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The Impact of First-Person Consent Legislation on the Supply of Deceased Organ Donors

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Abstract

From 1988 to 2001, the supply of transplantable organs grew by 140%, an accomplishment dwarfed by the simultaneous rise in the number of individuals awaiting a transplant, which increased by 650%. In response to the immense shortage and historically high family refusal rates, nearly all states have adopted first-person consent legislation, which allows for a donor card or one's name on a state donor registry to stand as sufficient consent to donate, and further prevents the family from overriding the decision of the donor. To date, no study has examined the efficacy of the policy across adopting states. I exploit the varied timing in the adoption of first-person consent legislation to examine the change in the supply of donors among states that adopted first-person consent in the late '90's and early 2000's using states with no such laws as controls. I demonstrate that states that passed first-person consent legislation before 2003 saw donation rates increase 10-15% beyond donation rates in non-adopting states. Taken together with typically low family consent rates when the wishes of the donor are unknown, my results strongly reinforce the need for actions that encourage more individuals to communicate their donation preferences, either explicitly via a registry or by discussing them with family.

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The data and analyses reported in the 2011 Annual Data Report of the US Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients have been supplied by UNOS and the Minneapolis Medical Research Foundation under contract with HHS/HRSA. The authors alone are responsible for reporting and interpreting these data; the views expressed herein are those of the authors and not necessarily those of the US Government.

I. Introduction

Between 1988 and 2011, the number of individuals awaiting transplant of a vital organ grew by 650% while the annual number of donors increased by only 140% (Figure 1). In the same time span, the ratio of transplants performed to the size of the waiting list fell from 84% to 25% (Organ Procurement and Transplantation Network [OPTN], 2014; Scientific Registry of Transplant Recipients [SRTR], 2012). Today's average transplant candidate has been waiting for an organ for more than two years and the median wait time for kidney transplants is nearly four years¹ (SRTR, 2012). Approximately 80% of all available organs come from deceased donors (after brain death or circulatory death) (OPTN, 2014). The growth of the transplant waiting list continues to outpace the marginal increase in organ donations year after year, while Organ Procurement Organization (OPO) estimates show recent declines in the number of identified potential deceased organ donors (SRTR, 2012, Table 4.2). On average, 18 individuals die each day while waiting for organ transplants (Health Resources and Services Administration [HRSA], 2013).

The shortage is not a new problem; since its inception in 1984, the Organ Procurement and Transplantation Network (OPTN) has been unable to secure enough organs to meet demand, and due to medical advances in recent years, mean survival times for those on the waiting list continue to increase, particularly for those awaiting kidney transplants (Siminoff, Arnold, Caplan, Virnig, & Seltzer, 1995; Klein et al., 2010; Traino & Siminoff, 2013). The U.S. has historically relied on altruistic donations, operating under what is known as informed consent whereby an individual must opt in and indicate their wish to donate before death. In the event that a potential donor's wishes are unknown, the next of kin is asked for consent. Contrary to the spirit of informed consent legislation, even when it can be verified that a potential donor has explicitly documented their desire to be an organ donor, it has long been the case that procurement professionals still request consent from the family even though it is not legally required (Siminoff & Lawrence, 2002; Edinger, 1990). Several studies reveal that the overall family refusal rate has hovered near 50% for decades. Family members cite confusion or disbelief about brain death², concerns about burial and disfigurement, and a lack of knowledge of the decedent's donation preferences as the largest factors for refusing donation (Gortmaker et al., 1998; Siminoff et al., 1995; Siminoff & Lawrence, 2002).

¹ For those on the waiting list as of 2007, the most recent year data was available

² Specifically, the belief that one can recover from brain death

In response to the continual shortage and persistently high family refusal rates, all states have passed legislation authorizing what is known as first-person consent for organ donation (Chon, et al., 2013). First-person consent laws explicitly allow for donations from deceased donors to proceed when intent to donate can be confirmed (via donor card, driver's license designation, or state donor registry) without requiring transplant professionals to obtain permission from the next of kin. Moreover, they expressly forbid a third party from overriding the donor's wishes unless they can produce confirmation of abrogation³ (Mesich-Brant & Grossback, 2005; Traino & Siminoff, 2013). Despite the fact that the legislation ensures consent to donate is irrevocable by a third party, it is unclear whether the legislation has had an effect on the supply of organ donors among all states. The general public has consistently expressed a high level of approval for donation with over 90% of adults reporting they support or strongly support donation and transplantation efforts (Health Resources and Services Administration [HRSA], 2012). This statistic is frequently (and misleadingly) cited to equate superficial general favor for the idea of donation with a personal intent to donate or willingness to consent on behalf of a family member (Siminoff et al., 1995; Tabarrok, 2004). Historically, consent rates have been substantially lower than the aforementioned statistic would indicate, drawing increased attention to respecting the wishes of those potential donors who have expressed intent to donate. First-person consent is intended to help narrow the gap between high levels of expressed general support for donation and low consent rates by ensuring that the decedent's wishes are carried out whenever they are documented. In nearly all cases, the legislation is enacted concomitantly with a compliant registry that provides a means to record and execute intent.

Using data containing the number of deceased organ donors by state from 1991-2006, I examine changes in the supply of deceased and brain-dead organ donors in response to first-person consent laws, the efficacy of which have yet to be studied across all states. Exploiting variation in the enactment of such legislation across states, I use a difference-in-differences approach to examine changes in the supply of donors in states that passed first-person consent laws in the late 90's and early 2000's using states without such legislative changes as controls. The results of my analysis show that, compared to non-adopting states, states that passed first-person consent legislation before 2003 saw an increase in donation rates of 10-15%. These

³ Although, some states require only a verbal expression of revocation in the presence of two individuals (one of whom is disinterested); written documentation is not always necessary (Uniform Law Commission [ULC], n.d.c).

findings are robust to various model specifications and definitions of the donor rate and suggest that first-person consent legislation leads to sizeable increases in the supply of organ donors.

