

Building A

Statewide Respite Coalition:

Where Do We Begin?

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The mission of the **ARCH National Respite Network** is to assist and promote the development of quality respite and crisis care programs; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.

The ARCH National Respite Network consists of two divisions. The **ARCH National Respite Resource Center**, the training and technical assistance division, previously provided staff support to service providers and families through consultation, training, evaluation, and research. In recent years, most services and information dissemination have been web-based.

The policy division, the **National Respite Coalition**, works on the State and federal policy level to secure quality, accessible, planned and crisis respite services for all families and caregivers in need of such services in order to strengthen and stabilize families, and enhance child and adult safety. With passage of the Lifespan Respite Care Act in 2006, the National Respite Coalition has been working closely with states by collaborating with State Respite Coalitions to hold State Lifespan Respite Summits. The purpose of the Summits is to educate the public, as well as state and local policymakers and programmers, about the Lifespan Respite Law, Model State Lifespan Respite programs, and strategies for implementation, including the important role of state respite coalitions mandated by the law.

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INTRODUCTION

From a historical perspective, respite is a relatively new service. Although there were a few respite programs in the 1960s, it wasn't until the 1980s that respite programs began to flourish. However, there is still a serious shortage of respite programs and providers nationwide, as well as insufficient funding and resources to serve all in need. In addition, fragmented funding streams, restrictive eligibility criteria, and lack of awareness and knowledge about how to access respite pose additional obstacles. A desire to overcome these barriers, coupled with the knowledge that strength is inherent in coalitions, lead to the growth of respite coalitions across the United States.

The first state respite coalitions were formed in the 1980s. By the mid-1990s coalitions began emerging in other states, creating opportunities for communication, coordination, and collaboration among the many players invested in respite. These groups go by various formal names: coalitions, associations, networks, councils, or task forces. Each statewide organization determines the type of coalition that will best forward its goals. Some groups have a single statewide structure, while others have regional systems that feed into a statewide structure. Their activities vary and may include state respite awareness days, conferences and training events, public policy activities, information and referral services, service coordination, voucher administration and networking.

While these groups have different forms and names, they share a common goal: to promote and improve respite and crisis care services within their state. Within every group, members provide a support system for each other and assist in making the most of opportunities and solving problems that are too big for one person or agency to manage. This guide is intended to assist states or groups that are considering forming coalitions by providing the tools necessary to begin building a respite coalition.

This guide was written to assist in coalition building activities. Although the focus is on respite coalitions in particular, the material can be used for building any coalition. It can be used as a general reference or as a workbook for team members as they progress through coalition development.

UPDATE

In 1997, Oregon passed the first state legislation authorizing a State Lifespan Respite Program – a coordinated system of community-based respite services serving individuals of all ages and special needs. Based on Oregon's success, state respite coalitions in Nebraska, Oklahoma, Wisconsin and Arizona followed suit, organizing and strengthening their base to help establish similar programs. All of these programs then joined forces with national organizations in 2000 to help form the Lifespan Respite Task Force, which led to the introduction of the federal Lifespan Respite Care Act. Through this grassroots effort, the legislation was enacted in 2006 and initial funding secured in FY 2009. The law mandates that state respite coalitions work in collaboration with the State's Aging and Disability Resource Center to design and implement a Lifespan Respite Program. The passage of the first state law in Oregon in 1997 gave other state coalitions a goal and a valuable organizing tool. The new 2006 federal law not only helped further invigorate existing state respite coalitions, it helped motivate additional states to establish coalitions. It is with this goal in mind that this guidebook was updated and with it the hope of establishing new State Respite Coalitions that can help make respite services across the lifespan available in every state.

COALITIONS — WHAT ARE THEY?

Coalitions are exciting, dynamic groups that evolve when individuals or organizations discover a common purpose and recognize that they can be more successful working together than alone. Through commitment, willingness to compromise, and careful planning, coalitions are capable of effecting great change within their member organizations and within their communities (HHS 1997). *Strengthening Homeless Families: A Coalition-Building Guide* (HSS 1997) describes three major types of coalitions. You should consider which of the following descriptions best portrays the kind of coalition you want to establish in your state.

GRASSROOTS

Some coalitions are organized by volunteers during a crisis to pressure policymakers to act. Although sometimes controversial in nature, grassroots coalitions can be very effective in achieving their goals, but they often disband or fade away when the crisis is resolved. This kind of coalition frequently arises in states when a major source of government funding for respite has been cut and respite consumers and providers unite to advocate for continued funding. When the goal is achieved, some of these groups may discontinue their efforts and disband. However, others coalesce, broadening their mission and establishing lasting coalitions.

PROFESSIONAL

Some coalitions are alliances formed by professional organizations, either in response to a crisis or as a long-term approach to increasing the members' collective power and influence.

COMMUNITY-BASED

Some coalitions include professionals, consumers, and grassroots leaders from a wide variety of community organizations who find common ground around a particular issue, such as respite, health care, or long term care.

WHAT SORT OF COALITION DO YOU ENVISION?

COALITION — WHAT'S IN IT FOR YOU?

