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A Running Commentary on the News

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Should Laws Push for Organ Donation?By *THE EDITORS*

Maye Webb

A New York assemblyman has [introduced a bill aimed at making the state the first to presume people want to donate their organs](#) unless they specifically say otherwise. Under current law, people give permission to donate their organs by checking a box on their driver's licenses or filling out a donor card.

The legislation, introduced by Assemblyman Richard Brodsky, a Westchester Democrat, is in two parts: the first step would end the right of the next of kin to challenge the decisions of their dead or dying relatives to donate their organs.

In a second measure, which is far more contentious, people would have to indicate in official documents — their driver's licenses, most commonly — that they specifically don't want to donate organs. If the box is not checked, it is presumed the person wants to donate.

What are the ethical and practical issues involved in changing the law? Is a "presumed consent" system an effective way to increase the number of organs available, and thus save lives, or will it deter public support for donation?

- [Arthur Caplan](#), professor of bioethics
- [Kieran Healy](#), sociologist
- [Sally Satel](#), American Enterprise Institute
- [Elaine Berg](#), New York Organ Donor Network
- [Mary Ann Baily](#), Hastings Center

The Ethical Good of the 'Yes' Option

Arthur Caplan is a professor of bioethics at the University of Pennsylvania School of Medicine. His most recent book is the "Penn Center Guide to Bioethics."

What can be done to increase the supply of organs that can be used for transplantation? In New York, as is true all over America, waiting lists grow every month and lives are lost because there are no hearts, kidneys, livers or lungs available.

This grim situation is especially frustrating since numerous polls and surveys show that most Americans are willing to be organ donors upon their deaths. Yet the system we have in place now — using donor cards and driver's license check-offs — to permit people to let their wishes be known does not capture the altruism and goodwill that is out there.

The check-off and donor card system we have now does not capture the altruism that is out there.

Cards and licenses get lost or misplaced or those who sign them fail to talk about their wishes with their families meaning that organs are buried or cremated when they could be saving lives.

There is a better and more ethical solution, and Assemblyman Brodsky's proposed legislation has pinpointed it — presumed consent or more felicitously, default to donation. Since most of us want to be organ donors upon our deaths, why demand that we carry cards or directives to prove it?

Why not put the burden on those who do not want to participate and require that they make their objection known by directive, through a family objection or in a state computer registry?

The ethical case is clearly on the side of defaulting to donation. There is nothing coerced or disrespectful in asking those who do not want to be donors upon their death to say so. Consent and altruism remain core values of organ donation — only the emphasis changes from the presumption of a "no" to one of "yes."

Changing the law will not in itself suffice. As the experience with presumed consent in Western Europe shows, education of the public and constant training of hospital personnel are essential. But, the numbers from Europe show what can be done — significant increases in organ supply with a shift in the law.

New York should take the ethical lead and show the way to the rest of the nation. Those hoping for an organ to live need to have a system that provides them with the best chance of benefiting from the altruistic, community-minded wish to help that the current system does not fully capture.

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Why Revive Old Fears?

Kieran Healy is associate professor in sociology and the Kenan Institute for Ethics at Duke University. He is author of *“Last Best Gifts: Altruism and the Market for Human Blood and Organs.”*

Proposals to introduce presumed consent in the U.S. often misunderstand how it really works in most of the countries that have it. Under informed consent, people are encouraged to opt in to a donor registry or sign a donor card. The next-of-kin can refuse consent if there is no record of the potential donor’s intent. Crucially, even with a record, procurement organizations will generally not override the next-of-kin’s wishes.

Advocates of presumed consent in the U.S. want to remove the next-of-kin from the donation process. Under presumed consent, the default is to assume participation. You sign a register if you wish to opt “out.” The problem is that, with few exceptions, presumed consent countries still allow the next-of-kin a role (usually veto power) in the donation process.

In Spain and Italy, growth in donation rates reflects better management, not the success of ‘presumed consent’ laws.

Spain is routinely cited as a successful example of presumed consent. But in Spain the next-of-kin still has veto power. Most of the growth in donation rates there happened well after the passage of presumed consent legislation.

Spain’s success is due to effective management of the transplant system, not a simple legal rule. Similarly, Italy’s donation rate grew rapidly in the 1990s thanks to investment in its system, not because of its long-standing presumed consent law. Some countries, notably Austria, do have “true” presumed consent, with no kin veto. But they do not outperform countries like the U.S. by any great margin.

It’s also worth remembering that, since the 1970s, the U.S. “transplant community” has worked hard to allay public concerns that surgeons might be too eager to harvest organs, or that the state might play too calculating a role in deciding what happens to the bodies of potential donors.

Support for donation was built up by publicizing the now familiar idea that organ donation is a unique, even sacred, sort of gift. A naive presumed consent proposal would run straight into this established understanding of donation.

Opinions change. Over the long run, efforts to garner support for a different understanding of donation might be beneficial. I don’t hold any particular ethical brief for informed over presumed consent. Some presumed consent systems work very well — just not for the reasons you think.

But I see little benefit in advocating a policy that revives old fears, especially when the results in most presumed-consent countries are not all that different in practice from — or better performing than — the current system.

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The Cost of an Altruism-Only Policy

Sally Satel is a resident scholar at the American Enterprise Institute and editor of *“When Altruism Isn’t Enough: The Case for Compensating Kidney Donors.”*

Out of all the adults in New York State, only a minuscule 13 percent are registered organ donors. Nationwide, almost three times as many have signed up. With such an abysmally low rate, how can Albany not pass the modest step of presumed consent?

