

BABIES, BODIES AND BUYERS

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In the thirty-five years since I began my career in legal education, much about the status of women, gender and sexuality has changed. There are the obvious triumphs: more female students, faculty and deans—as well as more bathrooms for more kinds of people than just “men.” Life is less lonely now, and conversation more intersectional. There is more openness about LGBT issues. There is marriage equality, however contested. And there is less general tolerance for open forms of harassment.

But challenges remain. While reproductive rights have always been at the center of women’s work in the academy, that conversation has changed in complex ways in recent years—in no small part because of revolutionary new assisted-reproductive and genetic technologies. From ooplasmic transfer¹ to pre-implantation genetic diagnosis² to the precise gene-editing capabilities of Crispr-cas9,³ these technologies can facilitate quiet forms of eugenic natalism. Increasingly, consumerist rather than dignitary notions of choice have been deployed to chase non-medical, cosmetic notions of human perfectibility. I worry that this shift signals an ever-more pervasive styling of bodies—including future bodies—as private property, and as inert clay-for-the-molding.

I am hardly alone in my concern that the ultra-contractarianism of our neo-liberal moment is not such a good thing when it dominates all crannies of human endeavor. Its narrowed understanding of corporeal integrity compromises many of the erstwhile goals of public accommodation for all. Below are three stories in which the personal is short-circuited as exclusively private rather than politically expressive as well.

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1 Sheldon Krinsky, *Is Ooplasm Transfer Safe for the Offspring*, 27 GENEWATCH 22 (2014).

2 Michelle Bayefsky, *The Regulatory Gap for Preimplantation Genetic Diagnosis*, 45 HASTINGS CTR. REP. 7 (2015).

3 Heidi Ledford, *CRISPR, the Disruptor*, NATURE MAG., June 3, 2015, <http://www.nature.com/news/crispr-the-disruptor-1.17673> [<https://perma.cc/4VZE-BXBA>]; see also, PAUL KNOEPFLER, *GMO SAPIENS: THE LIFE-CHANGING SCIENCE OF DESIGNER BABIES* (2015); Jennifer Kahn, *The Crispr Quandary*, N.Y. TIMES MAG., Nov. 9, 2015, <http://www.nytimes.com/2015/11/15/magazine/the-crispr-quandary.html> [<https://perma.cc/V3HB-YA7C>].

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The first story is about surrogate pregnancy—by now a comparatively old-fashioned technology of assisted reproduction, but one rife with the ethical challenges and cultural incoherence to which I allude. In late January of 2014, Kansas State Senator Mary Pilcher-Cook introduced a bill that would have criminalized the use of surrogate contracts in pregnancy and imposed a \$10,000 fine and up to a year in jail for anyone participating in such a transaction.⁴ The effort was quickly abandoned amid a blizzard of publicity that included pro-lifers battling pro-lifers; Republicans battling Republicans; invocations of God having hired the Virgin Mary as a surrogate; vaginal sonograms broadcast live in a Senate committee; and by a host of other posturing too easily dismissed as risible.⁵

If the bill hadn't been body-slammed into the dust by some of the sillier assertions of its chief proponent (Pilcher-Cook asserted, for example, that surrogacy creates children that are “not going to have either a biological mother, biological father or both”⁶), the discussion might have garnered more attention. The laws regarding surrogacy are a national jumble of inconsistent public policies, extra-legal technological engineering, free-market contracting, civil interventions, and criminal sanctions. However incoherent the Kansas attempt, there was a serious question at its center: whether individually-drafted private contracts are sufficient to settle questions of intended parenthood, or whether the “best interests of the child” standards governing custody, adoption, and other realms of family law should have greater sway.

While some states have long found surrogate contracts not in the public interest, at least ten already criminalize them.⁷ Many of those laws were passed in the very early days of ovum transplantation and have not been reviewed in the decades since. Hence, what laws are in place have not nearly kept up with the explosive technological revolution in

4 Tim Carpenter, *Fans, Foes, Argue Merits of Bill Banning Surrogacy*, CJONLINE (Jan. 27, 2014), <http://cjonline.com/news/state/2014-01-27/fans-foes-argue-merits-bill-banning-surrogacy#1> [https://perma.cc/S8KY].

