

AGING

with

*Dignity*

*Five Wishes America*  
Program Evaluation

October 30, 1999



# **EXECUTIVE SUMMARY OF THE *FIVE WISHES AMERICA* PROGRAM EVALUATION**

Advances in medical technology present us with a number of treatments that prolong life. Some people do not want such treatment, others wish to take advantage of every procedure available. Often, such decisions must be made when the patient is no longer able to state preferences. Legislation passed in 1991 known as the Patient Self-Determination Act provided patients with the opportunity and freedom to make their own choices and plan for the care they want to receive at the end of life. A key element in exercising this right, however, is the ability for patients to make their choices and effectively communicate them to family and health care workers prior to incapacitation. Extant research has shown that many advance directives fall woefully short in this respect.

The Commission on Aging with Dignity, in conjunction with Mr. Charles Sabatino of the American Bar Association Commission on Legal Problems of the Elderly, developed an advance directive document that was to be recognized nationally, easy to understand, simple to use, and accepted by the health care community. The document that was developed to be legally valid in 33 states and the District of Columbia. A generous grant by the Robert Wood Johnson foundation provided a significant amount of the financial resources necessary to develop and distribute the document.

Now, at the first-year anniversary of the project, Florida TaxWatch submits this program evaluation pursuant to the terms of the original grant application. Through the use of survey research and empirical evaluation, TaxWatch has determined that Aging with Dignity has achieved the stated objectives of:

- a. Communications success, reflected by the amount and quality of media coverage generated (newspaper, magazine, television, newsletter and Internet penetration);
- b. Recipient utilization; and
- c. Establishing an effective distribution network for the document.

Due to data limitations and time constraints there was not enough evidence to neither prove or disprove the final program objective of:

- d. Whether health and long-term care providers are willing to use *Five Wishes* institutionally and, if utilized, does this result in better care.

In general, it was concluded that *Five Wishes* is effectively addressing many of the problems which extant research suggests have been a stumbling block to full implementation of the Patient Self Determination Act and in assuring that palliative care is given in accordance with the wishes and desires of the patient.

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## SECTION 1

### THE PROGRAM EVALUATION AND ITS CONTEXT

#### Introduction

Advances in medical technology present us with a number of treatments that prolong life. Some people do not want such treatment, others wish to take advantage of every procedure available. Often, such decisions must be made when the patient is no longer able to state preferences. As a result, the Patient Self-Determination Act (PSDA) was passed in 1991. The passage of the act was designed to promote the education and understanding related to the benefits of advance directives (AD) to clearly promote and document a patient's preference for medical care. The declaration is designed to establish a surrogate decision-maker and offer patients a means to express decisions regarding end-of-life care when the patient may be incapacitated. The vast majority of AD's, however, limit their subject matter to medical care and are written in a technical language which is difficult for many to understand.

In an effort to solve the mounting concerns surrounding individual and care giver choices in care for those at the end-of-life and to advocate for the promotion of human dignity as America ages, the Florida Commission on Aging with Dignity (Aging with Dignity) was founded in 1996. A

primary programmatic element of Aging with Dignity has been the development and distribution of the *Five Wishes* advance directive document. Introduced in July of 1997, the original *Five Wishes* document was drafted specifically for use in the State of Florida. The *Five Wishes* was developed to facilitate family and physician discussion about end-of-life matters and to communicate care preferences to healthcare providers and loved ones. The unveiling of the document in Florida was an instant success. Within three weeks after its introduction, Aging with Dignity had received in excess of 100,000 requests for the document. A review of the mailing list generated from these requests showed that many of those requesting the document had residences or lived outside of Florida. The considerable response lead Aging with Dignity to consider a nationwide document.

The *Five Wishes America* project resulted from Aging with Dignity in consultation with Mr. Charles Sabatino of the American Bar Association Commission on Legal Problems of the Elderly. The initial objective of the project was to develop and review the statutes of all 50 states and adapt a document that would be legally valid in Florida, one which could be adapted for use throughout the country. In May of 1998 the Robert Wood Johnson Foundation granted Aging with Dignity \$492,003 to distribute a national version of the *Five Wishes* document .

The national document (Appendix A) was drafted to meet the statutory requirements of thirty-three states and the District of Columbia. (See document). Additionally, the draft document was circulated for "review and comment" by medical doctors, healthcare professionals, and advocates for quality end-of-life care throughout the country who were familiar with the increased complexity of health care decisions and end-of-life planning. The final stage in the development of the document was to utilize the services of Education Programs Associates, Inc. (EPA). EPA is a nationally

recognized organization which specializes in revising technically written documents into a more common language form which is easy to use and understand.

On October 22, 1998, Jim Towey, President of Aging with Dignity, was joined by Eunice Kennedy Shriver and Charles Sabatino to introduce the revised *Five Wishes*<sup>1</sup> document to a national audience at the National Press Club in Washington, D.C., and, thus, the *Five Wishes America* national distribution project was launched.

### **Purpose of the Evaluation**

The purpose of this deliverable under Florida TaxWatch's professional services contract with the Florida Commission on Aging with Dignity is to evaluate the *Five Wishes America* project supported by a grant received by the Robert Wood Johnson Foundation. This program evaluation will review four specific aspects of the program operations of the national project to determine:

1. Whether the communications success of the project is reflected by the amount and quality of media coverage generated (newspaper, magazine, television, newsletter and Internet penetration);
2. Whether *Five Wishes* was actually used by those individuals who received it;
3. Whether the organizations which distributed *Five Wishes* actually succeeded in an effective distribution of the document; and
4. Whether health and long-term care providers are willing to use *Five Wishes* institutionally and, if utilized, whether this results in better care.

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<sup>1</sup>It was decided to maintain the "*Five Wishes*" name instead of re-naming the document "*Five Wishes America*," to avoid confusion and to build upon the name recognition generated from the original Florida document.

