



Building and Sustaining Partnerships for Lifespan Respite Care Programs



What do we mean by collaboration?

“Alone we can do so little; together we can do so much.”

~ Helen Keller

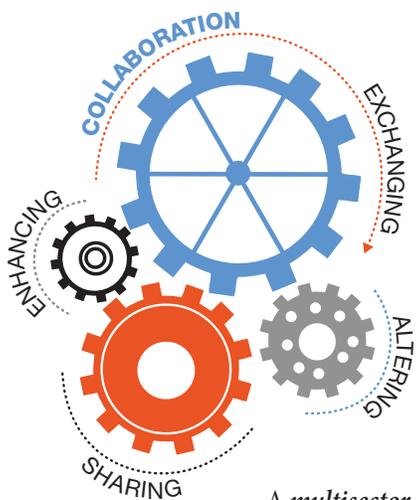
Collaboration, coordination, cooperation, and networking¹ – these terms are often used interchangeably and imply similar principles that reflect various levels of engagement among interested parties to attain similar goals. There are, however, some differences among these terms that increasingly imply more engaged and enhanced relationships.

Networking is *exchanging* information for mutual benefit. An example of networking is when organizations, programs, or individuals who have an interest in respite agree to meet monthly to share ideas and concerns. Many fledgling state respite coalitions function on this level.

Coordination is *exchanging* information and *altering* activities for mutual benefit and to achieve a common purpose. Coordination requires more organizational involvement than networking. It is most useful when all parties affected by proposed changes share in decisions about the possible consequences of the changes.

Cooperation is *exchanging* information, *altering* activities, and *sharing* resources, for mutual benefit, and to achieve a common purpose. Shared resources may include staff, workspace, training, information, funding, and, in some cases, legal arrangements. Cooperation is used, for example, when the state lifespan respite program and the Aging and Disability Resource Center (ADRC)/No Wrong Door (NWD) System² develop and share resources to assist families in finding respite and other services and supports.

Collaboration is *exchanging* information, *altering* activities, *sharing* resources, and *enhancing* the capacity of another organization, for mutual benefit, and to achieve a common purpose. Members of a collaborative effort view each other as partners and are willing to share risks, resources, responsibilities, and rewards. An example of collaboration would be a Lifespan Respite program in which several state agencies co-locate their respite funds under a single administrative system to award respite vouchers to qualified families.



A *multisector collaboration* is an alliance of public, private, and nonprofit organizations. Such collaboration is illustrated by public and private agencies, including the state lead agency, the ADRC/NWD, and the members of a state respite coalition all working together toward the creation of a Lifespan Respite system.

1 Adapted from: ARCH National Resource Center for Respite and Crisis Care (1993). *Helping Each Other Help Others: Principles and Practices of Collaboration*. [ARCH Fact Sheet No. 25.] Chapel Hill: Author.

2 For more information on the No Wrong Door System, see <https://nwd.acl.gov>

Why is collaboration a priority area for the Lifespan Respite Care Program?

“When you need to innovate, you need collaboration.”

~ Marissa Mayer

Collaboration and coordination are the driving forces for implementation of the Lifespan Respite Care Program (LRCP) in order to maximize the use of existing respite funding streams, reduce the confusion caused by disparate funding streams and eligibility criteria, and to enhance access to respite for all family caregivers regardless of age or disability. Lifespan Respite is defined by federal law as a “coordinated system of accessible, community-based respite care services for family caregivers of children or adults with special needs.” A “system” relies on seamless and ongoing partnerships to function effectively. By working with other existing efforts and coordinating service delivery, states and communities can prevent service overlap and reach more caregiving families across the lifespan.

What does collaboration in Lifespan Respite Care Programs mean?



“Unity is strength...

*when there is teamwork and collaboration,
wonderful things can be achieved.”*

~ Mattie Stepanek

Throughout the Lifespan Respite Care Act (P.L. 109-442) and in the Administration for Community Living’s (ACL) oversight of the program, coordination and collaboration have been mainstays of program development activities. In the ACL’s Lifespan Respite Funding Opportunity Announcements, coordination and collaboration are emphasized and in many instances, required. “To improve the statewide dissemination and coordination of respite services” is one of three main purposes of the program identified in the law. The program announcements go on to suggest “expansion of program capacity, new respite options, streamlining access to respite, and closer

collaboration between respite programs” as performance goals and indicators that states could use to demonstrate that they had achieved this purpose.

