# THE BODY MARKET: RACE POLITICS & PRIVATE ORDERING

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"Buy or Die" was the theme of a recent symposium on organ markets at the American Enterprise Institute hosted by Sally Satel. The symposium reflected a significant departure from traditional organ transplantation discourse. The symposium was an effort to study alternatives to the conventional discourse on organ procurement, specifically by a sustained dialogue on incentives. However, one reporter found a particular panel, Giving and Selling, to be hostile to medical ethics and well-established social norms.<sup>2</sup> The reporter compared proposals to cure the shortage of transplantable organs in the United States with the less-thanfavorable markets in Iran and the black market in prisoner's organs in China. The same reporter then offered a challenge to markets that silenced the room. She prophesied that poor minorities in the United States would be abused by compensated body-market systems. The reporter evoked the image of poor, powerless Black Americans becoming the surgical pawns of wealthy, presumably white transplant patients. This appeal was seductive, an easily captured image, pregnant with the backdrop of U.S. history. Perhaps for that reason, opponents to incentives in organ regimes argue that private ordering in organ procurement would sanction a neoclassical form of slavery.

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<sup>1.</sup> See American Enterprise Institute, Events, Buy or Die: Market Mechanisms to Reduce the National Organ Shortage (June 12, 2006), http://www.aei.org/events/eventID.1337/event\_detail.asp (containing complete webcast of panel discussion and summary).

<sup>2.</sup> See id. (listing Panel Two: Giving and Selling).

The reporter's passionate race-based challenge to organ incentives illustrates the presence of race and political correctness in organ transplantation discourse. Anti-commodification scholars insist that race matters in organ transplantation.<sup>3</sup> On this broader point they are correct: African Americans comprise one-third of the kidney transplant waitlist, they wait longer than any other ethnic population for organs, and they suffer the highest death rate while on the kidney transplant waitlist. So yes, race does matter in transplantation, but not in the way that those wedded to altruistic organ procurement describe or would lead us to believe.

Racial exploitation is now the powerful, conventional challenge to emerging discourses on alternative methodologies of procuring organs, especially markets. Yet, to what effect? Those committed to providing equitable opportunities to suffering patients must ask whether challenges to organ markets benefit patients, especially racial minorities? Reduced waitlists? Resolved racial disparities in organ allocation? These questions are relevant to any discussion about equity, access, and class in organ procurement and allocation in the United States. The evidence, including growing waitlists and thousands of deaths each year, informs us that altruistic organ procurement remains an ineffective approach to meet the growing demand for organs. Race becomes the dominant cover or proxy to justify exclusive reliance on altruism in organ procurement. The problem here is that race-based claims against organ markets serve to destabilize any discourse that might involve racial minorities contributing in non-altruistic ways to organ pools. Race plays as an expedient trope here, masking concerns that may be driven by other interests far removed from minority status, class, and access.

To be sure, there is a tremendous demand for organs in America, and the situation is worsening. As of August 15, 2007, there were 96,928 patients on the United Network for Organ Sharing (UNOS) waitlist. That number represents an increase of 400 patients in less than three months. Over 6000 of these patients will die before receiving an organ, and thousands of others will be unceremoniously removed from the waitlist because they are no longer attractive candidates, being too sick, weak, or old according to those who set the rationing priorities. Disproportionately, these individuals are African Americans, stuck in a strange quagmire, where policymakers expect strangers to donate organs and rescue them. This normative approach is utilitarian in theory, and although intended to equalize transplantation opportunities, it provides very little relief to vulnerable patients.

One significant complication in the utilitarian ordering of transplantation is the reliance on blind compassion. Another complication with that normative approach is that it refuses to consider the pragmatic or realistic ordering of collectives, including competing value systems and group biases. In essence it demands the surrendering of lives or organs, in this case with a promise for later returns. Yet, those goals must be understood as aspirational, with very little hope of imminent achievement. If more Americans believed that communal sacrifice is returned in equal measure they would readily surrender their organs at

<sup>3.</sup> See infra notes 13–16 an accompanying text.

<sup>4.</sup> United Network for Organ Sharing, http://www.unos.org (last visited August 15, 2007) [hereinafter UNOS].

procurement sites throughout the United States. But they do not. This Article does not argue against the value of aspirational thinking. To the contrary, the creation of just rules and regulations and the testing of those rules through a reliable, fair, and unbiased judicial system form an ideal that we strive for in our legal system.

The question then is whether equity and equality (or other noble goals) are achieved by the holding-out process, which utilitarianism demands. Moreover, criminal and civil law measures are introduced to police the organ procurement process to ensure that "holding-out" actually takes place and that no one behaves in his own interest or that of the group. What I mean here is that utilitarianism demands that we wait for utopia to arrive. At that point, we are to imagine, the utilitarian rules will all make sense and apply equitably and equally to everyone. In the meantime, those who do not benefit from the utilitarian ideal must simply wait for fantasy to be realized.

So how does this play out in real life, with real patients, with real families? Federal law criminalizes reimbursing poor, but clearly generous, persons willing to share an organ. In this way, it polices its utilitarian goals, ensuring that even if the system does not work efficiently or effectively at present, we will not be distracted by more libertarian or other models that might achieve the same desired goals. For example, an organ recipient can be fined and incarcerated for offering consideration for lost rent, household expenses, and other costs borne by the organ sharer.<sup>5</sup> The law upholds the spirit of its utilitarian objective, but it imposes unrealistic burdens on its citizens, including those who desire to assist vulnerable patients. For some patients, this type of policing amounts to an irreconcilable double bind. In general, all double binds suffocate the notion of pure or real choice. In this instance, the consequences are quite grave and irreversible. To acquire an organ outside of the very narrow statutory framework imposes the possibility of a felony conviction, a prison sentence, and a fine too steep for most to afford, especially poor Americans. Concomitant with the struggle to fit into the legal framework, suffering and death seem imminent for thousands on our transplant waitlists.

To place this in context with real patients and real families, the utilitarian approach to organ procurement exacts steep costs that extend beyond financial considerations, encompassing personal, emotional, and familial tolls. The losses are not borne exclusively by patients, but also by those who desire to ease their suffering.

Donors are expected to demonstrate great charity and restraint in looking beyond or ignoring the great emotional and financial costs of transplantation; these

<sup>5.</sup> See National Organ Transplant Act § 301, 42 U.S.C. § 274e (2006).

<sup>6.</sup> For this concept, see my earlier work, Michele Goodwin, Assisted Reproductive Technology and The Double Bind: The Illusory Choice of Motherhood, 9 J. GENDER RACE & JUST. 1, 7-16 (2005). In that article, I argue that the double bind is a heightened "catch 22," where a person must choose between two burdened options. See also R.D. LAING, SELF AND OTHERS (1969); Gregory Bateson, Steps to an Ecology of Mind: Collected Essays, in Anthropology, Psychiatry, Evolution, and Epistemology (1999); Gregory Bateson, Don D. Jackson, Jay Healy & John Weakland, Toward a Theory of Schizophrenia, 1 Behav. Sci. 4 (1956).

costs have significant meaning for donors and their families. Let us consider what this means, not in an abstract way, but in a manner that most Americans will experience. During the five weeks of post-operative hospitalization and recovery, donors risk the loss of wages. The federal government makes an exception for its employees. That is to say, the federal government rewards its employees who are organ donors by paying their salaries! But of course that offers little solace to non-government employees. That hardly accommodates the factory worker in North Carolina, or the house care worker in Michigan, or the entrepreneur in Minnesota. Much is to be gained by naming what is sacrificed in the current normative approach to organ procurement. When donors sacrifice wages to save the lives of others, we must look beyond the abstract and remember that their children must be fed, rent or mortgage payments must be made, and utilities and other bills need to be paid. We might invite donors to ignore these rules of responsible behavior, but they do so at their own peril. Thus, targeting poor Americans to be altruistic organ donors places a significant and unrealistic burden on them.

This Article has two main foci. It challenges the presumption that organs should always and only be altruistically acquired. In doing so, it takes on the wellworn race card rhetoric in the organ transplantation domain. In this Article, I describe "race card politics" as attempts to exploit race and obfuscate meaningful public policy inquiry and debate on alternative organ procurement regimes. Proponents of race card politics exploit prejudice for political advantage in procurement debates and play to racist fears among both Blacks and whites. To explain, many whites may be loathe to challenge race card presumptions in transplantation debates (and in the larger scheme of biotechnology, such as stem cell debates) for fear of being cast as racist and suffering reputational damage. On the other hand, race card politics can be equally destabilizing for people of color. In the transplantation context, it can serve to incite fear. Such fear may result in a backlash where patients of color avoid transplantation altogether (both donation and placement on waitlists). Race card politics can also be used to manipulate Blacks and other persons of color by exploiting a legacy of slavery, poverty, and abuse and conflating that socio-political history with contemporary attempts to breathe new life into transplantation.<sup>7</sup>

<sup>7.</sup> In the context of race-based politics in transplantation, it is worth noting that African Americans play a minor, if any real, role in perpetuating the "altruism or else" position. This could, in part, be explained by the very narrow platform that African Americans are given in transplant debates. Consider, for example, the President's Council on Bioethics, which called for hearings on transplantation issues in 2006 but failed to consider testimony from any African Americans despite African Americans making up onethird of the kidney transplant waitlist. See President's Council on Bioethics, Topics: Organ Transplantation, http://www.bioethics.gov/topics/organ index.html (last visited July 8, 2007) (providing transcripts and background material). So, while the Council was concerned about minorities being exploited by organ markets, the Council may not have grasped the importance of having people of color or economically disadvantaged individuals speak to those issues. Moreover, the President's Council on Bioethics has a noticeable imbalance: of the seventeen-member panel, there is only one person of color, the highly esteemed Dr. Benjamin Carson. See President's Council on Bioethics, Council Members, http://www.bioethics.gov/about/members.html (last visited July 8, 2007). Notwithstanding the lack of diversity on the Council, the questions of whether African

This Article peels away race card politics in organ transplantation in an effort to reveal a more complex and nuanced debate on organ markets. Second, to further that debate, it takes seriously the alternative of private ordering and choice. A core objective of this research is to establish a meaningful discourse on freedom to contract in organ transplantation. Thus, the objective here is not to replace race-based argumentation against organ incentives with an alternative race discourse. Some scholars may characterize the proposal in this Article as a daring race-based proposal for markets. Such a characterization would be an incomplete assessment of this effort. This Article seeks to establish a debate, and its ultimate conclusion rejects both exclusive reliance on altruism to cure organ shortages and the sexybut-misleading arguments that incentives necessarily hurt minorities, especially African Americans.

Part I critiques race as a proxy in organ transplantation disclosure. Part II builds from there, illustrating why race-based opposition to compensation for organ sharing ignores organ demand, particularly from Black patients. It provides a brief empirical overview of organ demand in the United States. Part III summarizes the Uniform Anatomical Gift Act (UAGA) and the National Organ Transplant Act (NOTA), which proscribe the transfer of "consideration" for organs and tissues. This section argues that lifesaving advancements in biotechnology to treat illnesses have outpaced the legislative process, leaving regulations from the 1980s to respond to contemporary crises. Part IV argues that regulated markets in human biological supply could not only better meet the demand for organs and other tissues but also transform African Americans into patients rather than simply donors. It argues that social justice can be better achieved through regulated markets for organs, ova, and even hair. In the absence of regulated markets, black markets and coercive, fraudulent secondary regimes will develop (and have developed) alongside altruistic procurement strategies; these are more oppressive than their regulated counterparts. This Article concludes in Part V by drawing on several strategies to increase the supply of organs and suggesting several key measures that might lead to more effective organ procurement.

#### I. RACE, MARKETS, & RHETORIC IN ORGAN TRANSPLANTATION

Collectively, the concerns of market skeptics can be narrowed to four consistent assumptions appearing in the popular discourse over the past thirty years. First, it is commonly argued that "offering financial incentives to donate organs would undermine free and informed consent." Second, bioethicists tend to agree that incentives coerce the poor to surrender their organs to the wealthy.

Americans would generally support being compensated for the economic losses associated with donation and would welcome tax relief or health care benefits in exchange for donation remain valid.

<sup>8.</sup> MARK J. CHERRY, KIDNEY FOR SALE BY OWNER: HUMAN ORGANS, TRANSPLANTATION, AND THE MARKET, at xi (2005) (critiquing a host of conventional arguments against considering incentives in organ sharing).

<sup>9.</sup> ARTHUR L. CAPLAN, Requests, Gifts, and Obligations: The Ethics of Organ Procurement, in IF I WERE A RICH MAN COULD I BUY A PANCREAS?: AND OTHER ESSAYS ON THE ETHICS OF HEALTH CARE 145, 151 (1992).

Third, scholars generally complain that organ commodification exploits the poor. <sup>10</sup> Fourth, and perhaps most effective at silencing any potential rebuttal in favor of markets, is the argument that organ selling is tantamount to slavery, reducing vulnerable minorities to toolboxes or salvageable parts and denying them their humanity and personhood. <sup>11</sup> In light of these considerations, Part I of this Article critiques the relevance and use of race in organ transplantation.

#### A. The Titmuss Principle

Anti-market proponents claim that an organ transplant market would render African Americans the pawns of wealthy, white Americans interested only in exploiting them for their organs. According to such speculations, African Americans would be in a pareto inferior position if they were to receive compensation for organ sharing. African Americans, it is suggested, might also be pressured to donate dying relatives' organs and quite possibly hasten their sick relatives' deaths. Some commentators even speculate that poor patients could be motivated by mercenary interests to physically and cruelly sacrifice relatives (i.e. murder by removing feeding tubes or more heinous acts) in order to donate their organs. Beyond being entirely unrealistic, these claims reveal the more troubling rhetoric of race in transplantation debates.

