

2012

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Hayley Cotter

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Recommended Citation

Hayley Cotter, *Increasing Consent for Organ Donation: Mandated Choice, Individual Autonomy, and Informed Consent*, 21 Health Matrix 599 (2011)

Available at: <https://scholarlycommons.law.case.edu/healthmatrix/vol21/iss2/8>

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INCREASING CONSENT FOR ORGAN DONATION: MANDATED CHOICE, INDIVIDUAL AUTONOMY, AND INFORMED CONSENT

Hayley Cotter[†]

INTRODUCTION

As of April 13, 2011, there were 110,758 individuals on the waiting list for an organ transplant in the United States.¹ The number of waiting list candidates greatly exceeds the number of available organs, and the gap between needed and available organs grows wider every year.² While the need for organs is growing five times faster than the number of available organs, rates of organ donation have remained stable.³ In fact, individuals whose organs are suitable for donation at their time of death may outnumber actual donors by more than three to one.⁴ As a result, many individuals on the waiting list die before they receive an organ; indeed, as many as sixty percent of candidates

[†] J.D. Candidate, Case Western Reserve University School of Law, 2011; B.A., Boston University, 2008. I would like to thank Professor Sharona Hoffman for her guidance throughout the writing process. I also would like to thank Nick Pompeo for his patience and sense of humor through many hours of editing, and my family for their love and constant support.

¹ UNITED NETWORK FOR ORGAN SHARING, <http://www.unos.org/> (last visited Mar. 10, 2011).

² Tom Farsides, *Winning Hearts and Minds: Using Psychology to Promote Voluntary Organ Donation*, 8 HEALTH CARE ANALYSIS 101, 102 (2000); Sheldon F. Kurtz & Michael J. Saks, *The Transplant Paradox: Overwhelming Public Support for Organ Donation vs. Under-Supply of Organs: The Iowa Organ Procurement Study*, 21 J. CORP. L. 767, 768 (1996).

³ A PRIMER FOR HEALTH CARE ETHICS: ESSAYS FOR A PLURALISTIC SOCIETY 163 (Kevin O'Rourke ed., 2d ed. 2000) [hereinafter A PRIMER FOR HEALTH CARE ETHICS]; Joseph L. Verheijde et al., *Recovery of Transplantable Organs After Cardiac or Circulatory Death: Transforming the Paradigm for the Ethics of Organ Donation*, PHIL. ETHICS & HUMAN. MED. (2007), <http://www.peh-med.com/content/pdf/1747-5341-2-8.pdf>. The waiting list is growing at a rate of twelve percent per year. RICHARD H. THALER & CASS R. SUNSTEIN, NUDGE: IMPROVING DECISIONS ABOUT HEALTH, WEALTH, AND HAPPINESS 177 (rev. and expanded ed., 2009).

⁴ Susan E. Herz, *Two Steps to Three Choices: A New Approach to Mandated Choice*, 8 CAMBRIDGE Q. HEALTHCARE ETHICS 340, 340 (1999).

die while on the waitlist.⁵ While multiple studies indicate overwhelming public support for organ donation, only ten to twenty percent of individuals who die with organs suitable for donation ultimately become actual donors.⁶ Most states in the U.S. currently utilize an “opt-in” system for organ donation, by which an individual or an individual’s family must explicitly consent before donation.⁷ Some countries utilize a presumed consent system by which individuals are assumed to be donors unless they have expressly stated otherwise.⁸ Although the current opt-in system has resulted in an organ shortage and extended waiting lists in the United States, a presumed consent system raises concerns about individual autonomy and informed consent and is politically unfeasible in the United States at present.

The failure of individuals to prospectively communicate their intent to donate organs and the failure of families to consent to donate the deceased individual’s organs are seen as major causes of the organ shortage in the United States.⁹ Increasing rates of consent in the United States is particularly complicated because the “distinct culture of pluralism, individualism, and self-determination” makes it more difficult to enact any method of increasing donations that could be seen as coercive.¹⁰ One proposal to increase rates of consent among potential donors is known as mandated choice, a system in which individuals are prospectively required to register their intention to donate or not to donate their organs when they die.¹¹ These registered choices are le-

⁵ THALER & SUNSTEIN, *supra* note 3.

⁶ Farsides, *supra* note 2, at 103; Kurtz & Saks, *supra* note 2; see Ronald M. Davis, *Meeting the Demand for Donor Organs in the US*, 319 BRIT. MED. J. 1382, 1382 (1999) (reporting that “a 1993 Gallup survey showed that 63% of respondents said they would sign up to donate under mandated choice.”); Aaron Spital, *Mandated Choice: A Plan to Increase Public Commitment to Organ Donation*, 273 JAMA 504, 504-06 (1995).

⁷ INST. OF MED., ORGAN DONATION: OPPORTUNITIES FOR ACTION 22 (James F. Childress & Cathryn T. Liverman eds., 2006) available at http://www.nap.edu/openbook.php?record_id=11643.

⁸ *Id.* at 28. Austria, Belgium, France, Finland, Greece, Italy, Norway, Portugal, Singapore, Spain and Sweden have enacted presumed consent legislation. Aaron Spital, *Obtaining Consent for Organ Donation: What Are Our Options?*, 13 BALLIÈRE’S CLINICAL ANESTHESIOLOGY 179, 185 (1999).

⁹ MICHAEL S. GOLDRICH, REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, REP. NO. 7-A-05, PRESUMED CONSENT FOR ORGAN DONATION 1 (2005), available at http://www.ama-assn.org/ama1/pub/upload/mm/369/ceja_7a05.pdf; Ellen Sheehy et al., *Estimating the Number of Potential Organ Donors in the United States*, 349 NEW ENG. J. MED. 667, 671 (2003) (reporting a study found that consent for donation was not obtained in 39% of cases among identified potential donors from thirty-six organ procurement organizations).

¹⁰ GOLDRICH, *supra* note 9, at 2.

¹¹ INST. OF MED., *supra* note 7, at 177.

gally binding upon the individual's death. Mandated choice differs from the current system of organ donation in which many individuals die without expressing a legally enforceable decision regarding organ donation.¹² Mandated choice has the potential to increase the organ supply while maintaining individual autonomy and preserving informed consent.

This Note analyzes mandated choice as a method of alleviating the organ shortage in the United States. Part I provides background information on organ donation and analyzes mandated choice as a potential solution to the growing organ shortage. Part II explores some of the criticisms of mandated choice, including issues of individual autonomy and informed consent. This section also discusses practical obstacles to the enactment of a mandated choice system, including cost, complexity, and legal liability. Finally, Part III of this Note argues that mandated choice is the best option for increasing organ donation in the United States. However, further research must confirm the effectiveness of mandated choice on a wider scale, and safeguards such as public education must be implemented to ensure that individuals' decisions regarding donation are fully informed and legally binding.

I. THE ORGAN SHORTAGE AND MANDATED CHOICE: BACKGROUND

A. Current Status of the Organ Donation Process in the United States

There is a chronic shortage of donated organs in the United States today.¹³ While many people die while on the transplant waitlist every year, the problem stems, not from a lack of transplantable organs, but from the failure of many suitable organs to make their way into the "supply stream."¹⁴ Ideal organ donors are typically young, relatively healthy people who have suffered an injury or accident,¹⁵ resulting in death according to neurologic criteria.¹⁶ Certain medical conditions, such as an actively spreading cancer or severe infection, can preclude

¹² *Id.*

¹³ Herz, *supra* note 4, at 340.

¹⁴ *Id.*

¹⁵ See Spital, *supra* note 8, at 182.

¹⁶ INST. OF MED., *supra* note 7, at 6. "Longer than 10 minutes of absent circulation is required for irreversible cessation of the entire human brain, including brain stem function." Verheijde et al., *supra* note 3.

a person from becoming an organ donor, but donor suitability is assessed on a case-by-case basis.¹⁷

The Uniform Anatomical Gift Act (UAGA) created the legal power for individuals to donate organs and tissue in the United States.¹⁸ This model legislation, drafted by the National Conference of Commissioners on Uniform State Laws, was adopted by all jurisdictions in 1968.¹⁹ The UAGA is periodically revised, and in 2006 the Act was amended to increase personal autonomy in organ donation.²⁰ Forty-five jurisdictions have adopted the 2006 UAGA, and the amended Act was introduced into the legislatures of three additional states in 2011.²¹ As previously stated, the United States utilizes an “opt-in” system of organ donation in which an individual gives explicit consent, prior to death, to donate his or her organs, or a decedent’s family explicitly consents to organ procurement after death has occurred.²² The UAGA states that no one can override the deceased’s previously expressed wishes regarding organ donation; however, most organ procurement organizations continue to seek family consent before proceeding with organ harvesting.²³ If the family opposes the organ donation, most organ procurement organizations will honor the family’s wishes, despite contrary language in the UAGA.²⁴ This approach is problematic, however, as one study showed that 82% of participants believed that first-person consent (deferring to the wishes of the decedent) was preferable to leaving the decision to surviving

¹⁷ UNIF. ANATOMICAL GIFT ACT § 14(c) (amended 2006), 8A U.L.A. 76 (Supp. 2010); UNITED NETWORK FOR ORGAN SHARING: ORGAN DONATION AND TRANSPLANTATION (Jan. 31, 2011), www.transplantliving.org/beforethetransplant/qa.aspx.

