The Naturally Occurring Communities (NOC) Toolkit

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800.658.8898

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Overview

Marketers and educators didn’t start the hospice movement in the United States – consumers did. Physicians didn’t change the birthing experience – women did. These and other social change movements demonstrate the need for consumers to lead change. Yet end-of-life providers often focus money and time educating other providers in an effort to improve end-of-life care and change the way people view death and dying. Provider–to–provider education alone isn’t going to change the way people die – a cooperative movement of consumers working together with providers and the entire community will make change happen.

In hundreds of communities across the country, end-of-life coalitions – providers and consumers working together – are making change happen. With this approach, improving end-of-life care and services becomes an inclusive process, rather than an exclusive provider–based activity. Examples include:

- Faith communities working together to support people who don’t have a caregiver
- Senior community residents leading a pain education campaign for facility staff
- A Native American community developing their own unique end-of-life care support system

End-of-life coalitions are learning to talk and listen to the people they want to reach to find out what is important to them, what they want and need, and to help identify how they can become actively involved in creating change.

The Tipping Point

In *The Tipping Point: How Little Things Can Make a Big Difference* (Little, Brown and Co. 2000), Malcolm Gladwell discusses the phenomenon of social change.
He examines how “social epidemics” happen -- how these new ideas become accepted and embraced -- how they reach a tipping point.

One section of *The Tipping Point* specifically speaks to the importance of social change agents understanding the power of naturally occurring communities (NOCs). Gladwell points to numerous examples of how small groups working together in communities have “tipped” a movement. In particular, he speaks to the power of working with already established small groups of people.

- “(John) Wesley realized that if you wanted to bring about a fundamental change that would persist and serve as an example to others, you needed to create a community around them, where those new beliefs could be practiced, expressed and nurtured.” Pg 173
- “…The lesson… is that small close-knit groups have the power to magnify the epidemic potential of a message or idea.” pg 174

These excerpts from Gladwell's book illustrate his conviction as well as other research about the power of small communities to expand or jump-start social change movements. End-of-life coalitions can further their mission of creating social change by spending time nurturing relationships and creating a mutual exchange of benefits with naturally occurring communities.
Naturally Occurring Communities

Naturally occurring communities (NOCs) are groups of people who have a shared reason for coming together. “Naturally” simply means that these communities come together and maintain themselves on their own, adapting their structures, characteristics, traditions and values as needed. People often self-select to belong to these communities. As agents of social change, coalitions need to go where people are – and harness the power of naturally occurring communities to tip the social change movement.

This Toolkit lays out a process for engaging naturally occurring communities in conversations and action to improve end-of-life care. The Toolkit will help you:

- Recognize community characteristics and elements of strong communities
- Use strategies to mobilize communities
- Understand the mutual benefits of partnering with NOCs
- Identify potential NOC partners
- Develop relationships, learn about and work with NOCs
- Customize messages, products and services
- Evaluate your efforts
- Sustain the partnership

Coalitions that share their passion and excitement with naturally occurring communities have tremendous potential to “tip” the end-of-life social change movement…one community at a time.
Understanding Communities

When you think about communities you belong to, what comes to mind? Most people think of “community” as the place where they live – their neighborhood, town, city, state or country.

Coalitions need to think about the concept of community in broader terms. Community exists when groups of people come together for a shared purpose. The purpose could be:

- living in a certain area
- working at the same organization
- believing in a faith tradition
- belonging to a cultural group
- having a common interest
- sharing a significant experience

These are all communities. Some may be more formal than others, having structure, a gathering place or time, and a set “membership” list. Other communities are informal, or unstructured. The text box (right) describes the characteristics of communities.

Types of Communities

Think about all the communities you belong to. Some people are active in only a few communities, while others are active participants or leaders in dozens of communities.
Examples of communities you might belong to include:

**Residential**  The county, city, town, neighborhood, building, and/or area where you live

**Family**  People who are related to you and/or who you identify as being your family

**Faith**  Your church, synagogue, mosque or other faith community, spiritual groups
Workplace The company or organization where you work – can include an entire staff or departments within a workplace

Social Groups which you choose to belong to because of a common interest, commitment or circumstance

Circumstance or Interest A community that forms as a result of a specific situation, condition or event (breast cancer survivors, Alcoholics Anonymous), or through shared interest or investment in a particular subject (book clubs, investment clubs, etc)

Communities within Communities
People seldom belong to just one community; indeed many people are members of several. As the community diagram below illustrates, in any one geographic community, numerous subsets of types of communities co-exist. Some communities are self-contained, while others spill over into other geographic communities. For example, a workplace could be part of a corporation with multiple locations in various cities, states or countries.

The diagram also illustrates the intersection between different types of communities. A family may have members who are part of a workplace community a faith community and the local Rotary Club.

These layers of communities are woven together by their shared members and the interaction of each “sub–community” with the others.
Strong Communities

People come together in groups for many reasons – but not all groups of people are true communities. Review the scenarios in below for examples of this concept.

Scenario 1:
Lucy works at a large corporation. She has 15 co-workers who work in her department in close proximity. They work well together and are very productive. Lucy knows very little about her co-workers and does not socialize with any of them. They have one annual social event, which is mandatory for all department members. Last year when Lucy was ill and missed a month of work, she did not hear from any of her colleagues.

Scenario 2:
Jane also works for a large corporation, and has 20 co-workers in her department. They work well together and are very productive. They have a pot-luck lunch once a month, which everyone looks forward to. The department enjoys participating in the annual cancer and AIDS charity walks together. When Jane hurt her knee and had to stay home for 4 weeks, her co-workers took turns bringing her work so she wouldn’t have to take family medical leave. They also brought food and care packages. When another co-worker’s husband died, everyone in the department attended a grief support training to learn how to best support their colleague.

Both Lucy and Jane are part of work teams. Yet, only Jane receives the benefits of community. She can rely on community support when she needs it. She belongs to a true community. Going back to our initial definition of community – Jane’s coworkers “commit themselves for the long term to their own, one another’s and the group’s well-being.”
Why is Jane’s workplace a community while Lucy’s isn’t? One possible answer is the shared common bond. There is something that binds the group together like glue. It could be a common interest or natural affinity for one another or it could be a product of what’s known as “culture by design.” Some leaders strive to create a sense of community in the workplace and other settings. They encourage members to get to know one another; they emphasize the organizational mission and create a community of people working to achieve that mission.

In a community, there is a shared commitment to everyone — not just the leadership or the “popular” people. Again in scenario two, when a co-worker’s husband died, the community again found ways to support the grieving wife.

Some groups of people never become communities. For any number of reasons they lack the glue that binds them together. This could be due to personalities, time constraints, and external barriers such as a prohibition on socializing in the workplace or another reason.

In frontier America (and still today in Amish communities), when a family needed a barn, the entire community gathered and helped build it together. The family described the kind of barn they needed, and the community members pitched in and made it a reality. This process depended on the collective vision, talents and experience of the community, as well as good communication and understanding of community systems. Everyone participated and celebrated together when the work was done, knowing that they would do it again for anyone in the community who had a need.

The “barn-raising” metaphor is common in discussions about cooperation, collective action and community support. Lots of communities support each other and do things together -- but what exactly is it that barn-raising

Without a sense of caring, there can be no sense of community.
communities have that enables them to undertake and accomplish such inspiring and effective community cooperation?

The term *social capital* refers to the cooperation, trust, reciprocity and support that binds the members of communities, and the inherent value and benefits that come from these connections. Green and Haines (2002) define social capital as “the norms, shared understandings, trust, and other factors that make collective action feasible and productive.” As the term implies, social capital is worth something – and it can be leveraged to solve community problems and make improvements.

According to Robert Putnam (2000), social capital works through multiple channels:

1. Information flow – learning and exchanging ideas
2. Norms of reciprocity (mutual aid)
   a. bonding networks that connect people who are similar
   b. bridging networks that connect people who are diverse
3. Collective action
4. Broader identities and solidarity (help translate “I” mentality into “we” mentality)

Barn-raising communities and other strong communities have a high degree of social capital. Strong communities are more likely to successfully engage in efforts to improve situations that affect them. As your coalition considers working with naturally occurring communities, keep in mind that the strength of the community will influence the success of your initiatives with them. Choose strong communities as partners in initiatives to improve end-of-life care and services, so that you can successfully “raise that barn” with them.
Helping Communities Help Themselves

For decades, the fields of social work, public health, economics and others have defined and theorized about the concepts of community development, community building, and community empowerment. While each of these concepts has specific definitions and strategies, they also have common threads regarding the process of working with communities to promote positive social change, including:

- The community identifies its own needs
- The community participates in developing goals and objectives regarding these needs
- The community participates in planning and taking action to address identified needs and enhance community well-being

Traditionally, these theories of community work generally focus on neighborhood communities, usually with goals in mind such as empowerment of residents, improving infrastructure, economic development and revitalization. Similarly, the community health development approach shares some of the common elements of these concepts, but focuses on the specific outcome of health improvement in communities.

For a community to be whole and healthy, it must be based on people's love and concern for each other.
Common principles of community building/development/empowerment and community health development

♦ **Initiatives are community specific** – initiatives are customized to the unique community. “One size” does not fit all.

♦ **Initiatives benefit from community assets** – every community has resources and talents to contribute to the efforts.

♦ **Initiatives require relationship building** – networks within the community are developed or enhanced, as well as connections to the larger community and others involved in the issues.

♦ **Initiatives involve collective vision** – community members identify their wants and needs and develop goals toward a shared vision of change.

♦ **Initiatives involve community decision-making** – community members have opportunities to affect and make decisions that affect their lives. Community members gain a sense of control.

♦ **Initiatives depend on community participation** – members of the community participate in all activities aimed at creating change.


Naturally occurring communities are not necessarily linked to neighborhoods – they “occur” whenever and wherever a group of people has defined itself as a community (see text box on page 1 of this section). If we expand the definition of “community” in this way, the common principles of these various concepts of community work can help us develop a basic framework for successfully engaging and working with naturally occurring communities.
Mobilizing Communities

Coalitions are involved in a variety of activities to improve end–of–life care. For many coalitions, the natural inclination is to focus on raising awareness and providing education. These are familiar activities and it is relatively easy to find an audience for educational programs.

However, if we ask people why they don’t talk about end–of–life issues with friends, family members or health care providers, very few of them report a lack of awareness or knowledge. Rather, the reasons for avoiding these conversations reflect our death–denying culture.

A Report by American Health Decisions, *The Quest to Die with Dignity* (1997), details the reasons that Americans do not want to talk about death and dying.

- They say it is “sad, depressing, bad luck,” or “too far in the future.”
- They say they are “too busy living to focus on dying.”

Most adults have experienced the death of someone they know. People understand the basic concepts related to how people die, they just do not want to think or talk about their own death or that of a loved one until it is absolutely necessary.

Therefore, our task is not just to raise awareness through education; it is to change the cultural context of death in our society. This goal is far bigger and broader than teaching people a skill or providing basic knowledge. Rather, what we need to change cultural mores about death and dying is a comprehensive engagement strategy that includes, but is not limited to, education and “marketing.”
This section of the Toolkit outlines four strategies that your coalition can use to mobilize communities, so that conversations about death and dying become as commonplace as discussions about other life transitions like birth, childhood development, or marriage/partnership. Examples of how each strategy relates to end-of-life coalition work are provided at the end of this section.

