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Crowding Out, Crowding In, and Financial Incentives for Organ Procurement

Benjamin E. Hippen and Sally Satel

Opposition to organ donor compensation based on fears of “crowding out” gathers empirical sustenance from an intriguing intersection of psychology and economics.¹ Drawing from an inference first offered by the late Richard M. Titmuss in his landmark 1971 study on blood procurement, *The Gift Relationship: From Human Blood to Social Policy*, motivation crowding theory challenges the premise that the supply of a good or service increases in response to an offer of monetary incentive.² Contemporary proponents of “crowding out” argue that, contrary to orthodox neoclassical economic theory, certain kinds of desired behaviors actually decrease in response to the offer of an incentive. Here we examine documented examples of crowding out to determine whether they support predictions that offering compensation to kidney donors would cause volunteer donation to decline so dramatically that the total number of available organs would fall below the precompensation baseline.

Blood Procurement: Richard Titmuss’s Gift Relationship

Among the most influential contributions to the scholarship on the social milieu of blood procurement was the work of Richard M. Titmuss, a professor of social administration at the London School of Economics. Titmuss

wrote widely about class inequality and was instrumental in shaping the British welfare state. In 1971 he published *The Gift Relationship*, which became a bestseller in the United States. The book ostensibly offers an empirical basis for the contemporary concern that offering incentives for transplantable organs might create the risk of crowding out altruistic donation. Reviewing the available data from surveys of blood procurement practices in the United States in the 1960–70s, where various forms of incentives (including monetary compensation) were offered to some blood donors, Titmuss concluded that less than 10 percent of all procured blood at that time was from truly voluntary donors—or, in Titmuss’s taxonomy, “voluntary community donors” who expected no personal gain.³ Contrasting this with blood procurement practices in the United Kingdom, where he found “99 percent” of donors to be of the voluntary community kind, Titmuss’s work became the progenitor of the thesis that incentives serve to “crowd out” *authentic* altruistic donation.⁴

Titmuss’s opposition to incentives was not predicated on the contention that they would actually reduce the total amount of blood available. The shortfall was concomitant with a rapid expansion in the availability and efficacy of multiple surgeries (cardiovascular and solid-organ transplant surgery) that drove the demand for blood and posed significant challenges to procurement organizations to keep up.⁵ Titmuss did argue, however, that commercialization introduced inefficiencies into procurement practices, such as the hoarding of blood by individual hospitals, wastage of blood products, and geographic variation in a stable and available blood supply at any one time.⁶

Titmuss’s conclusion that monetary and some nonmonetary incentives had a corrosive effect on altruistic donation inspired the U.S. Department of Health, Education, and Welfare to initiate a policy of promoting volunteerism in blood donation in the mid–1970s.⁷ A closer examination of the methodological and moral assumptions at work in *The Gift Relationship*, however, raises serious questions about his thesis. As a number of economists have noted, Titmuss relied too heavily upon anecdote and incomplete data, rendering his portrayal of the U.S. system inaccurate in many respects.⁸ By his own admission, Titmuss felt obliged to fill in a number of blanks: “There are so many inadequacies, gaps, and errors in the statistical data that at various points we have been forced to employ what one can only call

‘informed guesswork,’” he wrote.⁹ Part of this “guesswork” entailed making highly speculative numerical estimates of different sources of blood procured in the United States, in conjunction with further speculation regarding the motives of entire classes of blood donors.

An example of this methodological style was Titmuss’s synthesis of the distinct categories of “responsibility fee donor” and “family credit donor.” Responsibility fee donors were defined as people who received blood or blood products while hospitalized and were subsequently required by the hospital to “pay back” the blood, either by becoming donors themselves, finding others to donate in their stead, or paying the (high) cash value of the blood. Family credit donors each donated a unit of blood in exchange for insurance that would cover all their blood needs and those of their dependents for one year, an arrangement that could be renewed annually. Titmuss classified both “fee” and “credit” donors as nonaltruistic and reported that 52 percent of all blood procured in the United States from 1965 to 1967 came from individuals in one of these two categories.¹⁰

Titmuss permitted himself considerable latitude in assigning blood donors to these two categories. For example, he reported that 35 percent of the 6 million units of blood procured by the Red Cross in 1967 (which represented approximately half the blood collected that year) came from AFL-CIO factory workers through the union’s community outreach program. Without further elaboration or obvious justification, he qualified this example of apparently altruistic behavior: “If the facts were known,” he asserted, some significant fraction of this population would be responsibility fee donors or family credit donors, rather than the “voluntary community donors” he lauded elsewhere.¹¹ Thus, Titmuss’s case that compensated blood procurement rampantly crowds out authentically altruistic blood donation rested on defining altruism as parsimoniously as possible, leaving the percentage of authentically altruistic blood donors meager, indeed. Despite stacking the deck in this fashion, Titmuss’s own data undermined his thesis about the relationship between monetary incentives and procurement practices. Far from being the overwhelming source of blood procurement in the United States, purchased blood represented only 29 percent of blood procured, even during the heyday of compensating donors.¹² In contrast, since the United Kingdom had virtually no opportunities for blood procurement other than donation without strings attached, it is perhaps

unsurprising that “greater than 99 percent”¹³ of British blood donors qualified as authentically altruistic.