¹⁸ Spital, *supra* note 8, at 181; *UAGA PowerPoint Presentation*, THE NAT’L CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS, <http://www.uniformlaws.org/Shared/Docs/UAGA/UAGA%20PowerPoint%20Presentation.pptx> (last accessed Apr. 13, 2011).

¹⁹ *UAGA PowerPoint Presentation*, *supra* note 18. .

²⁰ *Id.*

²¹ *Legislative Fact Sheet—Anatomical Gift Act (2006)*, THE NAT’L CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS, <http://uniformlaws.org/LegislativeFactSheet.aspx?title=Anatomical%20Gift%20Act%20%282006%29> (last accessed Apr. 13, 2011). For access to each jurisdiction’s statute, see *Anatomical Gift Act (2006)*, THE NAT’L CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS, <http://www.nccusl.org/Act.aspx?title=Anatomical%20Gift%20Act%20%282006%29> (last accessed Apr. 13, 2011).

²² Spital, *supra* note 8, at 181.

²³ UNIF. ANATOMICAL GIFT ACT § 8(a) (amended 2006), 8A U.L.A. 76 (Supp. 2010).

²⁴ Spital, *supra* note 8, at 182; UNIF. ANATOMICAL GIFT ACT § 8 (amended 2006), 8A U.L.A. 76 (Supp. 2010); Farsides, *supra* note 2, at 104.

family members.²⁵ Furthermore, while various studies have shown that an overwhelming majority of Americans support organ donation, individuals often fail to prospectively document their intentions in some way.²⁶ As a result, surviving family members are left to speculate about the decedent's wishes and must decide whether to donate the decedent's organs at an extraordinarily difficult time.²⁷

Lack of expressed intent by the deceased is just one of the problems attributed to the growing organ shortage. Organ donation is an ethically complex area of medicine because a wide variety of religious and cultural beliefs exist regarding death,²⁸ and many myths surround organ procurement and donation. Some of the common barriers are include the myth that registered donors may not receive sufficient life-saving treatment as compared to non-donors,²⁹ the misconception that an individual's religion prohibits donation, the fear that donation will interfere with burial rituals, or the assumption that one's organs are not suitable for donation for some reason (age, illness, etc.).³⁰ In fact, the organ procurement organizations are not even contacted until life-saving efforts have ceased, so there is no risk that registered donors

²⁵ Spital, *supra* note 6, at 505.

²⁶ KANT PATEL & MARK E. RUSHEFSKY, HEALTH CARE POLICY IN AN AGE OF NEW TECHNOLOGIES 92 (2002) (finding that only twenty percent of Americans who express support for organ donation have signed donor cards); Herz, *supra* note 4, at 340 (stating that 85% of Americans support organ transplants and 69% would likely donate their own organs); Spital, *supra* note 6, at 505 (citing a 1993 Gallup poll in which only 38% had made their wishes regarding donation known to a family member); Jeremy Laurance, *Change Law on Organ Donation, Doctors Say*, INDEPENDENT (Nov. 2, 2009), <http://www.independent.co.uk/life-style/health-and-families/health-news/change-law-on-organ-donation-doctors-say-1813167.html> (finding that almost forty-five percent of study participants who expressed support for organ donation had not yet recorded their wishes).

²⁷ Spital, *supra* note 8, at 182; T. M. Wilkinson, *Individual and Family Decisions About Organ Donation*, 24 J. APPLIED PHIL. 26, 33 (2007).

²⁸ See Ann C. Klassen & David K. Klassen, *Who Are the Donors in Organ Donation? The Family's Perspective in Mandated Choice*, 125 ANNALS OF INTERNAL MED. 70, 71 (1996); see generally JAMES F. CHILDRESS, PRACTICAL REASONING IN BIOETHICS 266 (1997) ("Developments in transplantation . . . pose significant questions about the moral rights and obligations of individuals, families, health care professionals, and society at large in the transfer and use of [human body parts].").

²⁹ Laura A. Siminoff & Mary Beth Mercer, *Public Policy, Public Opinion, and Consent for Organ Donation*, 10 CAMBRIDGE Q. HEALTHCARE ETHICS 377, 380 (2001) (reporting that 24.6% of families expressed this concern); *Top 10 Myths*, CTR. FOR ORGAN RECOVERY AND EDUC., <http://www.core.org/Misconceptions.asp> (last visited Feb. 2, 2011); *Understanding Donation: Learn the Facts*, DONATE LIFE AM., <http://www.donatelife.net/UnderstandingDonation/LearnTheFacts.php> (last visited Jan. 29, 2010) [hereinafter *Understanding Donation*].

³⁰ *Top 10 Myths*, *supra* note 29; *Understanding Donation*, *supra* note 29.

will receive less vigorous treatment than non-donors.³¹ Decedents who have donated organs are not disfigured and can have viewings or funerals with open caskets just as they would if they had not donated.³² Most major religions, including Catholicism, Protestantism, Islam, and most branches of Judaism support organ and tissue donation.³³ While there are some illnesses and infections that can preclude an individual from becoming a donor, this determination can be made by doctors on a case-by-case basis.³⁴ There is no age limit for donation, and organs have been procured from individuals as old as eighty.³⁵ Public education about organ donation would help to dispel some of the myths surrounding the organ donation process and could encourage more individuals to register as donors.

Failure of individuals to prospectively record their wishes, unwillingness of Organ Procurement Organizations to enforce decedent's wishes, and common myths about organ donation all contribute to the growing organ shortage. Enacting a mandated choice system of obtaining consent for organ donation would address these problems and could significantly reduce the organ waiting list in the United States.

B. Mandated Choice: A Method to Alleviate the Organ Shortage

Mandated choice, or required response, is a method of requiring competent adults to prospectively register their wishes regarding organ donation in advance of death through various registration mechanisms.³⁶ Mandated choice is designed to increase personal autonomy by allowing individuals to ensure that their own personal beliefs will be reflected in how their bodies are handled at death. With clear indication from the donor herself, the wishes of the deceased supersede any objection by family members in a mandated choice system, "elim-

³¹ See *Understanding Donation*, *supra* note 29.

³² *Id.*

³³ See *id.*; *Organ Donation: Don't Let These Myths Confuse You*, MAYOCLINIC.COM, <http://www.mayoclinic.com/health/organ-donation/f100077> (last visited Mar. 4, 2010). While no religion formally forbids organ donation, certain sects such as Native Americans, Roma Gypsies, Confucians, Shintoists, and some Orthodox rabbis may discourage it. P. Bruzzone, *Religious Aspects of Organ Transplantation*, 40 TRANSPLANT PROC. 1064, 1067 (2008). For a more comprehensive look at the stances of individual sects regarding organ donation, see ORGANDONOR.GOV, http://organdonor.gov/donation/religious_views.htm (last visited March 27, 2011).

³⁴ *Organ Donation*, *supra* note 33; *Top 10 Myths*, *supra* note 29.

³⁵ *Organ Donation*, *supra* note 33.

