



# PLANTING THE SEED

*Establishing and Growing  
Your Family Caregiving Coalition*

2013





**E**stablished in 1996, The National Alliance for Caregiving is a non-profit coalition of organizations focused on advancing family caregiving through research, innovation and advocacy. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, government agencies, and corporations.

The Alliance conducts research and policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers make essential social and financial contributions toward maintaining the well-being of those they care for, the Alliance is dedicated to being the foremost national resource on family caregiving to improve the quality of life for families and care recipients. The Alliance also works closely together with family caregiving coalitions across the country. The growing number of caregiving coalitions in the U.S., range from statewide coalitions to those working at the local level, to those focused on statewide advocacy and those focused on ensuring the delivery of local services. Many have been around for more than a decade and many are younger or just beginning to develop and grow. To assist that growth and sustainability, the Alliance provides a variety of services such as the Annual National Conference for Caregiving Coalitions, which is a daylong training and networking forum, attended by approximately 150 community leaders from across the country. Throughout the year, the Alliance also provides webinar trainings, and maintains an active coalitions listserv. The Alliance also hosts quarterly family caregiving coalition webinars on important issues and hosts a national advocacy task force of coalition leaders to help guide the program. In addition to numerous web-based resources, we also encourage a mentorship program, networking coalitions more closely together, so that each of us can better advance and support family caregivers in the United States.

### **About the Guide**

The purpose of this guide is to offer guidance both to individuals and organizations who want to establish a family caregiving coalition in their community and to existing coalitions looking for tools to help them maintain, grow and strengthen their coalition. This is a living document that covers several topics, which coalitions can draw upon depending on their focus and needs. **Volume 1** covers what you need to know to start a coalition, from the planning steps, to creating a vision statement, mission statement, goals and objectives, and how to operationalize your coalition. **Volume 2** focuses on growing and maintaining your coalition, with topics including: strategic planning, decision making, projects and activities such as advocacy, education/ training, research, public awareness, information and referral, and evaluation and sustainability. The Alliance will continue to update and expand this guide.

Some of the sections in this guide are adapted from a training guide originally developed in 2003 by the AARP Foundation called “12 Keys to Building Caregiver Coalitions.” Eltzeroth, H., Duke, B., Wollerman, T. (2003). 12 Keys to Building Caregiver Coalitions. Retrieved from:

<http://www.caregiving.org/wp-content/uploads/2011/03/12-Keys-to-build-a-caregiver-coalition.pdf>

The original “12 Keys” was developed as a training tool and reference document for organizations interested in forming caregiver coalitions. It was based largely off a survey conducted by the AARP Foundation, in cooperation with the Administration on Aging (AoA), of caregiver coalitions that existed at that time to determine best practices in coalition formation. Since 2003, many more caregiving coalitions have been established, leading to new knowledge and the need for updated and additional tools that can serve the needs of today’s caregiving coalitions. At the same time, much of the content from the original “12 Keys” continues to prove helpful today and is repeated in this guide. To read the original “12 Keys.” Click on the following link:

<http://www.caregiving.org/wp-content/uploads/2011/03/12-Keys-to-build-a-caregiver-coalition.pdf>

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**VOLUME 2: GROWING A FAMILY CAREGIVING COALITION**

**STRATEGIC PLANNING**

**PROJECTS AND ACTIVITIES**

**ADVOCACY**

**EDUCATION/TRAINING**

**RESEARCH**

**PUBLIC AWARENESS**

**INFORMATION AND REFERRAL**

**DECISION MAKING**

**EVALUATION AND SUSTAINABILITY**



**VOLUME 1:**  
ESTABLISHING A FAMILY  
CAREGIVING COALITION

## BACKGROUND

Family caregivers are vital to healthcare delivery in this country. There are 65.7 million caregivers in the US and they are the backbone of the nation's long-term care system, providing the bulk of personal and health care support across the lifespan, for family members, friends, neighbors and others who may be ill, aging, or living with a disability. Millions of these caregivers function in isolation at significant expense to themselves, unaware of available support and services. Caregiving in the U.S. – Findings from a National Survey, identifies and profiles the impacts of family caregiving in society. Click on the following link to read the report:

[http://www.caregiving.org/pdf/research/Caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](http://www.caregiving.org/pdf/research/Caregiving_in_the_US_2009_full_report.pdf)

The nation's long-term care system is less a "system" than a fragmented array of services administered by different public and private agencies with inconsistent coordination and often gaps in services. Likewise, the system in place to support family caregivers as important players in providing long-term care support is basic and often inadequate to the task. The National Family Caregiver Support Program (NFCSP), a federal program administered by the Administration for Community Living, provides critical help to caregivers with a comprehensive array of services, but it is limited mostly to caregivers of the elderly and is woefully underfunded. Additional support from both public and private organizations, as well as citizens in the community, is needed.

Family caregiving coalitions can help develop new partnerships at local and state levels and present a coordinated approach to addressing the needs of family caregivers. Coalitions can ultimately provide family caregivers a variety of benefits, including new and improved services delivered to more caregivers; enhanced access to information and referral services, advocacy for state and federal legislation; and support networks or groups.

This volume is intended to provide a step-by-step guide of helpful strategies for starting a family caregiving coalition, whether at the state or local level. It starts with a detailed conversation about **planning**, which includes deciding why you want to create a coalition and who you want around the table. It is about organizing the first meeting and identifying the coalition's capabilities. The next sections focus on developing a **vision statement**, a **mission statement**, and **goals and objectives**, essential steps in developing agreement and a clear understanding of why the coalition exists, what is expected from the coalition partners, and what actions must be taken to ensure efficiency, accountability and success. A section on **operationalizing your coalition** provides details about how to communicate with coalition partners and what an effective meeting looks like. It also covers leadership – skills, structure and various styles of leadership – providing guidance on how to determine who takes the leadership role, who is a good leader, and how best to establish needed committees and workgroups. Financial management and funding are also key to bringing your coalition online and are also discussed in the operationalizing your coalition section.

**A CAREGIVING COALITION** is a community of organizations that has come together to address the needs of family caregivers across the lifespan. These coalitions can provide family caregivers, both families of origin(s) or families of choice(s), with information and referral services, educational outreach, research, respite and/or advocacy. A caregiving coalition presents a united voice working to meet the complex social, medical, physical, financial, spiritual, and emotional needs of family caregivers.



## PLANNING

Planning is essential to the success of building a coalition. Planning activities precede the very first organizational meeting of the coalition and extend throughout the existence of the coalition. Planning helps to rally those initially invited to participate, creates and validates the vision and mission and serves as a check on progress.

Before beginning a formal planning process, the following should be taken into consideration:

- Consider who will help create this coalition in the beginning stages – those individuals who have experience in collaboration and advocacy leadership, are tied to family caregiving and are willing to help develop ideas and invite others to participate.
- Consider whether you want a formal planning process to be the very first activity of the coalition. Success can be dependent upon the concurrent processes of action and formation, so you may decide it would be good for the coalition to work together first on a specific achievable project, such as a formal needs assessment project or educational conference.
- Consider the length of the planning process. State an end date so that those involved are convinced of the reality of a final product. Also, in light of time availability of partners, give thought to how the planning meeting(s) or activity will take place (frequency, duration, etc.).
- Consider who will facilitate the planning process. Even if the coalition has convened in a neutral setting, the informal leaders who initially brought the group together may not be the best to facilitate planning. An outside facilitator who is skilled and has a proven record at facilitating may be best. Facilitators can be found by checking out your local college or university or by drawing on coalition members' existing networks for a contact that is skilled in facilitation. For more information on what a skilled facilitator can offer your coalition, see these facilitation guides and tool kits. Click on the following links:

<http://www.unce.unr.edu/publications/files/cd/other/fs9725.pdf>

or

<http://oqi.wisc.edu/resourcelibrary/uploads/resources/Facilitator%20Tool%20Kit.pdf>

- Consider reaching out to caregiving coalitions in other states and communities. The Alliance can help you connect with other coalitions in our virtual network of family caregiving coalitions. Many are eager to help provide mentorship with your new coalition.

## Gathering Information

### Preliminary Assessment

As conveners begin conversations about starting a caregiving coalition, one of the first steps should be to gather information, starting with a review of existing demographic information about the state, region or local community and information available about family caregivers in the community. It is also important to find out if and when a needs assessment has been conducted on the needs of family caregivers or if family caregiving issues were included in a larger assessment of community needs. The information gathering process will help identify gaps in knowledge and will ultimately help define the reasons why organizations and individuals should come together now to form a caregiving coalition.

The first stage of information gathering, or a preliminary assessment, is an informal survey that should try to answer the following questions, understanding that it can be difficult to gather or know for sure some of this information:

- What's the estimated number of family caregivers in your community?<sup>1</sup>
- What services or resources are available to the caregiver? What services are lacking?
- What is the current level of utilization of these resources and services?
- Are there caregivers who are not utilizing services?
- Do the existing services address the variety of needs caregivers have at different points in their caregiving experience?
- What types of caregiving are families providing in the community?
- What are the barriers to access resources for the caregiver (time, cultural difficulties, filial or spousal responsibility, communication gaps, overwhelmed feelings)
- What coalitions relating to caregiving exist? What are other examples of the community's experience in collaborative efforts?
- What is the racial/ethnic breakdown?

