

# Annals of Health Law

---

Volume 23  
Issue 2 *Special Edition 2014*

Article 3

---

2014

## Flipping the Light Switch: New Perspectives on Default to Donation for Organs and Tissues

Daniel G. Orenstein

Layne M. Bettini

Follow this and additional works at: <https://lawcommons.luc.edu/annals>



Part of the [Health Law and Policy Commons](#)

---

### Recommended Citation

Daniel G. Orenstein & Layne M. Bettini *Flipping the Light Switch: New Perspectives on Default to Donation for Organs and Tissues*, 23 *Annals Health L.* 1 (2014).

Available at: <https://lawcommons.luc.edu/annals/vol23/iss2/3>

This Article is brought to you for free and open access by LAW eCommons. It has been accepted for inclusion in *Annals of Health Law* by an authorized editor of LAW eCommons. For more information, please contact [law-library@luc.edu](mailto:law-library@luc.edu).

## Flipping the Light Switch: New Perspectives on Default to Donation for Organs and Tissues

*Daniel G. Orenstein\* and Layne M. Bettini\*\**

### I. INTRODUCTION

Lights on or lights off? This simple decision is the first, basic question when entering a room. The decision depends on personal preferences and the circumstances, but the initial position of the light switch does not directly affect the choice. If the switch is “Off,” one can move it to “On.” If it is “On,” one can leave it be, and so on and so forth. Keeping lights off when out of a room is environmentally and financially beneficial, and advocates encourage doing so for both the direct impact and the secondary effects of encouraging consideration of energy consumption.<sup>1</sup> Keeping the switch “Off” is a simple illustration of a beneficial default, but the principle applies to more important and complex decisions, as well.

Organ and tissue donation is also a dichotomous choice: consent or decline. In the U.S., forty-two percent of adults are registered as donors.<sup>2</sup> Others have noted their support or objection in legal documents (e.g., advanced directives) or expressed them to family members. For those who have made an express decision, the type of consent system in place makes little practical difference.<sup>3</sup> However, public opinion data indicate that over ninety-five

---

\* J.D., Fellow and Adjunct Professor of Law, Public Health Law and Policy Program, Sandra Day O'Connor College of Law at Arizona State University; Deputy Director, Network for Public Health Law–Western Region; Lincoln Fellow for Ethics and Health Policy, Arizona State University Lincoln Center for Applied Ethics. The author was employed by the Donor Network of Arizona in the organ and tissue transplantation field from 2005-08. The views expressed here are solely those of the author and do not represent the official position of any organization or institution.

\*\* J.D./M.D. Candidate, Sandra Day O'Connor College of Law at Arizona State University and Mayo Medical School.

1. See generally Tufts Climate Initiative, *Climate change is real . . . . turn off your lights!*, <http://sustainability.tufts.edu/wp-content/uploads/lightingbrochure.pdf> (last visited May 22, 2014).

2. DONATE LIFE AM., NAT'L DONOR DESIGNATION REPORT CARD: THE CHALLENGE TO REGISTER MORE ORGAN, EYE AND TISSUE DONORS 7 (2013), available at <http://donatelife.net/wp-content/uploads/2014/04/DLA-Report-Card-39146-FINAL-2013.pdf>.

3. Emotionally, there may be important distinctions, as discussed *infra*. This is not to say that the consent system makes *no* difference, as evidenced by the failure to recover potential donors who are registered or otherwise specifically indicate willingness to donate be-

percent of Americans support donation.<sup>4</sup> This suggests that a large portion of the population that has not registered yet may wish to be donors. When unregistered individuals die, their families are responsible for donation decisions. Here the consent system matters a great deal. The difference between “opt-in” and “opt-out” approaches may dramatically impact decisions made by family members suddenly thrust into decision-making roles during the grieving process.

Considerable scholarly work has analyzed the potential impact of presumed consent on the availability of organs for transplant,<sup>5</sup> the prior limited use of presumed consent in the U.S.,<sup>6</sup> and ongoing debates over the autonomy interests of decedents and their families.<sup>7</sup> However, at least two other potential benefits of presumed consent have to date received less attention: the impact on eye and tissue donation, and improvements for donor families. Both serve the same larger goal: a more open, more effective donation system that improves the public’s health.

Presumed consent is a hard policy choice. It is a nudge, in the public health vernacular, but decidedly a hard nudge—perhaps even a shove.<sup>8</sup> Public health interests often require hard policy decisions. Presumed consent is not about eliminating personal choice, but rather committing to changing prevailing cultural norms. The existing opt-in system marginalizes donation as the exception, when public health needs indicate that it must instead be the norm. The U.S. continues to suffer from a serious shortage of organ and tissue donors.<sup>9</sup> If presumed consent can improve procurement rates directly or indirectly, or can improve the process for donor families, it is worthy of serious consideration.

This article explores the potential positive effects of a presumed consent system. Part II discusses presumed consent from a public health perspective

---

cause family members have not been reached or have refused consent. *See generally* Leonard H. Bucklin, *Woe Unto Those Who Request Consent: Ethical and Legal Considerations in Rejecting a Deceased’s Anatomical Gift Because There is No Consent by the Survivors*, 78 N.D. L. REV. 323 (2002).

4. U.S. DEP’T HEALTH & HUMAN SERVS., HEALTH RES. & SERVS. ADMIN., 2012 NATIONAL SURVEY OF ORGAN DONATION ATTITUDES AND BEHAVIORS 1 (2013), available at <http://organdonor.gov/dtcp/nationalsurveyorgandonation.pdf>.

5. *E.g.*, Amber Rithalia et al., *Impact of Presumed Consent for Organ Donation on Donation Rates: A Systematic Review*, 338 BMJ 284, 285-87 (2009).

6. *E.g.*, David Orentlicher, *Presumed Consent to Organ Donation: Its Rise and Fall in the United States*, 61 RUTGERS L. REV. 295, 300-02 (2008).

7. *E.g.*, Kyle Powys Whyte et al., *Nudge, Nudge or Shove, Shove-The Right Way for Nudges to Increase the Supply of Donated Cadaver Organs*, 12 AM. J. BIOETHICS 32, 34 (2012); Joseph L. Verheijde et al., *Recovery of transplantable organs after cardiac or circulatory death: Transforming the paradigm for the ethics of organ donation*, 2 PHIL. ETHICS & HUMAN. MED. 8 (2007); Bucklin, *supra* note 3, at 348.

8. *See* Whyte et al., *supra* note 7, at 35.

9. Donate Life Am., *Understanding Donation*, <http://donatelife.net/understanding-donation/> (last visited May 22, 2014).

and addresses several common arguments against adopting presumed consent. Part III examines the possible impact of presumed consent on eye and tissue donation, including procurement rates and other aspects of the field. Part IV analyzes the positive effects presumed consent may have on donor families and resulting secondary effects on views of donation.