We recommend that you learn about all of the strategies outlined below, and integrate the best of all of the strategies in your NOC partnerships and all of your coalition activities.
Community Education

Community education involves teaching information to a person or group. Successful educational endeavors rely on the investment people make in learning what you have to teach, and their willingness to integrate what they learn into their activities. Educational sessions that do not encourage participants to change behavior or take action, do not typically impact social change or practice patterns.

Below are the nine recognized principles of community education (Horyna and Decker, 1991). As you develop educational events, think about how to integrate these principles into the design and implementation of each program.

- **Self–determination**: Community members are in the best position to identify community educational needs and goals.
- **Self–help**: People are best served when their capacity to help themselves is encouraged and enhanced. When people are educated to assume ever-increasing responsibility for their own well-being, they acquire independence rather than dependence.
- **Leadership Development**: The identification, development, and use of leadership capacities of local citizens are necessary elements of ongoing self-help and community improvement efforts.
- **Localization**: Services, programs, events, and other community involvement opportunities closest to the target community have the greatest potential for a high level of public participation. Whenever possible, these activities should be located in the community for easy public access.
- **Integrated Delivery of Services**: Establishing close working relationships between organizations and agencies with related purposes can increase resources, and enhance the ability to meet goals and better serve the public.
- **Maximum Use of Resources**: The physical, financial, and human resources of every community should be interconnected and used to their fullest. Connections help meet the diverse needs and interests of the community.
• **Inclusiveness**: The segregation or isolation of people by age, income, sex, race, ethnicity, religion, or other factors inhibits the full development of the community. Community educational programs, activities, and services should involve the broadest possible cross section of community residents.

• **Responsiveness**: Successful educational programs and services are responsive to the continually changing needs and interests of communities.

• **Lifelong Learning**: Formal and informal learning opportunities should be available to people of all ages in a wide variety of community settings.

Community education is effective in teaching people who are willing to learn new skills and/or knowledge. Education is an important aspect of coalition work, but education cannot be the only focus of coalition initiatives.

**Marketing**

Coalitions “sell” messages, ideas and services as part of working to improve end-of-life care. Marketing involves convincing a person or group why they should do something. The four key marketing principles (Weinreich, 1999) (known as the four P’s of marketing) include the following:

• **Product** – service or item you are marketing

• **Price** – the cost to the user to purchase or use the product (money, time, energy, etc)

• **Place** – where and how the product is obtained

• **Promotion** – how you get the message about the product to your target audience

Marketing can be a useful and effective strategy for coalitions, but as with education, it can not stand alone. Marketing helps to increase visibility in the community, spread messages and promote specific events or activities.
Social Marketing

Non-profit and social causes often use the principles and techniques of marketing to influence the behaviors of a target audience. Social marketing is often used to improve the health of an individual or community. For example, social marketing techniques are employed by groups working to help people stop smoking, eat a balanced diet and vote. In social marketing, the product is a change in behavior or practice that you want people to adopt. In addition to the four P’s of marketing (above), social marketing also involves:

- **Publics** – members of the campaign or program and the people whose behavior you want to change
- **Partnership** – successful social marketing campaigns rely on partnerships between organizations and groups vested in the topic
- **Policy** – achieving lasting behavior change relies on an environment that supports the desired change
- **Purse strings** – unlike commercial marketing campaigns, social marketers are often forced to design and implement a campaign with very limited resources

Social marketing is a difficult concept to grasp, but it is extremely important in terms of helping community members see the need for, achieve and sustain a change in behavior.
Community Engagement

Community engagement is the process of creating community dialogue and responding to identified needs. It is listening, asking questions, considering all opinions and developing strategies.

Education and marketing involve doing things to people. Educational programs and marketing campaigns are typically designed to share information about your organization or initiative, and may not involve or engage your audience in what is important to them. These strategies are successful only when audience members are vested in learning or hearing your content and messages.

Community engagement is based on a dialogue with community members – you learn what is important to them, rather than simply delivering your messages to or at them. It is a process that, over time, involves an ever-widening circle of people, and builds community ownership of the engagement process. When the community owns the issue, they become the messengers. Below are some keys to successful community engagement:

- **Know your community**: It is important to know everything you can about your community – who lives there, what issues are important to them, where they get information, who are the formal and informal leaders in the community, what are the community assets – anything that can impact the social change process (see Learning About NOCs section).

- **Engagement doesn't end – it evolves**: Creating change and making improvements in programs and services takes time – time to learn what is important to people in the community, involve them in a change process, implement new systems, and evaluate the work you’ve done.

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**Community Engagement is ...**

- A two-way process of involving diverse stakeholders as participants in conversation and action on behalf of change.

- Education and marketing are components of engagement, not the same as engagement.
• **Be specific:** Effective engagement is audience and issue specific. For example, if your goal is to reach caregivers, then you must talk people who are or have been caregivers, asking them what they need, how they access support, where they learn about resources, etc.

• **Communication is key:** Engagement isn’t “talking at,” it’s “talking with” and listening to the community. Successful engagement incorporates strategies for communicating with all stakeholders involved in the issue.

• **Go where people are:** Don’t wait for people to come to you. Engagement involves being present in communities where people live, work, worship, play, meet and shop and learning from people in those communities.

• **Encourage action:** Stimulating personal or organizational action is a key component of engagement. Use every opportunity to challenge people to take action and make it easy for them to do so.

• **Listen, then let go:** Control of engagement initiatives belongs to the community, not your coalition or organization. The voice of the community needs to steer the coalition’s activities.

Community engagement combines the principles of education, marketing and social marketing, and is based on the ongoing and purposeful participation of the community in social change activities.

In a publication about community development, Sabine O'Hara (1999) wrote "As residents are isolated from the decisions which affect their own lives and livelihood, communication, networking, citizen involvement, community identity and trust are eroded as well." Conversely, engaging community members in conversations about important issues is a way to help improve a community on its own terms. Community engagement is a strategy that fosters social change driven by the public, and can help communities become participants in creating the "end-of-life agenda," rather than simply being passive consumers of it. Some of the benefits of community engagement are:
• An engaged public leads to a community of active members who are more knowledgeable about community resources and services
• When people are involved in community decision making, they are more supportive of community programs and projects
• Communities with high levels of interaction between providers and consumers are more likely to experience a greater degree of trust that those with less interaction
• Interaction through engagement can help providers of end-of-life care and services better understand the experiences and needs of consumers

The four strategies outlined in this section of the Toolkit each have a role in coalition work with NOCs. However, only community engagement integrates the concepts of the other three strategies and encourages both individual action and a commitment to the shared success of the entire community.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
</table>
| **Education** – teaches knowledge and skills | • Can heighten community awareness of issues  
• People in the community share what they have learned  
• Participants have the potential to use new knowledge and skills | • To benefit, people must want to learn the skills and knowledge  
• People have to find the information or event  
• Education alone does not typically change behavior or practice |
| **Marketing** – sells ideas and concepts | • Clearly identifies available services and resources  
• Potential to reach a large audience | • No opportunities for dialogue  
• Based on goals of coalition – what we want to sell  
• Difficult to determine effectiveness |
<table>
<thead>
<tr>
<th>Strategy</th>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Marketing –</td>
<td>• Communities learn about specific behavior changes that can enhance their well-being</td>
<td>• Audience must recognize the need for and benefit of the change</td>
</tr>
<tr>
<td>promotes personal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>behavior change</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Engagement –</td>
<td>• Communities communicate their needs, desires and wishes, and lead the social change</td>
<td>• Community must be open to the discussion and process</td>
</tr>
<tr>
<td>encourages ongoing</td>
<td>• Encompasses principles and tactics of education, marketing and social marketing</td>
<td></td>
</tr>
<tr>
<td>dialogue and discussion</td>
<td>• Promotes individual and community action</td>
<td></td>
</tr>
<tr>
<td>with the community about</td>
<td></td>
<td></td>
</tr>
<tr>
<td>what they want to learn,</td>
<td></td>
<td></td>
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<tr>
<td>services they desire, and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>change they want to make</td>
<td></td>
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</tbody>
</table>
Changing community perceptions, attitudes and behaviors related to end-of-life issues requires a multifaceted approach. Our death-denying culture makes it vitally important to weave end-of-life discussions and issues into the fabric of the community. Indeed, our task involves taking death “out of the closet” and normalizing discussions about hospice, advance care planning, funeral planning, grief and other related issues that are important to communities.

In order for community coalitions to improve the way people die, we must engage communities in dialogue and encourage action. Successful partnerships with naturally occurring communities utilize the principles of public engagement as the framework for all activities. This Toolkit expands upon these principles and outlines specific steps that coalitions can use to partner with NOCs.

Community Mobilization Example

The following tables demonstrate how coalitions can integrate the four strategies outlined above in relation to one of the most common coalition activities -- advance care planning initiatives. As you can see, all of the strategies are connected, with community engagement incorporating principles from the other three.

<table>
<thead>
<tr>
<th>Education</th>
</tr>
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<tbody>
<tr>
<td><strong>Self-determination</strong></td>
</tr>
<tr>
<td><strong>Self-help</strong></td>
</tr>
<tr>
<td><strong>Leadership Development</strong></td>
</tr>
<tr>
<td><strong>Localization</strong></td>
</tr>
<tr>
<td><strong>INTEGRATED SERVICE DELIVERY</strong></td>
</tr>
</tbody>
</table>
### Education

<table>
<thead>
<tr>
<th>Inclusiveness</th>
<th>• Everyone in the community should have access to hospice, advance care planning education and information, and caregiver trainings and support.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responsiveness</td>
<td>• Information developed for the community reflects current community needs.</td>
</tr>
<tr>
<td>Lifelong Learning</td>
<td>• Educational opportunities are developed and delivered to people across the lifespan.</td>
</tr>
</tbody>
</table>

### Marketing

<table>
<thead>
<tr>
<th>Product</th>
<th>• Information about why advance care planning is important.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Advance directive packets</td>
</tr>
<tr>
<td>Price</td>
<td>• Low or no monetary cost for advance care planning documents</td>
</tr>
<tr>
<td></td>
<td>• Cost to some people could be admitting that they will die and could need these materials</td>
</tr>
<tr>
<td>Place</td>
<td>• Speakers bureau presentations, health fairs</td>
</tr>
<tr>
<td>Promotion</td>
<td>• Advertisements, posters, bookmarks</td>
</tr>
</tbody>
</table>

### Social Marketing End-of-life Concepts or Related Behaviors

<table>
<thead>
<tr>
<th>Product</th>
<th>• Information about why completing your advance care planning is important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Advance directive packet</td>
</tr>
<tr>
<td>Price</td>
<td>• No monetary cost</td>
</tr>
<tr>
<td></td>
<td>• People admitting that they will die and talking about it</td>
</tr>
<tr>
<td>Place</td>
<td>• Speakers bureau presentations, health fairs</td>
</tr>
</tbody>
</table>
### Social Marketing End-of-life Concepts or Related Behaviors

<table>
<thead>
<tr>
<th>Promotion</th>
<th>• Advertisements, posters, bookmarks</th>
</tr>
</thead>
</table>
| Public         | • Internal – coalition members, staff and volunteers of member organizations  
                 • External – community at large, health care providers |
| Partnership    | • Hospitals, physicians, attorneys, estate planners, funeral homes, HMOs |
| Policy         | • Review ACP laws and statutes to strengthen them, ensure access to ACP information and physician compliance with written directives |
| Purse–strings  | • Funding sources include: individual donations, sponsorship, grants |
### Community Engagement Related to End-of-life Issues

