

**Report on the Division of Transplantation's Grant Program 1999-2004:
Social and Behavioral Interventions to Increase Organ Donation**

Prepared by
The Institute for Campaign Research and Evaluation
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Table of Contents

	Section	Page
I.	Overview and Summary of Report	3
II.	Findings from DOT Grant Program	7
II.a	Community Outreach and Media Campaigns	7
II.a.1	Community Outreach Campaigns	7
II.a.2	Community Outreach Campaigns with Mass Media Components	10
II.a.3	Division of Motor Vehicles (DMV)-Based Campaigns	12
II.a.4	Minority-focused Campaigns	14
III.	Worksite-based Campaigns	16
IV.	Professional Education	18
V.	School-based Interventions	19
VI.	Hospital-based Interventions	22
VI.a	Communication with Potential Donor Family Members	22
VI.b	End-of-Life Care Issues	23
VI.c	System-wide Hospital Interventions	25
VII.	Common Problems Experienced by Project Teams	27
VIII.	Potential Future Directions for the DOT Grant Program	28
IX.	List of Projects Reviewed	30
X.	Model of the interrelationship between public education and hospital-based efforts' success on improving organ donation outcomes	31

Summary Report: Social and Behavioral Interventions to Increase Organ Donation

Overview of the Division of Transplantation (DOT) Grant Program

In spite of its relatively recent inception, the DOT grant program has yielded promising replicable programs with demonstrable impact on improved public opinion and knowledge about organ donation, increased willingness to donate (as demonstrated through signed donor cards or through donor registry participation), increased rates of referrals of potential donors to OPOs by hospitals, and increased family consent rates for the donation of a loved one's organs. In turn, these interventions have yielded an impressive number of additional organs available for transplant, ultimately saving the lives of many people on the transplant waiting list.

Generally speaking, public education efforts in the area of organ donation, probably because of their "unproven" effects on public behavior, are largely under-funded. To address the need to systematically discover the best methods for increasing the public's willingness to donate organs (and to express their wishes to donate to family members), DOT began to fund "Model Social and Behavioral Interventions to Increase Organ Donation" in 1999. Projects had to be theory-based and have a rigorous evaluation component. One of the most unique aspects of the program is its requirement to establish a consortium of organ procurement professionals and researchers, assuring that programs would be faithful to the realities of public education about organ donation while maintaining methodological rigor. As a result, a pattern of findings has emerged that should provide a blueprint for creating more effective outreach campaigns that are linked to definitive outcomes ranging from increased knowledge and improved attitudes toward organ donation, and increased intent to donate to actual demonstrated behavioral willingness to donate (by signing a donor card or joining a donor registry) and ultimately, actual rates of organ donation.

The scope of this report

This report reviews grant projects that were funded in fiscal years 1999, 2000, and 2001 which submitted final reports by December, 2005 containing sufficient evaluation procedures that the level of success of the program could be assessed. It should be noted that many projects file for one-year no-cost extensions because the short 3-year time frame is often inadequate to fully complete the project and/or evaluation procedures. However, where solid preliminary data exist from ongoing projects, this information is integrated into the report.

Overview of Interventions

The establishment of public campaign principles to encourage donation have occurred only recently, given that only the projects initiated in the years 1999 - 2001 have been completed. One finding that has been clear is that organ donation promotion efforts cannot rely on principles thought to be effective with other health-related behaviors for several reasons, including:

- Donation happens only after death (no immediate consequences)
- Donation, the behavior that we are trying to encourage, does not (directly) benefit the donor
- As part of our promotional efforts, we require members of the public to think about their own deaths and to talk about their own deaths with their loved ones.

Contrast these conditions with traditional health promotional efforts such as smoking cessation, drug abuse prevention, and diet and exercise and it becomes clear that organ donation is indeed a unique health issue that requires innovative approaches.

The interventions funded by DOT can be divided into two general categories: Public education and hospital-based interventions. Public education projects include:

- Community outreach campaigns, many of which were focused on a particular minority community
- Mass communication campaigns, virtually all of which also include supporting grassroots efforts
- Campaigns involving the Division of Motor Vehicles as the site of organ donation decision-making
- Worksite campaigns
- Professional education for members of occupations that impact the public's willingness to donate, including doctors, lawyers, and funeral directors
- School-based interventions for high schools (including driver's education classes) and universities

Hospital-based interventions include:

- The development of in-house coordinator programs
- Transplant coordinator training, including communication practices during the requesting process, cultural awareness, and family grief processes
- System-wide hospital interventions to increase acceptance of organ donation

Summary of Theories Used as Foundation of Interventions

A number of theories have been used as the foundation of DOT-funded interventions. The most common primary theories include the theory of reasoned action, theory of planned behavior, the transtheoretical model (aka "the stages of change"), and the diffusion of innovations. At their core, most of these theories posit that behavior change (the willingness to sign a donor card, tell family members about their donation decision, consent to donation, or engage in improved potential donor referral behaviors) is a function of people's attitudes toward the behavior, feeling that they are actually able to perform the behavior, and their perceptions that their social group supports the behavior.

Overview of the Most Effective Methods/Evaluative Techniques

The two most solid evaluation techniques used in the grant-funded programs are:

1. Tracking an entire population's actual behaviors before and after and intervention (e.g. increases in DMV donor registries, number of referrals, family consent rates) in both control (no campaign or program to improve organ donation-related outcomes) and intervention locations.
2. Random sample surveys before and after an intervention, comparing responses between the group/location that receives the intervention and another similar group that did not. It should be noted that the random sample and the number of people who respond to the survey must be large enough to make valid comparisons between the two groups.

Summary of Most Important Findings from the DOT Grant Program: What Works

General findings:

- The involvement of a researcher from the start of project planning process yields the most valid program evaluation.
- University-based researchers (rather than commercial research firms) generally have more experience with rigorous program evaluation research. Academic researchers often have both more experience with and motivation to write peer-reviewed publications, which enhances the dissemination of findings of the DOT program.
- The Principal Investigator or de facto project leader (sometimes the Principal Researcher or co-Investigator) should be either local or on-site. Long-distance management of large project does not allow for adequate oversight of project activities, often leading to missed deadlines and a lack of adherence to the original project plan. Having an experienced leader at the helm of a project also appears to enhance the success of a project. Determination and problem-solving skills are a necessity for overcoming obstacles or re-negotiating access to intervention sites.
- Assembling an external advisory board with representation from all stakeholders appears to enhance the quality of the intervention that is ultimately developed for any given population.
- Although it is easy to believe that improving knowledge about organ donation (or the grieving process, or brain death, or the necessity of notifying OPOs of imminent death of a potential donor) will translate into actual behavior, it is important to take the intervention one step further. The targeted population must have this information translated into very practical, specific strategies that directly address the exact goal of increasing consent rates, referrals, etc., through scripting, communication training (practiced through role-playing), or by telling people exactly how they can become organ donors.

Campaigns centering on communities or the workplace:

- Campaigns that include an interactive component with volunteers or outreach workers trained to address myths common in each community appear to be more successful.
- Culturally similar outreach workers are an important element in successful interventions that target minority communities.
- Using appropriate settings within the community (e.g. churches and doctors' offices)—churches helps to overcome perceptions that donation runs counter to religious beliefs or that organ donation is part of a corrupt medical system. It is worth noting that medical mistrust is generally directed toward large medical institutions or unknown medical professionals rather than family practitioners.
- Developing partnerships with ethnically-specific community organizations, and developing a consistent presence at virtually all major events central to a minority community enhances the success of minority campaigns.
- Well-placed interactive kiosks offer the opportunity for people to acquire information about organ donation and, in the case of some states, the opportunity to sign up to become a donor.
- DMV-based registries offer an excellent opportunity to monitor the success of community outreach activities and media campaigns because they provide immediate evidence of increased willingness to donate.

- Community outreach campaigns work best when paired with media campaigns (and vice-versa).

