and interpreting our experiences is integral to a person's identity, agency, and dignity, so epistemic injustice should be considered a deep source of harm that affects a person's life as a whole.

Extending this idea to the case at hand, we argue that the disability paradox is indicative of structural testimonial injustice. Ableist assumptions interfere with the ability of able-bodied people to hear, understand, or believe the knowledge claims of people with disabilities and their family members. Rather than taking the testimony of people with disabilities seriously, nondisabled people tend to project their own fears and fantasies. Medical professionals may confidently think that they can accurately intuit what it is like have DS or raise a child with the condition, but it seems that they tend to both overestimate the negative effects of impairment on a person's quality of life and also fail to recognize many of the socially induced barriers to well-being.

Of course, medical practitioners are hardly alone in jumping to conclusions about what life must be like with DS. “Among people with little exposure to disabled people,” writes Marsha Saxton, “it is common to think that this [positive testimony] is a romanticization or rationalization of someone stuck with the burden of raising a damaged child” (Saxton 2010, 123). We are singling out medical professionals because they are in a unique position to cause considerable harm to free reproductive choice. On the one hand, medical professionals often possess what Fricker calls “credibility excess,” where knowers, based on their identity or social position, are granted more credibility than they might merit in some cases. On the other hand, people with DS and their family members often experience what Fricker refers to as “credibility deficits,” wherein a prejudice deflates the credibility afforded the speaker (Fricker 2007, 17). Due to this power imbalance, the information offered by physicians can easily eclipse or drown out other types of information. Bérubé spells out the implications, writing, “If we had no way of knowing how loving, clever, and ‘normal’ a child like Jamie can be, we would simply have to rely on the advice of ‘experts.’ And if those experts told us there was no way to raise such a child, we would probably believe them” (Bérubé 1998, 47).

In the following section, we extend our relational autonomy approach to consider how the state has an obligation to ensure the social scaffolding necessary for pregnant women to exercise informed, nondirected decision-making. Honoring that obligation will require the state to refrain from banning disability-selective abortions, but it will also introduce a commitment for it to take a more active role in regulating and standardizing information.

#### V. “Pro-Choice” Defense of Government Regulation

By now it should be clear that far too many medical professionals fall short of the ideals of nondirectiveness and informed consent that underpin even the thinnest standards of patient autonomy. So how do we fix this problem? Scholars in the humanities and social sciences, disability rights activists, and members of the medical and scientific community have furnished answers to this question by developing various recommendations to improve physician–patient relations and facilitate informed decision-making. In this concluding section, we survey these recommendations and call for three main policy reforms: (1) state-funded medical schools should include disability training as part of their standard curricula; (2) Congress should adequately fund the Kennedy-Brownback Act; and (3) lawmakers should reassess or repeal conscience clauses.

To begin, the current education system is not producing physicians with the requisite disability cultural competencies, so structural reform in the medical education system is warranted. According to survey data, medical professionals have reported feeling unprepared to treat patients with disabilities or patients pregnant with disabled fetuses in a manner informed by the lived experience of disability and its cultural components (Santoro et al. 2017). Studies have also shown that nearly a third of genetic counselors have been dissatisfied with the disability training they obtained in their graduate programs (Sanborn and Patterson 2014). In order to remedy the fact that medical professionals often do not recognize the social dimensions of disability, nor receive sufficient training on how to do so in their course curricula, Anita Ho advises medical professionals to adopt a posture of epistemic humility when discussing prognoses and available treatment options with patients (Ho 2011, 118–20). In her words,

Epistemic humility is a disposition as well as a commitment. It arises out of professionals' acknowledgment of the boundary of their expert domain as well as their fallibility. It means a commitment to make realistic assessment of what one knows and does not know, and to restrict one's confidence and claims to knowledge only to what one actually knows about his/her specialized domain. In particular, it is a recognition that knowledge creation is an interdependent and collaborative activity. (117)

As she describes it, epistemic humility requires physicians to be open to multiple forms of inquiry and knowledge, including subjective testimonies, in a collaborative project of knowledge production. An ethos of humility can curb the all-too-common tendency among clinicians to undermine the epistemic authority of people with disabilities and their family members.