Race card dynamics dominate opposition politics to organ compensation. Starting decades ago with Richard Titmuss's vitriolic claim that blood markets would be overwhelmed by "negro" participants who would inevitably pollute the blood supply if they were paid, <sup>13</sup> Blacks have been a transitional good in body part debates. Titmuss claimed that blood markets exploited African Americans' ignorance and their collective financial status. <sup>14</sup> Titmuss represented African Americans as conflicted, "skid-row" participants, likely to infect the blood supply through ignorance rather than malice. <sup>15</sup> Poor hygienic practices, prison histories,

<sup>10.</sup> Rick Weiss, A Look At ... The Body Shop: At the Heart of an Uneasy Commerce, WASH. POST, June 27, 1999, at B3 ("Rather than reducing disparities between the rich and the poor, compensation for organs might exacerbate the differences, turning the poor into surgical ward slaves or feudal donors for the rich.").

<sup>11.</sup> See Andrew Kimbrell, The Human Body Shop: Does America Want a "Free Market" in Organs and Tissues?, WASH. POST, July 1, 1990, at B3 (examining the "fast-growing market" for human "products" in the United States and the similarities that such a market may share with slavery); Weiss, supra note 10, at B3 ("Rather than reducing disparities... compensation for organs might exacerbate the differences, turning the poor into surgical ward slaves or feudal donors for the rich."); Karen Wright, The Body Bazaar: The Market in Human Organs is Growing, DISCOVER MAG., Oct. 1998, at 114, 120 (arguing that human body product commodification or patenting raises ethical issues akin to slavery).

<sup>12.</sup> See Kathleen Kerr, P.A. May OK Pay For Organ Donations/\$300 Toward Funeral Costs, Newsday, June 8, 1999, at A6 (quoting Arthur Caplan, who suggests that the human body should exist beyond the reach of defilement and scientific desecration); Weiss, supra note 10, at B3.

<sup>13.</sup> RICHARD M. TITMUSS, THE GIFT RELATIONSHIP: FROM HUMAN BLOOD TO SOCIAL POLICY 152 (1971).

<sup>14.</sup> *Id.* at 111–19, 151–52.

<sup>15.</sup> *Id.* at 111–19, 150–52.

and sexual promiscuity were among the behaviors he claimed would pollute the blood supply.<sup>16</sup>

Titmuss was right that such social histories are indicators or red flags for excluding blood, tissue, and organ donors. However, ascribing those characteristics primarily to Blacks played to the racial fears of the time more than it contributed to sound transplant policy. Testing blood, rather than skin color, matters more to keeping biological supply pools healthy. Titmuss's racially laden claims effectively cast Blacks and those willing to be compensated for supplying blood as immoral and unhealthy and provided a false sense of security to legislators that so long as blood was altruistically procured, our national supply would remain free from transmissible viruses and diseases. But Titmuss's narrow ideology was also wrong: African Americans were no more injurious to the United States blood supply if they were paid than unpaid. Altruism did not make blood safer. Testing and screening blood was the key to maintaining a healthy blood supply.

Titmuss zealously advocated the reorganization of blood supply in the United States, declaring that altruistic supply is not only morally superior to a commercial market but also safer, avoiding health risks associated with "skid-row" type donors attracted to blood selling. Titmuss's predictions proved to be incorrect and America's reorganization of blood supply and subsequent HIV scandal in the 1980s indicate the imperfections in Titmuss's analysis. The introduction of AIDS in the blood supply actually demonstrates serious flaws in the Titmuss hypothesis and the detrimental consequences of reliance on his theories. One commentator, Beth Nissen, noted that "government officials knew AIDS was being spread in gay bathhouses for years, [but] they did not close them." Far worse, even though "government officials knew the virus was in the nation's blood supply, for years they did not require screening." Nissen lamented that state officials were somehow complicit in this tragedy. She described how government researchers were underfunded and thus unable to "investigate the new disease."

Gay men, a population of responsible, financially stable, voluntary donors, happened to be "reliable givers" and "good volunteers." Some also happened to be the unsuspecting carriers of HIV. Thus, the altruistic system attracted donors who unwittingly contaminated the supply, resulting in numerous deaths. HIV-infected gay men, however, did not contaminate the supply because they were "bad" people with malevolent interests any more than a prior generation

<sup>16.</sup> *Id.* at 111–19, 145–47.

<sup>17.</sup> Cf. Kieran Healy, The Emergence of HIV in the U.S. Blood Supply: Organizations, Obligations and the Management of Uncertainty, 28 THEORY & SOC'Y 529, 531 (1999) (discussing socioeconomic aspect of Titmuss's claims).

<sup>18.</sup> See id. at 530.

<sup>19.</sup> World News Tonight with Peter Jennings (ABC television broadcast June 20, 1990).

<sup>20.</sup> *Id*.

<sup>21.</sup> Id

<sup>22.</sup> See Healy, supra note 17, at 533.

of commercial donors with hepatitis did.<sup>23</sup> During the height of the AIDS crisis, in fact, commercial blood banks reacted far more swiftly than comparable altruistic industries in other countries to implement more sophisticated screening and testing mechanisms.<sup>24</sup> They realized profitability, consumer confidence, and safety were at substantial risk if they failed to take precautionary measures.

Yet, the legacy of Titmuss's racial rhetoric remains difficult to overcome. Commentators opposed to incentive-based organ procurement suggest that allowing African Americans to receive compensation for their organs will ultimately reduce them to a slavery-like status, exploit their vulnerability, and compromise their dignity. Similarly, these race-sensitive concerns could arguably be far more prevalent in altruistic-based procurement systems.

Indeed, there are key differences between organ alienation and slavery, which are described in prior literature and worthy of brief address here.<sup>27</sup> Given the history of slavery in the United States, African Americans are significantly aware of harms that can be associated with treating bodies as property or "private" objects, particularly when there is no capacity for self-ownership. Nor are we as a society unfamiliar with the human body in the market domain in terms of genetic or biological acquisition.<sup>28</sup> For many centuries the body and its constituent parts have been traded, bonded, and insured, belying the claim that human bodies are incompatible with market valuation.<sup>29</sup>

<sup>23.</sup> Gays Would Have Stopped Giving Blood Earlier If Asked, Inquiry Told, CANADIAN PRESS NEWSWIRE, Mar. 29, 1995; Elizabeth Kastor, Blood Feud: Hemophiliacs & AIDS, WASH. POST, May 10, 1993, at B1; cf. Joyce Howard Price, Panel Mulls Allowing Gay Men to Give Blood: Banks Cite Better HIV-Detection Tests, WASH. TIMES, Sept. 14, 2000, at A1.

<sup>24.</sup> Michael Trebilcock et al., Do Institutions Matter? A Comparative Pathology of the HIV-Infected Blood Tragedy, 82 VA. L. REV. 1407, 1481 (1996).

<sup>25.</sup> Dan Brock & Douglas Hanto, Presentation at the MIT Hippocratic Society Conference: The Organ Trail: The Science and Ethics of Tissue Engineering, Organ Transplantation, and Organ Trafficking (Mar. 9, 2007) (surveying perspectives for and against organ compensation). For details about the conference, see MIT Hippocratic Society, 2007 Conference, http://web.mit.edu/hippocratic/www/2007.html.

<sup>26.</sup> Social pundits and policy makers take for granted the enormous pressure placed on family members, including children, and friends to donate organs to save relatives, co-workers, and others. Indeed, organ procurement organizations and hospitals hire sophisticated "requesters," people paid specifically to ask grieving relatives to donate organs. Commentators take for granted the rhetoric that encapsulates the "gift of life" movement. Indeed, the casting of organs as gifts tends to belie the fact that organs have financial as well as social value.

<sup>27.</sup> MICHELE GOODWIN, BLACK MARKETS: THE SUPPLY AND DEMAND OF BODY PARTS 198–203 (2006).

<sup>28.</sup> Katherine B. Lieber, Selling the Womb: Can the Feminist Critique of Surrogacy Be Answered?, 68 IND. L.J. 205 (1992) (foretelling the societal harm that might occur to women and children as a result of commodifying pregnancy through surrogacy); Kristi Ayala, Note, The Application of Traditional Criminal Law to Misappropriation of Gametic Materials, 24 AM. J. CRIM. L. 503 (1997) (examining the legal status of gametic materials as property and the risks of commodifying children).

<sup>29.</sup> DANIEL P. BLACK, DISMANTLING BLACK MANHOOD: AN HISTORICAL AND LITERARY ANALYSIS OF THE LEGACY OF SLAVERY 103 (1997); NATHAN IRVIN HUGGINS,

Yet, slavery is different from an incentive approach for organs. Were African Americans compensated for *voluntarily* providing their organs to save the lives of fellow citizens, such transactions would be far different from antebellum slavery, which was characterized by forced labor, economic exploitation, physical abuse, and a lack of bargaining power. There is a danger that when anticommodification scholars lightly compare slavery to organ markets, they trivialize the slave experience and overstate their case.

Despite this, few scholars actually challenge the notion that organ compensation is "just like slavery" or defend private ordering in body markets against claims of racism. As a result, African Americans are caught in a strange, conflicting matrix, which calls them noble and generous if they surrender organs and blood without compensation, but naïve, unsophisticated, and prone to exploitation and coercion if they are compensated for undergoing a non-therapeutic organ removal.

In addition to the racism seemingly inherent in scholarship that casts Blacks as naïve or potentially criminal if they are compensated for sharing organs, the discourse about organ and tissue procurement and allocation regimes also often portrays African Americans as victims rather than recipients or donors. Ironically, few scholars address these debates from the perspectives of Blacks, though they claim to speak for the interests of minorities. How are we to reconcile that African Americans are welcomed as altruistic participants in organ transplantation but excoriated and infantilized as market negotiators?

#### B. Who Benefits? Race Card Politics and Social Policy

So who benefits from efforts to perpetuate altruistic transactions as the exclusive (moral) mode of organ procurement in transplantation? This question extends beyond patients and must necessarily include often-overlooked participants who in fact are compensated in transplant exchanges, including organ procurement organization administrators, surgeons, nurses, hospitals, and even biotech companies that purchase tissues, organs, and other body parts from organ procurement organizations, which have acquired the parts for free. In these exchanges, the donors are notably the only individuals who are expected to "suffer gladly" or be altruistic.

BLACK ODYSSEY: THE AFRO-AMERICAN ORDEAL IN SLAVERY 106 (Vintage Books 1990) (1977); DOROTHY SCHNEIDER & CARL J. SCHNEIDER, SLAVERY IN AMERICA: FROM COLONIAL TIMES TO THE CIVIL WAR: AN EYEWITNESS HISTORY 54–55 (2000); RICHARD C. WADE, SLAVERY IN THE CITIES, THE SOUTH 1820–1860 (1964) (scrutinizing urban slavery, race relations, violence, and the legal and social conditions under which the chattel system thrived). Wade describes how public agencies were used in cities to discipline slaves:

Ordinances provided that a master could send Blacks to the local prison for "correction." He simply made out a slip for the number of lashes, gave it to the slave to be whipped, and sent him off to jail for punishment.... Increasingly... urban owners found the system convenient. It was easy and quick; it saved the master the grim experience of wielding the whip himself.

WADE, supra, at 94-95.

Race card politics in transplantation presents a powerful obstacle to meaningful social policy critique. The consequences are significant, because racebaiting here effectively corrupts the debate about biological markets. Blacks are treated as a transitional good—worthy of care, attention, and appreciation for organ giving, so long as they forgo compensation for their genetic resources. The same certainly does not hold true for the reproductive industry, which overwhelmingly and quite publicly targets white sperm and ova donors and rewards them generously. But the implications—or ripple effects—are far broader than race. For example, the pitiful state of our transplantation system is obscured. Further, evidence of children being used as donors<sup>30</sup> and of desperate American patients touring China, India, Pakistan, Brazil, and other countries for their organ supply<sup>31</sup> provides compelling reasons to rethink an "altruism only" procurement system.

The impact of spurious race claims in transplant policy has several distinct effects. First, race card politics in transplant debates ultimately harms patients by tethering their health options to a burdened, overwhelmed procurement and allocation system. Second, the politics of race are used to undermine free choice and private ordering, which can be tools of social justice and equitable redistribution of resources. Third, it weakens individual autonomy by restricting the choices available to informed individuals. Fourth, race card politics undercuts the bargaining power, collective needs, and interests of African Americans. To be clear, Blacks are not the only Americans affected by a failed national organ transplantation policy. To the contrary, they are simply the canaries in a suffocated transplantation system that inadequately responds to all patients. Curing transplantation policies by moving beyond altruism and considering alternative procurement approaches, including shared exchanges, compensation, and reimbursement for losses, will inevitably benefit all Americans.

Race card politics in organ transplantation regimes serves to destabilize meaningful debate and critiques of the current transplantation model. But more importantly, race card politics in transplantation undermines the autonomy and free choice of Blacks and other persons of color. The hypocrisy inherent in contemporary debates about organ compensation illuminates a deeply troubling movement in transplantation discourse. Specifically, the selective application as to what is commensurable and what is not and who can commodify and who cannot is confusing at best. For example, corporate profit from trading in body parts (unknown to the families of some donors) does not elicit the same sustained and

<sup>30.</sup> See Michele Goodwin, My Sister's Keeper?: Law, Children, and Compelled Donation, 29 W. NEW ENG. L. REV. 357 (2007).