5 *Id.*

6 Diana Reese, *Kansas Lawmaker Wants to Make Surrogate Motherhood Illegal*, WASH. POST, Jan. 29, 2014, <https://www.washingtonpost.com/blogs/she-the-people/wp/2014/01/29/kansas-lawmaker-wants-to-make-surrogate-motherhood-illegal/> [https://perma.cc/V8NA-JEK8].

7 CTR. FOR BIOETHICS & CULTURE NETWORK, *STATE BY STATE SURROGACY SUMMARY* (2012), http://www.cbc-network.org/wp-content/uploads/2012/08/State-by-State_Surrogacy_Sum_CBC.pdf [https://perma.cc/VA43-L746].

assisted reproduction. Even in states that purport to regulate, it is largely doctors and IVF technicians who call the shots as to what's acceptable in the realm of surrogacy and reproductive techniques.⁸

There is deep conceptual confusion, as well as outright conflict, about what is at stake in surrogacy. Employing a woman—often a poor or minority woman in strapped economic circumstance—to bear one's child is generally extolled in the language of gift, donation, altruism, joy, hope, sharing, and religiously-inflected fruitfulness.⁹ But it is, at present, a mostly commercial transaction, involving thorny issues of pregnancy as labor, childbirth as priced, equality of bargaining power, exploitation of bodies, and fairness of terms.

As a jurisprudential matter, surrogacy is a form of commodity exchange. It is usually governed by an individual contract purporting to broker the reproductive expectations, freedoms, and health of multiple parties: the donors of eggs, the donors of sperm, those to whom the law assigns parental rights, and those who provide their wombs as gestational spaces. All manner of emotionally-wrenching legal messes have attended this conceptualization of wombs as mere rental spaces with fetal rights of occupation. May a woman be contractually bound—forced in other words—to have an abortion if developmental abnormalities are detected?¹⁰ Or, since surrogacy is increasingly a transnational industry (driven by lower “production costs” of hiring surrogates in poor nations), what is the citizenship status of, say, a child born of an Indian surrogate, impregnated with the egg of a United States citizen, and a Danish sperm donor?¹¹

These questions are not only about the technology of assisted reproduction, but also

8 Tamar Lewin, *Surrogates and Couples Face a Maze of Laws, State by State*, N.Y. TIMES, Sept. 17, 2014, http://www.nytimes.com/2014/09/18/us/surrogates-and-couples-face-a-maze-of-laws-state-by-state.html?_r=0 [https://perma.cc/3W6U-CYGG].

9 See, e.g., Alex Kuczynski, *Her Body, My Baby*, N.Y. TIMES MAG., Nov. 30, 2008, <http://www.nytimes.com/2008/11/30/magazine/30Surrogate-t.html?pagewanted=all> [https://perma.cc/72GW-DMGF].

10 Mary Yarwood, *Two US Surrogates Carrying Triplets Refuse Abortion Demands*, BIONEW (Dec. 21, 2015), http://www.bionews.org.uk/page_598152.asp [https://perma.cc/A7DL-XHNC]; Brad Schrade, *California Surrogate: Atlanta Dad Demands I Abort a Triplet*, ATL. J.-CONST. (Nov. 27, 2015), <http://www.myajc.com/news/news/public-affairs/california-surrogate-atlanta-dad-demands-i-abort-a/npXhc/> [https://perma.cc/JAH3-5Y3S]; Carl Campanile, *Dad Demands Abortion After Surrogate Learns She's Carrying Triplets*, N.Y. POST (Nov. 25, 2015), <http://nypost.com/2015/11/25/surrogate-carrying-triplets-says-dad-demanding-she-abort-one/> [https://perma.cc/4XY8-FH5L].

11 Yasmine Ergas, *Babies Without Borders: Human Rights, Human Dignity, and The Regulation of International Commercial Surrogacy*, 27 EMORY INT'L L. REV. 117 (2013).

the technological ability to sustain life under circumstances that pit notions of value against one another in configurations of “fetal personhood” and women’s health. In one extreme instance, the state of Texas tried to keep a deceased woman, Marlise Munoz, on life support in order to sustain a fourteen-week-old fetus—despite certain developmental injury to the fetus. Texas law provides that “[a] person may not withdraw or withhold life-sustaining treatment under this subchapter from a pregnant patient.”¹² But Ms. Munoz was not a “patient” any longer when her husband sued to have her removed from life support. She had already passed away from a massive brain hemorrhage, and her fetus had already suffered significant oxygen deprivation. While her husband ultimately won the injunction, the application of the law to a corpse is an odd form of legal fictionalizing that literally deadens the mammalian interdependency of gestational processes.¹³