Media campaigns:

- A media campaign alone may not be enough to produce significant behavioral change.
- Campaigns targeting Hispanics should use Spanish-language messages with media placement in popular Spanish-language television programs
- People featured in campaigns should be ethnically/culturally similar to the targeted population.
- A single, general population campaign is unlikely to improve minority population outcomes. Parallel campaigns may be necessary.

School-based settings:

- A comprehensive curriculum needs to be presented to teachers who are themselves exposed to training/education about organ donation.
- Gaining the involvement of parents through a student assignment to conduct “parent interview” helps to expand the influence of a school-based intervention.

For hospital-based settings:

- In-house coordinators have demonstrated high effectiveness in improving organ donation-related outcomes (referrals, cooperation with hospital staff, consent rates) when compared to traditional, OPO-based coordinators.
- Specific communication training of requestors, health care providers, and other hospital personnel such as social workers or chaplains should include scripting and role-playing, especially with standardized patients, in order to improve targeted outcomes.
- Culturally-similar requestors have demonstrated a significantly positive impact on consent rates.

Findings from the DOT Grant Program

Community Outreach and Media Campaigns

Community Outreach Campaigns

Public education divisions of most organ procurement organizations (OPOs) in the U.S. tend to focus the bulk of their energy on community outreach events. These are generally low-cost activities with the opportunity to address myths and misconceptions about organ donation in a manner that is tailored to individual populations (e.g., school-aged children, church congregants, minority populations). Moreover, such events allow OPOs to put a “human face” on organ donation because OPOs frequently include testimonials from transplant recipients or donor family members as part of their outreach strategy.

Most of the funded programs in this area included multiple strategies, the most common of which was to support community outreach events with mass media campaigns; these projects are discussed in the next section. There are other successful strategies implemented by the consortiums funded by DOT, including community outreach activities paired with hospital-based activities, including efforts to re-train OPO requestors to be more effective through improved communication or to become more sensitive to important cultural issues, and/or to use OPO requestors who are culturally similar to potential donor families. The effectiveness of hospital-based aspects of these projects is evaluated in a subsequent section (“Hospital-Based Interventions”). Projects that were primarily based on community outreach but that reported airing radio PSAs, for example, but did not engage in a systematic evaluation of this (minor) media component are categorized for the purposes of this report to be “community outreach campaigns” and are discussed in this section.

Most community outreach projects systematically combine events that are held in different settings or that are designed to systematically target (again, in a systematic fashion) particular populations. One such example targeted the Asian and African American communities of central California¹. First, community outreach workers who were members of the African American, Chinese, and Filipino communities were hired and trained. Second, activities of these outreach workers focused on settings and events within the targeted communities, including churches, schools, and ethnic festivals. By partnering with community-based sponsors of these events, OPOs realized an unexpected long-term benefit: greater credibility within these minority communities. Two key outcome measures demonstrated the effectiveness of this comprehensive approach (which also included hiring culturally similar requestors). The results of a random sample pre- and post- telephone survey of community members showed significant improvements in the intent to donate organs. A second outcome measure showed an impressive increase in actual consent rates during the project period, compared to previous years. It is estimated that approximately 80 *additional* transplantable organs were realized as a direct result of the project over just two years, demonstrating the cost-effectiveness of a relatively simple set of outreach strategies.

Another project in Buffalo² successfully utilized the strategy of hiring and training community educators who were members of the targeted African American and Hispanic communities. Through a partnership with the area’s medical school, medical students assisted community

outreach workers in educating members of each community about organ donation in a variety of settings, including community centers, medical clinics, churches, and community events. The project demonstrated the efficacy of including interaction with an outreach worker rather than simply distributing informative brochures. Also, including a medical student added to the effectiveness of the program, as did hosting events at neighborhood churches. The project was able to demonstrate its effectiveness (through a random sample pre/post-test survey with a combined total of approximately 14,000 Latinos and African Americans) in reducing resistance to donation as well as increasing the willingness to talk with family members about donation. Perhaps most revealing are the steady increases in consent rates in both communities over the project time period: consent rose from a pre-project 26% to 31% in the first year of the project, 40% in the second year of the project, and 45% in the project's final year.

A project in Houston³ also used outreach in Black churches as a central strategy for increasing the willingness to donate among African Americans. However, these efforts were met with mixed results. LifeGift created a professionally produced manual for African American clergy and were successful in increasing the perceptions of clergy that organ donation was an important community issue. A detailed study in four area Black churches, however, demonstrated that there were few appreciable increases in the outcomes of interest (comfort level with organ donation, believing that organ donation is not against one's religion, medical mistrust, and willingness to have family discussions about donation), nor did actual donation consent rates rise during the project period. It is unclear what types of outreach activities the project team conducted in Houston churches and whether the information or persuasive appeals were tailored to the outcomes that were measured.

Yet another project that used churches as the primary site for outreach and education activities centered on the African American/Black, Haitian, and Hispanic communities in Miami⁴. Because the results of formative research demonstrated that 2/3 of Haitians and Blacks and half of Hispanics had not even considered becoming potential organ donors, this campaign focused on targeting barriers that included perceived inequities in the organ allocation system, medical mistrust, and the belief that donor families incurred extra costs. The project was able to improve knowledge about organ donation in all three ethnic groups, especially among Haitians, as well as the rate of family discussions about donation. However, Blacks were the only group that significantly improved on the rate of signed donor cards (from 10% to 16%). Interestingly, both the Miami project and the Buffalo project concluded that clinics were not a particularly efficacious site for outreach because outreach workers were interrupted when the patient was called into the office and because brochures alone did not appear to effect actual behavioral change.

However, outreach in a similar setting (hospitals) was successfully conducted through the use of interactive computer kiosks placed in hospitals in several cities in Louisiana⁵. Although it is clear from their results that most people sign up to become donors through the state's driver's license bureau, the kiosks were able to generate more donor registrations than all of the OPO's other community outreach events. Because the kiosks cost approximately 5-6 thousand dollars each and because maintenance costs were borne by hospitals (who were gifted the kiosks with the stipulation that organ donation information and access to the registry remained), this strategy

may be highly cost-effective when compared to the salary, benefits, and training costs associated with hiring additional outreach workers.

Overall, community outreach campaigns tended to focus on particular ethnic or racial groups, with an impressive rate of success. Partnership with community and religious organizations appear to be central to the success of these interventions, as is the use of culturally-similar community outreach workers to educate each community.

Community Outreach Campaigns with Mass Media Components

Because of the high cost of purchasing mass media many project teams elected to focus exclusively on community outreach activities. However, many DOT-funded community-based projects include some type of mass media component (radio, television, and/or print) because of the opportunities afforded by federal funding. It should be noted that because the efficacy of organ donation public education campaigns had not yet been tested (and indeed, principles that can lead to successful outcomes are still being evaluated), OPOs have been largely reluctant to devote significant resources to media campaigns. Thus, the grant program will eventually give OPOs the opportunity to determine future courses of action based on the lessons learned from these projects.

Two projects, one in California⁶ and the other in Arizona⁷, targeted Latinos with a Spanish-language media campaign. Interestingly, pre/post-test telephone surveys (conducted in Spanish) of Hispanics in Arizona revealed little movement in self-reported behavior change, such as signing a donor card (although there were such increases in California). However, both areas reported an increase in the willingness to talk about organ donation with family members. Perhaps as a function of increased family discussion about donation, actual consent rates rose in both areas during the project periods, and at a rate that exceeded any increase in consent by the White population, providing evidence of the effectiveness of such targeted campaigns. For example, consent rates in Arizona among Hispanics rose 11% while the consent rate for whites rose 6%. In Southern California, similar results were found for the same type of campaign. In addition to improvements in knowledge and attitudes as demonstrated through pre/post telephone surveys, Hispanic consent rate in Southern California increased from a baseline of 32% to 48%, 55%, and 57% during the three years of the project. Given the large population of Hispanics in California and Arizona, these projects have resulted in increased numbers of organs available for transplant which translates into many lives saved.