II. Background

As of this writing, a total of 47 states have enacted some form of the Uniform Anatomical Gift Act (UAGA) of 2006 which specifically prevents any family member or otherwise responsible party from revoking an anatomical gift made by a potential donor prior to death, which is known as first-person consent⁴ (ULC, n.d.b). The Act allows for consent to be expressed in several forms including donor status designation on a driver's license or ID card, a donor card, or via compliant donor registries⁵. Nearly all states have coupled their adoption of this law with the establishment of, or update to, an existing donor registry to bring it into compliance with first-person consent. Uniform acts are drafted to address problems that extend across state lines and serve as proposed laws for adoption in full or in part at the state level (ULC, 2014). Transplantation is necessarily time sensitive for vital organs and it requires great cooperation among states. Thus it is desirable that legislation be as consistent between states as possible, particularly in cases where potential donors are from another state. It is important to note that states pass the uniform laws individually and sometimes with modifications. I refer to the 2006 UAGA singularly since the portion of the law as it pertains to first-person consent is present and consistent across states that have adopted it.

The 2006 UAGA is an update to two prior versions of the Act. The first UAGA was promulgated in 1968 and quickly adopted by all states. It established that a donor card was *sufficient* consent for donation provided two witnesses had signed it (National Conference of Commissioners on Uniform State Laws [NCCUSL], 1968)). The 1987 UAGA removed the witness requirement and affirmed that consent from the next of kin was *not required* if the decedent had already consented to donate, though it did not forbid OPOs from requesting it, as was the general practice. The 1987 UAGA was adopted in 26 states and is occasionally likened to first-person consent since it clarifies the adequacy of documented intent. For the purposes of this analysis, I make the essential distinction that, by the current and generally accepted definition, first-person consent legislation expressly forbids any third party from overriding a documented donation decision.

⁴ Also known as donor designation or first-person authorization

⁵ Non-first-person consent registries are known as intent-only registries

There are two main pathways by which any legislation could impact donation rates under the policy of informed consent: by increasing the pool of potential donors or by increasing consent rates for donation. Only a very small proportion of the population is ever in a position to donate; primary circumstances of death among adult organ donors include motor vehicle accidents (MVAs), head trauma, suicide, and homicide (OPTN, 2013). Past studies have estimated the size of the potential donor pool to be somewhere between 10,500 and 17,000 individuals annually, roughly 1% of the 1.8 million annual fatalities that occurred in the same time period (Sheehy et al., 2003; Guadagnoli, Christiansen, & Beasley, 2003). OPOs have continually attempted to widen the potential donor pool by redefining and expanding donation criteria. Throughout recent years, OPOs have relied increasingly on marginal donors⁶ over the age of 60 who would not have met previous criteria (Punch, Hayes, LaPorte, McBride, & Seely, 2007). As a result, the age distribution of deceased donors has been shifting with declining proportions of younger donors while proportions of older donors have been on the rise (Sung et al., 2008). Concurrently, as an increasing number of states have implemented donor registries it has become apparent that older adults register as donors in lower proportions than relatively younger adults with 66% of those age 18-34 reporting they had registered as of 2012 compared to 52% for those over age 66. This is a significant improvement in less than a decade, however, and is nearly double the 26% of those over 66 who reported they had signed up when surveyed in 2005 (HRSA, 2012).

Demographic differences between the pool of potential donors and the population of registered organ donors are important since first-person consent legislation acts primarily through state organ donor registries, which historically have been the primary method of documenting consent and the most timely and straightforward way for procurement personnel to ascertain donor status. One of the main arguments for adoption of first-person consent is that it has the potential to increase donations by reducing dependence on families for consent, thereby increasing conversion rates if states work to increase the number of registered donors. OPOs and nonprofit organizations such as Donate Life America have placed substantial emphasis on registering as many donors as possible, particularly among racial and ethnic minority groups for whom consent rates have historically been low, but together who comprise over half the number

⁶Known as expanded criteria donors (ECD)

of individuals on transplant waiting lists (Donate Life America (DLA), n.d.). States have also worked hard to target segments of the population most likely to become potential donors.

Prior to the widespread adoption of the 2006 UAGA, nearly twenty states had enacted first-person consent of their own accord, including Pennsylvania as early as 1994, followed by New Jersey, Iowa, Ohio, and others. Nearly all of these states passed first-person consent legislation at the same time as they implemented a legally binding donor registry. New Mexico, West Virginia, and Florida had existing donor registries that were updated for compliance when they passed first-person consent, while Virginia did not implement a registry until several years after first-person consent was enacted (UNOS, 2010). Among states without first-person consent legislation, roughly one third enacted intent-only donor registries within the same time period. I make use of the variation in early adoption of first-person consent to investigate its impact on donation rates in comparison to states with no such legislation. I then narrow my focus to the states that passed first-person consent and compliant registries simultaneously to estimate the extent to which such registries have influenced donation rates.

III. Data

I obtained data on the number of deceased adult donors by state and the circumstance of their death from 1991 to 2006 from The Organ Procurement and Transplantation Network. The years of adoption of state-level first-person consent legislation were available from UNOS via the Internet Archives and were confirmed where possible using Westlaw Campus Research and individual state legislative websites. I compiled the years of enactment for state organ donor registries from Donate Life America's annual donor designation report cards. State-level health expenditure data was retrieved from the Centers for Medicare and Medicaid services.

Demographic data such as state levels of age, race, and educational achievement was compiled using the Current Population Survey's outgoing rotation group files (retrieved from the National Bureau of Economic Research [NBER]). I control for population density and adult population within each state, as well as median income, all of which were retrieved from the U.S. Census Bureau and the U.S. Statistical Abstract⁷. Income and healthcare expenditures were adjusted for inflation and are reported in 2012 dollars.

⁷ Intercensal population density calculated via linear interpolation

I control for whether a state has primary enforcement motorcycle helmet and seatbelt laws in any given year as they influence the number of motor vehicle fatalities and have been shown to affect donation rates (Dickert-Conlin, Elder, & Moore, 2011). Motorcycle helmet law data were retrieved from the Governors Highway Safety Association and seat belt laws and driver's license renewal lengths came from the Insurance Institute for Highway Safety. I also explore several different measures of the donation rate in my analysis, including donors per million population, donors per mortality, and donors per motor vehicle accident. Motor vehicle accident fatality data is from the Department of Transportation's Fatality Analysis and Reporting system (files via NBER) and includes all adult motor vehicle, motorcycle, and pedestrian fatalities. Mortality data was retrieved from the Center for Disease Control's compressed mortality files.