At the heart of the Lifespan Respite Care Program is successful collaboration across state agencies and local providers: The Lifespan Respite law requires that the **State Lead Agency** work in concert with an Aging and **Disability Resource Center (ADRC)/No Wrong Door System**, as well as a public, non-profit **statewide respite coalition or state respite organization** to provide a coordinated system of community-based respite for all family caregivers regardless of age or disability and to ensure that family caregivers have access to an array of support services.

Examples include:

-  **Arizona:** A major component of the Arizona LRCP grant project is public awareness campaigns about lifespan respite and the toll-free statewide **Caregiver Hotline** that provides caregivers across Arizona a simple way to find out about and access respite. This hotline is embedded in AZ Links, the Arizona ADRC project. The Arizona Caregiver Coalition is responsible for staffing and coordination of the hotline, and serves as a forum

for stakeholders. The Arizona Caregiver Coalition researches information on respite funding, barriers to respite, and identifying gaps in respite service. Area Agencies on Aging and community partners within the disability community in conjunction with the Arizona Caregiver Coalition maintain a database and calendar of statewide caregiver-specific resources that is used to provide information and referral to caregivers calling the hotline.

 **South Carolina:** The cornerstone of the South Carolina lifespan respite grant efforts has been ongoing partnerships between the SC Respite Coalition (SCRC), the Lieutenant Governor’s Office on Aging (LGOA), Family Connection of SC’s Family to Family Health Information Center (F2FHIC), and the Aging and Disability Resource Centers (ADRC). The strength of these partnerships is in how collaboration has enabled them to leverage other partners (formal and informal), including statewide representation of agencies, organizations and families through state and regional respite councils, as well as diverse funding sources. The most profound impact has been from the **state legislative appropriation of respite funds that are used for respite across the lifespan**. This was a combined effort of the partners over a period of several years, during which the funding went from one-time to a recurring line item and from serving seniors only to serving across the lifespan. In addition to increasing respite for families, these efforts have laid the foundation for broader partnerships with families, providers, higher education, and the medical and business communities.

 **Washington:** Washington State’s Aging and Long Term Support Administration (AL TSA) contracts with Homage Senior Services to host Lifespan Respite Washington (LRW) in supporting several grants related to respite including the Respite Coalition and Respite Voucher Program. The LRW works collaboratively with eight Tribes on an innovative opportunity through its **Tribal Respite Grant** to develop culturally relevant respite services for Tribal kinship caregivers. They are implementing respite models in collaboration with newly funded Tribal Kinship Navigators. Collaborative activities include: (1) Engaging Tribal partners and Navigators by providing information for outreach on new respite opportunities; (2) increasing Tribal participation in LRW activities; and (3) providing caregivers and respite providers with culturally relevant information about children with special needs. In addition, a collaborative relationship with the Washington State Department of Health (DOH) resulted in a multi-year innovative program to provide respite vouchers for families of children being served through the **Children with Special Health Care Needs (CSHCN)** program.

What tools and resources are available to support Lifespan Respite Care Program Lead Agencies, State Respite Coalitions, and ADRCs and their stakeholders in developing or maintaining collaborations?³

Collaboration Toolkit (from FRIENDS National Resource Center)

The Toolkit is based on Collective Impact theory that offers descriptions of each of the ten elements along with tools and resources. Collective Impact is a proven collaboration framework used to tackle complex social problems. <https://www.friendsnrc.org/activities-that-support-collaboration/collaboration-toolkit>

The Collective Impact Forum

This is the place for those practicing collective impact to find the tools, resources, and advice they need. It’s a network of individuals coming together to share experience and knowledge to accelerate the effectiveness and adoption of collective impact. <http://collectiveimpactforum.org/>

³ ARCH does not endorse specific collaboration tools or resources, but offers a range of possibilities for your convenience and suggests you review them for greatest applicability to your own work in collaboration. If you would like to know if these efforts have been evaluated, please contact the tool or resource developers directly.

