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Minority Organ Donation: The Power of an Educated Community

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Abstract

Background—In 1978 - Washington, DC, we became aware of the scarcity of minority donors especially African Americans.

Study Design—From then until now 4 decades later, we have been involved in a grass roots effort emphasizing community education and empowerment combined with the use of mass media which has successfully increased minority donation rates exponentially. This program was initiated with a \$500 grant from Howard University and subsequently funded by the National Institutes of Health grants and other funding totaling more than \$10 million between 1993 and 2008.

Results—Between 1990 and 2008 minority donations percentages have doubled (15%-30%). African American organ donors per million (O.D.M.) have quadrupled from 8 O.D.M. - 53 O.D.M between 1982 and 2008.

Conclusions—While the investment of \$10 million may seem substantial, when we look at the cost benefit ratio associated with the cost savings of \$135,000 per donor, it is small when compared to the more than \$200 million saved by kidney donors alone associated with the expected increase in minority donors percentage to 35% by 2010 or the equivalent of 1750 minority donors.

Introduction

Since the beginning of organ transplantation in the United States in 1954, the number of donated organs has been considerably lower than the number of patients waiting for organs (potential recipients). This lack of donated organs has been significantly pronounced with the African American population.¹ In 1978, in Washington, DC, an awareness of the scarcity of minority donors became evident especially among African Americans. From 1978 until now – 2009 - 4 decades later, an in-depth grass roots movement emphasizing community education and empowerment combined with the use of mass media has successfully increased minority donation rates exponentially. This program was initiated with a \$500 grant from Howard University and subsequently funded by the National Institutes of Health grants and other funding totaling more than \$10 million between 1993 and 2008.

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Methods

A brief look back into the formation of what has now become a national community grass roots strategy has revealed many successes. While in the initial stages of the local Washington, DC initiative (1978), a group of 40 individuals were convened to answer the pioneering question: Why were Blacks reluctant to become organ donors? From this question, five reasons or obstacles to donation were unmasked:

1. Lack of transplantation awareness;
2. Religious beliefs and misperceptions;
3. Distrust of the medical community;
4. Fear of premature declaration of death after signing a donor card;
5. Fear of racism (black donor preference for assurance of black receivership).²

It was observed that prior to these findings, only 2 of 40 participants had signed donor cards and after the session, all 40 were willing to sign donor cards.² This session revealed a possible strategy to addressing the obstacles to donation – a face-to-face dialogue, delivered by culturally sensitive and ethnically similar community messengers who were health care providers, transplant recipients, persons awaiting transplants, donors and donor family members.^{3,4}

Based upon these initial findings, the District of Columbia Organ Donor Program (DCODP) was born in 1982 in partnership with the Howard University Transplant Center and the National Kidney Foundation – National Capital Area. Subsequent to this, organ donor designations increased from 25 per month to 600 per month by 1986 and the number of organ donations from African Americans doubled.³

The local success of the DCOOP led to a partnership with the Dow Chemical Company in the form of the Take Initiative Program, from 1986-1993, resulting in the regional and national expansion of this Black Organ and Tissue Donor Program.² The DCOOP and the Dow Take Initiative Program were partially responsible for the following significant accomplishments:

1. Increasing the organ donor consent rate in the District of Columbia from 10% in 1978 to 51% in 1993.
2. Increasing the number of D.C. residents signing donor cards from 25 per month in 1982 to 750 per month in 1988.
3. Increasing the number of African Americans organ donors per million from 8 in 1982 to 20 in 1992.
4. Increasing the number of African American donors from 3% in 1982 to 11.6% in 1993.^{4,5,6} (From a Presidential Letter by Douglas Norman provided to Dr Callender by the United Network for Organ Sharing, January 1994.)

These remarkable accomplishments led to the conceptualization of The National Minority Organ Tissue Transplant Education Program by renowned transplant pioneer and surgeon, Dr Clive Callender. The ultimate goal of this program was to utilize these strategies and findings to increase organ and tissue donations within multiple ethnic minority groups, (i.e. African Americans, Hispanics/Latinos, Asians, American Indians and Alaska Natives).