It also begs the question of what would have happened if Ms. Munoz had been a gestational surrogate. She was, or her remains were, taxonomized as “patient”—and patients have rights, however vexed by fetal personhood laws. Pushing that vexation further still, what if she had instead been categorized outright as service dispenser? If the language of contract had imagined her body to be a passive fetal factory or “container,” would there have been more or less suasion in the attempt to hook up a “hired-out” body to pumps and bellows like a mechanized delivery system, effectively imagined without a brain? What happens, in other words, if a surrogate enters a contract that fails to address the risk of complications that threaten her health but not that of the fetus—would she be forced to carry the pregnancy to term either in life or even after death? If Texas’s attempt was ruled unconstitutional, the battle nevertheless underscores the degree to which there are implicit issues of dignity, bodily integrity, and public health in surrogacy arrangements. These issues defy and exceed the sphere of private contract.

Of course, Senator Pilcher-Cook’s proposal was motivated by an even deeper, if more familiar, conceptual divide: that of when the biological processes set into motion by the fertilization of a human egg will be conferred legal standing as “person.” Pilcher-Cook is among those who believe that full personhood is sparked from the moment of conception in any and all pluripotent cells. She assigns agency, autonomy, and a weirdly disembodied vitality even to frozen embryos stashed in laboratory refrigerators because the “value of a

12 TEX. HEALTH AND SAFETY CODE ANN. § 166.049 (West 2015).

13 Susan Dwyer, *Munoz Lesson: How the Law Fails Us at Beginning and End of Life*, AL JAZEERA AM. (Jan. 26, 2014), <http://america.aljazeera.com/opinions/2014/1/the-munoz-lessonhowthelawfailsusatthebeginningandendoflife.html> [https://perma.cc/KD9X-Y65M].

human being doesn't depend on their location."¹⁴ While one wishes to respect such a comprehensive notion of humanity, to reinforce such a belief with criminalizing consequence seems unduly inhumane.

Another issue at stake in the debate about surrogacy is the ever-expanding litter of parties implicated as potential parents: egg donor, sperm donor, "intended" (or purchasing) parent or parents, gestational carrier, and IVF inseminator (most commonly an impersonal medic, interlocutor, or technician). In the emerging science of ooplasmic transplantation, moreover—where ova are manipulated to alter mitochondrial lines—children may be born with the genetic ingredients of two mothers and one father. This latter is deservedly controversial among bioethicists because it directly tinkers with the human germ line, something that violates established conventions of medical and social science practice.¹⁵ And, as this latter implies, whatever's the matter with Kansas is most emphatically no longer a local question. If having children is reduced to a cipher for the projected vanities of self-centered reproductive consumers, then we have turned the enterprise of parenting into that of narcissism. Indeed, the desire for self-immortalization hovers at the edge of many discussions about the ethics of cloning, of potential genetic manipulation and selection of "designer babies," and of eugenic dreams fueled by purported racial, cultural, and aesthetic "superiority."

To clarify: a market model governing the production of children is my concern here. On the other hand, the attempt to criminalize surrogacy is a bit like trying to criminalize contraception or abortion; it comes too close to criminalizing sexuality, libido, intimacy. Despite my professional desire for legal clarity, it's probably the case that there's a complex of mystical, contentious, theologically bewildering dilemmas we are never going to answer with bright-lined legalisms. In an historical moment as unprecedentedly besieged by biological discovery and technological revolution as ours, we should resist that first gesture toward criminalizing all who do not adhere to the way things have always been.

Yet the exciting new technologies of creating and sustaining life should not blind us to the multiple ways we might otherwise make family, particularly if we relinquish the conceit that all our children must "look like us." There are, after all, more than a million homeless children in the United States; at least 600,000 in foster care; and, at any given time, at least 100,000 hoping for adoption. The worry is that the market for perfect and perfected

14 Reese, *supra* note 6.

15 *Inheritable Genetic Modification: 3-Person IVF*, CTR. FOR GENETICS & SOC'Y (Mar. 9, 2015), <http://www.geneticsandsociety.org/article.php?id=6527> [<https://perma.cc/B35V-AQLX>].

babies who are the mirror images of our airbrushed selves is a national and transnational business, driven by wealthy consumers—largely in the United States and Europe—and fed by wombs in poorer parts of the global economy.