IV. Identification Strategy

Nearly all states have enacted first-person consent and a compliant organ donor registry as of the time of this study. I focus on outcomes among states that adopted first-person consent on their own prior to the 2006 UAGA using states without such laws in the same time period as controls. A total of 19 states adopted first-person consent between 1994 and 2006, but to prevent any confounding effects that may result from the widespread adoption of the 2006 UAGA, I restrict the time period under consideration to years prior to and including 2006⁸. I investigate the sensitivity of my analysis to the inclusion of 2006 by running a separate analysis for the years 1991-2005. One of the primary mechanisms of action for first-person consent legislation is through the legally binding donor registries that are often simultaneously established. Many state donor registries rely heavily on their Departments of Motor Vehicles for new donor registrations (in addition to online signups), which indicates that it may take at least one complete driver's license renewal period for the majority of state residents to be presented with an opportunity to register if they do not seek it out themselves. If donor registration rates are truly a driving force behind donation rates, by restricting my analysis to years just prior to the first passage of the UAGA while including states that independently passed first-person consent as late as 2006, I may be unable to accurately capture the true impact of the legislative changes for other treatment states. Thus I exclude from consideration the eight states that passed first-person consent laws

⁸ The first states to pass the 2006 UAGA did so in 2007; it was approved by the NCCUSL for promulgation in July 2006.

between 2003 and 2006, which ensures each included state has at least four years past the enactment of the law in all specifications.

Treatment states are defined as the 13 states where first-person consent legislation was passed between 1994 and 2002. I designate the year after the legislation was passed as the first year of intervention. Before estimating the impact of first-person consent legislation, I first examine pre-existing trends in donation rates between treatment and control states. Figure 2 illustrates average donation trends for the 13 states that adopted first-person consent from 1994-2002 compared to the 30 states that passed no such law. The horizontal axis denotes the number of years from enactment of the law. Since treatment states enacted first-person consent at different times, control states were randomly assigned one of the seven years in the sample in which a treatment state passed first-person consent legislation, and then centered about that year. Treatment and control states exhibit strikingly similar trends until the year of intervention, when the average donation rate among treatment states increases sharply relative to the controls.

Table 1 highlights demographic differences between the treatment and control states. Treatment states have fewer motor vehicle accident fatalities, a slightly older population, and fewer minority residents than their control counterparts before the intervention. Treatment and control states are similar in terms of healthcare expenditures and median income while treatment states have slightly higher donation rates prior to passing first-person consent, measured as the ratio of adult donors per 100 MVA fatalities. The last column in the table provides an initial estimate of the average treatment effect suggesting that first-person consent states experience greater growth in donation rates than control states after enacting the law. I perform specification tests in Section V to further explore the validity of inferences based upon this identification strategy.

IV. Model

The goal of my analysis is to estimate the organ donation rate as a function of the first-person consent status of a given state in each year. I first consider the choice of the dependent variable where studies have traditionally used the natural log of donors per-million population (pmp). Ideally, the best measure of the donation rate would be the total number of donors divided by the total number of *potential* donors, which would include only those individuals whose cause and circumstance of death would have allowed for donation. Past analyses have conducted case

reviews of all deaths in a given geographical area to attempt to estimate the nation-wide potential donor pool (Guadagnoli, Christiansen, & Beasley, 2003; Sheehey et al., 2003). This procedure is extremely time consuming and cost-prohibitive; in recent years OPOs have begun to collect and analyze similar statistics, but no such measure of the donation rate is available for the time period under consideration for this study.

Gay (2006) suggests that a suitable alternative measure of the donation rate is the number of donors per motor vehicle accident fatalities. The likelihood that an individual from the general population would become a potential organ donor is far less than that of an individual who died in a motor vehicle accident. Thus I expect that scaling donors by total population will attenuate the estimated effect of first-person consent legislation relative to weights that better reflect the pool of potential donors. The total number of yearly motor vehicle fatalities was relatively stable between 1991 and 2006 (though it has since declined). In 1995 there were 15.9 motor vehicle accident fatalities per 100,000 residents, which fell to 14.3 fatalities per 100,000 residents by 2006. Adult donors who died in a motor vehicle accident made up the second largest share of total donors by circumstance of death, comprising 26.3% of total donations in 1995⁹ and 20% in 2006. If I instead follow Dickert-Conlin, Elder, & Moore (2011) and tabulate donors for whom an MVA was the circumstance of death, per-million population, I find an increase from 4.9 donors pmp in 1995 to 5.4 donors pmp in 2006. A comparison of donor rate trends at the state level reveals little difference in trends regardless of whether total donors are scaled by state population, mortalities, or motor vehicle fatalities, and the trends are strikingly similar when examining all states in aggregate. If anything, the volatility is minimized when total donors are scaled by MVA fatalities. I find only small differences in statistical significance and magnitude of estimates for the primary variables of interest between different measures of donation rates, which I further discuss in Section V.

I begin by estimating the following model

$$Donor\ Rate_{st} = \alpha + \gamma(FPC)_{st} + X_{st}\beta + \delta_s + \tau_t + \varepsilon_{st} , \quad (1)$$

where $Donor\ Rate_{st}$ is the natural log of donors pmp, donors per 1,000 mortalities, or donors per 100 MVA fatalities in year t in state s . I present primary results using donors per 100 MVA fatalities and present a comparison of regression results for all dependent variables in the

⁹ MVA fatalities are second only to death by natural and uncategorized circumstances. The OPTN did not collect circumstance of death prior to April 1994.

appendix. I consider only organ donors 18 years and older; though some states allow minors to join their donor registries, parental consent is still ultimately required for donation. I include state and year fixed effects (δ_s and τ_t , respectively) to control for unobservable state- and year-level trends that are correlated with the donation rate but not explained by the other independent variables. The first-person consent status of state s in year t is represented by the binary variable FPC_{st} . This variable takes a value of 1 in the first year after first-person consent legislation was passed and each year thereafter. The coefficient γ is the difference-in-differences estimate, the change in the average donation rate for treatment states relative to the counterfactual change. The covariate vector X_{st} includes socioeconomic variables that may affect donation rates such as the natural log of median income, population density, and the natural log of per capita healthcare expenditures. It also includes demographic controls such as state population proportions of high school graduates, age groups, and minority racial and ethnic groups. I also include dummy variables indicating whether the given state had a universal motorcycle helmet law and a primary enforcement seatbelt law in year t . An additional specification includes the percentage of women in the state senate, which serves as an effective proxy measure for the progressivity of a state as demonstrated by Besley and Case (2000). This particular regression necessarily omits Washington D.C. since it has no state legislature. All regressions are weighted by state population and are estimated using clustered standard errors robust to heteroskedasticity¹⁰.