An ongoing project in Charlotte, North Carolina⁸ is targeting African Americans with combined outreach activities and a supporting mass media campaign. Community-based activities include outreach in Black churches (presentations, church bulletin inserts), outreach through the Black Medical Association (continually stocking brochures with donor cards in all area clinics, doctor's offices and dental offices that serve primarily African Americans), and participation in Black community events (including festivals, health fairs, and sponsorship of a large annual gospel concert). The media campaign consists principally of radio and television PSAs produced by the Coalition for Donation, the national public education organization funded by OPOs. Because one of the key outcome measures is donor registry activity, the success of the program can be tracked in the interim. Relative to baseline activity on the DMV-based donor registry for both African Americans and non-African Americans, it is clear that over the course of the last seven months, African Americans are registering as donors at an increasing rate, and at a rate of increase that exceeds that of non-African Americans. The actual consent rate for donation among African Americans has jumped 56% during the project period, while the consent rate for non-African Americans has held steady, providing evidence that this African American targeted campaign is effective.

As with the community outreach campaigns, projects that reinforced grassroots efforts with media components tended to focus on specific minority groups. Perhaps because of the concentrated focus on the specific goal of changing behavior in a single population, these projects were highly successful, not just in raising knowledge or awareness about organ donation, but in improving actual consent rates for donation. These significant improvements in tangible outcomes have resulted in an increased number of organs available for transplant, which is especially important in the African American community where tissue-type matching issues remain a concern.

Division of Motor Vehicles (DMV)-Based Campaigns

There are two projects that use Drivers' License Bureaus as the primary context or target for interventions. A Chicago group⁹ developed a sequence of activities within a DMV with a predominantly African American clientele, including the distribution of ethnically tailored brochures containing information about organ donation and brief one-on-one discussions with a trained outreach worker. In addition to monitoring DMV donor registry rates, the researchers used the results of phone surveys to determine whether the intervention would have an impact on family discussions. Although donor registry rates did not improve significantly above the 26% baseline rate, people who had received the intervention and had registered as donors were significantly more likely to discuss their intentions with family members than those who had not received the intervention.

A somewhat different approach was taken by a Utah consortium¹⁰. Rather than using the DMV as the site of the intervention to promote the donor registry, the Utah team used a variety of media and other outreach strategies to promote the registry in advance of the decision-making process at DMVs. As a result of a combination of media campaigns, worksite interventions, direct mailings to zip codes where registrants were underrepresented, and other community outreach events, the donor registry grew from 54.4% to 63% of the population in just over two years. Similarly, the consent rate rose from 65.8% to 71.4% over the same period. Perhaps even more importantly, the consent rate of the families of potential donors who were on the registry was 97% (57 of 59 potential donors) while the same rate of non-registrants was 61% (51 of 83 potential donors). Thus, the registry is responsible for a net increase of 21 additional donors, representing a substantial number of additional transplants for potential recipients on the transplant waiting list. This project points to the importance of conducting further research on the impact of registries on donation rates, as well as to the potential of using DMV registry figures as evidence of the impact of public education campaigns.

Although there are few projects that focus on DMVs, this may be a promising avenue for further research for two reasons. First, DMVs represent a key point for organ donation decision-making for many people. Providing information in DMVs may assist people in making this important decision. Second, OPOs in states that have DMV-based registries have a built-in, immediate means of evaluating the effect of providing information in DMVs, or perhaps more importantly, the effect of all types of public education campaigns.

Minority-Focused Campaigns

One of the most notable features of the Division of Transplantation's grant program is the number of theory-based interventions that include a special (or exclusive) focus on minority populations. Especially important are campaigns targeting African Americans not only because of the disproportionate lack of willingness to donate organs, but because African Americans are overrepresented on the transplant waiting list. Hispanics, the largest minority group in the U.S., face not only cultural barriers to accepting organ donation but frequently language barriers as well. The attitudes, knowledge, and behavioral willingness of other minority populations such as various Asian minorities, the Arabic/Chaldean community, American Indians, and others, remain largely a mystery to researchers as well as to public educators in the organ procurement community. The DOT program has funded successful endeavors that shed light on the types of interventions that may be the most successful in a variety of cultural communities.

In 2004, DOT funded a number of special 2-year projects that required grantees to create media and grassroots campaigns that focus on minority communities. At least 75% of funds were required to be spent on media buys, a requirement that was intended to help test whether some degree of media saturation would produce a measurable increase in key outcomes of interest in minority communities. These projects will conclude next year; however, where available, preliminary findings from these projects are presented.

Many projects with an emphasis on minority communities targeted more than one community, depending on which minority groups predominated in an OPO's service area. A number of the findings have been discussed in earlier report sections; therefore, this section will focus on findings particular to each group.

African Americans/Blacks

Most projects targeting African Americans (or Blacks, a term that encompasses people of Caribbean or West Indian descent) focus on churches as an important setting for community-based outreach. In addition to this, successful projects have concentrated on building community partnerships with Black community and professional organizations and have made concerted efforts to have a presence at all community events, including having information tables staffed by African American staff and volunteers or even sponsoring one or more of these events. Cultural similarity of community outreach workers as well as transplant coordinators was a key part of successful interventions targeting the African American community.

Hispanics/Latinos

Hispanic outreach campaigns have been largely successful and have several elements in common. First, Spanish-language media messages were placed in Spanish-language programming. Similarly, Spanish-speaking outreach workers (either traditional OPO community education professionals or trained promotores) were a key element to building a presence in the community and delivering organ donation messages to the community. Second, as with outreach in the African American community, building partnerships with business, professional, and community organizations and developing a consistent presence at Hispanic community events was another important strategy in successful campaigns. Both pre/post evaluation phone surveys (conducted in Spanish) and monitoring of Hispanic consent rates

(compared to consent rates of Whites) demonstrated the success of these interventions in increasing the willingness to donate and improving perceptions of family and community support for organ donation.

Asians

There are only two campaigns thusfar that specifically target the Asian community (rather than simply monitoring the effect of a general campaign on Asians). However, these campaigns demonstrate the importance of employing culturally similar outreach workers and/or requestors who speak the language of the targeted community. As One Legacy points out, however, the Asian community is not mono-lingual; many languages are spoken even among people from a single country (China). However, by targeting the largest Asian groups and by building relationships with reporters from the newspapers that serve these communities, information about organ donation was able to be disseminated.

Worksite Campaigns

An alternate way of reaching the public with organ donation promotion messages can be accomplished by bringing campaigns to the workplace. Because workplaces are communities where people spend much of their time they may prove to be potentially productive contexts for public education, especially when the stories of co-workers who have been affected by organ donation are told through internal media, as is the case with three of the campaigns discussed below.

An early worksite campaign project was conducted in Kentucky with United Parcel Service¹¹. A campaign that included site visits and the use of internal media to disseminate information about organ donation as well as the personal stories of two UPS employees (a donor husband and the father of a girl on the transplant waiting list). External media in the form of billboards located on roads leading in and out of the UPS worksite were also used to disseminate general information about organ donation. A 10% stratified random sample responded to pre/post-test surveys. Compared to another branch of UPS that served as a control site, the intervention site showed statistically significant increases in the willingness to become a donor, to talk with family members about organ donation as well as the intent to talk with family about donation in the future, knowledge about organ donation, and attitudes toward donation.