The information gathered can be supplemented with ideas from those invited to the exploratory meeting (initial planners) by asking them to complete a brief questionnaire to get their views on the unmet needs in the community and, therefore, the need for a caregiving coalition.

### Caregiver Needs Assessment

The information gathered in the preliminary assessment may be sufficient to identify the needs of caregivers in the community. If, however, some of the information is outdated and not adequate to identify the needs of family caregivers in the current environment, the coalition may want to undertake a formal needs assessment study as one of its first projects. Local colleges and universities are good resources in conducting needs assessments because of their research expertise.

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<sup>1</sup> Resources to help you with the search: AARP study which identifies the number of caregivers in each state: <http://assets.aarp.org/rgcenter/ppi/lc/i51-caregiving.pdf>  
service agencies like the Area Agency on Aging or Alzheimer's Association, etc.

Conducting a formal needs assessment has a cost and requires an associated budget, depending upon the type and scope of the assessment to be conducted. The budget and timeline for completion should be considered in the planning process.

The extent of the needs assessment can vary based upon the budget and areas that the coalition has identified as containing the greatest gaps in knowledge. For example, a needs assessment may include some or all of the following:

- Survey of caregivers;
- Survey of service providers;
- Survey of other community groups and organizations with a voice in caregiving issues;
- Focus groups;
- Town hall meetings.

The Needs Assessment Worksheet in Appendix A may be of assistance in identifying the kinds of information that can be helpful.

### Considering the Advantages and Disadvantages of Collaboration

Groups interested in forming a coalition should review the advantages versus the disadvantages of a collaborative effort. By developing an understanding of why a coalition works, individual organizations will be able to see the benefit to the family caregiver in the community, to the coalition partners and to the coalition as a whole. Disadvantages should also be shared so that they are taken into consideration.

**Figure 1:** Possible advantages versus disadvantages of a collaborative effort

Advantages	Disadvantages
Allows an organization to increase its potential and have real impact on an issue, including enhancing influence in advocacy or legislative process	Members can get distracted from other work and can be a strain on resources
Can develop new leaders	Coalition may only be as strong as its weakest link
Can potentially reduce duplication of effort	Keeping the coalition together may lead to catering to the lowest common denominator
Can promote better understanding of the issues and effective strategic planning	Democratic principle of one group-one vote is not always acceptable
Increases available resources, development of tools and services, and potentially increases public awareness	Individual organizations may not always get credit for their contribution
Broadens organization’s scope, as well as communication and understanding of different roles among partners	
Builds a lasting basis for change	
Encourages networking and information sharing	

**CAREGIVER NEEDS ASSESSMENT** A process to identify the needs of caregivers and available services in a community so that gaps in services can be identified and needed services can be provided.

These advantages and disadvantages highlight several issues for consideration:

**Collaboration vs. Competition** Those convening an initial group to discuss the feasibility of forming a coalition should be sensitive to the competitive nature of health and social service delivery systems. Funding mechanisms, insurance contracts and other environmental factors have preserved a competitive atmosphere. Existing service providers and/or collaborative efforts, which reach out to family caregivers or whose mission is to help caregivers, may view another coalition in the community as competition.

**Power Structures** Power structures whether formal or informal (due to size, influence, range of service, etc.) exist and should be taken into account when forming a coalition.

**Resource Flow** Differences may exist between resources being contributed by individual partners for the good of the coalition. Collaboration supports mutual beneficial growth. Collaborative groups need to guard against being subject to the 80/20 rule where 20 percent of the partners do 80 percent of the work.

### Definition of Community

It is important to define “your community” early in the planning process. This will help to guide you in determining who the key stakeholders are within “your community” and how broad a constituency you hope to serve. You should be aware from the beginning of the different dynamics involved in creating and managing a coalition that may serve a small area like a local municipality, or one that may serve a large city, county or region, or even one that serves your entire state. “Your community” can be defined geographically, by a set of people or organizations with common ties, by professional discipline, by ethnicity or by other affiliations. You decide.

### Key Stakeholders and Recruitment

Once you’ve identified your community, you can begin to make decisions about who should be at the table. Identifying potential key leadership is also important at this point – those individuals who will help in the strategic development of the coalition (more in the leadership section below). The first step is to identify key stakeholders to invite to be part of the original convener group. These might include:

- Leaders in state or local government with jurisdiction over caregiver issues (e.g., the state’s National Family Caregiver Support Program specialist);
- Leading service provider organizations in your community;
- Family advocates who have a broad network of contacts;
- Leaders in aging services and the disability network;
- Local hospital social service providers;
- Physician groups;
- In-home direct care worker organizations;
- Nonprofits serving various chronic diseases.

You will want to identify those with potential leadership experience, a reputation for collaboration and obvious investment in family caregiving. For more information on choosing leaders, please see the leadership section below.

Once the original convening group has been assembled, it is time to develop a list of organizations and/or individuals you wish to invite to join a collaborative effort to address the needs of family caregivers. Below is a list of the types you may want to include.

- Family caregivers;
- Public and private organizations (e.g., local senior center, local cancer center, Independent Living);
- Voluntary health organizations (e.g., state and local chapters of Alzheimer’s Association, American Cancer Society, MS Society);
- Advocacy organizations and membership groups (e.g., Lions Club, Kiwanis);
- Major employers;
- Faith-based organizations and faith communities, (e.g., local parish nurse organizations);
- Cultural/Diversity/Groups that represent different cultures within the community (e.g., Latino Health Council);
- Existing coalitions that interface with family caregiving issues, (e.g., Falls Prevention Coalition);
- AARP state offices and representatives from AARP state chapters;
- Medicare regional offices;
- Administration on Aging regional offices, state departments on aging and local AAA offices;
- Political leaders and elected officials;
- Media (e.g., public television, print media);
- Kinship care organizations (e.g., Generations United);
- Women’s groups;
- Veterans organizations (e.g., the caregiver coordinator of the local VA medical center);
- Veterans service organization (e.g., Wounded Warriors);
- Legal service providers;
- State and local professional associations of educators;
- Cooperative Extension Offices;
- Hospital and Health Service Organizations;
- Research groups (e.g., geriatrics research);
- Nontraditional organizations and groups (think “out of the box”).

Appendix B provides a more detailed description about specific organizations/stakeholders.

**EXERCISE: WHOM SHOULD WE INVITE?** *Take a couple of minutes and think about which organizations to invite to participate in a discussion about the family caregiver's experience in your community. Think about some of the usual providers of services who may have an interest in these issues, but also think of others who may be concerned about family caregivers or regularly come in contact with family caregivers. Make a list of invitees.*

### **Desirable Member Characteristics**

As the membership is convened, it may be important to keep certain characteristics in mind.

- **Influence** Influence can be looked at in a variety of ways. Desired partners would have influence in the community and/or influence in gathering others to the table.
- **Leader/Contributor** Invited partners may include the leadership of an invited organization and/or those who contribute to the success of an organization. Leaders can make decisions on the extent of participation and the sharing of resources to achieve coalition goals. Contributors can help to define issues, inform content and address needs.
- **Commitment to Goals** Partners should exhibit commitment to caregivers and to caregiver issues. This may not be apparent in the beginning but should be monitored as a coalition forms and acts. Partners who can contribute to the fulfillment of the goal of the coalition are most welcome as are those who can serve as resource partners. Be aware that some partners may see the coalition primarily as a networking opportunity to promote their business, services or products. This behavior should be strongly discouraged from the beginning and if it continues, they should be asked to leave the coalition.
- **Diversity** It's important that the overall membership represents the unique cultural and ethnic groups in the community. A profile of the caregiver in the community (not just those receiving services) should be compiled and the invitee list should be re-viewed for inclusion.
- **Inclusion** An open door approach works best. Keep asking during the initial and subsequent phases of development, "Who should be at the table?"
- **Potential Collaborative Leadership** Invite a combination of informal and formal leaders from the community to participate in the coalition. These partners can help to provide leadership to the overall coalition, be identified for success later on and perhaps provide leadership to individual efforts and coalition projects.
- **Consensus and Compromise** A desire to work toward consensus would be a desired trait among those gathered. Therefore, the ability to develop creative solutions in partnership with others is essential. This skill may be readily apparent with some partners or technical assistance may help other coalition partners gain skills in consensus building.
- **Partner's Needs** It is important to the recruitment and ongoing retention of partners to understand each of the partner's needs and/or the needs of their organizations.

- **Dedication to the Task** Everyone invited to participate in the coalition will have fluctuating responsibilities in their profession and with the coalition, but each must be committed to the success of the coalition and its mission over the long-term.