Successful coalitions carry with them numerous benefits, both for consumers and their member organizations as well as for the coalition itself. As outlined in *Building and Maintaining Coalitions* (AARP Foundation 2001) and the *12 Keys to Building Caregiver Coalitions* (AARP Foundation, 2003), the benefits include—

FOR CONSUMERS:

- Availability of new and improved services delivered to more individuals
- Enhanced access to information and referral services
- Ability to participate in improving the quality of services
- Power to take action on their own behalf
- Support networks or groups

FOR ORGANIZATIONS:

- Promotion and growth of their programs
- Increased community awareness of programs and issues
- Increased revenue and saved resources through coalition efforts
- Development of new partnerships and increased service capacity through shared resources
- Improved cooperative service delivery
- Increased staff skills through cross-training and joint training

FOR THE COALITION

- Development of tools and services with pooled resources
- Effective strategic planning
- Enhanced influence in the advocacy and legislative process.
- Maximization of limited resources through shared information
- Improved communication and understanding among partner organizations
- Enhanced respect for the common mission
- An ongoing vehicle for education

According to Cohen et al. (1998, 2001) in versions of *Effective Coalitions*, successful coalitions are distinguishable by successful hallmarks. Coalitions:

- **Accomplish through collaboration** what single individuals or organizations cannot accomplish. By serving as an information clearinghouse that gathers and disseminates pertinent information to its members, a coalition creates a forum for discussion; develops a base for planning, education and advocacy; and maximizes use of facilities, staff and financial resources.
- **Prevent duplication of efforts**, filling gaps in service. When agencies become aware of each other's services and their consumer populations, they can collaborate in meeting unmet needs and avoid duplicating existing services.
- **Influence through advocacy**. With a sound communication system and strong leadership, a coalition can provide a unified voice in response to a specific situation or a general issue, advocating for more resources or for policy and legislative change.
- **Provide more opportunity for resource development**. Coalitions can pursue funding

opportunities either for projects of the entire coalition, for subsets of coalition members, or for individual member organizations, using resource planning and coordination to increase funding for all.

- **Create more public awareness.** By sharing resources and working together, coalition members can create and launch very effective public awareness campaigns.
- **Provide a more systematic, comprehensive approach to problems.** Through effective planning, a coalition can identify and delineate issues to be addressed, desired outcomes, methods to be used, activities and tasks required, implementation timelines, assessment procedures, available resources, and evaluation design.
- **Empower families** to work more effectively for themselves and to increase their knowledge. These tools will have a lasting effect on those families who are involved and will impact all family members, as well as other families who become involved in the process.
- **Generate new funding.** As a coalition grows, state officials, legislators, and policy makers will become more interested in its work, and stakeholder agencies may be more willing to channel funds directly to the coalition.
- **Have greater credibility than individual organizations.** The broader purpose and breadth of coalitions give them more credibility than individual organizations. In addition, coalitions reduce suspicion of self-interest
- **Provide a forum** for sharing information.
- **Provide a range of advice** and perspectives to the lead agency.
- **Foster personal satisfaction** and help members to understand their jobs in a broader perspective.
- **Foster cooperation** between grassroots organizations, community members, and/or diverse sectors of a large organization.
- **Build trust and consensus** between people and organizations that have similar responsibilities and concerns within a community.

FORESEEING OBSTACLES AND TIPS FOR SUCCESS

(Adapted from US DHHS, Strengthening Homeless Families, 1997 and Cohen, et al, 2002)

- **Seek Common Goals and Sense of Purpose.** Coalitions should continuously ask themselves “Who are we?” and “What do we want to accomplish?”
- **Utilize Joint Decision Making.** While coalition members may disagree on issues of power, territory consensus, programs, funding, and so on, representatives from all participating organizations should be involved in decisions on these and all other important issues.
- **Share Power and Responsibility.** A coalition is the antithesis of a bureaucracy, which operates on hierarchical principles. In a coalition, power and responsibility must be shared equally.
- **Trust and Use Open Communication.** Trust, along with vision, keeps the group together to get the job done. This will only occur if problems and conflicts are addressed with open communication.
- **Recognize and Deal with Turf Struggles.** It is not always possible to avoid turf struggles. However, a coalition should try not to exacerbate these areas of overlap and competition. At times, a coalition can be a constructive meeting place for openly discussing problem areas, establishing ground rules, and resolving turf issues. Formal and informal opportunities to understand the

differences in agency history, mandates, and funding issues may soften turf struggles.

- **Maintain Personal Integrity and Flexibility.** Individual members should stick to their principles but avoid getting locked into position based on their own personal interests.
- **Incorporate Self-Evaluation.** Once a goal is reached, the group needs to set new goals and move on.
- **Teamwork.** Responsibilities within the coalition should be shared among members. This helps build commitment and a sense of accomplishment.
- **Recruitment and Orientation.** New members should be recruited based on commonality of goals and needs, and, once on board, oriented to the coalition's purpose, goals, and procedures.
- **Watch Coalition Size.** A group larger than 12-18 people requires more resources and will sometimes take longer to develop group identity and common purpose. If you start small, it may lead to broadening the coalition at a later and more appropriate time.
- **Choose Activities Well.** Select activities that members will experience as successful—activities in which they have something unique to contribute. Make objectives compelling. Be sensitive to the fact that coalition work is not the main job of coalition members and keep assignments simple and achievable. Keep reminding people that it is okay to say no or to set limits.
- **Division of Labor.** Estimate how much of the footwork will be the responsibility of the lead agency and how much too realistically expect of members. Anticipate that members will not always fulfill their commitments. Be appreciative of what is done, rather than “moralistic” when people cannot accomplish everything they planned.
- **Maintain Vitality.** A group attempting to coordinate services or embark on a joint advocacy effort should expect more pitfalls than a group formed solely for the purpose of information sharing, as the former tasks are more complex and demand more commitment.

DEVELOPING A COALITION

There are a number of initial steps that need to be taken to develop a successful coalition.

PLANNING AHEAD

Planning is essential in every step of building a coalition. Before you even begin, it is a good idea to have a picture of what the actual or estimated respite needs might be across geographic areas of the state. Conveners should collect information that might be readily available from other sources such as the Family Navigator website hosted by the Family Caregiver Alliance (www.caregiver.org) and the National Respite Locator Service (www.respite locator.org). State-by-state information on the number of family caregivers and the economic value of their caregiving is also available (Gibson and Hauser, 2008). It is also important to find out if and when a needs assessment has been conducted in your state on the respite needs of family caregivers or if respite issues were included in a larger assessment of community needs. Even if the information is dated, it provides a starting point. Updating this information as a group will help define the reasons that organizations and individuals have come together and can be shared with organizations you later invite to join the coalition (AARP Foundation 2003).