## II. PUBLIC HEALTH AND PRESUMED CONSENT

The current U.S. approach to donation is an opt-in system that relies on individuals registering as donors.<sup>10</sup> Under this regime, for individuals whose wishes are unknown at death, decision-making falls to next of kin.<sup>11</sup> Because actual consent is required, the default is non-consent.<sup>12</sup> Presumed consent reverses the process, requiring those individuals opposed to donation to register their objection, thus transforming the process by making donation the default rule rather than the exception. Presumed consent faces significant opposition on the basis of core bioethical principles.<sup>13</sup> Ultimately, however, presumed consent is less dramatically different from the existing system than initial appearances might suggest, and it may yield significant public health benefits.

The Uniform Anatomical Gift Act (UAGA), revised most recently in 2009 and adopted by the vast majority of states,<sup>14</sup> grants authority for persons to donate bodily tissue after death.<sup>15</sup> The UAGA and state implementing legislation<sup>16</sup> strongly emphasize donor autonomy. Persons may register consent to donate directly via a donor registry or may state their wishes in

---

10. The Uniform Anatomical Gift Act, which articulates an opt-in regime, has been adapted in forty-six states and the District of Columbia, and has been proposed in Pennsylvania in 2014. Nat'l Conference of Comm'rs on Unif. State Laws, *Anatomical Gift Act (2006)*, [http://www.uniformlaws.org/Act.aspx?title=Anatomical%20Gift%20Act%20\(2006\)](http://www.uniformlaws.org/Act.aspx?title=Anatomical%20Gift%20Act%20(2006)).

11. UNIF. ANATOMICAL GIFT ACT § 9 (amended 2009), 8A U.L.A. 49 (Supp. 2013).

12. See § 8, 8A U.L.A. 49.

13. See Presidential Comm'n for the Study of Bioethical Issues, *Informed Consent Background* (updated Sept. 6, 2013), <http://www.bioethics.gov/sites/default/files/Informed%20Consent%20Background%20090413.pdf> (discussing the importance of informed consent as an ethical principle in biomedical and other human subject research).

14. *Anatomical Gift Act (2006)*, *supra* note 10.

15. Some differences between organ, eye, and tissue donation (collectively "donation") are discussed *infra* Section III.

16. *E.g.*, ARIZ. REV. STAT. ANN. §§ 36-841-36-864 (West, WestlawNext through legislation effective April 30, 2014 of the Second Regular Session of the Fifty-first Legislature); CAL. HEALTH & SAFETY CODE §§ 7150-7151.40 (West, WestlawNext through Ch. 13 of 2014 Reg.Sess. and all propositions on the 6/3/2014 ballot.); FLA. STAT. ANN. §§ 765.510-765.547 (West, WestlawNext through 2014 2nd Reg. Sess. of the 23rd Legislature through March 31, 2014); MINN. STAT. ANN. §§ 525A.01-525A.25 (West, WestlawNext through 2014 Regular Session through Chapter 166, except Chapters 149, 152, 157, 161, and 164); TEX. HEALTH & SAFETY CODE ANN. §§ 692A.001-692A.023 (West, WestlawNext through the end of the 2013 Third Called Session of the 83rd Legislature).

various legal documents, such as advanced directives or wills.<sup>17</sup> In most jurisdictions, donors may register at their local motor vehicle division and have a designation placed on their driver's licenses.<sup>18</sup> If a decedent has neither registered nor explicitly objected to donation, consent decisions fall to next of kin.<sup>19</sup>

No monetary or other incentives are permitted in exchange for consent,<sup>20</sup> so consent is presently sought on the basis of altruism, commonly invoked as seeking the "gift of life."<sup>21</sup> This mild encouragement sometimes works surprisingly well. In some states, over eighty percent of adults are registered donors,<sup>22</sup> though the national average designating donor status is just forty-two percent.<sup>23</sup> In 2012, over forty percent of actual donors were registered, the rest becoming donors based on next of kin consent.<sup>24</sup> The consent rate from family members is generally less than sixty percent under the best of circumstances, and far lower when the process does not follow a collaborative process that brings together healthcare staff and procurement organizations.<sup>25</sup>

The underlying assumption of the opt-in consent approach is that those who do not consent during life or express such wishes to family members do not wish to be donors.<sup>26</sup> While there may be no formal presumption of objection under an opt-in system, there is an implicit barrier created in that

17. U.S. Dep't Health & Human Servs., Health Res. & Servs. Admin., *Becoming a Donor*, <http://organdonor.gov/becomingdonor/index.html> (last visited May 22, 2014).

18. *Id.*

19. UNIF. ANATOMICAL GIFT ACT § 9 (amended 2009), 8A U.L.A. 49 (Supp. 2013) (requiring the authority to consent on behalf of a decedent to follow an explicit order of priority with ten categories of persons. In order of priority: 1) legal agent of the decedent; 2) spouse; 3) adult children; 4) parents; 5) adult siblings; 6) adult grandchildren; 7) grandparents; 8) adults who exhibited special care and concern for the decedent; 9) persons acting as guardians; and 10) other persons authorized to dispose of the decedent's body).

20. *But see* Muireann Quigley et al., *Organ Donation and Priority Points in Israel: An Ethical Analysis*, 93 *TRANSPLANTATION* 970, 971 (2012) (contrasting with Israeli policy, granting registered donors priority to receive transplants if needed during life).

21. *E.g.*, N.Y. Organ Donor Network, *Take Action*, <http://www.donatelifeny.org/take-action/register-to-become-a-donor> (last visited May 22, 2014) ("Enrollment in the New York State Donate Life Registry . . . legally empowers you to save lives—no one can reverse your decision to give the gift of life when you add your name to the database.").

22. DONATE LIFE AM., *supra* note 2, at 6. In Montana, eighty-two percent of the adult population is registered as of 2013. *Id.*

23. *Id.* at 4.

24. *Id.* at 1 (noting forty-one percent of recovered organ donors, forty-six percent of recovered tissue donors, and fifty percent of recovered eye donors were registered).

25. Laura A. Siminoff et al., *Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation*, 280 *JAMA* 71, 72-73 (2001).

26. *But see* DAVID PRICE, *HUMAN TISSUE IN TRANSPLANTATION AND RESEARCH: A MODEL LEGAL AND ETHICAL FRAMEWORK* 134-35 (2010) (arguing that allowing family member consent after death indicates that there is in fact no presumption of objection on the part of the decedent).

a family member might reasonably think, “If my loved one wished to donate, she would have registered.”<sup>27</sup> In contrast, several other nations use an opt-out system, also known as “presumed consent” or “default to donation.”<sup>28</sup> In such systems, donation may occur unless the decedent or next of kin expressly object.<sup>29</sup> Under this model, the underlying assumption is thus reversed: those who do not explicitly *decline* or make such wishes known to family members do not *oppose* donation.<sup>30</sup> As discussed in Part IV, *infra*, presumed consent facilitates the opposite thought, “If my loved one did not wish to donate, she would have opted out.”<sup>31</sup>

In order to respect decedents’ wishes, a key provision of the 2006 UAGA provides that consent registered by the decedent is not revocable by next of kin unless the decedent expressly indicated a subsequent objection to donation.<sup>32</sup> This legally authorizes procurement from a registered donor without family approval.<sup>33</sup> In practice, however, procurement organizations almost always consult family members.<sup>34</sup> In a number of cases, the family either refuses to participate or explicitly denies consent.<sup>35</sup> While the procurement organization could legally proceed with the donation in such cases, they rarely do so out of respect for the family’s wishes and concern for public perception of donation. On occasion, donation does proceed, which often results in a legal and public relations quagmire.<sup>36</sup>

The existing system already presumes that willingness to donate outpac-

27. *See id.* at 135.