³⁶ INST. OF MED., *supra* note 7, at 177.

inat[ing] surrogate decisionmakers at the time of death.”³⁷ Under mandated choice, registration of one’s desire to donate or not to donate is linked with a task, such as renewing a driver’s license or filing a tax return. Ideally, the individual would be required to respond to questions regarding organ donation before the task can be completed. For example, an individual wishing to renew his or her license could not do so before registering a choice regarding organ donation. Once an individual has registered intent to donate or not to donate, the decision will be legally binding upon the individual’s death and cannot be overridden by anyone else.³⁸

Mandated choice is “based on the belief that each person should control the disposition of his or her own body after death”³⁹ and promotes autonomy by ensuring that each individual’s previously expressed wishes will be followed in the event of death.⁴⁰ Individuals can even specify that they are only willing to donate particular organs, and these wishes will be followed accordingly.⁴¹ The family’s role in consenting to organ donation has been controversial, and “several jurisdictions have recently reconsidered or are reconsidering the family’s role,” with greater emphasis on the individual’s wishes, in accordance with individual autonomy.⁴²

Another important aspect of mandated choice is the potential for individuals to benefit from fully informed consent. “Obtaining consent is . . . one of the guiding principles that provide moral validation of organ transplant programs.”⁴³ Informed consent ensures that every patient has the right not to be subjected to medical treatment without the patient’s authorization, and violation of this right is legal battery.⁴⁴ Informed consent is based on the idea that every person “of adult years and sound mind has a right to determine what shall be done with his own body”⁴⁵ and “arises from the conviction that human beings are responsible for their own actions and their own destinies.”⁴⁶ For consent to be truly informed, the individual must have the opportunity

³⁷ Siminoff & Mercer, *supra* note 29, at 377; see P. Chouhan & H. Draper, *Modified Mandated Choice for Organ Procurement*, 29 J. MED. ETHICS 157, 159 (2003); Spital, *supra* note 8, at 186-87.

³⁸ INST. OF MED., *supra* note 7.

³⁹ Aaron Spital, Response, *Ethics, Mandated Choice, and Organ Donation*, 126 ANNALS INTERNAL MED. 251, 251 (1997).

⁴⁰ Spital, *supra* note 8, at 187.

⁴¹ Chouhan & Draper, *supra* note 37, at 158.

⁴² Wilkinson, *supra* note 27, at 26.

⁴³ Verheijde et al., *supra* note 3.

⁴⁴ ARNOLD J. ROSOFF, INFORMED CONSENT: A GUIDE FOR HEALTH CARE PROVIDERS 3 (1981).

⁴⁵ *Schloendorff v. Soc’y of N.Y. Hosp.*, 211 N.Y. 125, 129 (N.Y. 1914).

⁴⁶ A PRIMER FOR HEALTH CARE ETHICS, *supra* note 3, at 49.

to evaluate all options knowledgeably and to understand the risks of each available option.⁴⁷ Therefore, "the process of obtaining consent [for organ donation] must include the provision of an appropriate quantity and quality of information so that the person can make an informed decision."⁴⁸ The mandated choice model has the potential to fulfill the requirements of informed consent provided that individuals are only asked to indicate their choice regarding organ donation following a "meaningful exchange of information."⁴⁹

II. CRITICISMS OF MANDATED CHOICE: INDIVIDUAL AUTONOMY, INFORMED CONSENT, AND PRACTICAL OBSTACLES

Mandated choice has been criticized on several levels, particularly because several states have experimented with implementing variations of mandated choice with differing levels of success. Some critics argue that public support for increased organ donation is taken for granted, and it is not as "uniformly accepted in the United States as many in the transplantation community assume."⁵⁰ In fact, the effectiveness of a mandated choice policy does depend on the "presumption that most citizens will want to be donors."⁵¹ However, studies and polls conducted in light of the worsening organ shortage dispel the notion that Americans do not support organ donation.⁵² Despite criticisms of mandated choice, this system has the potential to increase the number of donated organs in a legally appropriate manner within the requirements of informed consent and consistent with individual autonomy.

A. Police Power to Enact Mandated Choice

Mandated choice is sometimes criticized as a coercive system, because individuals are forced to register a prospective decision regard-

⁴⁷ *Canterbury v. Spence*, 484 F.2d 772, 780 (D.C. Cir. 1972).

⁴⁸ Verheijde et al., *supra* note 3.

⁴⁹ GOLDRICH, *supra* note 9, at 4; Sandra Woien et al., *Organ Procurement Organizations Internet Enrollment for Organ Donation: Abandoning Informed Consent*, BMC MED. ETHICS, Dec. 2006, <http://www.springerlink.com/content/1623618159287674/>; AM. MED. ASS'N, PRESUMED CONSENT AND MANDATED CHOICE FOR ORGANS FROM DECEASED DONORS (2005), available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2155.shtml>.

⁵⁰ Klassen & Klassen, *supra* note 28, at 70.

⁵¹ A PRIMER FOR HEALTH CARE ETHICS, *supra* note 3, at 185.

⁵² See Herz, *supra* note 4, at 340 (citing a 1993 Gallup poll indicating that 69% of Americans responded that they would likely donate their own organs).

ing organ donation.⁵³ Decisions about the body are “prima facie” expressions of individual autonomy,⁵⁴ and critics of mandated choice argue that some individuals may want to exercise their autonomy by refusing to make a decision.⁵⁵ Critics argue that requiring a choice about organ donation is per se coercive, and that individuals who do not wish to think about death and organ donation should not be forced to do so against their will.⁵⁶

However, “society routinely limits individual autonomy when it interferes with the greater good,”⁵⁷ such as when the government requires helmets, seatbelts, or vaccinations. Requiring individuals to register their choice is consistent with the state’s police power under the Constitution. In *Jacobson v. Massachusetts*, the U.S. Supreme Court upheld the state’s authority to enact “health laws of every description.”⁵⁸ Furthermore, the state has discretion in determining the “mode or manner” in which it seeks to protect the public’s health.⁵⁹ In *Jacobson*, the Supreme Court upheld a constitutional challenge to a Massachusetts vaccination law permitting the city of Cambridge to require vaccination of its residents, with a five dollar penalty assessed to the noncompliant.⁶⁰ Under *Jacobson*, states and localities have broad power to enact legislation and regulations in the interests of public health, even if these regulations infringe on individual liberty to some extent.

The requirement that individuals register a decision under mandated choice is not impermissibly coercive because it does not encourage individuals to make a *particular* decision; rather, mandated choice only requires that individuals register *some* decision. Individu-

⁵³ Francis R. Sutherland, *Legislating Organ Donation: Problems With This Approach*, 30 ANNALS ROYAL C. OF PHYSICIANS & SURGEONS C. 33, 34 (1997).

⁵⁴ Wilkinson, *supra* note 27.

⁵⁵ See CHILDRESS, *supra* note 28, at 272.

⁵⁶ *Id.* at 271. Childress criticizes the “faulty conception of autonomy” in mandated choice, as well as the American Medical Association’s position that “‘Under mandated choice, individuals who feel this reluctance [to contemplate their own deaths and the disposition of their bodies after death] would have to confront it, thereby removing it as a barrier to donation.’” *Id.* (citing AM. MED. ASS’N, REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, REP. NO. 2-I-93, STRATEGIES FOR CADAVERIC ORGAN PROCUREMENT: MANDATED CHOICE AND PRESUMED CONSENT (1993), available at <http://www.ama-assn.org/resources/doc/code-medical-ethics/2155a.pdf>); see also Klassen & Klassen, *supra* note 28.

⁵⁷ E.A. Pomfret et al., *Solving the Organ Shortage Crisis: The 7th Annual American Society of Transplant Surgeons’ State-of-the-Art Winter Symposium*, 8 AM. J. TRANSPLANTATION 745, 750 (2008).

⁵⁸ *Jacobson v. Massachusetts*, 197 U.S. 11, 25, 37-39 (1905).

⁵⁹ *Id.* at 25.

⁶⁰ *Id.* at 37-39.

als are not coerced into donating their organs,⁶¹ and can even choose to donate only certain organs, if they have personal objections to donating any particular organ.⁶² The only thing individuals are not permitted to do in this system is to refuse to record a decision at all.⁶³ To avoid undue coercion under mandated choice, individuals do not receive privileges in association with the choice to donate organs, such as financial incentives or other benefits.⁶⁴ The only benefit that can be conferred after registering one's choice is the ability to complete one's desired transaction, such as completing driver's license renewals or tax returns only after responding to questions about organ donation.⁶⁵ However, the ability to complete these tasks cannot be affected in any way by the particular response an individual chooses to record. In short, mandated choice simply requires a recorded decision, and does not place emphasis on *which* decision individuals ultimately make.