Resources for Assessing Collaborations

Wilder Collaboration Factors Inventory

This inventory is a 40-item tool using 20 research-tested factors to understand strengths and opportunities of collaborative groups. This resource can be helpful in evaluating existing collaborations and for identifying key factors in effective collaborations. Online: <https://wilderresearch.org/tools/cfi> or in printable form: <http://www.ruralhealthlink.org/Portals/0/Resources/Wilder%20Collaboration%20Factors.pdf>

PARTNER Tool

PARTNER is a social network analysis online tool designed to measure and monitor collaboration among people/organizations. The tool is sponsored by the Robert Wood Johnson Foundation and designed for use by collaboratives/coalitions to demonstrate how members are connected, how resources are leveraged and exchanged, the levels of trust, and to link outcomes to the process of collaboration. The tool includes an online survey that you can administer to collect data and an analysis program that analyzes these data. By using the tool, you will be able to demonstrate to stakeholders, partners, evaluators, and funders how your collaborative activity has changed over time and progress made in regard to how community members and organizations participate. Online: <http://partnertool.net/>; 2-Page Summary: <http://partnertool.net/wp-content/uploads/2016/02/PARTNER-2-Page-Nov-2013.pdf>

Tools for Building Community Engagement

Community Engagement Toolkit

The Community Engagement Toolkit developed in 2013 by Tamarack: An Institute for Community Engagement provides an adaptable approach for designing a community engagement process to address specific issues in your community. The five steps of effective community engagement planning are outlined along with diverse examples of specific community engagement methods. <https://www.tamarackcommunity.ca/library/community-engagement-toolkit>

Community Tool Box

The Community Tool Box is a free, online resource for those working to build healthier communities and bring about social change. This resource includes 16 toolkits on a range of topics including creating and maintaining partnerships and increasing participation and membership. The mission is to promote community health and development by connecting people, ideas, and resources. <http://ctb.ku.edu/en/using-tool-box>

Resources for Building Statewide Respite Coalitions

ARCH State Respite Coalitions: A Compendium of Fact Sheets 2017

This compendium of fact sheets provides a state-by-state look at the 27 state respite coalitions that are affiliated with the ARCH Network (See State Respite Coalitions). Each state coalition fact sheet contains the following information: Start-Up Process and Coalition History; Structure; Staff; Funding; Membership; Meetings and Communication; Major Activities; Available Documents (e.g., Bylaws, Strategic Plans, Surveys, Brochures); and State Contact Information. <https://archrespite.org/library/compendium-of-fact-sheets-related-to-state-coalitions/>

Building a Statewide Respite Coalition: Where Do We Begin?

This guide is intended to assist those states or groups that are considering forming coalitions by providing the tools necessary to begin building a state respite coalition. Although the focus is on respite coalitions in particular, the material can be used for building any coalition. <https://archrespite.org/library/building-a-statewide-respite-coalition-where-do-we-begin/>

⚙️ **Infographic: What's the Key Ingredient for a Successful, Sustainable Coalition?**

As Lifespan Respite grantees and their State Respite Coalitions work to build diverse and meaningful partnerships for sustainability, ARCH developed this infographic to reflect lessons learned.

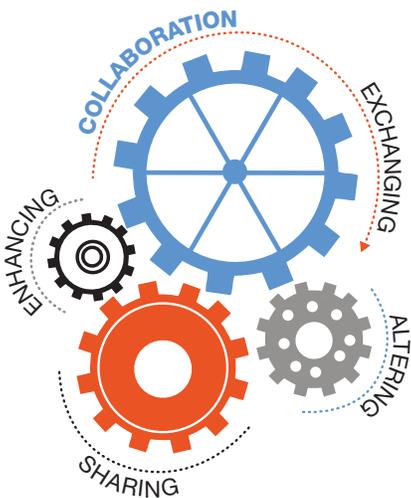
<https://archrespite.org/library/infographic-whats-the-key-ingredient-for-a-successful-sustainable-coalition/>

Sustaining Important Collaborations

⚙️ **Sustaining Lifespan Respite Systems: Lessons Learned and Practical Applications with a Checklist for Success (2016)**

With technical assistance from ARCH and The Finance Project, eight Exemplar States chosen from the Lifespan Respite grantees and partners, worked to develop comprehensive state sustainability plans for lifespan respite systems. Through in-depth interviews conducted as part of an evaluation of The Finance Project's technical assistance efforts, the Exemplar States shared the wisdom they gained from their actual experience in developing Sustainability Plans. Their challenges and successes, along with experiences shared by other states undertaking sustainability planning activities, informed this document on lessons learned in sustainability.

<https://archrespite.org/library/sustaining-lifespan-respite-systems-lessons-learned-and-practical-applications-with-a-checklist-for-success/>



Need more information?

If you have questions about your collaboration efforts in LRCP or want to know more about how ARCH Lifespan Respite Training and TA Center can provide targeted technical assistance in this area, please contact ARCH staff Jill Kagan (jkagan@archrespite.org) or visit <https://archrespite.org/>.



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