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My second story explores just such a consumerist model in the context of racialized desire. I attempt to show its contribution to imbalances in the ethics of care for our most vulnerable citizens.

In September, 2014, a mother named Jennifer Cramblett brought a lawsuit that pursued the question of bodies-as-property in unusually literal terms.¹⁶ Cramblett sued an Ohio sperm bank for mistakenly inseminating her with the sperm of an African American donor, “a fact that she said has made it difficult for her and her same-sex partner to raise their now 2-year-old daughter [Payton] in an all-white community,” according to the *Chicago Tribune*.¹⁷ Cramblett might have made a claim for negligence in mishandling the vials of sperm with which she was inseminated, for that much is generally recognized in law, having to do with loss of expectation resulting from failure of a duty of care in handling genetic materials. But a different claim is what made Cramblett’s case controversial and deeply disturbing: she filed for breach of warranty and emotional and economic loss as a result of “wrongful birth.” According to court papers, this claim was explicitly based on the deprivation of whiteness as a trait she thought she was purchasing.¹⁸ Fortunately, the wrongful birth suit was tossed out by DuPage County Judge Ronald Sutter a year later, in September of 2015.¹⁹ But while the story was hot news, the media reflected a rich panoply of social anxieties. Perhaps the most dramatic moment came during an interview with Cramblett on NBC News. “We love her,” she said of Payton. “She’s made us the people that we are.” Cramblett then burst into tears. “But,” she continued through clenched teeth,

16 Complaint, *Cramblett v. Midwest Sperm Bank, LLC*, No. 2014-L-010159 (Ill. Cir. Ct. filed Sept. 29, 2014), 2014 WL 4853400.

17 Meredith Rodriguez, *Lawsuit: Wrong Sperm Delivered to Lesbian Couple*, CHI. TRIB., Oct. 1, 2014, <http://www.chicagotribune.com/news/local/breaking/ct-sperm-donor-lawsuit-met-20140930-story.html> [https://perma.cc/5B3Y-9A94].

18 Complaint, *supra* note 16.

19 Clifford Ward, *Suit Filed Over Mix-up at Downers Grove Sperm Bank is Dismissed*, CHI. TRIB., Sept. 3, 2015, <http://www.chicagotribune.com/suburbs/downers-grove/news/ct-dupage-sperm-bank-suit-met-0904-20150903-story.html> [https://perma.cc/2PR3-S2HK].

“I’m not going to sit back and let this ever happen to anyone ever again.”²⁰

That disjunctive, the “but” clause of her despair, was reiterated throughout Cramblett’s court papers. Despite being “beautiful,” Payton was “obviously mixed-race.” While Cramblett purportedly bonded “easily” with the little girl, she “lives each day with fears, anxieties and uncertainty.”²¹ Her community is “racially intolerant,” plus Cramblett suffers from “limited cultural competency relative to African Americans,” having never even met one until she got to college.²² Then there’s Cramblett’s “all white” family, who can barely stand that she is gay . . . and dear lord, now this?²³ While Cramblett felt “compelled to repress” her sexual identity among family members, “Payton’s differences are irrepressible,” the lawsuit states.²⁴ “Jennifer’s stress and anxiety intensify when she envisions Payton entering an all-white school.”²⁵

But the infant Payton did not make Cramblett and her partner “who we are.” They lived a confined and reprehensibly oppressive life before she was born, and it was only because of her birth that they were forced to confront it. The better question is why or how they could have been happy with their lives before.

When Cramblett asserted that her town was “all-white”—in a state, in a nation, in a world that is absolutely not—one has to wonder how on earth that can be. The sad history of housing segregation in the United States is not a long-ago tale, no matter how much we tend to deny its reality. In 2014, there was a much-publicized encounter between Fox’s Bill O’Reilly and Comedy Central’s Jon Stewart, during which the two men discussed “white privilege.”²⁶ O’Reilly maintained that his accomplishments had nothing to do with race

20 Tracy Connor, *Black Donor Sperm Mistakenly Sent to White Mom Jennifer Cramblett*, NBC NEWS (Oct. 2, 2014), <http://www.nbcnews.com/health/womens-health/black-donor-sperm-mistakenly-sent-white-mom-jennifer-cramblett-suit-n215801> [<https://perma.cc/Q6MG-AJ6G>].

21 Complaint, *supra* note 16, at ¶ 22.

22 *Id.* at ¶ 23.

23 *Id.* at ¶ 25.