Ask the following questions as you begin to plan invitations and team building:

- Why choose one or the other individual or organization? What resources can they provide?
- Is this the right time for them to join the coalition?
- How can they be involved?
- Are there any barriers to recruiting these partners? If so, how can we overcome the barriers?<sup>2</sup>

As you approach potential partners, it is important to be able to articulate how they will benefit from being part of the coalition. Some benefits to individual partners may include:

- Enhanced knowledge of other service providers in the community;
- Opportunity for networking and new partnerships;
- Development of services or resources to help those served by partner;
- Increased skill building and competence;
- Enhanced awareness in community;
- Joint work among partners toward common goals;
- Improving the lives of family caregivers and their care recipients.

In addition, you should be able to make the case for how the coalition will benefit caregivers in your community and to explain the benefits of forming a coalition so that invitations can encourage collaboration. For example, a broad view of the benefits for the caregiver may include new and improved services delivered to more caregivers; enhanced access to information and referral services; advocacy for state and federal legislation; and support networks or groups. A review of the above list of advantages to collaboration will provide further information in helping to craft an invitation. Each coalition should amend and elaborate on these lists as they develop their membership and mission and issue invitations to additional partners.

**EXERCISE:** *Take a few moments and think about benefits which individual partner organizations can obtain by participating in the coalition. Record these benefits.*

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<sup>2</sup> University of Kansas, Create Coalitions and Partnerships: Outline for Creating Coalitions and Partnerships, Community Work Station [cited 21 August 2003]. Available through this link: [http://ctb.ku.edu/dothework/tools\\_tk\\_1.aspx](http://ctb.ku.edu/dothework/tools_tk_1.aspx)

As your coalition grows and works to retain current partners and to recruit new ones, it is important to:

- Adopt active listening skills to identify areas of concern with current partners;
- Utilize the contact network of existing partners to invite new partners;
- Have an orientation packet with an annual summary of activity available for coalition partners to use with their own organizations and also with potential partners;
- Periodically do an internal assessment to see how the coalition is doing and assess the satisfaction of a coalition partner.

## Coalition Formation

### Levels of Collaboration

There are different levels of collaboration. In order to begin to define expectations and the role of a partner, it would be good to review the different levels of collaborative efforts that exist. One of the categories identified in the literature suggests the following types:

Figure 2: Levels of collaboration

<b>NETWORKING</b>	Exchanging information for mutual benefit (does not require much time or sharing of “turf”)
<b>COORDINATING</b>	Exchanging information for mutual benefit <b>PLUS</b> altering activities for a common purpose
<b>COOPERATING</b>	Exchanging information, altering activities <b>PLUS</b> sharing resources for mutual benefit and common purpose
<b>COLLABORATING</b>	Exchanging information, altering activities, sharing resources <b>PLUS</b> a willingness to enhance the capacity of each other for mutual benefit and common purpose

It can be seen in the levels of collaborative efforts shown that both the level of commitment and direction of sharing differ.

### Articulating the Purpose of Your Coalition

Coalitions are formed for a variety of reasons, whether it be mandated by law, required to fulfill funding requirements or inspired by family caregivers and their advocates motivated to enhance services and support for family caregivers. That initial catalyst, along with the preliminary assessments of family caregivers in the community and a planning process that includes the creation of a vision and mission will all help to define a role and purpose for your coalition.

In other words, what will this gathering of expertise contribute toward the support of the family caregiver? Some possible purposes for a family caregiver coalition include one or more of the following:



- **Advocacy** The coalition becomes a voice with the family caregiver, advocating for changes in the law and regulations. This can include working with the local, state and federal governments to effect change. The coalition may select one particular group of family caregivers (e.g., caregivers of older persons or grandparents or other relatives caring for children with special needs).
- **Outreach** Outreach includes providing information, education and referral services to the public. Because information provided to caregivers may currently be limited in scope, depending upon the organization providing the information, and because funds for outreach may be limited within organizations, the coalition may gather to improve outreach to the community.
- **Raising Awareness** Family caregivers often don't self-identify. The coalition may help tell the story of the family caregiver to raise awareness of the resources available to caregivers. Awareness building may also take place with employers and others who interact with family caregivers in their day-to-day lives.
- **Service Provision** Coalitions may identify gaps in service delivery in the community. There should be some caution here since partners sometimes deliver services. A coalition may want to see if identified service gaps may best be filled by partners rather than having a coalition manage a service.

Coalitions can also be classified as grassroots, professional or community based.<sup>3</sup> These categories can inform the purpose of the coalition. A key component to success is linking your coalition with complementary state and national movements and taking advantage of their resources and their network of members.

### Coalition Scope

The definition of community and an initial idea of the purpose of the coalition can help to define the scope of the coalition. Scope can be defined in several ways.

- **Geographic** The scope of the coalition complements the definition of community. Is the community defined on a state, regional or local level? It may be possible for a collaborative effort to develop a network so that there is both a state and local presence with a given initiative.
- **Resource Levels** The resources available can define the scope of the coalition's work.
- **Partners/Members** The partners who join the coalition and who are willing to commit time and resources toward success may also define the scope of the coalition's work.
- The scope of the coalition may also change over time.

<sup>3</sup> ARCH National Respite Network and Resource Center. (Updated 2009). Building a Statewide Respite Coalition: Where do we begin?. p5. Available through this link:

[http://archrespite.org/docs/Building\\_Respite\\_CoalitionsUpdate\\_%28Final%29.pdf](http://archrespite.org/docs/Building_Respite_CoalitionsUpdate_%28Final%29.pdf)

## Preparing for the First/Organizational Meeting

### Organization

The first meeting is an important one. It will be a time when the original conveners meet again, and it will be the first meeting between potential partners.

### Invitations

The invitation process can involve several components. The first is contact by telephone to discuss the preliminary reasons for forming a coalition to help family caregivers. This call can be initiated by the planners seeking to form the coalition or by a subsequent contact made through networking. During these calls, organizers should take note of comments, reactions and suggestions. The calls should end with a call to action.

Following the initial solicitation of interested parties, a letter summarizing the details of a first meeting should be sent out. The letter can remind the potential partner of areas of common interest and possible mutual benefits.

### Agenda and Meeting

The first meeting should have the characteristics of all subsequently scheduled meetings and include:

- Start and end on time;
- Have an agenda;
- Use a sign-in sheet;
- Provide handouts;
- Make sure everyone has an opportunity to talk;
- Record minutes and distribute minutes before the next meeting;
- Have a comfortable meeting space and simple refreshments;
- Make sure decision making strategies are implemented appropriately;
- Choose a facilitator to lead difficult discussions if appropriate.

### Introductions

Have each share their name, organization and title and answer the question of how their organization helps family caregivers or why they are interested in family caregiver issues. Allow time for this process. Persons by nature of affiliation want to share what they know, who they are, and what their organization has accomplished or is actively working on that addresses family caregiver issues. This introductory experience allows them to share that information up front and may minimize interruptions later in the coalition formation process. It is also a great introduction to the expertise, both personal and professional, that exists in the room. You may even develop and distribute a brief bio on each attendee and their affiliation prior to the first meeting of the potential partners.

This introduction exercise should also take place at the beginning of the strategic planning process and for new partners at the first meeting they attend.

**Setting the Ground Rules**

The ground rules are to be identified by those gathered. The facilitator can begin the dialogue to identify the ground rules. Make sure that compromise and consensus building are mentioned in some way. If not, the facilitator should encourage the group to identify them as ground rules.

**Subsequent Meetings**

Subsequent meetings should have the characteristics listed above. A review of actions identified at the previous meeting should take place.

**Capabilities Assessment**

A survey should be conducted after the first meeting to assess the internal capabilities of the coalition. The partners should complete this capabilities review as a group. The dialogue may help inspire or remind partners of information that may be helpful to the coalition's work. The entire group should review the information listed to see if there is consensus and if anything is missing. Develop your own list of capabilities (organizational or individual) that you believe will best serve your coalition.

Suggested questions may include:

- What issues face the family caregiver today?
- What services does your organization provide to help the family caregiver?
- What services do you refer family caregivers to for assistance and support?
- What strengths does your organization bring?
- What strengths do you as an individual bring?
- What barriers do you see to the work of a coalition such as this?  
What solutions would address these barriers?
- What previous experience have you had with collaborative efforts?

The capabilities and capacities of the coalition help define realistic and achievable goals. The following exercise will help the coalition gather information on coalition capabilities.

**EXERCISE:** *List the services provided by the individual coalition partners. List the strengths each partner (organization) brings to the coalition. List the strengths each partner (individual) brings to the coalition. What time, talent or funds can partners contribute to the work of the coalition? If events or projects have been completed by the coalition, what did evaluations or feedback tell the coalition about their talents or strengths as a group? What resources does the coalition not have access to? What are some of the challenges faced by the coalition? What are some of the external environmental factors that affect the work of the coalition? What opportunities are present in the community that could help the coalition achieve its mission? Are there organizations that should be invited to join the coalition? Are there recent events (laws, requests for proposal, grant awards, etc.) that could contribute to the coalition's mission? Are there other collaborative efforts or organizations that might view the work of the coalition as a threat? Have there been recent changes in legislation or budgets that impact the effectiveness of the coalition? Is the awareness level on the issue of family caregiving where it should be?*

Information from this capability assessment can be added to the preliminary assessment gathered as part of the formation process. The coalition may view the internal/capability assessment as a fluid process and revisit it periodically when planning projects and activities.