HAS A FORMAL OR INFORMAL NEEDS ASSESSMENT BEEN CONDUCTED? WHAT WERE THE RESULTS?

RECORD A FEW OF THE KEY FINDINGS OF THE NEEDS ASSESSMENT THAT SUPPORT YOUR PLAN TO DEVELOP A COALITION

DEFINE THE MISSION

Begin with a vision. This is your dream, your ideal, and a description of what the coalition will be when your mission is accomplished.

The mission is a statement about the distinctive purpose for the coalition's existence. It succinctly identifies what the organization does (or should do), and for whom. It is developed from the needs of the stakeholders and customers who have a vested interest in the success and survival of the coalition. Think of who, what, where, when and why. You need to have a clear idea about who you want involved, what you want the coalition to offer, where you want your coalition to go, when you want things accomplished, and why the coalition is the solution. Your mission can always be altered, and should be reviewed every year.

Hand-in-hand with the coalition's mission and vision are its values. These are the guiding principles and beliefs that clarify ways in which coalition members conduct their activities as they seek to accomplish their mission. These values should be compatible with the values that you bring to your work and your life. They should be operational so that each member of the coalition can actually see them working as coalition members connect and interact with each other.

While you all may have come together with the express purpose of securing federal Lifespan respite funding or enacting state Lifespan legislation, when drafting your vision and mission statements, try to keep in mind the bigger picture – “the dream of high quality respite for every family.” For example,

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here is the VISION STATEMENT for the LIFESPAN RESPITE TASK FORCE, the group of 40 national organizations which first came together to draft the federal “Lifespan Respite Care Act:”

WE ENVISION AN AMERICA WHERE RESPITE IS READILY AVAILABLE AND EASILY ACCESSIBLE TO ALL CAREGIVERS.

The Task Force quickly grew to over 80 national organizations and 100 state and local groups. The following goals of the Task Force helped guide our strategy toward enactment of federal Lifespan Respite legislation and will continue to guide our efforts to implement lifespan respite nationwide:

- Universal availability of respite for all who seek it;
- Widespread acceptance that it is all right to ask for and receive help;
- Heightened awareness of caregiver needs;
- Easy access to an array of affordable respite services;
- Flexibility to meet diverse needs; and,
- Systems that meet the comprehensive needs of caregivers to locate, train, and pay for respite.

Write down your ideas about the VISION, MISSION, and VALUES of your coalition. You may want to refer to these notes as your coalition forms and begins to make strategic plans.

VISION: What vision do you have for the coalition? To help you think about developing a STATEMENT OF VISION, we have provided the following sample that is based on the VISION STATEMENTS which other respite coalitions have shared with ARCH. Do not feel limited by its content or length; some coalitions have more detailed statements and others are far briefer and more global in nature.

ALL CAREGIVERS IN OUR REGION WILL BE ABLE TO ACCESS CULTURALLY APPROPRIATE, HIGH QUALITY, AFFORDABLE RESPITE THAT WILL BE DELIVERED ACCORDING TO THE CAREGIVERS’ AND THEIR FAMILIES’ NEEDS, TIME LINES, AND SPECIAL CIRCUMSTANCES.

