

Caregiver Coalition Advocacy Guide

Uniting Voices, Building Community



**The National Alliance For Caregiving
January 2007**

The National Alliance for Caregiving

Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations.

The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients

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Introduction

Family caregivers in the United States are faced with many challenges as they undertake complex journeys to care for a family member or friend who needs long-term care. Most care in our country occurs within the context of families of origin or adoption.

Often family caregivers need to identify and coordinate services provided by complex health and social service systems that are difficult to navigate. Information discovered by caregivers is often provided in a terminology that is unfamiliar. Case management advice may be provided at points of admission or discharge. Support may not be available from other family members or neighbors in the community.

Communities at the national, state, and local levels have begun to develop collaborative efforts to meet the needs of family caregivers. Coalitions are undertaking efforts to help caregivers through information and referral services, educational outreach, and advocacy. These communities are realizing that collaboration brings together the personal experience and professional expertise that can meet the needs of caregivers. No one organization or service within a community can meet the complex social, medical, physical, spiritual, or emotional needs of family caregivers.

In addition to determining and meeting the needs of the caregiver, coalitions are also ideal forums to learn more about the caregiving experience in their communities and become a united voice on behalf of caregivers. This voice speaks for the changes needed in the delivery of services, for recognition of the valued role of caregivers, and in policies and regulations. The coalition's vision of improvement in the lives of caregivers serves as the catalyst for effective advocacy.

This guide will discuss the role of caregiver coalitions in advocacy, define ways to plan an effective advocacy campaign, and provide practical ways for coalitions to communicate and advocate on behalf of caregivers.

The National Alliance for Caregiving thanks Pfizer for its support in developing this guide. The Alliance has launched a newsletter, *The Caregiving Exchange: Supporting Caregiving Coalitions Across the United States*, and quarterly conference calls, and invites caregiver coalitions to share their advocacy experiences.

Caregiver Coalitions and Advocacy

Caregiver coalitions by nature of their missions serve in an ideal way to identify the needs of caregivers in a given community, determine the social, health, and supportive services needed, and advocate for changes within the community to support the family caregiver. Several reasons for supporting the role of the caregiver coalition follow.

- The coalition is a forum that can create a comprehensive definition of caregiver need through combined personal and professional expertise.
- Effective messages that can become core points for advocacy can be developed by the coalition.
- Coalitions create initiatives which can lead toward the adoption of programs or policy changes by the community.
- Coalition partners represent the diversity of the community.
- There are more possible points of contact brought to the table by each coalition partner.
- Coalitions offer varied ways of communicating with family caregivers as they encounter them at different points along the caregiving career of a person.
- Coalition partners bring organizational resources that can contribute toward a successful advocacy campaign.
- The coalition can be recognized as a credible source of information and support for caregivers and can contribute to the credibility of caregiving as an issue.
- The coalition offers opportunities to connect with other collaborative efforts to strengthen advocacy.

Is the Coalition Ready?

Before a coalition can advocate on behalf of caregivers, it should assess its degree of collaboration. The chart below summarizes the different levels of group activity. Advocacy will occur best in a coalition that is dedicated to multidisciplinary collaboration.

Networking	Exchanging <i>information</i> for mutual benefit
Coordination	Exchanging information for mutual benefit and <i>modifying activities</i> for a common purpose
Cooperation	Exchanging information, modifying activities, and <i>sharing resources</i> for mutual benefit and common purpose
Collaboration	Exchanging information, modifying activities, sharing resources, and <i>enhancing the capacity of another</i> for mutual benefit and to achieve a common purpose
Multi- Disciplinary Collaboration	A voluntary, strategic alliance of public, private, and non-profit organizations to enhance each others' capacity to achieve a common purpose by sharing risks, resources, responsibilities, and rewards. ¹

If the coalition, through consensus, has agreed to collaborate, then it becomes a united voice on behalf of caregivers.

Coalition partners are aware of the competitive nature of today's health and social service marketplaces. All partners come to the table looking for benefits for themselves and their organization. It is important for the coalition to monitor any differences or turf issues and resolve these in order to be successful.

An advocacy campaign needs a united voice. Partners at the table must see the value of collaboration. Some practical ways of encouraging collaboration include:

- Allowing coalition partners time at each meeting to share their organization's news as it relates to the mission of the coalition.
- Creating opportunities to co-brand outreach and advocacy activities. For example press releases can be developed which enable a coalition partner to announce its participation on the coalition in the local press and indicate its support of an advocacy effort.
- Reporting the results of evaluation activity of programs and advocacy activities to the coalition partners. Evaluation

¹ Himmelman, A (2001), On Coalitions and the Transformation of Power Relations: Collaborative Betterment and Collaborative Empowerment, *American Journal of Community Psychology*, Vol.29. 2: 277-284.

information should be in a format that allows partners to report back easily to their organization's leadership.

What is the Coalition's Vision and Mission for the Future?

The coalition should also have an idea of how they see the future for caregivers.

Effective coalitions have arrived at a vision and mission through collaboration. These statements become the test for all planned activities and growth of the coalition. The coalition also continuously works toward sustainability. A strategic focus on mission and vision supports efforts to build monetary and non-monetary resources needed to support the ongoing work of the coalition.

The coalition members, reflecting on the vision and mission of the coalition and in planning for sustainability, must ask themselves how they envision success in the future. This discussion defines what the coalition is passionate about. Before a coalition can be a voice of the forum for caregivers, it must have an internal energy that helps it to define its course for the future.

An effective exercise for the coalition to complete is one that helps the group to define its legacy. In this exercise, the partners can reaffirm their core vision and mission, and support efforts toward sustainability. Tom Wolff, author of *Planning for Sustainability, Creating a Legacy, Successfully Sustaining Your Community Coalition*, offers an exercise to define a legacy for the coalition that can help affirm a commonly held vision and highlight the passion of the partnership. (See Appendix A) A definition of legacy helps empower the coalition partners to collaborate and inspires advocacy.

What is Advocacy?

Each caregiver coalition should begin discussions about advocacy by coming to an agreement on the definition of advocacy.

A dictionary definition of advocacy states that it is an act of pleading for, supporting, recommending, or active espousal (adoption) of a cause. There can be confusion about the definition of advocacy. The following information may help to clarify what advocacy is for the coalition.

Advocacy and Activism

Advocacy as mentioned is defined as active support, especially the act of pleading or arguing for something. Activism is taking direct action to achieve a political or social goal. As noted by the National Family Caregivers Association in quoting Ira Byock, “advocacy by individuals can directly improve care for a patient. However, organized public participation, or activism, is required to alter institutional and professional policies, curricula, and standards of care.”²

Caregiver Advocacy vs. Advocacy and Caregivers

Some organizations define advocacy as case management or the empowerment of caregivers to manage care. This is an important resource or skill for the caregiver. Caregivers can use guidance on how to communicate effectively with health professionals and navigate the health system.

Advocacy as a Single or United Voice

Caregiver coalitions are aware that caregivers often feel isolated and experience stress as they care for another person. Educational programs and outreach may encourage a caregiver to advocate for change within his or her own experiences. Individual actions may lead to changes in a community or organization. Advocacy for changes in policy or service delivery may be most effective when there is a united voice that speaks on behalf of caregivers.

² National Family Caregivers Association, Activism,
<http://www.thefamilycaregiver.org/empowerment/activism.cfm>

Grassroots vs. Support

The coalition will need to decide how the voice of the caregiver is best expressed. Two possible options include:

- A) The coalition through the personal and professional expertise of its partners speaks on behalf of family caregivers, care recipients, and other family members.
- B) The coalition in consensus with its partners (including caregivers) creates a grassroots campaign in which the voice of the caregiver is directly heard.