<table>
<thead>
<tr>
<th>Know your community</th>
<th>Engagement doesn’t end – it evolves</th>
<th>Be specific</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Do people know what advance care planning (ACP) is?</td>
<td>• Short and long-term goals are developed:</td>
<td>• Engagement activities are segmented, focusing on specific members of the community.</td>
</tr>
<tr>
<td>• Where do people learn about ACP?</td>
<td>o X number of community forums on ACP.</td>
<td>• Engagement tactics and messages are specific for each audience</td>
</tr>
<tr>
<td>• Where can people get advance directives?</td>
<td>o Distribute X number of advance care planning packets.</td>
<td>o Education about starting conversations for hospital intake staff</td>
</tr>
<tr>
<td>• Are there cultural, spiritual, economic, etc. barriers to advance care planning?</td>
<td>o X % of hospital staff complete the ACP training.</td>
<td>o Listening to caregivers about what they need in relation to ACP</td>
</tr>
<tr>
<td>• Is there money available to fund ACP training?</td>
<td>o Partnerships formed with X number of employers and/or faith communities to provide ACP education.</td>
<td>o Newsletter article on how to give “the gift of peace of mind”</td>
</tr>
<tr>
<td></td>
<td>• Engagement plan is reviewed and modified every X months.</td>
<td>• Listening sessions held at locations where audiences gather</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• ACP documents are culturally specific, relevant, sensitive, etc.</td>
</tr>
</tbody>
</table>
### Community Engagement Related to End-of-life Issues

| Communication is key | • The engagement plan includes ongoing, proactive opportunities for community feedback and involvement  
  o Town hall meetings  
  o Feedback forms  
  o Open invitations for people to participate in activities  
• Advance care planning documents and processes reflect the needs and culture of the community |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Go where people are</td>
<td>• Engagement activities take place in local communities</td>
</tr>
</tbody>
</table>
| Encourage action     | • People are asked and encouraged to take action at every event, in every publication and during every interaction.  
  o Talk to your family about your wishes  
  o Complete an advance care directive (AD)  
  o Review and update your AD  
  o Give copies of your AD to your physician and family members  
  o Ask people you know if they have completed AD's  
  o Make AD's available to your employees  
  o Schedule a speakers bureau presentation on ACP for your community (faith, workplace, etc)  
  o Have a conversation with your physician about your end-of-life care wishes and goals  
  o Join the coalition  
  o Donate to our coalition |
| Listen, then let go  | • If your community tells you that ACP isn’t a priority, but caregiver support is, adapt your plan to meet their need.  
• As new people join the coalition, priorities may change. Allow the group to set the priorities, design strategies and implement. |
Recognizing the Rewards of Partnership

So far, we have discussed the characteristics of communities, how to identify strong communities and various strategies to deliver your messages about improving end-of-life care and services.

As discussed in the previous section, engagement initiatives involving naturally occurring communities (NOCs) can be different than traditional outreach and education campaigns, namely because of the opportunity for direct involvement of community members. End-of-life coalitions are frequently comprised of educators, human service and health care providers, and other professionals. While these are often strong, effective coalitions doing wonderful work, by their very nature they may be inaccessible to the public unless the public attends a coalition sponsored event. Engaging NOCs is an important step in making the “end-of-life agenda” accessible to everyone.

Why are so many end-of-life coalitions comprised of professionals and providers?

Professionals and organizations that directly or indirectly provide end-of-life care or services are motivated to participate in coalitions. Reasons for participation include:

- A mission or values that are aligned with the coalition
- Knowledge and expertise in the field of end-of-life
- Outreach goals that are forwarded through coalition activities
- An interest in increasing access to and/or promoting their services
- A desire to empower individuals and communities to make educated choices regarding end-of-life care
- A desire to create social and cultural change around death and dying

As agents of social change, it is important for professionals and providers to understand the power of naturally occurring communities to “tip” a change
movement. The perception that end-of-life coalitions are “owned” by professionals and not the community becomes a barrier to social change. One of the advantages of working with NOCs is that coalitions involve the community, eliminating this barrier.

Benefits for the Community

In their book, *From the Ground Up: A Workbook on Coalition Building and Community Development*, Gillian Kaye and Tom Wolff discuss the importance of empowering communities:

Professional human service approaches often overemphasize the deficits and needs of individuals and communities rather than their assets and capabilities. These approaches crowd citizens out of the process of defining solutions and strategies. While it is not true that citizens are the only experts, a marriage must be found between the service system and the “community way” of assessing and solving problems so there is a partnership between the two. (p.10)

Most coalition approaches to community work fall into two categories, *community based* or *community development* (Chavis and Floren, 1990). These approaches represent opposite ends of a continuum, and though both approaches have value, the community development approach more clearly focuses on empowering the community (from Kaye and Wolff, 2002).
The Naturally Occurring Communities Toolkit

<table>
<thead>
<tr>
<th>Community Based</th>
<th>Community Development</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providers (experts) determine needs, develop outreach strategies and provide services</td>
<td>Community identifies needs and has a voice in determining strategies to improve services</td>
</tr>
<tr>
<td>Aimed at identifying gaps in services and correcting deficit</td>
<td>Aimed at using community strength to address concerns</td>
</tr>
<tr>
<td>Vehicles of change are information, education, and improved services</td>
<td>Vehicles of change involve building community control and increasing community capacity</td>
</tr>
<tr>
<td>Professionals are key decision makers</td>
<td>Professionals are a resource for the community</td>
</tr>
<tr>
<td>Primary decision makers are providers and agency representatives</td>
<td>Primary decision makers are the community’s leaders</td>
</tr>
</tbody>
</table>

The community development approach outlined above helps foster community ownership and community control. When working with NOCs, it is important to go to them, to avoid creating barriers to partnership. Approaching a NOC from a community development perspective differs from traditional approaches in several ways.
<table>
<thead>
<tr>
<th><strong>Traditional Approaches</strong></th>
<th><strong>Community Development Approaches</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop fixed messages and educate community about available EOL services</td>
<td>Tailor messages and approach to the uniqueness of each community</td>
</tr>
<tr>
<td>Encourage the community to come to coalition events</td>
<td>Establish coalition presence at community events</td>
</tr>
<tr>
<td>Focus on community learning about coalition initiatives</td>
<td>Focus on coalition learning about the community</td>
</tr>
<tr>
<td>Recruiting individuals to join the coalition</td>
<td>Partnering with existing groups</td>
</tr>
</tbody>
</table>

Communities benefit from this availability, access and involvement in many ways, including:

- Participation in efforts to improve issues that directly affect them
- Involvement in decision making about issues that directly affect them
- Increased access to and connection with providers, professionals, and other traditional decision makers
- Opportunities to educate professionals working in the end-of-life arena about their concerns
- Increased *social capital* (or the benefits from cooperation, trust, reciprocity, and support that binds the members of communities working toward a common vision)

**Benefits for the Coalition**

*Outreach Advantages*

Communities, by definition, already have a sense of commonality and something that binds them. Coalitions working with NOCs can capitalize on
what already brings a community together. When people are invested in the well-being of each other and the community, end-of-life issues can become more important to them.

As community members are exposed to one another, the likelihood of a community having had an “end-of-life experience” is higher than that of an individual having had such an experience. Communities tend to be aware when a co-worker, neighbor, friend, teacher is sick, dying or caring for someone who is. They become powerful storytellers, one of the most potent forms of outreach. Because strong communities are likely to be aware of these events in their collective past, present and future, they may also have a sense of responsibility and motivation to address end-of-life issues, helping the coalition efforts to get the community “on the bandwagon.”

**Credibility**

One of the strongest benefits for coalitions working with NOCs is enhanced credibility. As coalitions seek funding, strive to change healthcare delivery systems or work to change legislative or regulatory policies, credibility becomes vitally important.

Developing relationships with gatekeepers can help ensure your coalition’s credibility in certain segments of the community. Gatekeepers are the leaders in parts of the community who, officially or unofficially, grant or deny entry into that part of the community. To earn acceptance in a community of which you are not a member, it is often necessary to demonstrate to the gatekeeper that you have a non-judgmental, non-threatening attitude and a genuine respect for the community. By working with NOCs and actively seeking the input of gatekeepers as you plan events and programs, your coalition’s relationships in the community can be enhanced.

Credibility is gained in other ways, such as your track record of success. Coalitions that can demonstrate a measurable improvement have credibility. Being associated or partnered with communities that are accepted as credible can also help enhance coalition credibility. Coalitions that have established
networks of influential, prominent or well-respected people and communities are more likely to be successful in receiving funding or other types of support.

In addition, coalitions working with NOCs may benefit from:

- Increased coalition exposure of coalition messages and activities to new audiences
- Potential for mutually beneficial ongoing relationships with communities
- Opportunities to receive direct feedback about coalition initiatives
- Increased awareness of the diversity of the larger community (communities within communities)
- Increased awareness of community perceptions of EOL issues
- Ability to quickly launch a grassroots campaign to lobby for change, such as a letter-writing campaign to state legislators
Working with NOC's – a Step-by Step-Guide

Below are the core principles for working well with naturally occurring communities. The steps progress as the relationship with the NOC and your partnership project develop. Keep in mind that you are working with the NOC, and that the community is involved in all decisions that affect them.

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<table>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>Know your coalition’s goals and why you want to work with a specific NOC.</td>
</tr>
<tr>
<td>2.</td>
<td>Develop relationships – build on existing relationships and develop new ones. Establish a friendly and familiar presence in the community.</td>
</tr>
<tr>
<td>3.</td>
<td>Learn about the NOC, its members, culture and structure.</td>
</tr>
<tr>
<td>4.</td>
<td>Determine the benefits and goals of partnership for the coalition and the community.</td>
</tr>
<tr>
<td>5.</td>
<td>Develop and customize products and services based on community strengths, coalition strengths, and your common goals and vision.</td>
</tr>
<tr>
<td>6.</td>
<td>Develop and deliver messages and identify what the community can do to be involved.</td>
</tr>
<tr>
<td>7.</td>
<td>Evaluate your efforts and progress toward goals and make adjustments if needed.</td>
</tr>
<tr>
<td>8.</td>
<td>Foster sustainability of efforts through maintenance and evolution of relationships.</td>
</tr>
</tbody>
</table>
Selecting NOC Partners

Now that we know some of the many benefits and advantages of working with naturally occurring communities (NOCs), we can look at how coalitions decide which communities to approach. Which communities should you get to know?

It’s important to consider your coalition’s mission, goals and current activities in considering which NOCs to approach and learn about. Some questions to guide you include:

- What segments of the community are underrepresented in the coalition?
- Which segments of our community encounter access barriers to end-of-life care and services?
- What relationships will our coalition need in order to be effective in promoting change?
- What relationships do our coalition members already have with NOCs?
  What NOCs do we already know?
- What are the strategic goals of the coalition?
- How can we expand our reach?

Know Yourself

It is important to know what your coalition hopes to gain by working with a particular NOC. In evaluating your goals, keep in mind that the key word in this kind of community work is with – work with the community. Broad goals that embrace the community development principles described in the previous section will help you to keep the focus on the community. Some broad goals include:

- Learn how that specific community is affected by end-of-life issues
- Assist the community in identifying:
  - Concerns and issues regarding end of life
o Strategies to make improvements
o Community strengths or assets that can help make those improvements
  • Increase community access to coalition and projects
  • Increase community membership in the coalition
  • Increase the community’s capacity to address end-of-life issues
  • Enhance community control of end-of-life care system changes
  • Promote true social and cultural change through community/consumer ownership of and participation in the end-of-life movement
Stay focused on your broad goals, letting them guide you in developing initiative-specific goals. Ask your coalition to consider the following:

- How can this initiative support the community?
- How can the project be customized to meet the community’s identified needs?
- How and to what extent will the community be involved in making decisions regarding the project?