### **Review of Preliminary, Needs and Capability Assessments**

At the first meeting, the facilitator or member of the group should be invited to present an overview of the information gathered by the convening group in the preliminary assessment and, if applicable, the needs assessment. At subsequent meetings, the coalition may want to spend more time reviewing and discussing the preliminary assessments, as well as the capability assessment once that information has been gathered. Those gathered should be invited by the facilitator to confirm, suggest revision or add to the assessment information. The idea in this step is to work toward a picture of the family caregiver, how he or she is doing in the community, and what services or resources are available to help.

Because family caregivers often fail to self-identify, it can be hard to find studies and statistics that highlight how their needs are being met and where the system is failing them. But the preliminary assessment, the needs assessment, and the capability assessment can help to define unmet needs. The gaps identified can indicate possible areas where collaboration in a state, region or community can assist family caregivers. Identified environmental factors and a picture of the family caregiving experience in a given community contribute to assessing the need for a community-based coalition and may indicate some initial directions for the coalition, including advocacy for legislation or educational outreach or planning to meet unmet needs. The information gathered would also help in the solicitation of funding as well as educating potential collaborators. The work you do will also identify possible areas of importance for recruiting partners.

The review of previous collaborative efforts may indicate a competitive environment. As a result, those convening a coalition may need to spend time building trust and creating cooperative working relationships. This review process summarizes what is known by the partners and by the group as a whole and can serve as a valuable introduction to the visioning process.

### **Additional Resources**

- Create Coalitions and Partnerships: Outline for Creating Coalitions and Partnerships: [http://ctb.ku.edu/en/dothework/tools\\_tk\\_1.aspx](http://ctb.ku.edu/en/dothework/tools_tk_1.aspx)
- Assistance in starting and/or sustaining a coalition: <http://gwaar.org/for-professionals/family-caregiver-support-for-professionals/10-articles/aging-programs-and-services/152-caregiver-coalitions.html>
- Building a statewide respite coalition: Where do we begin?: [http://archrespice.org/docs/Building\\_Respite\\_CoalitionsUpdate\\_%28Final%29.pdf](http://archrespice.org/docs/Building_Respite_CoalitionsUpdate_%28Final%29.pdf)
- How to Organize Alliances of Multiple Organizations Part 1: [http://www.ssireview.org/blog/entry/how\\_to\\_organize\\_alliances\\_of\\_multiple\\_organizations\\_part\\_1](http://www.ssireview.org/blog/entry/how_to_organize_alliances_of_multiple_organizations_part_1)  
and Part 2: [http://www.ssireview.org/blog/entry/how\\_to\\_organize\\_alliances\\_of\\_multiple\\_organizations\\_part\\_2](http://www.ssireview.org/blog/entry/how_to_organize_alliances_of_multiple_organizations_part_2)

## VISION AND MISSION STATEMENT

### Importance of Vision and Mission

Coalition partners need to develop agreement and have a clear understanding of why the coalition exists and their role in the coalition if they are going to be effective participants. Mechanisms to achieve these goals include the process of developing a vision and mission for the coalition and goals for action.

A clearly stated vision and mission helps all partners feel vested in coalition activities. The vision and mission identify the benefits of joining the coalition, contribute to clearly defined goals and support working relationships between the partners.

### Vision Statement

A coalition needs a vision. A vision is a global concept, our dream of the way things ought to be and a mental image of what success would look like. It is the pursuit of this image of success that will motivate the partners of a coalition to work together. The authority and vision of a few people cannot shape and drive your coalition - it must be a powerful and shared vision.

**EXERCISE:** *What are the top three dilemmas experienced by family caregivers today? List five services or policies that could help the family caregiver.*

The questions you answered are intended to start your thinking about a vision for the future.

**EXERCISE:** *If your hopes and dreams come true, what would this community look like five years from now with respect to the family caregiver? In other words, what changes or improvements would enhance the family caregiver's experience?*

### Mission Statement

If the vision statement is the articulation of a group's dream for a bright future, then the mission statement is its declaration of purpose. Your mission is what you are going to do to accomplish your dream and why.

A clear mission statement lets outside people know what general activities your coalition will undertake and who will be the beneficiaries. It explains the problem or need your coalition is trying to address and the common values, principles or beliefs guiding it. It communicates the essence of the coalition and what makes it unique. If you encounter resistance to this exercise, emphasize the benefit of the process to the exercise.

**EXERCISE:** *What are the two most important things that have to happen or be accomplished in order to bring about the change/improvement identified in your vision with respect to the family caregiver? Relate the mission statement to the vision statement developed by the group. Members can be ambitious and daring here.*

#### VISION STATEMENT

*Statement of your big picture dream of the way things should be.*

#### MISSION STATEMENT

*Statement of what you are going to do to accomplish your dream. It explains your purpose.*

Partners should participate in a facilitated discussion about the two things they recorded during the mission statement exercise. Dialogue between the facilitator and partners will help to group similar responses and prioritize which statements are important for consideration as part of the coalition's mission statement.

A mission statement that incorporates or captures what has been shared should:

- Describe what will be accomplished and why;
- Be concise (preferably one sentence in length);
- Be outcome oriented, stating a broad goal or goals that will be achieved;
- Be generally worded enough to allow a broad number of strategies;
- Give a general idea of the strategies that will be used to make a vision a reality.

The coalition partners should agree on the vision and mission statements. See Appendix C for Sample Vision and Mission Statements.

## GOALS AND OBJECTIVES

### Developing Your Goals and Objectives

The goals of the coalition and its objectives will define and prioritize the achievable actions agreed upon by the partners – they are a vital component of the coalition's "business plan;" how you intend to operate. These goals and objectives are born out of the vision and mission of the partnership and should be seen as the means by which they are fulfilled. In addition to consistency with the vision and mission statements, the partners should take into consideration the capabilities of the coalition so that the goals and objectives are realistic and achievable. Both the goals and objectives should be developed as a group and will take some time to create and to build consensus around. Keep in mind: goals are general statements of intent. They can be long-term or short-term goals (near-term). Objectives are the practical steps needed to help you achieve your short-term and long-term goals and are designed to be measurable.

Here are some examples of both:

#### Goals

- Encourage family caregivers to self-identify;
- Increase awareness of family caregiver challenges and resources;
- Promote and provide educational and training opportunities;
- Reach family caregivers where they are – in the workplace, hospital and clinic, and at home;
- Provide access to a full range of services – educate, support, nurture and sustained in their vital caregiving role;
- Investigate The National Alliance for Caregiving's role in advocating on behalf of family caregivers.

### Objectives

- Develop an outreach program to help family caregivers to self-identify;
- Strengthen services and resources to caregivers in my county;
- Improve online access to information on caregiving;
- Identify and respond to gaps in services to caregivers;
- Provide quarterly networking opportunities for caregivers, providers of services to caregivers, and anyone interested in the well-being of caregivers;
- Facilitate inter-agency referrals;
- Provide caregiver educational programs and resource information to social service providers, health care providers, family caregivers, employers, corporations and businesses, and the community at large;
- Develop an infrastructure to provide information to caregivers about services available in their community;
- Empower caregivers to be effective advocates through education and training courses.

**EXERCISE:** *List two goals for the coalition. A facilitated discussion will help identify similarities and differences to help partners reach consensus on goals. Partners should then review the goals as a group and indicate whether the goals are short term (within 12 months) or long term (one year or more). Partners should also be invited to review the goals in terms of influence (“I”) and control (“C”) according to the following categories:*

**I and C** *Coalition has both influence and control in accomplishing this goal*

**I and not C** *Coalition has influence but no control in accomplishing this goal*

**Neither I nor C** *Coalition has no influence and no control in accomplishing this goal.*

*Following this evaluation of the goals, the partners should be asked to vote on the goals by selecting the two goals for the coalition of those listed.*

Keep all of the recorded goals. Some may be helpful in future planning even if not selected during this process.

### Action Plan

An action plan is a blueprint, based on your goals and objectives, which lays out the steps necessary to ensure efficiency, accountability and success.

Appendix D contains a Sample Goals and Action Plan sheet. The coalition can do its own exercise based on this example. The exercise helps partners of the coalition to formulate an action plan.

Appendix D includes:

- Sample goal(s);
- Objective(s) to achieve the goal;
- Actions/Tasks to achieve objective;
- Responsibility;
- Timeline;
- Resources Needed;
- Communication (Who should know what).

## Evaluation and Sustainability

The development of goals and objectives and a subsequent action plan, coupled with vision and mission statements, will help your coalition when it comes time to evaluate your success. Evaluating the work of a coalition involves gathering information and interpreting it to answer your questions about the coalition's work. It is a process that helps you measure your success in achieving your goals and objectives, and it can suggest ways to improve over time.