This guide is focused on a coalition speaking on behalf of caregivers (Option A) Grassroots activism (Option B) can include some of the recommended communication strategies provided later in the guide.

Proactive vs. Reactive

Advocacy can also be viewed as proactive or reactive. Proactive advocacy is a creative strategic approach to influencing key decision makers and stakeholders. Reactive advocacy can take place in response to actions such as budget changes, a changing fiscal climate, or changes in policy.

Successful Advocacy

Advocacy Campaign

The enthusiasm to advocate for a specific change may lead to a coalition taking direct actions to encourage change. It is easier at times to pursue specific actions to advocate for a particular change. Timelines for pending legislation or legislative session schedules may lead to a coalition's call for action. Action is good but planning is an essential component of successful advocacy.

Much like the planning process for forming the coalition, there are key components in the process of assembling a strategy for advocacy. These components are defined in the Advocacy Cycle section of the Guide.

Characteristics of a Successful Campaign

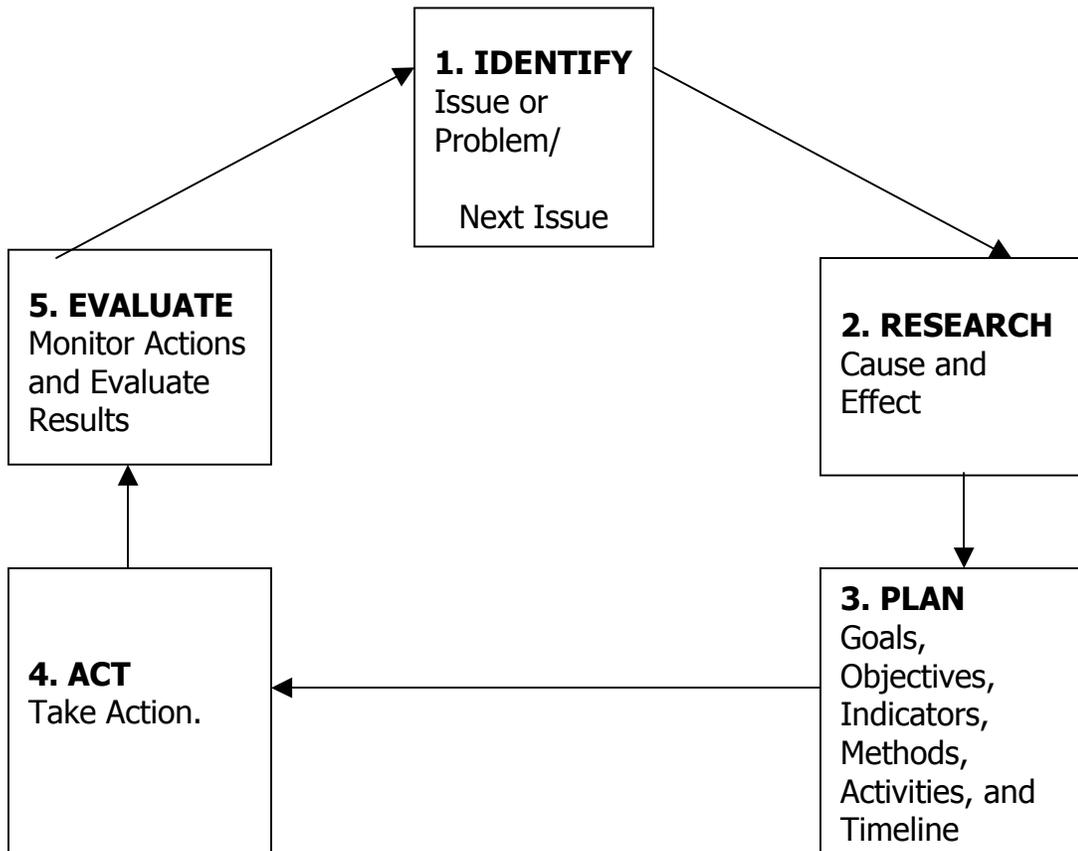
Characteristics of a successful campaign include:

Strategic	The campaign must be researched and planned carefully.
Series of Actions	Advocacy is not simply one phone call, petition, or letter but a set of coordinated actions.
Designed to Persuade	Convincing ideas and arguments must be offered to persuade people that the desired change is important and to gain their support.
Targeted	Persuasion efforts must be targeted at people who have the power to effect change.
Build Alliances	The campaign must include many stakeholders (both within and outside of the coalition) to increase the impact of the campaign.
Results in Change	The campaign must lead to a positive change in the lives of the people affected by the problem. Efforts should convince decision makers that "what we want is what they want." ³

³ Ayer, Victoria and Bunn, Colin, (2004) *Advocacy Campaign Management*, Advocacy Expert Series, Book I, Edition I

Advocacy Cycle

There is a cycle to the work of advocacy. The following diagram outlines the five components of an advocacy cycle.



Identify the Issue

It is important that the coalition take time to identify accurately the issue for the advocacy campaign. Sources of information can include:

- discussions of the coalition regarding gaps in service
- caregivers' expressed need(s) for change
- feedback received during outreach activities or the provision of supportive health and social services
- information gathered during needs assessment for the coalition
- advocacy alerts from state, regional, or national organizations

- legislative activity of local, state, or national government representatives
- media coverage
- advocacy campaigns of a coalition partner(s)
- a need expressed by the community

The definition of the issue may also include the selection of the community upon which the change will have an impact. . Communities are defined in many different ways, such as by geography, neighborhood, and common government--e.g., national, regional, state, or local. We can also define community by race, gender, sexual orientation, age, or marital status. In the arena of caregiver support, we define community in these ways and add a level of complexity – community can be defined by illness, disease state, disability, age of care recipient, age of caregiver, availability of insurance coverage, income eligibility criteria, urban versus rural areas of our country, life expectancy of care recipient, and other factors.

The selection of an issue by the coalition will require not only discussion but also some short-term compromises. An issue presented to the coalition may not be of high interest or a priority for all members. Available resources for advocacy can also affect the selection of issues. There should be open dialogue among coalition members regarding the prioritization of issues for advocacy.

The issue selected for advocacy according to *Organizing for Social Change*, a guide compiled by the Midwest Academy Manual for Activists, should meet the following criteria:

- Result in real improvement in people’s lives – Will we be able to see and feel the improvement?
- Give people a sense of their own power – Will people feel that they have won? This will build confidence to take on larger issues and loyalty with the coalition.
- Alter the relations of power – Power relations between citizens and legislators can be changed in three ways:
 - Building a staffed organization that is recognized as a center of power thus influencing the other side
 - Changing laws or regulations

- Electing to office people who are supportive of the coalition's positions

- Be worthwhile – Partners should feel that the advocacy campaign is worth their contributions of time, talent, or monetary resources.
- Be winnable – Make sure that the problem or issue selected is not too remote or too large. An achievable goal motivates those involved.
- Be widely felt – A majority should feel that this is a real problem and must agree with the solution developed.
- Be deeply felt – The issue selected must encourage action.
- Be easy to understand – Try to identify issues that do not require a lengthy and difficult explanation.
- Have a clear target – a decision maker -- Can the coalition readily decide who the decision maker is? A decision maker is a person, not an institution.
- Have a clear timeframe that works for you – An advocacy campaign has a beginning, middle and end.
- Be Non-divisive – Avoid issues that divide the coalition or community of caregivers. There may be some concessions made here.
- Build leadership – The issue is best advocated for when there are clearly defined roles throughout the campaign. Does the coalition have partners with expertise or who can serve as legitimate spokespersons? The leadership for an advocacy campaign may or may not be the leadership of the coalition.
- Set up your organization for the next campaign – The coalition may select an issue, which in turn will lead to the selection of other issues to improve the lives of caregivers.
- Have a pocketbook angle – Issues that gain or save money are usually widely and deeply felt.
- Raise money – Will the issue lead to action- specifically the donation of money to support an advocacy campaign?
- Be consistent with the coalition’s vision, mission, and values – Does the issue selected fit with the vision, mission, and values of the coalition?