If Titmuss was stingy in classifying blood donors in the United States as authentically altruistic, he was considerably more generous in analyzing the conduct of his own countrymen. In an effort to provide a more objective assessment of the (rather tendentiously assigned) motives of American and British blood donors, Titmuss used a survey he borrowed from the American Red Cross to canvass the attitudes of the latter. His expressed hope was that data from this survey would be useful in comparing the (self-identified) motives of the two groups.¹⁴ *The Gift Relationship* offered no comparison between the British blood donors he surveyed, however, and any comparable group of American blood donors. This omission is less surprising when one examines the two operative survey questions:

Q. 4: Please tick on the list below the *main* reason why you give blood?

- (a) General desire to help people
- (b) To repay in some way a transfusion given to someone I know
- (c) In response to an appeal for blood
- (d) Some of my friends/colleagues give blood and encouraged me to join them
- (e) Another reason (please state)

Q. 5: Could you say why you *first* decided to become a blood donor?¹⁵

It turns out that, in his analysis of the British responses to the American Red Cross survey, Titmuss gathered answers (a) through (d) under the rubric of “voluntary community donors.” The only way those surveyed could *fail* to be so categorized was to bypass the opportunity to choose from the offered menu of virtuous motives in favor of self-generating some less noble sentiment. Whether the answer to question 4 in some sense overdetermined the open-ended answer to question 5 was not considered, though the elicited answers to question 5 did uncover more nuance and complexity in respondents’ behavior. Among the 26.4 percent of people whose

open-ended answers were grouped under “altruism general and particular,” the majority repeated or slightly rephrased choice (a) from question 4: “a general desire to help people.” Titmuss tabulated other frequent answers under the categories of a “general appeal for donors” (18 percent) and “reciprocity” (9 percent), the second of which indicated a sense of obligation to repay blood given to the respondent or others; and more than 10 percent cited either reasons associated with the “war effort” or donation habits ingrained while in the armed services.¹⁶

Recognizing that this diversity of responses could not be gathered under a pristine definition of self-effacing altruism, Titmuss instead summed up the results as an extension of a communitarian concern among British donors:

What was seen by these donors as a good for strangers in the here-and-now could be (they said or implied) a good for themselves—indeterminately one day. . . . In not asking for or expecting any payment of money these donors signified the belief in the willingness of other men to act altruistically in the future.¹⁷

One is left to ponder the irony: If Titmuss had been less obviously self-serving in his classification of American donors, and more self-effacing in his classification of British donors, his comparative analysis of the motives of donors in these two countries might have been considerably more subtle and interesting than it actually is.

As we have observed, British donors had no choice in how they gave blood, since the opportunity to engage in any kind of material exchange, available to some blood donors in the United States, was simply not an option. Under conditions of plenty, this arrangement was not generally problematic for the British. But under conditions of scarcity, the limits of altruism as an organizational principle of blood procurement became plain. When the need became acute for plasma products that were more difficult to procure, such as concentrated Factor VIII,¹⁸ the flaws of the U.S. system of paid procurement seemed suddenly not so terrible, after all. As Douglas Starr relates, “Barely able to furnish enough whole blood, the [British] system proved incapable of marshalling an adequate plasma supply. . . . The nation’s government-funded fractionation centers at Oxford and Elstree did not expand their capacities in time,” with the consequence that

the United Kingdom had to import more than half of its Factor VIII from the United States.¹⁹

Altruistic blood donation in the United Kingdom, then, was decidedly “crowded in,” in the sense that any other means of procuring blood was illegal. But this system was only sustainable by aggressively, if quietly, patronizing the for-profit procurement system in the United States so as to remedy shortfalls in the supply of blood products such as concentrated Factor VIII. And, indeed, donor-only countries continue to be subsidized by the purchase of blood products from the United States—a \$6.6 billion worldwide market in 2005.²⁰ Presumably, Titmuss would not have found it appealing to have to defend a system of altruism that was organizationally dependent on a thin veneer of hypocrisy.

From a psychological standpoint, Titmuss believed that the altruistic impulses of prospective donors were oppressed by the very existence of a commercial market. The simple knowledge that some might be paid, he speculated, suppressed the giving spirit in others by suggesting to them that they “need no longer experience a sense of duty, of obligation, of responsibility for strangers.”²¹ Famously, Titmuss framed his argument in the vernacular of “freedom,” arguing that incentives for blood procurement infringed on the freedom to give blood to anonymous strangers. Donors, he argued, “should not be coerced or constrained by the market.”²² Prominent economists such as Kenneth Arrow have expressed bewilderment as to why Titmuss said “this willingness [to give] should be affected by the fact that other individuals receive money for these services.”²³ Moreover, it is unclear how Titmuss could be so certain of a dynamic process at play—that is, the suppression of altruistic intent—when his observations were merely static comparisons of two systems. Titmuss lacked any meaningful comparison between conditions before and after commercialization to undergird his robust cause-and-effect claims regarding the introduction of incentives and subsequent altruistic behavior.²⁴

At its best, Titmuss’s empirical work reveals that the internal motives of British blood providers in the 1960s were nuanced and complex, even when the opportunity to give blood was crowded in by laws requiring donation alone. Had Titmuss been less hostile in characterizing the motives of U.S. blood donors, he might have more thoroughly developed a key insight of *The Gift Relationship*, a point elucidated more clearly by contemporary

scholars: Even in a system where monetary incentives for blood procurement are prohibited, and donation is the only means available to provide and procure blood, donors have a plurality of motives, not all of which are coherently understood as “altruism.” This is problematic for those who would claim Titmuss as a forefather in identifying the process of “crowding out.” If multiple motives for donation are in play, then, first, there is no *necessary*, unwavering relationship between the organizational means of blood procurement and the specific motives for donation (that is, not all donors in a donor-only system are altruistic, and not all those taking incentives for blood are avaricious);²⁵ and, second, it is more difficult to make the case that *altruistic* motives are *uniquely* crowded out merely by the introduction of an opportunity to receive an incentive.