State-funded medical schools can facilitate a culture of epistemic humility by including disability training in their standard curricula. The Association of American Medical Colleges (AAMC) has recommended that medical schools create specially designed curricula to teach disability cultural competency. However, it is ultimately up to faculty and administrators to decide whether or how to do so since these measures are encouraged, but not required, for accreditation and licensure. The result is that medical schools vary greatly in the content and delivery of their disability curricula and training (Crossley 2015; Santoro et al. 2017). Disability cultural competency is completely overlooked at some medical schools, though a notable few have begun formally implementing disability training in their programs. The approach developed at the Jacobs School of Medicine and Biomedical Sciences at the University of Buffalo is especially promising. Integrated over four years of medical training and consisting of formal lectures, interviews, and clinical rotations, the program culminates in a four-week elective course in which students meet patients with disabilities and their families as well as patient advocacy groups and community organizations (Symons et al. 2009). By inviting people with disabilities and their families to share their own narratives, such programs recover the epistemic value of testimony while inculcating an ethos of humility among early-career physicians. As one student wrote in a reflective piece following an encounter with disabled patients and their families, "This was the first step in opening our eyes to the necessity of being able to fully understand what it means to care for those that may have an impaired ability to care for oneself" (Symons et al. 2009, 78). This specific approach may not work for all medical schools, but we nevertheless argue that state-funded medical schools should be incentivized or even required to formally integrate a requirement for curriculum on disabilities into its accreditation standards.

Next, medical practitioners and professional organizations have set their own standards for best practices to deliver information and counsel patients, but not all clinicians have chosen to follow these recommendations. In 2011, The National Society of Genetic Counselors (NSGC) developed and published guidelines on how to communicate a positive diagnosis of DS following screening to "ensure that families are consistently given up-to-date and balanced information about the condition." The guidelines specifically recommend that medical professionals "balance the negative aspects of Down syndrome, such as birth defects, medical complications, and developmental delay, with positive aspects like available treatments, therapies, and the ability for people with Down syndrome and their families to enjoy a high quality of life" (Sheets et al. 2011b, 435). Additional recommendations include providing patients with referrals to necessary specialists, as well as contact information for local support

services, including reference lists available from the National Down Syndrome Society ([www.ndss.org](http://www.ndss.org)) and the National Down Syndrome Congress ([www.ndscenter.org](http://www.ndscenter.org)).

Nonprofits have crafted useful resources as well. The Lettercase National Center for Prenatal and Postnatal Resources, which is part of the University of Kentucky's Human Development Institute, prepared a booklet titled "Understanding a Down Syndrome Diagnosis." This booklet is available in print and online for expectant parents who have received a prenatal diagnosis of DS but have not yet made decisions regarding their pregnancy options. Developed in collaboration with DS advocates and professional medical organizations, the booklet discusses medical issues and developmental delays that children with DS typically face, as well as contact information for medical specialists, DS advocacy groups, and support organizations. Importantly, the publication also addresses pregnancy termination and adoption as options.

These initiatives are commendable, and the proposed tactics offer a powerful corrective to the narrowly clinical and generally pessimistic counsel that pregnant women whose fetuses are diagnosed with DS typically receive from doctors. That said, these proposals are entirely voluntary since they are designed to persuade medical professionals to change their practice and rhetoric. Physicians do not have any incentive or obligation to adhere to these guidelines. Given the deeply entrenched ableist biases that pervade Western medicine, we are not optimistic that adequate solutions can be achieved by these voluntary, individual-level measures. Reproductive autonomy is a matter of justice, and women should be guaranteed access to comprehensive, balanced, and up-to-date information—they should not have to depend on the goodwill of individual physicians, nor should they have to be fortunate enough to live in a state with an exemplary disability information act.