- Coalition specific criteria – Are there other criteria the coalition has identified as it has defined its goals and objectives?⁴

Other criteria may include: recognition of resistance, the current legislative environment, political cycles, and opportunities for collaboration with other organizations or coalitions.

The coalition should consider developing a chart using the selected criteria and issues as cross tabs to monitor the selection of an issue.

Research the Selected Issue

The coalition should research information that shows the cause and effect of the issue being brought to the attention of legislators or others in the community.

Sources of information that caregiver coalitions can use include:

- the preliminary or comprehensive needs assessments completed as part of the formation of a coalition;
- academic research or literature reviews;
- information from national caregiver studies (*Caregiving in the US*, a study completed by The National Alliance for Caregiving and AARP or *State of the States in Family Caregiver Support: A 50 State Study* completed by the Family Caregiver Alliance);
- questionnaires and surveys;
- informal interviews;
- stories shared by caregivers;
- observations or focus groups.

Research should help to refine the definition of the selected issue. One approach is impact assessment.⁵ The following questions help to define the possible impact of an issue.

- What is the change we wish to achieve?

⁴ Bobo, Kim; Kendall, Jackie; Max, Steve, (2001) *Organizing for Social Change*, Midwest Academy Manual for Activists, Seven Locks Press, Minneapolis, Minnesota/Washington DC, pp. 23-27.

⁵ Leach, Evan PhD, (2005) *Transitions Assistance Programs*, www.tapconsults.com

- Who is affected by the change?
- In what direction (i.e., increase or decrease) do we want the change to take place?
- What is the quantifiable measure associated with the desired change?

Impact assessment can help the coalition look beyond the immediate issue or activity and identify the effect of a given effort. An example would be:

The City Caregiver Coalition seeks to increase new admissions to adult day health respite services for caregivers residing in Johnson City by fifty percent through a change in income eligibility requirements.

Plan

Much like the planning process for forming a coalition, the coalition needs create a plan for an advocacy campaign. The planning process should include:

- *Goals* should be defined which express the changes in policy or practice that are desired.
- *Objectives* should answer who will accomplish what, how, and in what timeline. Objectives for advocacy should also be realistic, achievable, affordable, and either short or long term.
- *Activities* are the specific tasks to carry out the defined objectives.

Make sure to identify ways to monitor the achievements of the goals and objectives. A campaign may involve the implementation of several strategies which occur simultaneously including enhancing the awareness of the general public or a specific community, educating professionals, informal and formal community leaders and legislators and their staff, drafting legislative goals for policy change, soliciting resources to support a campaign, and identifying and recruiting prospective allies for the campaign.

Act (Strategy)

The next phase of the advocacy cycle includes the development and implementation of a strategy. The important factors that form a strategy include:

- Review the goals and objectives;
- Identify whom to approach. Also identify allies and those who may be in opposition;
- Create the message;
- Identify tactics for delivering the message (including who will deliver the message);
- Identify what resources of, or actions by, the coalition may be required to achieve the goal.

Review of goals and objectives

Effective strategy links with the goals and objectives defined for the campaign. The coalition should review these as members begin to outline strategy.

Who to Approach?

An important part of planning and acting will be the identification of the persons you wish to approach. Questions to ask when identifying who to approach include:

- What is their degree of influence? Who do they have influence over? Who has influence over them?
- Do they agree with what you are proposing, are they against it, or are they neutral?
- What is their level of knowledge about the subject you are approaching them on?
- What issues are important to them? What is on their current agenda? Can you help them with any of these issues?

The coalition should also research and identify legislative committee assignments, key staff in government departments, business and community leaders who may influence change, and informal community

leaders. People from each of these categories may be able to contribute directly to an advocacy campaign and/or have connections that will enhance message delivery.

It is also important to identify any allies or persons who may be opposed to the issue selected by the coalition. And are there organizations or other coalitions whose strength and interests can add clout to the effort? Likewise, the coalition should identify possible sources of opposition and perhaps work on responses to the reasons for opposition.

What is the message?

The third component of action or strategy is the development of a message. The following are key points in the development of the message conveyed during an advocacy campaign.

- Receptivity of audiences – Research by the coalition should not only include who to communicate with but, as offered above, the coalition must know what influences the audience or what is important to them.
- Parameters of delivery – When will the message be delivered? Is it during a formal agenda such as a legislative hearing or event? How much time has been allotted for a meeting? Will you be able to deliver your comments in writing?
- Ability to form a Sound Bite – A sound bite description for the cause you are advocating should be developed by the coalition. The sound bite should be a very brief (perhaps 30 words) statement, which can be used at anytime by any of the coalition partners.
- Use in multiple settings – Messages are usually targeted toward legislators, government officials, or influential members of the community. The coalition should spend time developing a list of other persons who should receive the message as well.
- Review and revise when necessary – It is important for the coalition to monitor the message's applicability over time. Changes over time can contribute to changes in legislative agendas or the priority of issues.

The strengths found in a caregiver coalition provide an opportunity to create messages that resonate among the partners, between organizations, between the coalition and the community, and between communities. These connections are necessary for a united voice for, and on behalf of, caregivers. The messages created by a coalition are:

Comprehensive – The experience of the caregiver in a given community or state is more accurately captured when each organization is able to convey the expertise and caregiver experience from the perspective of a specific illness or challenge.

Relevant – The inclusion of many different experiences can aid toward receptivity by a broader audience.

Centered – The identification of differences and similarities between caregivers and organizations supporting caregivers can lend toward understanding of the missions, services, and needs of those served. But dialogue can also identify common ground. Caring Community, a coalition convened by WHYY, the public broadcasting station serving the greater Philadelphia region, recently produced documentaries that provided first hand stories of the caregiver. One story relayed the care of children with special needs; another, the experiences of spouses caring for their husbands with Alzheimer’s disease. At a screening of the documentaries, common ground was discovered by the father of the children with special needs. He said to the spouses caring for their husbands with Alzheimer’s disease: “You mourn the men your husbands once were, we mourn the men our children will never become.”

Other characteristics of a message include:

- The value of the proposed change to the person or organization being approached should be made evident.
- The strength in numbers of the coalition should be included in the message. For example: “Our coalition serves 5,000 caregivers who live in your district.”
- Double check that most recent changes have not decreased the relevancy of the message.
- The message should be flexible and constructed so that parts of the message can be delivered. There may need to be time for relationship building before the full message is delivered.
- Make sure that the ‘ASK’ part of the message is clear and understandable.
- The message should answer the coalition’s question – “What do we want out of this meeting?”

Who will deliver the message?

The coalition should select spokespersons who have a clear understanding of the message and be able to communicate in a clear and concise manner. They must also be able to convey the message without editorializing with personal opinion.

Other characteristics of the person delivering the message in an advocacy campaign include:

- has an established relationship with the organization or individual
- can achieve positive results from a dialogue
- has the ability to speak with humility (in other words, does not lecture the person the coalition is trying to influence)
- is passionate about caregiving and the work of the coalition
- understands what makes the issue identified resonate with the decision maker or key stakeholder and with the community
- invites conversation or dialogue.