Finally, we should note that Titmuss also drew a connection between commercialization and the safety of purchased blood. In *The Gift Relationship*, he documented unacceptably high rates of post-transfusion hepatitis in the United States from contaminated blood. He inferred that paying for blood eroded a sense of community, and that a commercial system attracted blood providers who were less concerned about their fellow men and the quality of the blood they gave than they were about the payment they would receive.

It is true that many of the individuals who sought to be paid for their blood at the time of Titmuss's study were disproportionately impoverished, engaged in high-risk behaviors, and at high risk for being infected with hepatitis. But this turned out not to be a compelling reason to condemn a commercial procurement system, as scholars were able to show that poor-quality blood did not flow from the cash payment per se, but rather from the donor population to whom the payment was offered, in conjunction with inadequate screening techniques.²⁶ Some voluntary blood-collecting groups reported that their donors' rates of hepatitis B were as high as those of paying groups, while some blood collected by commercial groups proved to be as disease-free as the cleanest donations obtained by the voluntary groups. Socioeconomic characteristics of donors, such as income level and location of residence, were more strongly correlated with testing positive for hepatitis antigens than whether or not the donor was paid.²⁷ Other collectors found they could avoid tainted blood by setting up procurement sites in middle-class neighborhoods where most prospective donors were employed

and owned their own homes.²⁸ Indeed, markers of social capital, such as higher educational level and being a stable, repeat donor, appeared to be the best predictors of uninfected blood.²⁹ One blood bank director was reported to have screened out undesirable donors by rejecting those who were unwilling or unable to give a home phone number.³⁰

But the most important facet of the challenge presented by viral hepatitis infection in the blood supply was the lack of a reliable, reproducible test to demonstrate the presence of the virus in donated blood. Once such tests (for hepatitis and HIV) became widely available, the rates of transfusion-related disease transmission plummeted. Indeed, some hybrid donation-commercial blood banks actually reported discarding more infected blood products from their altruistic donor population than from people who had been paid for their blood.³¹

Furthermore, the emergence of HIV in the blood supply in the early 1980s made it painfully clear that altruistically donated blood was not guaranteed to be safer even if presumably high-risk groups were avoided. Indeed, most of the infected blood came from a most socially conscious group with a strong, reliable record of voluntary blood donation: sexually active gay men.³² Another striking refutation of the assured safety of free blood was the scandal over France's HIV-contaminated blood supply in the early 1990s. Remarkably, French authorities *knew* the supply was tainted, yet allowed the blood to be used. It is perhaps an understatement to call this an affront to Titmuss's insistence that volunteer blood was safe blood.³³ Reliable, reproducible testing to identify and avoid transmissible disease proved to be far more important than identifying (correctly or not) the motives of the people who donated or sold their blood. As one commentator summarized the situation, "Safety is a matter of practice, not ideology."³⁴

Today the quality of blood provided to medical centers is very high.³⁵ In 1973, sensitive tests for hepatitis B were introduced, and, subsequently, tests to detect hepatitis C and HIV became available. Furthermore, the United States maintains a thriving domestic and export business in blood plasma, almost all of which is obtained from paid individuals.³⁶ It is abundantly clear that the safety of blood used in the clinical setting is not determined by whether or not it is paid for. Nevertheless, the National Kidney Foundation still subscribes to Titmuss's findings. In testimony before a congressional subcommittee in 2003, the foundation warned, "Payments for organs could

undermine the integrity of the organ donor pool as was the experience of paid blood donations.”³⁷

Other Examples of Crowding Out

Critics of a market in organs have cited other examples of crowding out to demonstrate how the introduction of a sanction (such as a fine) might paradoxically promote an undesirable behavior at the direct expense of a desired behavior, or how the introduction of a positive incentive to promote a desired behavior may seem to change its meaning or significance, rendering it less desirable than it was before the introduction of the incentive. We explore a few of these examples below.

Israeli Day Care Case. Historians Sheila and David Rothman amplified the concern that the introduction of incentives might result in fewer organs procured. Their arguments drew on a study of ten Israeli day care centers, undertaken in 2000 by Uri Gneezy and Aldo Rustichini, both pioneering scholars in the field of motivational crowding theory.³⁸ These private centers in Haifa operated on the understanding, not articulated in their tuition contracts, that parents were expected to pick up their children by a certain time, and that at least one teacher would have to stay late if they failed to do so. After a period of observation to establish control rates of late pickups, modest fines (U.S.\$2.50 in 2000) for delays longer than ten minutes were introduced in six of the ten centers. Within a week, the number of late pickups in the fine group increased significantly compared to the controls. After the fines were rescinded, the rates of late pickups remained comparable to pre-fine levels. This finding led the authors to conclude that “a fine is a price”—in other words, a charge for exhibiting an undesirable behavior can be perceived as a payment for offered services rather than as a penalty for doing something wrong. In this instance, the fine was a *fixed* price, and one apparently well worth paying in the judgment of many tardy parents. The intriguing empirical point is that the introduction of a financial incentive in this instance (or, in the case of the day care centers, a financial *disincentive*) actually encouraged rather than dissuaded undesirable behavior.

