Increasing the Supply of Organs to Save Lives: A Proposed Plan for National Organ Transplantation Insurance

Richard J. Bonnie and Gil Siegal

We are attaching a paper currently under review at a major medical journal in which we present the basic elements of a plan for what we are calling “National Organ Insurance” (NORI) designed to solve the persistent shortage of organs available for transplantation. We are now at work on an article for the legal literature in which we intend to explore the legal and moral foundations of our plan in greater depth and to develop its key components in more detail. The article will be organized as follows:

Part I will present an overview of the problem. After a brief history of transplantation and the current system for procurement and allocation, we will describe the shortage of organs, especially in this country, while noting that it is a world-wide problem. The shortage has been ameliorated modestly in US and other countries by liberalizing selection criteria (making more organs usable) and by increasing use of living donors. But, it is clear that the major problem is that many, if not most, of the transplantable organs are not legally available for transplant because explicit consent has not been given by either the deceased donor before death or by a responsible family member thereafter.

An enormous number of articles, reports and proposals have been written to address this problem over the past 20 years, especially during the last decade. What is most striking is how diverse and contradictory they are. Almost nothing is taken for granted in the literature. They differ widely in the ethical frameworks and in the assumptions on which they rest, as well as the degree to which they depart from acknowledged legal principles. We will present a brief anatomy of these proposals here, preparatory to discussing them in depth later on.

Part II will present a comparative view of the problem, presenting the experience of countries that are doing better than we are and highlighting aspects of their systems that differ from ours. One major difference (but not the only one) is that the law presumes consent rather than requiring explicit consent for retrieving organs.

Part III will present a critical evaluation of the proposed approaches, including educational interventions, moral suasion, use of financial incentives to encourage donation, preferred status on the waiting list based on promise to donate, shifting to presumed consent from the current system under which silence effectively delegates decision-making authority to next-of-kin, requiring people to say yes or no (mandated choice) and or dispensing with consent altogether.

Part IV will present our plan. We will begin by laying the conceptual groundwork. The foundational claim is that we need to change the moral premise of
organ donation, converting from pure altruism to reciprocity. The educational task is to get people to see that promising to be a donor is connected to the likelihood of an organ being available for them or their family members if one is needed; the governing social understanding should be reciprocal self-interest.

- Perhaps altruism is more virtuous, and it would be a perfectly acceptable premise for a system of organ retrieval if it produced enough organs, but our assessment is that it does not seem likely to do that.
- The state has a legitimate interest in “shaping” public moral understanding in the society’s best interests (compare the shaping of environmentalist norms or counter-terrorism norms)

The underlying concept is insurance – an effort to get enough organs into the pool so that everyone is protected if the need arises; the promise to donate is essentially the premium. In theory one could imagine a private insurance market (channeling organs of participants to participating patients) or a scheme under which prospective donors are given priority on waiting lists, but there are serious practical obstacles to doing this. In addition, such an arrangement will do nothing to help the uninsured who cannot afford the pay for the cost of transplantation. So, in a key move, NORI connects organ donation to public financing of transplantation. Our insurance model is based on a social contract, not a model of individual contracting as others have proposed.

A final foundational point is that we assume from the outset a strong (perhaps absolute) preference for individual autonomy of the living person in controlling the disposition of body parts after death. This autonomy claim is a constraint on the consequentialist perspective that otherwise governs our analysis. (But note that this assumption could be softened under some approaches… and is not absolute even now – e.g., autopsy in cases of suspected homicide.) However we depart from the current law and practice under which families are given effective authority to make these decisions, rejecting the claim that the family has any interest independent of the ante-mortem interest of the deceased.

We will then turn to the legal design of NORI. The plan is outlined in the attached article to which you might sensibly turn at this point. However, if you have time only for the outline version, here it is:

1. National financing of transplantation. This is not a huge cost and it is critically important to the integrity of the scheme – as a guarantee of an organ and as a symbol of the universality of the scheme.

2. National procurement system, preempting state law.

3. Participation or enrollment as the default

   - As the current opt-in system is now working, we think that the actual preferences of most people are not being honored (bec/ of the
psychological barriers to opting in, especially for young people, and the high refusal rates of families)
• In theory, presumed participation is the logical default based on mutual self-interest (whereas the current opt-in approach is most consistent with a system premised on altruism)
• The present system actually creates a massive (but unwitting) free-riding problem and this is a compelling argument against it.

4. Mechanisms and ramifications of opting out

• We recognize that a system of presumed participation could slide into indifference to autonomy, but we do not want this. A robust and meaningful opportunity to opt out is a good thing because (aside from showing respect for autonomy) it provides another insight to existing flaws and insensitivities.
• While people should have numerous genuine opportunities to opt out, it should not be easy or costless, psychologically speaking. In order to depress free-riding and reduce opting out, moral suasion is desirable. See the techniques we have suggested. (This replicates the vaccine exemption problem.)
• We do not think that many people will opt out, and therefore we do not think it will be necessary to eliminate intentional free-riding by conditioning eligibility for an organ on enrollment.

Part V will respond to criticisms that can be raised against the NORI plan, largely based on the assertion that we are unduly optimistic about its capacity to assure an adequate supply of organs and about its cost. Issues to be addressed include:

1. Meeting the demand - can NORI “guarantee” an organ for its enrollees? Skeptics point to the lack of sufficient number of suitable deceased donors to meet the real demand, even if the rates of donation were increased. The main concern is that there are many more potential recipients than those now appearing on the waiting list. We acknowledge that there will be a transition period before life-saving availability can be assured, but we do believe that this goal is achievable.
2. Cost: Skeptics also argue that financing of transplantation for all who need it will not lead to net savings, and will be very costly. Although we concede a large cost in the short run, we do believe that the program could save money in the long run.
3. Justice: A related concern is whether “exceptionalism” in public financing can be justified for transplantation. Why choose to pay for transplantation vs many other life-saving treatments?
4. Minorities and NORI – the validity of social contract theory in this context, addressing concerns about distrust, coercion and exploitation that might undermine NORI.