Theoretically, presumed consent could generate a significant volume of livers, hearts and lungs. About 2,000 such organs are needed statewide, and a single deceased donor can provide more than one kind of organ. But at its very best, presumed consent will put only a dent in the waiting list for kidneys that totals 7,300 people, according to the United Network of Organ Sharing.

Roughly 150,000 New Yorkers die each year, but less than 1 percent, or only 1,500 people, are likely to possess organs healthy enough for transplantation.

Why? There are not simply enough eligible posthumous donors. Roughly 150,000 New Yorkers die each year, but less than 1 percent, or only 1,500 people, are likely to possess organs healthy enough for transplantation. Again, this projection is extremely optimistic because it assumes that every New Yorker will agree to the default — or consent — status.

The answer to the kidney shortage is incentives for living donation. To the great credit of Assemblyman Brodsky, whose teenage daughter has received two kidney transplants in her young life, he knows that the organ shortage must be attacked on several fronts.

The assemblyman's package of bills contains a provision that would allow anyone who donates a kidney while living to receive a \$1,000 state income tax credit. (Living donation is common: a little under half of all organ donors nationwide in 2009 were friends or relatives.)

While I am skeptical that a tax credit of only \$1,000 would prove a sufficient incentive to promote living donation, the assemblyman's initiative is enormously important. It challenges the standard narrative that altruistic giving is the sole legitimate motive for donating.

The cost of our altruism-only transplant policy is readily measured in lives: the nearly six hundred New Yorkers — and 7,000 Americans — who die each year waiting for an organ that never comes. This is morally indefensible. Many potential donors would gladly accept a meaningful reward for saving the life of another.

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Setting Up Safeguards

Elaine Berg is the president and chief executive officer of the New York Organ Donor Network.

Virtually every survey done across the United States shows that 90 percent or more of Americans support organ donation. Considering “presumed consent” as a viable option is a natural extension of that logic.

Importantly though, in order to be considered, it is imperative that any system of presumed consent have robust safeguards to protect individual rights. There must be guarantees that every citizen is well-informed regarding their right to opt out, and the procedure to do so would have to be simple, accessible and barrier-free.

With guarantees that citizens know their rights to ‘opt out,’ a presumed consent system would work.

Multilingual education in communities lacking access to computers or English media would have to take place. There would need to be multiple types of outlets for opting out, including at social service agencies, schools, D.M.V.'s, places of worship and online. We would have to pay special attention to communities who may have broad concerns about donation.

The opt-out registries would have to be accessible to organ procurement organizations, which would be required by law to contact the registry every time there is a potential donor (we currently do this to determine folks who have registered to donate by opting in). Laws would have to specify that overriding a person's wishes to opt out is illegal.

All of this can be done. There are nearly 110,000 people waiting for life-saving organs in this country. We are not waiting for a cure. The solution is in our hands.

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This Is a Very Bad Idea

Mary Ann Bailly is a fellow of the *Hastings Center*, a bioethics research organization, and a member of the *Institute of Medicine Committee on Increasing Organ Donation*.

Assemblyman Brodsky's “presumed consent” provision is a very bad idea. Even if the public accepts it, it won't solve the problem of waiting lists for solid organs like kidneys.

Brodsky focuses on consent as the key problem in organ supply, and claims that it's a common practice for families to override the clearly expressed wishes of the deceased. This is simply not true. Families usually go along with the wishes of the deceased, and when those wishes aren't known and the family is approached in a sensitive manner, the family often concludes that the deceased would be in favor of it.

The real problem is that in order to be an organ donor, a person must die the right way and in the right place.

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As death approaches, a medical team must recognize that a person's medical condition makes donation a possibility and take steps to preserve organ function. (The classic donor is someone who is "brain dead" — breathing on a mechanical ventilator but declared dead on neurological criteria, often after trauma from an auto accident or gunshot wound.)

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After death is declared, the team must remove the organs, identify recipients, and put together recipients, organs and appropriate medical staff to do the transplantations — and do all this very quickly.

The total number of medically suitable potential donors in a year is small — certainly smaller than the number of people waiting for organs. Moreover, even if every potential donor had signed a donor card and every family respected it, the current health care system wouldn't be able to complete the complex process of turning consent into transplants for every donor.

And what on earth leads the assemblyman to think that the public will accept presumed consent? The state can authorize the taking of a person's body parts simply because of failure to check a box on a government form — a form that seems to be about getting a driver's license?

Many Americans don't trust the government or the health care system. Some already fear that signing a donor card may make physicians give up on them too soon, especially if the hospital is likely to lose money on their care. This legislation, if enacted, might only ratchet up those fears.

People who aren't sure how they feel about donation are quite likely to check the opt-out box. In fact, some current donors — unsettled by the aggressiveness of such a policy — may also decide to opt out. Presumably both the checked and the unchecked boxes will have to be respected as a matter of law. The provision could thus lead to a smaller pool of potential organ donors rather than a larger one.

Moreover, family members are more likely to question the validity of an unchecked box than a donor card as a clear expression of a relative's wishes, and may be very upset to have the organs taken abruptly with no input from them. The result is likely to be disruptive conflict in the clinical setting, and in the long run, a decline in public support for transplantation.

What could we do instead?

We could work harder to get actual (not presumed) consent to donation. We could improve the health care system's ability to get the most successfully transplanted organs from each donor.

We could expand the donor pool by figuring out how to get viable organs from people who die with a wider range of medical conditions and in a wider range of settings. And finally, we could reduce the need for human organs by developing better technologies to support people with organ failure.

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