<sup>31.</sup> William Saletan, Op-Ed., Scarcity of Organs Driving People to Travel Around the World, GUELPH MERCURY (Ont., Can.), Apr. 20, 2007, at A11; cf. Ed Carty, Lawyer Outlines Chinese "Organ Scandal," PRESS ASS'N NEWSFILE, Feb. 27, 2007 (discussing report by former Canadian official "alleg[ing] [that] the Chinese military routinely harvests organs from prisoners" and that hospitals "routinely offer" organ transplant surgery, even though "China has no organ donor scheme"); Paul Huggins, Expatriates Rallying Against China Killing Protesters for Organs, DECATUR DAILY (Ala.), Apr. 2, 2007 (same).

fervent cry.<sup>32</sup> This contradiction is hard to reconcile when some scholars decry the possibility that minorities should benefit individually or collectively from organ sharing. Currently, the body trading business nets more than a billion dollars per year in profits for biotech companies that acquire and sell body parts.<sup>33</sup> These parts range from corneas<sup>34</sup> and bones<sup>35</sup> to the more esoteric—foreskins<sup>36</sup> and placentas<sup>37</sup> for cosmetic products.

The challenge, it appears, lies in creating adequate regulatory precautions and monitoring—as currently exists in the U.S. altruistic procurement and allocation systems. By relying exclusively on altruistic procurement and using race as a shield to justify that policy choice, we avoid making tough decisions. To this end, altruism has been the less controversial (and less inspiring) approach to organ procurement. Introducing alternatives requires contemplating socially unattractive possibilities, including conceptualizing the human body in ways typically reserved for inanimate commercial goods.

The normative challenge in organ procurement is fashioning a system that promotes choice and allows individuals to flourish, rather than relegating them to pain, suffering, and imminent death. Ideally, we should aim to develop a procurement system that respects individual choice and that seeks to uncover and

Mark Katches et al., Federal Reports Conclude Body Parts Trade Should Be 32. More Open, ORANGE COUNTY REG. (Cal.), Jan. 6, 2001 (describing a previous investigation by the newspaper that "found that families are told nothing about profits generated from their loved ones' skin and bone" and reporting that federal investigators found that those participating in the trade in human body arts "should be candid with families about how skin and bone are used"); cf. Office of Tech. Assessment, U.S. Cong., New DEVELOPMENTS IN BIOTECHNOLOGY: OWNERSHIP OF HUMAN TISSUES AND CELLS 23 (1987), available at http://www.wws.princeton.edu/ota/disk2/1987/8719/8719.pdf ("Over the past decade, however, technological advances have resulted in new, enhanced methods for studying and using human body parts-particularly tissues and cells. . . . Human samples are not only an integral part of the biomedical research process, but they are now also used as a component of [or in the production of] a variety of commercial products ranging from drugs and vaccines to pregnancy test kits."); Jeff Nesmith, Funeral Home Thefts: Body Parts May Be Tainted. Patients Tested as 'Ripple of Fear' Reaches Atlanta, ATLANTA J.-CONST., Apr. 23, 2006, at A1.

<sup>33.</sup> Lori Andrews, The Battle Over the Body: Some Uses of Human Tissue, Donated Before or After Death, Go Beyond the Donors' Consent, TRIAL, Oct. 1, 2006, at 22, 22–29; Kerry Howley, Who Owns Your Body Parts? Everyone's Making Money in The Market for Body Tissue—Except The Donors, REASON, Mar. 1, 2007, at 20, 20–31; Renie Schapiro, Banking on the Gift of Tissue, MILWAUKEE J. SENTINEL, May 2, 2005, at G1.

<sup>34.</sup> Ralph Frammolino, *Harvest of Corneas at Morgue Questioned*, L.A. TIMES, Nov. 2, 1997, at A1 (questioning the morality of the resale of corneas taken without permission).

<sup>35.</sup> Anthony M. Destefano, *The Body Snatchers: Funeral Home-Based Ring Charged with Illegal Use of Cadavers to Sell Bones and Tissues*, NEWSDAY, Feb. 24, 2006, at A3; Tonya Maxwell, *Four Charged With Stealing Bones Implanted Locally*, CHI. TRIB., Feb. 24, 2006, at C3.

<sup>36.</sup> Jeanne Huff, Better Than Botox?: Enter The New Fountain of Youth—The Cosmeceutical—But Buyer Beware, IDAHO STATESMAN, Apr. 19, 2007 (Life), at 1.

<sup>37.</sup> Claire Coleman, Could Stem Cell Cream Be the Future of Face Care?, DAILY MAIL (London), Mar. 19, 2007, at 41.

respond to preferences. Weaknesses in any model are inevitable, but we need not settle on the most compromised choices in order to preserve the illusion that all patients suffer equally as in the case of the present model. As we consider the weaknesses of regulated markets in organ contexts, it is worth remembering that market skeptics' dissatisfaction with commodification of organs arises not from evidence of failure in a tested market, but rather from moral and political concerns, which they believe inherently spring from commodification.<sup>38</sup>

# II. RATIONING DILEMMA

The consequences of a utilitarian approach to transplantation are that the few organs acquired are shared through a strange but seemingly justifiable matrix. Again, the matrix becomes cover for shortfalls and inadequate supply. The most difficult challenge is deciding who lives and who dies.<sup>39</sup> The decisions are not personal; rather, they are driven by institutional pressures, even at the micro level.<sup>40</sup> Because so few organs are surrendered for transplantation, rationing, including who qualifies to be placed on waitlists, becomes a complex yet not wholly defined formula.<sup>41</sup> Whether one qualifies here may have less to do with evidence of illness or need for the organ and more to do with persistence, information, and the relationship with one's nephrologists.<sup>42</sup>

#### A. The Waiting Process

Sickness alone will not qualify a patient to receive an organ or even to be placed on a waitlist.<sup>43</sup> Patients must be recommended and placed on the waitlist by their doctors. The process, however, is not so easy. Many patients learn about kidney failure, for example, when it is absolutely necessary that they be dialyzed.

<sup>38.</sup> See MARGARET JANE RADIN, CONTESTED COMMODITIES (1996) (arguing that organ incentives would denigrate personhood and undermine human value(s)); Leon R. Kass, Organs for Sale? Propriety, Property, and the Price of Progress, in POLITICS AND THE HUMAN BODY: ASSAULT ON DIGNITY 153, 171 (Jean Bethke Elshtain & J. Timothy Cloyd eds., 1995) (arguing that human dignity is compromised by treating the body in market terms).

<sup>39.</sup> See, e.g., Arthur L. Caplan, Am I My Brother's Keeper?: The Ethical Frontiers of Biomedicine 129–50 (1997). See generally Stuart J. Youngner, Renee C. Fox & Laurence J. O'Connell, Organ Transplantation: Meanings and Realities (1996).

<sup>40.</sup> See Benjamin Hippen, The Case for Kidney Markets, NEW ATLANTIS, Fall 2006, at 47. Rationing in organ failure is nothing new. Indeed, a group infamously referred to as the "God Squad" in the late 1960s had the unfortunate task of determining who would be granted dialysis treatment in Seattle, Washington. The committee, an all white group of community leaders, which included a housewife, doctor, state government official, labor leader, lawyer, and a minister, used social criteria to determine moral, educational, and economic "fitness" for dialysis. The committee came under attack by some groups because it was biased against the uneducated, divorced, and poor.

<sup>41.</sup> GOODWIN, *supra* note 27, at 86 (citing Telephone Interview with Jack Lynch, Community Affairs Director, Gift of Hope (July 7, 2005)).

<sup>42.</sup> *Id.* at 95, 96–106.

<sup>43.</sup> Michele Goodwin, Altruism's Limits: Law, Capacity, and Organ Commodification, 56 RUTGERS L. REV. 305, 345 (2004). See generally CHERRY, supra note 8.

According to Jack Lynch, patients arrive in the emergency room units believing that there is possibly a urinary tract infection or an abdominal issue, often completely unprepared for the dramatic news that they will die unless they are immediately placed on dialysis.<sup>44</sup> Therefore, there is necessarily limited preplanning. At that stage, a patient is at a dialysis clinic several days per week, for several hours each visit. The patient's quality of life dramatically transforms: work, attending school functions for one's children, grocery shopping, and the other everyday acts that consume an unhampered life are all practically impossible.

It is at this point that the patient must often take affirmative steps to learn about transplantation and seek placement on a waitlist. Unsophisticated patients will often lack information about how to navigate the transplantation labyrinth. Limiting information is, in some fashion, another form of rationing. Again, not by absolute design or choice would we as a society prefer to keep patients uninformed and in the dark. Yet, at some point, a waitlist becomes meaningless when a patient will die before ever reaching the top. Therefore, we build in complications in these rationing matrixes, to go forth with some confidence that only a fraction of those who suffer will actually "qualify" for what we ration. In organ contexts, other criteria become the focal points of rationing, including lifestyle, work history, education, personal habits, and economic status. Some commentators have suggested that waitlist dynamics become a form of "green screening." Whether such suspicions of class-based politics in organ allocation are true, the fact remains

<sup>44.</sup> GOODWIN, *supra* note 27, at 87 (citing Telephone Interview with Jack Lynch, Community Affairs Director, Gift of Hope (July 7, 2005)).

<sup>45.</sup> Putting Patients First: Resolving Allocation of Transplant Organs: Hearings Before the Subcomm. on Health and the Environment of the H. Comm. on Commerce and the S. Comm. on Labor and Human Resources, 105th Cong. 216 (1998) [hereinafter Allocation of Transplant Organs Hearings] (testimony of Dr. Clive O. Callender) (commenting on institutional racism being "alive and well and thriving" in American healthcare and "the green screen," which he asserts is the financial barrier to Blacks receiving organ transplantation).

According to Dr. Clive O. Callender, a nefarious process of "green screening" plays a significant role in determining who ultimately is placed on transplant waitlists. Some transplantation procedures, including extra-renal, liver, and heart transplantations, are not funded by Medicare or Medicaid. Accordingly, only wealthy patients (with "green") can afford to pay for them. Poor and uninsured patients are not allowed on waiting lists because they lack the means to pay for the procedures. Id.; see also Carl M. Kiellstrand, Age, Sex, and Race Inequality in Renal Transplantation, 148 ARCHIVES INTERNAL MED. 1305, 1309 (1988) ("[T]he most favored recipient of a transplant is similar to the physicians who make the final decision: a young, white man."); Jay Greene, More Med Students Bone Up on Diversity Issues, SAN DIEGO UNION-TRIB., Nov. 22, 1999, at E3 (noting the importance of cultural competency training for physicians because of the diverse and often critical health care needs of nonwhite communities); Jeffrey Weiss, Doctors Soul-Searching After Bias Study: Unconscious Sexism and Racism May Be Killing Patients, HOUSTON CHRON., June 6, 1999, at A19 (reporting that a study had found that "[s]ome doctors are unknowingly afflicted with a dangerous combination of racism and sexism that may be killing some of their patients"); cf. Tom Corwin, Doctors Face Culture Issues With Patients, AUGUSTA CHRON. (Ga.), Feb. 9, 2000, at C6 ("[T]he success of the doctor-patient, the provider-client relationship is all about communication ...." (quoting Dr. Stinson, Deputy Assistant Secretary for Minority Health)).

that demand for organs dramatically outpaces supply. Inevitably, with such a limited pool of organs to share, many will be left out.<sup>47</sup> Thus, rationing norms simply become the modes by which to exclude people who otherwise would be subjected to a less scientific roulette or lottery. Who is left out, what resources remain available, and whether such tragedies can be avoided are questions worthy of address.<sup>48</sup>

In the mid-1980s, recognizing unmet organ demand as a national crisis, Congress mandated that the Secretary of Health and Human Services contract with a private entity to develop strategies to procure and allocate organs. The United Network for Organ Sharing (UNOS) was selected to contract with the government to oversee its organ transplant system. UNOS serves as the federal government's Organ Procurement and Transplantation Network (OPTN). Each year, OPTN releases its annual report, which chronicles the previous ten years of organ transplantation waitlist data. The OPTN report is an informative guide, detailing donor and recipient data by race, gender, state, organ donated, and whether the donor was living or deceased. Those statistics, along with information gathered from many in-depth interviews, including with Jack Lynch, a senior official at the Illinois Gift of Hope, enhance the brief discussion that follows.

Nearly 97,000 people are on the United States transplant waitlists.<sup>54</sup> Most of these people will wait years before an organ becomes available.<sup>55</sup> Thousands will die each year or be removed from the waitlists because they became too sick, and thus less attractive as organ candidates. Because so few organs are available for transplantation, rationing becomes an art and a necessity. The largest list happens to be for kidneys.<sup>56</sup> Nearly 73,000 people in the United States wait anxiously for the elusive phone call that a kidney donor has been located.<sup>57</sup> Scattered throughout the United States, this odd mix of men, women, and some children represents all socioeconomic classes, religions, and ethnicities. The gravity of the U.S. organ procurement program is placed in perspective by examining the empirical evidence of its shortcomings. One lens through which to

<sup>47.</sup> See, e.g., Sally Satel, Paying for Kidneys, WASH. POST, Apr. 30, 2007, at A15.

<sup>48.</sup> See generally Jim Warren, California Transplant Center Woes: OPTN/UNOS Board of Directors Response Major News Events in 2006, TRANSPLANT NEWS, Jan. 1, 2007 (describing the Los Angeles Times investigation of California-based organ transplantation centers and reviewing "the most important news developments in transplantation in 2006").

<sup>49.</sup> United Network for Organ Sharing, Who We Are, http://www.unos.org/whoWeAre (last visited July 9, 2007).

<sup>50.</sup> *Id*.

<sup>51.</sup> *Id.* 

<sup>52.</sup> E.g., Organ Procurement and Transplantation Network, 2006 OPTN/SRTR Annual Report, available at http://www.optn.org/AR2006/default.htm.

<sup>53.</sup> See, e.g., Organ Procurement and Transplantation Network, Data, http://www.optn.org/data/ (last visited Apr. 21, 2007) [hereinafter OPTN Data].