In order to standardize medical practice across states and uphold the integrity of information related to prenatal testing for the sake of women's autonomy, we recommend that the federal government adequately fund the Kennedy-Brownback Act. This funding will enable the Department of Health to collect and disseminate accurate, up-to-date, comprehensive information about test results and the range of outcomes associated with the diagnosed condition. Additional information should include patient support networks, including information about how expectant parents of fetuses diagnosed with DS can connect with other parents who have had the same experience through First Call programs.<sup>17</sup> In turn, medical providers should then be required to make this information accessible to patients via written materials.<sup>18</sup>

Finally, we encourage lawmakers to reassess and repeal conscience clauses, especially those that permit physicians to restrict patients' access to the balanced information necessary for decisional autonomy. Having rapidly expanded in the wake of *Roe*, most existing conscience clauses are vaguely written and deeply problematic for patients attempting to make autonomous decisions about their reproductive health. Troublingly, many women may not even realize that their healthcare provider or institution has policies against certain procedures related to reproductive care—including abortion—until it is too late for them to choose another provider (Swartz 2006, 289). At a minimum, physicians have a duty to inform patients of any personal convictions that may inform their approach to care, thereby enabling patients to decide as early as possible whether to continue the relationship. As Holly Lynch suggests, "Revelation of a potential mismatch will allow the patient to seek an alternative provider before investing a substantial amount of time and energy in developing a relationship with the refuser, and before a time-sensitive situation arises that could inhibit the search for an alternative physician" (Lynch 2008, 217–18). Insofar as the patient–physician relationship

should promote mutual respect, safeguard trust, and focus on patient care, such disclosures are a necessary practice in respecting patient autonomy. Vaguely written and devoid of standards explicating acceptable reasons for refusal and timelines for disclosure, existing conscience clauses undermine patient autonomy. Repealing conscience clauses would not prevent some physicians from masking cryptonormative recommendations as value-neutral clinical advice, but doing so would remove the cover of law from those who would impose their own beliefs upon their patients.

At this point, feminist readers may be wondering to what extent our call for governmental regulation in the name of women's autonomy differs from pronatalist, abortion-related informed consent statutes, often labeled "Woman's Right to Know" Acts. Although the exact content varies from state to state, these statutes typically require physicians to share specific details with patients, including information about the risks of the termination procedure, graphic material about fetal development and termination, and information regarding assistance to women deciding whether to continue their pregnancies. The professed aim of these statutes is to promote women's autonomy, suggesting that women confronting the choice to have an abortion need special safeguards to protect them from misunderstanding the nature and consequences of their decision and from the regret that might come from having an abortion without understanding important facts about the procedure beforehand. In *Planned Parenthood of Southeastern Pennsylvania v. Casey* (1992), the Supreme Court upheld the constitutionality of Pennsylvania's law, affirming the permissibility of states to require physicians to supply pregnant women with material designed to discourage abortion as a means of ensuring that women's choices are "mature and informed."<sup>19</sup>

We specifically distinguish our call for federal funding for the Kennedy-Brownback Act from "Woman's Right to Know" Acts along three dimensions. First, our proposal is addressing an empirically substantiated problem (that is, the premise that misinformation about DS colors prenatal screening and selective abortion has been well-documented), whereas the latter does not. The *Casey* decision cites the potential for psychological harm and regret as justifications for making state-authored information about nonselective abortion available to women.<sup>20</sup> At best, these risks seem to be hypothetical, rather than common occurrences. There is no proof that women are not already sufficiently informed of the risks and benefits of nonselective abortion, and the potential link between abortion and psychological harm or regret remains scientifically unsubstantiated. Second, whereas the Kennedy-Brownback Act mandates that *supplemental* material be made available to patients, "Woman's Right to Know" Acts allow the government to *supplant* the information that physicians provide, sometimes even going so far as making doctors recite a state-approved medical script containing misleading or incorrect clinical information. *Casey* held that states may adopt regulations to guide physicians as they inform the woman's free choice by supplying "truthful, non-misleading information."<sup>21</sup> Yet several studies have demonstrated that many state-developed materials fail to meet this standard in practice.<sup>22</sup> Finally, we endorse governmental regulations designed to inform, not influence, choice. By contrast, the *Casey* decision allows states to influence choice by expressing "a preference for childbirth" in order to "cause the woman to choose childbirth over abortion."<sup>23</sup>

Hence, it seems that "Woman's Right to Know" Acts are less about protecting the integrity of genuine informed choice and more about discouraging abortion by making it a more cumbersome and shame-filled process. In our view, pregnant women who choose to undergo prenatal screening cannot be self-determining if the information they are given is biased toward one outcome. When left to their own devices, medical

professionals err on the side of providing and framing information in a manner that is biased toward termination. Yet, following the *Casey* decision, state governments can provide information that encourages women to choose childbirth over abortion. In order to remove constraints to individual choice that result from undue influence in medical settings and state legislatures, governmental regulation at the federal level can potentially ensure that prenatal screening actually works for the sake of women's autonomy by better informing—not influencing or manipulating—women's reproductive decisions.<sup>24</sup>