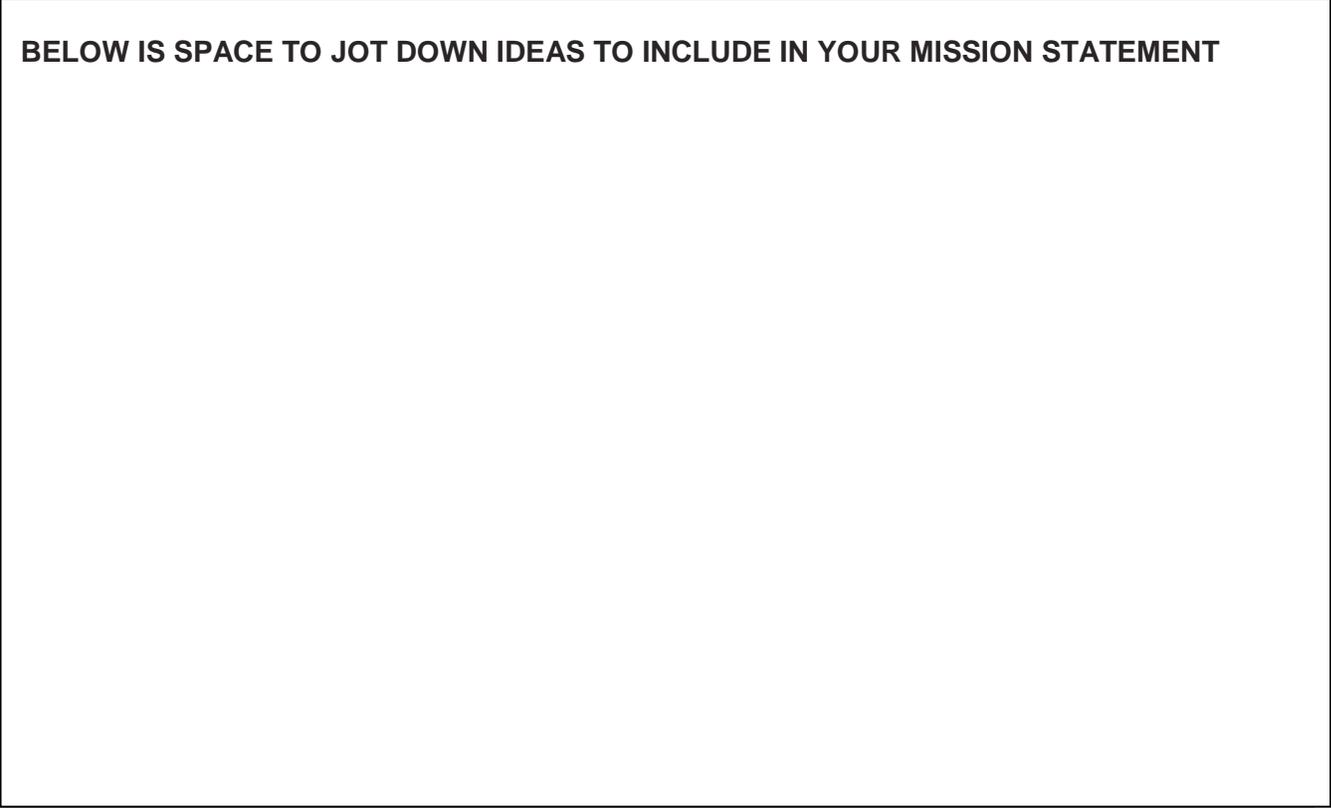
YOUR VISION STATEMENT

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MISSION: Take a moment to jot down some of ideas about the mission of your coalition. It may help to see a sample MISSION STATEMENT. The following statement combines ideas and language from mission statements that some coalitions have shared with ARCH:

THE MISSION OF XXX'S PLANNED AND EMERGENCY RESPITE COALITION IS TO SUPPORT AND PROMOTE THE DEVELOPMENT OF A COMPREHENSIVE, STATEWIDE RESPITE SYSTEM THAT IS RESPONSIVE TO THE NEEDS OF CAREGIVERS AND THEIR FAMILIES, AND ENHANCES THE QUALITY OF LIFE FOR INDIVIDUALS OF ALL AGES, INCLUDING THOSE WITH SPECIAL NEEDS.

BELOW IS SPACE TO JOT DOWN IDEAS TO INCLUDE IN YOUR MISSION STATEMENT



VALUES: It is critical that members of a coalition share a common set of values related to their working relationships and the operation of the coalition. A sample of a STATEMENT OF VALUES is provided below. It combines some ideas and language from value statements that other coalitions have shared with ARCH. As you review the sample, keep in mind that your statements can be as long or short as your coalition chooses. It can be in narrative form, or bulleted as in the sample below:

- ***WE WILL CONSIDER ALL SUGGESTIONS FROM COALITION MEMBERS AND WILL MAKE DECISIONS BASED ON CONSENSUS.***
- ***WE WILL OFFER ALL MEMBERS OF THE COALITION THE OPPORTUNITY TO PARTICIPATE IN COALITION DECISION MAKING.***
- ***WE WILL PROMOTE RESPITE THAT IS RESPECTFUL OF THE DIVERSE ETHNIC BACKGROUNDS OF FAMILIES IT SERVES.***

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- ***BECAUSE FAMILIES AND CAREGIVERS HAVE DIFFERENT NEEDS AT DIFFERENT TIMES, WE WILL ENCOURAGE AND SUPPORT THE DEVELOPMENT OF BOTH PLANNED AND EMERGENCY RESPITE PROGRAMS THAT ARE INCLUSIVE ACROSS THE LIFESPAN.***
- ***WE WILL SUPPORT AND ENCOURAGE RESPITE PROGRAMS THAT OFFER CONSUMER DRIVEN AND INDIVIDUALLY CHOSEN SERVICES***

WRITE DOWN THE VALUES YOU BELIEVE SHOULD DRIVE THE OPERATIONS OF YOUR COALITION

GOALS AND ACTION STEPS

In planning the coalition, it is critical that a clear, well-defined set of activities is articulated. Those activities should be conducted as means to very specific ends—your coalition goals. Goals are general ends toward which a coalition directs its efforts. One goal might be to expand public awareness about the benefits of a Lifespan Respite system in your state. Once goals are established, action steps can be identified so that the goals may be achieved.

CRITERIA FOR GOAL DEVELOPMENT

Goals should be in harmony with your vision, mission, and value statements. They should provide clear direction for action. The total number of goals should be kept to a minimum reflecting the importance

of prioritization. Goals should correspond to identified needs that your coalition is addressing (a section on articulating the need for your coalition begins on page 13). Initially, most coalitions set no more than three to five goals.

ACTION STEPS

Action Steps describe the methodology required to realize the goals. Action steps should include a time line and note the person responsible for completing each step. Try to develop an action step that is easily achievable and can show early success to keep coalition members engaged. An example of a goal and its action steps is offered below:

GOAL: DEVELOP A PUBLIC AWARENESS PLAN FOR RESPITE SERVICES AND THEIR BENEFITS TO THE COMMUNITY.

ACTION STEPS:

- 1. IDENTIFY VOLUNTEERS FOR THE “RESPITE AWARENESS” COMMITTEE**
- 2. HOLD AN INITIAL MEETING BEFORE THE NEXT COALITION MEETING**
- 3. DEVELOP A PLAN WITH ACTIVITIES, TIMELINES, BUDGET AND PERSONNEL REQUIRED FOR CARRYING OUT THE PLAN**
- 4. PRESENT THE PLAN AT THE NEXT COALITION MEETING FOR DISCUSSION, REVISIONS (IF ANY), AND A VOTE**

Note that the goal and its related action steps can be achieved in a relatively short period of time. Once the goal is achieved, other goals will be set by the committee based on the public awareness plan that is approved by the coalition.

What goals and corresponding action steps can you identify for your coalition? Brainstorm as many as possible. Later, you can prioritize the goals and select the most critical ones for your coalition to tackle.

GOAL:

ACTION STEPS:

GOAL:

ACTION STEPS:

GOAL:

ACTION STEPS:

GOAL:

ACTION STEPS:

DOCUMENT THE NEED

Once you have defined your mission, goals, and action steps, you will want to carefully lay out the reasons the coalition is being formed. Use this information to recruit potential members and, later, to form the basis of appeals to donors.