## General Methodology

A combination of survey and archival data was used to increase the breadth of information gathered and to provide a thick, rich understanding of program operations. This program evaluation utilized data collected from two sources: a national survey conducted over the months of July, August and September, 1999 of the recipients of the *Five Wishes* document (Appendix B); a survey of the distributors of the *Five Wishes* document and of health and long-term care providers willing to use *Five Wishes* institutionally (Appendix C). These two surveys allowed a review of a large variety of individuals, organizations and medical providers operating in varying markets throughout the country. Nonetheless, the surveys are limited because they only represent individuals, organizations and medical providers familiar to Aging with Dignity. Additionally, a number of archival records held by the Florida Commission on Aging with Dignity were used.

The largest of the two surveys conducted was of those individuals who received a copy of the *Five Wishes America*. Surveys were sent via U.S. mail to 1500 individuals selected from the list of approximately 30,000 known recipients of the *Five Wishes America* document. Additionally, another 300 recipients of the document were contacted by telephone interview. The final sample size was 329 recipients, representing a response rate of 18%, yielding a confidence level of 95% and an error tolerance level of +/- 5%. These return results are deemed acceptable for the purposes of this program evaluation.

Each of the following subsections will begin with a discussion of the theoretical goals and expectations of the project. From these theoretical goals more specific and explicit project objectives will be stated. Once objectives have been defined, a set of proximate indicators will be established. The range of the indicators used in this evaluation are the result, the purpose of the evaluation, the

evaluation timing, the resources available and the preferences of evaluators. The discussion on program measures will reflect operations which the evaluators undertook to convert indicators to formal measures of program performance. Finally, in each section program outcomes will be discussed. Outcomes can be divided into two categories; primary and secondary. Primary outcomes will be considered direct program impacts; secondary outcomes will be considered spillover effects that the program may have had on clientele, other groups, or organizations. In this section the outcome valence will also be discussed. The outcome valence can be either positive or negative. A positive valence indicates that program efforts have achieved progress toward accomplishing program goals. A negative valence indicates that progress towards the goals may have been achieved but agency clients or others are suffering negatively from the program in ways that were not anticipated. Figure 1 is a general guide to the evaluation methodology.

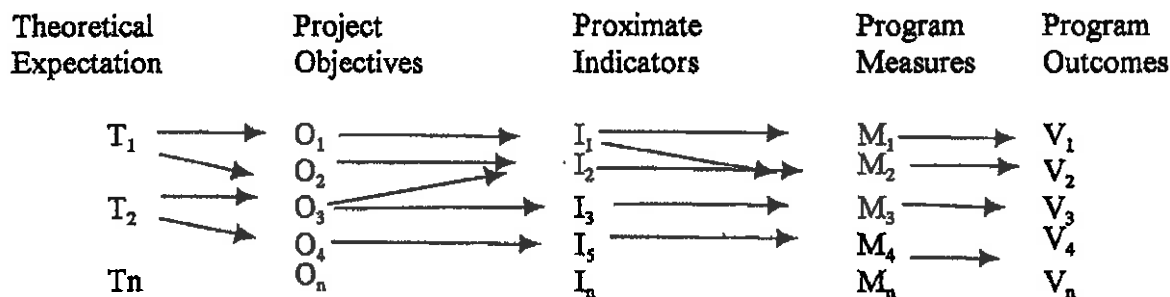


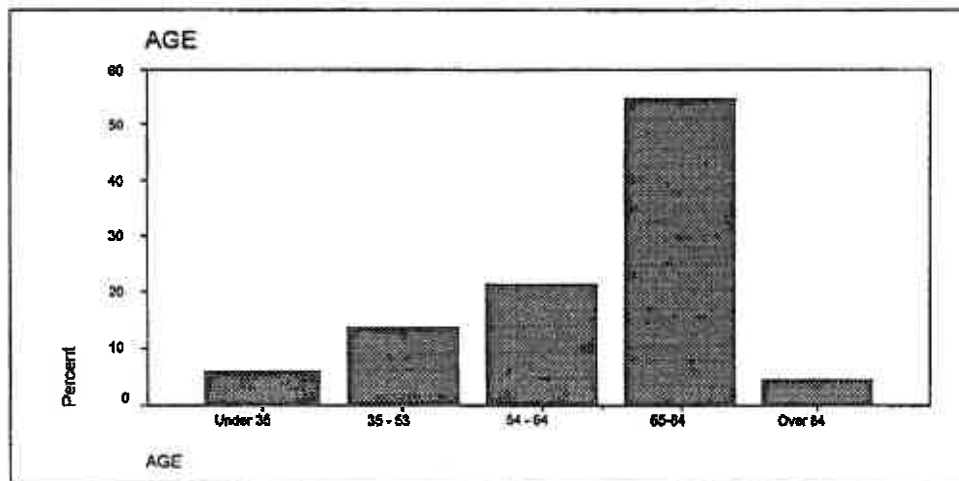
Figure 1. A guide to evaluation methodology

## SECTION 2

### GENERAL FINDINGS

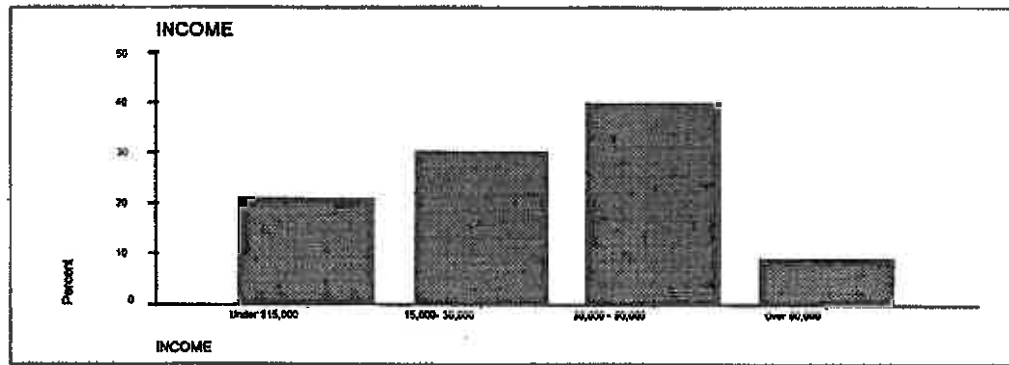
#### Characteristics of Respondents

This evaluation begins with an investigation of who completed the national survey. This was done to provide insight regarding who requested the *Five Wishes America* document. Survey results show that the majority of individuals who completed the survey were over the age of 65 (see Figure 2), with the majority being in the 65-84 year old grouping. Beyond the age demographic, nearly 75% of those that completed the survey were female and spoke English as their primary language.