**Know Your Stuff**

Before you talk to any community about your coalition, you must be able to articulate the general purpose and goals of the coalition. If you don’t already have one, you might want to develop a one-page information sheet stating the coalition mission and vision, goals, current members, activities, and other pertinent information. As an example, an information sheet developed by the Pinellas Partnership for End-of-Life Care is included in the Toolkit Appendix.

Also consider which type of NOC can enhance your coalition’s mission and vision through their resources. However, be cautious about selecting a NOC based solely on their ability to provide funds or other resources. Coalitions that “chase funding” rather than follow their mission are not successful over the long haul.

**Start With Existing Relationships**

Everyone in your coalition is a member of various communities such as faith groups, workplaces, clubs, neighborhoods, civic groups or other communities – and so the “seeds” of potential relationships with these communities exist.
### Coalition Members – Community Affiliations

<table>
<thead>
<tr>
<th></th>
<th>Juan</th>
<th>Alice</th>
<th>Frederick</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Church group</td>
<td>American Cancer Society local chapter</td>
<td>Hebrew studies group</td>
</tr>
<tr>
<td></td>
<td>Rotary club</td>
<td>Breast Cancer survivor’s group</td>
<td>NASCAR fan club</td>
</tr>
<tr>
<td></td>
<td>Neighborhood association</td>
<td>Retirement community</td>
<td>Jimmy Buffet “Saturday Night” club</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1st National Bank workplace</td>
</tr>
</tbody>
</table>

You can take a very informal inventory of the communities to which your coalition may have access. Simply ask coalition members to write down answers to the following questions during your next coalition meeting.

- What communities are you a member of?
- Which of these communities might have an interest in working with the coalition?
- Who are the people you know that are active members of established communities? Provide the name and the community name.
- Which of these people or communities might have an interest in working with the coalition?

Consider the concept of gatekeepers as you identify potential NOC partners. Gatekeepers are the leaders in parts of the community who, officially or unofficially, grant or deny entry into that community. Your coalition’s acceptance in a community is enhanced by including multiple gatekeepers involved in your coalition activities, and actively seeking their input as you plan events and programs. By exploring your coalition members’ connections and relationships, you may find that you have access to community gatekeepers or “ambassadors” that can provide you with an introduction to new communities.
Building Relationships

Reaching communities beyond your own “circle” involves building relationships. You have to extend yourself for others to know about your coalition, and to learn more about them. Anyone who has ever been in a relationship knows that it does not work well if it is \textit{all about you} – you have to take the time to listen and learn before promoting yourself in order for a relationship to develop.

The best way to develop new relationships with communities is to simply establish a helpful, familiar presence without directly promoting the coalition, its messages, or initiatives.

- Join and support established groups in the community. Sometimes relationships can be built through groups that are already known, and that already feel safe. The introduction to \textit{your} message will be more natural.
- Be responsive when a community is affected by end-of-life issues, and ask if there is any way you can help.
- Provide information and referral to other community resources that can be of assistance or benefit.
- Volunteer time or resources to support the community’s projects (walk-a-thons, car-washes, “paint your heart out” days, town celebrations, parades, etc). Ask coalition members what resources they can volunteer. Resources can include money, staff time, volunteers, space, food, in-kind donations, etc.
- Make offers without attachment to immediate outcome – establishing presence can’t be about anything but that. The benefit is that now they know you.

The goal is for members of communities beyond your coalition’s “inner circle” to be able to say, “I know someone from the coalition.” When you are building relationships with NOCs, these connections don’t necessarily happen through “end-of-life” experiences, but through community experiences.
In their book, *From the Ground Up: A Workbook on Coalition Building and Community Development*, Gillian Kaye and Tom Wolff (p.112) outline some practical outreach strategies to help build relationships with communities. They include:

1. **Reach Out to Community Leaders**
   ✓ Meet face-to-face with community leaders to help you learn about issues, gain access to others, help spread the word and disseminate information about the coalition.

2. **Go Door-to-Door**
   ✓ If you have the resources, do it! Face-to-face contact breaks down barriers and suspicions, provides you with unfiltered information and will help with your coalition’s community credibility.

3. **Street Outreach**
   ✓ Go to where the community is; don’t expect it to come to you. Street corners, basketball courts, or anywhere else the community is found are all places where you can do outreach.
   ✓ Send “credible” people to reach out – youth to youth, for example. If you can bring a community leader with you, great!

4. **Attend Community Meetings**
   ✓ Take time to attend meetings both as an observer and a participant. This sends the signal that you are interested in what the community is saying and doing.

5. **Tabling**
   ✓ What better way to reach the community than setting up a table with your information in front of a busy supermarket, or at community functions.

However you initially approach communities, make sure you:

✓ remain culturally sensitive at all times;
✓ spend more time listening than talking;
✓ have good, informative materials available in case you are asked for them; and
✓ convey your passion and excitement for the work you are doing -- let people know why the work is important to you.
Learning About NOC's

Now that you have started to develop relationships with communities, ask yourself, “Why is my coalition interested in partnering with this particular community?”

As we have discussed, communities form “naturally” for a variety of reasons, with formal, informal, tight or loose structures and processes. Learning more about specific communities can help you determine if they might be motivated to work on end–of–life issues, and what systems, structures and common bonds might enhance your joint efforts.

Finding information about NOC's

- Ask the “ambassadors” – members of your coalition or people you know who are members of the community.
- Read community–produced newsletters, papers, publications, websites, etc.
- Read professional publications, special interest magazines and other materials aimed at that particular audience.
- Attend community events.
- Ask community members to tell you who they are and what is important to them.
- Most of all, be prepared to listen, listen, listen.

To help guide your approach and dialogue with communities, ten aspects of communities are discussed below. As you develop relationships and get to know communities, use the questions that seem appropriate and will provide you and the NOC with helpful information. You don’t have to explore all the areas below or use all of the questions, but it is helpful to have a general...
understanding of the different aspects *from the perspective of the community*. Remember, the more you learn from the community about the community, the more likely your efforts are to be successful at achieving community empowerment and social change.
Ten Aspects of Communities
A process for learning about NOCs

1. Community Bond
Strong communities are bonded together by some common purpose, experience, interest, circumstance, belief, practice or other sense of universality. Knowing what brings a community together is crucial to understanding how to sensitively and effectively work in partnership with them.

- What are the common bonds in this community?
- How does the community acknowledge its common bonds?
- How does the community define itself in relation to these bonds?
- What makes this group of people a community?

2. History
One of the things communities share is history. Celebrating community history is part of how communities nurture and sustain themselves, reconnect, and revitalize.

- When and how did this community come together?
- Was the “birth” of this community in response to an event?
- How does the community celebrate and remember their common history?
- How has the community changed since it came together?
- What are the significant anniversaries or holidays?
- How have end-of-life issues impacted this community in the past?

3. Mission
Communities usually have some purpose for members, which in part, is how members find meaning in the experience of community. Sometimes this purpose is formally identified as a goal, task, or challenge, and sometimes the purpose is as simple as enjoying others in the community.
• Does the community have a stated mission, vision or goals?
• Has the community set and achieved goals in the past?
• What meaning do members of the community derive from participation?

4. Membership
In a strict sense, communities are defined by their members. After all, if no one was a member, there would be no community. It is important to have an understanding not only of who the community members are individually and collectively, but also about how the membership grows and changes.
• What are the demographics of the community?
• How is membership determined (invitation, open membership)?
• Who are the leaders, formal and informal?
• How do people join or leave the community?
• What is the primary motivation for membership (why do they want to belong)?
• Who are the gatekeepers to this community?

5. Cultural Values
Cultural values affect almost every other aspect of communities. Working with communities requires sensitivity to multi-cultural issues and a willingness to honor cultural values. Some coalitions confuse honoring values with adopting or endorsing them – you don’t have to share values to work with a community, you do need to know about and respect them. You only need to share a common vision to work with a community.
• What are the unique cultural, religious, spiritual, group, family or other values held by the community?
• How do these values drive or affect the community’s activities?
• How does this community learn? From faith? From experience? From evidence?
• How is trust established?
• How are relationships built?
• What are the accepted norms and patterns of behavior?

6. Structure
The structure of a community will influence many aspects of your work together. Pay attention to structural elements of the community and ask yourself if the structure lends itself to joint efforts.

• Location – “where” is this community? Where would you go to reach them?
• What is the leadership structure? Is the leadership formal or informal? How did the current leader come to be the leader?
• What is the organizational structure of this community?
• What is the decision-making style of this community? Does a leader make decisions? Do people vote? Do they make decisions quickly, or with great consideration?
• Are there meetings or other scheduled events? How often, and where?

7. Language/communication Styles
Language and communication styles affect interpretation, perspective, assumptions and how your motives are interpreted. Given that your intention is to communicate, to be effective you will need to explore language and communication styles thoroughly -- especially if they are different that yours.

• What is the primary language of the community?
• If English is not the primary language, how is communication translated?
• What, if any, non-verbal communication is significant?
• How and where and how often do they receive information?
• What are the main methods of communication? How do they share information?
• Are there newsletters or other publications?
• How does this community discuss end–of–life issues? Do they discuss the issues at all?
• What words and language do they use, especially when talking about the issues?
8. Current Circumstances
As is often said, timing is everything. Timing can help or hinder your efforts to work with a community. Depending on the current circumstances, the subject of end-of-life care could be very timely or not at all appropriate. Knowing the current circumstances can help guide your approach, and give you information about ways to offer assistance.

- How are end-of-life issues currently impacting this community?
- Has the community experienced a recent or current crisis of any kind?
- Is the community currently feeling exceptionally strong, or excessively weak? Why?
- Is there a significant date approaching (events, anniversaries, holidays, etc)?

9. Activities
Learning about community activities and projects can provide a wealth of information. A community’s activities reflect their values, structure, communication and common bonds, among other things. You may find that if you explore a community’s activities, you can save yourself the time and effort of “re-inventing the wheel” – if they are already working on similar issues, introducing the subject of end of life will be natural. Chances are, they have developed preferences for working on related issues and can share these with you.

- What activities or projects is the community currently involved in?
- Are activities ongoing, or do they complete a project and move on to another?
- Are there “themes” or types of projects the community undertakes?
- How do activities reflect community values and concerns?
- How is success of activities measured?
- How broad is community participation in activities and projects?
10. Connections

Just as you explored the connections your coalition has to various communities, exploring the NOC’s connections can reveal possibilities for future relationships. Community connections with other people and groups can help bring awareness and free publicity to your efforts.

- Who are the groups/people this NOC is connected with?
- What other NOCs do they have natural relationships with?
- Can members of this community provide easy access to other communities?

**Maintaining Relationships**

Maintain an ongoing dialogue with the community about what you’ve learned through your information gathering, and ask if you are on target.

Approach the community with questions, not with answers. Remember that the community is always the expert on how they deal with end-of-life issues. Let the information you’ve collected guide your questions.
Collecting information about a community will take time. You can make copies of this page and use it to take notes as you collect information. Use the *Ten Aspects of Communities* above as a guide to learn more about a community, exploring the questions that are relevant and appropriate.