From the results of this study, the Rothmans inferred that the “extrinsic motivations” of monetary gain from participating in a market in organs may “weaken moral obligations” and result in a “crowding out” of the intrinsic motivation of altruism, thus possibly reducing the number of organs:

As Uri Gneezy, a professor of behavioral science at the University of Chicago School of Business, observes: “Extrinsic motivation might change the perception of the activity and destroy the intrinsic motivation to perform it when no apparent reward apart from the activity itself is expected.” Although the case for the “hidden costs of rewards” is certainly not indisputable, it does suggest that a market in organs might reduce altruistic donation and overall supply.³⁹

Note that Gneezy did not extrapolate from a scenario involving a penalty (the day care example) to conclusions regarding rewards; the Rothmans made that leap. Indeed, a closer examination of Gneezy’s work undermines the Rothmans’ conclusion. In the aptly titled, “Pay Enough or Don’t Pay at All,” Gneezy argued that *small* payments may result in poorer performance than no payment at all. His conclusion was that the relationship between the amount of payment and improvement in performance is not always linear, and that at low levels of payment, performance may be inferior. As applied to organ markets, this is not an argument against payment in general, but against payments too small to improve performance, as suggested by the title of his paper.⁴⁰ Elsewhere, Gneezy and colleagues expanded on the thesis: “Our results demonstrate that individuals contribute more when large repayments are feasible than when nearly no repayment is feasible.”⁴¹ Gneezy’s data support an argument not against organ markets but against *price fixing*, whether the price is fixed at a small remuneration certain to fail as an incentive or at zero, which captures the current situation. If supply is reduced by a small, fixed reimbursement but increases in response to a larger reimbursement, Gneezy’s data offer an answer comfortably within the lexicon of neoclassical economics: “Pay enough, or don’t pay at all.”⁴²

Volunteer Work. Surveys and social psychology experiments have found that subjects are less willing to participate, or participate as strenuously, in a

task they had already agreed to perform for free if it is accompanied by an offer of money.⁴³ In social science surveys, volunteers often express a sense that an otherwise acceptable or even admirable undertaking assumes a “taint” when a reward is offered, or that they feel bribed. One proposed explanation of this phenomenon is that payment deprives the actor of the chance to signal to others that he is a charitable or civic-minded person. Apparently, the greater the desire to be liked and well regarded by others, the less effective rewards will be.⁴⁴

Kieran Healy has persuasively argued that the social expectations accompanying certain exchanges can shift when institutions and organizations work deliberately to shape the meaning of the exchange.⁴⁵ Perhaps an actor's need to behave altruistically can be fulfilled if the reward is specifically reserved for those most in need, for example.⁴⁶ Indeed, those put off by the fact that compensation is available to others would be wise to accept the reward themselves and donate it to a charity, thereby leveraging their altruistic impulses into helping even more people. As for the lost altruistic donors—those deterred entirely by the offer of the reward, and undeterred by the harm thereby visited on innocent third parties (that is, recipients)—there is some evidence that they can be replaced through recruitment of new donors who will accept compensation. This will only work, however, if, as we have discussed above, the original offer is made attractive enough to overcome any attrition from the altruist dissuaded by even the offer of an incentive.⁴⁷

Relevance of Crowding-Out Examples to Compensation of Kidney Donors

Few real-world data exist to indicate whether the ability to purchase organs crowds out kidney donation from either living or deceased donors. The data from individual countries need to be interpreted and understood in the context of a multitude of cultural particulars, some of which may not be known. Kidney and liver procurement trends in Hong Kong, for example, clearly illustrate the difficulty of drawing general conclusions. One critic of compensation has attributed a decline in Hong Kong's rates of living kidney donation to the 1997 transfer of the former British territory's sovereignty to China, which made it easier to travel to the mainland to illicitly purchase

organs from living vendors there.⁴⁸ Others have disputed this conjecture, citing the lack of change in the number of Hong Kong recipients who purchased kidneys elsewhere before and after 1997, the unchanged rates of organ procurement from the deceased, and an (unexplained) *increase* in the number of post-1997 Hong Kong living-liver donations, a procedure which is considerably more risky to donors than kidney donation.⁴⁹ In further support of the tenuous relationship between altruistic donation rates and the introduction of monetary incentives for organs, after the legalization of the sale of kidneys in Iran in 1988, the annual rate of (uncompensated) living donation remained stable at 11–13 percent.⁵⁰

Presumably, the ability to obtain a kidney from a stranger eases the burden on ambivalent would-be family donors as well as on the patients themselves, especially older individuals who are reluctant to ask their children to sacrifice an organ for their sake. But if those organs are not immediately available, as would undoubtedly be the case in the early stages of a compensation system in this country, the sense of obligation to help loved ones would likely remain. Significantly, none of the psychological experiments by motivation-crowding theorists focus on an activity like organ donation, in which the beneficial effects are immediate and the stakes are life and death. What's more, these experiments focus on the question of whether people who are prepared to perform an act voluntarily will be less willing to do so if they receive payment. They do not address the question at hand: whether those willing to donate their own or their loved ones' organs would become less willing if *others* had the option of getting paid.⁵¹

As the researchers in this area stress, it is difficult to extrapolate from highly controlled psychological experiments to the messier business of real-world decision-making. The Israeli day care study and a hypothetical market in organs are obviously discrepant in that living kidney donation is a one-time event, whereas picking up one's children at school on time is a comparatively repetitive exercise with comparatively minor consequences (as can also be said of another instance explored here—giving blood). The behaviors in question in the day care study were embedded in larger social relationships straddling the line between business and education—features not present in the organ market.