Consider adding a caregiver as a messenger. This may be a caregiver who serves as a partner on the coalition or perhaps a caregiver who can best relay personal experiences related to the selected issue. The following tips can help maximize a caregiver's participation in an advocacy campaign:

- A. Prepare and distribute background information that is understandable to lay persons for participating caregivers.
- B. Gather small groups of caregivers in preparation for advocacy activities. Caregivers can get to know one another and be supportive of each other as activities are undertaken.
- C. Meet with family caregivers to inform them of legislative agendas and help them connect their experiences and needs with issues selected by the coalition.
- D. Create an accessible, user-friendly source of ongoing information to caregivers about legislation and advocacy. Perhaps the coalition could develop a newsletter or e-mail listserve with information that can be offered to all participating coalition partners.
- E. All messages are equally important. Make sure that the caregiver's story and involvement is treated with the same importance as other participants in the advocacy campaign.

- F. Recruit past caregivers to participate in the campaign. Some of the former caregivers in our communities are looking for ways to give back. A past caregiver's knowledge of the resources, coping mechanisms, personal experiences, and gaps in services is a valuable resource. Many organizations are not aware of when a caregiver's journey ends. Coalition partners may be asked if they are in touch with caregivers after their caregiving journey ends or if they are interested in contributing to the recruitment of past caregivers.
- G. Consider using teams of coalition partners and caregivers in the advocacy campaign.

Resources and Actions

A strategy chart helps the coalition summarize actions to be taken and assess the resources needed. Appendix B offers an example of a strategy chart for possible use.

Evaluate the Advocacy Campaign and Activities

The coalition should identify indicators to monitor the success of the advocacy campaign. Indicators may answer the following questions:

- Have we achieved the objectives and activities outlined in our plan?
- What have we learned during the campaign?
- Are there any changes required in terms of resources or activities?
- Have there been any changes in the legislative process?
- Do we need to target any other legislators or influential departmental representatives?
- Are others in the community taking up the message?
- Is more funding accessible?
- Is the decision maker or key stakeholder who was targeted as part of the advocacy campaign now speaking on behalf of caregiver issues?
- Is the coalition now recognized as a credible source of information and support for caregivers?

- Has the media put greater attention on issues related to caregiving?

In addition to the evaluation of the advocacy campaign, the coalition should identify and keep track of any outcomes (e.g., legislation was introduced, a public hearing was convened, an awareness campaign resulted in increased correspondence to a government official) as a result of the campaign, and assess the collaboration of the coalition during the campaign.

Suggested Approaches and Ways to Communicate

Coalitions and Legislators

Issues related to funding and policy have a direct impact on the goals of a caregiver coalition. Key stakeholders who comprise a community-based caregiver coalition should include representatives of local government or state or federal legislators, depending upon the scope of the coalition's work.

Each party to legislative involvement on a coalition brings something to the other partners. As Tom Wolff and Bill Berkowitz offer in their *Coalition Building Tips*: “When you think about how unique coalitions are as multi-sectoral forums for community discussion, you can realize what a wonderful opportunity they present to politicians – certainly to get their message out but also to hear about community issues. Legislators find it extremely informative to hear even a single issue discussed from the coalition's point of view. If the coalition can take the next steps – by indicating community needs, then showing how legislators could address those needs, and then working in partnership with those legislators – you begin to see the formation of a wonderful marriage.”⁶

Some steps recommended by Tom Wolff and Bill Berkowitz include:

Laying the Groundwork – This would include learning who your legislators are and following issues of importance to those legislators in the local press. The caregiver coalition should consider forming a public policy committee to track selected policy issues and recommend actions to the full coalition.

Making the Contact: Getting off the ground – Invite legislators to your coalition meetings, special events, or outreach activities. You may also schedule a meeting with the legislator in his or her home district office. Do not forget to invite the legislator's staff as well.

Mobilize the Support – Legislators may view the coalition as a powerful means of support. Make sure, as a coalition, that you mobilize that support among the partners at table.⁷

⁶ Wolff, Tom and Berkowitz, Bill, *Coalitions and Advocacy: Working with Your Legislators*, *Coalitions Building Tips*, AHEC/Community Partnerships, 24 South Prospect Street, Amherst, MA 01002

⁷ Ibid

Effective Communication

Effective communication whether in a meeting, via letter, e-mail or telephone call should have the following characteristics:

- keep it short
- be respectful
- explain your connection to the issue
- state your concerns
- request a specific action
- give your reasons
- cite your expertise
- ask for a commitment of support
- express your appreciation
- encourage all colleagues to follow above

The Reading Recovery Council of North America offers these additional guidelines when communicating on behalf of the coalition:

- Identify yourself as a member of the coalition.
- Explain why the coalition was formed and identify the names of the participating organizations.
- When meeting about the coalition position, do not add confusion by identifying your own individual differences from the coalition position.
- Use all of the normal processes, such as visits, testimony, letters, phone calls, etc. Give the legislator information about how the positions relate to his or her district.
- Leave a written summary of the positions.
- Keep your relationships alive with other groups and organizations. Help them even as you seek their help. ⁸

⁸ Reading Recovery Council of North America,
<http://www.readingrecovery.org/sections/home/coalitions.asp>

Ways to Communicate

Letter Writing

A coalition may consider the use of letter writing as part of an advocacy campaign. Some tips when writing a letter to your elected representative include:

- Write legibly or type your letter and try to keep communication to one brief page. A personal letter is more effective than a post card.
- Include your name and address on both the letter and the envelope.
- Make your letter to the point.
- Give a reason for your position (support or opposition). Relay a brief personal experience in establishing the case.
- Let them know what you expect, e.g., “I hope I/we can count on your support.”
- Target and time your letter. Representatives give the most weight to letters from their own constituents. Remember you may need to send letters to legislators serving on committees. Keep an eye on the legislative schedule so your letter arrives at the right time.
- Follow up by thanking your representative when his/her actions support your position.

Here is an example of a letter from a caregiver from the Alzheimer’s Association

The Honorable _____
Any State Senate
State House, USA 99999

Dear Senator Doe:

I am writing to you about Assembly Bill (AB) 770. I’m 68 years old, retired for 4 years now, and have lived here in your district since just after the Korean War. I’m writing to you late at night, because my husband Frank has finally settled down and I have a minute to myself. I’ve never written a letter like this before.

Frank has Alzheimer’s disease. Alzheimer’s is a progressive disease of the brain that eventually will kill my husband. There are times when I think it will kill me, too. There is no one other than me that can take care of Frank; all our children and relatives live far away, and sometimes they don’t really understand what it’s like to be with him all day, every day, watching his confusion and his frustration with the loss of so many of his abilities and activities. The support group at the Alzheimer’s Association gave me a book about caregiving called “The 36 Hour Day”, which I think summarizes what my life has been like for most of the past 4 years.

I would like you to support AB 770 because it would establish a respite program for caregivers like myself. For a small investment of funds, this kind of program would give me (and hundreds like me) a break from time to time, so I can keep going. I want to keep providing the care Frank needs, but sometimes it is overwhelming. Right now, I can’t even get away to see the doctor about some of my own problems. This bill would provide temporary care for Frank, either in our home, or in a day care center or other facility, so I can take care of myself.

Would you please let me know what you will do? Thanks.

Sincerely,

Betty Middleton⁹

The New York City Caregiver Coalition recommended two other points related to a letter writing campaign:

⁹ Alzheimer’s Association, *Advocacy Handbook: Tips for Citizen Involvement in Public Policy*

- The coalition should identify the most appropriate person(s) to write the letter. Is there a degree of leverage with decision makers or key stakeholders that can be gained by inviting certain individuals to write letters?
- The coalition should carefully think about how letters are delivered. Does the coalition want to gather all of the correspondence and deliver it in one bulk delivery or does the coalition want to conduct a letter writing campaign in which individuals mail their letters to identified decision makers?

Letter writing can be integrated with other activities of an advocacy campaign. No one method of communication stands alone. Coalitions may also consider ways of making the letter writing process easier e.g. posting templates for coalition partners or caregivers on a website. Another way to encourage letter writing is to take letters that can be completed by attendees to educational seminars, conferences, or other support group meetings.