V. Placebo Tests

In order to ensure that underlying fundamental differences between treatment and control states do not bias estimates of the impact of first-person consent, I perform two assessments of my identifying assumptions. I first conduct an explicit test of the appropriateness of the selected control group by estimating a version of Equation (1) that includes lag and lead variables corresponding to up to three years prior and four years after the first-person consent intervention. Significant results for the lead variables would suggest potential reverse causality, indicating that the adoption of first-person consent was endogenous, potentially the result of declining donation rates. I estimate three specifications: the first includes state and year fixed effects, the second adds linear state-specific time trends, and the third includes quadratic state-specific time trends. Results are presented in Table 2 for each measure of the donation rate. The lead variable

¹⁰ Huber & White, by state.

corresponding to the year before first-person consent was passed is significant when the dependent variable is donors per 10,000 mortalities and donors pmp, and including only fixed effects (columns 1 and 4, respectively). When state-specific time trends are added, these false policy variables are no longer significant and the models that add quadratic state-specific time trends perform similarly. These results indicate a need to allow time trends to differ between states, thus I include state-specific time trends in all further specifications.

I also analyze the robustness of my model by estimating Equation (1) using artificial outcome variables upon which the enactment of first-person consent should have no impact. I estimate separate models using the natural log of state population, the natural log of mortalities, and the percentage of children living in poverty as outcome variables and present the results in Table 3. I include a fourth specification using the natural log of donors per 100 MVA fatalities as the dependent variable for comparison. The treatment variable has no statistically significant effect on any of the artificial outcome variables, which provides evidence in favor of the internal validity of the model.

VI. Results

Estimates from least-squares regression of Equation (1) are presented in Table 4, where the dependent variable is the natural log of donors per 100 MVA mortalities. All models include linear state-specific time trends as well as state and year fixed effects. The results provide significant evidence that the enactment of first-person consent legislation is associated with higher rates of donation. Column 1 shows that on average, donation rates are approximately 14% higher in first-person consent states, however since Table 1 revealed demographic differences between treatment and control states, I also estimate additional specifications including other potential determinants of donation rates. Column 2 reveals that population density is positively correlated with donation rates, a possible indication of the importance of proximity to medical facilities in identifying and preserving potential organ donors. Columns 4-6 indicate that primary enforcement seatbelt laws are negatively correlated with donation rates. Contrary to expectations, I find no significant impact from donor registries that have been in place past one full driver's license renewal period. Estimates of the effect of first-person consent are robust to the inclusion of additional covariates; overall, these specifications attribute roughly a 12.5-14.3% increase in donation rates to first-person consent laws. To further investigate the magnitude of

the estimated impact of the legislation, I present a comparison of all three measures of the donation rate in Table 5. The included independent variables for each model are the same as those in column 4 of Table 4. As predicted, the impact attributed to first-person consent when scaling donors by population is lower than that given by donors per 100 MVA deaths. Overall, first-person consent is associated with roughly 10-12.5% higher donation rates among treatment states. As a robustness check, I re-estimate excluding data from 2006 to ensure that any anticipatory trends leading up to the widespread adoption of the 2006 UAGA do not confound my estimates. Table 6 includes these results and they are relatively unchanged.

Since donor registries are the primary method by which individuals document intent to donate, I next exclude treatment states that did not simultaneously enact first-person consent and a compliant donor registry (Table 7). Estimates for explanatory variables are largely similar in magnitude and significance from previous regressions. The exception is that for the proportion of female state senators, which was not significant in previous regressions but is positively associated with donation rates when included here. The estimated contribution of first-person consent to donor rates is larger still after restricting the treatment group, ranging from roughly 15.5-18.3%.

VII. Discussion & Conclusion

My results identify a strong association between adoption of first-person consent and donor rate growth among treatment states. I find an even larger impact when considering only those states that implemented a legally binding donor registry at the same time. Enacting first-person consent on its own is a low-cost solution, and all states have enacted some form of the legislation with little objection. Past studies have raised concerns about the behavior of OPOs with respect to first-person consent illustrating that despite the laws, procurement professionals generally continued to seek family permission for donation, in some cases overriding the expressed wishes of the donor (Mesich-Brant & Grossback, 2005; Wendler & Dickert, 2001). Several OPO directors stated in 2001 that some members of their procurement teams were unwilling to consider going against the wishes of families who expressed opposition to donation, and others expressed concern that enforcing first-person consent would lead to negative publicity, unintentionally decreasing public support for donation in general (Sokohl, 2002). An anonymous survey of OPOs in 2013 revealed that even by the time most states had enacted first-

person consent, 20% of procurement organizations were still unwilling to proceed with donation unless they had the consent of the family. Moreover, 35% of OPOs report that they have yet to proceed with donation in the event that the donor's consent is clear but the family objects (Chon et. al 2013).

I found that first-person consent was associated with donation rates that were approximately 15.5-18.3% higher when enacted with a compliant registry simultaneously. It is not clear what portion of the increase in donation rates should be attributed to removing the need for familial consent or to the registries themselves, which allow healthcare professionals to both confirm and make families aware of a person's donor status. Siminoff & Lawrence (2002) found that in general, just over half of families of potential donors were uncertain about the wishes of the decedent, in which case families refused donation the majority of the time. It is well documented that family consent rates continually exceed 90% when the decedent has documented their desire to donate and especially when they had previously discussed their decision with their family (Rodrigue, Cornell, & Howard, 2005; Siminoff & Lawrence, 2002; Traino & Siminoff, 2013). Given that the expressed reluctance of OPOs to override family refusals only applies to a small fraction of cases, the primary barrier to realizing higher consent rates is the uncertainty families face about whether the decedent would have been willing to donate when no decision is documented. Some families report that they equate an unsigned driver's license or lack of registration as a clear indication the decedent had declined donation instead of assuming the donor was undecided (Anker & Feeley, 2010). This implies that the most successful actions will be those that lead more individuals to communicate their donation preferences, either explicitly via a registry or by discussing it with family.