In another study—this one involving labor markets—Gneezy and List highlighted observational differences between “hot” and “cold” decision-

making, which distinguish immediate and considered reactions to a situation, as well as “adaptation” responses to changing situations.⁵² Hot and cold decision-making may have implications for how organ donation and participation in an organ market are viewed more generally by potential participants, but here again there are presumably relevant differences between the psychological processes being studied by behavioral economists in the laboratory and those taking place in the real world. The methodological hazards of generalizing are only enhanced by an incomplete—even erroneous—understanding of the social and cultural assumptions at work, a point no less frequently overlooked in cross-cultural discussions of organ procurement as elsewhere.⁵³

Impact on Procurement of Deceased-Donor Organs

Even if the total number of organs procured were to increase in response to compensation, would market exchanges result in fewer being procured from deceased donors?⁵⁴ The infrastructure required for deceased donation is considerably more complicated and more expensive than that for living donation. A successful system of organ procurement from deceased donors requires hospital resources in the form of large and well-staffed intensive care units,⁵⁵ readily available operating room space, medical personnel who are competent in identifying and medically managing potential donors, procurement personnel who are skilled in successfully soliciting grieving family members, and laboratory facilities capable of performing sophisticated serologic and immunologic testing in a rapid, efficient, accurate, and reproducible manner. Once the organs are procured, another system is required to identify appropriate candidates for them and ensure a fair, reproducible, and transparent process of allocation. Since the availability of deceased donors is unpredictable, this parallel system must also be manned and ready at all times. The costs of maintaining the infrastructure of a robust deceased-donor program are significantly greater than those of procuring organs from the living in a controlled fashion during daylight hours.

By comparison, a potentially plentiful source of organs from living vendors substantially reduces the need for the effort (and the expense) of mak-

ing these resources available rapidly and continuously. Organ procurement from living donors can be done during the daylight hours with plenty of personnel around; donors can be screened and rescreened for transmissible diseases, which increases confidence in the safety of the donated organs; and the transplanted organs frequently function more quickly and with fewer postoperative complications than those from deceased donors.

These circumstances would seem to make a strong *prima facie* case for market organs crowding out deceased kidney donation, though this result would be tempered by a continuing need for organs not readily available—or available at all—from living donors, such as hearts, livers, and lungs. The concern over crowding out overlooks this difference between living and deceased organ procurement. When families decide to allow their loved ones' organs to be retrieved, they know that all viable organs will be taken, not just kidneys. There would be no logic in withholding the organs of the deceased simply because the supply of *kidneys* was enhanced through compensating living donors.

The Iranian experience supports this contention. Iran's donor compensation system, which was instituted in 1988 and is the only legal one in the world, is fraught with problems that prevent it from being a model we would want to emulate elsewhere.⁵⁶ These difficulties do not, however, bear upon the question of whether deceased and living donation can operate simultaneously;⁵⁷ and though some critics have alleged otherwise,⁵⁸ deceased organ donation has not been "crowded out" in the Iranian system by the existence of a ready supply of organs both donated and sold by the living. Prior to the year 2000, there was no legislative recognition of brain death in Iran. After brain death became legally recognized as such, rates of deceased donation in the country increased steadily, from 1.8 percent of all organs procured in 2000 to 15 percent in 2006.⁵⁹

Furthermore, altruistic living organ donation in Iran has coexisted with the purchasing system since the inception of the program, representing 11–13 percent of all procured organs since 1988.⁶⁰ While it is plausible that rates of living related donation would have been higher and the path to deceased donation might have been achieved earlier in the absence of organ purchasing, the fact remains that altruistic behavior persists in the case of living related donation and flourishes in the case of deceased donation. Altruistic behavior turns out to be more resilient than its defenders suppose.

Conclusion

Motivation crowding theory offers an intriguing series of challenges to a proposal for a regulated market in organs from living donors. Unsurprisingly, different critics of organ markets have different behaviors or motives in mind when expressing the worry that a market “crowds out” altruistic donation. Some decry the loss of the “altruism” component while accepting the neo-classical assumption that demand will generate supply. Others argue that market incentives will so adversely affect the meaning of organ donation as to violate the neoclassical assumption. The evidence, as we’ve seen, is rather more textured and complicated than that, but it clearly does not support the assertions of critics such as Richard Titmuss or Sheila and David Rothman that the introduction of market exchanges simply reduces either a desired motive (altruism) or a desired behavior (donation/procurement). As Kieran Healy has observed, a crucial challenge for proponents of organ markets is to design a system that is sensitive to “the organizational effort and cultural work that go into making these exchanges socially acceptable.”⁶¹ A more robust elucidation of this challenge has been the purpose of this chapter.

8

Rethinking Federal Organ Transplantation Policy: Incentives Best Implemented by State Governments

Michele Goodwin

So what should we do, legislatively speaking, when altruism is simply not enough to satisfy the growing demand for organs in the United States? Organ policy has been largely unaltered over the past two decades, a period in which the population of people needing transplants has changed dramatically in size and nature. What might be done to bring federal law in line with current circumstances?

Over twenty years have passed since the enactment in 1984 of the National Organ Transplant Act (NOTA), which prohibited the use of any “valuable consideration”—payment in any form—as an inducement for organ donation. NOTA also designated the United Network for Organ Sharing (UNOS), a private organization, to be its contracting agency to oversee organ procurement and allocation in the United States. The NOTA prohibition on compensating donors has created profound problems, severely constraining the avenues by which desperate patients can pursue organs. Their only choices are to risk death waiting on a seemingly endless UNOS list, or gamble with the possibility of incarceration and fines by seeking transplant options outside of NOTA’s narrow framework.¹

The federal gridlock in organ procurement policy created by the prohibition on compensation is a matter of grave national concern, and a number of questions that have not been closely examined by policymakers demand thoughtful response. On other occasions, states have been highly

effective laboratories for experimentation with innovative approaches to long-standing public policy problems. It is only natural to wonder at this juncture whether the federal government should allow the testing of novel state plans to procure more organs for transplantation. A simple amendment to section 301 of NOTA could permit applications for state-level waivers to the proscription on exchanging “valuable consideration” for organs. States granted such waivers would be free to develop pilot or demonstration organ procurement programs, which would provide invaluable information about the effectiveness of different approaches to this complex issue.