The mission of National MOTTEP is to decrease the rate and number of ethnic minority Americans needing organ and tissue transplants. As a result of National MOTTEP's

intervention and prevention strategies, the MOTTEP methodology has been applied nationally in order to accomplish the following goals:

1. Increase the number of individuals, especially ethnic minorities who are knowledgeable about organ/tissue donation and transplantation.
2. Increase the number of ethnic minorities who have family discussions about donation.
3. Increase the number of ethnic minorities willing to donate organs and tissues.
4. Increase the number of ethnic minorities who are willing to adopt healthier lifestyles and behavior patterns resulting in a decreased need for transplantation.

The program has been designed and implemented by national and community level coalitions in each of the MOTTEP sites. National MOTTEP utilized the same successful approaches it has used since its inception. The strategies are listed in Table 1.⁷

National MOTTEP has achieved an international reputation for its approaches. Committed to the use of community initiatives to elevate minority understanding of and commitment to the donation message, National MOTTEP is recognized as a pioneer in the use of its methodology and approach. The national initiative reaches an average of 700,000 individuals per year excluding media reach. Thus, National MOTTEP not only directly targets individuals through one-on-one counseling, workshops, presentations, and information dissemination at community events, but National MOTTEP has also garnered the support of faith-based institutions, providers, schools, colleges/universities, and the media. Through the use of these approaches, National MOTTEP has continued its successes in its targeted sites since its inception.

The shortage of organ donors has been and continues to be the number one problem in transplantation today. While the number of donors has increased over the years, the demand has also increased from 33,000⁸ on the national waiting list when National MOTTEP first received funding to over 100,000 in its 16th year of funding, thereby continuing the donor shortage. Moreover, minorities continue to constitute more than half of the kidney transplant waiting list (Figure 1).

National MOTTEP has effectively trained its sites to highly saturate the community with the information necessary to make *informed* decisions about donation and transplantation. The National MOTTEP methodology is completely replicable and with the proper uniform training, additional cities can easily adapt its strategies and model to promote donation and transplantation within minority populations. Training involves understanding the donation and transplantation process, building local advisory boards, volunteer recruitment and retention, media relations, partnership building, special event planning/hosting, time management, funds development and much more. The key is uniformity - making sure the primary message is always the same no matter where the MOTTEP site is located and what language is spoken.

National MOTTEP was developed as the first program of its kind in the country and was designed to: 1) educate minority communities on facts about organ/tissue transplants and how to maintain the health of key organs and tissues; 2) empower minority communities to develop programs to increase awareness; and 3) increase minority participation in organ/tissue transplant endeavors including signing organ donor cards, encouraging family discussions and promoting excellent health of kidneys, livers, hearts, lungs and other organs.

National MOTTEP has had many “firsts” in the transplant arena. Some include:

1. Implementation of the First Model National Minority Transplant Strategic Plan – 1995.
2. Implementation of the First National Latino/Hispanic Transplant Strategic Plan – 1995.
3. Developed the First National Asian and Pacific Islander Transplant Strategic Plan – 1995.
4. First to identify community as the most potent and cost efficient “change agent.” - 1993-1995
5. First to emphasize the importance of the combination of the “Prevent the Need”, and “Increased Need For Organ/Tissue Donors” as the most efficient mode of community transplant outreach - 1995.
6. First to take the fruits of the first minority donor education programs of the District of Columbia Organ Donor Program (DCODP) and the Dow Chemical Company Take Initiative Program (DOWTIP), and apply them to all minority groups through the NIH-MOTTEP Grant -1995-2000.
7. First to inaugurate National Minority Donor Awareness Day, August 1, 1996
8. First MOTTEP Latino/Hispanic Video - “UN REGALO DE VIDA” - 1996; First MOTTEP Filipino Video - “MOTTEP of Honolulu: Filipino Educational Video” - 1997; and First MOTTEP Native American Video - “A Legacy for Life” -1998

In an effort to effectively address its mission, National MOTTEP was the first national organization in the country to expand its original grassroots efforts to include a health promotion and disease prevention component that exclusively targeted youth as well as adults - thereby, decreasing the need for transplantation in the first place. The disease prevention aspect was added in 2000 to decrease the disproportionate rate of hypertension, diabetes and other diseases that affect minority populations. More specifically, a comprehensive, intensive outreach campaign focused upon uncontrolled or untreated diabetes mellitus, hypertension, proper nutrition, increased physical activity and avoiding the use of alcohol and other substances by minorities. All of these tools, strategies and accomplishments combined have contributed to the overall increase in ethnic minority donation rates.