One frequently proposed solution to help to mitigate uncertainty is mandated consent, wherein individuals are prompted to indicate their preference, typically when renewing a driver's license, signing up for state benefits, or filing tax forms. Such a law was enacted in 2011 in California and driver's license applicants are now made to choose either "Yes, I want to be a donor" or "No, not at this time", but data revealing any impact have not yet been made available (Donate Life California, 2011). In the early 90's, Virginia and Texas implemented a similar policy where registrants were required to choose between agreeing to donate, declining, or indicating they were undecided, however donor registrations did not increase as expected. After Virginia's policy had been in place for six months, 31% of individuals who had renewed their

licenses had registered to donate, 45% declined, and 24% were undecided. The refusal rate was 80% in Texas after the policy was implemented (Klassen, A. & Klassen, D., 1996; Siminoff, et al., 1995). It has been theorized that mandated consent returns such low registration rates because it forces upon individuals the uncomfortable consideration of their demise. Another potential contributing factor is fear and distrust, particularly among minorities, that healthcare professionals will not work as hard to save the life of a registered donor, or that brain death may be declared prematurely (Siminoff, et al., 1995). Such misunderstandings about the criteria for declaration of brain death and the donation process on a whole speak to the need for increased and targeted educational efforts.

Despite questions about first-person consent enforcement practices, there has still been significant progress in increasing consent rates in recent years. Data from 2013 indicate an average consent rate of 73.6%, a vast improvement over previous years (UNOS 2013). Some have questioned the value of exhorting donor registries when only a small proportion of actual donors had ever registered, proposing that registered donors were the *least* likely to become potential donors since historically, the primary circumstances of death for donors were indicative of a non-random, higher-risk sample of the population (Howard & Byrne, 2007). Though the transplantation system has long relied heavily on marginal donors out of necessity, the proportion of actual donors who had joined a legally binding registry before death has since increased significantly from 19% in 2007 to 41% in 2012. Donate Life America reported the total number of donors among all state registries was 109 million in 2012 indicating a national registration rate of 45.4% among adults, up from roughly 65 million registrations in 2007 (DLA, 2013). These statistics indicate that registered donors are no longer significantly underrepresented among actual donors. My results strongly reinforce the contribution of first-person consent and donor registries to increased deceased donation rates, but given the extent by which this growth is dwarfed by the immense backlog of demand for transplants (Figure 1), it is clear that further work is needed to encourage individuals to communicate and explicitly document their donation decisions.

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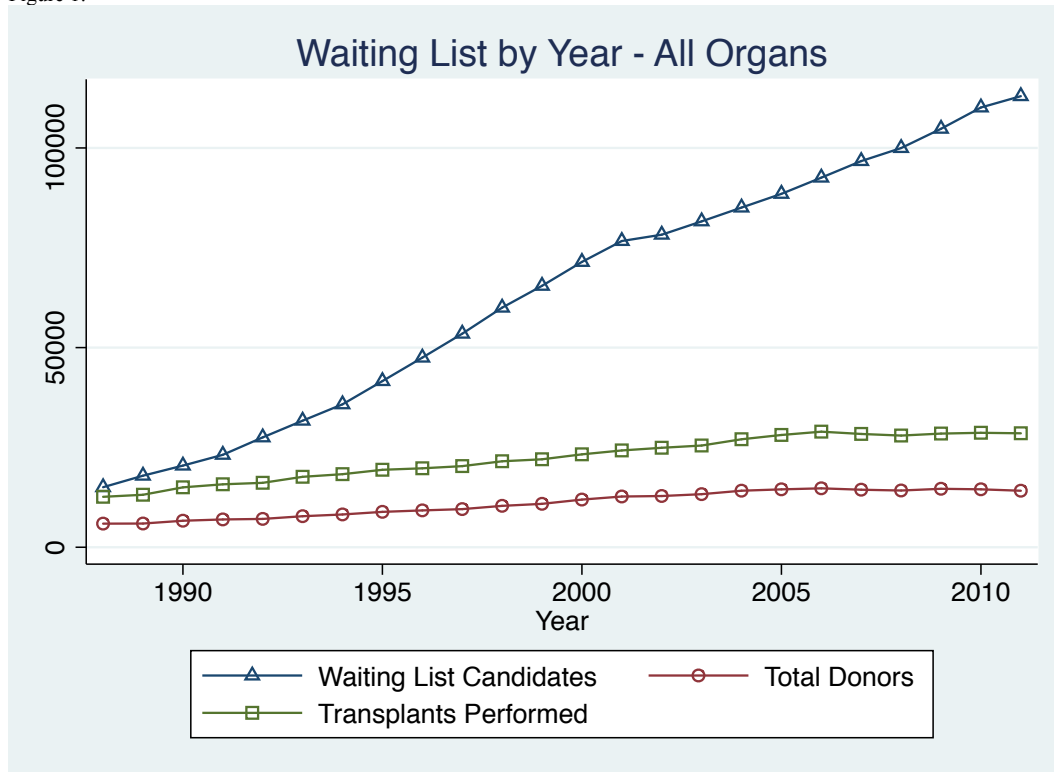
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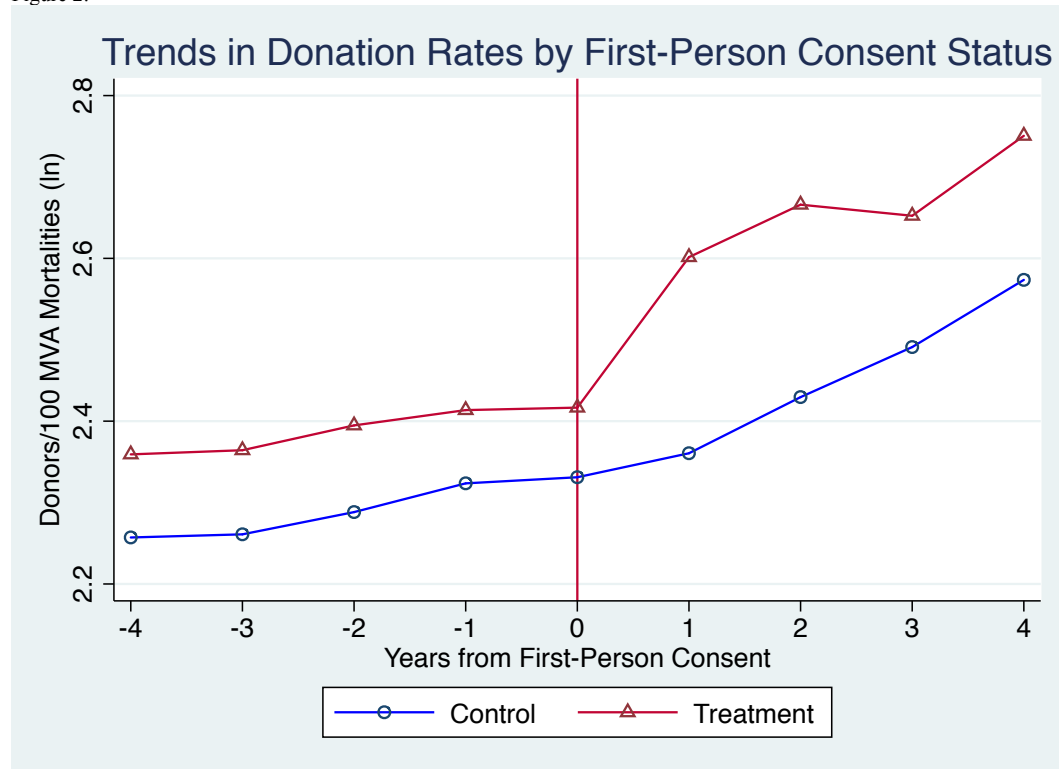
Appendix