Ultimately, we recognize the potential risks of legitimizing government regulation in the terrain of reproductive rights, and we certainly hope that our pro-autonomy rationale for regulating the delivery of information about prenatal screening will not fuel the call for more stringent restrictions on abortion in general. To prevent the anti-abortion movement from co-opting the rhetoric women's rights, we want to be perfectly clear about our position: we argue that the federal government has an obligation to affirmatively allocate the funds to ensure that up-to-date, comprehensive, and balanced information is made accessible to patients who choose to undergo prenatal screening in order to promote informed choice, but it is up to the patients to ultimately decide what they want to do with the information. Women have the capacity and right to determine for themselves what is best for their own reproductive health for whatever reasons they see fit. Nobody has a right to usurp this power or manipulate them into a particular choice; such decisions are rightly their own. We acknowledge that various moral, social, financial, and religious factors will influence whether a woman will choose to undergo prenatal testing and what decision she will make based on the information she acquires from the results. In a diverse society characterized by a variety of lived experiences, values, and preferences, we expect that people in similar situations will inevitably make different choices. This means that individual women—not doctors or the state—must determine whether they want to undergo prenatal testing, terminate a pregnancy following a positive result, carry the fetus to term, raise a child with DS, or choose adoption. Consistent with the principle of patient autonomy, therefore, pregnant women are the final decision-makers. The government can facilitate medical decision-making vis-à-vis the provision of accurate, balanced, and comprehensive information, but it cannot legitimately substitute its judgment by prohibiting termination under the guise of promoting disability rights or protecting women.

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## Notes

1 Various technologies for prenatal screening and diagnosis have been used since the 1970s, but the practice has only recently become a routine part of prenatal care. In 2007, the American College of Obstetrics and Gynecology (ACOG) expanded its prenatal screening recommendations to offer the option to all women, regardless of age. Moreover, major private insurance plans began to cover NIPT in 2013. One study has predicted that the routinization of NIPT will “expand the pool of women who opt for prenatal genetic screening each year from fewer than 100,000 to as many as 3 million” (Hayden 2012).

2 Although NIPT allows for remarkably accurate early detection of several genetic impairments, positive results still require confirmation via amniocentesis or chorionic villus sampling.

3 We chose to narrow our focus to DS for two reasons. First, DS is the most common chromosomal disorder in the United States, occurring in approximately 1 of every 733 live births, and prenatal screening

technologies to detect trisomy 21 have been around for over fifty years (Skotko, Capone, and Kishnani 2009). Second, DS is politically salient. It became a flashpoint in the national abortion debate after vice-presidential nominee Sarah Palin, whose son Trig has DS, drew enormous public attention to the issue on the campaign trail in 2008. Advocacy groups for and by people with DS and their family members (for example, the National Down Syndrome Congress and the National Down Syndrome Society) have also been particularly active in advocating for reforms to screening practices.

4 Stefanija Giric explains how many disability rights advocates and pro-life advocates have become “strange bedfellows” in the debate over prenatal screening and its implications. Yet these groups have very different rationales for opposing prenatal screening and selective termination. On the one hand, disability advocacy groups oppose the expanded use of NIPT on the grounds that prenatal screening is a discriminatory eugenic practice that devalues the lives of people with disabilities. Pro-life groups, on the other hand, value fetal rights over women’s reproductive rights, even though many have co-opted the rhetoric of disability rights and used the “vener of enhancing the position of disabled individuals” to advance their pro-life agendas (Giric 2016, 736).

5 The limited available data suggest that rates of termination vary by genetic condition, as well as by the mother’s socioeconomic background. Most studies put the rate of termination for DS in the US somewhere between 60% and 90% (Natoli et al. 2012).