24 *Id.*

25 *Id.* at ¶ 26.

26 *The Daily Show with Jon Stewart* (Comedy Central television broadcast Oct. 15, 2014), <http://www.cc.com/video-clips/4u4hqr/the-daily-show-with-jon-stewart-bill-o-reilly> [<https://perma.cc/N8JY-GLCZ>]; *see also* Erik Wemple, *Bill O’Reilly’s Levittown Denialism*, WASH. POST, Oct. 17, 2014, <https://www.washingtonpost.com/blogs/erik-wemple/wp/2014/10/17/bill-oreillys-levittown-denialism/> [<https://perma.cc/LGU4-24V8>].

and everything to do with hard work. Stewart pointed out that O'Reilly had grown up in Levittown, New York, a planned community to which the federal and local governments transferred tremendous mortgage subsidies and other public benefits—while barring Black people from living there—in the post–World War II period. O'Reilly thereby reaped the benefits of a massive, racially exclusive government wealth transfer. As legal scholar Cheryl Harris observed in a 1993 *Harvard Law Review* article, “the law has established and protected an actual property interest in whiteness”—its value dependent on the full faith and credit placed in it, ephemeral but with material consequences.²⁷

Bill O'Reilly's Levittown was racially restrictive not only by the developer's private choice; racial segregation was underwritten by federal banking policies and guidelines in the administration of the GI Bill. In the postwar era, not only Levittown but the entire United States became a land divided between “inner cities” and white suburbs because of loan practices that red-lined certain neighborhoods if Blacks lived there.²⁸ Ninety-eight percent

27 Cheryl Harris, *Whiteness As Property*, 106 HARV. L. REV. 1707 (1993).

28 RICHARD R.W. BROOKS & CAROL ROSE, *SAVING THE NEIGHBORHOOD: RACIALLY RESTRICTIVE COVENANTS, LAW AND SOCIAL NORMS* (2013); *see also*, Joshua Ruff, *Levittown: The Archetype for Suburban Development*, HISTORYNET (Oct. 4, 2007), <http://www.historynet.com/levittown-the-archetype-for-suburban-development.htm> [<https://perma.cc/9Z9S->]. Relevantly: _

In some ways, Levittown resembled the ethnic composition of the military during World War II: Jews, Italians, Irish and Poles living side-by-side. But also like most of the military, African Americans were unable to enter this melting pot. As with many homebuilders in his era, William Levitt didn't question the demands of his financial backers, the FHA, which supported nationwide racial covenants and “redlining”—or devaluing—racially mixed communities. Every Levittown rental lease and homeowner's contract barred those that were “not member(s) of the Caucasian race.”

Levitt defended the housing restrictions long after the first residents moved into Levittown, stating that he was just following the social customs of the times. “This is their [the white customers] attitude, not ours,” he once wrote. “As a company our position is simply this: ‘We can solve a housing problem, or we can try to solve a racial problem. But we cannot combine the two.’”

Even after the 1948 U.S. Supreme Court decision in *Shelley v. Kraemer* made racial covenants unconstitutional, the FHA continued to underwrite loans only to white neighborhoods. Although Levitt dropped the restrictive language from his leases, he kept up the policy in practice and fought the court's ruling for years afterward. “The elimination of the clause has changed absolutely nothing,” he announced in the *Levittown Tribune* in 1949. In 1958, a lawsuit charging discrimination was brought against Levitt in New Jersey, where his third planned community, Willingboro, was being built. In 1960, to avoid public hearings on the case, he agreed to desegregate Willingboro, though the sale of homes to

of home loans issued under the GI Bill went to whites, and only two percent to people of color.²⁹

Levittown remains one of the best-documented examples of the long-term distortion that discriminatory mortgage underwriting had in configuring the wealth gap between Blacks and whites. Black people became renters in a land of homeowners because of public policy that denied them access to the same opportunities to accumulate equity in real estate. And for those who were able to afford a home, the very fact of one's skin color lowered its value by virtue of the big red line that would instantly pop up around it. Today, Levittown remains eighty-nine percent white.³⁰

Jennifer Cramblett has exhibited no more awareness of this political history than did Bill O'Reilly. Yet imagine if she and her partner cared about the racism that pervades their environment, instead of suing for the cost of dealing with their "private" distress. Reframed as a civil rights agenda, it might help them to see that they face no more or less than what any Black family faces in the United States. They might begin to consider their claim of individual economic damages more in terms of a civil rights claim for affirmative action and a pushback against racial stigma. Perhaps they'd find renewed community and succor by working for fair housing, or by joining "Black Lives Matter" demonstrations, or by directly engaging with the homophobia and racism among family members as well as in political landscape.