The answers to key questions can tell you if your coalition is on track or needs to get back on track to meet its goals and objectives. The information can be used to help motivate coalition members, to build case statements when seeking funding or to market your coalition to the community and potential new members.

In addition to actively evaluating your coalition's success, the act of continually refining goals and objectives is important for caregiving coalitions that wish to remain relevant and to continue their work in the community. Coalitions are established as ongoing structures. The strength of the collaborative effort and mutual benefit gained by partners fortifies the energy level of the coalition.

While evaluation and sustainability will be discussed in more detail in Volume 2, these concepts are important to keep in mind as your coalition is just getting started. You need to think about and discuss what success will look like - both in the short term as your coalition meet its objectives and take specific actions, and in the long-term as you consider the coalition's impact on family caregivers in your community. You also need to think about what actions your coalition will take over time in order to sustain your membership and interest in your work.

## Additional Resources

- Definition of Goal:  
<http://en.wikipedia.org/wiki/Goal>
- Information about Goal versus Objectives:  
[http://www.diffen.com/difference/Goal\\_vs\\_Objective](http://www.diffen.com/difference/Goal_vs_Objective)
- Get Goals and Objectives into your business plan:  
<http://www.dummies.com/how-to/content/set-goals-and-objectives-in-your-business-plan.html>



## OPERATIONALIZING YOUR COALITION

The operations of the coalition contribute to its success. In this section, information will be shared on meeting style, the importance of communication, leadership considerations, organizational structure and funding.

### Establishing the Meeting Schedule and Style

#### Ground Rules

The importance of regular meetings and consistent communication with members cannot be overemphasized for the success of a coalition. Some of the important points regarding meetings can be found in the earlier section on planning, including the establishment of ground rules, an agenda and timely communication. While some of the following was shared previously, here is a good review.

Meetings can be kept effective by:

- Adopt a regular monthly meeting schedule. Having “dial-in” capability is a great bonus for those that can’t always travel to a face-to-face meeting;
- Set an agenda in advance of the meeting – include an opportunity for all to send in ideas for the agenda;
- Provide minutes that are timely and a complete description of what occurred at the previous meeting so that those who could not attend are informed;
- Allow an opportunity in the agenda for a select number of partners to talk about their organization and what they do, as well as their interest in and commitment to the coalition;
- Provide updates on all active projects;
- Insure to keep the vision and mission in mind (consider printing the vision and mission statements at the top of every set of minutes);
- Reach out to the partners about who is not at the table and identify how best to invite them. Then, make an assignment for outreach;
- Seek consensus;
- Address disagreements professionally and as quickly as possible.

### Meeting Characteristics

Beginning with the first meeting of the coalition, expectations should be defined, with a discussion on how the meetings should operate. It is usually helpful for the convener to lay out their view and then open the floor for discussion. The ARCH National Resources Center has documented what they found to be the common characteristics of a successful coalition, click on the following link:

[http://archrespite.org/docs/Building\\_Respite\\_CoaltionsUpdate\\_%28Final%29.pdf](http://archrespite.org/docs/Building_Respite_CoaltionsUpdate_%28Final%29.pdf)

to read the document, which can also be applied to meetings:

- Common goals and sense of purpose;
- Joint decision making;
- Shared power and responsibility;
- Trust and open communication;
- Personal integrity and flexibility;
- Self-evaluation;
- Teamwork;
- Recruitment and orientation.

### Communications

Regular and consistent communication is vital to the success of the coalition. Practical ideas for **internal** communication include:

- Develop a contact list, which contains name, title, organization, street address, city, state, zip code, telephone number, fax number and email address. This list should be shared at each meeting and circulated to make sure the contact information is up to date;
- Share the phone numbers and email addresses of the leadership so that partners can contact the coalition between meetings;
- Establish a listserv so that emails can be used effectively for communication. One individual who will screen requests and send out information should control the listserv;
- Send out calendar invites of the regular monthly meeting schedule – with a dial-in number if possible;
- Keep members posted on all activities of the coalition and cross promote events of member organizations;
- In the long-term, if possible, establish a website or webpage for use by coalition partners. This site could have bulletin boards for idea exchanges on current active projects and also have an area to post resources.

**External** communication is also important to promote the coalition, including its mission and activities, solicitation of new members and its successes:

- Have partners identify those in the community who should receive information, including philanthropic sources, government officials, other collaborative efforts in the region, faith-based organizations, professional and voluntary health organizations;
- Establish and utilize an email list for coalition updates and invitations to events and programs;
- Solicit the public information and media relations services from one or more of the partners to extend information to the media;
- As mentioned, media should be invited to be a partner on the coalition;
- Plan for and have information ready to address opposition which may come from other collaborative efforts or organizations in the community;
- Create communication strategies that help promote partners in external communication.

## Coalition Leadership: Skills, Structure and Style

Determining how the work of the coalition gets accomplished is a key issue. Since funding of a coalition (particularly in its earliest stages) is an ongoing issue (discussed below), in most coalitions there is dependence on volunteer staff or in-kind contributions of partners. Leadership should be identified for the coalition to allow for a consistent presence with its partnering members and for strategic planning to move the coalition forward.

### Leadership

*“The leadership of the community coalition is usually not found in a single charismatic individual. Rather, successful coalitions disperse their leadership and develop it among the members of the coalition.”<sup>4</sup>*

Thomas Wolff

*A Practitioner’s Guide to Successful Coalitions*

Identifying potential leaders for the coalition is one of the primary steps in pulling together the coalition and should occur early in the planning process. No one person should be expected to do the work by themselves. In fact, there is no quicker route to disaster than having one person make all the key decisions. Begin by identifying other community leaders invested in family caregiver support and have informal talks with them about forming this coalition and a vision of what the coalition can accomplish. Then ask for their help in establishing this partnership. They may only be able to commit to helping form the organization, but not to operating the coalition. This alone is a great asset, as the toughest job is getting the coalition started. It is highly recommended that 3 to 5 leaders be identified and secured to help initiate the coalition. Ongoing leadership can be determined once the coalition is formed.

<sup>4</sup> Wolff, T. 2001. A Practitioner’s guide to successful coalitions. *American Journal of Community Psychology*. Vol. 29.2: 173-191.

Once the initial leadership is established and the planning of the coalition is underway, ongoing leadership and the structure of that leadership can be discussed, perhaps even at the first meeting. Whether serving as an officer of the coalition, a committee chair, a work group leader, or project director, the skills and reputations of leaders at every level and period of time in the coalition should be considered, as each leader will help determine the overall success of this partnership.

### ***Leadership Skills***

Successful leadership skills include:

- Allowing opportunities for members to present their services without having the agendas of individual organizations overshadow the coalition's agenda;
- Involving other partners in the work and formation of the coalition early on;
- Clarifying expectations;
- Inviting others to join;
- Inspiring others, building confidence and cooperation;
- Providing organization to the work of the coalition;
- Serving as a good communicator;
- Developing new leaders;
- Managing resources;
- Building consensus.

### ***Coalition Structure***

Leadership within a coalition structure can vary from formal to informal. There is no right or wrong way to establish this, nor does it have to be "carved in stone." What is right is what is right for your particular coalition and it may change over time. Some coalitions prefer a formal approach with elected partners filling specific roles of service for the coalition for specific periods of time, such as one year. Others prefer an informal approach to leadership with shared roles in leading initiatives or leadership that evolves from the ongoing development of the coalition. Your coalition must also decide whether to establish committees, subcommittees or workgroups to complete the work of the coalition.

Some suggested structures include:

- Rotating Chair and Co-chair positions;
- Executive Committee or Board of Directors;
- Standing Committees and Working Committees as needed for ongoing or periodic projects/programs, needs assessment, fiscal affairs, etc.

Structure should allow for both the growth of the coalition in areas such as relationship building and support for the work of the coalition. To make the work of these various groups successful, suggested actions include creating workforces with clear goals,

objectives and realistic work plans, including measurable indicators of success. Coalition leadership should review the progress of each committee or workgroup. Each group working on an initiative should report back to the entire coalition on progress and resource needs.

#### ***A Note about Maximizing Partner Assets***

Coalitions should maximize the ability for partners to contribute in-kind services to complete identified actions and programs. The individual and organizational strengths identified during the internal assessment, as well as ongoing discussions, will help serve as a guide to connect opportunity and resource.

For example, if there is a need for public relations work to promote a program or upcoming event, the need should be presented to the partners to see if there is a partner whose organization could contribute their strength in public relations. Partners may be able to contribute in-kind services to support the infrastructure needs of the coalition.

Some partner organizations have a volunteer corps to support them. Does any of the work of the coalition serve as an opportunity to engage these volunteers?

Other partner organizations may have the resources to help co-sponsor events as a way of enhancing awareness of their organization in the community.

Partner organizations should leverage the value of the coalition and its work so that they can identify opportunities that may arise within their professional organizations and that can be enhanced through coalition involvement.