<sup>54.</sup> UNOS, supra note 4.

<sup>55.</sup> *Id.* 

<sup>56.</sup> OPTN Data, supra note 53.

<sup>57.</sup> UNOS, supra note 4; see also OPTN Data, supra note 53.

view the strains on the current system is to observe actual waiting lists and death rates.

Chart I: U.S. Organ Waitlist Data

#### Waiting list candidates as of June 2, 2007

All *	96,607
Kidney	71,913
Pancreas	1,676
Kidney/Pancreas	2,339
Liver	16,845
Intestine	230
Heart	2,744
Lung	2,731
Heart/Lung	119

<sup>• &</sup>quot;All" is less than the sum due to candidates waiting for multiple organs.<sup>58</sup>

Organ donation happens to be at the highest levels ever recorded. However, that fact often obscures the reality that at its best, our organ delivery system is deeply arthritic and prone to failure. Every four hours a patient in the United States dies while waiting for a kidney. In 2000, 47,280 people were waiting for kidneys. As of August 21, 2006, the waitlist had increased by over forty percent to 67,373. During the past year, over 4,000 more people have been added to the list. Well over one-third of these patients are African American. Independent of this data, however, it must be understood that thousands of Americans never even make the waitlists. These are individuals who will spend their final months connected to dialysis machines, which serve as their life support.

<sup>58.</sup> This data is provided by the Organ Procurement and Transplantation Network. OPTN Data, *supra* note 53.

<sup>59.</sup> ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK, 2005 OPTN/SRTR ANNUAL REPORT tbl.1.3, (2006), available at http://optn.org/AR2005/default.htm (follow "Download 2005 Annual Report" hyperlink or follow "Data Tables" hyperlink) [hereinafter 2005 ANNUAL REPORT].

<sup>60.</sup> OPTN Data, *supra* note 53.

<sup>61.</sup> Organ Procurement and Transplantation Network, Organ by Ethnicity, http://www.optn.org/latestData/step2.asp (choose category "Waiting List"; then choose Count: "Candidates"; then follow "Organ by Ethnicity") (last visited July 9, 2007) (listing 25,001 African American kidney transplant candidates) [hereinafter OPTN Organ by Ethnicity].

Between 1990 and 1999 the organ procurement waitlist more than tripled, from 16,026 registrants to receive organ transplantation to 56,678.<sup>62</sup> By the end of 2000, the total number of patients on the waitlist was 74,800.<sup>63</sup> By September 2003, over 80,000 Americans were on waitlists for organs.<sup>64</sup> As of July 2007, almost 97,000 Americans were on the waitlists. Other striking statistics also characterize contemporary challenges for organ transplantation. For example, waiting times consistently increased for all organ transplants, exacerbated by an influx of potential recipients on waitlists.<sup>65</sup> Moreover, this trend includes the increasing morbidity rate among patients dying before ever receiving the needed transplant.<sup>66</sup>

The alarming number of Americans awaiting "the gift of life" grows steadily,<sup>67</sup> increasing annually while lawmakers, ethicists, and physicians grapple with best practice proposals.<sup>68</sup> Unfortunately, state and federal proposals and media campaigns have yet to yield meaningful national (or even significant state) results,<sup>69</sup> as illustrated by the alarming 2006 death rates.<sup>70</sup>

<sup>62.</sup> Goodwin, *supra* note 43, at 344 (citing ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK, 2000 OPTN/SRTR ANNUAL REPORT, at 10 (noting that this number reflects the number of registrations and not the number of persons on the waiting list; the total number of patients is less than a two percent difference from the number of registrants)).

<sup>63. 2006</sup> OPTN/SRTR ANNUAL REPORT, supra note 52, at tbl.1.3.

<sup>64.</sup> See Organ Procurement and Transplantation Network, Current U.S. Waiting List, available at http://www.optn.org/latestData/rptData.asp (last visited Sept. 23, 2006).

<sup>65.</sup> See id.

<sup>66.</sup> See Goodwin, supra note 43, at 344 (citing 2000 OPTN/SRTR ANNUAL REPORT, at 34).

<sup>67.</sup> Id. (citing 2000 OPTN/SRTR ANNUAL REPORT, at 15); see also Mark F. Anderson, The Future of Organ Transplantation: From Where Will New Donors Come, to Whom Will Their Organs Go, 5 HEALTH MATRIX 249, 253 (1995); Phyllis Coleman, "Brother, Can You Spare a Liver?" Five Ways to Increase Organ Donation, 31 VAL. U. L. REV. 1, 2–3 (1996) (stating that the number of individuals in need of organs exceeds the number of organs available); Jack M. Kress, Xenotransplantation: Ethics and Economics, 53 FOOD & DRUG L.J. 353, 364–84 (1998) (discussing the possibility of increasing organ supply through xenotransplantation).

<sup>68.</sup> See, e.g., Coleman, supra note 67, at 26–41 (offering several ways to address the demand for organs, including nationalization, use of pediatric donors, and market systems); David E. Jefferies, The Body as Commodity: The Use of Markets to Cure the Organ Deficit, 5 IND. J. GLOBAL LEGAL STUD. 621, 644–57 (1998) (proposing the use of a market-based system to alleviate the organ shortage and meet demand); Kress, supra note 67, at 379–81 (recommending xenotransplantation to increase organ supply); Barbara A. Noah, Racial Disparities in the Delivery of Health Care, 35 S.D. L. REV. 135, 169–77 (1998) (offering solutions to end the racial disparities in the delivery of health care services, with attention given to organ transplantation).

<sup>69.</sup> See Jefferies, supra note 68, at 622. Jefferies highlights the increasing organ shortage in his article, pointing out that although a variety of systems have been proposed, and many implemented, their results have been less than positive, or as he says "they have failed." Id. Failure is the one uniform characteristic shared by the various state and federal proposals and mandates. Id.; cf. Coleman, supra note 67, at 3 (characterizing the shortage as "severe and tragic").

<sup>70.</sup> See OPTN Data, supra note 53.

By 2010, according to Dr. Benjamin Hippen, a member of the American Organ Coalition, Americans will wait on average ten years for an organ.<sup>71</sup> For those waiting for kidneys, this time period can be a death sentence, as they will rely on dialysis, which generally keeps a patient alive for less than five years.<sup>72</sup> And those who actually receive organs may not receive "ideal" organs, but instead those that give only the shortest lease on life.

### B. Race Factors That Actually Matter

The racial politics cabined in organ-procurement discourse obscures the more nuanced and relevant issues in organ transplantation, namely those concerning availability. Behind the fog of racial panic about markets, incentives, and compensation proposals rests an unambiguous and unanswered problem: too few viable organs are placed under the altruistic procurement pools (deceased and living), and this dilemma disproportionately affects African Americans. How this might be resolved is addressed later in this Article. For now, it is important to make the case for understanding the race factors that actually matter in transplantation.

Census data show that African Americans comprise roughly 13% of the total U.S. population. Yet, that figure does not comport with the organ demands that arise from that population. As a point of comparison, consider that of the 76,796 patients registered to receive a kidney, 26,507 are African American.<sup>73</sup> Their demands for organs, particularly kidneys, are unique according to a broad range of factors, including environment, biology, lifestyle, health care access, diet, stress, and other dynamics.<sup>74</sup> With such great demand, one must necessarily

<sup>71.</sup> Benjamin Hippen, Presentation at The American Enterprise Institute (June 12, 2006).

<sup>72.</sup> E.g., Rebecca D. Williams, Living Day-to-Day with Kidney Dialysis: Quality Improvements Continue for Devices and Clinics, FDA CONSUMER MAG., Jan.—Feb. 1998, http://www.fda.gov/FDAC/features/1998/198\_dial.html ("Dialysis survival in the United States after one year is 77 percent, according to the National Center for Health Statistics. After five years it is 28 percent, and after 10 years it is about 10 percent. Transplant survival rates are higher: 77 percent of patients survive 10 years after a living-relative donor.").

OPTN Organ by Ethnicity, *supra* note 61 (last searched on August 16, 2007). See, e.g., Susan Abram, Diabetes in L.A. Continues to Climb: Blacks, Latinos are Especially Hard Hit, DAILY NEWS L.A., Aug. 7, 2007, at N4; Diabetes: New Diabetes Report Documents Devastating Effects in New York City, OBESITY, FITNESS & WELLNESS WEEK, Aug. 11, 2007, at 240 ("Among racial/ethnic groups, black New Yorkers have the highest death rate from diabetes, dying at three times the rate of white New Yorkers."); Kevin McCoy, Deadly Disparity in Transplants: Blacks & Hispanics Deprived, DAILY NEWS (N.Y.), Aug. 8, 1999, at 6 (exploring "the fairness question by comparing the population of whites, Blacks and Hispanics in New York City and eight surrounding counties with racial breakdowns of patients who received transplants in the region from 1996 through 1998"); Albert W. Morris, Jr., Health Literacy: More Than Reading a Prescription, EBONY, July 2005, at 121 ("Blacks are 13 percent of the population but are about 30 percent of those with kidney failure."); Brigid Schulte, Minorities Face Unequal Health in U.S.: Statistics Show Ethnicities Encounter Higher Illness Rates, FT. WORTH STAR-TELEGRAM, Aug. 2, 1998, at 1 (reporting on research conducted over several months by a team of Knight Ridder reporters, "interviewing 250 doctors, scientists, government officials, epidemiologists, minority advocates and patients"); Nightline: America in Black

consider supply, quality of life, and from there the social, policy, and cultural perspectives that influence both the demand and supply.

In recent years, the median waiting period for organs has increased substantially. In 1994, the wait for a kidney was 715 days, and by 2001–2002 it increased to 1,284 days for whites and inexplicably to 1,842 days—nearly two years longer—for African Americans. By the end of 2006, so few kidney transplantations had occurred, as compared to need, that OPTN did not calculate an overall median waiting time for 2003, 2004, or 2005 registrants for its report because fewer than fifty percent had transplanted. Public health officials and transplant coordinators agree that the statistics will likely worsen with the expanding population of patients diagnosed with diseases that lead to kidney failure, including severe obesity and diabetes.

African Americans are uniquely affected by the stagnant supply pool: they suffer the longest waits and experience the highest death rates on transplant waitlists. <sup>79</sup> Yet their plight is rarely treated as a cause for investigating alternatives such as organ-sharing programs promoted through churches and other organizations, compensation regimes, or possible remedies under traditional civil rights legislation such as Title VI. <sup>80</sup> Nor has the suffering of African American patients and others inspired UNOS to chart an alternative vision for organ

and White (ABC television broadcast Feb. 24, 1999) (interviewing doctors, patients, and medical students about race and health, including a discussion with Dr. Clive O. Callender about racism in organ transplantation referral process); see also Roberts S. Gaston et al., Racial Equity in Renal Transplantation: The Disparate Impact of HLA-Based Allocation, 270 J. Am. Med. Ass'n 1352, 1352–53 (1993); J. Michael Soucie et al., Race and Sex Differences in the Identification of Candidates for Renal Transplantation, 19 Am. J. KIDNEY DISEASE 414, 415 (1992).

- 75. 2005 ANNUAL REPORT, supra note 59, at tbl.1.5.
- 76. Organ Procurement and Transplantation Network, 2003 OPTN/SRTR ANNUAL REPORT tbl.1.6, available at http://optn.org/AR2005/default.htm (follow "Download 2003 Annual Report" hyperlink).
- 77. Organ Procurement and Transplantation Network, Kidney Kaplan-Meier Median Waiting Times for Registrations Listed 1997–2002, http://www.optn.org/latestData/step2.asp (choose category "median waiting time"; then choose organ "kidney"; then select "waiting time by ethnicity") (last visited Apr. 20, 2007).
- 78. See 2006 OPTN/SRTR ANNUAL REPORT, supra note 52, at tbl.1.5 (follow "Data Tables" hyperlink; then follow "1.5 Time to Transplant New Waiting List Registrations, 1996 to 2005" hyperlink).
- 79. Goodwin, *supra* note 43, at 343; Organ Procurement and Transplantation Network, Organ by Ethnicity, http://www.optn.org/latestData/step2.asp (choose category "waiting list"; then choose Count: "Candidates"; then follow "Organ by Ethnicity") (last visited Aug. 21, 2006); *see also* sources cited *supra* note 74.
- 80. IOM Report on Increasing the Number of Organ and Tissue Donors in the US Called Too Cautious by Some Observers, TRANSPLANT NEWS, May 30, 2006 (noting that despite the very persuasive claims in the IOM report about transplant disparities and deaths resulting from a shortage in the supply of organs, incentives and alternative therapies such as stem-cell exploration and development were omitted, rejected, or simply not recognized as viable alternatives).

procurement.<sup>81</sup> To the contrary, alternative approaches to organ procurement often become stymied by liberal paternalism that generally ignores African Americans as organ consumers and recipients and focuses almost exclusively on the quality of their organs as *altruistic* donors.

So, does race matter in allocation and rationing? Sure it does, but not as some liberal commentators might suggest. Race matters in that more organs are needed to save the lives of the thousands of African Americans suffering from organ failure. Without an increase in supply, they will continue to encounter extended waits on transplant lists, while the quality of their health deteriorates. Others will be removed from the waitlists as they become less desirable transplant patients. Race also matters in terms of institutional choice: who should decide how organs are to be obtained? Why should African Americans or any others be denied the opportunity to organize within their communities to receive an organ? Whether to barter for an organ or give a family a college scholarship, a house, or simply pay the utility bills in recognition for sharing an organ should be a question perhaps better left to individuals to decide.