Because this worksite campaign used only one company and could not pinpoint the campaign elements that contributed to campaign success, a subsequent campaign¹² using six matched worksites was planned, using universities as the sites of two types of campaigns (contrasted against control sites). The project, called the University Worksite Organ Donation Project (conducted in AZ, AL, NC, NJ, PA, and TX) heavily utilized internal media including campus papers and newsletters in addition to more traditional outlets such as billboards and radio. In one of the quasi-experimental conditions, only media messages (including those that featured the stories of members of the university community) were used to promote organ donation. In another condition, the media campaign was supported by on-site visits by OPO staff and volunteers. A random stratified pre/post-test mail survey demonstrated that compared to the control condition, there was a statistically significant advantage to adding on-site visits on whether respondents reported signing a donor card or talked to family about organ donation. However, the media-only campaign did not produce results that were statistically different from the control condition. The project organizers argue that the outreach component offers community members the opportunity to “put a human face” on the issue of organ donation because many volunteers are transplant recipients or donor family members. Additionally, the site visits provide an opportunity to ask questions about organ donation that may linger even after seeing ads or billboards promoting organ donation.

In Chicago¹³, a worksite campaign was developed that involved 12 companies, each with three separate branch locations which were randomized to the three quasi-experimental conditions: control (general health presentation, with organ donation information imbedded), basic (a concerted educational effort that included testimonials from transplant recipients), and enhanced (where additional information was provided to help employees persuade family members to also become donors). The interventions were delivered via “lunch and learn” sessions. Based on a pre-test survey and one month follow-up post-test survey, the project demonstrated success in

producing greater willingness to donate and greater perceptions of the benefits of donation relative to the control groups. The intervention groups as well as the control groups showed statistically significant increases in the willingness to talk with family members. However, it should be noted that only between 5 and 45 people attended these sessions, with an average attendance of 22 people. Although access to corporations to conduct lunch-and-learn sessions is generally easy to negotiate, the limited number of people within large corporations who receive the message compromises the total potential impact of this type of worksite intervention. The extra time and effort to secure company-wide access for a comprehensive worksite campaign is likely to reap far greater rewards because public education necessarily operates on an economy of scale.

A larger-scale series of worksite campaigns was developed in New Jersey¹⁴. This ongoing project has completed campaigns with 18 companies, but will eventually reach employees in a total of 45 companies. Companies are divided into three quasi-experimental conditions that mirror those of the University Worksite Organ Donation Project (mass media campaigns contrasted against campaigns that also include on-site visits by staff and volunteers). In addition to expanding the number and diversity in the type of companies reached, campaigns last only 10 weeks. Preliminary results from pre/post-test telephone or paper surveys of a random sample of employees indicate that campaigns that include on-site visits are more successful than those that use only internal media to disseminate information about organ donation. Further, campaigns that publicize the stories of co-workers who have been touched by organ donation are more effective than campaigns that use only general stories about local people who have been personally affected by organ donation. These findings generally mirror the results of both the United Parcel Service Project and the University Worksite Organ Donation Project. Project researchers intend to conduct an in-depth analysis of the structural features of organizations that contribute to the success (or failure) of worksite campaigns, which should help other OPOs make decisions about where best to devote limited public education and outreach resources.

Worksite campaigns show considerable promise for replication. A blueprint for successful campaigns is slowly emerging, which includes particular elements, multiple on-site visits to encourage employees to become declared donors, and publicizing the personal stories of employees from each organization. Gaining (and maintaining) access to large organizations for worksite campaigns appears to be the principal challenge facing these campaigns, which nevertheless hold the promise of reaching many thousands of people with organ donation information as well as easy opportunities to become potential organ donors.

Professional Education

Because there are a number of professions that have potential impact on public attitudes toward organ donation, it is important for members of those professions to be knowledgeable about donation. Thus, some project teams elected to focus on professional education for medical professionals, lawyers, clergy, and funeral directors. Funeral directors in particular have a potentially powerful (negative) impact on families' willingness to donate, although the exact number of cases where funeral directors have influenced families against donation has not yet been determined. Funeral directors' own lack of knowledge about organ donation combined with the added burden (in both time and expense) of preparing a donor's body for burial has undoubtedly both contributed to the problem.

Funeral directors have been targeted by two projects in New York. The National Kidney Foundation¹⁵ conducted a multi-phase intervention. The project began with formative research that revealed that funeral directors knew little about the organ donation process—and that organ procurement organizations knew little about the funeral process. This led to the development of a “Best Practices” document that was then distributed to organ procurement organizations in Connecticut, Iowa, and North Carolina, who in turn distributed it to a large number of funeral directors. Comparisons of pre- and post-test internet surveys demonstrated improvements in OPOs' perceptions of funeral directors support of clients' decision to donate, which rose from 48% to 63%. One of the most surprising findings was that before the intervention, 29% of funeral directors did not believe that a normal open-casket funeral could be held for organ donors. After the intervention, only 13% reported this belief. Although the evaluation of the program is limited by low response rates, lack of a matched-sample, and the lack of inferential statistical tests of the data, it does appear that both the OPO community and funeral directors could benefit from mutual education about the nature of the others' mission.

In Buffalo, funeral directors¹⁶ *

Because clergy also have powerful influence over parishioners' decision-making about spiritual issues (particularly in the African American community), LifeGift³ developed a program designed in large part to educate the clergy of Black churches. Formative research led to the development of two sets of materials: a resource manual for clergy as well as a package on the Biblical perspective on organ donation for use in Sunday schools and churches. As a result of the intervention, the proportion of clergy responding that the issue of organ donation is important in the Black community rose to two-thirds. Unfortunately, the project did not translate into a greater willingness to donate organs among the parishioners of these clergy.

Lawyers who offer estate planning services are another potentially important outlet of organ donation information. Because clients are already in a mental state where they are confronting the eventuality of their own deaths, it was posited that they would be more receptive to organ donation information. The project team¹⁷ first educated lawyers in the Buffalo area through the use of in-service informational sessions as well as continuing legal education and provided lawyers with brochures to give to clients. As a result, the project did increase clients' pre/post-test knowledge about organ donation by 73%, increased family discussions by 33% and increased the rate of signed donor cards or registries by 16%. However, preliminary reports

have indicated that the primary barrier faced by the project has been convincing individual lawyers employed by the firms which granted access for the program to actually distribute the information. This is apparently due to the amount of billable time associated with speaking with clients about organ donation. It should be noted, however, that another key part of the project involved the development of a curriculum on organ donation for law schools in the area; however, because the project has a one-year extension, the evaluation of any results associated with the curriculum have yet to be reported.

There are also medical schools that have been receptive to curricula on organ donation. Medical students at University of Buffalo, after receiving a special unit on organ donation, had the opportunity to participate in community outreach in the African American and Hispanic communities. Their assistance with outreach produced the most effective of the three interventions to improve the willingness of the public to donate. This project² is reviewed in more detail in the “Community Outreach Campaigns” section.

Projects that have focused on professional education have met with mixed success thus far, at least as far as can be evaluated using social scientific methodology. While it is true that maintaining access to the population of interest is an important issue, it appears that evaluation efforts were sometimes compromised by low response rates and weak research methodologies. This certainly does not mean that professional education does not hold promise, but rather that stronger projects are needed to evaluate the potential impact of professional education projects on improving the rates of organ donation.

School-Based Interventions

Several interventions have focused on educating school-aged children in high school settings. These educational interventions have been done in three different contexts: health education classes, driver's education classes, and through the internet.

A traditional classroom-based intervention was conducted in Buffalo¹⁸, which began with the development of an organ donation curriculum to educate teachers about the issue. The project then contrasted the effect of having the project team lead classroom presentations and discussions against teacher-led programs. Compared to control groups, pre/post-test surveys demonstrated that both groups did equally well in increasing student knowledge and willingness to donate organs. Especially innovative was the component that required students to interview their parents about their views about donation. This part of the intervention had a substantial impact on parents donation-related behaviors: 20% of parents reported having signed a donor card as a result, with another 46% reporting that they would now "seriously consider" becoming an organ donor. As with smoking cessation and seat belt use, it appears that organ donation may be another issue where young people have a strong influence on their parents' attitudes.