Email

Network- Centric Advocacy (www.network-centricadvocacy.net) offers the following quote from Nielson about e-mail:

“A striking conclusion from the study is that processing e-mail is a stressful burden on people. Users frequently told us that they were too busy to deal with certain email messages and that they considered any fluff in messages a waste of time. When users "check their email," they're dealing with multiple requests for their time, including messages from their boss, colleagues, and family. People just want to be done with most email, and quickly move past anything that is not absolutely essential.”¹⁰

The following tips are offered to enhance the use of e-mail in an advocacy campaign:

- *The most valuable “property” is the ‘From’ and ‘Subject’ lines.*
- *Set up ‘From’ addresses that are informative, e.g., 2min2help.*

¹⁰ Network-Centric Advocacy, http://www.network-centricadvocacy.net/2003/12/how_to_write_em.html

- *Have a very clear and specific subject line.*
- *People seem to like confirmation e-mails whenever they do something.*
- *Tell the reader what they want to know first, e.g., We want you to...*
- *Include contact information of the sender.*
- *Design the text so that the top lines can be scanned.*
- *Be very brief and to the point.*
- *Make sure the e-mail answers key questions that may be raised.*
- *Remember that attached e-newsletters have a low “open- and-read” rate.¹¹*

Here is an example of an e-mail

To: mjones@snate.gov

From: asmith@nyccaregivercoalition.gov

Re: Support of Senate Bill 123

Dear Senator Jones,

Please support Senate Bill 123, the Caregiver Respite Support Bill.

I have been caring for my wife for the past seven years. I am working full time and continually try to balance my family, work and her care. Access to respite care like adult day care will enable me to get a break from caregiving responsibilities to take care of myself. Please let me know what action you take in support of this important Senate Bill to help caregivers.

Thank you.

Bill Smith
Street Address
Any town, State 99999

Telephone Calls

Another way to contact a legislator or influential person is by telephone. The ALS Association in their on-line Advocacy Center reminds us that telephone calls are usually taken by a staff member, not the member of Congress. Ask to speak with the aide

¹¹ Ibid, Network Centric Advocacy

or staff person who handles the issue about which you wish to comment.¹²

The Family Caregiver Alliance offers the following tips for telephone calls:

- Introduce yourself and give your affiliation. Be sure to mention if you are a constituent.
- Explain why you are calling.
- You may also need to communicate your position to a committee that is hearing a bill or budget item. If you are not sure of the committee's name or contact information, ask for it.
- Consider the use of a fax to communicate with a legislator and his/her staff.¹³

Coalitions may consider developing a script that can be used by callers.

In-Person Visits to Legislative Offices

Have a well-prepared message when arriving for a visit with a legislator. Come to the meeting with both a story that has an impact on caregivers in their jurisdiction and also have data that reflect the prevalence of a given situation. This might include: the statistical impact on the community in terms of appropriate utilization of services; cost savings obtained by respite programs; impact on community employers in terms of lost productivity; dollars saved by the role of the caring family; and estimated costs of the request being made. Have an idea of the legislator's voting record, the current agenda of the legislator, and committee appointments. Also, are there ways that you can help the legislator in his or her desire to serve the jurisdiction and help him or her understand the depth of the caregiver experience at home?

Your visit may be with a staff person. Staff may include personal staff to the legislator as well as staff to a legislative committee. Their role is not to be underestimated. They handle constituent needs, draft legislation, handle correspondence, and coordinate schedules. Committee staff members do these things plus investigate issues of importance to committee chairpersons, organize hearings, and develop policy. It is suggested that a visit with a staff person for relationship-building may be

¹² ALS Association, A Reason For Hope, Advocacy Action Center, <http://capwiz.com/alsa/issues/basics/?style+comm>

¹³ Family Caregiver Alliance, Advocacy Tips for Family Caregivers, www.caregiver.org

advisable prior to a visit or visits requesting action by a given legislator or committee.

If you meet with a staff person, do not forget to say that you would like to see the legislator if he or she comes in the office. Make sure you make this request in a way that respects the role of the legislative staff person. Also, do not forget that the meeting is a two-way event. Listen carefully to what advice or counsel is offered.

The coalition should leave behind a summary of information covered during the meeting.

Follow-up all meetings with a thank you note that summarizes the meeting and your understanding of next steps.

The Hawaii Caregivers Coalition recently held a State Capital Day to visit legislators. Feedback indicates that this first event will form a firm foundation for the introduction/ re-introduction of caregiver issues at the next session of the Hawaii State Legislature. They advise that coalition partners should always know their local, state, and federal legislators. They also add that the coalition should be consistent with its message, i.e., focused, precise, and unwavering.

Invite Legislators to Events

Invite your legislator to attend events that your organization of caregivers may be hosting. This is a great opportunity for the legislator to meet directly with people who are on the caregiving journey. Annual or neighborhood caregiver conferences, town meetings, health and social service fairs or other events sponsored by the Caregiver Coalition offer an ideal opportunity to engage a legislator in an effective way.

The following tips are offered when arranging and hosting a legislative visit:

Preparation:

Your visit with legislators will be successful if you remember to do the following in preparation for the visit:

- Call or write the legislators and ask them to accompany you to an event. If an event is being held on the site of a health and social service agency, invite the legislator to take a tour. Send details, time, location, map, etc.

- Provide background materials about caregiving, the site of the event, and services offered, and the agenda for the day.
- Offer to provide transportation to and from the visit.
- Provide refreshments (breakfast, lunch, coffee, and/or cookies) if possible.
- Follow-up the letter of invitation with a telephone call.
- Set the date, time, and place and begin planning.
- Decide who will participate to represent the Caregiver Coalition.
 - *Notify the selected participants of the date, time, and location of the visit.*
 - *Specify the purpose of the visit and the agenda – who will say what when.*
 - *Prepare written materials and share with all participants in advance if possible. Include information on the caregivers in the region, their experiences, demographic descriptions, and costs incurred. Include the names, titles, phone numbers, fax numbers, and e-mail addresses for all participants. Provide written brochures, videotapes, and pamphlets as appropriate.*
- Obtain permission from the care recipients, caregivers, or family members (when appropriate) for consent.
- Arrange transportation or respite as needed.
- Reconfirm all the arrangements with all participants, including the legislator, no later than 48 hours prior to the visit.

During the visit:

- Provide name tags for the legislator's convenience.
- Review the agenda and provide background information about caregiving.
- Observe the visit.
- Take note of the legislator's questions during the visit.

- Provide time for the legislator to talk with caregivers, care recipients, and their families. Remember the importance of sharing the experiences of the caregivers and their stories.
- Explain how the issue selected by the coalition for advocacy helps caregivers.
- Prepare caregivers and coalition partners selected for the visit to think proactively about issues and questions they want to address when interacting with the legislator.
- Respond to any questions the legislator may have.
- Keep the schedule as agreed upon in advance with the legislator unless the legislator specifically indicates that additional time and discussion are desired.
- Take photographs during the visit and submit a short article concerning the visit to the local newspaper. (Black and white photographs provide greatest clarity for publicity purposes, but many media outlets now can use color photographs.)
- Thank the legislator for participating in the visit.

Following the Visit:

- Write a thank you letter to the legislator and to each person who participated in the visit.
- Provide any follow up information requested.
- Issue an open invitation for the legislator to return for another visit and to consider the coalition as a resource on caregiver issues. The coalition may consider inviting the legislator to be a caregiver for a day and shadow that daily life of a constituent to learn more about the challenges faced by families.