28. Amanda M. Rosenblum et al., *The Authority of Next-of-Kin in Explicit and Presumed Consent Organ Donation: An Analysis of 54 Nations*, 27 NEPHROLOGY DIALYSIS TRANSPLANTATION 2533, 2533 (2012).

29. *Id.* at 2541.

30. *See id.* at 2533.

31. *See* Orentlicher, *supra* note 6, at 300. Some U.S. states formerly used a form of limited presumed consent, such as for deaths under medical examiner jurisdiction, but generally now follow the opt-in approach of the 2006 UAGA. *Id.*

32. UNIF. ANATOMICAL GIFT ACT § 8(a) (amended 2009), 8A U.L.A. 49 (Supp. 2013) (“[I]n the absence of an express, contrary indication by the donor, a person other than the donor is barred from making, amending, or revoking an anatomical gift of a donor’s body or part if the donor made an anatomical gift of the donor’s body or part under Section 5 or an amendment to an anatomical gift of the donor’s body or part under Section 6.”). This language firmly protects the wishes of the decedent, even if contrary to those of family members, and is even stronger in this regard than prior language from the 1987 UAGA. *See* UNIF. ANATOMICAL GIFT ACT § 2(h) (1987), 8A U.L.A. 2 (Supp. 1988) (“An anatomical gift that is not revoked by the donor before death is irrevocable and does not require the consent or concurrence of any person after the donor’s death.”).

33. UNIF. ANATOMICAL GIFT ACT § 8(a) (amended 2009), 8A U.L.A. 49 (Supp. 2013).

34. *See* Rosenblum, *supra* note 28, at 2541.

35. Siminoff, *supra* note 25, at 71.

36. *See, e.g.*, Allison Manning, *Family Loses Fight to Keep Son’s Organ from Donation*, COLUMBUS DISPATCH (July 12, 2013, 9:05 AM), <http://www.dispatch.com/content/stories/local/2013/07/11/Judge-ordered-family-to-let-brain-dead-son-donate-organs.html>.

es donor registration.<sup>37</sup> Millions of Americans are registered, but less than half of procurements come from this group.<sup>38</sup> Health care, medical examiner, and funeral home staff routinely refer deaths to procurement organizations or approach family members for donation consent themselves.<sup>39</sup> Most hospitals are obligated to refer deaths and imminent deaths to procurement organizations.<sup>40</sup> Approaching family members when a decedent was unregistered recognizes that many still wished to be donors. By extension, it also assumes that those who objected would have expressed this; otherwise approaching the family would inappropriately circumvent the decedent's wishes. In this light, a presumed consent system is more similar from existing practices than may appear at first glance.

A "soft" presumed consent system, as used in a considerable majority of presumed consent countries, permits next of kin to override the presumption of consent even if the decedent did not register any objection.<sup>41</sup> In a "hard" presumed consent system, as used in countries like Belgium and Sweden, only the decedent's formal objection can override the presumption—family members have no legal authority to do so, even if they produce evidence that the decedent actually opposed donation.<sup>42</sup>

Soft presumed consent retains a significant role for donor families. This is more similar to the existing U.S. system and represents a better approach. Failures of previous presumed consent regimes in the U.S. appear to be the direct result of woefully inadequate communication with donor families, and such mistakes should not be repeated.<sup>43</sup> Appropriate and significant contact between procurement staff and families impacts how families view donation and is associated with higher consent rates under the existing system.<sup>44</sup> Such contact is equally important under a presumed consent system.

37. See DONATE LIFE AM., *supra* note 2, at 5-8 (indicating that in 2012 there was a forty-two percent Donor Designation Rate, yet seventy-six percent of adults willing to donate believe they are registered to be organ or tissue donors).

38. *Id.* at 1 (noting that registered donors account for forty-one percent of organ donors, forty-six percent of tissue donors, and fifty percent of eye donors).

39. Donate Life Am., *Tissue Donation*, <http://donatelife.net/understanding-donation/tissue-donation/> (last visited May 22, 2014).

40. 42 C.F.R. §§ 482.45, 485.643 (West, WestlawNext through May 15, 2014; 79 Fed. Reg. 27,771).

41. See Rosenblum, *supra* note 28, at 2542. Some notable adopters of soft presumed consent include: Armenia, Austria, Belarus, Chile, Colombia, Costa Rica, Croatia, Czech Republic, Ecuador, France, Italy, Luxembourg, Norway, Paraguay, Slovenia, Spain, Tunisia, and Turkey. *Id.*

42. *Id.*

43. See, e.g., Newman v. Sathyavaglswaran, 287 F.3d 786 (9th Cir. 2002) (concerning parents who brought suit following procurement of their child's corneas after death without notice to them); see also Orentlicher, *supra* note 6, at 305-08 (describing two cases involving absence of notice to family members of organ retrieval from deceased patients).

44. See Siminoff, *supra* note 25, at 76-77.

Presumed consent should not alter efforts to encourage individuals to join donor registries. An individual's stated wishes are preferable to presumption of any kind. Presumed consent addresses solely those whose wishes are not known. Personal reflection and family conversations owing to a policy change to presumed consent may even increase registry participation by emphasizing the importance of affirmatively stating one's preferences. When an individual explicitly consents or rejects donation, that decision should receive firm legal support.

Some question whether presumed consent plays too much into the inaccurate but long-standing public fears that medical professionals may provide lesser care to individuals in instances where organs could be recovered.<sup>45</sup> The transplantation community has worked for decades to counter such misperceptions.<sup>46</sup> Although such erroneous beliefs are difficult to purge, presumed consent could actually lessen, rather than exacerbate, these concerns. In fact, a larger pool of potential donors should provide less reason to worry about unethical actions based on organ scarcity.<sup>47</sup>

Many may object to presumed consent on the basis that it is inconsistent with general principles of informed consent in health care. The right of competent adults to refuse unwanted medical treatment is well-established.<sup>48</sup> However, a more apt analogy is the unconscious emergency room patient, who, like a decedent, cannot express their wishes. Such patients are usually treated aggressively, on the premise that most individuals would desire this if given the choice.<sup>49</sup> According to opinion data, donation is also the majority choice by a wide margin.<sup>50</sup> There are distinctions, of course, including emergency room care being intended to save or improve the patient's life; yet this, too, has a conceptual analogue in donation. Nothing more can be done for the donor, but donation can save and enhance the

---

45. E.g., Kieran Healy, *Why Revive Old Fears?*, N.Y. TIMES, May 2, 2010, [http://roomfordebate.blogs.nytimes.com/2010/05/02/should-laws-encourage-organ-donation/?\\_r=0](http://roomfordebate.blogs.nytimes.com/2010/05/02/should-laws-encourage-organ-donation/?_r=0). (arguing that advocating for presumed consent could raise fear among patients and their next of kin that quality of care will lessen in order to favor organ procurement).

