ARCH National Respite Network And Resource Center

Sustaining Lifespan Respite Systems:

Lessons Learned and Practical Applications with a Checklist for Success

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SUSTAINABILITY was ranked a top training and technical assistance priority by ARCH Lifespan Grantees in a recent needs assessment. Responding to this need, ARCH partnered with The Finance Project (http://www.lifespanrespite.memberlodge.org/Sustainability_Tools) and instituted the Sustainability Planning Project. With technical assistance from The Finance Project, eight Exemplar States worked to develop comprehensive state sustainability plans for lifespan respite care. 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 the following ***Lessons Learned***.

Sustainability means that something continues over time. But the "something" that continues may differ according to person or group. The ***Lessons Learned*** presented here focus on the perspective of state ***Planning Partnerships***. Planning Partnerships are groups that work collaboratively across programs and across agencies to help *coordinate and sustain systems of care* across the lifespan—that is, the infrastructure supporting respite.

Sustaining Coordinated Systems of Respite

The Lifespan Respite Care Act defines lifespan respite care as:

> *Coordinated systems of accessible, community-based respite care services for family caregivers of children or adults with special needs.*

Respite systems encompass policies and services for persons of every age, with varying physical and mental health conditions. They occur in a variety of private and group settings. Coordination of respite systems is supported in part by State Lifespan Respite grants, funded by federal dollars, and administered by the state agency on Aging, the state Medicaid agency, or another governor designated agency. The grantee agency is responsible for administration of the overall Lifespan Respite Care Program, but may assign tasks to a State Respite Coalition for implementation.

Keeping in mind the Lifespan Respite Care Act and a *systems* perspective, there are four key focus areas important to supporting sustainable lifespan respite care: ***People, Plans, Practical Actions,*** and ***Policies***.

DEFINITIONS

SUSTAINABILITY—Ultimately, sustainability refers to the continuity and stability of a state's Lifespan Respite Care Program—that is, their *coordinated system of accessible, community-based respite care services for family caregivers*. As states work toward this ultimate goal, they may focus on sustaining elements of the system including, for example, their respite coalition, voucher programs, volunteer training, or a website that helps families obtain information or access.

FAMILY CAREGIVER—Family members, foster parents, or other adults providing ongoing unpaid care for an adult or child with a special need.

RESPITE PROVIDER—An individual providing direct care to a child or adult with a special need to allow a caregiver to take time away from caregiving responsibilities.

RESPITE SERVICE—An entity that oversees funding, administrating and coordinating direct care, or access to direct care, for children or adults with special needs. This service may be a stand-alone respite program, or it may be a service (such as vouchers) that is part of an array of services available through an umbrella agency, organization or initiative.

LIFESPAN RESPITE CARE PROGRAM—The federal Lifespan Respite Care Program refers to *coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs* with the intention of reducing duplication of effort and assisting in the development of respite care infrastructures at state and local levels. http://www.acl.gov/Programs/CIP/OCASD/LifespanRespite/Index.aspx

PLANNING PARTNERSHIPS—A gathering of diverse stakeholders representing aging, disability, health, veteran and other groups that meet in order to plan and sustain "coordinated systems of accessible, community-based respite care services for family caregivers of children or adults with special needs" for a state or region in accordance with the Lifespan Respite Care Act. This group takes different forms in different states. For example, it may be part of a State Respite Coalition, or it may be a group assembled by the state grantee.

STATE RESPITE COALITION—A grassroots membership organization composed of state and local, public and private organizations, which represent individuals with disabilities or chronic conditions of all ages; family caregivers; community and faith-based organizations and respite, social service and health care providers. Most State Respite Coalitions focus on advocacy, networking, and public education. Some coalitions also provide training and respite vouchers. They may be run by volunteers or paid staff. Most exist as informal structures, while others are formalized within or as 501(c)(3) nonprofit entities.

SUSTAINABILITY PLANNING WORK GROUP—A gathering of diverse stakeholders that meet to develop a written plan that will help to ensure the continuity and stability of their state's coordinated systems of community-based respite services. Lifespan Respite Planning Work Groups take different forms in different states. Some states form new partnerships for the purpose of funding Lifespan Respite. And some states use their **State Lifespan Respite Coalition** for planning.