Using the baseline information you compiled in the planning stages, determine strategies for building on that data. Hold focus groups, investigate state agency websites, or survey state agencies directly to compile readily available demographic information about the state, including the number of family caregivers, the number of adults and children with disabilities and various chronic conditions, existing respite services and other data. Write a fact sheet explaining the need for respite in your state, citing statistics and any other useful information. This document should clearly state the reasons the coalition is needed, such as a growing need for respite, inadequate funding, short supply of quality providers, the need for central information and referral, and so on. All of this should be documented with references and resources. The fact sheet should also clearly state the benefits of joining the coalition. These may include increased publicity about respite in general, which will benefit member programs; potentially more funding for respite and for training and recruiting respite providers; and the coordination of respite services.

Create a chart depicting the possible future structure of the coalition and the initial time frame for the development of the coalition.

Compose a letter explaining the evolution of the coalition and inviting potential members to a meeting to learn more. The letter should contain a clear time frame for immediate future activities, for example, “You will receive a follow-up call from one of our members prior to the meeting to answer your questions and verify attendance.” You may also want to say, “After the meeting, you will receive minutes from the meeting and another follow-up call to discuss your current thoughts about the development of the coalition, and review the benefits of the respite coalition to your organization.” The letter should be signed by all organizing members.

INCLUDE EVERYONE

The coalition must strive to represent everyone in the state who has an investment in respite and crisis care issues. The coalition should encourage participation from family members, providers, public and private agency representatives, and legislators. Members should represent various regions of the state, be culturally diverse, and interested in respite from a variety of perspectives. If certain groups are not represented regularly at coalition meetings, special effort should be made to keep them informed of coalition decisions and activities. Many state coalitions recently have expanded their respite initiative to include caregivers and family members who need respite across the lifespan and organizations that provide those services.

Depending on whether a coalition plans to serve a particular group of persons with special needs or disabilities or wants to include those interested in lifespan respite, a list of potential members should include:

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- **Family caregivers.** Make sure at least two or three family caregivers (parents, adult children, spouses, other relatives or legal guardians) are included in your coalition. The caregivers should be able to look at respite from a broad perspective, not just from their own need, and be good advocates as well.
- **Respite providers.** Be as inclusive as possible. Collaboration makes for a strong coalition. If the coalition is “lifespan” in nature, be sure to include providers of respite for older Americans as well as those who provide care to individuals with developmental disabilities, physical disabilities, behavioral challenges, mental illness, and so on.
- **Local and state officials.** Invite local, regional, and state officials involved with health and human services, such as representatives of departments of child health and welfare, mental health, disabilities, social services, health care and public health, aging, veterans, and Medicaid waiver representatives. Make sure to invite someone representing Aging and Disability Resource Centers since they are obligated under the Lifespan Respite Care Act to participate in program implementation.
- **Community organizations.** Some faith-based organizations, hospitals, residential care facilities, Head Start programs, kinship care programs, nursing homes, adult day care, home health agencies, area agencies on aging, senior centers and assisted living facilities may provide or support respite.
- **Nongovernmental State Organizations.** State chapters or affiliates of organizations like United Cerebral Palsy; Easter Seals; AARP; ALS; Multiple Sclerosis Society; The Arc; Parkinson’s Association; AARP; Alzheimer’s Association; Mental Health Association; National Alliance for Mental Illness all know the need for respite. Most of these have affiliations with their national organizations which are active in the Lifespan Respite Task Force, a national coalition of state and national groups advocating for Lifespan Respite.
- **Other local funders.** Local foundations and the United Way should be included.
- **Educational organizations.** University departments of social work, child development, gerontology; university centers on disabilities; and others with a common interest in respite can be crucial to your coalition.

WHO ARE THE STAKEHOLDERS, COMMUNITY LEADERS, CONSUMERS, PROVIDERS, AND POLICY MAKERS WHO SHOULD BE INCLUDED IN THE DEVELOPMENT OF YOUR COALITION? LIST AS MANY POTENTIAL RECRUITS AS YOU CAN IDENTIFY.

This list should be as detailed as possible, with the name, address, and phone number of each potential recruit. Also list the name of the person responsible for contacting each individual and the time frames for doing so.

RECRUIT AND TRAIN MEMBERS

Once you have developed a list of whom to recruit, the next step is to convince them of the importance of forming a respite coalition. Your potential recruits will want to know:

- Why the coalition is needed
- That the coalition is not duplicating efforts
- How the coalition will help make their task easier and help them meet their goals
- How the coalition will help them serve their population better

Once members have been recruited, the work is not done. New members should receive adequate orientation and training, which clarifies expectations and time commitments. Ongoing orientation and training is also necessary.

STRUCTURING THE COALITION

Coalitions benefit from structure early on in the development process. Each existing coalition has its own structure and you will need to determine how your coalition will be set up, organized, and managed. Coalition members must resolve many details, including the infrastructure, staffing, annual meetings, board of directors, officers, and nonprofit status. Funding—or the lack of it—will have a significant impact on many of these decisions. In the beginning, if funding is not yet available, give focus to the fledgling coalition by developing a written plan. Coalition structures vary from state to state, but three general structures have been identified among our own network of organized state respite coalitions. For a list of state respite coalition contacts and state point of contact, see <http://chtop.org/ARCH/State-Respite-Coalitions.html>.

1. **Formalized coalitions with mission and goals.** Some have a form of outside financial support to jump start their coalition. Other coalitions are supported through in-kind contributions from members and supportive organizations. These groups usually meet bimonthly or quarterly.
2. **Coalitions which have expanded their structure to include a strategic or business plan** and have considered the possibilities of hiring a director and becoming a private, not-for-profit organization, a step that would enhance the coalition's ability to leverage additional dollars.
3. **Coalitions which are not-for-profit organizations** are incorporated; and have by-laws, officers, Boards of Directors, and/or committee structures.