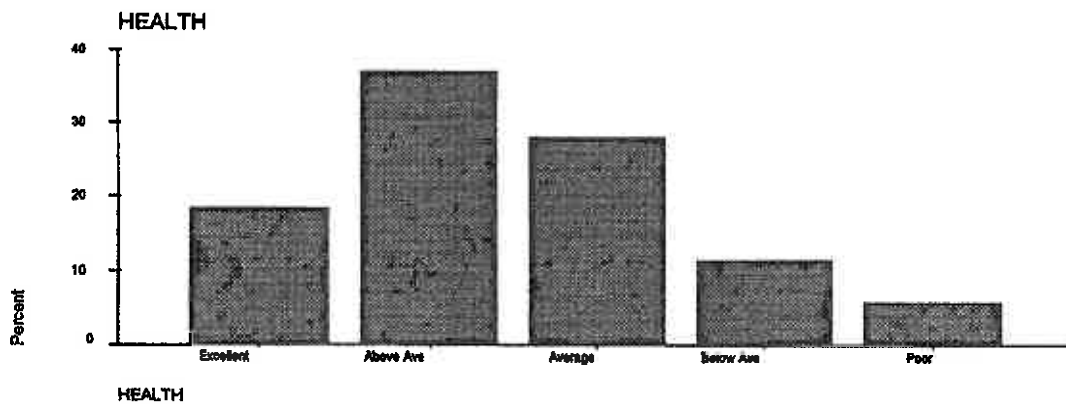
**Figure 2. Age of Respondents**

With regard to race, nearly 70% of all respondents were white, 12% Hispanic and about 8% African-American. Another general demographic gathered was that of income level. Figure 3 demonstrates that the vast majority of respondents could be considered in the upper middle economic class with nearly 45% of the respondents in the \$30,000 - \$90,000 per-year income range.



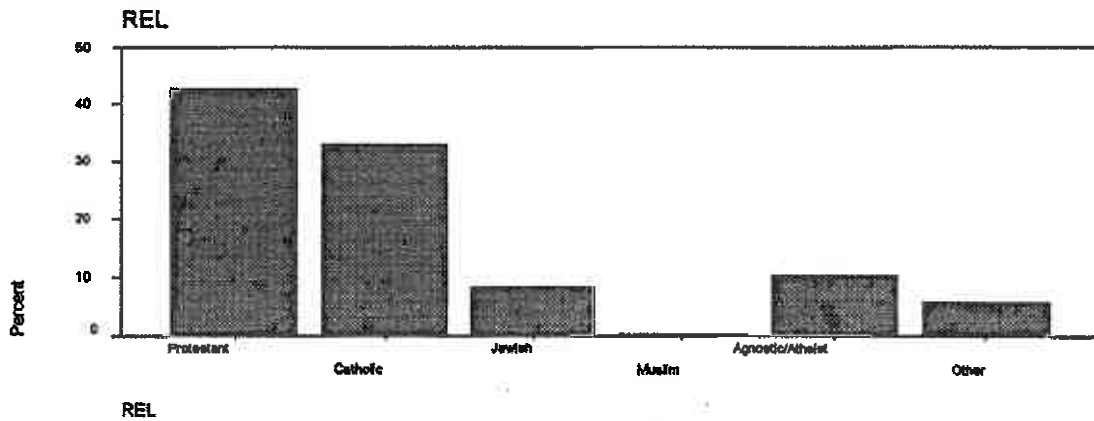
**Figure 3. Income of Respondents**

In general, the survey respondents saw themselves in average-to-excellent health; only about 20% considered themselves below average or in poor health (See Figure 4)



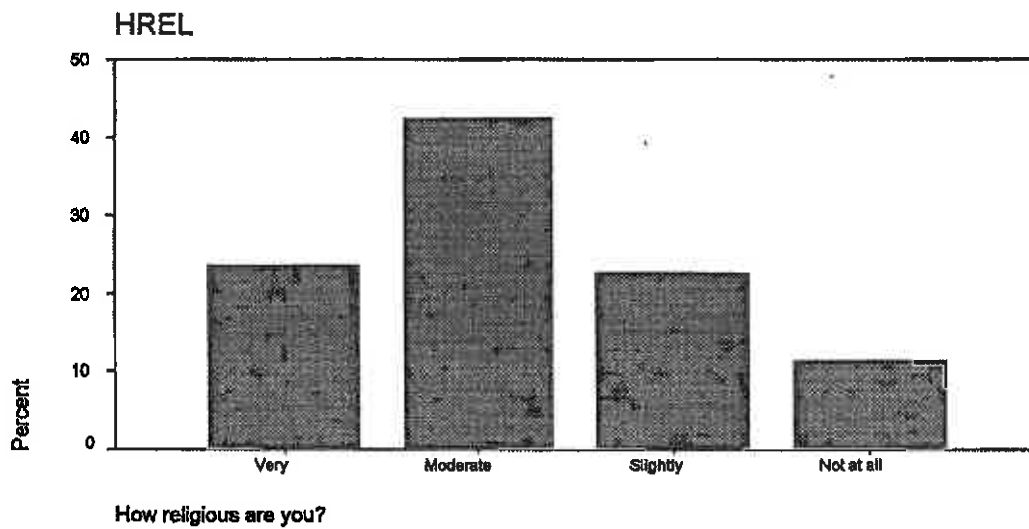
**Figure 4. General Health of Respondents**

Finally, religious preference and religiosity were investigated. Here, as shown in Figure 5, the three predominate religious groups within the country are represented as Protestant, Catholic and Jewish individuals. These three groups make up nearly 80% of all respondents.



**Figure 5. Religions of Respondents**

The last variable measured in these general results was religiosity. This is defined as an individual's self-evaluation of his or her own religiousness. In Figure 6, it is seen that most respondents saw themselves as moderately religious.