Figure 1:



Sources: SRTR, Table 1.3; OPTN, 2014

Figure 2:



Mean donation rates for 13 treatment and 30 control states weighted by state population.

Since first-person consent was introduced at different times for treatment states, control states were randomly assigned to a treatment state whose corresponding enactment year was assigned to be year zero for the control state.

Table 1: Summary Statistics 1991-2006

	Before Intervention			After Intervention			DD
	Treatment	Control	Difference	Treatment	Control	Difference	
Donors/100 MVA fatalities (ln)	2.336 (0.323)	2.223 (0.344)	0.113*** [0.002]	2.779 (4.632)	2.514 (4.632)	0.265*** [0.000]	0.152
Median per capita income	53974.410 (7,760.106)	52754.170 (6,831.680)	1220.24 [0.138]	54107.392 (7,470.286)	54107.392 (7,470.286)	1931.65 0.065	711.41
Healthcare expenditure per capita	12361.747 (1,364.064)	12161.786 (1,309.183)	199.961 [0.176]	13430.043 (1,655.581)	13430.043 (1,655.581)	1050.18*** [0.000]	850.219
MVA deaths per 100,000 population	14.734 (3.940)	15.998 (5.078)	-1.264*** [0.008]	16.307 (5.150)	16.307 (5.150)	-2.646*** [0.000]	-1.382
Percent age 18-34	0.337 (0.029)	0.350 (0.029)	-0.014*** [0.000]	0.325 (0.026)	0.325 (0.026)	-0.027*** [0.000]	-0.013
Percent age 35-49	0.308 (0.017)	0.313 (0.017)	-0.005*** [0.007]	0.308 (0.014)	0.308 (0.014)	-0.003 [0.176]	0.002
Percent age 50-64	0.190 (0.016)	0.183 (0.017)	0.007*** [0.000]	0.215 (0.021)	0.215 (0.021)	0.006** [0.011]	-0.001
Percent over age 65	0.165 (0.020)	0.153 (0.017)	0.012*** [0.000]	0.152 (0.017)	0.152 (0.017)	0.023*** [0.000]	0.011
Percent African American	0.091 (0.054)	0.129 (0.101)	-0.038*** [0.000]	0.097 (0.047)	0.118 (0.089)	-0.022 [0.005]	-0.016
Percent Hispanic	0.054 (0.075)	0.138 (0.127)	-0.084*** [0.000]	0.062 (0.066)	0.105 (0.121)	-0.043 [0.000]	-0.041
Observations	119	249	368	89	231	320	688
States	30	13	43	30	13	43	43

Means weighted by state population. Income and healthcare expenditures in 2012 dollars.

Control states are centered about the intervention year of randomly matched treatment state.

DD column contains initial difference-in-difference calculation (difference after – difference before).

Robust standard errors in parentheses, clustered at the state level; p-values in brackets.

* p<.10, ** p<.05, *** p<.01

Table 2: Placebo tests - Lags and Leads

	Donors per 10,000 mortalities (ln)			Donors per million population (ln)			Donors/100 MVA fatalities (ln)		
	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)
Lead: t+3	-0.0107 (0.055)	0.0561 (0.051)	0.0893 (0.058)	-0.0068 (0.057)	0.0604 (0.052)	0.0948 (0.057)	-0.0277 (0.054)	0.0142 (0.058)	0.0532 (0.062)
Lead: t+2	-0.0404 (0.043)	0.0346 (0.048)	0.0590 (0.051)	-0.0369 (0.044)	0.0367 (0.048)	0.0610 (0.052)	-0.0438 (0.050)	-0.0017 (0.053)	0.0288 (0.051)
Lead: t+1	-0.0887** (0.035)	-0.0112 (0.045)	0.0083 (0.039)	-0.0894** (0.035)	-0.0144 (0.045)	0.0044 (0.039)	-0.0563 (0.035)	-0.0154 (0.042)	0.0077 (0.035)
Intervention year: t	0.0041 (0.052)	-0.1215 (0.155)	0.0426 (0.159)	0.0106 (0.052)	-0.1206 (0.154)	0.0403 (0.157)	0.0743 (0.064)	-0.0385 (0.162)	0.1260 (0.156)
Lag: t-1	-0.0090 (0.055)	-0.1031 (0.132)	0.0371 (0.138)	0.0020 (0.056)	-0.0989 (0.131)	0.0378 (0.136)	0.0684 (0.060)	-0.0305 (0.136)	0.1163 (0.133)
Lag: t-2	-0.0508 (0.048)	-0.1159 (0.115)	0.0054 (0.107)	-0.0406 (0.048)	-0.1130 (0.113)	0.0054 (0.105)	-0.0188 (0.044)	-0.1007 (0.112)	0.0240 (0.102)
Lag: t-3	-0.0389 (0.047)	-0.0728 (0.098)	0.0126 (0.087)	-0.0343 (0.047)	-0.0745 (0.097)	0.0085 (0.087)	0.0023 (0.048)	-0.0702 (0.092)	0.0276 (0.077)
Lag: t-4	0.0509 (0.042)	-0.0008 (0.078)	0.0453 (0.071)	0.0544 (0.042)	0.0005 (0.078)	0.0445 (0.071)	0.0724* (0.038)	-0.0055 (0.069)	0.0493 (0.063)
Fixed Effects	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
State Trends	No	Yes	Yes	No	Yes	Yes	No	Yes	Yes
Quadratic Trends	No	No	Yes	No	No	Yes	No	No	Yes
Observations	671	671	671	671	671	671	671	671	671
R ²	0.998	0.998	0.999	0.998	0.998	0.999	0.997	0.997	0.998

Each lead and lag variable is a dummy variable equal to 1 in one year for each state.