State Respite Coalitions

The Lifespan Respite Program law authorizes competitive grants to eligible state agencies in collaboration with a public or private non-profit State Respite Coalition or organization. State Respite Coalitions serve four key functions that support continuous, accessible, quality respite care services.

1. **Coalitions intentionally bring together aging and disability groups.** Person- and family-centered, seamless services are dependent upon thoughtful coordination that crosses categorical lines. Coalitions further this goal by bringing together primary partners in respite service.
2. **Coalitions ensure respite expertise.** Coalitions bring together knowledgeable representatives from a range of programs and agencies, and service recipients, families, caregivers and advocates, in order to ensure that expertise is broad, deep, and representative.
3. **Coalitions help to ensure global outreach.** Families and caregivers are more likely to find and use needed services when accessibility is not dependent upon difficult to identify or locate service entry points.
4. **Coalitions may advocate and fundraise.** Government funded programs and agencies may be restricted from advocacy and fundraising, while coalitions may help educate and advocate for respite.

1 PEOPLE

In our state, context is extremely important.
~ Grantee

Lifespan Respite programs and services exist in multiple contexts—bureaucratic, political, economic, cultural, human and historical. If Lifespan Respite planning is to be relevant, useful and viable, those contexts must be acknowledged, anticipated and considered by Planning Partners who have deep and intimate knowledge of them. Lifespan Respite Planning Partners, through their human and working relationships with one another as well as with others outside their group, build the foundation for sustainability.

1. **Be strategic and inclusive.** (The **checklist** below and on the inside back cover helps identify who to include in your Planning Partnership.)

   ✔ **Seek diversity among Planning Partners.**
   In addition to the obvious key players—child-focused, aging and disability groups—, think also about underserved populations, such as Veterans and military families, working caregivers, ethnic or minority caregivers, or children or elders at risk for abuse or neglect.

WHO are the people in your coalition?

✓ Do 50% of the members have the qualities in the blue columns?
✓ Does at least one member have political clout (direct or indirect)?
✓ Do members from key organizations have decision making power?

Your coalition should *include or have strong connections with* people in the following systems. Make sure each box on the left can be checked.	Personal experience with respite	Professional knowledge of respite	Political clout and connections	Decision making power
☐ Faith communities	☐	☐	☐	☐
☐ Private sector non-profit organizations, such as The Red Cross, Easter Seals, March of Dimes	☐	☐	☐	☐
☐ Private sector businesses and empoyers, such as banks, corporations, manufacturing companies	☐	☐	☐	☐
☐ Volunteer organizations and clubs, such as DECA, Rotary, Kiwanis	☐	☐	☐	☐
☐ Health care sector, both private and public agencies and individuals	☐	☐	☐	☐
☐ Children's, aging, and disability groups, such as Family Voices, AARP, The Arc, Wounded Warriors	☐	☐	☐	☐
☐ Education community, including public schools, colleges and universities	☐	☐	☐	☐
☐ Charitable foundations, such as community foundations	☐	☐	☐	☐
☐ Philanthropic individuals, especially with name recognition and a history of giving	☐	☐	☐	☐
☐ Legislators and other policy makers	☐	☐	☐	☐
☐ Veterans and military families	☐	☐	☐	☐

One grantee talked about moving to a place of greater sustainability "because of the people who were able to make an impact legislatively." Notice in her explanation the link between planning and legislation.

A lot of lessons were learned about meetings. We started out with a lot of committees. We don't have as many committees anymore… If we need to pull a group together for something, that happens, but the coalition acts more in an advisory and advocacy capacity. The strong membership means that when you need to pull a group together, you can. With any task force or coalition, you reach a point where you move to a different level, and it might spin off to something else. You know in our grant for this year, we proposed that the coalition would take a step further and request that the legislature do a task force or study group on caregivers… That's the level we're at, and where we want to go next.

✔ **Include persons with skills, connections, and first-hand knowledge—especially care recipients and families.**

These persons can be effective advocates and fundraisers—key functions of **Lifespan Respite Planning Partnerships**.