However, National MOTTEP's primary activities have remained the design, implementation, and evaluation of educational programs for national use in order to increase the number of minority Americans who take active roles in organ and tissue donation and who hold family discussions. To support these campaigns, MOTTEP utilized the following strategies:

- Established networks of speakers, (i.e., youth, parents, celebrities, transplant recipients, donor family members, transplant candidates, health care professionals) who were available to religious and community-based organizations to promote organ and tissue health;
- Identified, accessed and utilized print media and radio technology to increase awareness among minority audiences of organ and tissue health;
- Supported and sponsored national and local forums which targeted public, private and community leaders who then disseminated information to minority communities on organ and tissue health;
- Established a library of audiotapes, videotapes, print and other materials which are made available for duplication;

- Followed up on any media coverage related to organ and tissue health to generate a greater knowledge of issues related to organ/tissue health; and
- Collaborated with an exceptionally large range of other community-based organizations in order to implement health promotion and public awareness campaigns at each of the sites in the targeted cities.

In 2001, National MOTTEP designed the “Love Yourself, Take Care of Yourself” in-house campaign. This slogan was easily adapted and adopted by the community due to its simplicity and truth. Once National MOTTEP began promoting this theme, the community more readily bought into the donation message and the community became even more empowered. This theme gave credence to National MOTTEP as it relayed the common message to the community that the organization cared about the community first by promoting healthy lifestyles versus what it had previously thought – that MOTTEP was only promoting organ/tissue donation.

The uniqueness of National MOTTEP continues to be the variation of creative activities nationally and locally designed to increase awareness. Several national videos have been produced and are frequently requested. They have contributed to the awareness of donation and transplantation.

- **“How Do You Say Thank You? An African American Perspective on Organ and Tissue Donation” (1999).** The video, funded by the Nicholas Green Foundation, received many positive comments and the Department of Health and Human Services ordered additional copies for placement in Community Health Center waiting rooms across the country.
- **“Your Life, My Life, Our Life” (2002)** – This video and brochure living donation campaign was funded by Roche and has become one of the most requested video and brochures within the community as it educates the community about living kidney donation and addresses the most frequently asked questions.
- **“Saving Your Life Through Prevention” (2003)** – This video was produced in partnership with Howard University Hospital – Department of Food Services and focuses on eating nutritious meals, exercise, etc. to prevent the need for transplantation.
- **National MOTTEP** – (2009) – This video educates communities on all of the organs and tissues that can be donated. The video features individual recipients and donors such as cornea, marrow, heart, bones, liver and includes a disease prevention youth message.

Other national activities designed to increase awareness and participation included an e-mail campaign encouraging persons to sign donor cards and have a family discussion; and a radiothon, whereby each site participated on a morning radio talk show and other radio stations were requested to play PSAs featuring former Surgeon General David Satcher and former Assistant Surgeon General Kenneth Moritsugu (donor husband and father). National MOTTEP was able to reach more than seven million persons (combined activities and media) through National Minority Donor Awareness Day – August 1st activities on one day – in one year.

The National MOTTEP website (www.mottep.org) which also serves as an educational tool reaches an average 5,000 per month. Many requests for additional information now come via the website. The website is continuously updated and provides disease prevention as well as organ and tissue donation information. The site also features celebrity spokesperson

– Chef Rock Harper (former Winner of TV Reality Show – Hell's Kitchen) promoting National MOTTEP's disease prevention theme – “Love Yourself, Take Care of Yourself!”

The local MOTTEP site efforts continue to play a significant role in empowering and educating local communities. Examples of local MOTTEP site accomplishments include:

Honolulu, Hawaii - Since implementation in 1995, MOTTEP of Honolulu has been working with the Organ Donor Center of Hawaii and primarily targeting the Filipino community. Within the first 3-4 years, the program's success is documented through an increase in the Filipino donor consent from 3% to 27%. Over the past several years, organ donation consent rates among Filipinos have steadily increased: **40% in 2004, 67% in 2005, and 71% in 2006**. It is evident that MOTTEP's public education efforts to improve organ donation rates among the Filipino population have been effective and it is imperative to sustain this success. The result of this successful program is evidenced in increased donor consent in the Filipino community from 3% to 71%. MOTTEP of Honolulu is expanding the model to include the Hawaiian Pacific Islander communities.