46. See Gift of Life Donor Program, *Busting Myths About Organ Donation*, <http://www.donors1.org/learn2/myths/> (last visited May 22, 2014) (explaining that medical professionals prioritize saving a patient's life before any consideration of potential organ procurement).

47. See Orentlicher, *supra* note 6, at 322-24 (explaining arguments both for and against the proposition that more donors will alleviate potentially unethical action by physicians).

48. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 279 (1990) ("The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.").

49. John C. Moskop, *Information Disclosure and Consent: Patient Preferences and Provider Responsibilities*, 7 AM. J. BIOETHICS 47, 47 (2007).

50. Sara Krieger, *Incentivizing Organ Donation: A Proposal to End the Organ Shortage*, 38 HOFSTRA L. REV. 757, 759 (2009).



lives of organ and tissue recipients. Those who desire less aggressive or non-standard care in the emergency room—e.g., Jehovah’s Witnesses, persons with Do Not Resuscitate orders—generally have the burden to express these wishes.<sup>51</sup> Similarly, those who object to donation have every right to do so, but may reasonably be made responsible for recording their objections, rather than imposing decision-making on family members.

Individual autonomy is a core value of bioethics, and debates over proper protection of this interest in donation are extensive. Many scholars argue that presumed consent threatens autonomy, noting that it is a marked break from the informed consent generally required for medical procedures.<sup>52</sup> This is only one of the various ethical concerns raised by proposals for presumed consent for donation.<sup>53</sup> However, others persuasively argue that the existing opt-in system can equally violate autonomy by failing to procure organs and tissues from those who wish to donate but whose wishes were not known.<sup>54</sup> While these debates continue, it is critically important to en-

51. *Do not resuscitate orders*, MEDLINEPLUS (updated Apr. 7, 2014), <http://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000473.htm> (“If you DO want to receive CPR, you don’t have to do anything. If you do NOT want CPR, talk with your doctor about a DNR order.”); Douglas R. Migden & G. Richard Braen, *The Jehovah’s Witness Blood Refusal Card: Ethical and Medicolegal Considerations for Emergency Physicians*, 5 ACAD. EMERGENCY MED. 815, 815 (1998) (“It is general practice for adult Witnesses to carry on their person a wallet-sized advance directive card refusing blood.”); Nayna Philipson et al., *Surrogate Decision-Making: How to Promote Best Outcomes in Difficult Times*, 9 J. NURSE PRACTITIONERS 581, 583 (2013).

52. See, e.g., Maryellen Liddy, *The New “Body Snatchers”: Analyzing the Effect of Presumed Consent Organ Donation Laws on Privacy, Autonomy, and Liberty*, 28 FORDHAM URB. L.J. 815, 852 (2001) (arguing that presumed consent is not necessary due to adequate available alternatives); Alexander Powhida, *Forced Organ Donation: The Presumed Consent to Organ Donation Laws of the Various States and the United States Constitution*, 9 ALB. L.J. SCI. & TECH. 349, 353-54 (1999) (asserting that presumed consent laws in many states will likely be found unconstitutional under the Fourteenth Amendment’s Due Process Clause).

53. See, e.g., Orentlicher, *supra* note 6, at 317-20 (explaining the ethical differences between the risks of mistakenly taking an organ from an actually unwilling individual based on presumed consent compared to mistakenly not taking an organ from an actually willing person); Marie-Andrée Jacob, *Another Look at the Presumed-Versus-Informed Consent Dichotomy in Postmortem Organ Procurement*, 20 BIOETHICS 293, 297-98 (2006) (emphasizing the potential burden on vulnerable populations and arguing that default rules should run counter to the position of the stronger party in consent decisions, specifically against the government in the case of donation). In light of significant differences in consent rates across racial/ethnic lines, any change to a presumed consent structure must also include specific outreach to inform minority populations of changes to consent rules to avoid unduly burdening individual autonomy among individuals in these groups.

54. Orentlicher, *supra* note 6, at 313-16 (discussing the risks involved with presumed and actual consent for both patients that wanted to donate and those that did not). Instances of family members overriding the wishes of registered donors by refusing consent is a separate but important issue that is not addressed here. See generally Bucklin, *supra* note 3 (describing the legal and ethical implications resulting from allowing next of kin to block consent). There are a variety of other issues at stake, as well, including the impact of various

sure proper education and assistance to enable all individuals to make choices consistent with their wishes.

At the same time, organ and tissue donation is more than a health care issue: it is a public health issue. Favoring an outcome that benefits the public's health despite minimal intrusion on individual autonomy is consistent with established norms of public health ethics, provided that autonomy receives proper consideration and protection and there is no intentional harm to individual interests.<sup>55</sup>

Presumed consent does have an inescapable paternalistic character. Opting out carries no repercussions, but making consent the default choice is a nudge toward a specific course of action. Choosing not to donate may result in harm to others (e.g., those awaiting a transplant who may not receive one), arguably inviting the harm principle<sup>56</sup> as an ethical justification. However, this argument is unlikely to overcome the self-regarding nature of control of one's own body, even after death. As a result, a legitimate justification of presumed consent must embrace its paternalistic qualities, even if mild compared to other public health interventions.

Though deserving significant deference and protection, individual autonomy is not an inviolable principle. From a public health ethics standpoint, proper balancing of individual autonomy interests against public health goals permits at least some degree of non-coercive paternalism, even for wholly self-regarding behavior.<sup>57</sup> The encroachment on individual autonomy in presumed consent is minimal, and the public health need is great. There must be a default rule—either consent or non-consent. The government has the authority to choose the one that encourages behavior that is beneficial to public health. The current system, in some respects, *discourages* donation by making it the exception, rather than the rule.

The modern mantra of public health advocates has been “Making the Healthy Choice the Easy Choice.”<sup>58</sup> Public health policy can leverage default options for the benefit of individual and public good without unduly compromising free choice.<sup>59</sup> These policies can and should strive to make

---

systems on vulnerable populations. *E.g.*, Jacob, *supra* note 53 (discussing the pressure and risks of exploitation for vulnerable populations in donation consent).

55. See LAWRENCE O. GOSTIN, PUBLIC HEALTH LAW: POWER, DUTY, RESTRAINT 43 (2d ed. 2008).

56. See *id.* at 47-49 (explaining harm principle as an ethical basis for public health intervention).

57. See, e.g., James F. Childress et al., *Public Health Ethics: Mapping the Terrain*, 30 J.L. MED. & ETHICS 170, 171-72, 175-76 (2002).

58. *E.g.*, Harvard Sch. of Pub. Health, *Obesity Prevention Source: Making Healthy Choices Easy Choices*, <http://www.hsph.harvard.edu/obesity-prevention-source/policy-and-environmental-change> (last visited May 22, 2014).