Furthermore, statutes governing matters within the scope of the states' police power are presumed to be constitutional absent "any factual foundation of record for deciding that the limits of power had been transcended."⁶⁶ The American Medical Association's Council on Ethical and Judicial Affairs has reviewed mandated choice and concluded that it is an ethically viable method of increasing the supply of organs available for transplantation.⁶⁷ As previously discussed, the organ shortage is worsening in the United States, the need for organs is growing five times faster than the number of donated organs, and many people on the waiting list will die before receiving a transplant.⁶⁸ Requiring individuals to prospectively indicate their wishes through mandated choice will raise awareness about organ donation, preserve individual autonomy by making the wishes legally binding, and alleviate the severe shortage of donated organs.⁶⁹ Mandated choice falls within the states' police power as a reasonable health law

⁶¹ Herz, *supra* note 4, at 342.

⁶² Chouhan & Draper, *supra* note 37, at 158.

⁶³ *Id.*

⁶⁴ *Id.*

⁶⁵ Herz, *supra* note 4, at 341; Spital, *supra* note 8, at 186.

⁶⁶ *W. Coast Hotel Co. v. Parrish*, 300 U.S. 379, 397 (1937) (upholding a state law establishing a minimum wage for women).

⁶⁷ AM. MED. ASS'N, *supra* note 49.

⁶⁸ A PRIMER FOR HEALTH CARE ETHICS, *supra* note 3, at 163; THALER & SUNSTEIN, *supra* note 3; Verheijde et al., *supra* note 3.

⁶⁹ THALER & SUNSTEIN, *supra* note 3, at 179 ("[M]andated choice . . . could still lead to a significant increase in donations and hence save a lot of lives."); Herz, *supra* note 4, at 342; Karen Sokohl, *First Person Consent: OPOs Across the Country Are Adapting to the Change*, UNOS UPDATE: SEPT.-OCT. 2002, at 1 [hereinafter *First Person Consent*], available at http://www.unos.org/docs/registires_combined.pdf ("[T]he donor's decision is paramount and should be respected at all costs.").

designed to save the lives of the 110,758 individuals on the transplant waiting list with minimal intrusion into personal autonomy.⁷⁰

B. Autonomy Under a Mandated Choice System

Some critics argue that forcing individuals to make a choice infringes on individual autonomy and that surviving family members should have the authority to decide whether or not to donate the decedent's organs. Although any compulsory requirement infringes on autonomy to some extent,⁷¹ mandated choice allows for more individual autonomy than any other system of consent for organ donation.⁷² This is because an individual's wishes will become legally binding under mandated choice, so any small loss of autonomy is outweighed by the guarantee that the individual's wishes will be honored.⁷³

1. Individual Autonomy and First-Person Consent

Opponents of mandated choice argue that forcing individuals to make a choice may result in a decrease in donations because individuals who object to recording a choice would be more likely to refuse consent to donate as a matter of principle.⁷⁴ However, individuals may be more likely to want their decision recorded if they know that the decision will be binding and their wishes will be honored, because they will know that their choice is meaningful and that they are in control of how their bodies are handled at death.⁷⁵ In addition, there is no evidence to support the argument that implementing mandated choice would negatively affect public opinion regarding organ donation, and current studies show that support for organ donation among the American public is high.⁷⁶

Allowing individuals to determine what can or cannot be done with their bodies after death "seem[s] consistent with laws that allow people to dispose of their property more or less as they wish when they die."⁷⁷ Under mandated choice, the organ donation is still conducted in accordance with a living person's wishes, even though those

⁷⁰ UNITED NETWORK FOR ORGAN SHARING, *supra* note 1. This figure is accurate as of April 13, 2011.

⁷¹ See Farsides, *supra* note 2, at 107; Sutherland, *supra* note 53, at 30.

⁷² Spital, *supra* note 8, at 188.

⁷³ Farsides, *supra* note 2, at 107.

⁷⁴ CHILDRESS, *supra* note 28, at 271.

⁷⁵ Farsides, *supra* note 2, at 105.

⁷⁶ Spital, *supra* note 39 ("There is also no evidence that mandated choice would turn public opinion against transplantation; in fact, opinion surveys suggest otherwise.").

⁷⁷ Farsides, *supra* note 2, at 105.

wishes are actually being carried out after the person has passed away.⁷⁸ The registered decision to donate one's organs after death should be honored just as wills are honored for the disposal of property after death.⁷⁹ As one commentator observed, "[w]e honor deceased persons' wishes about willing their favorite chairs. Should we honor less their wishes about their own bodies?"⁸⁰

Critics of mandated choice also argue that the decision to donate well in advance of death may be very different from the decision that would ultimately be made at the time of death,⁸¹ and that forcing people "to commit to a specific, isolated end-of-life decision is coercive and shortsighted."⁸² However, organs suitable for donation often come from young people who die unexpectedly and suddenly, when there is no opportunity for donation to be discussed.⁸³ The suggestion that individuals be required to state their intent to donate or not to donate when they are admitted to a hospital may be ineffective because "hospital questionnaires will not reveal the intentions of some of the most frequent organ donors, namely, those who die from injuries in traumatic motor vehicle accidents and are usually incapable of making donation decisions by the time they enter the hospital."⁸⁴ In these scenarios, the individual is not capable of making the decision personally, and the family may not be able to make a rational decision in the "emotionally charged atmosphere following death."⁸⁵ Mandated choice requires a prospective choice so that individuals can make an objective and "deliberate decision about organ donations in a calm atmosphere. . . ."⁸⁶ By requiring individuals to contemplate their feelings about organ donation in advance of a life-or-death situation, mandated choice makes it more likely that an individual will make a rational decision that is consistent with that individual's personal, moral and religious beliefs.

⁷⁸ Herz, *supra* note 4, at 343.

⁷⁹ Wilkinson, *supra* note 27, at 28.

⁸⁰ Herz, *supra* note 4, at 343.

⁸¹ PATEL & RUSHEFSKY, *supra* note 26, at 95.

⁸² Klassen & Klassen, *supra* note 28, at 73.

⁸³ See Spital, *supra* note 8, at 182.

⁸⁴ Adam J. Kolber, *A Matter of Priority: Transplanting Organs Preferentially to Registered Donors*, 55 RUTGERS L. REV. 671, 686-87 (2003).

⁸⁵ PATEL & RUSHEFSKY, *supra* note 26, at 95; *see also* Spital, *supra* note 8, at 187.

⁸⁶ PATEL & RUSHEFSKY, *supra* note 26, at 95; A PRIMER FOR HEALTH CARE ETHICS, *supra* note 3, at 185.

2. Family Autonomy

Section 8(a) of the Uniform Anatomical Gift Act states that an individual's expressed intent to become a donor cannot be revoked by anyone other than the donor himself, and that obtaining the consent of any other person is not required or permitted.⁸⁷ In practice, however, most health care professionals still seek the consent of surviving family members regarding whether or not to donate the deceased's organs.⁸⁸ This practice of deferring to family wishes is on the decline, however, in states where organ procurement organizations (OPOs) will harvest organs from individuals who have expressly recorded their wishes to be donors, despite family opposition.⁸⁹

Some critics of mandated choice argue that it allows for the views of the family to be overridden in favor of the expressed wishes of the deceased, and that the surviving family members should have more of a say in determining whether or not to donate a loved one's organs.⁹⁰ Some commentators fear that a policy of overriding family members' wishes could result in lower rates of donation, as individuals may hesitate to register as a donor if they have concerns that it may cause additional grief to family members.⁹¹ Proponents of requiring family consent emphasize "that it is the family, not the deceased patient, who comes home from the hospital, talks to their friends, neighbors and community about their experience at the hospital and shapes public opinion about organ donation among those they know."⁹² Yet there are conflicting studies on how the American public views the family's role in the donation decision process. While one Gallup survey showed that most respondents believed that the individual's wishes should be respected rather than overridden by the wishes of family members, another study indicated that Americans believe that obtaining family consent is an important element of the organ donation process.⁹³

⁸⁷ UNIF. ANATOMICAL GIFT ACT § 8 (amended 2006), 8A U.L.A. 76 (Supp. 2010), *supra* note 17; Woien et al., *supra* note 49.

⁸⁸ See Spital, *supra* note 8, at 182.

⁸⁹ See *First Person Consent*, *supra* note 69, at 1.

⁹⁰ See Klassen & Klassen, *supra* note 28, at 70; Siminoff & Mercer, *supra* note 29; Verheijde et al., *supra* note 3; Steve Libowitz, *Rethinking Mandated Choice: Ann Klassen Questions the Viability of an Initiative to Increase Organ Donations*, THE GAZETTE: THE NEWSPAPER OF THE JOHNS HOPKINS UNIVERSITY, July 8, 1996, <http://www.jhu.edu/~gazette/julsep96/jul0896/choice.html>.