**Name of Community ________________________________**

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Community Bond</td>
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<tr>
<td>History</td>
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<tr>
<td>Mission</td>
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<tr>
<td>Membership</td>
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<tr>
<td>Cultural Values</td>
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<tr>
<td>Structure</td>
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<tr>
<td>Language/Communication Styles</td>
<td></td>
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<tr>
<td>Current</td>
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<td>Circumstances</td>
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<tr>
<td>Activities</td>
<td></td>
</tr>
<tr>
<td>Connections</td>
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</tbody>
</table>
Developing Partnership Goals

As you are now aware, there are numerous benefits to partnering with a naturally occurring community (NOC). However, these benefits may not yet be clear to the NOC. It is important to think about and to outline the benefits of partnership for both your coalition and the NOC early in the relationship. Knowing the mutual benefits of partnership will help you to align goals, find common ground and form the basis of the relationship.

From early in the relationship, the NOC may have a very specific idea of how they would like to partner with your coalition, or they may need more information about the coalition, end-of-life issues and the needs of their community to identify a clear goal. In either case, it may be worthwhile to conduct a mini-planning meeting to identify the goals of partnership from both the NOC and coalition perspectives. A planning meeting can help the coalition focus on the desires of the community through discussion of the potential benefits and costs of the partnership for the NOC.

The Exchange

The exchange theory in social marketing says, “…what we offer the target market (benefits) has to be equal to or greater than what they will have to give (costs).” (Social Marketing: Improving the Quality of Life, p. 217).

We are asking NOCs to:

- Talk about a subject that they may not want to talk about
- Devote time to a new partnership
- Use their resources to work with us

Identifying perceived and actual costs and benefits for the community is a necessary step in working with NOCs. Taking time to listen to the community
about the costs they associate with partnership is key to understanding how you can work with them to best meet their needs.

Below is a sample Cost–Benefit List for a NOC. Once you begin to develop your relationship with each potential partner NOC, be sure to make your own list and revise it as necessary.
### ACME Plastics Workplace Community

**Cost–Benefit List**

<table>
<thead>
<tr>
<th>Costs</th>
<th>Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Confront cultural taboo of death and dying issues</td>
<td>• Support and resources for community members</td>
</tr>
<tr>
<td>• Time diverted from other projects</td>
<td>• Assistance with their “mission” of serving their employees and stakeholders</td>
</tr>
<tr>
<td>• Financial, time, resource or “energy” costs of implementing joint projects</td>
<td>• Support and resources for employees facing end-of-life issues</td>
</tr>
<tr>
<td>• Time/resources to communicate information about joint projects to community members</td>
<td>• Reduced turnover, absenteeism, etc. in the workplace</td>
</tr>
<tr>
<td>• Up-front investment in learning about EOL issues</td>
<td>• Increased sense of community</td>
</tr>
<tr>
<td></td>
<td>Increasing the “value” of the community from the perception of those outside the community (potential new employees, stockholders)</td>
</tr>
</tbody>
</table>

It may be helpful for both the coalition and the NOC to prepare a list of expected costs and benefits for the community, and then to compare them. If you are aware potential concerns related to the costs, you can discuss these honestly and openly. If you have a sense of the benefits or perks the community looks forward to, you can emphasize them in the discussion. You will find that this kind of discussion can help both the coalition and the NOC begin to identify goals for partnership.
Identifying the Goal

An initial step in developing a partnership is to decide on your focus or goals. The focus is something that is developed collaboratively with the NOC and is based on the:

- mission and values of the community and coalition
- self-identified needs of the community
- community and coalition resources

One way to approach goal development is to identify an outcome that you can work together to achieve. An outcome statement describes a result or condition the community desires.

Outcome statements:

- Describe a specific result that the community wants
- Identify community strengths, assets and resources that can create opportunities to achieve the outcome
- Outline community-identified barriers to achieving the outcome
- Identify strategies that can utilize community strengths to achieve the outcome

The ultimate goal of an outcome statement is to transform a generalized issue into a targeted, well-defined goal — one that can be reached or at least addressed by engaging the community. You’ll use the initial outcome statement as you gather information and formulate your plan. In all likelihood, you will change the focus slightly as you continue to listen to and work with the community.

The table below illustrates two sample outcome statements that address common NOC-coalition partnership focus areas.
### Sample Outcome Statements

<table>
<thead>
<tr>
<th>Desired Outcome</th>
<th>NOC–Identified Barriers</th>
<th>NOC Strengths</th>
<th>Partnership Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workplace community members who are caregivers have access to resources and a support system</td>
<td>Workplace management does not know what support and services employee caregivers need</td>
<td>Responsive workplace leadership style and open communication system</td>
<td>Conduct an open discussion forum on caregiver issues</td>
</tr>
<tr>
<td></td>
<td>The HR department is not aware of local resources available to support caregivers</td>
<td>A variety of community resources for caregivers have been established by local agencies</td>
<td>Develop a community caregivers’ resource guide for managers and the HR department</td>
</tr>
<tr>
<td></td>
<td>Employees and managers don’t know how to support peers who are caregivers</td>
<td>Strong workplace community socialties</td>
<td>Conduct “lunch and learn sessions” on caregiver support</td>
</tr>
<tr>
<td>The residents of XYZ retirement community communicate their end-of-life wishes to their families and</td>
<td>People do not understand advance care planning, including living wills and health care surrogates.</td>
<td>XYZ retirement community has 2 educational events a month and are scheduling speakers for future events</td>
<td>Develop a presentation on advance care planning and deliver it at the educational event once a year</td>
</tr>
</tbody>
</table>
It is important for the coalition and NOC to be clear about their respective goals for the partnership or initiative. Either separately or together, the NOC and coalition should each write out several potential outcome statements and analyze each one, using the questions below to test them:

- Is each outcome or goal realistic?
- Are the barriers something that you can influence/eliminate?
- Do the community strengths identify specific, current community resources and assets?
- Do the strategies use the strengths and address the barriers you identified?

In the early stages of your partnership with the NOC it may be prudent to choose one goal and one strategy. Once the group has organized, planned and begun implementing the initial strategy, you can revisit the other strategies or goals and add an additional project to your partnership work.

**Getting Started**

If you’re having trouble identifying outcomes, conduct the following exercise with your planning group.
• Ask the group to divide into smaller groups of three or four people.
• Distribute markers or crayons and flipchart paper.
• Instruct the groups to envision an ideal community – one ten or fifteen years in the future after your coalition and the community have completed the work and improved end-of-life.
• Allow the groups 15–20 to create their drawing and then ask them to describe them to the larger group.
• As the facilitator listen for the words used to describe the drawings and write them on a flipchart.
• Use the list of words as a springboard for a discussion about what the partnership between the NOC and coalition can collaborate on to serve the needs of the NOC.
• Take the results and write outcome statements as described above.
Creating and Customizing Products and Services

Your coalition and the naturally occurring community (NOC) may decide to develop “products” – resources, tools and other items – or services as part of your partnership efforts. Deciding what kind of products or services to develop should be based on the self-identified needs of the community, your partnership goals, and the available time and resources of your coalition and NOC members.

Your coalition may already have already developed products, services or programs that you have offered to the general community. It’s important to inventory what you already have “in stock,” and what you could conceivably offer before you begin working with a NOC. That way you can have the list ready if the NOC asks, “what can you offer to our members?”

Develop a Menu

Review the list below and draft your own “menu” of products and services. You can have this menu available to share with NOCs as you develop your relationships with them.

The following items can be modified in numerous ways to meet the unique needs of each community. Listed under each item are free tools and resources provided on the National Hospice and Palliative Care Organization’s websites:

- [www.caringinfo.org](http://www.caringinfo.org) for NHPCO ‘s consumer resources
- [www.CaringInfo.org](http://www.CaringInfo.org) for NHPCO’s coalition resources

1. **Informational materials.** You may decide to develop materials or use other informational resources. Many community or national organizations informational materials you can distribute.
• NHPCO consumer resources: a list of free and low-cost materials, as well as several examples of community resource guides.

2. **Educational presentations.** Coalitions can develop a speaker’s bureau and host seminars and conferences. Presentations can provide an important service for your community.

• NHPCO coalition resources: packaged presentations, topic lists, titles, and additional resources to help you develop and deliver presentations.

3. **Support network.** Your coalition can help communities develop internal support networks, such as a neighbor-to-neighbor program.

• NHPCO coalition resources: a step-by-step process for starting a “neighbor-to-neighbor” community support program. Other models for providing this type of support are also referenced.

4. **Peer support groups.** Support groups can be tremendously beneficial for people affected by end-of-life issues such as caregivers, those newly diagnosed with a life-threatening illness and people who are grieving a loss. You can teach people how to start and lead peer support groups and/or provide facilitators for groups.

5. **Crisis intervention.** When tragedy strikes, communities often need short-term counseling or support from trained professionals. If members of your coalition are certified in critical incident stress management or traumatology, your coalition can be a resource for those affected by crisis and disaster in your community.

6. **Conversation starters.** Sometimes a barrier to completing advance care planning documents is reluctance to start conversations with friends and family about personal wishes. Your coalition can develop and disseminate conversation starters at community events.
• NHPCO consumer resources: a conversation starter, values history and other resources are provided to help you offer this service.

7. **Articles and stories for publications.** Raising awareness is an important step in the process of improving end-of-life care in a community. Newsletter articles in community newspapers, company and neighborhood newsletters and other venues publicize your activities and educate the public.

• NHPCO coalition resources: messages and ideas to help you develop stories and press releases.

8. **Opportunities to find meaning.** One way to enhance a shared sense of meaning is to provide opportunities to contribute toward the common good, working together to improve the community.

• NHPCO consumer and coalition resources: a list of opportunities to become involved, volunteer or contribute toward improving end-of-life care in your community.
Ordering Off the Menu

The most enjoyable restaurant meals start with a waiter who tells you what’s fresh, what’s good, and what is recommended. He or she listens attentively to your specific requests, and then serves you each item in a timely, respectful and efficient manner – always asking if you need something else. Your coalition can do the same thing for a NOC.

1. **Placing the order.** The questions you ask during conversations can help you make suggestions to the NOC about which items to order.

2. **Serving the food.** Good service relies on attentive service and good timing. Knowing what’s important to the community, their current and future priorities and other information you’ve learned will help ensure that what is delivered meets the needs of your customers.

3. **Presentation matters.** Make sure the information you provide is up-to-date and that your materials look professional. No one wants to eat food that doesn’t look appetizing.

4. **Good ingredients make the meal.** We’ve provided you with the initial “ingredients and recipes.” Take time to follow the step-by-step instructions and you’ll be sure to wow your customers!

Together with your NOC partners you can identify which of your existing products and services you can tailor and what you might develop together to achieve the goals of the coalition/NOC partnership.

The NOC you are working with must be an active partner in selecting the product, service or program to be implemented in the community. If the coalition selects the program and “does it for or to” the NOC, then the community members can’t have ownership over the process. Every aspect of the initiative you select should be based on the goals the NOC and coalition develop together (refer to the *Developing Partnership Goals* section of this Toolkit).
Capitalizing on Existing Opportunities

The Bill Moyer’s series *On Our Own Terms* served as a catalyst for more than 300 coalitions to engage their communities around end-of-life issues. Similarly, the PBS show, *& Thou Shalt Honor*, sparked events in communities across the country. These major media events do not happen often, but there are other ways to capitalize on existing opportunities to bolster your engagement activities.