✔ **Include persons with academic or research/evaluation expertise.**

These persons can support activities like grant writing, performance measurement, and group facilitation.

✔ **Include persons from diverse locations around your state.**

Just as partners should come with diverse experience and expertise, they should also represent a variety of regional interests in planning and outreach.

✔ **Include agency and organization partners with desirable characteristics.**

Agency and organization partners should make a strong commitment to respite, have sufficient capacity and dedicated resources, internal stability, and a mindset that welcomes challenging situations and a desire to work through them.

2 **Share leadership, and plan for leaders' succession to ensure continuity of mission and projects.**

✔ **Seek and mentor potential leaders.**

Some State Respite Planning Partnerships or Coalitions appear to be very strong for a period of time because of the strength of a single leader, but the coalition declines when the leader leaves. Look among planning partners for talented and committed potential leaders, and mentor them to become future leaders, so that the strength of Planning Partnerships and Coalitions will not rest on a single individual.

- ✔ **Share leadership positions.**
  Leadership may be shared through the Executive Committee, through joint-chair positions, and/or through committee chair positions.

- ✔ **Protect historical knowledge.**
  To ensure that that Planning Partnership or Coalition history and intentions are accurately transmitted when key leadership positions change, at least one (and preferably more) original Planning or Coalition Partners with first-hand knowledge should serve on the Planning Group's Core or Executive Committee.

- ✔ **Stipulate leadership activities in writing.**
  Those elements important to leadership sustainability (Mentoring, Shared Leadership, and Original Coalition Partners) should be stipulated in writing in your planning group's Bylaws or Policies and Procedures.

③ Establish enduring and productive partnerships.

- ✔ **Involve Partners in activities that are authentically meaningful to them.**
  Consider individual interests, abilities and personal time constraints.

- ✔ **Encourage opportunities for communication and warm formal and informal relationships among Planning Partners.**
  Collaborative work should be productive and personally rewarding to those involved.

One grantee affiliated with a state agency acknowledged that when personnel changes at administrative levels in state bureaucracies occur, sustainability is "an uphill battle." At one point when key personnel were changing and the sustainability project was in jeopardy, the grantee felt like giving up. Then she realized that Coalition members were proceeding in their own way.

We have been talking for a while about developing a training curriculum for workers, and several agencies have been approaching this on their own...We're not starting from scratch. It's a real thing. They decided to just keep going. It's kind of exciting. I was the one who said, 'Maybe we should wait and see who's in charge, and get their permission.' Then I thought, 'Wait. Maybe I've been a bureaucrat too long.'

One State Respite Coalition, over the period of a decade or so, built a coalition with strong local involvement of nearly 150 members who meet every two months via videoconference. Teleconferences include a reporting process, so that participants are "aware of why they are there," the grantee explains. The state coalition also includes an informational or training/technical assistant component—arranged by an active Education Committee—that is not only engaging, but strengthens the quality of services and systems over time. Meetings are promoted in advance, and attendance is strong. Refreshments were served, and from the grantee's description, one got a feeling of collaboration and social cohesion. "People wanted to meet more frequently than they were currently meeting," the grantee told us.

2 PLANS

Success depends upon how you define success.
~Grantee

Once Planning Partnerships are formed, the real work begins. Collaborative planning allows partners to define success consistent with their mission and vision, and to identify the steps and strategies needed to achieve it. The task of collaborative planning will be challenging at times. But it is also absolutely essential in order to develop supportive policies and accomplish practical actions that ensure financial sustainability. States may want to form a Sustainability Planning Work Group as a subset of their Coalition or Planning Partnerships to complete the following tasks.

1. **Develop a sustainability plan.**

- ✔ **Develop a plan that is true to your mission, articulates a clear vision.** Help others see what you want to achieve going forward. Select a format useful to you—for marketing, leveraging funds, developing projects, and so on.

- ✔ **Include clear goals and objectives, and specify strategic and practical actions to achieve these.** Because planning partners come with different perspectives and priorities, a consensus around mission and goals is likely to result in broad commitment. Specifying practical actions helps to show what commitment means in real terms and provides guidance about the resources and supports necessary to meet commitments.