⁹¹ Klassen & Klassen, *supra* note 28, at 70.

⁹² Klassen & Klassen, *supra* note 28; Libowitz, *supra* note 90.

⁹³ Siminoff & Mercer, *supra* note 29, at 380; Spital, *supra* note 6, at 506.

Those who favor the family's right to consent argue that families need to be part of the process of obtaining consent even if this results in fewer donations because superseding the wishes of the family might exacerbate an already painful situation.⁹⁴ However, an individual's decision under mandated choice will have been registered far in advance of death under calm, deliberate circumstances, and this careful decision should not be overridden by a spontaneous decision made by family members in a time of stress and shock.

Currently, most organ procurement organizations will not harvest organs from an individual against family wishes.⁹⁵ However, some jurisdictions are moving away from this traditional model, including the Center for Organ Recovery and Education (CORE), which serves parts of Pennsylvania and West Virginia.⁹⁶ CORE "basically turned the process upside down" when it began proceeding with organ harvesting over family objections in response to the enactment of a Pennsylvania statute mandating first-person consent.⁹⁷ CORE's policy is controversial and was initially difficult for some hospital staff members who felt that the family's wishes should not be overruled.⁹⁸ Under CORE's policy, families are informed that "the deceased patient documented a wish to donate and that this wish will be honored."⁹⁹ If the family continues to oppose donation, CORE continues discussions with the family while moving forward with procedures to carry out the transplant process.¹⁰⁰ Brian Broznick, the executive director of CORE, acknowledged that situations where it became necessary to supersede the family's wishes became difficult, especially experiencing the family's initial anger. However, Broznick also explained that some of these families ultimately became involved in CORE and later stated that they were "glad [CORE] pushed them, because if [CORE] hadn't, they wouldn't have been able to fulfill their loved one's final wish."¹⁰¹ Overall, CORE has found that families rarely oppose donating the deceased's organs "when they are *informed* about it."¹⁰²

⁹⁴ Libowitz, *supra* note 90.

⁹⁵ Thomas May et al., *Patients, Families, and Organ Donation: Who Should Decide?*, 78 MILBANK Q. 323, 323-24 (2000).

⁹⁶ See *First Person Consent*, *supra* note 69, at 1; May et al., *supra* note 95, at 324.

⁹⁷ Karen Sokohl, *How We Did It: Four OPOs Talk About What Worked in Developing Their Donor Registries*, UNOS UPDATE, Jan.-Feb. 2003, at 22 [hereinafter *How We Did It*], available at http://www.unos.org/docs/registires_combined.pdf.

⁹⁸ See *First Person Consent*, *supra* note 69, at 3; May et al., *supra* note 95, at 325.

⁹⁹ May et al., *supra* note 95, at 324.

¹⁰⁰ *Id.*

¹⁰¹ *First Person Consent*, *supra* note 69, at 3.

¹⁰² May et al., *supra* note 95, at 324.

Although some commentators are critical of the diminished role for family members under mandated choice, there are compelling reasons to enforce registered choices, in particular, the individual autonomy of the decedent at the time he or she registered his or her decision. One possible compromise between these two positions is to allow three choices in the mandated choice system: “yes,” “no,” and “defer to family wishes.”¹⁰³ This possibility is discussed further in section III.

C. Cost and Complexity of Mandated Choice

Opponents of mandated choice argue that the cost of implementing and maintaining such a system would be prohibitive.¹⁰⁴ Implementing a national database to record individuals’ consent or refusal to donate would require a new bureaucracy in some states,¹⁰⁵ and the United States does not currently have a “uniformly successful system of centralized registration of persons.”¹⁰⁶ However, supporters of mandated choice argue that such a system can be designed in a cost-effective and streamlined manner,¹⁰⁷ and may even be “more cost-effective than competing treatment modalities,” such as continuing to treat a person with methods other than an organ transplant.¹⁰⁸ The health care system is already plagued by limited funding resources, and if facilitating organ transplants is more economically sensible than other treatment options, any system that could increase the number of transplants performed would help to relieve this economic burden.¹⁰⁹ As previously stated, donor registries could be organized through the Department of Motor Vehicles in many states, which is how the current opt-in system of organ donation operates. This option would not require a great deal of additional bureaucracy or funding.

A mandated choice system requires minimal time and energy for the individuals who are registering their choices.¹¹⁰ This task can be easily completed in conjunction with other tasks such as filing tax documents or renewing a license, or by accessing the internet, if an online registry is available. However, the amount of effort expended

¹⁰³ Farsides, *supra* note 2, at 108-09.

¹⁰⁴ See Klassen & Klassen, *supra* note 28, at 70, 72.

¹⁰⁵ Eike-Henner W. Kluge, *Improving Organ Retrieval Rates: Various Proposals and Their Ethical Validity*, 8 HEALTH CARE ANALYSIS 279, 288 (2000).

¹⁰⁶ Klassen & Klassen, *supra* note 28, at 72 (arguing that even the U.S. census does not result in 100% participation).

¹⁰⁷ Herz, *supra* note 4, at 345.

¹⁰⁸ Kluge, *supra* note 105, at 279.

¹⁰⁹ *Id.*

¹¹⁰ Davis, *supra* note 6, at 1382.

by government officials and organ procurement organizations in maintaining an organ donor registry will vary from state to state depending on which method of registration that state chooses to employ. In recent years, organ donor registries have proliferated throughout the country, with varying levels of success.¹¹¹ In Arizona, for example, the organ donor registry cannot be operated in conjunction with the Division of Motor Vehicles because the state requires license renewal so infrequently and there are currently no questions on Arizona driver's license applications asking about organ donation; therefore, the state had to create an independent registry from scratch.¹¹² In Virginia, the donor registration system had multiple options, and the result has been increased operator error and a three-to-one ratio of non-donors to donors.¹¹³ This situation has been compounded by state budget cuts that have made it more difficult to reform the system at this time.¹¹⁴

Coordinating donor registries is made even more complicated by the fact that some organ procurement organizations, such as LifeCenter Northwest, serve multiple states and must navigate consent laws and registration requirements for each state. Conversely, four organ procurement organizations cover the state of Ohio, where the registry is now maintained by the Bureau of Motor Vehicles, and while this complexity does represent a daunting administrative burden,¹¹⁵ it has not proven to be a barrier to enacting effective organ donor registries. For example, in Ohio, all four organ procurement agencies have "developed close working relationships with both state entities" responsible for funding and maintaining the donor registry.¹¹⁶

In addition to the cost of implementing the organ donor registry, an effective mandated choice system would require public education,

¹¹¹ See Karen Sokohl, *The Nuts and Bolts of Developing Donor Registries: States Across the Country Have Varied Experiences*, UNOS UPDATE, Nov.-Dec. 2002, at 6 [hereinafter *Nuts and Bolts*], available at http://www.unos.org/docs/registires_combined.pdf; see, e.g., IOWA DONOR REGISTRY, <http://www.iowadonorregistry.org/> (last visited Feb. 4, 2011).

¹¹² *How We Did It*, *supra* note 97, at 22.

¹¹³ *Nuts and Bolts*, *supra* note 111, at 7.

¹¹⁴ *Id.*

¹¹⁵ *How We Did It*, *supra* note 97, at 23; Klassen & Klassen, *supra* note 28, at 72; see also LIFE BANC, <http://www.lifebanc.org/> (last visited Apr. 13, 2011); LIFE CENTER // WHAT DOES IT MEAN TO PASS LIFE ON?, <http://lifepassiton.org/> (last visited Apr. 13, 2011); LIFE CONNECTION OF OHIO, <http://www.lifeconnectionofohio.org/aboutus.html> (last visited Apr. 13, 2011); LIFELINE OF OHIO, <http://www.lifelineofohio.org/> (last visited Apr. 13, 2011).

¹¹⁶ *How We Did It*, *supra* note 97, at 23.

which could be costly to implement.¹¹⁷ For example, Utah spent approximately \$80,000 on billboards and television advertisements when switching to a mandated choice system.¹¹⁸ However, states must weigh the cost of implementing a mandated choice system against the potential benefit provided by the system.¹¹⁹ While the costs of implementing the registry and educating the public may initially be high, in future years the system would be more well-established and would not require as much money annually. Finally, the need to address the growing number of wait list candidates dying each year before donated organs become available outweighs the costs of setting up the system.