59. See, e.g., RICHARD H. THAYER & CASS R. SUNSTEIN, NUDGE: IMPROVING DECISIONS ABOUT HEALTH, WEALTH, AND HAPPINESS 4-8 (2008).

the choices that positively impact health the default choices, particularly where they do not infringe on individual autonomy. More commonly, this approach applies to self-concerning behavioral choices with public health implications (e.g., diet).<sup>60</sup> However, the message can also apply to individual decisions that impact the health of others, as is true of organ and tissue donation.

Public health already takes this approach to some health care decisions that impact the health of others, such as childhood immunization.<sup>61</sup> Parents may forego vaccinating their children, but must take explicit action to do so because the legal default is immunization.<sup>62</sup> While all states permit exemption for medical reasons, and nearly all do so for religious beliefs, less than half allow exemption for reasons of conscience, generally.<sup>63</sup> Though such a mandate undoubtedly infringes on individual autonomy, the serious threat of communicable disease justifies the approach, and states have ample public health legal authority under their police powers.<sup>64</sup> A presumed consent donation system is a far lighter touch that is also justified by prevailing public health interests.

With respect to issues of autonomy and parental rights, it should be noted that presumed consent should not apply to minors. Minors lack legal capacity to make many medical decisions,<sup>65</sup> and their actual donation consent

60. *Obesity Prevention Source: Making Healthy Choices Easy Choices*, *supra* note 58.

61. James G. Hodge, Jr. & Lawrence O. Gostin, *School Vaccination Requirements: Historical, Social, and Legal Perspectives*, 90 KY. L.J. 831, 857-58 (2002) (“Despite the mandatory nature of compulsory school vaccination laws, the state’s power to require children to be vaccinated as a condition of school entrance has been widely accepted and judicially sanctioned.”). *See, e.g.*, N.Y. PUB. HEALTH LAW § 2164 (McKinney, WestlawNext through L.2014, chapters 1 to 22, 50 to 60).

62. *See, e.g.*, 25 TEX. ADMIN. CODE § 97.62 (West, WestlawNext through 39 Tex.Reg. No. 3512, dated April 25, 2014, as effective on or before April 29, 2014) (“To claim an exclusion for reasons of conscience, including a religious belief, a signed affidavit must be presented by the child’s parent or legal guardian, stating that the child’s parent or legal guardian declines vaccinations for reasons of conscience, including because of the person’s religious beliefs.”).

63. Nat’l Conference of State Legislatures, *States with Religious and Philosophical Exemptions from School Immunization Requirements* (Dec. 2012), <http://www.ncsl.org/research/health/school-immunization-exemption-state-laws.aspx>.

64. *See Jacobson v. Mass.*, 197 U.S. 11, 27 (1905) (finding that individual liberty interests do not outweigh the authority of states under their police powers to protect community health against epidemic disease through mandatory vaccination).

65. Rhonda Gay Hartman, *Adolescent Decisional Autonomy for Medical Care: Physician Perceptions and Practices*, 8 U. CHI. L. SCH. ROUNDTABLE 87, 91 (2001) (“Legal treatment of adolescent autonomy for medical decision making is based on a presumption of decisional incapacity.”). Minors have at least some authority to make decisions in certain medical matters, particularly related to testing and treatment for sexually transmitted diseases, but their consent authority is generally considered limited. *See* B. Jessie Hill, *Medical Decision Making By and On Behalf of Adolescents: Reconsidering First Principles*, 15 J. HEALTH CARE L. & POL’Y 37, 41-43 (2012). However, the legal landscape regarding minors’ medical decision-making capacity is a complicated one, and even the common assumption

would be ineffectual if contrary to parental wishes,<sup>66</sup> making presumed consent demonstrably inappropriate. Additionally, like other next of kin who may provide consent, parents may have limited due process and quasi-property rights regarding the bodies of their children.<sup>67</sup> Such rights would likely be stronger for parents than other next of kin.<sup>68</sup> The complexity of issues of autonomy regarding minors alters the balance of individual interests and public health benefit discussed above, necessitating a different approach that relies exclusively on parental consent. For adults, however, the public health benefits of presumed consent argue in favor of such an approach.

### III. PRESUMED CONSENT AND EYE AND TISSUE DONATION

Although they share many similarities, there are key differences between organ transplantation and eye and tissue transplantation. The U.S. Food and Drug Administration (FDA) regulates tissue transplantation, while the U.S. Department of Health and Human Services (HHS) Health Resources and Services Administration regulates organ transplantation.<sup>69</sup> Organs are in much shorter supply, owing largely to the specific circumstances required to facilitate procurement.<sup>70</sup> As a result, requirements and restrictions are sometimes more flexible. For example, many decedents who would not be medically suitable eye or tissue donors may be suitable organ donors.<sup>71</sup>

---

that minors generally lack legal capacity in this area is not unassailable, at least with respect to adolescents. *Id.*

66. UNIF. ANATOMICAL GIFT ACT § 8(g)-(h) (updated 2009), 8A U.L.A. 49 (Supp. 2013).

67. See *Newman v. Sathyavaglswaran*, 287 F.3d 786 (9th Cir. 2002) (finding due process right in control of child's corneas after death); *but see* *Ga. Lions Eye Bank, Inc. v. Lavant*, 335 S.E.2d 127 (Ga. 1985) (finding no constitutionally protected rights in a decedent's body that would invalidate a system that failed to provide notice prior to procurement of child's corneas and noting that any quasi-property rights must bow to the state's public health authority where exercised reasonably, impartially, and not inconsistently with general state policy); see also *Brendan Abel, Physician Assisted Homicide in Organ Donations After Cardiac Death: The Failure of Biotechnologies to Comply with the Uniform Definition of Death Act and the Dead Donor Rule*, 7 J. HEALTH & BIOMEDICAL L. 573, 582-83 (2012) (discussing conflicting judicial treatment of presumed consent under older presumed consent frameworks). Of note, even if there are property rights in a decedent's organs and tissues, it is a long-established power of the state to determine how property rights are distributed in the absence of the known wishes of the decedent. See, e.g., RESTATEMENT (THIRD) OF PROP. § 2.1 (1999) (discussing general principles of intestacy).

68. See, e.g., *Pierce v. Soc'y of the Sisters*, 268 U.S. 510 (1925) (establishing substantive due process right of parents to control upbringing and education of children).

69. U.S. Food & Drug Admin., *Tissue and Tissue Product Questions and Answers* (updated Oct., 14, 2009), <http://www.fda.gov/BiologicsBloodVaccines/TissueTissueProducts/QuestionsaboutTissues/ucm101559.htm>.

70. Ellen Sheehy et al., *Estimating the Number of Potential Organ Donors in the United States*, 349 NEW ENG. J. MED. 667, 671 (2003).