Attend Legislator Sponsored Fairs and Summits

State and federal legislators often sponsor health fairs or events for older constituents in their communities. Try to find out who is organizing the forum and if any theme has been identified. Contact the legislator's staff and let them know your coalition and/or a group of caregivers would like to speak with the legislator about caregiving issues. Discussion prior to the event may enlist the legislator in support of the issue identified by the coalition. The coalition may help the legislator

become informed about the issues, offer speakers for the event, or offer to plan educational outreach during the event. The coalition may even ask if its members could set up a table to interact with caregivers about important pending legislative issues or desired changes.

Participate in a Public Hearing or Forum

Public hearings, town meetings or forums can provide you with an opportunity to deliver your concerns about an issue. If there is a request to register to participate or to speak at the meeting, make sure that you complete the requested process. Some tips for participating in a public hearing, forum or town meeting include:

- Arrive early to receive handouts and reports and adjust to any room changes.
- Be sure to sign in so your presence is noted.
- Sit in front where you can be seen.
- Bring handouts or position papers for distribution.
- If there is an opportunity for questions, ask a question about caregiving or support of caregivers (Be sure to mention your name and the name of the coalition.)
- Use the meeting as an opportunity to approach a hard-to-reach legislator.
- Take photos, if allowed, for newsletters.
- At the end of the meeting, introduce yourself to the staff person who handled the meeting or forum.
- Bring along a friend.
- Write a follow up letter to officials who express an interest in or support your issues.¹⁴

Testifying before a Public Body

The Alzheimer's Association offers the following tips when a public official or legislator requests comments or suggestions at a public hearing:

- Think of testifying as telling your story.
- Develop an easily understood 5-minute statement including strong facts, arguments for changes, and real examples of ways people are affected.

¹⁴ Alzheimer's Association Advocacy Handbook, Participating in a Public Hearing or Forum, p 12

- Practice your testimony.
- Prepare a two-minute version of your statement in case you get cut short, as well as a complete written statement to submit for the record.
- If possible, go to another meeting of the committee or public body to see how testimony is received.¹⁵

¹⁵ Alzheimer's Association Advocacy Handbook, Testifying Before a Public Body

Storytelling: Awareness vs. Connection

Many individual social service and healthcare agencies seek to reach out to caregivers. They usually attempt to relay information about illness, injury, and resources. This is most frequently done through literal messages using professional terminology for an audience who may often not relate to or understand the information conveyed. Indeed, these messages often convey information to the caring family and others. But the effectiveness of this type of message transaction to effect change is limited.

Calls to action by caregivers or on behalf of caregivers may not be heeded because the call is not heard and the message is not comprehended. The telling of one's story to explain personal experiences allows both teller and listener to connect. In this connection, needs are better understood, and the likelihood that a story relates to the listener's personal experiences is increased. The emotional impact may aid in advocacy campaigns.

There is a need to convey experiences to the general public, to those who are caregivers, and to those who can effect change via policy or supportive services. The art of storytelling relays experience and empowers the caregiver to connect. A caregiver coalition in its advocacy campaign can be a meaningful forum to extend much-needed stories into the community.

Coalitions should offer guidance on what makes an effective story, determine how stories will be integrated into the campaign, and perhaps develop a repository of stories that can be used at any time.

Andy Goodman in a newsletter article entitled *7 Questions to Sharpen Your Stories* states that "good stories cut through the clutter and connect with people's hearts, opening their minds to your point of view. Dull stories don't and, all too often, that's what public interest groups are telling."¹⁶

An excerpt from the newsletter:

- 1) **Who's the protagonist?** – Just as a car needs a driver to get it where it's going, stories need someone to drive the action. This person (or group of people) is called the protagonist, and traditionally structured stories follow protagonists in pursuit of clearly defined goals. To help your audience identify with the

¹⁶ Andy Goodman, *Seven Questions to Sharpen Your Stories*, Free Range Thinking, October 2003, www.agoodmanonline.com

- protagonist and enter the world of your story, don't be afraid to name names (when appropriate) and provide enough physical description or background to let them see this individual in their mind's eye.
- 2) **What's the hook?** – Another technique for drawing people in is beginning the story where the audience is. This is your story's hook – the description of a place, circumstance, or premise that everyone understands and with which they readily identify. If the subject of your story is global warming, for example, starting with facts about concentrations of carbon dioxide in the atmosphere is not going to engage the average person. On the other hand, saying, "Have you been reading about the incredible heat wave in Europe?" is more likely to get heads nodding.
 - 3) **What keeps it interesting?** – Predictable stories are boring, and no matter how proud you are of a recent victory, if your story boils down to, "We identified a goal; we pursued a goal; we reached that goal!" you're not likely to have audiences rapt with attention. "The stuff of storytelling," says Robert McKee, a renowned Hollywood script doctor "is the gap between what we think will happen when we take an action, and what actually happens." Take another look at that success story of yours and see if you can recall any barriers or surprises that cropped up along the way. From the listener's perspective, that's where the story gets interesting.
 - 4) **Where's the conflict?** – There is no drama without conflict, and comedies, for that matter, also fall flat without it. Heroic action always comes into sharper focus when juxtaposed against villainous misdeeds, and while your stories will probably not reduce to simple-minded battles of good versus evil, it helps to have clearly defined heroes and villains with different notions of how the story should end.
 - 5) **Have you included telling details?** – Recently I heard a story about a small community in West Virginia whose economy collapsed when its primary industry, coal mining, was shut down. The narrator described the place as "a company town" but the image of a controlling and penny-pinching company became vivid when she added that every home was required to turn on its porch lights at 7:00PM each evening "...because that's how the mining company made sure the streets were lit." A single telling detail such as that can replace a paragraph or more of description and good stories have just enough telling details to set the scene and people with it with colorful characters.

- 6) **What's the emotional hook?** – By consenting to read or listen to a story, the audience subconsciously enters into a contract with the storyteller in return for their time and attention – an increasingly valuable commodity, not so incidentally. They expect more than a recitation of facts. They want an emotional experience that makes the time worthwhile. “Our appetite for story is a reflection of the profound human need to grasp the patterns of living,” says McKee, “not merely as an intellectual exercise, but within a very personal, emotional experience.”

- 7) **Is the meaning clear?** – Finally your story should have a crystal clear moral, a reason for taking this particular journey. “We don’t need more information,” writes Annette Simmons in *The Story Factor*, “We need to know what it means. We need a story that explains what it means and makes us feel like we fit in there somewhere.”¹⁷

These stories cannot stand alone, as there is a need to present quantitative information to explain the cause and effect of the issue of caregiving. Legislators in particular are interested in how many people, especially in their jurisdiction, are affected by an issue.

¹⁷ Ibid, Goodman, A.

Position Statements and Briefing Books

Information on legislative priorities and position statements can be found in the goals of a legislative session and in the position statements of organizations that support caring families. For example, position statements are available from many of the disease specific organizations such as the Alzheimer's Association, the American Cancer Society, the leukemia and lymphoma organization, and others.

A strategic vision of an organization may influence its position papers and agendas for advocacy. A coalition should take the time to create position statements that can identify issues, provide background information, and state reasons for change. The preparation of a position statement may serve as a tool to help build consensus on an issue, educate coalition partners about the identified issue, and become a reference resource for coalition partners.

A briefing book or folder is also an effective way to inform legislators or influential people. An outline for a book may include:

- I. Define family caregiving: demographics, what family caregivers do, estimated number of caregivers in their jurisdiction, estimated cost savings from caregivers substituting for paid and institutional care, and burdens to the caregiver.
- II. Share information on the identified issue: Tell the reader the issue, provide legislative references if needed (House or Senate Bill), explain what exists and what needs to be changed.
- III. Share statistics in graphic form if possible.
- IV. Share qualitative information or stories/experiences shared.
- V. Research and include a summary on recent research, check research by government agencies, offer a critique if applicable.
- VI. Include position statements such as the *Principles of Family Caregiving* or the coalition's own statement(s).
- VII. Include press releases or press clippings from the local press.
- VIII. Include any related correspondence such as letters of support from coalition partners or community organizations. Remember to include an expression of thanks for their time and consideration.