D. Potential Legal Liability Under a Mandated Choice System

Opponents of mandated choice argue that hospitals and doctors may be exposed to liability in some cases in which the family's wishes are overridden in favor of following the deceased's decision to donate. One commentator stated that "[dead] patients don't sue, but live families do," and explained that fear of being sued was cited as one reason why family consent is often still sought even when the deceased has recorded his or her wish to become an organ donor.¹²⁰ However, under the Uniform Anatomical Gift Act, doctors are supposed to defer to the expressed wishes of the deceased despite the wishes of any opposing family members:

. . . in 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 6.¹²¹

Therefore, doctors and hospitals should take the action indicated by the valid donor card without fear of liability.¹²² Doctors' obligations to enforce decisions in the donor registry can be analogized to

¹¹⁷ See Verheijde et al., *supra* note 3; see generally Woien et al., *supra* note 49, at 7 (citing the "costly public education programs necessary for the implementation of a mandated choice").

¹¹⁸ *Nuts and Bolts*, *supra* note 111, at 6.

¹¹⁹ Klassen & Klassen, *supra* note 28, at 72.

¹²⁰ May et al., *supra* note 95, at 333.

¹²¹ UNIF. ANATOMICAL GIFT ACT § 8 (amended 2006), 8A U.L.A. 76 (Supp. 2010).

¹²² May et al., *supra* note 95, at 333-34.

doctor's obligations to follow advance directives.¹²³ Accordingly, doctors may need to be more concerned about exposing themselves to liability if they override the expressed wishes of the deceased.¹²⁴ Some commentators argue that would-be recipients of donated organs may even have a cause of action against those who override the potential donor's wishes "given the legal status of gifts after death and the rights this bestows on recipients."¹²⁵

III. RECOMMENDATIONS: A PROPOSAL TO INCREASE CONSENT FOR ORGAN DONATION THROUGH MANDATED CHOICE

Several states have implemented variations of mandated choice with varying levels of success, and reviewing these states' experiences is useful in determining the strengths and weaknesses of such programs, in addition to identifying the safeguards that must be in place for a successful system. An ideal mandated choice system must preserve individual autonomy by making registrations legally binding, while still allowing individuals the option to designate a family member to make decisions regarding donation on their behalf. Registrations must be made in accordance with the requirements of informed consent after adequate education efforts and in a venue where the registrant can truly contemplate all available information and ask questions before making a decision. The venues available for registration must be broad and inclusive to reach as many individuals as possible. Finally, mandated choice systems should initially be enacted as pilot studies to confirm the system's effectiveness in raising the number of donated organs.

A. Registration Under Mandated Choice

1. Registration Options

Under the ideal mandated choice system, registrants will be presented with three options regarding whether or not they wish to be organ donors: "yes," "no," and "defer to family wishes."¹²⁶ If the individual chooses the "defer to family wishes" option, the individual should be required to state which particular family member should

¹²³ See THE LEWIN GROUP, INC., ANALYSIS OF STATE ACTIONS REGARDING DONOR REGISTRIES (2000), *available at* <http://aspe.hhs.gov/health/orgdonor/state%20organ%20donor%20registries.htm>.

¹²⁴ May et al., *supra* note 95, at 333-34.

¹²⁵ *Id.* at 334.

¹²⁶ Farsides, *supra* note 2, at 108-09.

have the authority to make the decision on that individual's behalf. This preserves the individual's right to allow surviving family members to make whatever decision feels most comfortable to them while avoiding the problem of how to proceed when surviving family members disagree about whether or not to donate the individual's organs.¹²⁷ In addition, individuals must have the opportunity to change their minds at any time and must be able to easily register their new decision.

A true mandated choice system should not offer an option of "unsure" or "undecided," because a system that allows registration of a non-response is really not mandating that individuals make a choice.¹²⁸ In addition, including an "undecided" option can actually lead to a decrease in registered donors, as demonstrated by the results of mandated choice in Virginia. Virginia was one of the first states to implement a partial version of the mandated choice system,¹²⁹ where registrants are required to declare themselves as donors, non-donors, or undecided when they update their licenses.¹³⁰ High numbers of registrants identified themselves as "undecided," resulting in an overall decrease in the total number of organ donors.¹³¹ The option of registering as "undecided" may be an important factor affecting how many people choose to register as donors,¹³² and highlights the need for a more robust public education system to encourage individuals to register as donors.¹³³

¹²⁷ Under the UAGA, the decision to donate a decedent's body or parts may be made by any member of the following classes of persons who is reasonably available, in the order of priority listed: (1) an agent of the decedent at the time of death who could have made an anatomical gift under Section 4(2) immediately before the decedent's death; (2) the spouse of the decedent; (3) adult children of the decedent; (4) parents of the decedent; (5) adult siblings of the decedent; (6) adult grandchildren of the decedent; (6) adult grandchildren of the decedent; (7) grandparents of the decedent; (8) an adult who exhibited special care and concern for the decedent; (9) the persons who were acting as the [guardians] of the person of the decedent at the time of death; and (10) any other person having the authority to dispose of the decedent's body.

UNIF. ANATOMICAL GIFT ACT § 9(a) (amended 2006), 8A U.L.A. 76 (Supp. 2010). In the event of disagreement, "the gift may be made only by a majority of the members of the class who are reasonably available." *Id.* at § 9(b).

¹²⁸ RICHARD H. THALER & CASS R. SUNSTEIN, *NUDGE: IMPROVING DECISIONS ABOUT HEALTH, WEALTH, AND HAPPINESS* 180 (2009).

¹²⁹ Libowitz, *supra* note 90.

¹³⁰ Klassen & Klassen, *supra* note 28, at 72.

¹³¹ See GOLDRICH, *supra* note 9, at 3.

¹³² *Id.* (reporting that 24% of Virginians refused to indicate a choice under Virginia's mandated choice system).

¹³³ See GOLDRICH, *supra* note 9, at 5.

The inclusion of a "defer to family wishes" option is important because a default choice must be established in any mandated choice system to cover those who refuse to respond or who are not covered by the methods of registration. A "yes" default would resemble presumed consent. Presumed consent would violate the principle of informed consent and would infringe on individual autonomy, and is not a feasible alternative in the U.S. for reasons already discussed. Presumed refusal (a default "no" response) carries the risk of a decrease in organ donors,¹³⁴ as demonstrated by Texas's brief experiment with mandated choice. In 1991, Texas began requiring individuals to make a choice regarding organ donation when they renewed their driver's licenses.¹³⁵ Texas House Bill 271 stated that "[a] statement of gift must be executed each time a driver's license or personal identification card is renewed, reinstated, or replaced."¹³⁶ The statute further stated that:

If the decedent is a donor 18 years of age or older, the decedent's anatomical gift made under Section 692.003, including a gift made under Section 11B, Chapter 173, Acts of the 47th Legislature, Regular Session, 1941 . . . shall be honored without obtaining approval or consent of any other person.¹³⁷

Individuals in Texas were only given the option of saying "yes" or "no" as opposed to being given a third option to allow family members to decide.¹³⁸ An answer was not actually required in order for individuals to renew their licenses, so in practice Texas's system did not truly mandate choice.¹³⁹ Individuals who refused to answer or who were not asked for some reason were registered as responding "no."¹⁴⁰ This "no" registration could not be overridden by family members, even if the decedent simply had not been asked while at the registry.

¹³⁴ GOLDRICH, *supra* note 9, at 3. The Institute of Medicine rejected enactment of mandated choice because of the possibility that a mandated choice system could potentially result in a decrease of donors, as people who feel coerced into making a decision may decide to register as non-donors. Woien et al., *supra* note 49.

¹³⁵ Verheijde et al., *supra* note 3.

¹³⁶ 1991 TEX. GEN. LAWS 1204.

¹³⁷ *Id.* at 1205.

¹³⁸ Verheijde et al., *supra* note 3; Herz, *supra* note 4, at 342.

¹³⁹ In fact, license registry employees often did not even ask individuals the questions about organ donation. See Herz, *supra* note 4, at 342.

¹⁴⁰ *Id.*

The resulting eighty percent refusal rate led to a reduction in organs available for transplant, and the Texas law was repealed in 1997.¹⁴¹

A default response of “defer to family wishes” would preserve the status quo of the “opt-in” system and avoid the problems experienced in Texas, but may not result in an increase in organ donations, as this is how our system currently operates. An alternative would be to enact a default of “defer to family wishes” in addition to requiring that the individual designate which family member will be responsible for the decision, and perhaps requiring that the family member be notified in advance.¹⁴² This option would avoid the problem of what to do when surviving family members disagree about whether or not to donate a decedent’s organs. This option may also spark discussion between family members regarding donation, as family members would be more likely to take the time to determine each other’s wishes if they know in advance they will be held responsible for making this decision should the need arise.