Instead, Cramblett seemed engulfed by the same race panic that has put the bodies of other children at risk. Little Payton dispossessed her mother by being born, taking the space of a more qualified, more desired white candidate, erupting into the world as damaged goods—a neighborhood defiled as well as a family disappointed. "God's punishment," according to some radio and online hate trolls. "Mistake," according to the court papers.³¹ That poisonous geography of mistrust confines us all, whether trapped within carceral walls at one extreme or gated communities at the other. We are left with a segmented society that does not know itself as whole, our reflection lost in the narrowest shards of a broken mirror.

blacks was highly orchestrated. Racial covenants were not specifically criminalized until the Civil Rights' Fair Housing Act of 1968.

29 MELVIN OLIVER & THOMAS SHAPIRO, *BLACK WEALTH, WHITE WEALTH* (2006).

30 *QuickFacts Levittown CDP, New York*, U.S. CENSUS BUREAU, <http://www.census.gov/quickfacts/table/PST045215/3642081> [<https://perma.cc/9BK2-MPN6>].

31 Complaint, *supra* note 16, at ¶ 17.

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My third story is also about children as “damaged goods.”³² Again, my concern is the assessment of bodies for their utility rather than treated as righted, sensate beings. For the last several years of my classes in bioethics, I’ve pondered the policy implications of the case of Ashley X, Seattle’s so-called “pillow angel.”³³ Ashley, now a teenager, was born with a debilitating form of encephalopathy that limited her brain’s development to the mental capacity of a baby, not more than a few months of age. She is sensate, she smiles, she seems at times to recognize her family members and to enjoy music. But she can barely move on her own and will never learn to speak. When she was six, Ashley’s parents subjected her body to a series of interventions ostensibly designed to keep her small, easy to lift and thus less prone to bedsores, and to render her permanently childlike.³⁴

To these ends, her breast buds were removed, in part because of a family history of breast cancer but, more immediately, to accommodate the harness straps that hold her upright. According to her parents’ blog, “developed breasts . . . would only be a source of discomfort to her.”³⁵ Her appendix was removed because were she to get appendicitis it was feared she would not be able to communicate her distress. She was given sufficiently high doses of estrogen to insure that her growth plates would close, limiting her height. This, despite the fact that estrogen at such doses carries other risks, most significant an increase in the incidence of blood clots; but her parents felt that being able to easily lift her outweighed that possible detriment. Her uterus, too, was removed, to spare her the pain of menstrual cramps “or pregnancy in the event of rape.”³⁶

One of the more remarkable aspects of this case is that these surgeries were done with-

32 This Section of my essay borrows from the article I wrote for *The Nation*. See Patricia Williams, *Judge Not*, NATION (Mar. 12, 2007), <https://www.thenation.com/article/judge-not/> [<https://perma.cc/8JYL-2PJT>].

33 See WELCOME TO ASHLEY’S BLOG, DEDICATED FOR THE WELLBEING OF PILLOW ANGELS, PREPARED BY HER PARENTS, <http://pillowangel.org> [<https://perma.cc/7VKD-F4DW>]; see also Ed Pilkington & Karen McVeigh, ‘Ashley treatment’ on the Rise Amid Concerns from Disability Rights Groups, GUARDIAN (Mar. 15, 2012), <http://www.theguardian.com/society/2012/mar/15/ashley-treatment-rise-amid-concerns> [<https://perma.cc/6C3W-MQDA>].

34 DAVID R. CARLSON & DEBORAH A. DORFMAN, WASH. PROTECTION & ADVOCACY SYS., INVESTIGATIVE REPORT REGARDING THE ‘ASHLEY TREATMENT’ (2007), http://www.disabilityrightswa.org/sites/default/files/uploads/Full_Report_InvestigativeReportRegardingtheAshleyTreatment.pdf [<https://perma.cc/N2JF-GFFX>].