Media

An advocacy campaign also includes raising awareness in the community. Meetings with legislators can occur simultaneously with press releases or media coverage. A particular request for action may receive greater attention when the awareness of the general community is raised.

Check with the partners on the coalition to see if any of them have good contacts established with the media. If not, the coalition should appoint some of its partners to research the media. Information gathered should include key personnel, operating policies, audiences, and deadlines. Coalition partners should note which journalists spend time on issues that are similar to the ones on the coalition's agenda.

Guidelines offered by the Advocacy Institute of Washington, DC include:

- 1) **“Make sure the information is timely** – Initiate stories when your issue is timely; relate your issue to a local event or news story in your community.
- 2) **Localize the issue** – Stories about broad national issues or distant locales may be important but from a community newspaper's standpoint they are less likely to increase circulation or viewership. Try to use local examples and statistics when presenting the issue.
- 3) **Accent the human interest angle** – Explain how your issue affects people. Use personal stories to get the message across.
- 4) **Demonstrate support for your issue** – Use quotes or have a person of prominence in the community or state as a spokesperson.
- 5) **Always make sure that your sources are credible** – Make sure the information is correct and consistent with the facts.”¹⁸

When framing an issue, the Advocacy Institute recommends:

- *“Shape the issue to your advantage in the press or media by using labels or symbols that reflect shared public values.*
- *Frame your position positively.*
- *Speak on behalf of the community and not as supporters of a specific action or legislation.”*

¹⁸ The Advocacy Institute, Using the Media to Advance Your Issue, Washington DC, 202-777-7575 or infor@advocacy.org, 2004.

It is useful to prepare kits for the press. These kits can be available during an advocacy campaign but also at events sponsored by the coalition. A kit may include:

- background information and position papers;
- fact sheets and Q&A brochures;
- quotes or endorsements of your issues by prominent legislators and authorities;
- biographies of issue spokespeople and organizational contacts; and
- a news release (make sure the news release covers who, what, when, where, why, and how.)

Other effective ways to engage the media include meeting with editorial boards, being available for interviews, or writing letters to the editor.¹⁹

The Caring Community coalition convened by WHYY, a public broadcasting station serving the greater Philadelphia Pennsylvania region, recently completed *Circle of Love*, a project that included three half-hour television documentaries, ten 2-minute segments and a community based outreach campaign. The goal of the project was to connect with caregivers and enhance awareness in the community. A qualitative research study completed with this project confirmed the impact of the use of story to connect with caregivers and empower them to share their experiences.

¹⁹ Ibid, The Advocacy Institute

Keeping Track of Legislation

The coalition will need to keep track of legislation it introduces or of legislation that supports the goals of the advocacy campaign. The Reading Recovery Council of North America offers the following guidelines:

- Make sure that you receive a copy of legislative bulletins and materials sent to you personally or to your organization by state and national organizations.
- When contacting your legislator regarding a bill you are interested in, ask that his or her office keep you informed of hearings and other developments.
- Ask the committee chairperson or staff to keep you informed of hearings or other activity on the bill.
- Watch for newspaper articles and schedules of committee hearings.
- Call the legislative information office for bill status and pertinent phone numbers for the legislative body.
- Obtain the daily and weekly status publications published by most legislatures when they are in session.
- Check for web site access to this information from your state legislature.
- Participate in legislative networks.²⁰

²⁰ Reading Recovery Council of North America,
<http://www.readingrecovery.org/sections/home/coalitions.asp>

Sharing Successes, Lessons Learned and Planning Ahead

The coalition should keep a close record of the activities undertaken as part of the advocacy campaign. Note successes, but also monitor the processes used to implement the campaign. Share information from the evaluations completed including: resources used or needed, adherence to the established timeline(s), or relationships formed or affected by the advocacy effort. All of the information can be helpful as future advocacy campaigns are planned.

Caregiver coalitions are invited to submit information about their advocacy campaigns to the National Alliance for Caregiving. The Alliance has launched a newsletter, *The Caregiving Exchange: Supporting Caregiving Coalitions Across the United States*, and quarterly conference calls for coalitions, and invites caregiver coalitions to share their advocacy and other experiences.

Resources

Advocacy and Coalitions

Advocacy.org – A project of the Advocacy Institute offers helpful information on coalitions. A link to a page with information on empowering coalitions can be found at: <http://www.advocacy.org/coalitions/>.

Reading Recovery of North America – Guidelines for coalitions and advocacy. <http://www.readingrecovery.org/sections/home/coalitions.asp>

Caregiver Information and Research

National Alliance for Caregiving - is dedicated to providing support to family caregivers and the professionals who help them and to increasing public awareness of issues facing family caregivers. Links to publications and studies completed by the National Alliance for Caregiving can be found at: <http://www.caregiving.org>

Of note would be:

Caregiving in the US: Findings From a National Caregiver Survey

Full Report: <http://www.caregiving.org/data/04finalreport.pdf>

Executive Summary: <http://www.caregiving.org/data/04execsumm.pdf>

Family Caregiving and Public Policy: Principles for Change

<http://www.caregiving.org/data/04execsumm.pdf>

Toward a National Caregiving Agenda: Empowering Family Caregivers in America

<http://www.caregiving.org/data/summit.pdf>

The National Alliance for Caregiving also has a summary of national legislation, which can be found at: <http://www.familycaregiving101.org>

Family Caregiver Alliance (FCA) – FCA is a public voice for caregivers. Their pioneering programs—information, education, services, research, and advocacy—support and sustain the important work of families nationwide caring for loved ones with chronic, disabling health conditions.

Research includes the recently released:

State of the States in Family Caregiver Support: A 50 State Study

- this includes *Caregiving Across the States Online Resource*

www.caregiver.org

National Family Caregivers Association - supports, empowers, educates, and speaks up for the more than 50 million Americans who care for a chronically ill, aged, or disabled loved one. NFCA reaches across the boundaries of different diagnoses, different relationships, and different life stages to address the common needs and concerns of all family caregivers. They are committed to improving the overall quality of life of caregiving families and minimizing the disparities between family caregivers and non-caregivers.

Articles and Information pieces on caregiver advocacy

<http://www.thefamilycaregiver.org/empowerment/activism.cfm>

Family caregivers and Public Policy

<http://www.thefamilycaregiver.org/empowerment/policy.cfm>

The United Hospital Fund - The United Hospital Fund is a health services research and philanthropic organization that addresses critical issues affecting hospitals and health care in New York City and the nation. The Fund's Families and Health Care Project aims to advance public and professional understanding of the crucial role of family caregivers in the health care system, and to stimulate the development of sound policies and programs that support their needs for education and training, emotional support, and information and communication.

Publications, among others include:

Family Caregivers on the Job: Moving Beyond ADL's and IADL's

ed. Carol Levine

http://www.uhfnyc.org/pubs-stories3220/pubs-stories_show.htm?doc_id=227103

Always on Call: When Illness Turns Families into Caregivers,

ed. Carol Levine

http://www.uhfnyc.org/pubs-stories3220/pubs-stories_show.htm?doc_id=248521

Survey of Family Caregivers (Visiting Nurse Service of New York)

ed. Carol Levine, Alexis Kuerbis, David A. Gould, Maryam Navaie-Waliser, Penny Hollander Feldman, and Karen Donnelan

http://www.uhfnyc.org/pubs-stories3220/pubsstories_show.htm?doc_id=97890

Grassroots and the Legislative Process

The American Association of Ambulatory Surgery Centers offers a summary on grassroots advocacy and the legislative process. While not directly about caregiving it offers good information that can be transferable to coalitions working toward changes in caregiving.

http://www.aaasc.org/advocacy/grassroots/gr_guide.html

Information on educational programs on working with legislators can be found at:

<http://www.thecapitol.net/PublicPrograms/WorkingWithCongressAndStaff.html>

Legislative Information

The Leadership Council of Aging Organizations is a coalition of 53 national non-profit organizations concerned with the well-being of America's older population and committed to representing their interests in the policy-making arena.