In the Washington, D.C. area¹⁹, 15 diverse schools participated in a drivers' education program. Half of the schools were assigned to a control condition, while the other half received a 90-minute educational program consisting of videos, presentation of factual information about organ donation, and open discussions. Both groups were given t-shirts and freebies for their participation in the study. Results, however, were mixed. Both the control and intervention groups increased in their intent to donate, as measured by pre/post surveys. (Pre-test surveys were administered two weeks before the intervention and post-tests were administered immediately after the intervention.) However, knowledge did increase in one set of intervention group schools (n = 5).

An educational web-based intervention²⁰ targeting children was developed by a Michigan team. "The Transplant Journey" (www.transweb.org) leads users through the transplant process, highlighting both information about human biology as well as the impact of organ transplants on people's lives. Half the students were randomly assigned to a control group and were directed toward a website that provided information about the common cold. At the end of both educational units, students (N = 490) were given the opportunity to follow a link to the Michigan donor registry. Nearly 16% of the control group students followed the link to the registry, while almost 22% of the intervention group students took the opportunity to visit the registry. Although this difference did not prove to be statistically significant, pre/post-test comparisons on measures of knowledge, attitudes, and willingness to donate all showed a statistically significant advantage for the intervention group.

Other projects targeting school-aged children are currently in progress. The findings from these three projects are somewhat mixed and it remains to be seen which intervention elements are associated with the most favorable outcomes.

Hospital-Based Interventions

There are several types of interventions that targeted systems centered in hospital settings. The first involved training transplant coordinators (also called requestors) to be more effective in their approach of potential donor family members. The second involved training transplant coordinators and/or other hospital staff involved with transplantation on end-of-life care issues. A third type of intervention attempted to change hospital procedures or organizational culture as a way to reduce internal barriers to organ donation (such as a reluctance to refer potential donors to the OPO because of the extra work that donors represent to nursing staff). A fourth type of intervention examined the effect of having transplant coordinators work “in house” at hospitals, rather than being headquartered at OPOs.

Communication with Potential Donor Family Members

One of the most successful and ambitious interventions of the DOT grant program involves altering the manner in which transplant coordinators approach the families of potential donors. The “presumptivity” approach²¹ posits that by changing the way organ donation is framed to family members and by more or less scripting the interaction with language that presumes that families will consent to donation when given the opportunity, consent rates will increase. The first year of the project was devoted to carefully crafting the training curriculum, using feedback from a diverse advisory board consisting of project staff (which includes bioethicists), a psychologist, a communication consultant, donor family members and a transplant coordinator. After gathering feedback on the evolving curriculum, OPO training sessions were scheduled. Coordinators at four OPOs (serving a total of seven states and 480 hospitals) were trained in the presumptive approach in full-day sessions that consisted of lectures and a number of role-plays.

One notable feature of the presumptivity approach is that rather than emphasizing the surgical procedure that donors undergo as part of organ procurement, transplant coordinators are instructed to talk about the heroic ability of donors to save lives and of the continuing living legacy that donors have. The improvements associated with the presumptivity approach were quite dramatic. Consent rates increased 10% or more, frequently exceeding a total consent rate of 70%. The positive effect of the training was seen across ages, ethnicities, educational levels, and religions. Especially positive effects were noted when requestors were ethnically similar to potential donor family members: nearly 80% when ethnically similar requestors used the presumptivity approach, versus 54.2% with dissimilar requestors using the standard approach. Such a dramatic set of results cannot be ignored. Indeed, the investigators report that they have been deluged with requests for their training program from a number of OPOs.

A similar program was designed by a consortium led by the South-eastern Organ Procurement Foundation in Virginia²², except that efforts focused on testing the effects of training transplant coordinators on end-of-life issues and personal stress reduction in 15 OPOs (8 in the intervention group and 7 in the control group). The “Passages to Change” project included four training sessions spread over the 2-year project period; each lasted 1 ½ days and included 20-25 coordinators. Training sessions used lectures, role-plays, discussions, experiential activities and multi-media presentations. By raising awareness of requestors that family members progress

through a series of stages in their donation decision-making process, it was hoped that consent rates would rise. Before the intervention, consent rates in both the intervention and control groups hovered near the 50% mark. In years 2 and 3 of the project, the intervention group's consent rate rose to 56% and 55%, respectively, while the control group's consent rate was 51% and 49% over the same two years, indicating that the intervention resulted in approximately a 5% advantage. This represents a significant increase in the number of donors and the number of organs available for transplant.

A slightly different, innovative approach in Albany²³ incorporated volunteer donor mothers as part of the OPO team that approached potential donor families. Rather than trying to actively persuade families to donate, the MOD Squad, consisting of volunteer donor mothers who undergo psychological screening prior to their participation in the project, act as family advocates and provide both material and emotional support to the bereaved families. However, these donor moms do relate their own experiences with organ donation and provide important information about brain death and the donation process as well as the benefits associated with organ donation. This intervention was conducted at three OPOs and was evaluated not only by comparing consent rates but through the use of qualitative interviews of donor and non-donor families who did/did not receive the MOD Squad intervention. The intervention was associated with perceptions of a more positive hospital experience, with particular gratitude being expressed for the emotional and psychological support provided by MOD Squad volunteers. Additionally, intervention group members were more likely to report that they had been given sufficient time and information needed to make an informed decision about donation. Actual consent rates support the conclusions of the qualitative studies: the consent rate in the intervention group rose to 72.6%, while the consent rate in the control group was 58.3%. Project statisticians controlled for the age of the potential donor (because parents of young children are more likely to consent to donation), which did reduce the advantage of the intervention group to 5.1% (a difference that was still statistically significant). Again, this is clearly an intervention that has the potential to save a rather large number of lives if it were to be replicated nationally.

A less successful program in Virginia²⁴ centered on developing a "family communication coordinator" protocol that utilized hospital chaplains as the center of a team designed to serve potential family members. One key objective was to reduce the burden on hospital staff in the hopes that this would increase the number of referrals of eligible donors to the OPO. Indeed, the number of referrals did increase, which is a fundamental first step toward increasing the number of organs available for transplant. However, actual consent rates for donation decreased over the project years (from a baseline of 67% to project year rates of 43%, 42%, and 48%). There was, however, a significant reduction of role stress among hospital nurses, which is likely the reason for the increase in referrals of potential donors. The reasons for the drop in consent rates need to be carefully examined. Unfortunately, the project team concludes that there is no advantage for ethnic matching with potential family members, an unwarranted and potentially harmful conclusion for two reasons: 1. this strategy has been consistently associated with success among other OPOs; 2. the intervention described here uses hospital chaplains who provide spiritual counsel to potential donor families, not actual requestors. The credibility afforded to spiritual leaders may well transcend issues of race and ethnicity, compared to the

assumed vested interest that transplant coordinators have when speaking to potential donor family members.

Another project that sought to reduce the occupational stress of organ procurement coordinators was conducted in New York²⁵. Coordinators could attend five sessions focusing on stress management, peer support, research findings on effective strategies for increasing donation, cultural competence, and ethics. Unfortunately, the coordinators participating in the program did not rate the curriculum very favorably, which is likely one reason that consent rates did not increase. A second reason centers on the fact that requestors were expected to translate their learning into changed approaches to the request process, rather than explicitly demonstrating through the program how the concepts could apply. It is probably no coincidence that this is the central strength of the presumptivity approach.

In summary, it is notable that interventions that do not involve specific skill training for transplant coordinators (with a well-received curriculum) did not result in appreciable change in consent rates. On the other hand, successful interventions in this category of projects generally increased consent rates through improved communication with donor families, whether through specially-trained transplant coordinators or through screened and trained volunteers who were themselves donor mothers. Increasing coordinators' knowledge of the donation decision-making process that family members undergo also appeared to result in improved consent rates.

End-of-Life Care Issues

Interventions that focused on improving end-of-life care focused on health care providers as well as organ procurement coordinators. Enhancing end-of-life care included providing psychological support to family members, enhanced ability to explain brain death, cultural sensitivity, and general communication skills; the specific skill sets focused on varied by project.