35 *Id.*

36 *Id.*

out ever appointing a guardian *ad litem* for Ashley. No one within the hospital or its ethics board stopped to consider that it is illegal in all fifty states to sterilize a minor without such oversight. While parents are assumed to have the best interests of their children in mind and to be able to consent on their behalf for routine medical procedures, this situation was hardly routine. Moreover, it conflated the interests of the parents as understandably burdened caretakers with the interests of Ashley—who for all her cognitive deficits was not incapable of feeling pain. Indeed, who of us, with full capacity to consent, would undergo the painful invasiveness of a full hysterectomy just to prevent cramps or as a prophylactic against rape’s violations? Why then should it be permitted in the case of someone who has no capacity to protest? Even assuming a life at the hands of sexual predators were so predestined a fate, why not birth control pills?

The outcome in this case was also very wrong as a matter of ethics and public policy. There was, in the national debate about this case, a popular consensus that the parents were well motivated, so who are the rest of us to judge? Or, as Peter Singer put it in a *New York Times* op-ed: “she is precious not so much for what she is, but because her parents and siblings love her and care about her.”³⁷

I do not question either how much Ashley’s parents love their daughter or how overwhelming their responsibilities must be. I do, however, fault the hospital establishment for allowing these surgeries to happen—and to happen informally, without due process. In essence, the hospital allowed ethical questions about Ashley’s long-term care and comfort to be privatized by deferring so unquestioningly to her parents’ posited love. The hospital created an extreme presumption in favor of (often cash-strapped) caretakers that was heedless of medical necessity. Given a presumption premised on “love” rather than medical imperative, why not remove all her teeth to spare her the pain of cavities? Why not excise her fingernails to spare her the pain of accidentally scratching herself? Why not remove one of her healthy spare kidneys and donate it? That might make her and the world a little lighter. If I’m not the one who loves her, who am I to judge? That facile shrug allows us to ignore that Ashley’s body was not altered to correct any physical need of her own but to address tenuous suppositions about long-term social pressures: she’d be more included in family events, she’d be less attractive to rapists (if not child molesters), she’d be more portable for the convenience of caretakers. Real medical benefits, such as lessened risks of cancers or appendicitis, were entirely speculative. Indeed, the hormones, including estrogen, used

37 Peter Singer, *A Convenient Truth*, N.Y. TIMES, Jan. 26 2007, <http://www.nytimes.com/2007/01/26/opinion/26singer.html> [<https://perma.cc/9XZJ-ZJS2>].

to fuse her bone plates potentially increase the risk of some cancers.³⁸ Still, much of the debate about Ashley's treatment since 2006 has tended to leave the decision to parental determination of risk-benefit analysis, and to dismiss regulatory oversight as some kind of invasion of privacy.

Recently, however, the debate has reemerged in the context of the Zika virus's link to sharply increased incidence of encephalopathy among broad populations. In Brazil, El Salvador, Colombia, and now in some southern parts of the United States where mosquito infestation is a threat, public health officials have recommended that women postpone pregnancy until the danger is controlled. It has been interesting to see how these discussions intersect with other discussions about the legality of abortion, and access to contraception and health insurance; it remains to be seen whether the "best interests" of encephalopathic children born during an epidemic will be left to the private decision-making of families, or if we might expect the intervention of some broader public program of support. Says Tarah Demant, senior director of Amnesty International's Identity and Discrimination Unit, "It's putting women in an impossible place, by asking them to put the sole responsibility of public health on their shoulders by not getting pregnant, when over half [in Latin America] don't have that choice."³⁹

As medical ethicist Harriet Washington points out in her book, *Medical Apartheid*, the very notion of privacy is inflected by the aesthetics of gender, race, and class.⁴⁰ Ashley is a white, middle-class, and now perpetually-little girl. That embodiment evokes a very particularly-imagined social response. But one wonders if the debate about how we treat such children will shift if the numbers of such children rises from rarity to a more diverse demographic. Will doctors so compliantly agree to suppress testosterone in boys—or effectively chemically castrate them—in order to keep them less disruptively aggressive, or to prevent them from developing secondary sex characteristics? Similarly, I wonder if poor or Black children will be so easily romanticized as "pillow angels." Alternatively, what will it mean if the privatized decisions of parents of "burdensome" children like Ashley emerge as public policy?

38 *About Cancer's Risk Factors: Hormones*, NAT'L CANCER INST. (Apr. 19, 2015), <http://www.cancer.gov/about-cancer/causes-prevention/risk/hormones> [<https://perma.cc/PRE3-HRRH>].