**Figure 6. Religiosity of Respondents**

In conclusion, it can be said that the respondents of this survey mirror much of older America. They were primarily English speaking, white, middle class, Christian-Judeo women over 65 who see themselves in fairly good health. Taking these demographic characteristics into account, the next section explores whether the *Five Wishes America* project achieved communications success.

### SECTION 3

#### **THE COMMUNICATIONS SUCCESS OF THE *FIVE WISHES* AMERICA PROJECT**

Research has shown that while individuals may express an interest in discussing advanced planning for treatment, should they become incapacitated they expect healthcare workers (doctors, nurses, and social workers) to initiate the discussion (Emanuel, Barry, Stoeckle, Ettleson, & Emanuel, 1991). Though legislation requires health care organizations to develop an internal policy regarding advance directives, in practice, many of these providers are merely satisfying the minimum requirements of the law (Davitt, 1992; Sabatton, 1993).

The *Five Wishes* document was specifically designed to go beyond the minimal requirements of facilitating the communication between patients and healthcare workers and also to facilitate communication between patients, family members and/or health care surrogates. Additionally, the issue content of the *Five Wishes* document goes beyond minimal legislative requirements to address the emotional and spiritual wishes of the patient. In the words of Ira Byock, a medical doctor and author of *Dying Well*:

*Five Wishes* is a valuable new resource for Americans wishing to control their own destiny. Beyond allowing us to avoid medical treatments we don't want, for the first time, *Five Wishes* enables us to specify the types of personal care that 'matter most' to us as individuals. Every person should have one, discuss it with our families and make sure our physicians know our wishes.

To communicate this message Aging with Dignity associated with Burness Communications to launch a nation-wide media campaign. A copy of the *Five Wishes* media plan is attached as Appendix D.

The communications strategy, a key program element, was designed to incorporate media at the national, state and local levels and to achieve two objectives:

- (1) generate an increased level of media coverage regarding *Five Wishes* in terms on units of media coverage on the national level; and,
- (2) educate the public on issues of advance care planning, the importance of palliative care and the *Five Wishes* document.

Three proximate indicators of the foregoing objectives are media frequency, message content and how respondents initially heard of *Five Wishes*. As measures of the first two indicators, Aging with Dignity tracked unit media coverage and completed a media content analysis from May of 1998 through April of 1999. Members of the staff reviewed national news media including newspapers, magazines, television and newsletters. A list of the media reviewed is attached as Appendix E. Figure 7 is a graphic representation of the units of *Five Wishes* media coverage. As demonstrated by the graph, media coverage peaked in the month of October, 1998, surrounding the launching of the national media campaign on October 22, 1998.

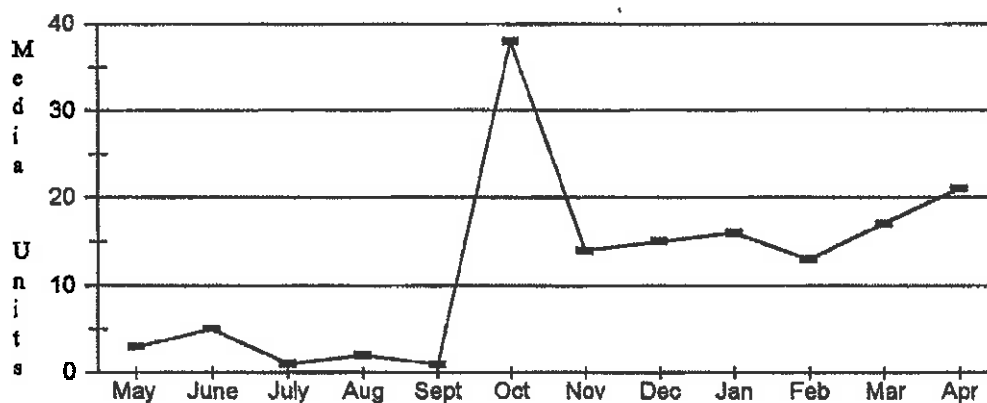


Figure 7. Units of *Five Wishes* Media Coverage

Within 24 hours of the national *Five Wishes* introduction Mr. Towey was interviewed or featured on the *NBC Today Show*, *CNN Headline News*, *CNN*, *CNNfn*, and *NPR's All Things Considered*. *Five Wishes* also appears in at least 13 major print media sources including *USA Today*, *The Washington Times*, *The Philadelphia Enquirer*, *The Miami Herald*, *The Houston Chronicle* and the *San Jose Mercury News*.

More significant, in terms of sustaining the *Five Wishes* project, media coverage during the months of November, December of 1998, and January, February 1999 remained three to four times higher than the months previous to the national campaign, In March, April of 1999, media coverage began an upward trend.

Media content analysis was used as the proximate indicator of the goal of educating the public on issues of advance care planning, the importance of palliative care and the *Five Wishes* document. Here, the measurement process used was to count the percentage of articles in which key concepts of *Five Wishes* appeared the media reviewed. (See Figure 8).

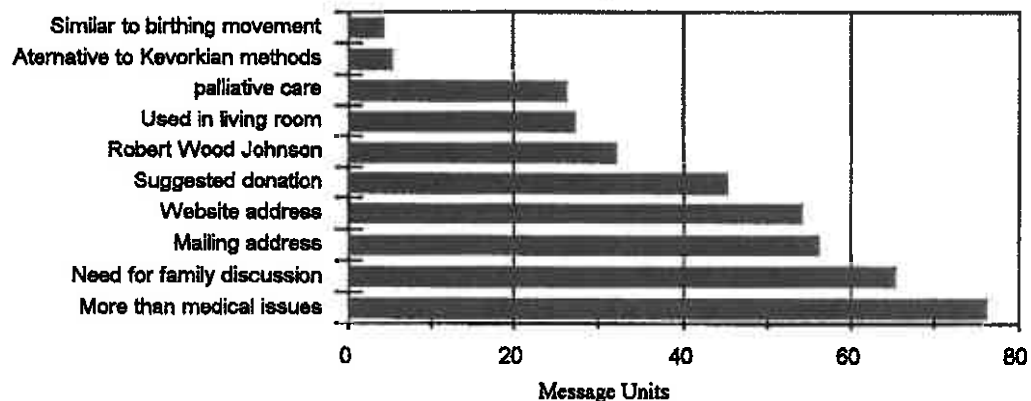
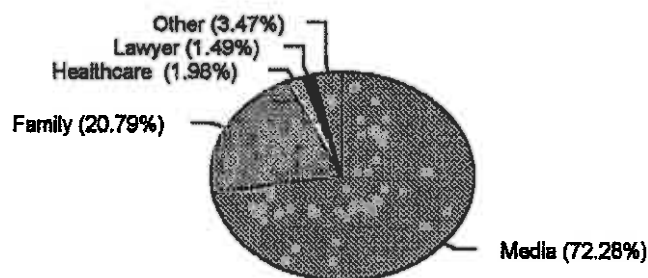