Many coalitions, however, form loose organizations at first, with assistance from state and provider personnel willing to take the lead until a more formal structure is put in place. For more information on 17 state respite coalitions affiliated with ARCH, see *State Respite Coalitions, A Compendium of Fact Sheets, 2008-09*. Each fact sheet contains information on coalition history, structure, membership, staffing, major activities, a list of available documents (e.g. bylaws, brochures, procedures, etc.), and

contact information.

CHARTER MEMBERS

Charter members are those individuals who form the core group interested in developing a coalition and who ultimately extend invitations to include more stakeholders. The charter members of the organization will be responsible for developing an initial plan for handling the day-to-day affairs of the organization prior to the development of a more comprehensive long-range strategic plan. To begin, it is imperative that one individual be designated as the lead person to take responsibility for the coalition until a more permanent arrangement can be put into place. As part of the initial plan, steps should be taken to insure the success of the coalition by making decisions about the long-term arrangements for the coalition. This initial plan should include provisions to recruit leadership, encourage shared leadership, and develop a mentoring system as a way to ensure the success of the coalition if the leadership should change for any reason.

It is during this initial planning phase that the charter members should address the coalition's vision, mission, and values. These will be refined later during the strategic planning process. Additionally, officers should be established and by-laws written. Members should discuss what they think the coalition's ultimate structure should be. By starting this discussion early on, members will be able to foresee the pros and cons of their decisions. For example, if the organization plans to remain totally volunteer run, the budget will be smaller. Depending on the mission and goals of the organization, more permanent employees who can fully put their energy into meeting the coalition's goals may be required to be effective and successful. Although planning the structure of a coalition is an activity to be determined by the coalition, you may want to record your thoughts in preparation for those discussions.

JOT DOWN YOUR IDEAS ABOUT THE COALITION'S STRUCTURE

FUNDING THE COALITION

The Initial Budget

Some coalitions may choose to develop an initial funding plan, also known as a preliminary budget, to plan for future costs of coalition activities. The budget should be realistic, and, if moving toward not-for-profit status is a goal for the coalition, the budget should plan for that as soon as possible. The plan should outline possible funding sources, list who is responsible for exploring each source, and set a time frame for reporting to the charter members on possible resources. In-kind services should be given a value, if at all possible. A minimum budget would include the following expenses:

- Personnel
- Payroll taxes
- Legal Services
- Travel
- Office Rent and other office related expenses
 - Printing and Copying
 - Telephone
 - Equipment
 - Postage/Mailings

Coalitions have found financial resources in a variety of ways and at different stages in their developmental process. Wisconsin received start-up funds through state respite legislation thanks to many coalition members, who were active in the legislative process that led to obtaining those funds. However, the majority of coalitions simply formed through the sincere interest of respite advocates, with no financial assistance. At some point, members decided it was time to formalize their structure and developed a budget. They then approached their state agencies or advisory boards (or both) that had demonstrated their commitment to the coalition by volunteering their time or resources, and received funding. The North Carolina Coalition is housed and partially funded by the state's Easter Seals/UCP organization. Other coalitions sought funding from a state agency or organization interested in funding respite projects for a particular population, such as the aging (the State Department on Aging) or those with developmental disabilities (the Developmental Disabilities Council).

Nine of the organized state respite coalitions have full or part-time paid staff. Only five coalitions reported that they collected membership fees. Possible benefits for members include reduced rates for products, conferences and training, newsletters, access to information for members only, and so on.

Alternative Funding Sources

In the event adequate start-up funding is not secured, the coalition needs to consider a number of alternatives.

Fee for service: Is there any service or product that your coalition can provide for a fee? These might include access to a statewide data base of respite providers, educational videos, fact sheets, conferences, respite training manuals, training programs, or service delivery guides.

Fundraising: This can be an intensive way to raise money to start a coalition. Make sure to determine in advance whether the effort, time, and resources that will have to go into the fund-raising

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event or product will produce a large enough benefit to the coalition. A budget must be developed for each fundraising activity. Then, it must be determined if the revenue generated actually is large enough to warrant the expenses, including the in-kind contribution of volunteer time. Time might be better spent on seeking funding for coalition staff. Annual events can be more beneficial to the coalition once the coalition is recognized and established in the state. Member organizations should consider sharing resources and undertaking joint fund-raising efforts.

Grant writing: This can be a time-consuming effort, but with thorough research it can be beneficial. Organizations and businesses that offer grants typically follow a defined process for awarding grants. Find organizations that solicit grants; scrutinize the ones who fund similar organizations; become familiar with their process and application requirements; and develop your proposal. Seek help with grant writing from experienced grant writers in your coalition, or search out organizations that help train individuals in grant writing in your state. The University of Delaware Center for Disabilities Studies (CDS), through a contract with Delaware's Governor's Commission on Community-Based Alternatives for Individuals with Disabilities, coordinated the Delaware Caregivers Support Coalition (DCSC), which includes family members, service providers, and advocates. The Coalition developed a plan for a *Delaware Lifespan Respite Information Network*, a statewide system to provide respite across the lifespan from birth through aging and across all disability classifications and successfully obtained a three-year grant from the Dupont Foundation to implement the plan.

Federal Funding: Occasionally, federal funding may be available to help start or support a state respite coalition. Tennessee initially received federal Maternal and Child Health funds to start their coalition. The Lifespan Respite Program or other federal initiatives may also support the work of the state respite coalition if it is directly linked to the purpose of the program or agency announcement. For information on potential federal funding, check the ARCH issue brief, *Building Blocks for Lifespan Respite: Guide to Federal Funding Sources* and periodically check the federal website www.grants.gov.