39 Charlotte Alter, *Why Latin American Women Can't Follow The Zika Advice to Avoid Pregnancy*, TIME MAG., Jan. 28, 2016, <http://time.com/4197318/zika-virus-latin-america-avoid-pregnancy/> [<https://perma.cc/R76M-ABAS>].

40 HARRIET WASHINGTON, *MEDICAL APARTHEID: THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT* (2008).

The glib libertarianism of “Who are you to judge?” masks not only inequalities of social response but also our failure to grapple with the woeful state of a healthcare system that leaves all Americans, even middle-class families like Ashley’s, so burdened. The United States is still the wealthiest nation on earth, yet we cannot find the resources to provide the common medical devices that would have better enabled Ashley’s family to care for her, unaltered, in their home: a simple hoist, mattresses that prevent bedsores, the assistance of home healthcare workers. Ashley’s parents apparently felt driven to such lengths because they did not wish to institutionalize her as she grew older, bigger, more cumbersome. They feared her institutionalization with good reason, that fear reflecting but a fraction of the anxiety generated by our public health crisis.

If we reimagined Ashley’s humanity as something larger than a private burden to be borne by a single family, we might align her debilitation with that of Alzheimer’s patients, or the severely mentally ill, or veterans whose bodies or minds have been shattered by war, or whole populations who have been cognitively disabled by lead poisoning enabled by privatized cost-cutting metrics, as is alleged to have happened in Flint, Michigan. Unlike Ashley, their bodies cannot always be surgically miniaturized or pixied-up with heavenly pet-name metaphors. They are full-grown, complex, their bodies heavy with sorrow, with need. Perhaps it is they who will provoke a collective re-examination—a call to judgment—of our polity’s obligations to broader notions of human dignity. Perhaps then the public health issues would be a bit more obvious. Perhaps then we might not turn so quickly to carving up the body as a response to the scandalous deficiencies of our public hospital system, and the scandalous costs of our private one.

Nor is this just about health *per se*. Remember that cognitive limitations notwithstanding, Ashley’s body was otherwise developmentally healthy. Our commitment to equal valuation of life is sorely tested by such examples of cost-benefit as human metric. For example, one wonders if the Texas hospital that constructed its argument for the forcible extraction of use-value from Marlise Munoz’s body in order to bring her fetus to term, might have then gone on to handle that child’s predicted developmental problems with the same spirit of efficiently utilitarian body-minimizing surgical dispatch that Ashley met.

In any event, I have often wondered why the administration at Seattle Children’s was so woefully inattentive to the propriety of seeking a hearing before performing radically experimental surgeries that included sterilization. My instinct is that philosophers like Nikolas Rose are quite right to point out that we have increasingly displaced the do-no-harm care ethic of “doctor-patient” with the choice-driven ethic of buyer-seller, i.e., service-pro-

vider/consumer preference.⁴¹ Consider the case of parents who “gift” their teenage daughters with nose jobs or breast enhancement; or the family who adopted a baby girl from China, and then subjected her to plastic surgery in order to “Westernize” her eyes.⁴² The pervasive availability of elective plastic surgery is just one example of how issues of social stigma have been minimized by treating them as matters of contract. This habit of thought has shifted our attention in quiet but powerful ways away from the hard political work of maintaining our right to be, to exist in the world without having to disguise, apologize or suffer for our raced, gendered, or non-normative bodies.

In the United States, we think of ourselves as “inalienably righted.” Yet when gender, race, and class play against one another as they do in each of these stories, one sees a pronounced tension between contract’s sloshy alienations and the constitutional right to have rights. A rather siloed, consumerist set of mind is pervasive in our culture. But it is an inadequate and ultimately hubristic stance when sitting on the brink of a technological revolution permitting ever-greater “efficiencies” of transformative body alteration, “designer babies,” and germ line (or heritable) modification. This points to our work going forward: we must begin to excavate the ethical, legal and social implications of our incautious yet far-reaching proprietary exploitations—of traits, of reproduction, of identity, and of citizenship. We must begin to have some thoughtful normative account of whether and to what degree incoherent pockets of private profitability will continue to map the collective face of our nation, or even the fate of our species.

41 NIKOLAS ROSE, *THE POLITICS OF LIFE ITSELF: BIOMEDICINE, POWER AND SUBJECTIVITY IN THE TWENTY-FIRST CENTURY* (2007).

42 Alicia Ouellette, *Eyes Wide Open: Surgery to Widen the Eyes of an Asian Child*, 39 HASTINGS CTR. REP. 15 (2014).