Figure 8. Media Content of Coverage

The data in Figure 8 reveal that in nearly 75% of the articles examined during May, 1998 to March, 1999 time-period, presented a message that dying is more than just a medical moment and that individuals have the right to inform health care workers and family of their comfort preferences in advance being incapacitated. The second most prominent theme in media coverage during the May to March period was that of the need for family discussion appearing in excess of 60% of the media coverage examined. Additional messages which appeared in over one-third of all the media coverage examined were the street address and Web site address to Aging with Dignity, the request for a donation and the association with the Robert Wood Johnson Foundation. The messages that *Five Wishes* should be completed in the living room and that it was a tool to establish palliative care appeared in excess of 25% of all media coverage. The messages which appeared least in the media were those of *Five Wishes* being an alternative to Kevorkian type methods of end-of-life care and the correlation between the birthing movement and the advance directive movement.

Perhaps the most significant indicator in determining the outcome of media success is the number of individuals who were motivated by the media coverage and message to actually request a copy of the *Five Wishes* document. Figure 9 shows that nearly 75% of those individuals surveyed heard about *Five Wishes* through the media campaign.



**Figure 9. How Respondents Heard About *Five Wishes*.**

The two primary outcomes of the media portion of the *Five Wishes* America project were to achieve increased national media attention for the *Five Wishes* document and to educate individuals about the project. The project had a significant increase in the units of media coverage and has been able to sustain coverage since the introduction of the document at the national level. Additionally, as demonstrated by the data, the media content or salient message of the project reached the target audience.

A secondary outcome which demonstrates the success of the media campaign is the percentage of individuals who ordered the *Five Wishes* document as the result of media coverage. The data demonstrates that nearly 75% of the individuals who responded to the survey learned of the *Five Wishes* document through the media.

One unanticipated negative outcome of the campaign was the strain that was placed on the Aging with Dignity Staff to meet the demand for the *Five Wishes* document. The old adage "Be careful what you wish for, you might get it" comes to mind. In just six months more than 200,000 copies of *Five Wishes* were circulating and more than 550 organizations were actively distributing the document. The media success led to workload pressures unforeseen in the grant application. Nonetheless, Aging with Dignity has strived to meet requests for the document in a timely fashion.

In general, it can be concluded that the media campaign for the *Five Wishes* project shows signs of success. The three indicators chosen to determine the media success of *Five Wishes* Project are of a positive valence which indicates that Aging with Dignity is making progress towards successful accomplishment of the goals set forth in their grant proposal and media plan. While ordering the document is important, a more salient factor is the completion of the advance directive. The next section examines this issue.

## SECTION 4

### THE UTILIZATION OF *FIVE WISHES* BY THOSE WHO RECEIVED IT

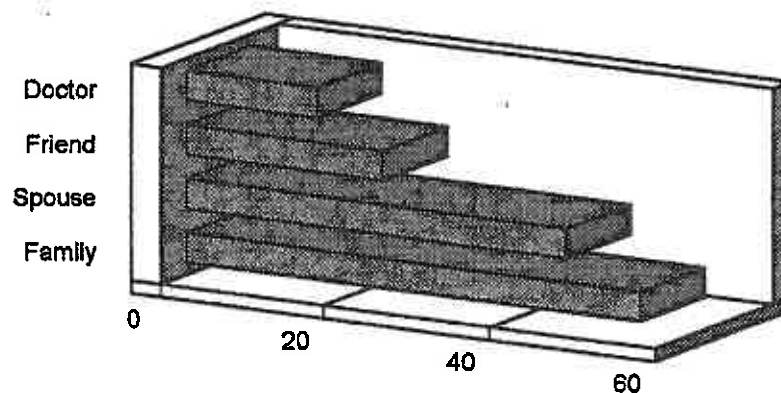
This section of the program evaluation examines whether individuals who received a copy of the *Five Wishes* document completed it. *Five Wishes* was designed to increase patient involvement in decisions regarding life-sustaining treatment in the event that they are incapacitated. The document can help individuals communicate their wishes to surrogate decision-makers only if it has been completed and properly executed. Emanuel, Barry, *et al.* (1991) showed that, while most individuals expressed a desire for some form of end-of-life planning, only 18 percent of the general public had actually drawn up a form of advance directive. One project objective for this portion of the *Five Wishes* program is to have a significant number of recipients of *Five Wishes* to complete the form.

A second project objective for this portion of the *Five Wishes* program is to have the respondents relay their wishes to surrogate decision-makers, whether a spouse, physician, friend or relative. Even if an advance directive is completed and properly executed, it is of little value if not relayed to decision-makers.

Finally, a number of barriers are often mentioned as a reason for not completing advance directives (Emanuel, Barry, *et. al*,1991), for example, patients' expectations that physicians would take the initiative and feelings that such matters were more relevant for older people or those in poor health. Research also has shown that the median time between advance directive documentation and death is 1.2 years (Hammes & Rooney, 1998). Accordingly, the timeliness in which a recipient completes the document should be considered as a secondary indicator of the success of this objective. Therefore, other indicators of interest are those factors that were correlated with the use

or non-use of the document and recipients' attitudes towards the *Five Wishes* document. Program measures of these indicators are once again drawn from the national survey of recipients of the *Five Wishes* document.