Johns Hopkins²⁶ developed an experiential training program for ICU physicians, nurses, chaplains, social workers, and transplant coordinators, and encouraged them to work as interdisciplinary teams. Training sessions were spread over six months and included three ½-day sessions. These sessions included a variety of topics including cultural sensitivity, legal and ethical issues, shared decision-making, communication skills, and shared decision-making. The intervention utilized standardized patients so that participants could role-play and practice new communication skills. The project team reported some difficulties in persuading health care providers to operate as a team, and some types of health professionals (e.g. physicians) reported more difficulty in dealing with families on an emotional level. Impressively, consent rates rose in intervention hospitals from a baseline of 30-35% to 43.2%, which equated to an increase of 9 extra donors (approximately 27 additional transplants) over just two years of the project; the results of the training program can be expected to endure beyond the project period, however, so increased donation rates are likely to be maintained.

A state-wide project in Georgia²⁷ similarly sought to develop a team-building approach across 15 hospitals in 7 cities. Hospital and OPO staff participated in the program; on average, 44 people from 14 hospitals participated in monthly sessions to discuss a variety of issues related to barriers to increasing organ donation. Not surprisingly, the project did increase levels of satisfaction and comfort between staff members of OPOs and hospitals. Although there were no significant changes in attitudes and knowledge about organ donation, knowledge of end-of-life issues did increase significantly pre- to post-test among intervention group members. More importantly, although both the intervention and control groups experienced increased donation rates, the rate of increase was significantly greater among intervention group hospitals than controls.

Another project that enhanced end-of-life care for potential organ donors and their families was developed by the New England Organ Bank²⁸. The project first assembled an Organ Donation Advisory Committee and a Family Support Team for each of the three participating hospitals (17 other hospitals served as controls). The members of the Family Support Teams attended one-day training sessions on communication and psychological support skills, as well as how to coordinate care for families. Team members also learned how to convey bad news and explain brain death. Over 18 months of the intervention period, referrals increased at a greater rate in the intervention group (18% vs. 7%), which approached statistical significance ($p = .07$). Unfortunately, consent rates did not increase. However, it should be noted that the training sessions did not directly address how to increase donation rates, but rather focused on factors that were thought to indirectly impact donation rates through increased satisfaction among patient families. The intervention did increase perceptions of emotional support, increased communication skills, professional gratification, and OPO-hospital collaboration.

End-of-Life Care interventions for hospital staff and transplant coordinators varied in their capacity to improve consent rates. The most significant factor that seems to be associated with successful projects is the explicit focus on translating the knowledge gained through the intervention into specific applications for actually improving rates of organ donation.

System-Wide Hospital-Based Interventions

Two projects attempted to implement a systemic approach to increasing referral and consent rates in hospital settings. As seen in a number of projects reviewed earlier in this report, OPOs are only one part of an entire system that impacts families' willingness to donate, including transplant coordinators (who may be based in either OPOs or hospitals or both), funeral directors, and hospitals (particularly doctors and nurses who interact with trauma patients). Treating a hospital as an entire system which must be changed in order to improve transplant outcomes is certainly an ambitious endeavor which requires a great deal of commitment on the part of participating hospitals, as well as the project team that attempts to implement such a change.

Certainly one of the most successful interventions of the DOT grant program to date was a four-state, eight-hospital replication of a program that had previously increased donation substantially in two Houston hospitals²⁹. The project team posited that housing transplant coordinators within hospitals would improve efficiency in hospitals' donor referral processes, reduce stress on doctors and nurses by freeing up time that could be spent treating other patients (rather than counseling bereaved family members or explaining brain death), and provide better sources of timely organ donation information to potential donor family members at a critical moment in the decision-making process. Transplant coordinators were recruited and trained, then continuously monitored by the project team. The intervention was an unqualified success. In detailed statistical analyses, comparisons were made not only pre- to post-test, but among hospitals in the same OPO region as well as nationally. Nationally, intervention hospitals had 35% more minority referrals and 7% higher consent rates across all ethnic groups (60% vs. 53%) and a 9% greater consent rate among minorities (51% vs. 42%). The same general pattern of results was found when analyses were performed by city and region.

Interestingly, quantitative surveys of nurses at hospitals seem to indicate that at hospitals with in-house coordinators, nurses develop more favorable attitudes and greater knowledge about organ donation than at hospitals without in-house coordinators. (More detailed statistical analyses are needed on these findings.) Speaking to the systemic effect that in-house coordinators have, the project final report states, "...the presence of an [in-house coordinator]...may also have an indirect effect on favorable donation outcomes by providing nurses in that hospital with more donation information as well as by enhancing appreciation of the work that OPOs do in helping hospital staff and families." The project team does caution that organizational adjustments need to be made, particularly by OPOs, to accommodate in-house coordinators' needs if this system is to be replicated. However, because of the high number of lives that can be saved through increased numbers of transplants by making this system-wide adjustment, OPOs and hospitals should certainly consider implementing this type of adjustment.

Another project in Wisconsin³⁰ sought to increase rates of organ donation by understanding, then improving, levels of knowledge about DCD (Donation after Cardiac Death) among transplant coordinators as well as hospital staff, including physicians. After extensive formative research (including interviews with nurses, physicians, administrators, clergy, social service staff and donor families), and aided by an external Advisory Board, the project team developed

a brochure that explained DCD in ways that targeted key areas of concern among people potentially involved with organ transplantation. Internal support for developing a protocol for DCD was gained rather quickly throughout the Wisconsin OPO's many service area hospitals. As a result, the project doubled the number of hospitals with DCD protocols, from 8 to 16, with another 8 on the verge of adopting a DCD protocol at the time the final report was being written. This led to an increased number of donors, from 12 DCD donations in the year prior to the project to 27 DCD donations during the final year of the project (an increase of 125%). It is unfortunate that another matched OPO system was not used as an experimental control to test whether DCD donations were increasing even in the absence of the intervention and whether the rate of increase of DCD donations was statistically greater among intervention hospitals. Nonetheless, this can be considered a successful intervention.

A different model for the development of new protocol to increase donation in hospitals was developed in Mississippi³¹. The project team took an established procedure, the Clinical Practice Analysis (CPA), which had been used to evaluate group and individual performance of physicians on a number of other types of diagnoses, and applied it to organ donation. In regular section meetings facilitated by a "physician champion," both group and individual performance data were presented regarding organ donation referral, consent, and conversion. Focus groups at the beginning of the project identified perceived barriers to the organ donation process, the findings of which were translated into educational interventions and improved protocols within the hospital. As a result of the project, referral rates rose from 67% at baseline to 95% in 2005. The consent rate relative to the number of potential cases rose from 15% to 37% from baseline to project conclusion, although the absolute consent rate dipped dramatically (50% to 23%) at mid-project period, concluding with a rise to 47%. It should be noted, however, that the project did not target transplant coordinators with educational interventions or improved protocols. In fact, because the number of potential donors doubled from the first year to the second (and third) years, and doubled *again* by the final year, it is likely that transplant coordinators may have been overwhelmed by the increased activity over such a short period of time. Coping with the dramatic increase in the number of potential donors can only be addressed by the OPO; this does not speak to the success of the hospital staff intervention. In fact, this hospital-based program's ability to improve referral rates extended beyond organ donation to include tissue donation, which rose from 90% to 100%, with consent rates rising from 6% to 10%.

[Note: The North Shore Jewish Health System project would fit into this category of interventions, but the printout of their PowerPoint slides provides insufficient information about their evaluation. However, because 3 of the 5 hospitals dropped out of the project, the data are likely to be quite weak.]