#### III. STATUTORY GIFT CONTRACTS

The classical model of contracts adheres to a few essential concepts and principles. Among the fundamental classical rules is the cardinal principle "of respecting and enforcing voluntary choices." The core principles in contract law define spaces in life as well as death. Contract negotiations in the burial, disposal, and donation of the dead have long been part of American jurisprudence and protected at the state level by the Uniform Anatomical Gift Act (UAGA)<sup>83</sup> and at

<sup>81.</sup> See Payment Subcomm., Ethics Comm., United Network for Organ Sharing, Financial Incentives for Organ Donation (1993), available at http://www.unos.org/resources/bioethics.asp?index=4 (recommending against pursuing financial incentives to cure organ shortages until they "are widely accepted as different from the purchasing of organs"); see also Ian Ayres et al., Unequal Racial Access to Kidney Transplantation, 46 Vand. L. Rev. 805, 842 (1993); Gaston et al., supra note 74; Soucie et al., supra note 74, at 415; Richard Epstein, Op-Ed, Kidney Beancounters, Wall St. J., May 15, 2006, at A15. But see Charles B. Fruit, Letter to the Editor, Organ Donors, For Love and Money, N.Y. Times, May 19, 2006, at A24 (arguing against financial incentives).

<sup>82.</sup> See Anne Bottomley & Nathan Moore, "You Will Never Finish Paying": Contract and Regulation, Globalization and Control, 31 N.Y.U. REV. L. & Soc. CHANGE (forthcoming 2007, on file with author).

<sup>83.</sup> UNIF. ANATOMICAL GIFT ACT (UAGA) (1987); see also Brotherton v. Cleveland, 923 F.2d 477 (6th Cir. 1991); Arnaud v. Odom, 870 F.2d 304, 308 (5th Cir. 1989) ("Louisiana has indeed established a 'quasi-property' right of survivors in the remains of their deceased relatives."); Fuller v. Marx, 724 F.2d 717, 719 (8th Cir. 1984) ("Under Arkansas law, the next of kin does have a quasi-property right in a dead body."); In re Estate of Moyer, 577 P.2d 108, 110 n.5 (Utah 1978) ("It appears that the modern view adopted by a majority of courts that have considered the matter recognize that there is a property right of some nature, sometimes referred to as a quasi-property right.").

In 2006, the NCCUSL promulgated a revised version of the UAGA. REV. UNIF. ANATOMICAL GIFT ACT (2006). Eighteen states have adopted the revised act, and thirteen others have introduced it in their 2007 legislative sessions. NCCUSL, A Few Facts About the Revised Uniform Anatomical Gift Act (2006), http://www.nccusl.org/Update/uniformact\_factsheets/uniformacts-fs-uaga.asp (last visited Sept. 2, 2007).

the federal level by the National Organ Transplant Act (NOTA).<sup>84</sup> Frequently, financial transactions attend these negotiations, which are grounded in the most fundamental aspects of classical contracts. Thus, the introduction of private ordering to the disposition of the dead could hardly be characterized as new.

#### A. The Gift Contract

The National Conference of Commissioners on Uniform State Laws (NCCUSL) enacted the UAGA in 1968. Promulgation of the original UAGA immediately followed the first successful liver transplant performed in 1967<sup>85</sup> and subsequent heart and pancreas transplants in 1968. The UAGA's implementation signaled an urgent call for donation awareness and state action. The UAGA regulates the procurement of organs from cadaveric donors and establishes ethical and legal guidelines for organ transplantation. In the period spanning the last forty years, the UAGA has been revised with more liberal policies on organ and tissue procurement and greater clarity on ambiguous donation issues. Yet, notwithstanding subsequent amendments, the 1968 Act still serves as the basic blueprint for organ donation in the United States.

The 1968 UAGA did not foreclose financial compensation for organs or other body parts. In fact, E.B. Stason, Chair of the UAGA Drafting Committee, suggested that "the matter [of compensation] should be left to the decency of intelligent human beings." Stason's characterization is consistent with the notion that the 1968 UAGA may have had more immediate relevance for those performing medical research than those interested in pursuing transplantation, since organ transplantation was still a very new therapy, rejection rates were high, and anti-rejection medications were yet to be perfected. Cyclosporine, an anti-

<sup>84.</sup> National Organ Transplant Act, 42 U.S.C §§ 274–274e (2006). See generally National Organ Transplant Act: Hearings on H.R. 4080 Before the Subcomm. on Health and the Environment of the H. Comm. on Energy and Commerce, 98th Cong. (1983) [hereinafter NOTA Hearing].

<sup>85.</sup> See, e.g., United Network for Organ Sharing, Timeline of Key Events in U.S. Transplantation and UNOS History, http://www.unos.org/whoWeAre/history.asp (last visited July 12, 2007).

<sup>86.</sup> See, e.g., Carlyle C. Ring, Jr., Chair, and Sheldon Kurtz, Reporter, Report to the Committee of the Whole, Revised Uniform Anatomical Gift Act (200\_) 1 (Jun. 24, 2005), http://www.law.upenn.edu/bll/archives/ulc/uaga/2005AMAnatomicalReport.pdf.

<sup>87.</sup> See, e.g., UNIF. ANATOMICAL GIFT ACT § 5(b) (amended 2006).

<sup>88.</sup> Id. § 5.

<sup>89.</sup> By 1973 all states had adopted the main provision of the UAGA. In 1987 the NCCUSL amended the UAGA to provide for greater organ procurement. The revisions clarified ambiguities found in the original Act. For example, the 1987 revisions made it clear that a donor's wish to provide her organs at death would be respected by physicians, thereby overriding the possible objection of her next-of-kin. Goodwin, *supra* note 27, at 114–15. Only twenty-six states have adopted the 1987 version. *Id.* at 115; *accord* Russell Korobkin, *Buying and Selling Human Tissues for Stem Cell Research*, 49 ARIZ. L. REV. 45, 48 n.15 (2007).

<sup>90.</sup> E. Blythe Stason, *The Uniform Anatomical Gift Act*, 23 Bus. Law. 919, 928 (1968) (assuming that payment would be rare and that crafting a prohibition would "not be easy" and concluding that until payment "becomes a problem of some dimensions," the matter should not be addressed through legislative prohibition).

rejection medication, reshaped the future of organ transplantation but was not approved for general use until 1983. However, long before successful organ transplantation, dead bodies and body parts were needed for medical and scientific research. One can only speculate as to why the 1968 UAGA contained no prohibition on compensating donors. But Stason's comment indicates that the question regarding payments for organs and other body parts was intentionally left open and that Stason believed that not all payments would be unethical.<sup>91</sup> Thus, it would be a mistake to characterize the original drafting committee of the UAGA as supporters of an exclusive altruism procurement model. Instead, their emphasis was on authority to donate: who had it and when could that authority be exercised?

The UAGA is significant for the contractual authority that it grants to relatives for the disposal of human bodies. According to the UAGA, disposal can include contracting with an organ procurement organization, hospital, or doctor to donate the body or its organs. The provisions within the UAGA provide for express authorization of donations for medical, educational, and research purposes. 92 The UAGA provides for donations of any human body or body part to:

- any hospital, surgeon, or physician, for medical or dental education, research, advancement of medical or dental science, therapy, or transplantation;
- any accredited medical or dental school, college or university for education, research, advancement of medical or dental science, or therapy;
- any bank or storage facility, for medical or dental education, research, advancement of medical or dental science, therapy, or transplantation;
- any specified individual for therapy or transplantation needed by him.93

The 1968 UAGA accomplished several goals. It established the scope of cadaveric donations, clarified the donation process, and categorized parts of the body for donation. It also provided a legitimate, regulated means for university hospitals and research facilities to supply cadavers, which were needed for medical research purposes. 94 The 1968 UAGA created a standardized method of donating organs and other body parts posthumously, defining "parts" as: blood, organs, tissues, arteries, eyes, fluids, or "any other portions of a human body." Finally, the UAGA identified and ranked "next-of-kin," who could consent to (or by

See id. at 927-28. 91.

<sup>92.</sup> UNIF. ANATOMICAL GIFT ACT § 3 (1968).

<sup>93.</sup> 

<sup>94.</sup> See generally GOODWIN, supra note 43, at 376.

<sup>95.</sup> UNIF. ANATOMICAL GIFT ACT § 1(e) (1968).

default object to)<sup>96</sup> donation, and established a right for adults to donate their bodies or parts thereof. <sup>97</sup>

But the desire for clarity that emerged from this new legislation also bred ambiguities. Should family members' desires to donate trump the silence of the deceased? Equally, should the prior wishes of the deceased to donate override family refusal? The UAGA did not address living donations in 1968 (nor does it now), and it continues to draw a clear distinction between living and deceased donations. The 1968 UAGA provided for at least two types of donations upon a donor's death. First, a donor could pre-designate her body or parts for transplantation. This decision was effectuated by a will or witnessed document. Today, this is most often accomplished at departments of motor vehicles with a statement or sticker on a donor's driving license. The second mode of cadaveric organ donation was designated to family members, who, in order of ranking (spouse, parents, and children), could donate the decedent's body or its parts, even over the preexisting objections of the deceased.

#### B. The 1987 UAGA & NOTA

Three major events prompted both the 1987 UAGA amendment and the creation of the National Organ Transplant Act (NOTA) of 1984. First, the 1968 UAGA created a narrow framework for organ donation and consequently became an inadequate organ procurement initiative, especially in light of biotechnological advancements, including immunosuppressant medications that made transplants the gold standard response to organ failure. Furthermore, the UAGA lacked the savvy and sophistication of a well-organized publicity campaign: branding, spokespersons, sound bites, and images. Most importantly from a public health perspective, the process of donating organs was cumbersome, including requirements of notations in a will and other proofs of intent to donate that did not work under the realities of emergency-room dynamics and the urgency of organ removal at death. Altruistic organ procurement simply did not keep pace with the demand for organs. 99

<sup>96.</sup> A common criticism of the Act was its ambiguity regarding what have become essential issues. The Act failed to make explicitly clear that one's next of kin could not revoke the donor's "gift."

<sup>97.</sup> UNIF. ANATOMICAL GIFT ACT § 2(b) (1968).

<sup>98.</sup> Pub. L. No. 98-507, 98 Stat. 2339 (codified as amended at 42 U.S.C. §§ 201, 273-74 (2006)).

<sup>99.</sup> This could possibly be attributed to the number of living donors decreasing in critical areas like kidney donation. Perhaps relatives were relying on the altruism of others to meet the dying needs of their loved ones. See generally William H. Bay & Lee A. Hebert, The Living Donor in Kidney Transplantation, in ORGAN TRANSPLANTATION AND REPLACEMENT 272 (G. James Cerilli ed., 1988) (describing the use of living donors for kidney transplants and health risks to the donors).

#### 1. Difficulty Obtaining Consent

One significant barrier to organ procurement was obtaining timely consent for organ donation. <sup>100</sup> The 1968 UAGA was logistically problematic for procuring organs for transplantation. It provided for donation through wills or nontestamentary documents, such as donor cards. Both methods were ineffective. Viable organs must be retrieved immediately upon death to ensure transplantability. Wills delayed the process because the document had to be found, read, and possibly probated. After the necessary measures are taken to execute the donor's will, her organs are no longer viable for transplantation. Theoretically, donor cards provided a useful means of effectuating intent to donate. However, other obstacles arose. For example, registered donors often forgot to carry their cards and to notify their next-of-kin. Without the donor card and consent of their next-of-kin, donors' organs could not be harvested. <sup>101</sup> Thus, the intent to donate was rendered meaningless as donors organs could not be procured without various proofs of consent.

## 2. Valuable Consideration

A second motivation to redraft organ legislation was that more non-related living donations occurred, and with them, the possibility increased that gifts, incentives, and other forms of "valuable consideration" might be exchanged. The UAGA was drafted with three clear assumptions. First, it was expected that only related persons would donate organs to sick patients. Second, it was presumed that relatives would not seek "valuable consideration" for donating an organ. Third, the entrepreneurial activities of unlicensed doctors alerted government officials that organs had a market value and that a potentially lucrative, unregulated industry could emerge that might harm patients and organ suppliers. The problem with banning valuable consideration (i.e. no payments, or forms of bartering or acknowledgement) is that it left all organ donations to be exclusively procured through altruism, and organ donations to be treated as "gifts."

A recent position statement, prepared by the Associate General Counsel to UNOS, Malcolm E. Ritsch, Jr., explains that "[g]ifts do not [i]nvolve

<sup>100.</sup> Jesse Dukeminier, Jr., Supplying Organs for Transplantation, 68 MICH. L. REV. 811, 825–31 (1970); see also Carolina A. Nadel & Mark S. Nadel, Using Reciprocity to Motivate Organ Donations, 5 YALE J. HEALTH POL'Y L. & ETHICS 293, 301–02 (2005).

<sup>101.</sup> UNIF. ANATOMICAL GIFT ACT § 2(b) (1968). The next-of-kin was authorized to donate only in the absence of the deceased's objection. Thus, relatives were provided authority to donate their kin's body if the decedent had not provided notice intending the contrary. This section authorized and ranked family members in order of greater "right" to donate:

<sup>(1)</sup> spouse

<sup>(2)</sup> an adult son or daughter

<sup>(3)</sup> either parent

<sup>(4)</sup> adult siblings (sister or brother)

<sup>(5)</sup> guardian

<sup>(6)</sup> any others authorized or obligated to dispose of the body

Id. (amended in UNIF. ANATOMICAL GIFT ACT § 3(a) (1987) and in Rev. UNIF. ANATOMICAL GIFT ACT § 9(a) (2006)).