71. Even HIV-positive donors may be acceptable for organ procurement, at least for

While not as immediately impactful in the life-saving sense, eye and tissue transplantation is nonetheless of enormous importance. In 2012, there were over 46,000 corneal transplants and over 1 million tissue transplants performed in the U.S.<sup>72</sup>

Statistical evidence is mixed regarding whether presumed consent will significantly increase organ donation rates compared to opt-in approaches.<sup>73</sup> However, the impact on eye and tissue donation rates is less studied, and there is reason to suspect the impact could be more substantial. Generally, the percentage of viable organ donors recovered is quite high. A number of factors explain this. Most people are familiar with organ donation and have generally positive opinions of the transplantation system.<sup>74</sup> Medical facilities routinely refer potential organ donors to procurement organizations and are usually required to do so.<sup>75</sup> When suitable donors progress to brain death, organ procurement teams take charge of case management, ensuring that viability is maintained while arrangements for transplantation into a waiting recipient are made.<sup>76</sup>

Eye and tissue donation are simpler than organ donation in the practical sense. Procurement can proceed up to twenty-four hours after death.<sup>77</sup> Corneas are preserved and refrigerated, and they can be transplanted several

---

transplantation in HIV-positive recipients. *See, e.g.*, Sara Reardon, *United States to Allow Transplants of HIV-Infected Organs*, NATURE (Nov. 13, 2013).

72. Donate Life Am., *Statistics*, <http://donatelife.net/understanding-donation/statistics/> (last visited May 22, 2014).

73. *Compare* Rithalia, *supra* note 5 (citing donation rate increases as high as thirty percent after introduction of presumed consent), with Brian J. Boyarsky et al., *Potential Limitations of Presumed Consent Legislation*, 93 TRANSPLANTATION 136 (2012) (discussing confounding factors that show presumed consent not functionally increasing donation rates).

74. Felix Cantarovich, *An International Opinion Poll of Well-Educated People Regarding Awareness and Feelings About Organ Donation for Transplantation*, 20 TRANSPLANT INT'L 512 (2007); *Statistics*, *supra* note 72; Sara K. Kahan, Note, *Incentivizing Organ Donation: A Proposal to End the Organ Shortage*, 38 HOFSTRA L. REV. 757, 759 (2009) (citing THE GALLUP ORG., 2005 NAT'L SURVEY OF ORGAN & TISSUE DONATION ATTITUDES & BEHAVIORS 5, 9 (2005)).

75. 42 C.F.R. §§ 482.45, 485.643 (West, WestlawNext through May 15, 2014; 79 Fed. Reg. 27,771).

76. Ass'n of Organ Procurement Orgs., *An Organ Procurement Organization's Role in the Organ Recovery Process*, [http://www.aopo.org/userfiles/Donation\\_Process.pdf](http://www.aopo.org/userfiles/Donation_Process.pdf) (last visited May 22, 2014).

77. Am. Ass'n of Tissue Banks, *Printable Update for Insertion Into Standards D5 400* (Mar. 18, 2010), <http://www.aatb.org/index.asp?bid=43> (permitting procurement up to twenty-four hours after asystole if body is adequately cooled within twelve hours after asystole); EYE BANK ASS'N OF AM., MEDICAL STANDARDS § D1.600 (2011), available at <http://www.restoreight.org/wp-content/uploads/2011/11/Medical-Standards-October-2011.pdf> (allowing variable acceptable time intervals between death and procurement, but recommending procurement as soon as possible after death); *see also* *Cornea Donation*, Donate Life Am., *Cornea Donation*, <http://donatelife.net/understanding-donation/cornea-donation/> (last visited May 22, 2014) ("Cornea donation usually happens within 12 hours of death.").

days after removal.<sup>78</sup> Tissues can be frozen and held even longer before transplantation.<sup>79</sup> And yet, the percentage of viable eye and tissue donors recovered is far lower compared to organ donors. While nationally nearly seventy-three percent of eligible organ donors are recovered, this drops to less than thirty-two percent for cornea donors.<sup>80</sup> Fewer people are familiar with eye and tissue donation, and may not realize they or their family members could be donors.<sup>81</sup> The need for corneal tissue was among the primary motivations for early U.S. presumed consent statutes.<sup>82</sup> Though these systems had significant flaws (most dramatically the lack of family notification and consultation), they were highly effective in increasing the supply of corneas for transplant.<sup>83</sup>

Practical concerns may limit the direct impact of presumed consent on eye and tissue procurement. In addition to ethical issues discussed above, staffing and other resource limitations may militate in favor of not pursuing procurement before families have been contacted to provide complete medical and social history, even if procurement might be legally permissible based on presumed consent. As observed by Professor Orentlicher, among others, the Eye Bank Association of America did not oppose eliminating presumed consent in the 2006 revisions to the UAGA, at least in part because medical and social history requirements negated much of the functionality of presumed consent statutes as they existed at that time.<sup>84</sup>

Unlike organ procurement, where the procurement team operates in an environment they control after the process begins, eye and tissue procurement is much more varied and unpredictable. Staff must obtain medical records from all relevant institutions and other entities involved in care leading up to death. This may include physicians' offices and hospitals, as well as other entities, such as first responders (e.g., police and fire departments). The records are necessary to establish information required to determine transplant, including time of death and medications and fluids administered.<sup>85</sup> Such records may be transferred to procurement organizations

---

78. *Cornea Donation*, *supra* note 77.

79. *Tissue Donation*, *supra* note 39.

80. United Network for Organ Sharing, *Reported Eligible Deaths and Recovered Deceased Donors 2008-2013* (Mar. 7, 2014), <http://www.aopo.org/userfiles/file/DonationData/Reported%20Eligible%20Deaths%20and%20Recovered%20Deceased%20Donors%202008-December%202013.xlsx> (reporting 6487 total recoveries among 8936 eligible deaths for 2012); EYE BANK ASS'N OF AM., 2012 EYE BANKING STATISTICAL REPORT 14 (2013), available at [http://www.restore sight.org/wp-content/uploads/2013/04/2012\\_Statistical\\_Report\\_FINAL-reduced-size-4-10.pdf](http://www.restore sight.org/wp-content/uploads/2013/04/2012_Statistical_Report_FINAL-reduced-size-4-10.pdf).

81. *Statistics*, *supra* note 72 ("According to research, ninety-eight percent of all adults have heard about organ donation and eighty-six percent have heard of tissue donation.").

82. Orentlicher, *supra* note 6, at 302-03.

83. *Id.* at 302-05.

84. *Id.* at 307.

85. Among other elements, a full accounting of medications and fluids is required to

under a specific exception to the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule.<sup>86</sup> While entities that commonly exchange patient records are usually familiar with the applicable rule, others that do not regularly transfer records or interact with procurement organizations sometimes resist releasing records, potentially endangering the viability of procured tissue, particularly corneas, which remain viable for only a matter of days.<sup>87</sup>

In some respects, presumed consent might be more appropriate for eye and tissue donation than for organ donation. As noted above, one of the primary objections to presumed consent is the persistent—albeit factually inaccurate—fear of unethical reduction in care for registered donors in the interest of “harvesting” their organs.<sup>88</sup> For eye and tissue transplantation, such concerns should never attach. Organ donors are brain dead—a concept that still suffers from widespread misunderstanding<sup>89</sup>—but generally have artificially-maintained heart and lung function, and procurement most often takes place within the hospital where the patient has just received medical treatment. Confusion and concern conflating donation and treatment are mistaken, but conceptually understandable. Eye and tissue donors, however, have no cardiopulmonary function. No additional medical care is possible. Procurement usually takes place hours after death, often at a separate facility, medical examiner’s office, or even funeral home. Based on these distinctions, it might be preferable in theory to separate the consent process for each type of donation, adopting presumed consent for eye and tissue donation, but maintaining actual consent for organ donation. In practice, however, this might lend unwarranted credibility to persistent fears about organ donation practices and unintentionally decrease organ donation consent rates. Moreover, although rare, abuse in the eye and tissue transplant field is not unheard of.<sup>90</sup> As such, a consistent system across all forms of donation is the better approach absent future evidence to the contrary.