Chicago, IL/NW Indiana - Rev. Franklin Burns initially was identified as the Local Program Coordinator of this MOTTEP site. Rev. Burns was a kidney recipient and pastor in Gary, IN. He was personally responsible for at least 25 donations directly linked to his local MOTTEP presentations about organ/tissue donation and transplantation as reported by the Chicago Organ Procurement Organization – Regional Organ Bank of Illinois (now Gift of Hope).

U.S. Virgin Islands - MOTTEP of the U.S. Virgin Islands Territorial Coordinator – Lillian Sutherland – was instrumental in getting legislation passed for the territory to have the donor designation placed on its driver's licenses. This was a “first” for the territory. In addition, highway billboards to promote the message of organ/tissue donation were placed all over the islands of St. Croix and St. Thomas in key areas such as island airports and near the University of the Virgin Islands. MOTTEP of the U.S. Virgin Islands also played a key role in getting the month of October recognized each year as Family Month. This observance places emphasis on family discussions around organ/tissue donation and healthy living through various family focused activities all month.

The USVI Director - Ms. Lillian Sutherland – also authored the first 4-book series in the transplant arena designed to educate youth on organ/tissue donation. These books were distributed to youth organizations, at youth-based events and libraries free of charge.

1. The Children Who Wanted to Know
2. Jane's Class Makes Big News
3. Yes, Together We Can
4. Mom, Dad, I Don't Want to be Sick

Prominent government officials have supported this effort by contributing either the Foreword or Note to Parents for each book. They included: Former Secretary of Health – Tommy Thompson; Former Surgeon General - Dr. Richard Carmona; Director – NIH National Center on Minority Health and Health Disparities – Dr. John Ruffin and others.

Detroit, MI - MOTTEP of Detroit participates in more than 400 community based activities each year and has tripled donation rates within the Detroit area from **5%** when MOTTEP first began activities to over **15%**. MOTTEP of Detroit is one of several sites

that utilize technology to increase the number of potential donors through the statewide registry.

The above examples illustrate that MOTTEP sites have expanded beyond just awareness. These sites have significantly impacted donation and transplantation by using their community leadership to influence policy changes, utilize technology and increase donation rates. National MOTTEP emphasizes the *Triple-A Effect* – moving communities from *Awareness to Action and Accountability*. An educated community is an empowered community.

The MOTTEP Triple-A Effect is further based on the MOTTEP Community-Based Health Promotional Model as illustrated below. (Table 2).⁹ The model helps to determine that if individuals are to change their behavior, it is necessary to identify where they are on the behavior change interventions to move them to more advanced stages of change.

Results

National MOTTEP has utilized pre-intervention and post-intervention survey questionnaires as tools for program evaluation. The evaluation segment of this campaign provided guidance as it related to whether the proper message and messengers (ethnically similar) are actually making a difference in changing knowledge, attitudes, behaviors and beliefs within minority communities.

The information collected with the pre- and post survey questionnaires allowed National MOTTEP to utilize data in many ways besides determining whether persons wished to become donors or if they would be willing to donate the organs and tissues of loved ones. The collected data also provided invaluable information as to how many youth participants smoked, drank alcohol, exercised regularly and ate healthy. Additional results included the actual impact of the program through persons reached via community events and activities as well as media events.

National MOTTEP generated more than 10 billion media impressions through national media outlets including Black Entertainment Television, JET Magazine, Black Enterprise, the Bloomberg Financial Network, the BBC, Dear Abby newspaper column and many other national and international media organizations.

National MOTTEP conducts its evaluation model at various levels including program and participant levels. Figure 2 illustrates the evaluation model at the participant level.

The pre-intervention and post intervention questionnaires determine the effectiveness of the program. National MOTTEP currently has more than 10,000 matched data sets within the data base which has been analyzed by an independent data analysis consultant.

As National MOTTEP continues to be a leader in minority organ/tissue donation education and empowerment, it was the first national organ/tissue donation education program to establish a community-based evaluation tool to effectively measure the effectiveness of the program and measure the community's response.

Pre/post data were collected from 6,789 youth participants, ages 12-18, to determine the immediate effects of the intervention. The changes were highly significant ($p < .01$) on nine of eleven variables measured. Significant pre/post changes included three domains of attitudes towards donation - beliefs about organ/tissue donation, understanding of end stage renal failure (illness prevention) and future plans about organ/tissue donation – all changed in a positive direction.

The results of the MOTTEP methodology indicates that culturally appropriate health education programs designed for targeted population groups can change attitudes, beliefs and behavioral intentions.