'[c]onsideration.''<sup>102</sup> He emphasizes, "[t]here is no 'valuable consideration' under NOTA [section] 301 in any . . . living donation arrangement[].''<sup>103</sup> According to Ritsch, neither the donor, recipient, nor anyone else is to receive any "valuable consideration" for organ donation because "the donation is a 'gift' and gifts dwell outside the normal legal, psychological and emotion contexts of a contract.''<sup>104</sup> Ritsch argues that "a gift is a voluntary transfer of something beneficial from a donor to a beneficiary who receives it without paying the donor for it.''<sup>105</sup> And yet, this line of argument is unconvincing precisely because expressions of appreciation are often aspects of consideration in many kinds of donations. Jane Baron has noted the linguistic and social implications in contract, gift, and donation language. She writes:

Indeed, the definition contrasts sharply with non-lawyers' understandings of gifts. Anthropological, sociological and psychological studies of gifts all suggest that gifts and bargains are alike exchanges, differing only in that bargains involve the exchange of commodities, while gifts may involve the exchange of noncommodities such as status, obligation, "psychic reward" or the like. The "purely" one-sided donative transfer is not part of the "reality" non-legal social scientists have studied. 106

Despite UNOS's attempts to distinguish an agreed gift (organ donation) made under its program from a contract, arguing that a contract does not involve donative intent, that line of reasoning does not comport with social expectations or the objective of its program that donations should be binding and enforceable. We are hardly to believe that UNOS is indifferent to the legitimacy of the signed donor statements or that it believes donors (in this case the relatives of deceased persons) have the moral or legal authority to revoke donations just before organs are to be implanted into their new hosts. Jane Baron describes the common law shift in the last century that distinguishes contracts from gifts, specifically on the point of consideration, which she describes as being inconsistent with social expectations. As a matter of social utility, and to encourage gift-giving, donations often result in some form of a "replied" acknowledgement of a gift, such as status or, as with charitable contributions that earn tax credits, direct financial benefit.

According to Ritsch, consideration is what makes contracts binding, and without it, as he argues is the case in organ donations, one can simply withdraw the gift. The distinction at that point, however, is that the organ donated is no longer a gift if it is withdrawn. There are other threshold problems with UNOS's stand on this issue. For example, how is withdrawing the gift possible in cadaveric

<sup>102.</sup> Williams Mullen, Position Statement: Kidney Paired Donations, Kidney List Donations and NOTA § 301, at 3 (Sept. 18, 2006), http://www.unos.org/ContentDocuments/NOTA\_301\_Position\_Paper\_-\_September\_18,\_2006.pdf.

<sup>103.</sup> *Id.* 

<sup>104.</sup> *Id.* at 3–4.

<sup>105.</sup> *Id.* at 3.

<sup>106.</sup> Jane B. Baron, Gifts, Bargains, and Form, 64 IND. L.J. 155, 157 (1989).

<sup>107.</sup> *Id*.

<sup>108.</sup> *Id*.

contexts where the kidney, liver, or heart is implanted?<sup>109</sup> Indeed, recent efforts to strengthen organ donation in the United States focus on giving greater deference to the contract model. For example, the Illinois legislature enacted a bill that forces hospitals to ignore relatives' considerations (and threats of lawsuits) if the donor has agreed to donate. Thus, the driver's license or other expression of donation is treated not only as evidence of intent but also as a binding agreement.

However, this Article is less concerned with the question of whether gifts should or should not be considered contracts. Rather, it is the broad reading of consideration in organ transplant contexts as well as the prohibitions on incentives that concern this work. For decades, the prohibition on consideration was interpreted to extend to even non-related organ donation and paired organ transplants. Paired kidney donations "involve[] two living donors and two beneficiaries—the original intended recipient of each donor is incompatible with the intended donor but compatible with the other donor." Donations of that kind were considered to contravene the intent of organ legislation. Policy analysts for UNOS declared paired exchanges operated outside of the scope of altruism and were necessarily grounded in valuable consideration. Here, then, is the problem: if love is "valuable consideration," what isn't?

The major drawback for paired exchanges, which could be interpreted as a more assertive form of altruism, was that they operated outside of the confines of the UNOS waitlist process. This fact likely troubled policymakers far more than how contracts are defined. First, such donations involved individuals "skipping" the waitlist. Second, paired kidney donations involved the exercise of individual autonomy and authority, without the involvement of governmental bureaucracy. The threat of paired kidney exchanges, however, demonstrated that individuals might better organize among themselves in the transplant realm than through relying exclusively on government lists.

But perhaps the more problematic feature of the broad prohibition on "valuable consideration" in American organ transplantation is that it treats individuals differently than cosmetic companies and biotech corporations.<sup>112</sup>

<sup>109. 2</sup> JAMES SCHOULER, A TREATISE ON THE LAW OF PERSONAL PROPERTY § 57, at 60–61 (2d ed. 1884) (describing a gift as a contract, and suggesting that in the alternative, a gift "originates in a contract").

<sup>110.</sup> Cf. Mark S. Nadel & Carolina A. Nadel, Using Reciprocity to Motivate Organ Donations, 5 YALE J. HEALTH POL'Y, L. & ETHICS 293, 320-21 (2005) ("[A] preference might be considered 'valuable consideration' for an organ donation" and therefore "to avoid any confusion, laws that now ban compensation for organs should be amended to add this form of reciprocity/insurance to the list already exempted from such bans.").

<sup>111.</sup> Williams Mullen, supra note 102, at 5.

<sup>112.</sup> See generally Sandra Blakeslee, Lack of Oversight in Tissue Donation Raising Concerns, N.Y. TIMES, Jan 20, 2002, at A1; CryoLife Tries to Bounce Back: Tissue Recall by FDA Spawns Losses, ATLANTA J.-CONST., Aug. 28, 2003, at D1; Law Firms File Suit on Behalf of Transplant Patient Who Allegedly Received Illegally Harvested Body Parts: Suit Alleges That Untested Bones in Transplant Led to Positive Hepatitis Test Results, Bus. Wire, Mar. 23, 2006, available at http://www.aegis.com/news/bw/2006/BW060315.html; M.A.J. McKenna, Tissue Transplant Firm Linked to 14

Currently, hundreds of biotechnology companies in the United States and not-for-profit organ procurement organizations flout the "valuable consideration" provision by purchasing, processing, and selling organs, bones, skin, "and ... subpart[s] thereof." The companies trade on international stock exchanges and are part of the portfolios of mutual funds and hedge funds. Clarity within the transplantation system necessitates questioning the spirit, purpose, and legitimacy of a law that permits companies to profit on human body parts clandestinely obtained, and yet restricts individuals from organizing among themselves to save the lives of sick patients in their communities. This double standard is difficult to justify in light of the thousands of avoidable deaths each year. Ultimately, the valuable-consideration clause in NOTA raises significant problems in contemporary organ and tissue jurisprudence and conflicts with the social policy which motivates the law.

#### 3. NOTA and The Threat of Body Snatchers

In the wake of transparent attempts to introduce markets into the American organ transplant system, Congress introduced NOTA in 1984.<sup>114</sup> The language of the statute is clear and broadly restrictive, declaring that "it shall be unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce." Section 301 of NOTA imposes criminal penalties and fines of "not more than \$50,000" or imprisonment for "not more than five years, or both."

The primary cause for NOTA's enactment and the subsequent UAGA revisions related to the possible introduction of markets into a rigidly defined altruistic organ transplantation paradigm. Anxieties ran high in 1983, when J. Barry Jacobs, a self-described organ broker, proposed buying and selling organs from people of color in the Caribbean. Jacobs, a physician whose license to practice had been revoked, proposed brokering kidneys for a fee and commission. His plan attracted media attention and drew criticism from politicians. Fears associated with slavery, child abductions, and body snatching for organ removal heightened tensions in the transplant community and among policy makers in Washington, D.C. Under his plan, Medicare or Medicaid would reimburse organ costs. For wealthier clients, the recipient would pay a fee ranging from \$2,000–\$5,000 for his brokerage services and a capped price for the organ. Jacobs' testimony before Congress sank his program, but inspired Congress to create legislation on organ transplantation. Prior to Jacobs' plan, Congress had not addressed transplantation.

Infections, ATLANTA J.-CONST., Mar. 15, 2002, at A1 (discussing the death of Bryan Lykins, a student in Minnesota, who died of bacterial infection as the result of his knee surgery).

<sup>113.</sup> Michele Goodwin, Private Ordering and Intimate Spaces: Why The Ability to Negotiate is Non-Negotiable, 105 MICH. L. REV. 1367, 1383 (2007); see also 42 U.S.C. § 274e (2006).

<sup>114.</sup> Pub. L. 98-507, 98 Stat. 2339 (codified at 42 U.S.C. §§274-274e).

<sup>115. 42</sup> U.S.C. § 274e.

<sup>116.</sup> *Id* 

The 1987 revisions of the Uniform Anatomical Gift Act reflected Congressional interests by incorporating language that proscribed organ sales and also by clarifying issues that were less defined in the original UAGA. Among the critical areas left vague were: (1) whether, and for what purposes, organ donations could be the subject of sales;<sup>117</sup> (2) the extent of coroner or medical examiner authority to retrieve organs and under what circumstances or guidelines;<sup>118</sup> (3) whether requiring hospitals and physicians to request organ donation was ethical or even practicable;<sup>119</sup> and (4) whether relatives could cancel the donor's effectuated gift.<sup>120</sup> These issues faced greater scrutiny in the drafting of the amended UAGA in 1987. Ironically, Congress did not bother to define more specifically its own interests in transplantation. Rather, NOTA simply served as a very restrictive covenant on organ donation, which allowed companies to bargain, exchange, enter agreements, and otherwise contract to sell human body parts, but left individuals to rely on waitlists and depend upon the blind generosity of others.

# IV. PRIVATE ORDERING & AUTONOMY: RECASTING SOCIAL JUSTICE

There are many reasons to rethink the presumption underlying current legislative schemes, which favor altruism and government control of organs over private negotiations with government oversight. One of the concerns expressed in this Article is the need to promote a greater supply of organs for transplantation. However, another concern is the use of race card politics to undermine potential transplant-procurement alternatives that could benefit communities including those most desperately in need of organs, particularly Black Americans. As discussed above, race has been used to destabilize thoughtful discussion about how to help minorities who need organs. Arguments suggesting that alternative transplantation paradigms, including markets, lie outside of minorities' interests fail to engage Blacks and others as fully incorporated beings, capable of negotiating on their own and creating their own status. In this Part, while being careful not to ignore the precautionary warnings about markets, this Article raises the question of liberal paternalism and contests the Rawlsian notion that the social contract works equally for all.

#### A. Whose Body Is It Anyway?

Whether individuals should be free to opt-out of federal programs, such as the U.S. transplant waitlist process, in favor of private agreements or to structure private relationships where none currently exist are questions of

<sup>117.</sup> But see UNIF. ANATOMICAL GIFT ACT § 10 (1987) (prohibiting the posthumous sale of organs). This prohibition is retained in the 2006 revision. Rev. UNIF. ANATOMICAL GIFT ACT § 16 (2006).

<sup>118.</sup> Unif. Anatomical Gift Act § 4 (1987).

<sup>119.</sup> See id. § 5 (requiring hospitals to routinely inquire about organ donation at or before hospital admission); 42 U.S.C. § 1320b-8 (requiring, among other things, that families be made aware of the option to donate and organ procurement agencies be notified of potential donors).

<sup>120.</sup> UNIF. ANATOMICAL GIFT ACT § 2(h) (1987) (prioritizing donor's preferences over an objection by the donor's family).

significant political and legal magnitude. For some scholars, these are moral questions that strike at the heart of how we value and protect certain members and classes in society. Some scholars even argue that Black Americans are better off on dialysis than receiving a transplant if it becomes a matter of markets. More generally, liberal scholars traditionally reject private ordering in favor of government regulation, positing that classical law and economics theory maximizes efficiency, but at the risk of more important social values including "individualism over community." 122

Critics of private ordering recite an important list, which includes civil rights legislation, environmental protection laws, and policies that dismantle institutionalized gender discrimination in employment, education, and even sports, as testaments to the government's power to promote equality and correct social wrongs. Other scholars who critique contract theory argue that "references to freedom and autonomy to describe contractual terms or decisions where choice is constrained and freedom circumscribed" offer an illusory choice because private ordering is not the solution some of us wish it to be. 123 Are they wrong? Not entirely. At times, there are "blatant violations of liberal norms" in private negotiations. 124 Sometimes there is not any negotiating at all—simply signed contracts. Stewart Macaulay's groundbreaking work in contracts exposes the nature of contractual dealings among car dealers in Wisconsin, and his work has been widely cited on this point. 125

Yet, contracts are unavoidable in a functioning society, and the erasure of contracts in organ transplantation invites the prohibition of all other forms of interactions commonly associated with goods and services, including the ability to barter, bargain, negotiate, substitute, and exercise free and creative will. Why would we as a society restrict individuals from negotiating within their communities for an organ and yet promote biotechnology and the companies that aggressively procure, process, and sell body parts? Restrictions on private ordering in organ transplantation hamper the creation of alternative communities. For example, UNOS disfavors private "altruistic" organ-sharing programs such as

<sup>121.</sup> At the MIT conference, Organ Trail: The Science an Ethics of Tissue Engineering, Transplantation, and Organ Trafficking, sponsored by the MIT Hippocratic Society on March 9, 2007, http://web.mit.edu/hippocratic/www/2007.html, Dan Brock suggested that some studies show that Blacks fare better on dialysis. Dr. Brock did not cite the study that he referred to, nor did he posit any agreement with the study. The problem here is that dialysis is not a cure; it does not cure or even treat the organ failure—it simply cleans the blood well enough to allow another day to live. To suggest that African Americans are better off being tethered to a machine several days per week ignores quality of life concerns and is at best an unproved hypothesis waiting for a real answer.