With regard to the completion rate of the document, data from the national survey showed that 52% of those who received the *Five Wishes* document completed it. When compared with 1991 data from Emanuel, Barry, *et al.*, the current survey's completion rate seems favorable. The data from the national survey also showed that of those who completed the document, the majority (63%) discussed their *Five Wishes* with someone else. Figure 10 shows that most respondents discussed their wishes with either family members (55%) or their spouse (46%). Friends comprised the third largest group (24%) of those whom recipients discussed their wishes with, while doctors were the smallest group consulted (16%). Interestingly, none of the respondents discussed their wishes with their attorney.



**Figure 10. Discussing Your Wishes**

Timeliness of completion of the *Five Wishes* document was measured in terms of the Pearson's correlation between when an individual received the document and whether the recipient completed the document. The data show a significant correlation between those who received the document recently and completing the document (-.32 Pearson correlation, significant at the 0.01 level, 2-tailed). Thus, the longer a recipient has the document, the less likely it is that the individual will have completed it. The correlates to the completion of the document also were determined. The data in Table 1 suggest that the most significant correlate to completion of the *Five Wishes* document was having attended a seminar.

**Table 1. Pearson's Correlations Between Selected Variables and Completion of *Five Wishes***

	Pearson Correlation	Sig (2-tailed)*
Seminar Attendee	.376	.000
Already had an AD	-.025	.659
Age	-.174	.003
Sex	.045	.431
Race	-.233	.000
Language	-.162	.004
Religion	-.001	.988
Religiosity	-.034	.555
Health	-.207	.000
Income	.280	.000
n=323		

\* in social science research it is generally agreed upon that a variable with a 2-tailed significance level of .05 or below is statistically significant.

Surprisingly, age was inversely correlated with completion. This suggests that younger individuals are more like to complete the document. This variable, however, must be referenced within the context of the average age of the respondent being in the 65 - 84 year old age group. White individuals were significantly correlated with completion, as well as those who speak English.

Neither religion nor religiosity were significantly correlated with document completion. Finally, as a respondents' level of income increased, so did the likelihood of their completing the document.

When compared to other data of individuals who express an interest in advance directives and whether or not they completed a document, the data demonstrate that recipients of *Five Wishes* are nearly three times more likely than the regular population to completed an advance directive. Additionally, the majority of those individuals who completed the document used the opportunity to discuss their care with their spouse, family, friends or a doctor. In reviewing the correlates of completion, it can be said that a secondary outcome of this section of the evaluation is that the seminars given by Aging with Dignity are the most salient factor in the completion of *Five Wishes*. Although not conclusive, the other correlates found to be significant in the completion process could reflect a bias in the construction of the *Five Wishes* document or media placement. Therefore, further exploration of this may be warranted. In summary, primary and secondary outcomes of this portion of the evaluation generally demonstrate a positive valance and suggest that this project goal of *Five Wishes* utilization is being met.

## SECTION FIVE

### *FIVE WISHES* AND THIRD PARTY DISTRIBUTION

Aging with Dignity began only a few short years ago as a small grass-roots organization dedicated to the cause of enhancing the quality of life for those nearing the end-of-life. In an effort to leverage the limited time and capabilities of the full-time staff, it was determined that a nationwide network of agents would be cultivated to both promote and distribute the *Five Wishes* document. Initially, Aging with Dignity, utilized the Last Acts coalition to promote distribution among the many Partner organizations. Additionally, state government officials were asked to distribute the document including Florida Governor Jeb Bush and the Maryland Attorney General's Office.

Aging with Dignity staff report a distinct pattern in establishing a distributor:

- a. Members of the organization learn about *Five Wishes* through the media;
- b. They contact Aging with Dignity for information;
- c. A sample copy of *Five Wishes* is sent to the organization for review;
- d. The organization contacts Aging with Dignity to finalize the details of distribution; and
- e. Copies are sent to the organization.

In total, in excess of 550 groups (as of May 1, 1999) have requested copies of *Five Wishes* for distribution. Among them are hospitals, churches, synagogues, doctor and law offices, hospice services and social service agencies. Table 2 lists the number of organizations that have contacted Aging with Dignity about distribution of *Five Wishes* by primary business type.

Table 3 shows that this network of potential distributors lies primarily in the eastern half of the country with Colorado being the only state in the West with a significant number of groups requesting information on distribution. Due to the early release of the Florida document and the location of the Aging with Dignity offices, Florida has the greatest number of requests.

**Table 2. Requests by Business Category (as of May 1, 1999)**

<b>Type of Business</b>	<b>Number of inquiries</b>
Healthcare Provider	163
Religious	103
Miscellaneous	83
Senior Organizations	44
Attorneys	42
Academia	28
Retirement Communities	19
Community Based Organizations	10
Government	9
Funeral Directors	7

**Table 3. Group Requests by State (as of May 1, 1999)**

<b>State</b>	<b>Number of Requests</b>
Florida	143
Pennsylvania	35
Colorado	28
New York	23
Iowa	22
Michigan	21
Virginia	21
New Jersey	20
Illinois	19
Missouri	18

Not all organizations who request the document for distribution can be considered actual distributors. Of those organizations contacted 55 have identified themselves as distributors of the *Five Wishes* document. Aging with Dignity has not set a definitive number of requests that qualifies a group as a distributor. However, as shown in Table 4, a number of groups and organizations have requested 1000 copies or more. As shown by the Table, the network of distributors is similar to the total number of requests by groups in that it lies in the Eastern half of the country.