Although research evaluation has been extremely important, shown in Figure 3, MOTTEP illustrates how all of the factors work together to determine the outcomes of its outreach strategies.¹⁰

Tables 3-5 illustrate the increases in donors, donation rates, organ donors/million as well as the impact on donation rates with a national structured effort (MOTTEP) versus areas without a national effort – (non-MOTTEP).

Between 1990 and 2008 minority donations percentages have doubled (15%-30%). African American organ donors per million (O.D.M.) have quadrupled from 8 O.D.M. – 53 O.D.M between 1982 and 2008. Table 4 quantifies the success of the only national minority public education program of its kind in the world!

Discussion

Since the half lives for kidney transplants range from 5.3 (A.A.) to 12.2 (Asian), 50% of all grafts survive at least 5 years and most more than 9 years, it is clear that the financial benefit to the government supporting a national donor education program such as this would save millions of dollars. Outpatient dialysis costs \$40,000.00/yr per patient and transplants break even after 3 years, this would provide an average savings of \$30,000.00/yr for each year the grafts survives over 3 years assuming a graft survival rate of 6 years. Each donor (living or deceased) would save at least \$135,000.00 per donor ($1.5 \times \$30,000.00 \times 3$ years - 55% deceased donors provide an average of 3 organs/donor and 45% living donors provide 1 organ/donor). Assuming outpatient kidney transplant costs after 3 years = \$10,000.00, looking at the graphics presented above, it is clear that the cost benefit ratio of a model national donor education program such as the one presented here is a worthy investment whose benefits greatly outweigh the under-funded support currently provided.

While the investment of \$10 million may seem substantial, when we look at the cost benefit ratio associated with the cost savings of \$135,000 per donor, it is small when compared to the more than \$200 million saved by kidney donors alone associated with the expected increase in minority donors percentage to 35% by 2010 or the equivalent of 1750 additional minority donors.

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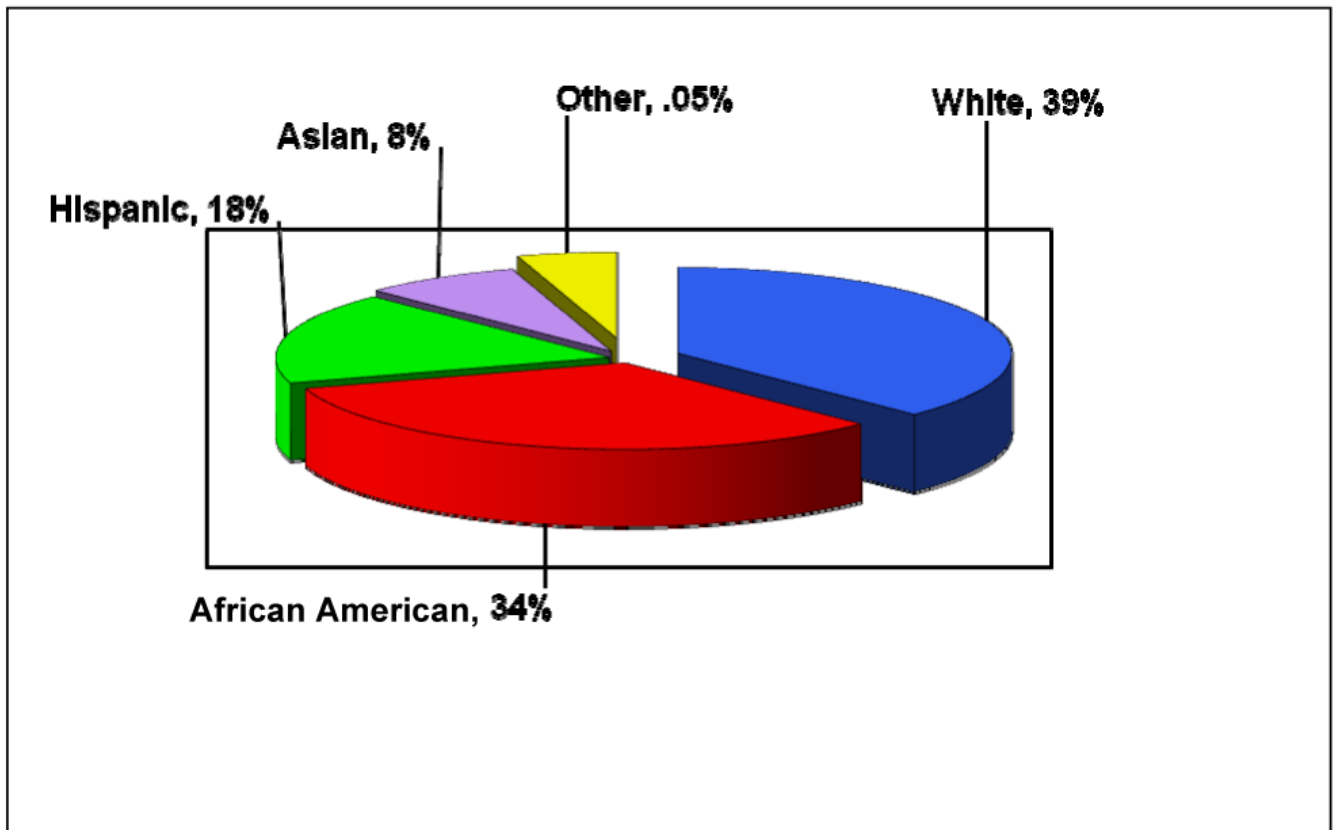