For example, for the past two years, Florida Hospices and Palliative Care (the state hospice association) has created a special theme for the state during National Hospice Month (November). In 2002, they decided to use hospice month as an opportunity to demonstrate support for caregivers. They disseminated the *Only Human: The Faces of Caregiving* presentation and outreach materials to every hospice in the state and encouraged hospices to use the materials for outreach during November. They capitalized on National Hospice month, which already heightens awareness, to demonstrate support for a growing concern – caregivers. In 2003, the chosen theme for Florida was “Supporting America’s Heroes,” focusing on public education about how to support veterans at the end of life. Florida Hospices and Palliative Care, in partnership with the Hospice–Veterans Partnership of Florida created and disseminated outreach materials to celebrate our nation’s veterans. Some of the resources created for these events are available on the National Hospice and Palliative Care Organization’s websites:

- [www.nhpc.org](http://www.nhpc.org)
- [www.CaringInfo.org](http://www.CaringInfo.org)

The NOC you are partnering with may already have events planned throughout the year. Talk about ways you can capitalize on their momentum and integrate elements of your work into community events so that end–of–life issues become part of the community.

Other specific ideas include:
• National Family Caregiver Month (November) – host a special on the public access channel
• March 30 is Doctor’s Day – you can provide physician offices with a community resource guide.
• Pastoral Care week is in October – provide local faith leaders with resources or training
• Health observances are days, weeks, or months devoted to promoting particular health concerns. You can tailor events for selected observances based on the focus of your NOC partnership. Go to the National Health Information Center’s web site at http://www.healthfinder.gov/library/nho/nho.asp for a complete listing of these observances.

You can also create opportunities:

• Request that the Governor, Mayor or Legislature declare a “day” of celebration tied related to your partnership activities
• Ask public figures to spend a day visiting the community and promote it to the media
• Use clips from On Our Own Terms or & Thou Shalt Honor videos to spark discussions at presentations or town hall meeting

Timing and Planning

Timing is everything. We’ve all heard it before, and we know timing is relevant in community organizing. Pay attention to other activities and commitments of the NOC, the amount of time you and the NOC have to allocate to each project and your ability to promote, implement and manage multiple events.

In learning about the NOC, you’ve discovered some information about the structure, culture and other aspects of the community you are working with. If the NOC is more formally structured and embraces systems to accomplish goals, you can work together to develop a detailed implementation plan for each activity or event. As you outline your engagement activities, develop a timeline for each step of your campaign. Include an implementation date and
amount of time needed to promote each one. Once you have a general time line, you can create a “to-do” list for each initiative or activity. As an example, the project plan and other materials created for the Pinellas Partnership for End-of-life Care’s 2003 workplace outreach campaign are provided in the Appendix.
Crafting Messages

Have you ever played the “telephone game?” You say something to someone else who repeats what they heard; they repeat it to someone else, and so on. The result? Often what the last person hears is not even close to the original statement.

The same thing can happen when your coalition delivers messages. You may think you are clearly stating a message, but some or all of your audience may interpret something entirely differently than you intended. All communication including presentations or written materials can be compromised if your messages are not clear.

The best way to ensure that people understand your messages is to be clear and concise. Use simple language that is commonly understood, regardless of age, educational level, cultural background or experience. You may want to test your language with members of your target group to check and see if the message you intended to send is the one that is actually received. You can do this through focus groups, surveys or interviews.

Since our goal is to engage the community in a dialogue about end-of-life issues, developing messages is especially challenging. The majority of America does not talk or think about the topic until they or someone they know is facing an end-of-life issue. In addition, coalitions working with naturally occurring communities (NOCs) must learn and incorporate community-specific language and cultural mores into their standard messages.

The National Institutes of Health Plain Language Initiative provides excellent resources that can help you develop clear messages.

A handout summarizing these concepts is in the Toolkit Appendix. For further information visit http://execsec.od.nih.gov/plainlang/
Message Development Basics

What do you want people to know about your coalition or initiative? When you give a presentation or talk to members of the community, what do you want them to take away from the conversation? The answers to these questions will shape your message development process.

Simply stated, messages are those key points you want to convey to your audience. Whether you are writing a press release, speaking to the rotary, meeting with a potential partner or talking to caregivers – you have to have a message to deliver.

Effective messages:

- Communicate the issue -- who, what, why
- Motivate people to join your efforts, learn more or otherwise get involved
- Use language that speaks to your target audience
- Are consistent

Communicate the Issue -- Who, Why, What

The first step in developing a message is to clearly state what you are trying to communicate – the “who, what, and why.”

Who: The primary audience you want to target. These are members of the naturally occurring community.

Examples may include working caregivers, people living in a retirement community or members of a faith community.

Why: Briefly explain the concept of your message – this could include why advance care planning is important or why support caregivers.
What: What you want to offer to the primary audience. The “what” is based on community wants, needs and available resources. The “what” may include:

- **Product**: advance care planning packet, resource guide
- **Service**: training class, information and referral service, grief support groups
- **Action**: participate in a partnership project, join the coalition, talk about your end-of-life wishes, complete advance directives

Motivate People

There are several key factors involved motivating in people:

1. **Bring it to the local level.**
   - What are the needs of the NOC members?
   - How is this community impacted by end-of-life issues?
   - What segments of the community are underserved?
   - Who is working with you to address these issues?

2. **Communicate the “what’s in it for me” factors.**
   - What would motivate the community to partner with the coalition? Be specific.
   - What benefits might the community derive from working with your coalition?
   - What happens when end-of-life issues are not addressed?
   - How will working together help create social change?

3. **Tell stories to illustrate your points.**
   - Does the community have stories or real-life examples of their experiences?
   - Use interviews, case studies and other information to paint the picture.

4. **Ask for something.**
• What do you want people to do?
• How can they help?
• Who do they contact?

Use Language that Speaks to Your Audience

In order to speak the language of your target audience, you need to use their “own words.” As you develop a relationship with the NOC, take time to learn about their language and communication styles (see Learning About NOC’s section). If the community has any written communication tools such as brochures or newsletters, review them to learn about the accepted written language styles.

Testing messages with various audiences is the best way to see what works and what doesn’t. Testing doesn’t have to be a time or resource intensive process. You can have coalition or NOC members ask people what they think about a flyer, a list of phrases, or other materials you’ve developed. Be sure to specifically ask what they like and don’t like -- and why.

The Hospice of the Florida Suncoast conducted interviews and focus groups to test how certain language was understood. We learned that several terms commonly used by hospices to describe services are either misunderstood or not understood at all. One example is the term “bereavement services,” which is intended to mean the range of support available after the loss of a loved one. Some hospice survivors understood the term to mean a memorial service. This teaches us that the language used by providers doesn’t always resonate with the community.

Use Consistent Messages

Over time, when people see or hear your messages they should recognize them as belonging to your initiative. This helps you build momentum and name recognition; it also separates your work from others working on similar issues.
1. Select one or two messages or tag lines that appear in every publication and are mentioned in every presentation.
   • Keep these messages or tag lines simple.
   • Tailor the message to each audience – make it relevant to them.

2. Integrate the messages into all materials.
   • Ask everyone involved to promote the same messages.
   • Be creative about when and where you can promote your messages – fax cover sheets, e-mail signatures, the building marquee.

3. Consider shelf life.
   • Stretch your budget by creating print materials that have a long shelf life (can be used for a long time and aren’t date sensitive).
   • Develop messages that are about more than a single event you are promoting.
Writing the Message(s)

The process you use to develop messages is up to you. The following tool can help you visualize and craft a message.

![Message Development Box]

**Problem/Issue/Outcome:** State the problem, issue or outcome (PIO) that you want to address – and your “solution” or strategy to address this issue.

**Definition:** Briefly describe the PIO in a clear, direct and straightforward manner. Include the financial impact, number of people affected and any other clear and compelling information (statistics).

**Reason:** This reason or rationale includes:
- why this should happen now
- reasons for addressing the PIO
• quotes from community members about the rationale

**Impact:**
This is the “what’s in it for me” part of your message, the benefits for the community. The impact includes colorful words to illustrate the issue and what will be solved as a result of the initiative.

**Action/Response:**
What you are doing about all of the above in a one-line summary statement. Be sure to include a call to action – something the community can do.
The Naturally Occurring Communities Toolkit

Message Development Box

Sample message for a faith community developing a community caregiver support program.

Definition
- Many community members have said they need help caring for a family member.
- With support, caregivers and seniors can remain part of our community.

Reason
- Community spirit
- “What I need most is help caring for my husband” – Ethel, community member
- Right now 30% of the community is caring for a relative.

PIO
A community caregiver support network can provide vital assistance to community members caring for a family member.

Impact
- Someday you or a family member might need help.
- Caregivers in the community will be able to access resources and support.

Action/Response
- Volunteer a few hours a month to support a caregiver or senior
- Attend our community caregiver support network training.
- Frequently call and offer specific help to caregivers you know.

Delivering Messages

Once you’ve developed your messages, you’ll need to deliver them. There are a variety of ways to communicate messages to your audience.

Marketers call message delivery systems channels. The channels selected are based on your goals, target audiences, messages, time line, and coalition and NOC resources. The following chart summarizes the types of channels, examples of each, and the pros and cons.
<table>
<thead>
<tr>
<th>Outreach Channels Comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>
| Individual or Group Delivery| Speakers bureau presentations, continuing education presentations, community forums, town hall meetings, phone calls, ambassadors, outreach visits | • Tailored messages  
• Opportunities for dialogue | • Small audience  
• Time/staff intensive  
• Hit or miss attendance |
| Organizational or Community | Health fairs, hot lines, conferences, resource library, parade, open house | • Large audience  
• Opportunity to expand messages and dialogue with attendees | • Hit or miss attendance |
| Mass Media/Communication    | Television, print media, radio, brochures, newsletters, posters, bookmarks, billboards, placards, videos, web page, point-of-sale displays, buttons | • Potentially huge audience | • Cost  
• Inability to target message  
• No opportunities to clarify messages or dialogue  
• Hard to evaluate effectiveness |

Adapted from: Brookes and Weiner, 1995; Kotller and Andreasen, 1996; Andreasen, 1995; NIH, 1992
Ideally, you will use a variety of message delivery methods to ensure that your primary audience has multiple opportunities to read, hear or otherwise receive your message. Some of the channels above could be described as **effective** in that they attract attention and can inspire people to take action. Others are more **efficient** – they reach large numbers of people compared to the resources expended. Good engagement campaigns utilize effective and efficient channels to reinforce one another and increase the chance of exposure.

Regardless of the delivery systems you select, you will need to customize your message and create tools appropriate for the delivery system. For example:

<table>
<thead>
<tr>
<th>Method</th>
<th>The Method Requires</th>
<th>Message Content and Format</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Presentations</strong></td>
<td>• Talking points</td>
<td>• Bulleted messages</td>
</tr>
<tr>
<td></td>
<td>• A “packaged presentation”</td>
<td>• Stories that illustrate the point</td>
</tr>
<tr>
<td></td>
<td>• Materials to distribute</td>
<td>• Statistics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Event details – date, time, location</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Call to action</td>
</tr>
<tr>
<td><strong>Health fairs or outreach visits</strong></td>
<td>• Materials to distribute</td>
<td>• Specific details</td>
</tr>
<tr>
<td></td>
<td>• A display board or poster</td>
<td>• Photos</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Statistics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Contact information</td>
</tr>
<tr>
<td><strong>Media outreach</strong></td>
<td>• Story for a community newsletter</td>
<td>• A “personal” story about someone in the community</td>
</tr>
<tr>
<td></td>
<td>• Public service announcement</td>
<td>• Quotes</td>
</tr>
<tr>
<td></td>
<td>• Press release</td>
<td>• Statistics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Contact information</td>
</tr>
<tr>
<td><strong>Electronic communication</strong></td>
<td>• Web page</td>
<td>• Photos</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Text for the web page</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• One line messages</td>
</tr>
<tr>
<td>Email</td>
<td>A credible “sender”</td>
<td></td>
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<tr>
<td>------------</td>
<td>----------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>An attention-grabbing subject line</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bulleted points</td>
<td></td>
</tr>
</tbody>
</table>
Selecting Messengers

The messengers you use can help lend credibility to the message. Many people will either believe or discount your message based on who delivers it.