---

determine whether a donor’s blood has been too diluted to ensure viability of disease testing (“hemodilution”). U.S. FOOD & DRUG ADMIN., GUIDANCE FOR INDUSTRY: ELIGIBILITY DETERMINATION FOR DONORS OF HUMAN CELLS, TISSUES, AND CELLULAR AND TISSUE-BASED PRODUCTS (HCT/PS) § (V)(F)-(G) (2007), available at <http://www.fda.gov/downloads/BiologicsBloodVaccines/GuidanceComplianceRegulatoryInformation/Guidances/Tissue/ucm091345.pdf>.

86. 45 C.F.R. § 164.512(h) (West, WestlawNext through May 15, 2014; 79 Fed. Reg. 27,771).

87. Based on authors’ own recollection and experience.

88. Healy, *supra* note 45.

89. See Lawrence O. Gostin, *Legal and Ethical Responsibilities Following Brain Death: The McMath and Muñoz Cases*, 311 JAMA 903 (2014); Editorial, *Jahi McMath: Expert Criticizes Keeping Girl on Ventilator*, L.A. TIMES, Jan. 13, 2014, <http://articles.latimes.com/2014/jan/13/local/la-me-ln-jahi-mcmath-ventilator-20140113>.

90. See Michael Powell & David Segal, *In New York, a Grisly Traffic in Body Parts Illegal Sales Worry Dead’s Kin, Tissue Recipients*, WASH. POST, Jan. 28, 2006, at A03.

## IV. PRESUMED CONSENT AND DONOR FAMILIES

Many of the best candidates for donation die unexpectedly. Sudden trauma (e.g., motor vehicle accident or gunshot) or swift disease processes (e.g., heart attack or stroke) are common causes of death among donors.<sup>91</sup> Even registered donors do not always discuss their decision with family members. As a result, most decedents' families are in an exceedingly difficult position when approached regarding donation. In the wake of losing a close family member, they must make decisions about what the decedent would have wanted, often with little or no guidance or indication of her wishes. Family members are understandably prone to applying their own values to the question, rather than the decedent's.<sup>92</sup> The concept and details of donation are complex and better understood through personal reflection, rather than a time-sensitive decision thrust upon grieving relatives. Such circumstances may put family members at odds with procurement organizations, as well as other family members. There is an explicit hierarchy of family members who may provide consent for donation,<sup>93</sup> but if family members hold conflicting beliefs, what begins as a discussion about an altruistic "gift of life" can instead produce additional strain for an already bereaved family.

Presumed consent absolves decedents' families of many concerns inherent to the current opt-in system. A family can be more confident in their decision to proceed with donation, knowing they are not making a decision their loved one strongly opposed. Donation registration efforts would continue, and donation advocates would still encourage registered donors to discuss their wishes with family members. The key change in presumed consent is viewing those who say nothing as having no objection to donation. This allows inclusion of those who support donation but fail to express those beliefs directly, while respecting the autonomy of those opposed by providing a simple and effective means to opt out.

Presumed consent removes the current need for family members to provide consent and shifts the burden from the family to the decedent, who ultimately has the greatest interest in her own body.<sup>94</sup> This is consistent with a

---

91. U.S. Dep't of Health & Human Servs., Health Res. & Servs. Admin., *Organ Donation: The Process*, <http://www.organdonor.gov/about/organdonationprocess.html#process1> (last visited May 22, 2014) ("Most donors are victims of severe head trauma, a brain aneurysm or stroke.").

92. Paula Boddington, *Organ Donation After Death—Should I Decide, or Should My Family?*, 15 J. APPLIED PHIL. 69, 76 (1998); Orentlicher, *supra* note 6, at 311-12.

93. See *supra* note 11, at § 9a(1)-(10).

94. One could argue that this interest terminates at death, but existing legal and ethical norms generally acknowledge an autonomous interest in bodily integrity that also encompasses treatment of one's body and remains after death. *Contra* Tillman v. Detroit Receiving Hosp., 360 N.W.2d 275, 277 (Mich. App. 1984) (holding that constitutional privacy rights terminate at death and cannot be invoked by decedents' families or estates in relation to pre-



bioethical focus on personal autonomy.<sup>95</sup> With an appropriate and extensive public education campaign, potential donors will have the opportunity to become informed about the new process, allowing them to make an informed decision about opting out if they so choose. The current system places the information burden on families, who are inundated with information about donation almost immediately after a family member's death—an unnecessary and unwelcome stress. Those opposed to donation currently have limited incentive to express their position because non-consent is the default. Under a presumed consent approach, the family of a decedent who did not opt out could be confident that she generally supported donation, or at least was not strongly opposed to it. Under the existing approach, families may be hesitant to consent, particularly when family members disagree, for fear that donation would violate the decedent's wishes.

For consent to legitimately follow from silence, all affected individuals must be properly advised of their right and opportunity to object, as well as the necessity of recording such objection. The essential educational campaign may itself produce positive impacts on donation. As individuals and families discuss the impact of the new system, they may be more likely to carefully consider their own views and to make their wishes known. This may increase donation rates, as more discussion within families regarding donation is associated with higher likelihood of donation.<sup>96</sup> Such benefits may also be derived from a mandated choice system,<sup>97</sup> but presumed consent has the benefit of clearly proclaiming that donation is publicly supported, socially beneficial, and the normal course of action absent specific, personal objection.

The existing opt-in system also suffers from a lack of uniformity. Although the legal structure across jurisdictions is consistent,<sup>98</sup> the family approach methodology used by various procurement organizations, in-house coordinators, and hospital staff is not.<sup>99</sup> Different approaches beget different consent rates, indicating that the opt-in system does not apply equally to all decedents and their families. For example, health care practitioners who ask

---

sumed consent donation of corneas). Family members may also claim limited quasi-property or due process rights in decedents' bodies that poorly constructed presumed consent systems potentially violate. *See Brotherton v. Cleveland*, 923 F.2d 477 (6th Cir. 1991) (finding a due process violation in the removal of decedents' corneas despite widow's stated objection, where coroner's policy was not to review records for evidence of objection before permitting procurement).

95. GOSTIN, *supra* note 55, at 48.

96. Siminoff, *supra* note 25.

97. THALER & SUNSTEIN, *supra* note 59, at 180-82; Aaron Spital, *Mandated Choice*, 273 JAMA 504 (1995).

98. Nationally, forty-six states and the District of Columbia have enacted some form of the 2006 UAGA. *See supra*, note 10.