This category of interventions is arguably the most complex to manage and yet holds some of the greatest promise for increasing rates of referral as well as consent for organ donation. In-house coordinators are so remarkably successful that they should be considered a "best practice" in the area of organ procurement. While this type of intervention is not without its complications for implementation, the number of lives saved through increased rates of donation is surely an adequate payoff. Similarly, developing DCD protocols and then educating hospital staff on these protocols have been highly successful, warranting replication in other parts of the country.

Common Problems Experienced by Project Teams

Some of the grant-funded project teams experienced problems that are common to most funded projects; few of these problems appear to be specific to the organ procurement field.

First, several projects suffered from unevenness in the implementation of the intervention. This was most common to multi-site projects where liaisons at each site could not be adequately supervised. Second, some projects struggled with the revocation of access to the study sites. The leaders of some project teams were able to recover access through negotiation with study site personnel, while others did not appear to try to preserve access.

This second issue points to the importance of having adequate project leadership. Some projects appear to have been “handed over” to community outreach staff within the OPO even though the Principal Investigator of the project was named as the Executive Director/CEO of the OPO. While some projects in this type of situation were ultimately successful, a disproportionate number of these “handovers” to staff members inexperienced with the complex administrative tasks inherent to grant-funded projects had significant difficulties. A charismatic, likeable leader(s) also appear to facilitate cooperation among OPOs when projects span OPO service areas. (However, this is not to imply that this is a sufficient condition for multi-OPO project success.) Another theme among projects experiencing significant problems is the loss of project leadership when key personnel either left the OPO or otherwise withdrew from the project.

Another personnel issue pertains to the involvement of researchers. The most successful projects involved researchers in the development of the project so that solid intervention procedures could be incorporated. These projects had ongoing involvement from researchers throughout the project period. On the other hand, researchers who were simply “tagged on” to project teams who had responsibilities limited solely to intervention evaluation often found themselves in a position where the intervention simply could not be evaluated because the methodological design was deeply flawed. Similarly, academic researchers (rather than market researchers) have an inherent motivation to construct interventions that can be subjected to rigorous evaluation procedures because their professional reputations rest on the ability to publish results in peer-reviewed journals. Market researchers’ responsibilities, on the other hand, end when a final report is delivered to the OPO. The requirement to disseminate grant project findings then fall to OPO staff, who have little or no experience writing journal articles.

Finally, hiring culturally competent personnel to staff minority-focused projects was occasionally an issue. Project teams that already had these staff members on board were able to navigate potential obstacles such as identifying appropriate sites for interventions, the right types of community partners, and could inform other project team members of potential problems such as whether key concepts could be translated into another language. Some projects assumed that being promised access by a leader of an association meant that member organizations would indeed cooperate. An important lesson is that access must be negotiated with every site that would be included in a project; even then, access is sometimes difficult to maintain.

Potential Future Directions and Recommendations for the Division of Transplantation Grant Program

The increasing sophistication of projects funded by DOT is evident from reviewing recent applications and progress reports. There are an increasing number of academic-based researchers who have partnered with OPOs and who have been disseminating the results of successful programs. This, in turn, has generated increasing interest among social science researchers to create new programs. Changes in rules that now allow applications from non-501c3 organizations mean that researchers can now act as Principal Investigators on projects, further motivating them to compete for funding in partnership with OPOs. Because the success of a project cannot be determined without rigorous methodological design and evaluation procedures, it is important that researchers play a more important role in projects than they had in many earlier projects.

It would also be productive for grant reviewers and OPO professionals to recognize the interrelationships between different types of interventions, including hospital-based programs and public education campaigns. There appears to be a dichotomy in how interventions are viewed; unfortunately, many people appear to subscribe to the view that one type of intervention will have a greater impact on organ donation than the other. As an example, the Mississippi project with an ostensible focus on hospital staff justifiably pointed to OPO/requestor issues that impacted consent rates. More systemic approaches—or at least, interventions that acknowledge all of the stakeholders who impact donation—are needed. The figure that appears in the next section of this report may help to illustrate how each type of intervention can impact the success of the others.

These recent successes and changes in the DOT grant program lead to several recommendations for the future. First, rather than “reinventing the wheel” by funding very similar projects in different parts of the country, national replication grants should be awarded to test the applicability of successful approaches to the entire U.S. (or at least to large regions of the U.S.). The most expensive element of most projects generally has been the evaluation component. Research personnel costs, costs for phone surveys or printing and postage costs for mail surveys, and incentives to increase response rates or to encourage project participation have accounted for a relatively high proportion of total project costs. National replication grants led by PIs of successful projects would not need to spend funds on the development of a proposed intervention; virtually all materials would already be available for immediate use. Similarly, evaluation procedures could be simplified. Rather than extensive surveys of knowledge, attitude, and behavioral intent, evaluation could focus on “hard” behavioral outcomes, such as increases in DMV donor registry rates, referral rates, or consent rates at intervention sites. In the case of hospital-based interventions, the PIs of successful grant-funded projects could take project materials “on the road” to train OPO or hospital staff in proven techniques that will increase donation.

DOT can facilitate the development of innovative new programs to increase donation by creating an easily accessible website to host electronic resources, including survey measures, ads, PSAs, training protocols, school curricula, and “best practices” documents, including those generated by project staff of successful interventions. Additionally, where appropriate,

providing access to final reports of completed projects could prove helpful to prospective applicants who seek to avoid the mistakes of past projects. These reports may also stimulate ideas for more innovative approaches to interventions targeting the same populations or contexts.

This review of programs funded by the Division of Transplantation have demonstrated that there are a large number of successful programs which are saving the lives of people on transplant waiting lists. In some cases, by carefully examining analyses of project outcomes we can pinpoint exactly how many transplants were likely to have resulted from a funded program. Longer funding periods (four to five years rather than the current three years) would allow us to track long-term effects of these programs or assess the cumulative effects of interventions with multiple components. This would add even greater strength to the findings of the cost-effectiveness of many of the approaches developed through the DOT program.