What makes a messenger effective? A messenger that resonates with one group could fall flat with another. So how do you select the best messengers?

Effective Messengers:

- **Know the audience they are addressing**
  - What are the biggest needs of your audience?
  - Which of their concerns can you address?
  - What language should you use to communicate with them?
  - How do you need to customize your basic message so it works for this audience?
  - What are the core values of your audience in relation to this issue?

- **Are credible to the audience**
  - The group knows them or knows something about them.
  - The audience trusts what they are saying
  - They may be members of the group that they are addressing:
• Communicate effectively
  o Speak clearly and concisely (as defined by the group they are addressing)
  o Use stories and data appropriately, based on the audience and topic

• Know the issue inside and out
  o Know the information and the messages
  o Can answer questions
  o Know when and to whom to refer questions they can’t answer

• Have a story to tell
  o Can share either a personal story or another relevant story with conviction
  o Know how and when to share stories effectively
  o Demonstrate a passion for the issues

• Dress appropriately based on the audience and circumstances
  o Wear clothes that communicate respect for and familiarity with the audience, venue and circumstance

• Use audio visual equipment sparingly
  o Use AV only to enhance messages
  o Use AV as an aide, not as only means of delivering messages

Ideally, the messenger will be a member of the community you are trying to reach, or someone who is known to the community. Work with the leaders of the NOC to identify potential effective messengers.

Once you’ve identified the messengers, provide them with information. Messengers need information about:

• their audience
• overall goals of the NOC/coalition partnership
• details about available resources, products or services
• how, when and where to refer people for additional information
• call to action messages and the importance of communicating what people can do to become involved

Developing and delivering messages is a key component of your NOC partnership. Be sure to involve the NOC in every step of the process.
Measuring Success

If you partner with a naturally occurring community (NOC), how will you know if your efforts are successful? If you don’t think about this before you begin the work of the partnership, you may never know what you have achieved. Evaluation planning starts when you form the partnership and is revisited each time you begin planning a new project.

Measuring the Success of the Partnership

It is important to think about how you will measure success before you begin the partnership project. Knowing what success is before you start will help you know when you achieve it. The following questions can help:

- How do members of the NOC feel about the partnership?
- How do members of the coalition feel about the partnership?
- What do the members of the NOC see as the biggest challenge(s) working with the coalition?
- What do the members of the coalition see as the biggest challenge(s) working with the NOC?
- Do both groups feel the partnership has been mutually beneficial in helping to reach their goals?
- What worked? What didn’t?

There are several ways to evaluate success:

- Invite or hire a third party to do a formal evaluation
- Conduct a written self-assessment for all coalition and NOC members involved in the partnership to complete
- Have an open discussion with everyone involved in the partnership and project
Keep it Simple

The word “evaluation” can intimidate people who think it is a complicated process, or just for researchers. Evaluation is simply the process of measuring impact. An evaluation is not a value judgment – it is detailed feedback that you can use to strengthen your efforts and ensure you are meeting the needs of the community. The key to successful evaluation is simplicity. The purposes for evaluating your efforts include:

- Assessing whether your work makes a difference
- Identifying the changes needed to improve your partnership
- Determining whether or not the partnership or program should continue

<table>
<thead>
<tr>
<th>How Will You Know If…</th>
<th></th>
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<tbody>
<tr>
<td>…the partnership makes a difference in your community?</td>
<td></td>
</tr>
<tr>
<td><strong>Sample:</strong> Forty residents completed advance care planning documents and talk about them with their family and the staff at the health center.</td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td></td>
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<td>2.</td>
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<td>3.</td>
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</thead>
<tbody>
<tr>
<td>…changes are needed to improve the campaign?</td>
<td></td>
</tr>
<tr>
<td><strong>Sample:</strong> Community caregivers do not yet feel adequately trained to provide hands-on care to faith community members.</td>
<td></td>
</tr>
<tr>
<td>1.</td>
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<tr>
<td>2.</td>
<td></td>
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<p>| | |</p>
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<tbody>
<tr>
<td>…you should continue the campaign?</td>
<td></td>
</tr>
<tr>
<td><strong>Sample:</strong> The grief support groups have at least 8 participants each.</td>
<td></td>
</tr>
</tbody>
</table>
How Will You Know If…

1.

2.

3.

Regularly collect information that helps you answer the questions above. You can develop similar questions specific to your work to guide your evaluation process.
Evaluating Programs and Services

It is important to evaluate any programs and services that are developed as part of the partnership. Consider each event, program, brochure – everything the partnership produces. What would success look like?

Sample Measures of Success

<table>
<thead>
<tr>
<th>Event/Program/Material</th>
<th>What is Success?</th>
<th>Did you Achieve It?</th>
</tr>
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<tbody>
<tr>
<td>Community training program</td>
<td>• 50 attendees</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Ninety percent of attendees evaluated the sessions as excellent</td>
<td></td>
</tr>
<tr>
<td>Caregiver support networks in the workplace</td>
<td>• A support group is offered once every two weeks for employees</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Employees started a caregiver support team that provides meals</td>
<td></td>
</tr>
<tr>
<td>Town hall meeting on advance care planning</td>
<td>• 40 attendees</td>
<td></td>
</tr>
<tr>
<td>conversations</td>
<td>• Strong interactive participation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Five attendees volunteered to join the project committee</td>
<td></td>
</tr>
</tbody>
</table>

Use the following suggestions to help you identify possible measures of success for individual programs and services.

- Activities conducted
The Naturally Occurring Communities Toolkit

- Number of materials distributed
- Number and location of advertisements
- Attendance at meetings, trainings and support groups
- Number of calls to a hotline
- Number of public inquiries received as a result of an advertisement or flyer
- Articles printed
- Number of trainings offered
- Number of caregiver support networks established
- Number of outreach presentations delivered

Evaluating Impact

In addition to focusing on what you’ve produced, it’s helpful to look at what happened as a result of your accomplishments. The chart below is a simple way to look at the impact of your efforts.

<table>
<thead>
<tr>
<th>What We Did</th>
<th>What Happened</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conducted 2 caregiver training sessions</td>
<td>55 people attended our caregiver trainings, 90% report that the training helped them recognize opportunities to create meaning in their life</td>
</tr>
</tbody>
</table>
*Developed by Touchstone Consulting with the assistance of the Community State Partnership program office.

Evaluation doesn’t have to be complicated or time consuming. The key is to consider your evaluation methods before you begin implementing the campaign activities.
Sustaining Partnerships

Successful partnerships require ongoing attention to relationships, activities and systems in order to be sustainable. As your NOC-coalition partnership evolves, periodically assess your progress or status in each of these areas:

### Sustainable NOC–Coalition Partnerships

1. Promote community ownership
2. Focus on recruitment, retention and recognition of people involved
3. Evaluate progress
4. Have diverse resources
5. Use mission– or goal–based decision making
6. Have a leadership development plan
7. Focus on teamwork and collaboration

At least once per year, ask members of the NOC and coalition to complete the following checklists.

<table>
<thead>
<tr>
<th>Community Ownership</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>The partnership has participation from a diverse cross-section of the community</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community members and coalition members are actively involved in partnership activities.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The partnership represents the demographics of the NOC community</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The partnership regularly seeks input from all NOC members</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partnership activities/programs/services are accessible to everyone in the community</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Events/programs and services are accessed by a cross section of the community</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Ownership</td>
<td>Yes</td>
<td>No</td>
<td>Unsure</td>
</tr>
<tr>
<td>--------------------------------------------------------------</td>
<td>-----</td>
<td>----</td>
<td>--------</td>
</tr>
<tr>
<td>Community members are regularly invited to take personal action and participate in partnership activities</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Membership

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>The partnership celebrates successes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We recruit people to join our activities and discussions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We know why people are motivated to participate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We work to keep people involved in the partnership</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Evaluation

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>We are making progress toward goals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We evaluate each event, program and/or service</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We review evaluation results and make changes when necessary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We share evaluation results with the partnership</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We have measurable results from the work we do</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Diverse Resources

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource development is purposeful and ongoing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The partnership has diverse resources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community strengths support our efforts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mission– or Goal–Based Decisions</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-----</td>
<td>----</td>
</tr>
<tr>
<td>Every decision is based on the vision/mission or goals of the partnership</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The vision, mission and/or goals are regularly reviewed and updated as needed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partnership members know the vision, mission and/or goals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long–term, sustainable change is one of our goals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We have clearly identified our vision for the future</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Leadership Development</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>We know who the current and future leaders of the partnership are</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Our leaders effectively delegate tasks</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Our leaders include community representatives</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is a clear decision–making structure/system</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Teamwork and Collaboration</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication is ongoing and purposeful</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All members of the partnership have a voice</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work is distributed among all participants</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conflicts are resolved effectively</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication channels work for all involved</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Some NOC’s may want to partner with you for a limited period of time. Others may decide to work on specific projects. Hopefully, you will benefit from establishing long-standing relationships with communities. All of these partnerships are valuable as we work to engage communities to improve end-of-life care.
Bibliography and Resources


Kretzmann JP and McKnight, JL (1993). Building communities from the inside out: A path toward finding and mobilizing a community’s assets. Chicago, IL: The Asset–Based Community Development Institute.


National Issues Forums web page. www.nifi.org


Tennessee Primary Care Association S.E.A.R.C.H. Online Manual/Community Development http://www.tnpca.org


Appendix
The Pinellas Partnership for End-of-Life Care is a community coalition of individuals and groups that share the common goal of enhancing access to quality end-of-life education, information and services. Committed to comfort and compassion when it's needed most, the coalition encourages the development of new ideas and solutions, seeks to strengthen collaborative initiatives, enhances networking opportunities and promotes quality end-of-life care for all Pinellas County residents. The coalition is a community-based affiliate of the Florida Partnership for End-of-Life Care.

For more information, contact Mike Bell, Pinellas Partnership Coordinator, at (727) 586-4432 or Mikebell@thehospice.org.

Vision

A community prepared to experience the end of life with dignity, meaning and respect.

Mission

The mission of the Pinellas Partnership for End-of-Life Care is to:

• Create opportunities for public dialogue;
• Encourage conversation about end-of-life issues as a natural part of community life;
• Enhance consumer understanding and participation in end-of-life decision making;
• Engage diverse communities through culturally sensitive initiatives;
• Advance palliative care and pain management initiatives through community and professional education;
• Issue a “call to action” for our community to influence public policy related to end-of-life issues; and,
• Encourage provider partnerships which ensure that all individuals receive exceptional end-of-life care and services.