State and year fixed effects are included in all regressions as well as variables corresponding to primary enforcement motorcycle helmet and seat belt laws, healthcare expenditures, population density, race, ethnicity, and age groups.

Robust standard errors in parentheses, clustered at the state level

* p<.10, ** p<.05, *** p<.01

Table 3 - Placebo Test: Pseudo Dependent Variables

	(1) Population (ln)	(2) Mortalities (ln)	(3) Child poverty (%)	(4) Donors/100 MVA fatalities (ln)
First-person consent	-0.0077 (0.006)	-0.0032 (0.004)	-0.0056 (0.006)	0.1247** (0.060)
Median income (ln)	0.0326** (0.014)	0.0271* (0.014)	-0.2099*** (0.041)	-0.4538** (0.196)
Healthcare expenditures per capita (ln)	-0.0444 (0.051)	0.1151 (0.080)	0.0577 (0.054)	-0.7250* (0.363)
Population density	0.0001*** (0.000)	0.0002*** (0.000)	0.0000 (0.000)	0.0014*** (0.000)
Percent African American	-0.1492* (0.076)	-0.1559 (0.094)	0.3155 (0.211)	0.2762 (1.107)
Percent Hispanic	0.1253 (0.078)	0.1545* (0.079)	0.3601** (0.151)	-3.2588** (1.239)
Percent high school graduates	-0.1249 (0.091)	-0.0228 (0.086)	-0.0955 (0.171)	-0.5052 (1.283)
Percent age 18-34	-0.0831 (0.091)	-0.0320 (0.100)	0.0052 (0.239)	-0.1790 (1.277)
Percent over age 65	-0.4475*** (0.136)	-0.1193 (0.123)	0.0173 (0.213)	-0.0686 (1.610)
Motorcycle helmet law	-0.0129*** (0.004)	-0.0086*** (0.003)	0.0055 (0.004)	0.0493* (0.028)
Primary enforcement seatbelt law	-0.0005 (0.005)	-0.0032 (0.004)	0.0047 (0.009)	-0.0790** (0.036)
Observations	688	688	688	688
R^2	1.000	1.000	0.865	0.898
AIC	-4700.9720	-4328.3939	-3389.8036	-808.1243

Regressions 2 – 4 weighted by state population

All models include state and year fixed effects and state-specific time trends

Robust standard errors in parentheses, clustered at the state level

* p<.10, ** p<.05, *** p<.01

Table 4: Dependent Variable – Donors per 100 MVA Mortalities (ln)

	(1)	(2)	(3)	(4)	(5)	(6)
First-person consent	0.1430** (0.064)	0.1367** (0.063)	0.1280** (0.060)	0.1247** (0.060)	0.1287** (0.060)	0.1305** (0.059)
Median income (ln)		-0.3645* (0.186)	-0.4321** (0.193)	-0.4538** (0.196)	-0.4162** (0.206)	-0.4084* (0.203)
Healthcare expenditures per capita (ln)		-0.7446** (0.344)	-0.5625 (0.343)	-0.7250* (0.363)	-0.6131 (0.383)	-0.5965 (0.372)
Population density		0.0017*** (0.000)	0.0015*** (0.000)	0.0014*** (0.000)	0.0053 (0.003)	0.0057 (0.003)
Percent African American			0.0136 (1.115)	0.2762 (1.107)	0.2354 (1.120)	0.3357 (1.074)
Percent Hispanic			-3.2217** (1.366)	-3.2588** (1.239)	-2.8798** (1.348)	-2.8562** (1.348)
Percent high school graduates			-0.3925 (1.273)	-0.5052 (1.283)	-0.4792 (1.315)	-0.4290 (1.293)
Percent age 18-34			-0.1793 (1.346)	-0.1790 (1.277)	-0.0495 (1.237)	-0.0343 (1.237)
Percent age 35-49			1.7595 (1.850)	1.8799 (1.793)	2.3563 (1.786)	2.3332 (1.778)
Percent over age 65			-0.5363 (1.565)	-0.0686 (1.610)	0.3526 (1.592)	0.3579 (1.588)
Motorcycle helmet law				0.0493* (0.028)	0.0382 (0.026)	0.0342 (0.025)
Primary enforcement seatbelt law				-0.0790** (0.036)	-0.0680* (0.035)	-0.0662* (0.034)
Percent female in state senate					0.3839 (0.245)	0.3928 (0.241)
Registry in place past one license renewal period						0.0308 (0.053)
Observations	688	688	688	688	672	672
R^2	0.890	0.893	0.897	0.898	0.899	0.899
AIC	-777.4029	-795.0533	-803.3062	-808.1243	-800.9779	-799.6286

Regressions weighted by state population

Models 4 and 5 omit Washington D.C. since it has no state senate

All models include state and year fixed effects and state-specific time trends

Robust standard errors in parentheses, clustered at the state level

* p<.10, ** p<.05, *** p<.01

Table 5: Dependent Variable Comparison

	(1) Donors/10k mortalities (ln)	(2) Donors/1m population (ln)	(3) Donors/100 MVA mortalities (ln)
First-person consent	0.1011* (0.054)	0.1057* (0.054)	0.1247** (0.060)
Median income (ln)	-0.1897 (0.187)	-0.1951 (0.189)	-0.4538** (0.196)
Healthcare expenditures per capita (ln)	0.1036 (0.345)	0.2631 (0.363)	-0.7250* (0.363)
Population density	0.0008** (0.000)	0.0009*** (0.000)	0.0014*** (0.000)
Percent African American	-0.1587 (1.070)	-0.1654 (1.096)	0.2762 (1.107)
Percent Hispanic	-1.3373 (1.065)	-1.3082 (1.044)	-3.2588** (1.239)
Percent high school graduates	-0.1818 (1.121)	-0.0797 (1.121)	-0.5052 (1.283)
Percent age 18-34	0.0361 (1.239)	0.0872 (1.231)	-0.1790 (1.277)
Percent age 35-49	1.4177 (1.671)	1.4693 (1.653)	1.8799 (1.793)
Percent over age 65	-0.6408 (1.441)	-0.3127 (1.411)	-0.0686 (1.610)
Motorcycle helmet law	0.0040 (0.035)	0.0082 (0.035)	0.0493* (0.028)
Primary enforcement seatbelt law	-0.0734* (0.039)	-0.0761* (0.039)	-0.0790** (0.036)
Observations	688	688	688
R^2	0.814	0.801	0.898
AIC	-929.9997	-923.3264	-808.1243