#### ***Leadership Style***

It is important to remember that the coalition is built upon the goodwill of volunteers, so it is highly recommended that a collaborative leadership style be adopted in order to build and successfully maintain these invaluable relationships.

In their book, *Collaborative Leadership: How Citizens and Civic Leaders Can Make A Difference*, Chrislip and Larson describe a collaborative leader as one that can “inspire commitment and action, lead as problem solvers, build broad based involvement and sustain the participation of the partners.” The abilities to resolve conflicts constructively, communicate clearly and honestly, facilitate group interaction and develop leadership in others are also identified as important.<sup>5</sup>

There are a variety of leadership styles evident across all kinds of organizations, and we encourage you to explore them further by clicking on the following link:

[www.mindtools.com/pages/article/newLDR\\_84.htm](http://www.mindtools.com/pages/article/newLDR_84.htm)

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<sup>5</sup> Chrislip, D. Larson, C. (1994). *Collaborative Leadership: How Citizens and Civic Leaders Can Make A Difference*. Michigan: Jossey-Bass

However, coalitions will most likely flourish with a collaborative form of leadership, called “transformational leadership.” According to Mindtools.com, transformational leaders have recognized integrity, they inspire people with a shared vision of the future, they set clear goals and motivate people towards them, they manage delivery, and they communicate well with their teams. Likewise, they expect the best from everyone on their team as well as themselves. This leads to high productivity and engagement from everyone in their team. The strength (and sometimes weakness) of this style relies on everyone playing their part in contributing to the partnership. It calls on all the partners to participate in some capacity of service.

#### *Aspects of Transformational Leaders*

- A good listener, receptive to what other people say, even in disagreement;
- Persuasive in speaking about their work and the value of the coalition – never coercive;
- A trust and consensus builder;
- A strong conceptualizer, inviting input from others and sharing of resources and skills.

Yet, it is also important to realize that no single leadership style will be effective in every situation – this will depend on the unique aspects of people in the partnership and the situation the partnership faces. That’s why, in many organizations, both transactional and transformational leadership styles are useful. Transactional leaders (or managers) ensure that routine work is done reliably, while transformational leaders look after initiatives that add new value. But still, collaboration should be the ultimate goal and overarching style.

It is also recommended that the leadership of the coalition should be evaluated periodically to make sure that it is effective for your coalition. Inspired commitment, consistent action and broad-based involvement by coalition partners are signs of good leadership.

#### **Decision-Making**

There are various ways to make decisions within a coalition, and different types of decision making may be required by different situations. For example, coalitions can choose to have an individual leader make some decisions, can assign committees to take responsibility for various decisions, can require a majority vote, or can choose to build consensus. While Volume 2 will provide a more in-depth discussion of how coalitions can use decision making methods to address conflict, it is important at the outset for coalitions to consider how they will go about making decisions.

Conflict, differences of opinions, turf issues, and sometimes indecision are to be expected in any collaboration. However, participation in the planning process, orientation to an established vision and mission, a focus on shared goals versus differences among partners, and having an agreed-upon method for making decisions can contribute to resolution and cooperation.

## Financial Management and Funding the Coalition

### Non-profit vs. Tax-exempt Status

Many organizations believe that non-profit and tax-exempt mean the same thing. However, it is very important to know that granting nonprofit status is done by the state, while applying for tax-exempt designation (such as 501(c)(3), the charitable tax-exemption) is granted by the federal government. Most states grant non-profit status through a special division of their Department of State and is usually done through the incorporation process. Check with your individual state as to their process of granting non-profit status.

Section 501(c) of the United States Internal Revenue Code (26 U.S.C. § 501(c)) provides that 28 types of nonprofit organizations are exempt from some federal income taxes. Deciding which is the best option for your organization to apply for is dependent on your mission and how you decide to carry out that mission. It is also important to know that non-profit status from the state must be obtained prior to requesting tax-exempt status from the IRS. A full discussion of 501(c) options is found here:

<http://www.irs.gov/pub/irs-pdf/p557.pdf>

### Formal or Informal 501c Status

In the earliest stages of a coalition's formation, many choose to operate under the non-profit and tax-exempt "umbrella" of one of their partner organizations, essentially operating as a program of that organization. This informal status allows for initial (but limited) fundraising and time to form an operational structure for the coalition. It is important to realize that the coalition is restricted in its activities by the status of the "umbrella" organization and has no independence of its own. You may also be restricted in the funding that you go after, because you may be competing for funding with the parent organization. A burden to apply for a tax-exempt status can be that there is a filing fee to apply and forms to complete.

Whether the coalition decides to apply for formal, tax-exempt recognition by the state and IRS or chooses to operate for a while under an umbrella, you will be raising and managing funds in order to do the business of the coalition. In either situation, you must be prepared to follow standard accounting procedures, as a legal and ethical matter and to protect the integrity of your organization. If you apply and are successful in gaining non-profit status, then you must file an annual 990 form with the IRS and should undergo an annual audit. For a full description and the application for 501(c)(3) please click on the following link to download the Applications for Recognition of Exemption, IRS Package 1023:

<http://www.irs.gov/Charities-&-Non-Profits/Application-for-Recognition-of-Exemption>

## Budget

In order to plan effectively for the work of the coalition, it is necessary to create a budget, which identifies categories of expense and estimates cost and revenue. The calculation of costs should include funds for the infrastructure work of the coalition. This indirect cost should also be included each time the coalition plans a project. Staffing time should also be considered, but it may be viewed as an in-kind contribution (and treated accordingly) from those partner organizations providing staff for a project.

## Key Funding Considerations

- **When** Fundraising should be ongoing. Waiting until grant funds are exhausted is too late. As soon as one grant or source of funding is obtained, coalition members should be looking for the next. When the coalition is a result of a state initiative, funds may have been part of the state budget. However, because the funds are part of the state budget, they may be subject to budget cuts.
- **Who** Some coalitions assign the fundraising responsibility to a committee or (in rare situations) a consultant or paid staff member. Others may assign the responsibility to a partner with fundraising experience. Still others may form a committee or workgroup - based upon the project or activity - and draw from the wide expertise of partners or even the broader community. Regardless, it is vital for the assignment of this responsibility to have vigilant oversight. The best approach is one that works best for the coalition. However, if a particular organization within the organization is the primary fundraiser that organization may have or be perceived as having more control over the project or activity funded.
- **501(c)(3)** Many grant opportunities are only open to organizations that have a 501(c)(3) tax exempt status from the IRS. Without this status the coalition may have limited fundraising options.
- **NFCSP (National Family Caregiver Support Program)** Every state has funds available for coalition development from this program. In order to apply, your coalition will have to meet basic provisions required by your state. Be sure to check with your state office to know those requirements. Further, many state NFCSP policies require that aging units should be a member of a local family caregiver coalition or coordinating committee with other local providers who currently provide support services to family caregivers. For example, in Wisconsin, they are encouraged to utilize NFCSP funds to support coalition activities, because it's considered outreach, education and support to caregivers. To learn more click on the following link:  
[http://www.aoa.gov/aoaroot/Press\\_Room/Products\\_Materials/fact/pdf/Natl\\_Family\\_Caregiver\\_Support.pdf](http://www.aoa.gov/aoaroot/Press_Room/Products_Materials/fact/pdf/Natl_Family_Caregiver_Support.pdf)
- **Grant Writing** Grant writing can be time consuming and difficult for those who do not do it on a regular basis. However, many organizations use The Common Grant Application Format, and it may be helpful to become familiar with this format. However, you should always contact grantmaking organizations directly to get their individual forms. Similarly, The Catalog of Federal Domestic Assistance publishes basic guidelines for preparing a grant. Please click on the following link:

<https://www.cfda.gov/?s=generalinfo&mode=list&tab=list&tabmode=list&static=grants>



- **Dues** Many coalitions require partner organizations to provide a nominal annual dues fee, both to support the operation of the coalition and to put everyone on an even level in terms of basic contributions. Also, many grant applications require a statement that all members financially contribute to the organization.

### Developing a Funding Statement

Going through the exercise of putting down on paper the reasons organizations or individuals should give to your coalition, money is a good first step to starting your fundraising project. It is recommended that you have this statement reviewed by fundraising experts within your partner network – they are a great resource for your ongoing funding process. In developing this statement, you will have a position that you can adjust based upon the requirements of the funding source, but you will have the basic information available in one place. The Funding Statement utilizes the information developed in your planning process and presents it in a logical format so that it is easy to see the benefit of funding your coalition’s activities. A Sample Funding Statement is included in Appendix E.

### Share Your Story

As mentioned previously, develop and share stories of the coalition’s successes and especially of the lives that the coalition’s work impacts – these are powerful tools in funding raising and ongoing promotion of the organizations mission.

### Where to Look

Sources of funding exist in many places. A coalition should not be totally dependent upon any one source of funding. The coalition should utilize its collaborative strength to identify available funds, such as local foundations or business leaders who are or have been caregivers. Keep in mind that there may be some protection of “funder turf” among your partners. Partners whose power position is fortified by a long-standing stream of funding from certain sources or newer partners seeking to establish themselves may both feel a sense of protectiveness over information related to funding or may see a possible conflict between their own plans for funding and that of the coalition. So, be clear on your goals and respectful of these hard-won funding sources – treat them like gold!