6 North Dakota Code, 14-02.1-04.1.

7 Ohio Revised Code, Section 2919.10.B1.

8 Prenatally and Postnatally Diagnosed Conditions Awareness Act, PL No 110-374; 2008.

9 Indiana Code, 16-35-9.2-1.A.1.

10 The Supreme Court’s decision in *Roe v. Wade* (1973), which protects a woman’s right to choose abortion, hinges on a constitutional right to privacy found in the due process clause of the Fourteenth Amendment.

11 *Canterbury v. Spence*, 464 F.2d 772, 782.

12 *Canterbury v. Spence*, 464 F.2d 772, 782.

13 Although several studies conducted in the US have indicated that public trust in physicians has declined over time, Americans still trust the medical system more than other institutions like Congress, religious institutions, and the police (Blendon, Benson, and Hero 2014). Observing that rates of public trust have remained higher in many Western European countries, some researchers have blamed this decline on the commodification of healthcare in the United States (Huang et al. 2018). When patients do consult other sources of information, such as those found on the internet, they are motivated by a desire to play a more active role in their treatment rather than by a distrust of their physicians (Hu et al. 2012).

14 In a survey of nearly 500 primary care physicians who have prenatally diagnosed DS, 13 percent admitted that they emphasized the negative aspects of the condition so that parents would favor a termination, and 10 percent actively urged parents to terminate (Skotko 2005, 670–71).

15 In the wake of *Becker v. Schwartz* (1978), some physicians may worry that failure to encourage termination in light of positive diagnoses of DS might expose them to “wrongful birth” litigation, wherein a physician is accused of medical malpractice for negligently failing to disclose to the prospective parents the risk of having a child with a genetic impairment. Although most states allow for such litigation, they vary widely in their conceptions of birth-related torts like “wrongful birth” and by the standards used to evaluate negligence and damages. See Strasser 2004, 822–43.

16 Carl Cooley and colleagues evaluated genetic counselor and parent responses to a video describing parents’ experiences in raising a child with DS. They found that the two groups’ responses to the film differed significantly. 14 percent of 29 genetic counselors versus 89 percent of 36 parents felt the film accurately portrayed parental experiences. The majority of the genetic counselors who viewed the film rated it as being “too positive,” refusing to believe that the benefits of parenting a child with DS could outweigh the challenges (Cooley et al. 1990).

17 First Call programs are comprised of volunteer parent mentors who listen, share, answer questions, and provide valuable information about the challenges and rewards of raising a child with DS.

18 It would be a mistake to allow the government to intrude into the communication between patients and providers since physicians need room to use their professional discretion. For example, physicians should not be forced to recite a congressionally scripted statement or perform a medically unnecessary and invasive procedure on patients against their will. We are merely suggesting that physicians be required to provide

information-rich, well-vetted, federally approved written information to women who receive positive prenatal test results for DS to supplement the clinical counseling they will receive.

**19** *Planned Parenthood v. Casey*, 505 U.S. 833 (1992), 883. The *Casey* decision upheld a number of regulations regarding abortion, including an informed consent requirement, a twenty-four-hour waiting period, and a parental notification requirement.

**20** *Planned Parenthood v. Casey*, 505 U.S. 833 (1992), 882.

**21** *Planned Parenthood v. Casey*, 505 U.S. 833 (1992), 882.

**22** The Guttmacher Institute found that state-written materials making claims about a link between abortion and breast cancer, the psychological impact of abortion, and fetal pain were “misleading or altogether incorrect” (Richardson and Nash 2006, 7). Recently, Cynthia Daniels and colleagues collected all statements regarding embryological and fetal development from the state-developed information packets (a total of 896 statements about fetal development across twenty-three states). They then recruited a team of seven specialists in embryological and fetal anatomy through the American Academy of Anatomists to evaluate the medical accuracy of the materials. The study finds that nearly one-third of the informed consent information is medically inaccurate, and that medically unsubstantiated information is concentrated primarily in the earlier weeks of pregnancy when women are most likely to seek an abortion (Daniels et al. 2016, 191–94).

**23** *Planned Parenthood v. Casey*, 505 U.S. 833 (1992), 883.

**24** See Bagenstos 2006, 427 for a strict antiregulation “pro-choice” position. Samuel Bagenstos maintains that “disability rights advocates cannot endorse regulation in the abortion context without setting a precedent that may be applied to scale back abortion rights in areas that go far beyond disability.”

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