Origins of American Organ Transplantation Policy

Organ transplantation policy has not always been a matter of federal law; in fact, before NOTA, the federal government essentially left this issue to the states. The first policy effort to address organ scarcity in the United States was initiated at the state level with the enactment of the Uniform Anatomical Gift Act (UAGA) in 1968. The UAGA was a model law which, by the early 1970s, was adopted in nearly identical form by all fifty states and the District of Columbia. Its creation was spurred by the National Conference of Commissioners on Uniform State Laws (NCCUSL), which convened a group of highly esteemed individuals, recruited and appointed by various state governors, to draft an organ transplant policy. Chairing the commission was E. Blythe Stason, a professor of law and former dean and provost of the University of Michigan.²

Most transplant scholars and commentators suggest that the UAGA focused primarily on *who* possessed the authority to donate, and under what circumstances organ donation could be made. These observations are accurate but incomplete. To credit the UAGA and its drafters with only determining who could donate organs ignores the framers' intent. Led by Stason, the commissioners made strides toward considering incentives as a means of organ procurement by leaving the question open to individual state legislatures and, ultimately, the democratic process.

Although commentators differ on whether the omission from the UAGA of direct language on this point was intentional or an oversight,

there are indications that leaving the question of incentives for states to decide was reasoned and deliberate. As a dean, provost, and commissioner, Stason was known for being meticulous, methodical, and purposeful in the examination of ideas and the implementation of policies.³ If the framers intended to ban the sale of organs, with Stason at the helm of the commission, they would have done so. But, Stason observed at the time, the commissioners felt that “the matter [of payments] should be left to the decency of intelligent human beings.”⁴

After presenting the model law to their home states for ratification and enactment, legislators sought to work within the spirit of the original draft. Thus, in a radical shift, states that had previously enacted laws to ban payments for organs and body parts—among them Massachusetts, Delaware, Hawaii, Maryland, and New York—*repealed* those regulations.⁵ In so doing, they, too, were expressly leaving open the question of incentives, payments, and other forms of valuable consideration, at least for the posthumous disposition of organs and human tissues.

Stason himself said that the UAGA drafters contemplated incentives and supported allowing states the flexibility to decide those matters. In interviews and writings after the enactment of the UAGA, the commission chair remarked that the question of payments was intentionally left open for states to decide.⁶ Demonstrating a nuanced view of what organ transplantation in the United States would become, Stason acknowledged that the possibility of donors demanding payments might arise, but he did not hold that all payments would be unethical, immoral, or illegal.⁷

Federalism and Organ Transplantation

For the next sixteen years, the 1968 UAGA as adopted by the states was the only law governing organ transplantation in America. In devising a national policy on organ transplants in the 1980s, the federal government did not initially set out to change the UAGA’s tacitly open position on incentives. In fact, early drafts of NOTA were silent on payment for organs; they focused, rather, on the creation of a nationwide procurement and distribution system. The restriction on payment or in-kind exchange for an organ was prompted as an afterthought and due, almost entirely, to

the activities of one man: a physician named H. Barry Jacobs, of Reston, Virginia.

In the fall of 1983, Jacobs, whose medical license had been revoked five years earlier on a conviction for Medicare fraud, was making plans to establish an organ brokerage called the International Kidney Exchange. According to a 1985 account in the *Virginia Law Review*, “Jacobs intended to solicit healthy individuals to sell one of their kidneys at their chosen price. A person needing a transplant would pay for the cost of the kidney plus \$2000 to \$5000 for Jacobs’ service” to, as the *New York Times* put it, “escape the tyranny of dialysis.”⁸ Prior to his emergence on the scene, there had been no evidence of commerce in transplantable organs in the United States.⁹

In November 1983, Jacobs presented his plan to a House of Representatives subcommittee chaired by Representative Al Gore Jr., at a hearing entitled *Procurement and Allocation of Human Organs for Transplantation*. His testimony was not well received—Jacobs’s pugnacious manner could not have helped his cause—and he became the lightning rod for a general outcry against the idea of paying for organs.¹⁰ Section 301, a provision prohibiting payment, was soon inserted into the draft bill.¹¹ It stated, “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.” Violators could be fined up to \$50,000, imprisoned for as long as five years, or both.¹²

NOTA proponents may have believed that the law left open many possibilities for states. But such an assessment would have been misleading. To the essential question—what powers do local governments retain to craft organ transplantation policies that respond to local dynamics and needs?—NOTA did not provide an answer, except in the negative. It made clear that certain authority was removed from states and citizens, prohibiting the legal implementation of any incentives or “valuable consideration” (an ambiguous term, which broadly included anything thought to generate financial and even *emotional* value) in local organ transplant policies. After 1984, state programs to offer individuals any sort of incentive for donating their organs risked running afoul of federal law.¹³

The federal move to ban all forms of “consideration” was a radical step, not in what it specifically entailed—banning payments—as individual

states could have enacted such measures (as Virginia had¹⁴); but because it significantly removed autonomy at the state level by extensively encroaching upon state authority. In fact, states had collectively addressed organ transplantation before the federal government's involvement by ratifying the UAGA. Shortly after NOTA, the UAGA was redrafted to comply with the new federal law. By that time, however, Stason had died. The vision of the 1968 UAGA was gone,¹⁵ and states no longer had the opportunity to consider incentives.