<sup>122.</sup> See Elaine A. Welle, Freedom of Contract and the Securities Laws: Opting Out of Securities Regulation by Private Agreement, 56 WASH. & LEE L. REV. 519, 521 (1999).

<sup>123.</sup> Goodwin, supra note 113, at 1383–84 (quoting Deborah Post, Beyond the Bargain Model: Status and Power in the Law of Contracts (unpublished manuscript, on file with author)).

<sup>124.</sup> Id. at 1384.

<sup>125.</sup> Stewart Macaulay, Non-Contractual Relations in Business: A Preliminary Study, 28 AM. Soc. Rev. 55 (1963).

LifeSharers<sup>126</sup> and other kidney exchange groups that promise their members organs should they need them. LifeSharers and other organizations of its kind, including Black churches and fraternities/sororities, were they encouraged to start such programs, could further build social ties and create different forms of community.

UNOS claims that proactive, independent organ sharing violates ethical and utilitarian norms. They suggest that patients and their donors who participate in organ-based internet solicitation contravene the waitlist process. They argue that these patients effectively "skip the waitlist." Some doctors, including Douglas Hanto, have asserted that they will and have refused to treat patients who violate the UNOS tradition. Dr. Hanto suggests that transplants that take place outside of the UNOS process are "unfair" to those patients who wait months and even years for organs. UNOS and some bioethicists characterize zealous patients as taking away resources owed to persons on the waitlist. This rationale is problematic for a number of reasons, not the least of which is that our government does not own our bodies and therefore is not entitled to count them as part of its organ scheme.

But more importantly, the arguments are misguided. Patients on the U.S. waitlists are no more harmed by patients who receive an organ from a stranger through a website than if the organ were made available by a relative in Switzerland or Mississippi. To the contrary, patients who receive organs through private processes help to relieve the competition for organs by removing themselves from the demand pool. Imagine a glass bowl of blue marbles representing donated organs through the UNOS process. If a patient seeks an orange or red marble, she has not harmed the patient waiting for the blue marble. Indeed, she has increased the odds that patients waiting for the blue marble will actually be a recipient. In other words, the U.S. organ-procurement system cannot count donors or organs that it does not have. While we have a waitlist for recipients, we do not have a waitlist of living donors. Finally, penalizing responsible patients who dare to save their own lives and therefore create the means to support their families and communities casts a shadow on the motivations and ethics of the U.S. organ-procurement process.

<sup>126.</sup> David J. Undis, Changing Organ Allocation Will Increase Organ Supply, 55 DEPAUL L. REV. 889, 896 (2006) ("UNOS says that '[o]ur formal position is that UNOS does not endorse LifeSharers's approach. But, UNOS does not intervene in directed donation if it is allowed by state law." (quoting E-mail from Anne Paschke, Public Relations Manager, UNOS, to David J. Undis, Executive Director of LifeSharers (Feb. 12, 2004, 16:19 EST) (on file with David J. Undis)).

<sup>127.</sup> Sally Satel, The Kindness of Strangers; And the Cruelty of Some Medical Ethicists, WEEKLY STANDARD, May 29, 2006 ("Hanto had his staff phone [a potential transplant patient] right away to deliver shocking news: Beth Israel would flatly refuse to do her transplant if the only donor she could find was a kind-hearted stranger who responded to the article."); see also Virginia Postrel, Editorial, "Unfair" Kidney Donations, FORBES, June 5, 2006, at 124 (quoting Douglas Hanto as saying "we won't do them," in reference to transplants that involved solicitations and negotiations outside of the UNOS waitlist process); cf. Organ Donor Club Grows, Has Critics, UNITED PRESS INT'L, June 14, 2006 ("Dr. Douglas Hanto of Harvard Medical School said organs should go to the person who needs it the most, not to people because they are members of a club.").

Contract law is socially understood as the synonymous twin of choice. Choice itself is about freedom, and more importantly it is about power: the power to negotiate, bargain, consider, evaluate, and accept or decline services. Critics of private ordering suggest that terms of contracts often disserve minorities and therefore private ordering is a poor choice for people of color. But that reasoning warrants serious scrutiny. What better to empower persons of color than the very tools that help everyone else?

Rather than harming Blacks, private ordering in organ transplantation might benefit African Americans in any number of ways. First, private ordering could reduce African Americans' need to rely on the U.S. transplant waitlist process. Instead of waiting for the blue marbles, they could seek red, orange, or green. Second, private ordering might benefit African Americans indirectly, by reducing the number of patients waiting for blue marbles, and moving them up in the queue. Allowing others to privately order in transplantation opens the waitlists to those with the least economic wealth or social and familial connections. Such choices would not be illusory, but rather pragmatic opportunities to obtain organs.

Contracts need not be measured by wealth, which is often assumed in the transplantation literature. Commentators assume that in an organ market Blacks will be priced out and unable to participate. This assumption overlooks several factors. First, Blacks have tremendous spending power in the United States. In Durham, North Carolina the spending power of African Americans in 2006 was \$2.5 billion dollars. <sup>128</sup> Nationwide, African American spending power is estimated at \$799 billion dollars annually. <sup>129</sup> Indeed, the spending power of African Americans exceeds that of many nations around the world. Second, as with LifeSharers, group donations, directed donations, and collective bargaining within organizations such as churches, fraternal and sorority organizations, and other institutions unique to Black life, exchanges could very well take place without financial compensation. Or, it could be possible that service exchanges become the tools of organ transplantation. Bartering reduces the need for financial exchanges, but nonetheless acknowledges and responds to the value of the exchange.

Contracts and private ordering can also be tools for social justice. Certainly limiting or thwarting individuals' ability to enter binding agreements does nothing to reinforce their status as full citizens. Rather, individuals are further disadvantaged and marginalized when their ability to participate in a social, political, or legal expression is proscribed. The line of argument most often offered in this context is that people of color and the economically disenfranchised always lose in contracts that exact high costs. <sup>130</sup> For example, Margaret Radin and Nancy Scheper-Hughes argue that to surrender a dead relative's kidney in exchange for a financial consideration is a morally and socially burdened choice that exacts too

<sup>128.</sup> Shuchi Parikh, N.C. Minorities Prospering, CHRON. (Duke U.), Jan. 30, 2007.

<sup>129.</sup> Vicky Eckenrode, Sway at the Supermarket: Minorities in Florida and Georgia are Spending Record Amounts, FLA. TIMES-UNION, Sept. 1, 2006, at D1.

<sup>130.</sup> See generally Creola Johnson, Payday Loans: Shrewd Business or Predatory Lending?, 87 MINN. L. REV. 1 (2002).

high a toll on personhood. 131 Others suggest that acquiescence or agreement to engage in a kidney sale demonstrates irrational behavior worthy of criminal and financial penalties. 132

Yet, a host of contradictions spring from these positions. Life insurance is a premium on the dead, with value ascending according to social and economic value of the deceased. This well entrenched social model is lauded for its stability and ability to restore families after one of its members dies. Ultimately, it remains a value on the dead. During a recent workshop at Columbia University Law School, one scholar responded that the distinction between life insurance and payments for a deceased person's kidney is that the beneficiaries of a life insurance policy are not required to surrender anything but the death certificate. That point is true, and perhaps it is an observation to simply be conceded were it not for the fact that benefactors surrender value throughout their lives in order to bring about the deferred payment. The problem, then, in more precise terms is that some commentators believe organs should not have a financial value.

However, valuing organs and other body parts is unavoidable in the spheres of contemporary biotechnology and is to some extent logical, unless the government is to underwrite or subsidize all surgeries in the United States. Approximately one million tissue transplants take place in the United States each year. 133 These surgeries rely on human body parts to cure or treat patients. 134 Many of these surgeries are so common that they are serviced at clinics and through outpatient facilities. So who pays? Hospitals, clinics, doctors, insurance companies, and the unwitting consumers pay for organs, tendons, heart valves, skin, and other body parts. Altruism's first and last stop is with the organ donor. Beyond donation, transplantation is organized around traditional economic norms, involving payments for services rendered and goods transferred. Surgeons receive compensation for the operation, hospital staff earn their wages based on providing technical support for transplants, executives and staff at the organ procurement organizations earn salaries (and bonuses) based on their ability to recruit organ donors and supply organs to their region, and even the pilot who flies the organ to its destination receives compensation for his labor. Failure to acknowledge these services by payment is actionable as a breach of contract or fraud.

Commentators also suggest that poor people never benefit from contracts because they lack the sophistication of more seasoned players. <sup>135</sup> Industry, they suggest, will always be more sophisticated and possess greater leveraging strength than the individual. <sup>136</sup> Yet, to suggest that there is never any benefit to the disadvantaged player in contract negotiations ignores that even marginal benefit

<sup>131.</sup> See generally Radin, supra note 38; Nancy Scheper-Hughes, Postmodern Cannibalism: Black Market Trade of Human Organs, WHOLE EARTH, June 22, 2000, at 16 (discussing the pernicious side of black markets in human organs).

<sup>132.</sup> See NOTA Hearing, supra note 84.

<sup>133.</sup> Schapiro, supra note 33.

<sup>134.</sup> *Ia* 

<sup>135.</sup> *Cf.* Welle, *supra* note 122, at 521, 576 ("Freedom of contract in an unregulated securities market is a naive myth" due to a mismatch between its theoretical underpinnings and the realities of the marketplace.).

<sup>136.</sup> See id.

can be a good. An example is best made by the most difficult of services, including building railroads, working in rescue as a police officer or fire fighter, or even working in mines. In each of these examples, individuals help to save lives based on rendering a service that is life-risking. In each example, individuals receive compensation, and in some cases, their family members also receive financial acknowledgement in the form of "survivor-line of duty pensions." For some members of society, working on a railroad or in a mine happens to be the best and perhaps only choice at a particular time, and in a particular region, to improve their social and economic standing. Yet, these jobs involve high risks, and neither will result in financial opportunities equal to jobs in other locations even if the workers possess equal skill. As we know, however, poverty is not resolved by denying individuals the right or opportunity to work in mines, on railroads, or even on highways. Practical concerns arise here, including who will perform those essential tasks that inevitably result in great benefit to society.

A claim that human flourishing cannot coexist with organ markets deflects attention not only from affirmative benefits of incentives, but also from the varying degrees between commodification models. In other words, unless we, as a society, are absolutely opposed to all incentives and markets, we might better serve the future discourse in this domain to distinguish what forms of commodification are worse than others by degrees. Incentives are, by design, meant to lure individuals into considering options that might normally be less attractive. Thus, incentives can be tools of persuasion.

It would therefore be a mistake to lump all incentive programs together, to conflate their usefulness, or to suggest that they are always negative tools or that they promote negative social behaviors. Nor should acceptance of incentives imply that activities associated with the incentive are immoral or unethical. For example, scholarships are incentives often used to attract the most competitive students by providing a commitment of financial support. Financial support viewed in this context transforms the incentive into an insurance policy against the student's parents becoming ill, unemployed, or somehow unable to pay tuition. Likewise, incentives to attract individuals to participate in medical studies as well as programs to attract healthy young men and women into military service represent different points on a spectrum of seemingly acceptable commodification. Yet, even within those spheres some incentives might be conceived as less conscionable or more coercive than others.

So what are we to do? The consequences of ignoring the possible advantages of incentives to promote cadaveric organ sharing or payments for living donations are extreme. Incentives could enhance health opportunities for all Americans, especially those most often at the margins. Organ donation by African Americans has increased in recent years, but demand still dramatically exceeds supply. High blood pressure, diabetes, hypertension, and stress, conditions disproportionately affecting African Americans, contribute to widespread organ

<sup>137.</sup> Sewell Chan, Line-of-Duty Death Benefits For Officer's Work After 9/11, N.Y. TIMES, Mar. 21, 2007, at B1 (describing law signed by Governor Pataki that allowed beneficiaries of workers to claim benefits they would not have otherwise received).

failure.<sup>138</sup> African American patients will continue to experience the longest waits while on America's transplantation waitlists, until more organs become available for transplantation. Because they suffer the highest rate of mortality while on the transplantation waitlists this issue deserves urgent address.

#### B. All Bodies Created Equal?

Race, as a subtext in commodification debates, may be so polarizing that the only spaces in which private ordering or contract law is free from intense contestation happen to be the domains where whites may be significantly more or exclusively valued (or perceived as such), including as babies, embryos, mothers, and fathers. <sup>139</sup> Indeed, the most rapidly expanding approach to incentives happens to unfold in the family-law context, including women and household labor, <sup>140</sup> adoption. <sup>141</sup> and assisted reproduction. <sup>142</sup>

Scholarship in these domains suggests a new trend toward private ordering, which engages market concepts in the sacred, intimate spaces of the body and personhood itself.<sup>143</sup> Recent scholarship in reproductive and family law

139. Since the adoption market is largely unregulated, the cost discrepancies in adopting children of differing races are strikingly large: the cost of adopting a white child might be upwards of \$35,000 while the same agency charged \$12,000 to \$19,000 for children with African American heritage. Dusty Rhodes, *Baby Trade*, ILL. TIMES, Feb. 17, 2005, *available at* http://www.illinoistimes.com/gyrobase/Content?oid=oid%3A3990. *See generally* Bonnie Miller Rubin, *Adoption Bill Targets Legal Loopholes*, CHI. TRIB., Mar. 27, 2005, at C1 (discussing problems in certain adoption agency practices).

Additionally, newspaper advertisements show a great demand for white ova to be used in fertility treatments. See Couple Seeks Eggs for \$100,000, VERO BEACH PRESS J. (Fla.), Feb. 9, 2000, at A16 (indicating the known highest public offer seeking eggs ran in Stanford University's student newspaper, offering \$100,000 for "the eggs of a bright, young, white athlete").