- ✔ **Specify performance measures that measure progress toward and achievement of goals and objectives.** Include process measures that help you stay on track toward attaining your goals, and outcome measures that let you know when it's time to celebrate.

To learn more about performance measurement, evaluation and survey reports, see: *Measuring Systems Change and Consumer Outcomes: Recommendations for Developing Performance Metrics for Statewide Lifespan Respite Programs, 2014.* http://archrespite.org/images/docs/2014_Guidebooks/PerformanceMeasurmentGuide_web.pdf

A Written Plan Is Important

The importance of a written plan that clearly documents your planning coalition's or group's vision and intention is evident in the words of this grantee.

I do think we've got some (chance for sustainability). We're going into this new phase of (our state's) lifespan respite (system) with a clear vision that someone has written down, with objectives. We know what we want going forward. We've put it on paper. So if one of us gets hit by a bus tomorrow, no one else has to try to figure out what this was about.

The written plan also enables planning groups to be ready and to take advantage of what one grantee called "political windows of opportunity."

- ✔ **Revise your plan as needed.**
  A written plan is a placeholder—a best guess made before you begin working toward goals. As circumstances change, and as you learn from practical activities, update your plan to fit your needs.

2. **Find a facilitator to guide you painlessly through the process of plan development.**

- ✔ **Make sure your facilitator is caring, skilled, and experienced.**
  Group leaders are not necessarily skilled facilitators. Look for facilitation skills among planning partners, or engage skilled facilitation outside the group.
- ✔ **Actively involve planning group members.**
  During planning activities, minimize "paper shuffling" and actively involve planning group members in brainstorming. Assign technical writing and organizing tasks to one or two planning group members who have the skills and the time to accomplish the task. Then present ideas in writing to the larger group for review.
- ✔ **Encourage full participation by freeing group leaders from facilitation responsibilities.**
  Typically leaders of planning partnership are leaders because of their knowledge and expertise. When they are freed from facilitating, they can add their knowledge and expertise to the planning process without too little input, or too much influence.

3. **Take the long view.**

- ✔ **Distinguish between human time and institutional time.**
  Institutions and organizations tie target dates and timelines to funding cycles that may not line-up with your planning groups' schedule. As long as you make the process and product useful to your group, it is fine to be out of sync with institutional deadlines. Keep meeting according to schedule and continue working on your written plan. Remember that your plan is a living document that will change over time in order to be useful. And as long as the group sees it as useful, they will be willing to commit time to it.

Adapt to Change

Without exception, each grantee from an exemplar state recognized that change—in government administrations, in personnel, in funding, in priorities—is inevitable. Therefore, grantees anticipated change, and strategized to reduce the threat of change as part of sustainability planning—through shared leadership, succession planning, or strategic partnerships, for example. When change occurs, take it in stride and use your strong planning group to review and revise your plan as needed.

Use a Skilled Facilitator

Those grantees that used skilled facilitators reported having a positive experience with planning. In the words of one grantee:

One of our members, our evaluator from (a neighboring university), she's also a great facilitator. She knows how to do planning. So we paid her out of the grant. She did a two-day meeting, and we used the logic model and some other things we had gotten from the project itself...She did some really interesting things. She made it participative so that every person was engaged. And she got to the point of what the sustainability plan was looking for. Every person was absolutely engaged in it…We couldn't have done it if she hadn't been the facilitator. I really believe that. So she's the one who got us the answers, who pulled it together in terms of indicators and that type of thing. That's how we got to where we are today, with excellent facilitation.