Transplantation after NOTA

Federal intervention in organ transplantation through NOTA has had several consequences. As the critical shortage of organs in the United States has worsened, attempts to enact responsive legislation to address the need for them have largely failed or been indefinitely stalled. UNOS now holds a monopoly on legitimate organ procurement, controlling not only how organs come into the transplant system, but also the criteria for who receives them. While the benefits of UNOS, such as its capacity to collect data, are clear, its drawbacks include a lack of efficiency and effectiveness in meeting procurement goals and a pernicious national system of organ rationing.

Perhaps the most problematic result of NOTA, however, has been the disturbance of a fine balance between Congress and the states in developing transplant policy to respond to circumstances that inevitably are experienced more intensely at the local level. Local governments and patients are bound to an antiquated and chaotic organ procurement system and left with very few options for experimentation with different approaches to solving this problem.

Pennsylvania is the only state that has challenged NOTA's ban on valuable consideration in any way. In 1994, the Pennsylvania legislature passed the Burial Benefit Act, which provided modest reimbursement of hospital or burial expenses of deceased donors—expenses that would have been incurred whether or not the organs of the deceased were retrieved. The burial act was intended as a “thank you” to the families of deceased donors, state authorities said, but, clearly, it could also have served as an incentive

for family members to give permission for retrieval of a loved one's organs because the benefit here inured to them.¹⁷

The act also established the Organ Donation Awareness Trust Fund, all contributions to which are voluntary.¹⁸ It authorized use of 10 percent of that fund to defray medical or funeral expenses of the deceased, with an upper limit of \$3,000 for any one family, although at the time of creation the fund was only large enough to offer \$300 to each family of four hundred anticipated donors.¹⁹ From 1994 to 1999, the Pennsylvania legislature invested significant financial and community resources in studying whether this new law would conflict with federal law.²⁰

The plan stalled, however, in the final stage—all that it lacked was a signature from the state secretary of health—over concern that the funeral benefit was a violation of NOTA's prohibition on "valuable consideration" for organs.²¹ A state representative sought clarification from the U.S. Department of Health and Human Services (HHS) in December 2000 regarding whether reimbursement of donor funeral expenses violated federal law, but was told that HHS could not provide a determination and he should consult the Department of Justice for a definitive interpretation of Section 301, a criminal statute.²² There is no evidence that this was pursued. In the end, Pennsylvania state legal department decided not to test the limits of NOTA by offering incentives for deceased donation and instead directed the funds intended for incentives away from funeral expenses for the deceased and toward reimbursement for food, travel, lodging, and lost wages incurred by living donors—costs already authorized under NOTA.²³

A Pragmatic Return to the States

The federal government already has considerable experience with waiver programs. Indeed, some of most generously funded federal programs incorporate state waiver provisions, including the No Child Left Behind Act and the Social Security Act.²⁴ In the latter case, section 1115 grants authority to the secretary of the U.S. Department of Health and Human Services to waive specific requirements, allowing greater flexibility for states to meet the needs of recipients in the Aid to Families with Dependent Children (AFDC) program and to balance those needs

with state interests. The waivers also enable states to implement pilot programs and experiment with existing projects that promote the purposes of the AFDC program.

During the peak years of welfare reform, between 1993 and 1996, the HHS approved welfare waivers in forty-three states. According to the department, the projects resulting from the waivers ranged from “modest demonstration projects, limited to a few counties,” to others that promoted “dramatic statewide changes in the AFDC program.”²⁵ These waivers constituted the first wave of welfare reform in the United States, as “many of the concepts included in state waiver requests were later incorporated into the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996.”²⁶

Wisconsin was a trailblazer in the use of waivers for welfare reform. Between 1987 and 1997, then governor Tommy Thompson cut the welfare caseload by 60 percent, far exceeding the effects of the robust economy and low unemployment that marked the decade.²⁷ Other states were inspired by Wisconsin’s success and used waivers to transform their welfare rolls.

Beyond providing freedom from federal strictures, waivers also generate policy knowledge, as different states approach reform with different strategies. In June 2006, for example, HHS granted waivers to five states to tailor their child welfare programs.²⁸ One, Michigan, is concentrating on greater investments in early intervention services. The waiver to Virginia allows federal foster care funds to pay monthly subsidies to families who assume legal guardianship of children, removing them from state custody.²⁹ Iowa is creating a managed-care demonstration project that focuses on providing services and support to special-needs youths between the ages of eleven and sixteen so they can stay in their own homes.³⁰

In the case of welfare, states were granted waivers to experiment with reform because the problems with the federal welfare laws were widely recognized, and the states were demanding the freedom to act. The question is whether any such demand exists today for state experimentation with organ policy. If states were granted waivers from NOTA, would they use them? It is hard to say, but there is at least some evidence of interest.

In Wisconsin in 2003, for example, state representative Steve Wieckert, with the support of the transplant community, introduced a bill

allowing donors to claim a \$10,000 state tax deduction to cover lost wages and expenses for travel, lodging, and medical care incurred by organ donors.³¹ The result was the first tax incentive law for organ donation in the country.³² The proposal of similar laws by two dozen states in the less than five years since then, with more than a dozen adopting them, suggests that the desire to experiment is widespread.³³

Model Waiver Language for NOTA

Because the federal government has limited how states might sensibly meet organ demand at the local level, the best—and seemingly only—way, as long as NOTA is in effect, would be to allow them to waive out of the act by way of demonstration projects. Much can be gained by the use of waivers, nationally as well as at the state level, by decreasing the national waiting lists for organs and reducing federal costs. The goal would be to move patients from very costly subsidized dialysis treatments to organ transplants, which not only would save millions of dollars each year but would also promote better health outcomes for sick patients.