- 140. See, e.g., Katharine Silbaugh, Commodification and Women's Household Labor, 9 YALE J.L. & FEMINISM 81 (1997).
- 141. See, e.g., Martha M. Ertman, What's Wrong with a Parenthood Market?: A New and Improved Theory of Commodification, 82 N.C. L. REV. 1, 8–10 (2003); Michele Goodwin, The Free-Market Approach to Adoption: The Value of a Baby, 26 B.C. THIRD WORLD L.J. 61 (2006); Elisabeth M. Landes & Richard A. Posner, The Economics of the Baby Shortage, 7 J. LEGAL STUD. 323 (1978).
- 142. See, e.g., Lori B. Andrews & Nanette Elster, Regulating Reproductive Technologies, 21 J. LEGAL MED. 35 (2000); Judith F. Daar, Art and the Search for Perfectionism: On Selecting Gender, Genes, and Gametes, 9 J. GENDER RACE & JUST. 241 (2005); Michele Goodwin, Assisted Reproductive Technology & The Double Bind: The Illusory Choice of Motherhood, 9 J. GENDER RACE & JUST. 1, 1 (2005).
- 143. See Martha Albertson Fineman, The Neutered Mother, the Sexual Family, and Other Twentieth Century Tragedies 228–30 (1995); June Carbone, What do Women Really Want? Feminism, Justice and the Market for Intimate Relationships, in Feminism Confronts Homo Economicus: Gender, Law, and Society 405, 406 (Martha Albertson Fineman & Terence Dougherty eds., 2005); Eric Rasmusen & Jeffrey

<sup>138.</sup> E.g., Allocation of Transplant Organs Hearings, supra note 45, at 215–17 (testimony of Dr. Clive O. Callender) (commenting on Blacks' health care and organ transplantation); see, e.g., Nightline: America in Black and White, supra note 74 (interviewing doctors, patients, and medical students about race and health, including a discussion with Dr. Clive O. Callender about organ transplantation).

contextualizes commodification and illustrates the incomplete state of commodification theory, which fails to account for social nuances and overstates commonalities or political, social, and moral realities of groups.<sup>144</sup>

Once scrutinized, arguments to distinguish private negotiations in family planning and reproduction from the organ supply illuminate subtle, real differences, but those differences are not so compelling as to justify our failure to consider alternative transplant approaches. Rethinking organ commodification offers an opportunity for commentators to move beyond the all-or-nothing approach to commodification and instead explore what aspects of commodification we can live with in a modern, biotechnology-rich society and to distinguish those from the cruder, more debasing types of private ordering.

The consensus against selling human organs is problematic because it inadequately addresses the distinction between different body parts, privacy rights, and the strength of ownership rights in bodies. Autonomy is an important feature of the discourse in constitutional, contract, and tort law. The right to be free from the bodily interference of others as well as the right to exercise rights found within and associated with the body are well protected by United States Supreme Court jurisprudence. The reproductive and family planning realms are examples of market spheres interacting with the human body. The human reproductive market has flourished during the past twenty years. Ova, sperm, and now embryos are exchanged for financial consideration. What is the social benefit of encouraging a reproductive market and yet discouraging incentives in organ transplantation? Who benefits from denying incentives to coexist with altruistic organ donations?

# V. PRIVATE ORDERING: A FEW THOUGHTS ON SYSTEM CHANGE

Developing a framework that promotes organ exchanges while preserving altruism may be far less complicated than prior scholarship or current public policy indicates. The organ crisis, after all, has little to do with a shortage of organs. But federal legislation prohibits and criminalizes the use of any organ obtained outside of altruistic procurement. The challenge, for lawmakers, lobbyists, and advocates, is repealing the National Organ Transplant Act, specifically the section on valuable consideration, and crafting procurement alternatives that acknowledge the value of organs.

As indicated in prior scholarship, several alternatives are immediately available to enhance organ procurement and increase organ supply in the United

Evans Stake, Lifting the Veil of Ignorance: Personalizing the Marriage Contract, 73 IND. L.J. 453, 486 (1998); Barak D. Richman, Essay, Firms, Courts, and Reputation Mechanisms: Towards a Positive Theory of Private Ordering, 104 COLUM. L. REV. 2328, 2362 (2004); Silbaugh, supra note 140; Viviana A. Zelizer, Intimate Transactions, in THE NEW ECONOMIC SOCIOLOGY: DEVELOPMENTS IN AN EMERGING FIELD 274 (Mauro F. Guillén et al. eds., 2002).

<sup>144.</sup> Martha Ertman, Commercializing Marriage: A Proposal for Valuing Women's Work Through Premarital Security Agreements, 77 Tex. L. Rev. 17, 48 (1998); Martha Ertman, Love and Work: A Response to Vicki Schultz's Life's Work, 102 COLUM. L. Rev. 848, 850 (2002); Ertman, supra note 141, at 27–28.

<sup>145. 42</sup> U.S.C. § 274e (2006).

States: presumed consent, directed donations, and commodification. <sup>146</sup> Cloning, stem-cell therapies, and xenotransplantation also offer future alternatives for organ enhancement or supply, but pose greater risk to human health, and are far too premature to guarantee success. Nor are these alternatives without controversy. Indeed, the problems, as well as the benefits, that attend to these models are worthy of detailed scrutiny and consideration.

The proposal that I find the most promising to increase organ supply is a hybrid system that supports donor altruism, but decriminalizes incentives and other forms of consideration in organ procurement to allow a coexistence and mutual support. This hybrid approach would maximize organ supply without disturbing altruism or minimizing the value of autonomous decision-making. 147 In prior scholarship. I drew the line of acceptability at incentives for deceased organ donations, leaving out incentives and forms of compensation to living donors. 148 That type of proposal seemed more pragmatic and likely to push the dialogue forward on organ incentives without offending those whose opinions in this discourse matter, including policymakers. That discourse has served its purpose by opening a dialogue on incentives for body parts of the deceased. It also exposed the hypocrisy and contradictions in a regime that permits and encourages companies to profit from buying and selling body parts but denies that right for individuals. Additionally, it advanced a discourse that scrutinizes the imbalance in living donations frameworks, particularly as between reproductive donors and organ donors.

The proposal argued for in this Article recognizes that incentives, exchanges, and other forms of compensation connected with deceased donations may not extend far enough and that those alternatives to altruism deserve consideration in living organ-sharing contexts. To move organ transplantation discourse forward, there are several recommendations that should be considered.

First, the National Organ Transplant Act should be amended to include a waiver provision. Waivers are not a new concept to federal or state legislation. The No Child Left Behind Act as well as along with welfare reform and other legislation include waiver provisions that allow states to creatively manage health, education, and social problems at the local level. A waiver in the NOTA would allow states to apply to the Secretary of Health and Human Services for an exemption to compliance with the Act based on a proposal that could best suit the state in promoting organ sharing and donation. Such a provision would promote creativity and acknowledge the efforts of states to increase the regional and national supply of organs. Programs developing as a result of the waiver provision could be narrowly tailored to suit each individual state. Yet, successful programs would serve as a model for other states. Waiver programs would also allow local activists, community groups, patient groups and legislators to be more intimately involved in the development of sound policies addressing the redistribution of human resources.

<sup>146.</sup> E.g., GOODWIN, supra note 27, at 21, 117–67.

<sup>147.</sup> *Id.* at 21–22, 193.

<sup>148.</sup> See, e.g., Goodwin, supra note 43, at 319–20.

Second, Congress should enact the Paired Kidney Exchange Act, also known as the Charlie W. Norwood Living Organ Donation Act. <sup>149</sup> This bill would amend NOTA to eliminate confusion as to whether paired exchanges violate the spirit and integrity of the valuable consideration clause of NOTA. <sup>150</sup> The valuable consideration clause is problematic on many levels as described in this Article. Paired organ exchanges move sick patients off of waitlists and off of dialysis. There is a real financial benefit to removing patients from dialysis. Each year, the federal government pays \$60,000–\$90,000 per individual on dialysis through Medicaid and Medicare funding. <sup>151</sup> Paired kidney exchanges are expected to completely remove those costs as people with newly transplanted kidneys do not require dialysis. The saving to the government is expected to be \$470–\$500 million over ten years by moving people off of dialysis. <sup>152</sup>

Third, increase government spending on immunosuppressant medications for transplant patients. Funds are better utilized moving Americans off of dialysis and restoring their health with organs. Organ transplants do not require subsequent dialysis treatments, nor do they tether a patient's life to any sort of machine. But immunosuppressant medications can be expensive and will be necessary for the life of the organ. However, government funding covers only the first three years of medication post operation. On consideration, funding transplants and the medication to sustain the transplanted organ should be a priority over dialysis.

Fourth, attention should be redirected from penalizing those who attempt to share their organs with others to developing policies that effectively monitor and regulate shared exchanges, incentives, and other types of creative responses to organ demand. Rethinking the continuum of acceptable human exchanges on a line that includes ova, sperm, embryos, milk, hair, and organs should bring about greater honesty and clarity in transplantation. The moral compass in this domain should be recalibrated to respond to social expectations, needs, and levels of acceptability. How much commodification is too much? We do not exactly know as the lines have not been adequately studied.

Fifth, as part of government oversight and regulation, social, psychological, and medical histories should be acquired. Social histories reveal behaviors and other habits likely to impact the quality of organs, and this result will more effectively ensure the effectiveness of our transplant scheme. Negative social history would not foreclose the party from donating. To the contrary, an "impacted organ"—one less salubrious—might satisfy the needs of an individual with a similar health condition who realizes that an optimal organ would not reverse her most severe medical condition, such as HIV/AIDS, hepatitis, or cancer,

<sup>149.</sup> H.R. 710, 110th Cong. (2007).

<sup>150.</sup> Bob Kemper, Norwood Bill Would Ease Organ Donations, ATLANTA J.-CONST., Mar. 7, 2007, at A12.

<sup>151.</sup> *Id.* (estimating that the bill would save Medicaid at least \$220,000 in dialysis costs for each patient who received a paired kidney donation).

<sup>152.</sup> See, e.g., Press Release, Congressman Jay Inslee, House Honors Fallen Colleague by Passing Kidney-Donation Bill (Mar. 7, 2007), available at http://www.house.gov/inslee/issues/health/house\_passes\_norwood\_bill.html (containing an estimation by "[t]he Congressional Budget Office . . . that legalizing paired kidney donation would save about \$30 million over 5 years and \$500 million over 10 years").

while the impacted organ might nonetheless provide a quality of life currently absent from her life.

Sixth, there should be an effort to reduce the reliance on children to supply organs and other body parts. A serious flaw in the exclusively based altruistic procurement process is that it fails to adequately meet demand. Demand always outpaces supply. Thus, one unintended byproduct of a transplant system designed around altruism is the use of children and incompetent adults to supply the organs for family members. The use of children as organ suppliers is a coercive feature of altruistic organ supply. Children should not be reduced to rescuers of a poorly designed transplant system. Yet, the use of children in organ procurement contexts demonstrates the desperation in our transplantation system. It evidences how families are locked into a system for which there are limited or no answers except to use their children as an organ supply pool. A more open, regulated market would provide more alternatives, reducing this coercive tendency.

Seventh, consider race as a part of a process to examine healthcare needs and to determine what will motivate individuals to share their organs. To this end, political correctness and racist ideology that warn against allowing African Americans to organize collectively within their communities should be rejected. Lessons from the civil rights movement are relevant and instructive here. When African Americans rejected the second-class citizenship offered by back seats on buses and organized among themselves to pool resources and walk, bicycle, or carpool, they brought about change to a system that seemed needlessly wedded to an outdated mode of operation. It was not until African Americans struck out on their own that they were able to seize the promise of choice, independence, and autonomy from a system that failed to serve their interests. A page can be lifted from that era.

#### **CONCLUSION**

Within a few years, all Americans in need of an organ will likely wait ten years for one. Thousands more will die annually or be unceremoniously removed from transplant lists because they are the "undesirables": too old or too sickly. We limit their choices and threaten them with incarceration and fines if they zealously advocate for themselves. Their options are narrowly circumscribed: risk death by waiting on the U.S. transplantation lists, risk incarceration by feeding, housing or clothing a family for their deceased-one's organ, buy an organ from a vendor in India or Pakistan, or use a child to be their donor.

Private ordering can help bring about beneficial changes in social policy that might otherwise be ignored. These changes benefit the wealthy, but can also benefit those otherwise perceived as vulnerable and shut out. If any lesson was learned from the civil rights movement and organized response to Jim Crow politics, it was that when given the opportunity to organize on their own, individuals and groups can bring about powerful changes. Indeed, those changes

<sup>153.</sup> See Curran v. Bosze, 566 N.E.2d 1319, 1343 (Ill. 1990); Strunk v. Strunk, 445 S.W.2d 145 (Ky. 1969); Little v. Little, 576 S.W.2d 493, 494 (Tex. Civ. App. 1979); Goodwin, *supra* note 30, at 360, 377.

can happen far more rapidly when left to individuals than government. That at least was the lesson of boycotts, sit-ins, teach-ins, and other forms of social organizing, which benefited the very groups that shouldered discrimination. Ironically, then as well as now, it might be collective organizing and not government intervention that moves those most disempowered toward greater social justice.

Behind the veil of race card politics lie the murky, fundamentally troubling questions that must be addressed if we are to save lives through organ transplantation. Curtained and covered in race card politics are the daunting statistics that reveal African Americans are disparately impacted by an exhausted organ procurement system, which under serves them, expects far too much, gives too little, and exacts a heavy toll. African Americans are not the only group that risks death by waiting on the U.S. transplant lists. They are simply the canaries in the mines, all too often waiting for organs that may never become available.