### Funding Types You Should be Familiar With

- **In-Kind** Donations of services or products, but not cash (e.g., free advertising, office supplies or equipment, consulting services). These are generally considered “unrestricted” donations.
- **Grants** Funds given by an individual, corporation or foundation in support of a specified project or program of the coalition (e.g., public education campaign, purchase of equipment). These are “restricted” funds because they are designated for specific use.
- **Dues** Funds paid by members of the coalition to support the operation of the partnership.
- **Donations/Gifts** Funds or property that can be converted to cash (e.g., stocks, cars, real estate) contributed to support the work of the coalition. These are most often “unrestricted” contributions, but may be “restricted” if the donor so chooses.

- **Sponsorships** Funds given to underwrite specific events or programs where the sponsor receives public recognition for their contribution (e.g., run-walks, galas, etc.). These are “restricted” contributions.

**EXERCISE:** *Take a few minutes to think about all the sources of money in a given community, which could support a coalition dedicated to helping family caregivers. Make a list of these sources.*

## CONCLUSION

There are many steps to take and considerations to make when people come together with a common purpose to form a coalition. Forming a coalition can seem overwhelming at times and it is not without challenges. This volume is intended to take the mystery out of the process and, instead, to guide you through it so the work that needs to be done is clear and that the process is done with intention, and, most importantly, so that your coalition can build a solid foundation for the important work of supporting family caregivers that is to come.

Once your coalition is established, refer back to this guide for support in maintaining and growing your coalition. Volume 2 focuses on several topics that can help your coalition plan strategically; enhance its activities with regard to advocacy, education and training, research, public awareness, and information and referral; engage in effective decision making; and implement critical evaluation and sustainability measures.

## APPENDIX A: NEEDS ASSESSMENT WORKSHEET

The following worksheet can be helpful in identifying the kinds of information that will be valuable in a needs assessment

### Needs Assessment Worksheet

#### Part 1: Family Caregivers

Information Needed	Possible Sources of Existing Data
How many family caregivers are estimated in the community?	U.S. Census Bureau AmericanFactFinder click:
What cultural groups are represented among the caregivers? What are the percentages?	<a href="http://factfinder2.census.gov/faces/nav/jsf/pages/index.xhtml">http://factfinder2.census.gov/faces/nav/jsf/pages/index.xhtml</a>
What is the estimated number of family caregivers receiving services?	CDC Behavioral Risk Factor Surveillance Survey click:
What is the relationship between the caregiver and recipient? <ul style="list-style-type: none"> <li>• Spouse</li> <li>• Parent</li> <li>• Grandparent/kinship</li> <li>• Individual with development disabilities</li> <li>• Relative</li> </ul>	<a href="http://apps.nccd.cdc.gov/brfssQuest/ResultsV.asp?StartPg=1&amp;EndPg=10&amp;TopicID=44&amp;fromyr=Any&amp;toyr=Any&amp;Text=&amp;Join=AND&amp;SUBMIT 1=+Go+">http://apps.nccd.cdc.gov/brfssQuest/ResultsV.asp?StartPg=1&amp;EndPg=10&amp;TopicID=44&amp;fromyr=Any&amp;toyr=Any&amp;Text=&amp;Join=AND&amp;SUBMIT 1=+Go+</a>
How long on average has the family caregiver been providing care? (months, years)	Administration on Aging click:
What percentage of family caregivers in the community are employed? <ul style="list-style-type: none"> <li>• Full Time</li> <li>• Part Time</li> <li>• Contractual</li> </ul>	<a href="http://www.aoa.gov/AoARoot/Aging_Statistics/index.aspx">http://www.aoa.gov/AoARoot/Aging_Statistics/index.aspx</a>
What percentage of caregivers are providing long distance care?	AGing Integrated Database (AGID) click:
What are the primary conditions or illnesses of the care recipients?	<a href="http://data.aoa.gov/">http://data.aoa.gov/</a>  Individual State Departments of Aging

## Needs Assessment Worksheet

### Part 2: Services

Information Needed	Possible Sources of Existing Data
<p>What organizations in the community are providing care, services and support?</p>	<p>National Family Caregiver Support Program Resource Room click:</p>
<p>What services are being provided?</p> <ul style="list-style-type: none"> <li>• Information and referral</li> <li>• Respite</li> <li>• Caregiver support groups</li> <li>• In-home services</li> <li>• Case management</li> <li>• Counseling/social work</li> <li>• Meals on wheels</li> <li>• Transportation</li> <li>• Financial assistance</li> <li>• Legal advice/assistance</li> <li>• Health services</li> <li>• Other</li> </ul>	<p><a href="http://www.aoa.gov/aoa_programs/hcltc/caregiver/index.aspx#resources">http://www.aoa.gov/aoa_programs/hcltc/caregiver/index.aspx#resources</a></p> <ul style="list-style-type: none"> <li>• AARP</li> <li>• Administration on Aging</li> <li>• Alzheimer’s Association</li> <li>• American Society on Aging (ASA)</li> <li>• Area Agencies on Aging (AAA)</li> <li>• The Eldercare Locator</li> <li>• Caregivers</li> <li>• Chamber of Commerce</li> <li>• Colleges and Universities</li> <li>• Community Organizations</li> <li>• Educational Organizations and Associations</li> <li>• Family Caregiver Alliance</li> <li>• Generations United</li> <li>• Home and Community-based Services</li> <li>• Kinship Care Services</li> <li>• Legal Aid</li> <li>• Legal Counsel for the Elderly</li> <li>• Local Networking Groups</li> <li>• National Alliance for Caregiving</li> <li>• National Association of Area Agencies on Aging</li> <li>• National Council on Aging (NCOA)</li> <li>• Care Action Network (CAN)</li> <li>• National Respite Coalition</li> <li>• Nonprofit Organizations</li> <li>• Respite Programs</li> <li>• Social Services</li> <li>• United Way</li> </ul>
<p>What are the unmet needs identified by the professionals providing care?</p>	
<p>How are services supported financially?</p>	
<p>Where or what is the initial point of contact for services?</p>	
<p>Are urban, suburban and rural areas well served?</p>	
<p>Are all cultural and ethnic groups well served?</p>	

**Needs Assessment Worksheet**

*Part 3: Community*

Information Needed	Possible Sources
<p>Are there other related collaborative efforts/ groups active in the community? If so:</p> <ul style="list-style-type: none"> <li>• What are their missions?</li> <li>• How long have they been in existence?</li> <li>• Do any address caregiving issues? If so, what issues?</li> <li>• How do these groups define the communities they serve?</li> <li>• Would any of these groups consider you a competitor?</li> </ul> <p>Who is participating in the existing collaborative?</p> <p>What challenges/difficulties have these groups faced?</p>	<ul style="list-style-type: none"> <li>• Networking</li> <li>• Professional contacts</li> <li>• Business contacts</li> <li>• Coworkers</li> </ul>

## APPENDIX B: SUGGESTED STAKEHOLDERS

**Family Caregivers** Include those to be served and those who are family caregivers in the categories defined (kinship care, care for older persons). Because of their personal care responsibilities, there may need to be discussion here as to how to invite family caregiver participation. For example, should a family caregiver who has recently completed the journey of caregiving be invited? Are there ways to solicit input from caregivers? What work does the coalition need to do to facilitate the family caregiver's participation (i.e., orientation to terminology, making sure communication is two way, affirming needs identified in assessment)?

**Public/Private** Be sure to invite those from both the private and public sectors of support for family caregivers. Government agencies and service providers from other organizations such as nonprofit organizations or faith-based organizations should be invited.

**Stakeholders** Invite those in the community who are providing services to care recipients or caregivers. This would include health systems, hospitals, physician practices, social service agencies, legal services organizations, Area Agencies on Aging and home health providers.

**Voluntary Health Organizations** Voluntary health organizations such as the Alzheimer's Association, American Cancer Society, American Diabetes Association, MS Society, etc. Each of these organizations most likely has a local presence and may bring strengths in advocacy and supportive services for care recipients and caregivers experiencing different diseases, disabilities or chronic illness.

**Advocacy Organizations and Membership Groups** Look to advocacy organizations for diseases and disabilities, but also include organizations that have caregivers as members for other reasons of affiliation such as senior groups, fraternal groups and chambers of commerce.

**Employers** Statistics show that a large number of caregivers are employed. Inviting employers in the region helps extend awareness and contributes to creative approaches and sharing of resources. Include small, moderate and large-sized employers; include those in different industries or areas of service; include those who may have a business interest in caregiver issues (e.g., financial planners), include those with creative Human Resources policies that are supportive as well as those who do not have such support.

**Faith-Based Organizations and Faith Communities** Invite representatives of denominational leadership, especially social service agencies within faith-based organizations; invite faith leaders from the community as defined and try to identify not just pastoral leadership but also the leadership of outreach or health initiatives.