If the federal government wanted to empower states to experiment with different approaches to solving the organ crisis, how could it be done? Granting them waivers from the National Organ Transplant Act would be surprisingly simple. Section 301 of NOTA could be amended with language enabling them, as follows:

(a) In order to receive federal approval for waivers of the provisions of the National Organ Transplant Act, states must demonstrate a negative impact of the current legislation. A negative impact can be demonstrated by chronic organ shortages in the state, extended waiting-list times, disparate impacts on selected categories of persons, such as the elderly or children, or other conditions that limit the states' ability to meet the needs of potential organ recipients.

(b) Waivers can be implemented for three-year periods and are renewable based on need and subject to approval by the secretary

of health and human services. At the termination of the waiver provision, states are required to submit a detailed report outlining the successes of and obstacles to their programs. States must also provide a financial analysis to help assess which programs more effectively met the needs of citizens and reduced the costs associated with transplantation.

(c) States will be responsible for collecting, aggregating, and analyzing organ transplant data for waiver projects. Data collection should be based on models currently in use by UNOS, which specify donors by categories of living and deceased, but it should also be expanded to include specific classes of donors that result from pilot projects, including paired donors, directed donors, reimbursed donors, and others.

(d) States are not required to participate in waiver programs. Those that choose to participate in pilot projects shall be required to submit waiver applications to the secretary of health and human services. To receive approval for waivers, states must be willing to conduct rigorous evaluations of the impact of their demonstration programs. States may, for example, be required to assign patients on the waiting list randomly to control groups or experimental groups that are subject to the waiver. Equally, states may be required to track donors among the different donation categories.

(e) States may be required to track and compare success rates among different categories of donors and recipients. Success is defined as receiving an organ transplant. States may postpone until the waiver expires implementation of future federal organ procurement legislation to the extent that such rules are inconsistent with ongoing waiver provisions and protocols. States may choose to maintain or extend waivers to continue monitoring or evaluating their programs without a showing of further negative impact. States may apply for waivers and later choose not to implement the waiver programs without penalty.

(f) States are required to show that waivers are cost-neutral, but only over the life of the waiver, rather than each year. “Cost-neutral” shall be interpreted to mean that costs do not exceed state and federal contributions prior to the waiver implementation. Waivers may be reapproved for three-year increments over the life of the waiver program. Termination of the program shall be subject to congressional determination. Waivers are subject to the approval of the secretary of health and human services.

Four principles would guide experimental programs made possible by the model waiver: saving lives; promoting better information collection and sharing; enhancing organ donation efficiency by providing as many options as possible to link patients with healthy organs; and improving cost-benefit ratios. The model encourages the development of strategies to reduce overall state and federal expenditures in the renal failure area by moving sick patients from dialysis to transplant, thereby enhancing survival rates while bringing down overall costs and maximizing the effectiveness of fund allocation. The language provides flexibility to states in the creation of programs while promoting consistency in data collection by basing it on models currently in use by UNOS.

The model waiver also attempts to address the very concerns that led to the enactment of NOTA—namely, that rogue opportunists might attempt to exploit the poor, circumvent legislative protocols, and otherwise undermine the dignity and legitimacy of the transplant system. States that wish to participate in the waiver program must demonstrate a negative impact of the current federal legislation. Although the threshold for doing so is high, most, if not all, states already meet the standard with chronic organ shortages, extended waiting-list times, or disparate impacts on selected categories of groups, any one of which conditions would sufficiently demonstrate that the intended goals of NOTA are not being reached. The model waiver promotes accountability as well, with its three-year implementation periods, renewable only based on indicated need and application to the secretary of health and human services. Requirements to supply data evaluating the success of the program and a financial analysis at the time of expiration hold a state further accountable.

The language of the model waiver could be applied to any of a variety of state organ procurement programs. While programs need not be incentive- or market-based, waivers are intended to free states to follow those objectives if they so choose. Pennsylvania's Burial Benefit Act, for instance, would have fit the waiver model. Interested states would probably elect to implement their waivers on a pilot basis, with funds for a compensation program coming from state revenues or supportive private sources, such as charities or foundations. Federal contributions might be feasible as well. Specifically, savings to Medicare from patients exiting dialysis could be passed on to the states through an arrangement called gain-sharing, in which hospitals and physicians can receive a portion of the savings they generate for Medicare through creative deployment of federally funded health-care resources.³⁴

Such pilot programs would also generate information about donor compensation that the current national organ procurement system completely lacks. Those who suggest that incentives will never reduce waiting lists, or that they will exploit the poor, or that they will cause "crowding out"—meaning altruistic organ donation will go down if alternative models are introduced³⁵—cannot prove their claims because they lack evidence. Equally, economists who have long suggested that introducing incentives into transplant regimes will likely save lives and dramatically reduce waiting lists have little evidence to support their contentions. The model waiver attempts to remedy this deficiency by promoting—indeed, mandating—data collection, which is crucial to the overall health of any procurement system.

Finally, the model waiver responds to the demands and concerns that emerge from the geography, demography, and values of each state. Conceivably, the trigger for organ-sharing lies outside of markets but is not quite met through traditional modes of altruism. Perhaps religion matters in these discussions, or values such as trust and confidence in the local procurement network. The best and only way to find out is to allow states to become laboratories of democracy for organ transplantation. Granting waivers to federal law that allow states to experiment is the best possible example of collaborative federalism.