Figure 1. Racial breakdown of the kidney transplant waiting list. Minorities total: 61% (as of November 2009). Source: UNOS/OPTN Database.

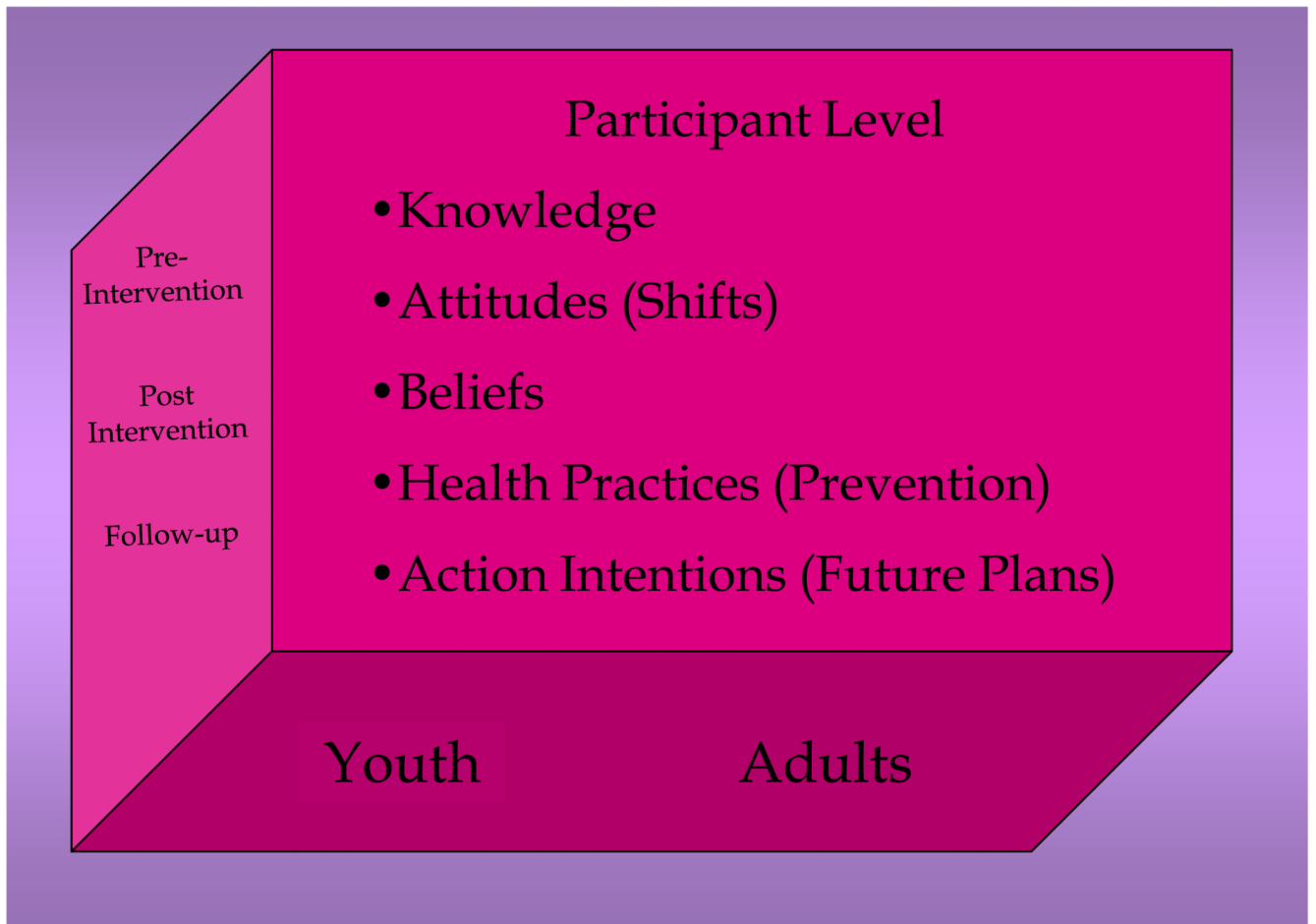


Figure 2. Minority Organ Tissue Transplant Education Program (MOTTEP) evaluation model at the participant level.

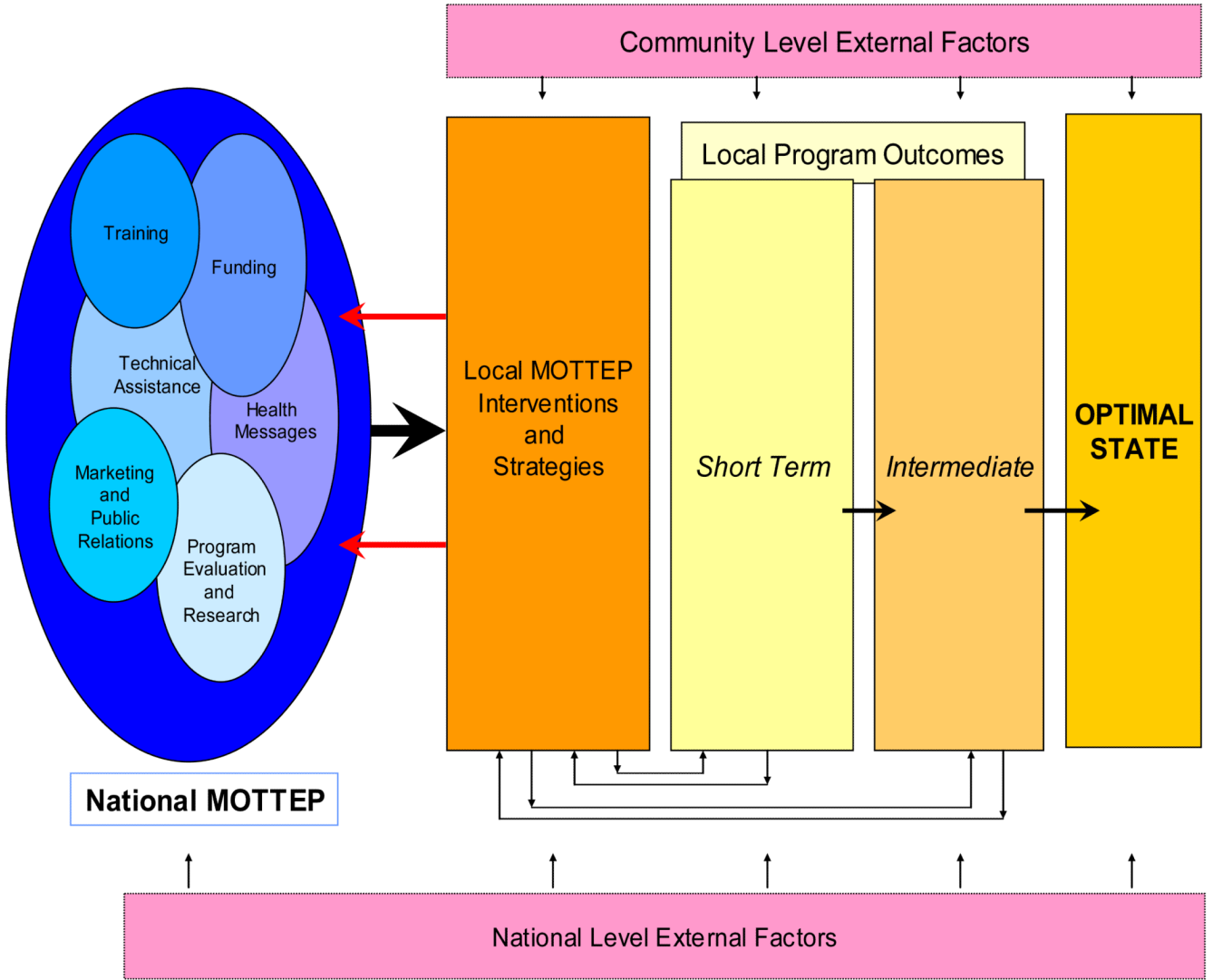


Figure 3. All of the factors work together to determine the outcomes of the Minority Organ Tissue Transplant Education Program (MOTTEP) outreach strategies.