Regressions weighted by state population

All models include state and year fixed effects and state-specific time trends

Robust standard errors in parentheses, clustered at the state level

* p<.10, ** p<.05, *** p<.01

Table 6: Robustness Check – Exclude 2006
Dependent Variable – Donors per 100 MVA Mortalities (ln)

	(1)	(2)	(3)	(4)	(5)	(6)
First-person consent	0.1473** (0.062)	0.1424** (0.060)	0.1417** (0.058)	0.1360** (0.057)	0.1415** (0.056)	0.1437** (0.055)
Median income (ln)		-0.3730** (0.184)	-0.4796** (0.190)	-0.4950** (0.195)	-0.4712** (0.202)	-0.4646** (0.199)
Healthcare expenditures per capita (ln)		-0.7165* (0.426)	-0.5421 (0.337)	-0.6409 (0.388)	-0.5325 (0.394)	-0.5190 (0.387)
Population density		0.0015*** (0.000)	0.0012*** (0.000)	0.0012*** (0.000)	0.0051 (0.003)	0.0055 (0.004)
Percent African American			0.0429 (1.150)	0.3982 (1.118)	0.3279 (1.152)	0.4089 (1.112)
Percent Hispanic			-3.3361** (1.472)	-3.4082** (1.291)	-3.0975** (1.373)	-3.0937** (1.370)
Percent high school graduates			0.3464 (1.244)	0.1533 (1.271)	0.1844 (1.294)	0.2338 (1.261)
Percent age 18-34			-0.2795 (1.316)	-0.2245 (1.232)	-0.0905 (1.195)	-0.0696 (1.194)
Percent age 35-49			1.5306 (1.805)	1.7222 (1.732)	2.1826 (1.717)	2.1774 (1.709)
Percent over age 65			-1.1320 (1.491)	-0.5859 (1.549)	-0.1979 (1.506)	-0.1800 (1.503)
Motorcycle helmet law				0.0655** (0.028)	0.0548** (0.025)	0.0508** (0.025)
Primary enforcement seatbelt law				-0.0837** (0.038)	-0.0701* (0.038)	-0.0678* (0.036)
Percent female in state senate					0.3756 (0.243)	0.3846 (0.240)
Registry in place past one license renewal period						0.0274 (0.055)
Observations	645	645	645	645	630	630
R ²	0.891	0.894	0.898	0.899	0.900	0.901
AIC	-767.7277	-779.3266	-790.1006	-796.2556	-788.9514	-787.4395

Regressions weighted by state population

Models 4 and 5 omit Washington D.C. since it has no state senate

All models include state and year fixed effects and state-specific time trends

Robust standard errors in parentheses, clustered at the state level

* p<.10, ** p<.05, *** p<.01

Table 7: Simultaneous First-Person Consent Legislation and New Registry Enactment
Dependent Variable – Donors per 100 MVA Mortalities (ln)

	(1)	(2)	(3)	(4)	(5)	(6)
First-person consent	0.1834*** (0.067)	0.1694** (0.069)	0.1601** (0.065)	0.1553** (0.067)	0.1631** (0.064)	0.1676** (0.064)
Median income (ln)		-0.3768* (0.203)	-0.4424** (0.212)	-0.4752** (0.212)	-0.4559** (0.220)	-0.4513** (0.218)
Healthcare expenditures per capita (ln)		-0.7549** (0.339)	-0.5669 (0.371)	-0.7626** (0.371)	-0.6381 (0.396)	-0.6122 (0.384)
Population density		0.0016*** (0.000)	0.0014*** (0.000)	0.0014*** (0.000)	0.0041 (0.003)	0.0046 (0.003)
Percent African American			0.3035 (1.227)	0.6600 (1.219)	0.7571 (1.232)	0.9224 (1.174)
Percent Hispanic			-3.0606* (1.555)	-3.0572** (1.359)	-2.5962* (1.460)	-2.5121* (1.447)
Percent high school graduates			-0.4190 (1.341)	-0.4855 (1.304)	-0.3745 (1.366)	-0.2431 (1.318)
Percent age 18-34			-0.3534 (1.548)	-0.4177 (1.472)	-0.3400 (1.425)	-0.3123 (1.429)
Percent age 35-49			2.1760 (2.099)	2.2531 (2.039)	2.7483 (2.005)	2.6921 (1.996)
Percent over age 65			-0.4800 (1.690)	0.0934 (1.715)	0.5960 (1.677)	0.6389 (1.670)
Motorcycle helmet law				0.0525* (0.030)	0.0405 (0.027)	0.0342 (0.028)
Primary enforcement seatbelt law				-0.0902** (0.035)	-0.0755** (0.034)	-0.0730** (0.033)
Percent female in state senate					0.5117** (0.248)	0.5317** (0.240)
Registry in place past one license Renewal period						0.0486 (0.057)
Observations	624	624	624	624	608	608
R ²	0.896	0.899	0.903	0.904	0.906	0.906
AIC	-730.2479	-745.1656	-753.5298	-760.7094	-754.9494	-754.4401

Regressions weighted by state population

All models include only those states that simultaneously enacted first-person consent and a compliant donor registry.

Excluded states are Kansas, New Mexico, Virginia, and West Virginia.

Models 4 and 5 omit Washington D.C. since it has no state senate

All models include state and year fixed effects and state-specific time trends

Robust standard errors in parentheses, clustered at the state level

* p<.10, ** p<.05, *** p<.01