99. Siminoff, *supra* note at 25.

about organ donation apologetically or say that they are legally required to do so receive far more refusals than procurement organization staff specifically trained in how to approach a family member.<sup>100</sup> The more tactful and successful approach includes providing more information to the family and spending more time with the family discussing the issues.<sup>101</sup>

Many families learn about organ donation for the first time during the approach for consent. The more surprised a family is about donation when approached, the more likely they are to refuse.<sup>102</sup> The public education campaign necessary to implement presumed consent would provide information sooner,<sup>103</sup> rather than surprising families with complex details during a particularly difficult time. This begins the process of fostering a culture that views donation as the norm, rather than the exception implied by an opt-in system. Eventually, the decisional inertia that presently works against donation should abate as donation becomes the more conservative and commonplace decision.<sup>104</sup> This will further relieve the burden on family members, and may also increase the supply of donor organs and tissues.<sup>105</sup>

The support provided to families would also change in a presumed consent system. Procurement organization staff are well-trained in how to discuss donation with family members and provide appropriate support during and after the donation process.<sup>106</sup> Many health care staff are, as well. But, generally speaking, staff involved in the consent process are not social workers, counselors, or mental health professionals,<sup>107</sup> although procurement organizations do frequently provide families with referrals to such professionals.<sup>108</sup> This is indicative of the proper role for procurement organization staff as facilitators of all aspects of donation, from consent to procurement to family support. For registered donors, this process works well.

100. *Id.*

101. *Id.* The procurement organization approach results in more donations even when controlling for factors such as initial family reaction. *Id.*

102. *Id.* at 74.

103. *Organ Donation: Presumed Consent to Start in December 2015*, BBC NEWS (Sept. 10, 2013, 10:05 AM), <http://www.bbc.co.uk/news/uk-wales-24032031> (“[P]eople will be given plenty of information on how the new system works and what their choices are.”).

104. See William Samuelson & Richard Zeckhauser, *Status Quo Bias in Decision Making*, 1 J. RISK & UNCERTAINTY 7 (1988) (asserting that individuals will generally stick with the status quo when faced with important decisions).

105. See Rosemary A. Robbins, *Signing an Organ Donor Card: Psychological Factors*, 14 DEATH STUD. 219, 226 (1990) (asserting that psychological stress and physical anxiety are notably correlated with an unwillingness to donate organs).

106. Liva Jacoby & James Jaccard, *Perceived Support Among Families Deciding About Organ Donation for Their Loved Ones: Donor vs. Nondonor Next of Kin*, 19 AM. J. CRITICAL CARE e52, e53 (2010).

107. *Id.*

108. E.g., LifeNet Health, *How Does the Process Work?*, [http://lifenethealthpo.org/all\\_about\\_donation/how\\_does\\_the\\_process\\_work](http://lifenethealthpo.org/all_about_donation/how_does_the_process_work) (last visited May 22, 2014) (outlining donor family support up to eighteen months after donation).

Staff are able to approach families in a role of providing information and facilitating the donation process, bringing family members into a positive discussion about fulfilling the decedent's wishes.<sup>109</sup>

Where the potential donor is not registered, the consent approach can take on an unpleasant veneer of salesmanship. Though procurement organization staff are well-trained to avoid such appearances, health care staff may not always receive the same training.<sup>110</sup> Regardless of the care and tact of the approach, families may nonetheless feel that staff are "selling" donation. This may color families' views and negatively affect their relationship with the procurement organization. An opposite problem may also arise when approaches are overly cautious and tacit in solicitation of consent, leading family members to hesitate when uncertain of a decedent's wishes because donation appears to be the disfavored choice.<sup>111</sup> Presumed consent would allow staff to discuss donation from the position of facilitator—rather than salesperson or supplicant—more akin to the approach taken for registered donors. Although even that relationship is imperfect, as evidenced by existing family vetoes,<sup>112</sup> it remains generally positive and should improve further if presumed consent succeeds in altering the cultural view of donation. Presumed consent would allow procurement organization staff to do what they do best: offer attentive care and relevant information to families, assess the medical potential for donation, and facilitate the donation process.

Commenters rightly point to family objection as a primary obstacle to improving donation rates, and they argue that presumed consent does little in and of itself to resolve the issue.<sup>113</sup> While the impact of presumed consent may not be immediate, it may ultimately be profound. Beyond direct gains in procurement of suitable donors through an expanded consent pool, presumed consent offers further gains through the secondary effects of changing cultural views and norms regarding donation. Current discussion and promotion of organ and tissue donation focus on "The Gift of Life," and emphasize the altruistic nature of consent. This is laudable, accurate, and entirely appropriate given the current consent structure. A change in this paradigm from "gift" toward "duty" or at least "moral obligation" would be even better. Presumed consent may not succeed in shifting the conversation quite that far, but even a change in what is considered "normal" would pay significant dividends from a public health perspective and

---

109. Siminoff, *supra* note 25, at 74.

110. Jacoby & Jaccard, *supra* note 106, at 59.

111. See T. Elizabeth Weathersbee & Douglas W. Maynard, *Dialing for donations: practices and actions in the telephone solicitation of human tissues*, 31 SOC. HEALTH & ILLNESS 803, 812-13 (2009).

112. Siminoff, *supra* note 25, at 74-75.

113. Orentlicher, *supra* note 6, at 297.

could serve to change the views of many families in the future.<sup>114</sup> Families making donation decisions in the absence of a clear expression of the decedent's wishes are understandably prone to cautious and conservative decision-making. This creates a decisional inertia that amplifies the effect of the existing rule and limits donation.<sup>115</sup> Changing the default rule shifts the balance by making donation, rather than non-donation, the conservative choice. This should also reduce the incidence of families overriding a decedent's clear desire to donate, which has historically been a significant problem.<sup>116</sup>

#### V. CONCLUSION

The existing opt-in approach to organ and tissue donation in the U.S. is largely functional, but flawed. The system as it stands leaves too many recipients on waiting lists. It fails to recover tissue from too many willing donors who do not adequately express their preferences. And it unnecessarily burdens donor families. Transitioning to presumed consent will not correct all of these shortcomings instantaneously, and it will not solve them by itself. But by leveraging the power of default legal rules to change the choice to donate from the exception to the norm, presumed consent has the potential to change the way Americans think about donation—a key first step in improving donation rates for all types of tissue and easing the process for donor families. Opt-in and opt-out systems both hinge on choice, but the latter offers numerous public health benefits. The time has come to flip the switch to “On” for donation.

---

114. See Eric J. Johnson & Daniel G. Goldstein, *Defaults and Donation Decisions*, 78 *TRANSPLANTATION* 1713, 1714-15 (2004) (presenting data that questions phrasing that reflects presumed consent was associated with increased willingness to be a donor and comparing donation rates between opt-in and opt-out countries).

115. Whyte et al., *supra* note 7, at 34.

116. Orentlicher, *supra* note 6, at 312; Bucklin, *supra* note 3.