An individual’s decision to respond “yes” and register as a donor must be legally binding under informed consent. Illinois recently enacted First-Person Consent legislation, creating a mandated choice system in which an individual’s decision is legally binding. Before the enactment of this First-Person Consent legislation, the families of one in five individuals who had registered their intent to become an organ donor overruled the decision to donate.¹⁴³ Today, nearly four years after the enactment of this mandated choice system, Illinois has a sixty percent rate of donor signup, compared to the national average of thirty-eight percent,¹⁴⁴ indicating the importance of honoring individual’s wishes for how they want their bodies to be handled after death.

In order to alleviate concerns that people may change their minds about organ donation over time, a mandated choice system must incorporate a method by which people can change their registration easily if they so choose. The opportunity to register a change in wishes would be fairly simple with an electronic registry,¹⁴⁵ and other methods of registration could also be designed to “facilitate periodic

¹⁴¹ CHILDRESS, *supra* note 28, at 271; Siminoff & Mercer, *supra* note 29; Verheijde et al., *supra* note 3.

¹⁴² Farsides, *supra* note 2, at 109 (“This decision must be explicitly acknowledged by kin and/or any selected proxy.”).

¹⁴³ Jesse White, Sec. of State, *First-Person Consent Fact Sheet*, LIFE GOES ON.COM (Oct. 2005), http://www.cyberdriveillinois.com/publications/pdf_publications/ex7.pdf.

¹⁴⁴ Richard H. Thaler, *Opting in vs. Opting Out*, N.Y. TIMES, Sept. 27, 2009, at BU6, available at <http://www.nytimes.com/2009/09/27/business/economy/27view.html>.

¹⁴⁵ Spital, *supra* note 8, at 186-87.

but regular review.”¹⁴⁶ Allowing individuals to change their mind with “unlimited frequency” would preserve their autonomy, and the most recent registration decision would be honored.¹⁴⁷

2. Venues and Methods of Registration

The methods by which individuals can register their intent to donate or not donate are an important component of ensuring that a mandated choice model meets the requirements of informed consent. Registration of one’s choice to consent or not to consent to organ donation can be completed through a variety of methods. Driver’s license applications and renewals, tax returns, applications for state identification cards, hospital admissions paperwork, and registration websites are some of the proposals for running a mandated choice model.¹⁴⁸ Whichever method states choose to employ, individuals must be able to register their choice in a setting where they can contemplate their decision and have the opportunity to ask any questions they may have about the donation process, and the registration methods must be as inclusive as possible to reach the maximum number of potential donors.

Many states currently allow citizens to express their desire to become an organ donor on driver’s license applications, but this method of registering is not ideal as the motor vehicle bureau “setting is not conducive to making important postmortem decisions.”¹⁴⁹ The decision of whether or not to donate requires serious thought, and should not be made impulsively in a hectic or stressful environment.¹⁵⁰ Rather, individuals should be asked to register their choices only in situations where they can carefully consider their decisions. Ideally, individuals should have advance notice that they will be asked to make a choice so that they may educate themselves and ask questions if necessary.¹⁵¹ The need for advance notice is highlighted by the failure of the mandated choice system in Texas, where many individuals were not advised that they would have to answer this question when they came to renew their licenses, and evidence showed that registry employees often did not even ask the questions about organ donation.¹⁵²

Another problem with utilizing the motor vehicle bureau as the main venue in which individuals register their choices is that not all

¹⁴⁶ Chouhan & Draper, *supra* note 37, at 158.

¹⁴⁷ Herz, *supra* note 4, at 341.

¹⁴⁸ Siminoff & Mercer, *supra* note 29; Spital, *supra* note 8, at 186.

¹⁴⁹ Kolber, *supra* note 84, at 687; *see also* GOLDRICH, *supra* note 9, at 2.

¹⁵⁰ Spital, *supra* note 8, at 187.

¹⁵¹ *Id.*

¹⁵² Herz, *supra* note 4, at 342.

individuals obtain driver's licenses or other forms of state-issued identification.¹⁵³ The same problem would occur if organ donation registration was linked only with tax returns, because there are people who do not file tax documents. The form of registration utilized under a mandated choice system must be easily accessible and as inclusive as possible to achieve maximum donation rates.¹⁵⁴ Iowa, for example, offers three methods for people to register as donors: by phone, by mailing in a brochure found in DMV branches, hospitals and libraries, or by visiting a website.¹⁵⁵ Individuals who register online must also sign and return a postcard once their request is processed in order for their registration to be legally binding.¹⁵⁶

In Illinois, a mandated choice system with multiple registration options has proven to be very successful. Illinois enacted the First-Person Consent Organ/Tissue Donor Registry on January 1, 2006.¹⁵⁷ This legislation makes an individual's decision to register as an organ donor legally binding regardless of any family opposition.¹⁵⁸

The Secretary shall offer, to each applicant for issuance or renewal of a driver's license or identification card who is 18 years of age or older, the opportunity to have his or her name included in the First Person Consent organ and tissue donor registry. The Secretary must advise the applicant or licensee that he or she is under no compulsion to have his or her name included in the registry. An individual who agrees to having his or her name included in the First Person Consent organ and tissue donor registry has given full legal consent to the donation of any of his or her organs upon his or her death.¹⁵⁹

This legislation also gives the Secretary the authority to establish additional methods by which an individual may have his or her name included in the First Person Consent organ and tissue donor registry.¹⁶⁰ Accordingly, Donate Life Illinois has been established to facilitate registration.¹⁶¹

¹⁵³ GOLDRICH, *supra* note 9, at 2.

¹⁵⁴ Chouhan & Draper, *supra* note 37, at 158.

¹⁵⁵ *Nuts and Bolts*, *supra* note 111, at 7.

¹⁵⁶ *Id.*

¹⁵⁷ *First-Person Consent Fact Sheet*, ILL. SEC'Y OF STATE (Jan. 31, 2011), <http://www.lifegoeson.com>.

¹⁵⁸ *Id.*

¹⁵⁹ 625 ILL. COMP. STAT. 5, § 6-117(g)(1) (2009). Records are to be kept by the Secretary of State.

¹⁶⁰ *Id.* at § 6-117(g)(2).

¹⁶¹ DONATE LIFE ILL., <http://www.donatelifellinois.org/> (last visited Mar. 28, 2011).

Illinois's success under mandated choice illustrates the importance of having many opportunities to register one's decision to become a donor. While Virginia and Texas restricted their registration to driver's license applications or renewals, Illinois allows individuals to register over the phone, online, or at a driver's services facility.¹⁶² The online system is easily accessible, and the phone option is an important alternative for those who may lack internet access. Most importantly, any of these registration options encourage individuals to consider donation before facing a life or death situation, when making an informed decision may be difficult or impossible. By providing multiple methods of registration instead of restricting recruitment efforts to subsets of the population who perform particular activities (obtaining driver's licenses, filing tax returns, etc.), mandated choice could reach more potential donors.

The method or methods of registration employed by the states under mandated choice must be user-friendly and easy to complete. In Virginia, the "biggest battle [under mandated choice has been] with the development of the registry itself."¹⁶³ The high rate of refusals to donate in the Virginia system have been attributed to a higher rate of operator error, with resulting refusals outnumbering positive responses three to one.¹⁶⁴ Registration methods that are too complex or difficult to understand could result in lower rates of organ donation, so states implementing mandated choice must be careful to make sure registration is accessible and easy to use.

Furthermore, the mandated choice registry must be easily accessible to organ procurement organizations and health professionals. In many cases, health professionals do not look for an organ donor card, and this may negatively impact donation rates.¹⁶⁵ A computerized online donor registry, whether nationwide or statewide, would be more accessible for health professionals in determining whether or not an individual with suitable organs has registered as a donor.¹⁶⁶ A nation-wide registry would be most beneficial because of the challenges faced by organ procurement organizations that serve multiple states. For example, the Center for Organ Recovery and Education, which serves western Pennsylvania, West Virginia, and portions of New

¹⁶² *Id.*

¹⁶³ *Nuts and Bolts*, *supra* note 111, at 7.