A summary of legislative information can be found at:

<http://www.lcao.org/legagenda/index.htm>

Legislative Resources

United States Senate

www.senate.gov

United States House of Representatives

www.house.gov

National Conference of State Legislatures

<http://www.ncsl.org/public/sitesleg.htm>

State and Local Governments on the net

<http://www.statelocalgov.net/index.cfm>

Status of Legislation (US Senate or House)

<http://thomas.loc.gov/home/c107query.html>

Public Policy

Judy Meredith, *Real Clout: Influencing Public Policy in the 90's*. Single copies are available without charge from Meredith and Associates Inc., 30 Winter Street Boston MA 02108, 617-338-0954.

How and Why to Influence Public Policy. Available for \$5.00 from the Center for Community Change, 1000 Wisconsin Avenue, NW, Washington DC 20007, 202-342-0567.

The 20/20 Vision Education Fund publishes two to four page fact sheets on specific advocacy topics. Among them are "Writing Letters to the editor;" "Taking Action to the Airwaves", "Tips on Making Letters and Phone Calls Effective"; "Getting Active On Line". Single copies are free of charge from the Fund, 1828 Jefferson Place NW, Washington DC 20036, 202-833-2020.

Storytelling

Andy Goodman, *Storytelling as Best Practice*, Andy Goodman, 3250 Wilshire Boulevard, Suite 1400, Los Angeles, CA 90010 or www.agoodmanonline.com

G L O S S A R Y ²¹

Act	Legislation that has been passed by a legislative body or signed into law by the executive
Advocate	Literally, “one who is a voice on behalf of another”
Aide	An assistant to a public official
AB-___	Assembly Bill (followed by the appropriate number), used commonly by state legislatures
Amendment	The proposal by a member of a legislature to alter the wording of a bill for consideration
Appropriation (Budget)	Legislation that directs the spending of public funds for a specific program, agency, or other purpose authorized by law
Authorization	An act that creates or extends a program
Bicameral	A legislature consisting of two houses
Bill	A proposed law that is introduced to a legislative body
Calendar	A listing of items for action by a committee or house of a legislative body
Caucus	An informal meeting of a group of members of a legislative body; sometimes convened by interest or political party
Committee	A sub-group of a legislative body permanently established by rules to consider and report legislation and to monitor the implementation of programs enacted, usually organized by subject area, as in a Health and Wellness Committee
Conference Committee	A meeting between members of the House and Senate to iron out a compromise between different versions of a bill. Once a compromise is reached, the conference report is voted upon and sent to the Executive for approval.
Convene	To assemble, call together a meeting
Ex Officio	The holding of one office by virtue of holding another
Fiscal Impact	The effect of a proposal on the budget
Floor	A colloquialism describing the interior meeting room of a legislative body; matters before the body are referred to as “on the floor” or “going to the floor”
Hearing	A committee meeting where testimony is taken from witnesses about an issue or specific bill
HR-___	House of Representatives (followed by the resolution number)
Initiative	A proposal put directly before voters, bypassing the legislative process
Joint Resolution	A measure offered in one house and agreed to by the other; such as those passed declaring National Family Caregivers Month

²¹ Adapted from the Alzheimer’s Association Advocacy Handbook

Glossary, continued

Journal	The official chronological record of proceedings. Also referred to as a digest or record
Lobbyist	A person paid to represent the interests of a group to a governmental body
Mark-up	The process by which a subcommittee or committee revises legislation. Once completed, the measure is ready for debate.
Officers	The portion of the legislature elected by its members to serve in positions of authority, such as the Speaker of the House. (Also known as leadership)
Passage	Favorable action on a measure
Quorum	The number of members required to be present before business can be transacted
Reading	The presentation of a bill before either house by reading the title thereof: a stage in the enactment of a bill
Referendum	The method by which a measure adopted by a legislature may be submitted for popular vote
Rules	The methods of procedure adopted by a body for its own governance
S-__	Senate Bill (followed by the appropriate number)
Session	The period during which a legislature meets, set by each state's constitution
Skeleton Bill	In some states, a measure introduced in outline form, substance to be added at a later date
Table	A motion to delay matters indefinitely
Unicameral	A legislature consisting of one house, such as in Nebraska or a city or county council
Veto	The Executive's formal disapproval of legislation. A bill can become law if an override vote is successful in each house of the legislature. In Congress this requires a two-thirds majority. In some states, governors have authority to veto single line items of an appropriation and this is called a line item veto.

Appendix –A-

Legacy Exercise

Creating A Legacy²²

Instructions: Work with your team to identify the change you are trying to create through your work. Begin to plan ways to sustain your legacy.

Identifying a Legacy: As a team, read the following scenario:

It is 5 years from now and your local newspaper has decided to do a feature story on your work. The story will focus on changes and accomplishments that have occurred through your work over the last five years. The reporter is coming today to interview you about the history of problems and issues in the community, how people came together, and the changes that the community has undergone.

To help you think about what you want to say to the reporter:

- Fill out the Worksheet on page 2.
- Once that sheet is completed, work with your team to answer the questions that follow and write the story and the headline.

²² Tom Wolff, Planning for Sustainability, Creating a Legacy, Successfully Sustaining Your Community Coalition, Tom Wolff & Associates, 24 South Prospect Street, Amherst, MA 01002, tom@tomwolff.com

WORKSHEET **Creating a Legacy**, Page 2

Instructions: Before writing your article, fill out the chart below to help guide your talking points with the reporter. The changes in community might include policy changes, program changes, norm changes, changes in relationships, etc.

	Example of Change in the Community
<p>Programs Refers to the creation of new programs or modification of existing programs</p>	
<p>Policies Pertains to agency level (e.g. protocols, interagency agreements) and larger public policy level change (ordinances, legislation, funding policy)</p>	
<p>Practices Includes changes within an agency or between organizations</p>	
<p>Changes in Community Norms Pertains to the community claiming ownership of your coalition's activities. Community residents have mobilized to sustain community efforts. Outreach has modified attitudes and behaviors regarding caregiving.</p>	
<p>Changes in Relationships and Partnerships</p>	

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Appendix -B-
Sample Strategy Chart

Goals	Organizational Considerations	Constituents Allies Opponents	Targets	Tactics
<p>Long Term</p> <p>State Caregiver Respite Plan is fully funded and operational.</p> <p>Intermediate Term</p> <p>Legislation supporting respite is passed</p> <p>Short Term Goals</p> <p>Identify influential legislative or municipal sponsors</p>	<p>Secure resources needed for campaign – in-kind donation of lobbyist or government relations staff of coalition partner.</p> <p>What do we want to get out of the campaign?</p> <p>Fund expenses, gain influence in certain districts, and develop caregiver grassroots campaign.</p> <p>What outstanding problems do we need to solve?</p> <p>Caregivers are difficult to enlist.</p> <p>Coalition partners agree.</p>	<p>Constituents</p> <p>Coalition partners</p> <p>Health systems</p> <p>Allies</p> <p>Professional Associations</p> <p>Academic Institutions</p> <p>Opponents</p> <p>Other collaborative efforts or coalitions</p>	<p>Mayor</p> <p>Governor</p> <p>State legislators</p> <p>City Council</p>	<p>Media campaign to increase awareness</p> <p>Engaging human resource managers association</p> <p>Letter writing campaign to legislators</p> <p>Legislative Visit Day</p>

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