Table 1Minority Organ Tissue Transplant Education Program strategies⁷

Approach	Brief Description
Community participation and direction	Because every community is different, the program involves diverse community persons in varied levels in the planning and implementation of their own community-based activities designed to meet MOTTEP's mission and goals.
Face-to-face presentations	MOTTEP makes presentations at social, civic, and faith-based events, especially to smaller audiences where there are more opportunities for discussion.
Collaboration and partnerships	Collaborating with religious, social, civic, and other local organizations to promote the program's mission and goals while encouraging viable partnerships is extremely important and productive. MOTTEP has collaborated with more than 300 organizations since 1995.
Media promotion	The media (radio, television and print) play a critical role in the promotion of MOTTEP's message. MOTTEP has generated more than 10 billion media impressions since 1995.
Information dissemination	MOTTEP has developed culturally sensitive and informative brochures, videos, PSAs, flyers, fact sheets, and other information for community dissemination.
Evaluation	MOTTEP has developed comprehensive quantitative and qualitative surveys to gauge the effectiveness of its programs.

MOTTEP, Minority Organ Tissue Transplant Education Program.

Table 2

Minority Organ Tissue Transplant Education Program Community-Based Health Promotion Model

Stages	Some Key Elements
Community analysis	Defining the community. Assessing community capacities, barriers and readiness for change.
Design and initiation	Establishing a core planning group of community members, organizations and agencies. Establishing the local MOTTEP organizational structure. Defining the mission and goals of the local MOTTEP. Clarifying the roles and responsibilities of the local MOTTEP advisory board members, staff and volunteers. Acquiring appropriate training to enhance local MOTTEP capacity.
Implementation	Generate community participation. Develop strategic plan for activities. Utilization of multiple strategies that potentially influence community norms. Integrate community values into program, materials and health messages.
Program maintenance consolidation	Integrate intervention activities into networks. Establish regular communication links with other local MOTTEP programs. Develop strategies for ongoing recruitment of staff and volunteers into long term projects.
Dissemination-reassessment	Reviewing outcomes from program effectiveness studies. Updating the community analysis. Revising the strategic plan to include new program directions and modifications.

Based on the Bracht and Kingsbury 5-stage Community Promotion Model.¹⁰ (Reprinted with permission Jossey-Bass, San Francisco.)

MOTTEP, Minority Organ Tissue Transplant Education Program.

Table 3
Minorities Donate in Proportion to their Population Distribution

Ethnicity	Population rate, %	Donation rate, %
White	71.7	72.1
African American	12.7	12.6
Hispanic	10.9	12.2
Asian	3.8	2

UNOS/OPTN Data as of April 4, 2003. Population information based upon 2000 Census.

Table 4
Cadaveric Donors per 1,000 Evaluable Deaths and Number of Donors by Ethnicity and OPOs, 1995-1998

Ethnicity	Donation Rate, %	Donors	Donation rate, %	Donors	p Value*
White, Non Hispanic	59.3	4,928	59.2	11,279	0.02
White, Hispanic	105.9	1,055	47.4	886	<.01
African American	43.4	1,263	32.9	1,286	<.01
Other	50.7	228	42.4	272	<.01

Source: International Scientific Registry

* National Minority Organ Tissue Transplant Education Program (MOTTEP) versus Non National MOTTEP.

Table 5
Increase in Minority Donation Rates, Organ Donors Per Million and Percentages

Ethnicity	No. of donors		Organ donors per million		Donation rate, %	
	1990	2008	1990	2008	2000	2008
African American	659	2007	22.4	53	11.2	14
Hispanic/Latino	518	1957	22.9	50	11.2	14
Asian	73	424	10.3	35.3	2.7	2.9
Total minority donors	1,250	4,988	55.6	138.3	25.1	30.9

Source: UNOS/OPTN Database – January 2009.