WHAT PUBLIC, PRIVATE, OR FAITH-BASED ORGANIZATIONS MIGHT BE ABLE TO ASSIST WITH START-UP COSTS OR OPERATING EXPENSES, AS WELL AS DONATIONS OF OFFICE SPACE, STAMPS, PAPER AND OTHER ITEMS THAT MIGHT BE USED BY THE COALITION?

Non-Profit status: Many coalitions seek not-for-profit status. Note that forming a *non-profit* corporation (state level) does not automatically mean the organization is 501(c) (3) for Federal tax purposes. Organizations with gross receipts of \$5,000 or more must apply to the Internal Revenue Service for recognition of tax-exempt status. There are a number of reasons an organization may want to do this. Many grant-making organizations will only fund tax-exempt nonprofit organizations. Some groups may wish to attract private donations, which are tax deductible to the donor if the organization is a legitimate tax-exempt nonprofit. Other groups may seek 501(c) (3) tax-exempt nonprofit status to take advantage of applicable tax exemptions as afforded by the Internal Revenue Service. If your state coalition plans to seek a formalized financial arrangement with the State lead entity that applies for a federal Lifespan Respite Grant, having the 501(c)(3) designation would probably be a requirement.

The National Council of Non-Profit Associations has affiliates in thirty-six states that can assist organizations hoping to become nonprofits in a number of ways. A list of state associations is available on the Web at <http://www.councilofnonprofits.org/salocator>. For steps on how to establish a formal 501(c) (3) tax-exempt nonprofit organization, see <http://www.citmedialaw.org/legal-guide/nonprofit-organization>. Also, the NJ Council of Non-Profit Associations has prepared a guidebook *Thinking of Forming a Non-Profit? What to Consider Before You Begin* that can be downloaded at <http://www.njnonprofits.org/ThinkingOfForming.pdf>.

On the other hand, filing for nonprofit status is a tedious, time-consuming process. It requires a more formal structure than some respite advocacy groups may want to undertake. Prior to receiving not-for-profit status, organizations must develop a board of directors, by-laws, and articles of incorporation and meet many state and federal requirements.

WHICH MEMBERS, OR POTENTIAL MEMBERS, OF YOUR COALITION ARE CONNECTED WITH POSSIBLE SOURCES OF SUPPORT AND COULD HELP THE COALITION MAKE FRUITFUL CONTACTS WITH THOSE SOURCES?

SUSTAINING THE COALITION

DEVELOP A BUSINESS/STRATEGIC PLAN

Within the first year or so, it is important for the coalition to have a business or strategic plan that will outline the long-term vision of the organization. Doing so will help the coalition look at where it is going and how it is going to get there, and will allow members to revisit the original mission and broaden the vision to include any new issues, agendas and services. In addition, organizations are more likely to fund a coalition if it has developed a strategic plan. To assure objectivity, it is best to hire a consultant to put the plan together for you. At this time, the budget should be reviewed as well. Developing a business plan can be time-consuming and expensive, but the coalition will gain professional respect and integrity by going this extra distance. The Pennsylvania Coalition benefited from a graduate program at local university to review and revise their strategic plan.

KEEP PEOPLE INVOLVED

To maintain momentum, it is essential that a coalition keep people involved and informed. Genuine recognition, appropriate feedback, and timely information all help keep members engaged in the process of building the coalition. If key players, whether they are paid staff or volunteer board members, are competent, enthusiastic, and well informed, the coalition will grow and participation will be high.

The AARP Foundation (2001) has put forth a number of priorities for keeping people involved while the coalition accomplishes its goals. These include the following:

- Committed, passionate and strong leadership with clear administrative responsibilities
- New leaders who are groomed and ready to replace leadership as needed
- Focused, simple, and straightforward goals and objectives that are achieved before others are added
- Committed resources—money, people, time, and in-kind—to pay for initiatives
- Early development of useful products such as multilingual brochures, training materials, resource directories, and fact sheets to meet community needs while publicizing the coalition
- Outreach and networking through community-level needs assessment forums for consumers and providers
- Continued recruitment and education of diverse members to broaden the coalition's perspective and so that no one individual or group holds too much influence

Several state respite coalitions (AL, IA, NC, TN), though fundraising or other means, have been able to establish respite voucher programs to help families in their communities pay for respite. In addition to advocacy and networking, directly assisting families often allows coalition members to feel a heightened sense of accomplishment. As a result, members were more likely to stay involved and even assume greater leadership roles.

Members of the coalition will also have to determine how often meetings are going to take place and where. Coalition leaders must strive to arrange meetings so that participation is high. Consistency is the

best policy; having meetings at regular, planned times and at the same location helps members meet their commitment. Remember also that teleconferencing and regional meetings, when appropriate and especially when traveling may be prohibitive, offer more people the opportunity to be involved:

- Schedule meetings at times that are convenient for caregivers
- Hold meetings in locations that are easily accessible for caregivers
- Provide or reimburse respite care during meetings and conferences
- Give stipends to compensate a family member or provider for any expenses
- Assist with transportation through the use of volunteers, bus tokens or taxi fare
- Assign a current caregiver member to serve as a mentor to a new caregiver and assist them in becoming comfortable with the organization

Without these benefits, the coalition limits important input into the decision-making process.

THE SPACE BELOW IS PROVIDED FOR YOU TO RECORD YOUR SUGGESTIONS FOR THE RECRUITMENT AND RETENTION OF COALITION MEMBERS

RAISE PUBLIC AWARENESS

Two major goals of most respite coalitions are to increase awareness of the need for respite and to educate the public regarding its effectiveness. Because these are important activities, coalitions are well advised to focus at the earliest opportunity on plans to achieve these goals. Because individuals and organizations will have different levels of knowledge about respite, a variety of educational tools and approaches need to be available. The most effective way to ensure this is through a Respite Awareness Committee, charged with developing an ongoing education campaign geared to basic, intermediate, and advanced levels of knowledge.