**Table 4. Major Distributors of *Five Wishes* (as of May 1, 1999)**

Name	Location	Copies
Chesapeake General Hospital	Chesapeake, VA	5000
Morehead Memorial Hospital	Eden, NC	3000
Mission St. Joseph	Asheville, NC	2650
Rainbow Hospice	Park Ridge, IL	2600
DuBois Regional Medical Center	DuBois, PA	2000
Genesis Medical Center	Davenport, IA	2000
Illinois Collaboration on End-of-Life Care	East Alton, IL	1600
Sibley Memorial Hospital	Washington, DC	1000
Human Resource Development Corp.	Enterprise, AL	1000
Bronson Methodist Hospital	Kalamazoo, MI	1000
Jameson Care Center	New Castle, PA	1000
Area Agency on Aging	Boone, NC	1000
Mercy Hospital	Miami, FL	1000
Lancaster General Hospital	Lancaster, PA	1000
Life's Decisions Institute	Potomac, MD	1000

The above data demonstrate that a third-party distribution network is beginning to take form and that great strides have been made to achieve distribution outside of Florida with only one major distributor located within the state.

Proximate indicators of the success in establishing this network, however, go beyond just measuring the number of distributors. The success of the program can be measured in Aging with Dignity capacity to leverage its ability to distribute the document. The task at hand is to measure the primary program outcomes of building a pro-active distribution network for *Five Wishes*, the secondary outcomes of recruiting organizations willing to conduct seminars on *Five Wishes* and, finally, leveraging groups with a desire to learn more about *Five Wishes* and its distribution.

The program measures used in this section of the evaluation come from a survey of 72 organizations that have requested the *Five Wishes* document for distribution. Table 5 shows how the organizations classified themselves.

**Table 5. Self-classification of Distributors**

Distributor Type	Number of organizations
Healthcare Provider	31
Religious	14
Miscellaneous	6
Senior Organizations	5
Attorneys	4
Academia	3
Retirement Communities	2
Community Based Organizations	3
Government	4

While not exact, this sample closely enough resembles the population described in Table 2 for the purposes at hand.

To determine the success of recruiting a pro-active network of distribution agents, the organizations were asked the following question:

How does your organization distribute *Five Wishes*? (Select all that apply)

- a. Set it on a counter in our lobby
- b. Sent it in mass mailings
- c. Mailed it to those who requested it
- d. Distributed it through workshops
- e. Distributed it through personal contact by an organization representative
- f. Distributed at a one-time event
- g. Other

Those organizations which responded with an answer or answers of solely a-c were determined to be passive distributors of the *Five Wishes* document. Those responding d - f or favorably in the other category were determined to be pro-active.

Table 7 shows that 18 or 25% of the distributors distribute *Five Wishes* solely through passive means. The remainder of the distributors use at least one, if not several, alternative active means of distribution which involve end-user contact. The Table shows that 31% of all distributors use multiple means of distribution.

**Table 7. Methods of Distribution**

Method	Number of Distributors	Percentage
Non-user contact methods	18	25
User contact methods	54	75
Multiple methods	22	31

The fact that 3/4 of all distributors are distributing the *Five Wishes* document by employing one or more user contact methods suggests a positive outcome for the program. Further analysis of the data demonstrates that there are no significant organizational characteristics determining the types of organizations which are most likely to use user contact methods as opposed to those that use passive distribution methods. These data suggest a positive valence for the primary outcome of achieving a distribution network using pro-active methods.

A secondary outcome to be explored in this report is the number of distributors who have given a seminar or workshop for client. Previous data in this evaluation have shown that workshop attendance significantly affects document completion. The survey data show that 19 groups, or 26% of the distributors, have given at least one seminar on *Five Wishes*. One organization among them gave six (6) seminars while, the majority held only one seminar. Table 8 shows the name of organizations which have reported giving a seminar on the *Five Wishes* document and the number of attendees at those seminars.

Though this data do not produce any definitive findings as to the success of the seminars, one can see that, in general, the seminars appear to have been well attended. This area appears to be ripe for further exploration as case studies to disclose factors leading to seminar attendance and perceived success.

A final secondary outcome in determining the success of building a distribution network is to determine if those groups who have requested information from Aging with Dignity are interested in investing financial and human resources to learn about *Five Wishes*. Of those organizations

**Table 8 Distributor Seminars**

<b>Organization Giving Seminar</b>	<b>Number of Seminars</b>	<b>Attendees</b>
Fort Myers Presbyterian Apts.	1	20
13th Judicial Circuit of FL	1	25
Heritage Hospice	1	35
Christ the King	1	40
South Carolina Baptist Ministries for the Aging	1	50
First Assembly of God	1	75
Bon Secours Health System, Inc.	1	100
N. Penn Home Health	1	n/r
The Oasis Renewal Center	2	20
Denver Dept. of Social Services	2	33
Taylor Hospice	2	80
Genesis Medical Center	2	n/r
Fourth Presbyterian Church	3	50
Venice Presbyterian Church	3	500
Garden State Hospice	6	100
Davis & Jones, PA	n/r	25
St. Cloud Chiropractic Clinic	n/r	n/r
n/r	n/r	n/r
Rainbow Hospice	n/r	n/r
n/r = not reported		

Surveyed, 16 organizations said that they would be willing to pay \$75.00 for an instructional video on *Five Wishes*. This represents close to 30% of those groups which consider themselves distributors.

The data on the success of establishing a distribution network for the *Five Wishes* document appears to show a positive valence. In all three measures of program outcomes nearly one-third of the distribution force is either pro-actively distributing the document, giving seminars or willing to invest in learning more about the document.

## SECTION 6

### *FIVE WISHES* IMPACT ON THE HEALTH CARE COMMUNITY

There is a substantial body of research (Health Line, 1997, 1998, 1999) which has reported an ongoing disconnection between the completion of an advance directive and its implementation by the health care community. This research suggests, among other things, that advance directives seldom effect health care decision making at the end-of-life (Consumer Reports, 1993; Health Line, 1997). The primary concerns voiced by the research is that few advance directives, (1) promote real planning between the physician, patient, and family in the event of a fatal disease; (2) contain explicit enough directives to guide medical care; and, (3) are actually documented in patient medical files.

A program goal of the *Five Wishes* was to create a document to answer these three concerns. This final section of the Report seeks to determine if *Five Wishes* health and long-term care providers perceptions of the *Five Wishes* document make a difference; if utilized, do they result in better care.