**Cultural/Diversity** Diversity is an essential category of inclusion. A view of the overall community population helps define the goals for inclusion from different communities, which comprise the overall community defined for the coalition. What cultural groups, geographic or civic communities, etc., exist and need to be included?

**Out of the Box** Think outside of the box. What other groups are in the community? Entertainment, the arts, education, parent groups, health and fitness organizations, etc. should be considered for membership.

**Existing Coalitions** In the needs assessment we mentioned the need to review the history of other collaborative efforts in the community to serve as a barometer of how collaborative can function. Existing coalitions should also be invited to send representatives to the meeting.

**AARP State and Local Organizations** Invite representatives from the AARP state office, AARP chapters and NRTA unit members. AARP's contacts with those 50 years of age and older can help reach out to the care recipients and family caregivers in your community.

**Medicare Regional Offices** Medicare regional offices are involved in the dissemination of helpful information to family caregivers. Inviting representatives from the Medicare regional offices can help identify family caregiver needs and provide a venue for the Medicare offices to disseminate valuable information.

**Administration on Aging Regional Support Centers** For state coalitions, consider extending an invitation to the Administration on Aging regional offices to participate in the coalition. The Administration on Aging is home to the National Family Caregiver Support Program and can provide valuable information to states reviewing and developing effective means of outreach. State and local Department on Aging and AAA offices should also be contacted.

**Political Leaders** Invite political leaders from all levels of local, state and federal government. While specific committee appointments or platforms may not specifically mention caregivers, the invitations should be extended.

**Media** Media in a community, including print, Web, radio and television, should be invited. Partners may have expertise in services or caregiver issues. Media leaders are available in communities as experts in information dissemination.

**Kinship Care Organizations** Invite representatives from any kinship care organizations in your state or community. A growing number of grandparents are raising grandchildren and representatives of these organizations can help identify the needs of this population and help inform content for outreach.

**Women's Groups** Women, according to research, provide the majority of in-home care in our country. Include representatives from women's organizations including advocacy organizations like the League of Women Voters and organizations formed around women's health issues.

**Veterans' Organizations** Veterans are represented in those receiving care at home. The dissemination of information and supportive services via veterans' organizations may be a good idea in your community. Look for Veteran's Affairs health service providers, American Legion, Veterans of Foreign War and other veterans' organizations. Inclusion of representatives from these organizations can also help define care recipient, caregiver and family needs in your community.

**Government** Representatives from state and local government offices that have activities relating to caregiving issues can be valuable partners.

**Universities and Geriatric Education Centers** Gerontology, Social Services, Human Services, Research, and other university departments with an interest in aging and intergenerational issues should be contacted. With their expertise in research, they may be especially helpful in Needs Assessment and evaluation activities.

**State and Local Professional Associations of Educators** School board associations, state teachers associations, state principal associations, school guidance counselors, special educators, etc., can address issues important to grandparents and other relatives raising children.



## APPENDIX C: SAMPLE VISION AND MISSION STATEMENTS

### Sample Vision Statements

- Family caregivers in our state (or community) are able to live balanced lives and have the caregiving supports and services they need.
- Caregivers and care recipients will have the best possible quality of care.
- All Virginia caregivers will be valued, respected, and supported and will have easy access to information, education and services.

### Sample Mission Statements

- To improve the experience of the family caregiver through a one-stop source for information and referral/access to service.
- To promote knowledge of, sensitivity to and action around caregiving issues.
- CCC is dedicated to ensuring that caregivers' concerns are effectively recognized and addressed thru advocacy, education, and empowerment.
- The Virginia Caregiver Coalition will passionately work to improve the experience of caregiving through education, advocacy and access to resources.

## APPENDIX D: SAMPLE GOALS/ACTION PLAN

### Goal

To provide information to family caregivers about services available at the state level.

### Objective(s)

- Develop State Information Guide for Family Caregivers

### Action(s)

- Develop criteria for information to be included in guide
- Develop tool to be used for inventory of services for caregivers
- Develop list of contacts/agencies to solicit for information
- Complete inventory of information and services helpful to family caregivers
- Contact state organizations that did not respond
- Draft information guide
- Send draft listings out for review and proof edit
- Identify method(s) of distributing guide
- Compile and make changes
- Print and disseminate

### Responsibility

- State Department on Aging
- AARP State Office
- State Senior Volunteer Corp Office
- Media

### Timeline

- |  |                       |
|--|-----------------------|
| • Criteria, tool, list                 | End of first quarter  |
| • Inventory and follow up              | End of second quarter |
| • Method of dissemination, draft, edit | End of third quarter  |
| • Print and disseminate                | End of fourth quarter |

### Resources

- State and philanthropic funds
- Volunteer hours
- In-kind contributions of partners

### Communication

- Monthly update to state coalition
- Update to state agencies contributing information

## APPENDIX E: DEVELOPING YOUR FUNDING STATEMENT

In order to sell your coalition to potential funders, you will need to present information on who you are, the need for your coalition, the benefits of your coalition and the benefits of financially supporting your coalition, whether through sponsorship, grants or government allocations.

An effective coalition is achieved through the engagement of the stakeholders including opinion leaders, policy makers, organizations, formal and informal caregivers, and community members. You will need to sell your coalition to both gain momentum to develop the coalition and to sustain it. Some sample statements on the mission, need, goals and benefits of coalitions have been provided to assist in positioning your coalition for potential funders.

### **Mission**

Our coalition consists of 22 organizations representing the nonprofit, private and government sectors. Our mission is to improve the experience of the family caregiver through a one-stop source for information and referral/access service.

### **Need**

The family caregiver is the primary source of support for those individuals needing assistance or care in our communities. While the informal family caregiver may be providing the largest amount of assistance as a group serving those in need, family caregivers are unorganized, vulnerable to changes in the health care industry and receiving less support as increasing numbers of individuals are needing care.

With the growing numbers of people who need support to live on their own and children being raised by others, private and public organizations are now offering many different options in the home and community. Public and private agencies offer a range of programs and services with no one agency able to meet all the needs of a caregiver. Social service organizations and public agencies generally have little interaction with each other, even if they are trying to serve the same consumers.

Our coalition recognizes the value of the family caregivers and their need for support, and the need for relevant research to assist decision makers on policy and best practices. Our coalition wants to strengthen the areas of availability, quality, standards and accountability.

### **Goals**

Our coalition has four primary goals (your coalition may have more or less and should reflect your mission); Service Provision, Advocacy, Outreach and Awareness.

### **Service Provision**

Our coalition serves to promote greater cooperation among all agencies delivering services to a community. Just as the family caregiver cannot be the sole provider, one agency cannot be the single solution. Our coalition links resources and agencies to expand capacity for service delivery in our state.

### **Advocacy**

We serve as a voice for the family caregiver, advocating for changes in public policy and legislation. Our coalition proactively creates and introduces research, policies and best practices for decision makers. Our members serve as consultants to state and community leaders, promoting relevant research on caregivers and new innovations in service delivery.

### **Outreach**

Our coalition markets information to community providers and family caregivers to increase accessibility and visibility of available services. A single service delivery organization does not have the incentive, scope or resources to provide the full spectrum of support services available in a community to the family caregiver.

### **Awareness**

Our coalition generates visibility for caregiving issues, addressing the problem of self-identification among family caregivers and the overall lack of understanding in the public at large. Given the progressive demands of caregiving, many family caregivers do not recognize themselves as serving in a caregiving role. Our coalition raises awareness on caregiving issues, promoting resources available to caregivers and targeting information to employers and community members who have interaction with the family caregiver.

### **Benefits of a Coalition**

The current service delivery system is fragmented and vulnerable to the constant changes in the health care system. One organization's efforts cannot effectively address the challenges of the family caregiver alone. Through our coalition, we can significantly raise the visibility of caregiver issues, mobilize resources and advocate for funding and expansion of services. Benefits would include identifying a single point of entry and enhancing and enforcing quality of care.

### **Benefits for the Family Caregiver**

Direct benefits for the family caregiver include improved support services, access to information and referral services, advocacy for state and federal legislation and development of support groups. The family caregivers will be removed from isolation and recognized as a unified group to better position themselves for improved and additional support services.

### **Benefits to the Funder**

By becoming a financial supporter of our coalition, you are becoming a partner in our efforts to improve the well-being of family caregivers in our state. We serve as a catalyst to improve services provided to caregivers, and we rely on the generosity and commitment of leaders in our state to support these ongoing efforts.

As a state coalition, we are in a position to leverage our resources to have a larger impact on state policy and legislation, impacting the quality of service delivery at the local level. Every dollar of your donation has a wider reaching effect by contributing to research, developing best practices and solidifying a fragmented network to support the family caregiver.

As a donor, you will be recognized in our publications, special events and media opportunities. You will have access to additional information sharing with our member organizations and receive quarterly updates on the progress toward our goals. Your donation is tax deductible to the fullest extent of the law.







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