¹⁶⁴ *Id.* During the first six months of this program, approximately one million drivers were asked to register, and 45% registered as non-donors, resulting in a decrease in the number of organs available for transplant. Klassen & Klassen, *supra* note 28, at 72; Libowitz, *supra* note 90.

¹⁶⁵ Farsides, *supra* note 2, at 104.

¹⁶⁶ Spital, *supra* note 8, at 186-87; *see also* Sheehy et al., *supra* note 9, at 673.

York, can only access an online registry for Pennsylvania residents and must use the state license registry for individuals in the other states it serves.¹⁶⁷ LifeCenter Northwest, which serves portions of Alaska, Montana, Idaho, and Washington, also faces the challenge of serving multiple regions with different processes for registering to be an organ donor.¹⁶⁸

A nation-wide registry could be assembled through a process similar to registration for Selective Service for young men.¹⁶⁹ While a nation-wide registry would be most efficient for a streamlined organ procurement process, implementation of such a registry might not be immediately feasible because first-person consent laws vary from state to state; however, this does not necessarily have to be an obstacle to states enacting mandated choice. For example, Ohio is covered by four different organ procurement agencies and multiple state agencies collaborate to fund and maintain the organ donation registry.¹⁷⁰ Even without the benefits provided by nation-wide registration, mandated choice is still a feasible policy on a state-by-state basis.

B. Public Education as a Necessary Component of Informed Consent

Since increasing consent is one of the most effective ways to boost the number of organs available for transplant,¹⁷¹ mandated choice represents an opportunity to reach more potential donors to educate them about organ donation and to obtain consent to harvest their organs in the event of brain death.¹⁷² Public education about organ donation is essential for a registrant's consent to be truly informed under mandated choice. The failure of mandated choice in Texas is attributed largely to the lack of public education surrounding the initiative.¹⁷³ By contrast, the First-Person Consent statute in Illinois mandates that potential registrants be provided with a brochure explaining that there is "no compulsion to have his or her name included," and that "he or she may wish to consult with family, friends, or clergy before doing so."¹⁷⁴ Another section of the Illinois statute provides

¹⁶⁷ *Frequently Asked Questions*, CENTER FOR ORGAN RECOVERY AND EDUCATION, <http://www.core.org/faq.asp> (last visited Feb. 2, 2011).

¹⁶⁸ *How We Did It*, *supra* note 97, at 23; *Donate Life Today—Be an Organ and Tissue Donor*, LIFE CENTER NORTHWEST, <http://www.lcnw.org/> (last visited Feb. 1, 2011).

¹⁶⁹ Kolber, *supra* note 84, at 686.

¹⁷⁰ *How We Did It*, *supra* note 97, at 23.

¹⁷¹ Spital, *supra* note 8, at 179.

¹⁷² *See id.* at 186-88.

¹⁷³ Verheijde et al., *supra* note 3; *see also* Herz, *supra* note 4, at 342.

¹⁷⁴ 625 ILL. COMP. STAT. 5, § 6-117(g)(1)(i) (2009).

additional authority for "education and awareness activities."¹⁷⁵ These provisions are important components of ensuring the informed consent of all donors; however, all brochures and activities must fulfill the "informational needs of an average, reasonable patient" in order to promote truly informed consent.¹⁷⁶

Education is also important because studies have shown that "merely getting people to contemplate donation issues for two minutes lead to 23% of them signing an available donor card."¹⁷⁷ While donor cards themselves may have limited effectiveness (as health professionals do not always look for them or, if they do, may not enforce the decision written), in the absence of alternative methods of registration, donor cards are important for their "ability to educate and stimulate family discussions."¹⁷⁸ Even critics of mandated choice have acknowledged that public education has "more potential to increase donation,"¹⁷⁹ and public education would be an important component of any successful mandated choice system.

Since online registration would be one of the most efficient methods for conducting a mandated choice system, the issue of whether or not a website can provide adequate information must be addressed. Informed consent requires the "disclosure of all relevant information necessary for that person to make an informed decision based on personal values and preferences."¹⁸⁰ One study reviewed web sites looking for "minimal information recommended by the United States Department of Health and Human Services for informed consent," and determined that such websites did not constitute informed consent.¹⁸¹ Rather, these websites provided mostly "promotional" information,¹⁸² and lacked "basic factual knowledge for the potential donor on essential aspects of the organ donation process."¹⁸³ States would need to address this problem before enacting mandated choice programs that rely heavily on websites or online registration.

The most basic solution would be to improve these websites to include more comprehensive and unbiased information. Another possible solution would be to establish "hotline" numbers in conjunction with registration websites so individuals could call for additional information if they felt they were unprepared to make a choice based on

¹⁷⁵ *Id.* at § 6-117(g)(5).

¹⁷⁶ ROSOFF, *supra* note 44, at 38.

¹⁷⁷ Farsides, *supra* note 2, at 108.

¹⁷⁸ Spital, *supra* note 8, at 183.

¹⁷⁹ Klassen & Klassen, *supra* note 28, at 70.

¹⁸⁰ Woien et al., *supra* note 49.

¹⁸¹ *Id.*

¹⁸² *Id.*

¹⁸³ *Id.*

the information already provided. Alternatively, to avoid the potential for “self-serving bias in information disclosure” and to “maintain transparency and public trust,” states could have an independent organization without a conflict of interest be responsible for public education and registration efforts.¹⁸⁴

C. Need for Further Research

While multiple studies previously cited indicate strong support for mandated choice and for organ donation in general, the link between generally asserting a willingness to donate and actually affirmatively documenting consent has not been definitively proven.¹⁸⁵ Empirical data on the effects of a mandated choice system is limited,¹⁸⁶ although states like Illinois have reported higher rates of consent to donation under such a system.¹⁸⁷ Nonetheless, critics of mandated choice are correct to assert that additional quantitative research is needed to study the effectiveness of this system in increasing rates of donor consent and organ donation.

The American Medical Association supports the implementation of pilot studies in smaller populations to determine the effect of mandated choice before such a system is widely implemented.¹⁸⁸ Such studies could address several important criteria, such as any change in the number of transplants performed, the number of individuals giving or withholding consent, and the number of people refusing to record a choice at all.¹⁸⁹ The studies conducted thus far indicate that support for organ donation in general, and mandated choice in particular, is high, but more quantitative studies are needed to confirm the efficacy of mandated choice on a broader scale.

CONCLUSION

Mandated choice represents an opportunity for states to facilitate registration of more organ donors and to potentially increase the number of organs available for transplant. Under mandated choice or any other system of procuring organ donations, the supply of organs still might not be sufficient to eliminate the waiting list entirely, even if all

¹⁸⁴ *Id.*

¹⁸⁵ See Klassen & Klassen, *supra* note 28, at 72; see also Herz, *supra* note 4, at 346.

¹⁸⁶ Herz, *supra* note 4, at 346.

¹⁸⁷ Thaler, *supra* note 144.

¹⁸⁸ AM. MED. ASS'N, *supra* note 49.

¹⁸⁹ GOLDRICH, *supra* note 9, at 4.

potential donors became actual donors.¹⁹⁰ A waiting list could still exist for some organs, while the waiting list would be eliminated for other organs if all potential donors became actual donors.¹⁹¹ However, given the current shortage of organs and the number of waiting list candidates who die before receiving an organ, any increase in the number of donated organs is beneficial. In fact, each individual donor can save up to seven lives depending on how the organs are distributed (if the decedent donates all organs or just some organs; if each recipient is given just one organ or multiple organs, etc.).¹⁹²

While not guaranteed to raise the number of organs available for transplant, mandated choice is the most ethical approach for attempting to do so. The ideal mandated choice system described in this Note allows individuals the autonomy to determine how their bodies will be handled after their death, while preserving the individual's right to leave decisions regarding donation with a family member if they so desire. A mandated choice system must include appropriate public education efforts to dispel myths regarding organ donation and to raise awareness about the critical need for donor organs so that individuals will be able to make a fully informed decision before they register. Finally, an ideal mandated choice system will include multiple venues and methods for registration to reach the maximum number of potential donors. Provided that these safeguards for autonomy and education are met and that further quantitative research confirms the efficacy of mandated choice on a broader scale, mandated choice is the most promising option for solving or alleviating the critical shortage of donor organs in the United States.

¹⁹⁰ Sheehy et al., *supra* note 9, at 673.

¹⁹¹ *Id.* See UNITED NETWORK FOR ORGAN SHARING, *supra* note 1, for an up-to-date list of how many candidates are waiting for each organ.

¹⁹² See May et al., *supra* note 95, at 324.