To expand awareness the Coalition should plan events like Respite Awareness Days or Lifespan Respite Summits as well. The purpose of these events is to:

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- Increase the awareness of state leaders concerning the need for, and the availability, and outcomes of, respite and crisis care services within their state;
- To educate partners, state leaders, and the public about the lifespan respite care program, available funding, and model state lifespan respite systems;
- Facilitate statewide interagency collaboration between respite and crisis care services;
- Support state and local respite professionals and caregivers as leaders in promoting awareness of respite and crisis care services.

Coalitions may also want to schedule Governor's Proclamation Days on respite to coincide with state legislative sessions.

WHAT RESPITE AWARENESS ACTIVITIES WOULD WORK IN YOUR COMMUNITIES? (BRAINSTORM YOUR IDEAS EVEN IF THEY SEEM "PIE-IN-THE-SKY" AT THE PRESENT. EVEN IF YOU DO NOT SELECT THEM, THEY MAY SPARK OTHER, MORE DOABLE IDEAS.)

EVALUATE YOUR PROGRESS

A coalition needs to continually look at where it wants to go and how effective it is at getting there. One example of a coalition evaluation tool prepared by *Coalition Works (1998)* can be downloaded at <http://coalitionwork.com/resources/tools/>. Other assessment tools can be found at: http://www.coalitioninstitute.org/Evaluation-Research/Coalition_Assessment_Tools.htm. Success can also be assessed by reviewing coalition goals and objectives to identify which have been met. Other coalitions report that they will have been effective when state respite legislation is passed or they have implemented a State Lifespan Respite Program and maintained or increased their funding.

GETTING HELP

ARCH NATIONAL RESPITE NETWORK AND RESOURCE CENTER

The ARCH National Respite Network and Resource Center began promoting the development of statewide respite coalitions in 1992, when ARCH first offered stipends to states to host State Respite Awareness Day events. ARCH assisted states in planning events, and strongly encouraged the inclusion of all respite and crisis care programs in the state in the process. In many states, State Respite Awareness Days were quite successful, and participants realized the benefits of working together. A number of these groups continued to collaborate and eventually formed state coalitions.

Recognizing the effectiveness of state respite coalitions, ARCH continued to promote their development with workshops on how to start a respite coalition offered each year at the ARCH National Respite and Crisis Care Conference. ARCH dedicated the winter, 1998, issue of *The Network News*, its newsletter, to statewide respite coalitions. In 1998, ARCH hosted the Coalition Building and Networking Institute, the first national meeting specifically for state respite coalitions and continued to actively provide training and technical assistance to state coalitions until 2004.

With initial support from the Christopher and Dana Reeve Paralysis Foundation, and later from the Jacob and Valeria Langeloth Foundation, the ARCH National Respite Coalition (NRC) took on some of the training and technical assistance previously offered by the ARCH Resource Center. NRC initiated the concept of State Lifespan Respite Summits several years ago, in conjunction with state respite coalitions, to strengthen their coalition building efforts, and to help them prepare for their new legislatively mandated role to collaborate with the state lead agency and the state Aging and Disability Resource Center to apply for and implement federally-funded statewide Lifespan Respite Programs. State Summits have also been held with the assistance of the NRC to initiate the building of new state respite coalitions in several states. The NRC continues to actively support state respite coalitions and the ARCH membership through additional networking opportunities, including conference calls, an email listserv, timely funding and legislative alerts, fact sheets, respite blogs, and state news updates (also posted on the ARCH website). In addition, NRC helps to link new coalitions with experienced representatives from more established respite coalitions.

ABOUT THE STRUCTURE OF THE ARCH NATIONAL RESPITE NETWORK

Respite and crisis care consumers and service providers are also networking at the national level under the leadership of the ARCH National Respite Network (NRN) and the National Respite Coalition. The NRN, which works toward keeping families together by promoting the development of respite options nationwide, has two divisions. The ARCH National Respite Resource Center offers web-based information on a broad range of subjects relating to providing respite and developing respite coalitions, and maintains a National Respite Locator Service. Each year, a state respite coalition, in collaboration with the ARCH NRN, hosts the Annual National Respite Conference, which still focuses on coalition building and networking opportunities. The ARCH National Respite Coalition (NRC) is the policy division of the NRN. The NRC helps state and local communities understand policy, educate policy makers, build strong advocacy coalitions, and helps develop legislation at the state and national level to address respite issues.

In September 2009, the ARCH National Respite Network and Resource Center received a federal grant from the Administration on Aging to provide training and technical assistance to the growing Lifespan Respite Network. ARCH will once again assume the work to help states build and sustain their state respite coalitions, and ultimately help states develop and implement state Lifespan Respite Programs.

CONCLUSION

Forming a coalition may be a viable step for those interested in promoting and improving respite issues in their State. It has proven to be an effective mechanism for respite consumers, providers, and agencies in many states and State Respite Coalitions must now collaborate in the implementation of federally funded Lifespan Respite Programs. Statewide respite and crisis care groups can create opportunities for communication, coordination, and collaboration among respite stakeholders. Coalition members provide a support system for each other and assist in making the most of opportunities and solving problems that are too big for one person or agency to manage.

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WEBSITES

- ARCH National Respite Network and Resource Center: <https://archrespite.org/>
- ARCH National Respite Locator: <https://archrespite.org/respitelocator>
- ARCH National Respite Coalition: <https://archrespite.org/national-respite-coalition>
- ARCH State Respite Coalitions: <https://archrespite.org/state-respite-coalitions>
- Coalition Works: <http://coalitionwork.com/resources/tools/>
- Family Caregiver Alliance, Family Navigator: <https://www.caregiver.org/family-care-navigator>
- National Alliance for Caregiving – Coalition Guides: <http://www.caregiving.org/coalitions/coalition-resources/>

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