Founding Partners:

Area Agency on Aging of Pasco-Pinellas, Inc. • Bon Secours Maria Manor
Moss Feaster Funeral Homes • Project GRACE • St. Petersburg College
St. Petersburg General Hospital • The Hospice of the Florida Suncoast

Pinellas Partnership for End-of-Life Care
(727) 523-2426 • fax: (727) 586-5213
Pinellas Partnership for
End-of-life Care

Workplace Outreach Project

Contact Information:

Mike Bell, 2003 Chair
The Hospice of the Florida Suncoast
300 East Bay Drive, Largo, FL 33770
(727) 588-2722
mikebell@thehospice.org

The Pinellas Partnership for End-of-Life Care:
Area Agency on Aging • Bon Secours Maria Manor • Morton Plant Hospital •
Moss Feaster Funeral Homes • Project GRACE • St. Petersburg College • St.
Petersburg General Hospital • The Hospice of the Florida Suncoast
## Pinellas Partnership for End-of-Life Care
### Workplace Outreach Project Plan

<table>
<thead>
<tr>
<th>Task</th>
<th>Assigned to</th>
<th>Due Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review toolkit</td>
<td></td>
<td>ASAP</td>
</tr>
<tr>
<td>Identify businesses to contact and seek stakeholders or key contacts within each business</td>
<td></td>
<td>Ongoing</td>
</tr>
<tr>
<td>Develop flyer to promote project</td>
<td></td>
<td>Done</td>
</tr>
<tr>
<td>Explore copyright issues and purchasing/ printing options</td>
<td></td>
<td>March 31</td>
</tr>
<tr>
<td>Purchase toolkits</td>
<td></td>
<td>March 31</td>
</tr>
<tr>
<td>Develop categories of local resources</td>
<td></td>
<td>March 31</td>
</tr>
<tr>
<td>Develop format for local resources</td>
<td></td>
<td>March 31</td>
</tr>
<tr>
<td>Identify additional customization opportunities</td>
<td></td>
<td>March 31</td>
</tr>
<tr>
<td>Find list of businesses by size</td>
<td></td>
<td>March 31</td>
</tr>
<tr>
<td>Determine criteria for size delineation</td>
<td></td>
<td>March 31</td>
</tr>
<tr>
<td>Develop outreach messages</td>
<td></td>
<td>March 31</td>
</tr>
<tr>
<td>Develop protocol to respond to inquiries and requests</td>
<td></td>
<td>April 14</td>
</tr>
<tr>
<td>Determine faculty for HR presentations</td>
<td></td>
<td>April 14</td>
</tr>
<tr>
<td>Final copy of resource list</td>
<td></td>
<td>April 14</td>
</tr>
<tr>
<td>Develop stickers with contact information for Toolkits</td>
<td></td>
<td>April 14</td>
</tr>
<tr>
<td>Finalize messages</td>
<td></td>
<td>April 14</td>
</tr>
<tr>
<td>Develop outreach presentation draft</td>
<td></td>
<td>April 14</td>
</tr>
<tr>
<td>Print resources list and stickers – send to printer</td>
<td></td>
<td>April 14</td>
</tr>
<tr>
<td>Train coalition members to do outreach visits</td>
<td></td>
<td>April 28</td>
</tr>
<tr>
<td>Develop and implement outreach plan/calendar</td>
<td></td>
<td>April 28</td>
</tr>
<tr>
<td>Assemble books</td>
<td></td>
<td>April 28</td>
</tr>
<tr>
<td>Develop manager/staff EOL workplace training</td>
<td></td>
<td>May 1</td>
</tr>
<tr>
<td>Develop evaluation strategy</td>
<td></td>
<td>May 1</td>
</tr>
<tr>
<td>Task</td>
<td>Assigned to:</td>
<td>Due Date</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------</td>
<td>----------</td>
</tr>
<tr>
<td>Implement evaluation plan</td>
<td></td>
<td>May 1</td>
</tr>
</tbody>
</table>
Free Resources to Help You Support Employees!

Recruitment and retention of workers is one of the most challenging issues in today’s economy. One effective strategy for improving morale and increasing retention is a comprehensive program that assists employees in their efforts to balance work and family responsibilities, including caregiving responsibilities for ill family members, and the issues associated with terminal illness and death.

Addressing end-of-life issues as they affect the workplace is good business! Employers who implement end-of-life programs will benefit from their efforts through improvements in:

- Employee morale
- Productivity
- Commitment to the organization
- Retention
- Job satisfaction

The National Hospice and Palliative Care Organization Workplace End-of-Life Implementation Tool Kit was developed for employers of all sizes. The Tool Kit outlines many low-cost or no-cost options available to support your employees who are managing the care of a terminally ill person or dealing with grief, while addressing recruitment, retention and productivity concerns.

No matter what the size of your business or your human resources budget, the National Hospice and Palliative Care Organization Tool Kit has a plan for you and your employees!
Free Resources on Caregiving and Grief Available for Local Employers

PINELLAS COUNTY, FLORIDA - July 18, 2003 – A free resource is now available for employers in Pinellas County to assist in supporting employees who are care giving for seriously ill family members and coping with issues associated with caregiving, serious illness and death and loss.

The National Hospice and Palliative Care Organization Workplace End-of-Life Implementation Tool Kit was developed for organizations of all sizes. The tool kit outlines many low-cost or no-cost options available to support employees who are caring for someone with a serious illness or dealing with grief, while addressing recruitment, retention, and productivity concerns.

The free tool kits are available in limited quantities through the Pinellas Partnership for End-of-Life Care, a coalition of organizations committed to improving community awareness and services related to end-of-life issues. The founding partners of the Pinellas Partnership for End-of-Life Care are: Area Agency on Aging of Pasco-Pinellas, Inc., Bon Secours Maria Manor, Moss-Feaster Funeral Homes, Project GRACE, St. Petersburg College, St. Petersburg General Hospital, and The Hospice of the Florida Suncoast.

“Supporting employees is the right thing to do and it makes good business sense,” according to Pinellas Partnership for End-of-life Care member Kathy Brandt. “Studies have shown that employers who provide programs like these realize greater employee retention.”
Employers who wish to receive a free National Hospice and Palliative Care Organization Tool Kit and a free presentation about how to use the ideas in their business should call (727) 523-2426.

#####
Pinellas Partnership for End-of-life Care
Workplace Outreach Project

Talking Points

The Problem:
- In 1999 the US Department of Labor estimated that 30 percent of the work force was involved in caring for an aging parent or relative. Over the next 10 years, the government expects that figure to jump to 54 percent.
- Nineteen percent of elders live with family caregivers who work; 46% live 20 minutes or less from the working caregiver; and 18% live over an hour away.

The Costs:
- 42% of full-time employees expect to take on caregiving duties within five to seven years.
- According to a 2003 study from the Grief Recovery Institute:
  - Grief from the death of a loved one costs businesses an estimated $37.5 billion each year
  - Family crisis = $9 billion
  - Death of acquaintance = $7 billion
  - Pet loss = $2.4 billion

The Questions:
- How are you supporting employees who suffer a loss?
- How many caregivers work for your business?

The Opportunities:
- More and more businesses are realizing the financial implications of caregiving and grief in the workplace and taking proactive steps to support employees.
- Supporting employees doesn’t have to be resource intensive and many businesses are realizing they can’t afford not to implement family support programs.

The Offer:
- The Pinellas Partnership for End-of-life Care has a free resource to help your business learn more about providing support to employees facing end-of-life issues.
- The “Helping Employees Deal with End-of-life Issues Tool Kit is available (in limited quantities) to any business in Pinellas committed to learning more about and implementing procedures to support employees.
- The Tool Kit has sample policies and procedures, information for managers, and a local resource guide that lists numerous resources your employees can access at no or low cost.
- For a limited time, we are also offering a free training on grief in the workplace for businesses with 25 employees or more.
- To learn more about how you can get a free Tool Kit and the free training, complete the flyer.
How to Help Someone Who is Grieving

1. **Talk to them.** Often a simple word, touch on the arm can mean so much to the person who is grieving.

   Examples of statements you can say to a grieving person:

   - I am sorry for your loss
   - I cannot imagine how you feel.
   - I do not know what to say.
   - “I remember a story you told me about ____ (the deceased).” A simple, happy memory is often helpful.

2. **Listen.** Don’t try and “fix” the person, simply listen with compassion to what he/she is saying.

   If a person seems embarrassed or appears to be choking back tears, it may be helpful to mention that crying provides healthy relief. Attempting to distract the bereaved from his/her grief through forced cheerfulness shows little or no understanding of what he/she is going through.

3. **Ask how you can help lighten their workload.**

   Simply taking minutes for a meeting, moving a deadline back, offering to switch shifts or cover if they need to leave early can help ease their burden.

4. **Don’t isolate the person.**

   If you are going to lunch, ask if the person would like to join you. Make a point of saying “hello” each day.

5. **Pay attention.**

   The symptoms of normal grief we went over were provided to give you clues about how the person is doing. If you notice that the person appears to be having an especially difficult time, they may need grief counseling. Signs to look for include:

   - Increased absenteeism
   - Patterns of sleeplessness/increased sleep
   - Lack of appetite for prolonged periods of time
   - Changes in personal habits, including hygiene, work longer hours, etc.
   - Major changes in personality

   If you observe these over a long period of time, please be sure to tell your supervisor.

For more information or assistance call the Pinellas Partnership for End-of-life Care at 727-523-2426.
Plain Language

The information in this handout is taken from The National Institutes of Health Plain Language Initiative website, http://execsec.od.nih.gov/plainlang/

The Plain Language Initiative of the National Institutes of Health requires the use of plain language in all new documents written for the public, other government entities and fellow workers. Writing that is clear and to the point helps improve communication between the government and the public since clear material takes less time to read and understand. U.S. Health and Human Services Secretary Tommy G. Thompson urges that all government documents use plain English and avoid both jargon and highly technical language. Because part of the NIH mission is to reach all Americans with health information they can use, NIH must try to communicate in a way that helps people to easily understand research results.

✓ Communicating clearly is its own reward – it saves time and money, and it improves reader response to your message. Using plain language avoids creating barriers that set us apart from the people with whom we are communicating.

Plain language is:
- grammatically correct language that includes complete sentence structure and accurate word usage.
- clear writing that tells the reader exactly what the reader needs to know without unnecessary words or expressions.

Plain language is not:
- unprofessional writing.
- a method of "dumbing down" or "talking down" to the reader.

Certain hallmarks characterize plain language. These include:
- common, everyday words, except for necessary technical terms;
- "we," "you," and other personal pronouns;
- the active voice;
- logical organization; and
- easy-to-read and understand design features, such as bullets and tables.

Some points to remember:
- Answer your reader's questions
- Use language appropriate for your reader
- Include only necessary details
- Use the active voice
- Use personal pronouns such as "we" and "you"
- Use short sentences and paragraphs
- Use tables, lists, and other easy-to-understand design features
Plain Language Resources

- **The National Institutes of Health Plain Language Initiative**
  - http://execsec.od.nih.gov/plainlang/
  This Web site contains many resources to help writers achieve the goal of plain language.

- **National Cancer Institute (NCI) Usability.Gov**
  - http://www.usability.gov/
  The National Cancer Institute (NCI) developed this Web site to serve as an on-line resource for those involved in Web design and management at NCI, NIH, and other Federal agencies. It assists in design and testing of the usability of Web sites.

- **Plain English Network (PEN)**
  - http://www.plainlanguage.gov/
  The Plain English Network (PEN) is an informal Government-wide group dedicated to improving communications from the Federal Government to the public. The group provides services to encourage use of plain language to communicate better, increase compliance, and improve public relations. The PEN training is based on the handbook, *Writing User Friendly Documents*, which was established as the standard for plain language in June 1998.

- **Plain Language On-line (Rapporter Communications), Canada**
  - http://www.web.net/~plain/PlainTrain/
  Otherwise known as PlainTrain, Plain Language On-line is a Canadian initiative for on-line training. It includes a training module on Legal Language. Plain Language and Literacy and Plain Language in Education are two other modules being considered.

- **The Plain Language Association International**
  - http://www.plainlanguagenetwork.org/
  This site includes numerous resources pertaining to plain language in government, law, and business. In addition, it provides information on its upcoming international meeting.

*The information in this handout is taken from The National Institutes of Health Plain Language Initiative website, http://execsec.od.nih.gov/plainlang/*