A primary outcome of having reached this goal is the acceptance of the *Five Wishes* document by the health care community. Data for this section were gathered from the 15 health care providers who completed the provider section of the distributor survey. In this sample, 14 providers answered that they would honor a person's wishes if the *Five Wishes* document were completed; no health care providers stated that they would not honor the document. Health care workers' attitudes towards *Five Wishes* were measured by asking them to compare *Five Wishes* with other living wills they had seen. Table 9 presents the survey results. As is shown by the Table, in excess of 80% of the respondents felt that *Five Wishes* was easier to understand than other living wills they had seen. Nearly 47% (7) of the respondents felt that *Five Wishes* was more likely to encourage discussion

among families and in excess of 40% (6) felt that *Five Wishes* was more likely to encourage discussion with health care professionals. Not displayed in Table 9 is the fact that five (33%) of the health care providers felt that *Five Wishes* exceeded other advance directives in all five areas surveyed and nine (60%) of the healthcare providers felt *Five Wishes* was exceeding other advance directives in two or more areas.

**Table 9. Comparison of *Five Wishes* with other Advance Directives**

Attitude	Health care providers with positive response
Easier to understand	12
Covers broader range care issues	7
Easier to complete by oneself	7
More likely to encourage family discussion	7
More likely to encourage discussion with health care workers	6

While this sample may not be indicative of the health care population in general, these results do show that *Five Wishes* is looked upon by those who completed this portion of the survey as being a user friendly document. Perhaps this will overcome some of the long-standing difficulties of advance directives, and it may improve decision-making at the end-of-life. Further research using a larger sample of medical providers may provide more definitive evidence that the document would have a significant effect in this area.

## SECTION SEVEN

### CONCLUSIONS AND RECOMMENDATIONS

The Patient Self-Determination Act is viewed by many as a human rights triumph. The legislation provided patients with the opportunity and freedom to make their own choices and plan for the care they want to receive at the end of life. A key element in exercising this right, however, is for patients to have the ability to make their choices and effectively communicate them to family and health care workers. Extant research has shown that many advance directives fall woefully short in this respect.

Aging with Dignity proposed the *Five Wishes America* Project with the lofty objective of "changing the way Americans talk about and plan for the care they want to receive at the end-of-life." A generous grant from the Robert Wood Johnson Foundation provided Aging with Dignity the financial resources with which to develop and distribute an advance directive document that was to be recognized nationally, one easy to understand, simple to use, and accepted by the health care community. In conjunction with Mr. Charles Sabatino of the American Bar Association Commission on Legal Problems of the Elderly, a document was developed that was eventually legally valid in 33 states and the District of Columbia.

At the one-year anniversary of the project, Florida TaxWatch was hired as a third party evaluator to determine Aging with Dignities achievement of four project objectives:

- a. Whether the communications success of the project is reflected by the amount and quality of media coverage generated (newspaper, magazine, television, newsletter and Internet penetration);
- b. Whether *Five Wishes* was actually used by those individuals who received it;

- c. Whether the organizations which distributed *Five Wishes* actually succeeded in an effective distribution of the document; and
- d. Whether health and long-term care providers are willing to use *Five Wishes* institutionally and, if utilized, whether this results in better care.

A combination of data from three sources was used by Florida TaxWatch to evaluate the *Five Wishes* project's success: (1) a national survey of recipients of the *Five Wishes* document; (2) a survey of distributors of the *Five Wishes* document and of health and long-term care providers willing to use *Five Wishes* institutionally; and (3) archival data.

Since the introduction of the *Five Wishes* national document the project has enjoyed regular media exposure at both the national and local levels. Units of media coverage typically were four to five times higher after the national campaign was put in place than in the months preceding the establishment of the media plan. Additionally, this media coverage stresses those concepts that make *Five Wishes* a unique document. This should improve its implementation.

A key program objective was to help individuals assure themselves that their end of life choices are understood and implemented. When the survey research done in relation to this evaluation was compared with existing research data, it was shown that the recipients of *Five Wishes* are nearly three times more likely than the regular population to have completed advance directives. Additionally, the majority of those individuals who completed the document used the opportunity to discuss their care with their spouse, family, friends or a doctor.

Upon reviewing correlates of completion, it can be suggested that a secondary outcome of this section of the evaluation would be that the seminars given by Aging with Dignity are the most salient factor in the completion of *Five Wishes*. The success in this area can be attributed to *Five Wishes'* ability to overcome some of the most common barriers to completing the document.

Further, it can be concluded that an effective distribution network is beginning to form. While there has been no definitive description of a "distributor", there is an emerging group of organizations who are in regular contact with Aging with Dignity, who actively participate in disseminating the *Five Wishes* document, and are will to contribute valued organizational resources to become more effective in distributing the product. Such a network will significantly leverage Aging with Dignity's efforts in the are of media coverage and distribution.

Finally, *Five Wishes* received a significant favorable response from those heath care workers surveyed. The sample, however, could not be deemed reliable for purposes of broader generalization to the heath care population as a whole. The sample suffered from being small and clearly was biased due to the fact that respondents were either distributors of the *Five Wishes* document or had inquired about it. Additionally, due to Aging with Dignity's emphasis on pre-planning, few heath care workers experienced the implementation of the document. It is suggested that definitive data on this aspect of the project will not be available until there is greater mortality in the population of *Five Wishes* users over the next few years.

The research findings lead TaxWatch to proffer the following recommendations:

1. Though it was concluded that the project has been successful in achieving its communications goal, the data demonstrate that the *Five Wishes* message is not reaching minority and working-age populations. Aging with Dignity should, in its media plan, develop a strategy which will specifically target these untapped populations.
2. Aging with Dignity should look to organizations, not solely as distributors, but rather seek to establish new collaborative relationships with other organizations. Current staffing levels at Aging with Dignity are stressed due to the success of the project. By forging collaborative relationships with key organizations, Aging with Dignity can leverage it ability to conduct the media campaign, deliver seminars and handle simple distribution of the product.

In conclusion, Florida TaxWatch believes that the *Five Wishes* program is experiencing notable success in achieving at least three of the four stated program goals: (1) communications success; (2) document completion; and (3) development of a distribution network. The unavailability of data limits the ability to either confirm or deny the project's success in influencing health care workers' willingness to use the document and its effect on patient care.

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