Projects Reviewed

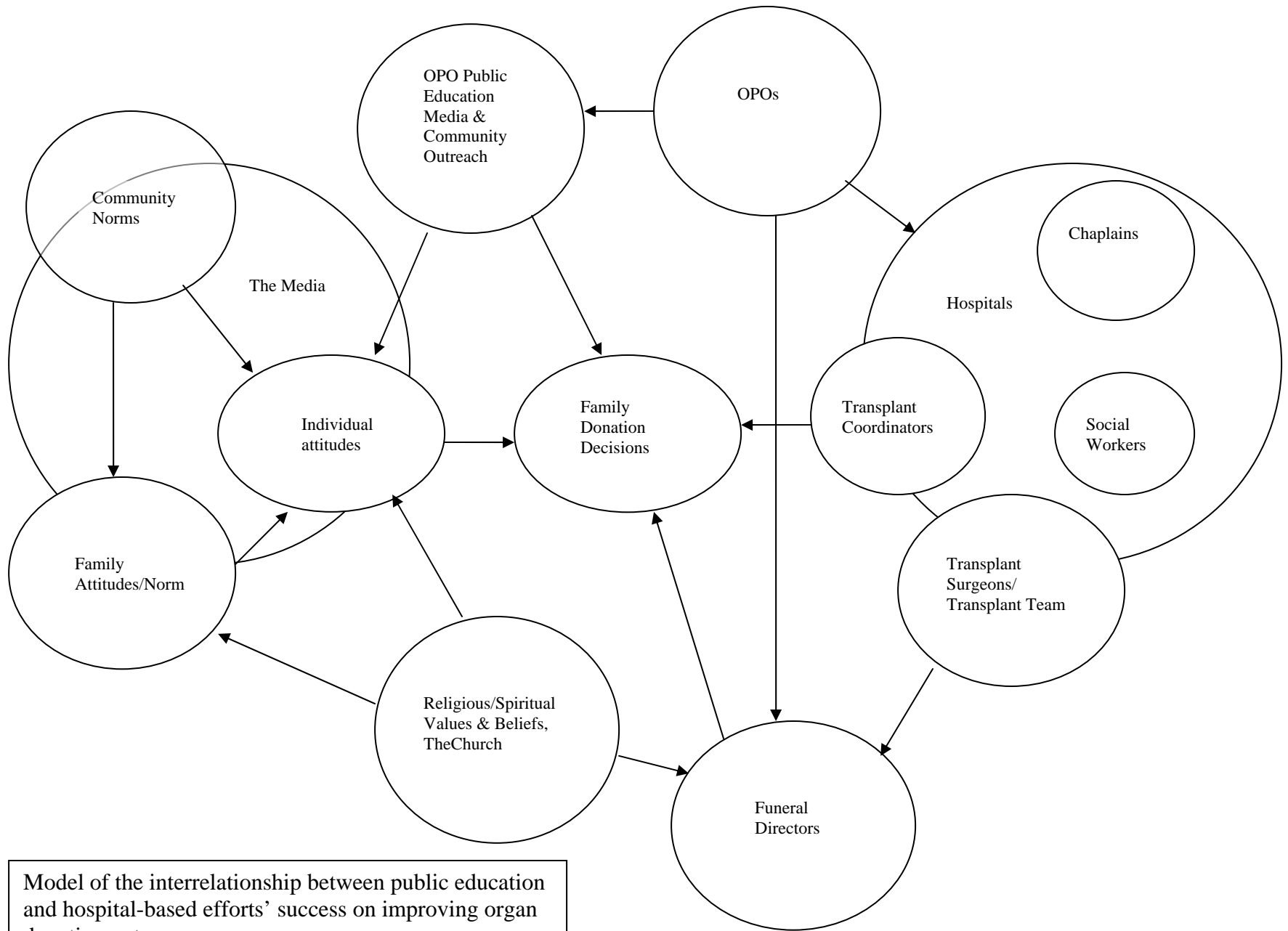
Reference # in Report	Project Type	Project Title	Applicant Organization	State (Addtl. States)	Grant #
1	Community Outreach & Media Campaigns	Proposal for funding to increase organ donation consent rates involving targeted minority populations	California Transplant Donor Network	CA	1 H 39 OT 00013
2	Community Outreach & Media Campaigns	Decision for Life: An intervention to increase organ donation in the African American community, Phase 1 and 2 combination	Upstate New York Transplant Services	NY	1 H 39 OT 00010
3	Community Outreach & Media Campaigns	African American community outreach project: Phase I project	LifeGift Organ Donation Center	TX	1 H 39 OT 00014
4	Community Outreach & Media Campaigns	A model intervention for increasing intent to donate in primary care centers and churches in Miami-Dade County, Florida	University of Miami	FL	1 H 39 OT 00074
5	Community Outreach & Media Campaigns	Kiosk Learning Center	Louisiana Organ Procurement Agency	LA	1 H 39 OT 00028
6	Community Outreach & Media Campaigns	Increasing organ donation within the Hispanic community through mass media public education: Phase 1 + 2 combination	Golden State Donor Services	CA	1 H 39 OT 00026
7	Community Outreach & Media Campaigns	Comprehensive approach to raising organ and tissue donor consent in the Hispanic population	Donor Network of Arizona	AZ	1 H 39 OT 00021
8	Community Outreach & Media Campaigns	The LifeShare project: A multi-media and grassroots campaign to promote African American organ donation	LifeShare of the Carolinas	NC	1 D71S PO 4140
9	DMV-based interventions	Impact of educational interventions regarding organ donation on the declaration of intent to	Gift of Hope Organ and Tissue Donor Network	IL	1 H 39 OT 00001

		donate and on family discussions in the African American community			
10	DMV-based interventions	Improving organ and tissue donation through a comprehensive donor registry and statewide community outreach campaign	Intermountain Donor Services	UT	1 H 39 OT 00078
11	Worksite Campaigns	Increasing commitment to organ and tissue donation through a worksite intervention	Kentucky Organ Donor Affiliates	KY	1 H 39 OT 00012
12	Worksite Campaigns	The University Worksite Organ Donation Project	The New Jersey Sharing Network	NJ (NJ, TX, AZ, AL, NC, PA)	1 H39 OT 00120
13	Worksite Campaigns	Corporate Contributions for Life: Supporting organ/tissue donation awareness in the workplace	National Kidney Foundation of Illinois	IL	1 H 39 OT 00086
14	Worksite Campaigns	The New Jersey Workplace Partnership for Life	The New Jersey Sharing Network	NJ	1 R39 OT 03410
15	Professional Education	Attitudes and needs for improving the funeral and organ/tissue donation process: Pre-test and post-test in 3 pilot markets	National Kidney Foundation, New York	NY	1 H 39 OT 00005
16*	Professional education	[Funeral Home Directors]	Upstate NY Transplant Services	NY	
17	Professional Education	Legacy for Life: Lawyers' role in organ and tissue education	Upstate NY Transplant Services	NY	1 H 39 OT 00076
18	School-based interventions	Talk it Up: Students and families discussing organ donation	Upstate New York Transplant Services	NY	1 H 39 OT 00051
19	School-based interventions	Say YES! To organ and tissue donation: Implementation and evaluation of a promising youth intervention	Howard University	Washington, D.C.	1 H 39 OT 00029
20	School-based interventions	Measuring the effectiveness of a multimedia internet based approach to increasing donor registry	Organ Procurement Agency of Michigan	MI	1 H 39 OT 00002

		participation			
21	Communication with Potential Donor Family Members	A study of the presumptive approach to consent for organ donation	Trustees of the University of Pennsylvania	PA (PA, WA, MN, ND, SD, WI)	1 H 39 OT 00073
22	Communication with Potential Donor Family Members	Staged-based curriculum-training for procurement coordinators to increase family consent for organ and tissue donation	South-Eastern Organ Procurement Foundation	VA	1 H 39 OT 00030
23	Communication with Potential Donor Family Members	Testing and replication of a model volunteer program, Phase 1 and 2	Center for Donation and Transplant	NY	1 H 39 OT 00007
24	Communication with Potential Donor Family Members	Replication of family communication protocol to increase organ and tissue donation	LifeNet	VA	1 H 39 OT 00068
25	Communication with Potential Donor Family Members	Project to support donation: Changing the culture of organ and tissue donation (Factors related to organ donation: A stress and Bereavement intervention in a stressful environment)	New York Organ Donor Network	NY	1 H 39 OT 00047
26	End-of-Life Care Issues	Interdisciplinary experiential training for end-of-life care and organ donation	Johns Hopkins University	MD	1 H39 OT 00004
27	End-of-Life Care Issues	The Renaissance state-wide initiative to increase organ donation rates in Georgia	Emory University	GA	5 H39 OT 00019
28	End-of-Life Care Issues	Phase I: Increasing organ donation by enhancing end-of-life care: A family centered, quality improvement program	Education Development Center	MA (MA, NH, RI)	1 H39 OT 00016
29	System-wide Hospital Interventions	Project to increase organ recovery from Level I Trauma centers, Phase 2 project	LifeGift Organ Donation Center	TX (TX, WA, MI, IL)	1 H39 OT 00011
30	System-wide Hospital Interventions	A model for the implementation of donation after cardiac death (DCD) protocols	University of Wisconsin Hospitals and Clinics	WI	1 H39 OT 00064

DOT Grant Program Report

31	System-wide Hospital Interventions	Assessment of Mechanisms to Improve a Hospital's Organ Donation Process	Mississippi Organ Recovery Agency	MI	1 H39 OT 00061
? No report	School-based interventions	Project Team Life: An organ and tissue donation and transplantation K-12 public school curriculum kit	Oklahoma Donor Coalition	OK	1 H 39 OT 00022
? No findings	Community Outreach	A model intervention for increasing African Americans' intent to donate in two Alabama counties	Alabama Organ Center	AL	4 H39 OT 00055



Model of the interrelationship between public education and hospital-based efforts' success on improving organ donation outcomes