Challenges to Sustainability		and How to Counter Them
1 **Changes in agency leadership.** When state political leadership changes, new agency and program appointees may not possess a clear understanding of respite. Government transitions may influence the stability and sustainability of respite services and initiatives in either direction.	→	**Have a clear, concise, compelling plan to share with new leaders.** Your core group should include people who are likely to remain through times of change, and who are able to articulate the importance of respite and convey the groups' goals and plans to new leaders.
2 **Power concentrated in a single leader.** Planning and coordinating groups led by a take-charge, dynamic personality may appear strong while that person remains in a leadership position, but when that person leaves, there may be a leadership vacuum.	→	**Seek and mentor leaders, and share leadership.** Make sure your core group includes more than one person who knows the groups' history and understands its shared purpose. Discuss the importance of shared leadership at the time your group is formed, and consider writing guidelines or bylaws that formally incorporate ways to share leadership and pass knowledge to new members.
3 **Planning groups without clout.** Successful planning and coordinating groups include multiple ways for members to share their ideas and talents. But without someone who can influence organizations or policies, even the best ideas and plans may not materialize.	→	**Look for people who understand the importance of respite and who have authority and influence.** The core group should frankly discuss inviting individual members who have decision-making power within key organizations, and members who have influence in drafting and/or advocating for legislation and policies that support respite.
4 **Groups lacking shared purpose and meaning.** If groups are too large in number or too professionally distancing in tone, some members may feel reluctant to share ideas. Shared purpose requires shared participation, and these foster the commitment from all members that is necessary for sustainability.	→	**Build consensus around a common mission and goals.** Groups and coalitions meet for many reasons—to plan, learn, exchange information, conduct business, and to form partnerships and friendships. Whatever your purposes, make them clear for each meeting. If tasks or group dynamics become challenging, find a skilled facilitator—either from within or outside the group—to help smooth the path forward.
5 **People unskilled at interpersonal relationships and collaborative work.** Some groups include persons with the right credentials, but without the willingness or know-how to work in true collaborative partnerships. Strong interpersonal relationships are fundamental to success.	→	**Choose members wisely.** Encourage opportunities for communication and warm relationships among planning partners. From the outset, invite people who want to, and are skilled at, working collaboratively.

3 PRACTICAL ACTIONS

I'm an opportunist. I saw (The Finance Project) as an opportunity to work not just on lifespan respite, but more broadly on sustainability in everything we do.
~Grantee

Perhaps more than an opportunist, this grantee is a pragmatist. State Lifespan Respite Programs and Planning Partners approach coordination at a system infrastructure level in a variety of practical and useful ways—direct service, training, funding, registries, and technology, to name a few. According to representatives from Exemplar States, concrete deliverables that are tangible and desirable to stakeholders are key to systems level sustainability.

1 Forge state agency fiscal partnerships.

✔ **Identify populations served by multiple agencies.**
Respite care recipients fall into more than one defining category. For example, children with disabilities may also be at increased risk for child maltreatment. Veterans with physical injuries may also need mental health support. Work cooperatively with the multiple agencies serving these populations to minimize bureaucratic barriers, and maximize accessibility to services.

✔ **Address identified service duplications and gaps across agencies.**
Use needs assessment data about existing funding streams, populations served, service duplications, and service gaps to identify agencies and programs that should be working collaboratively to plan, fund and/or provide respite services.

In an example of the importance of forging state agency fiscal partnerships, Arizona Lifespan Respite Program contracts with the state's Title V Children with Special Health Care Needs Program to fund respite for this population through a statewide Lifespan Respite voucher program. Tennessee channels state funds from the Department of Mental Health and Substance Abuse Services for its Family Directed Respite Voucher program.

❷ Encourage statewide programs and initiatives to incorporate lifespan respite activities.

✔ **Identify state agencies and programs that serve populations known to benefit from respite services.**
Invite stakeholder participation from the breadth of those organizations that serve potential respite recipients.

✔ **Offer models for ways to incorporate respite into program missions and guidelines.**
Encourage program-to-program support by creating forums for informational and educational exchanges.

❸ Use multiple financing strategies.

✔ **Optimize and maximize existing financial resources.**
The Finance Project identifies four strategies to maximize existing resources: shifting funds from higher- to lower-cost programs; operating efficiently; reinvesting funds saved; and embedding lifespan respite activities into ongoing efforts. http://www.lifespanrespite.memberlodge.org/Resources/Documents/Sustainability_Toolkit/Financing_Strategies.pdf

Incorporate Lifespan Respite Activities into Statewide Initiatives

One grantee spoke about "bringing the right people to the table so we can begin to embed respite more fully into existing programs." The strategy this grantee used to accomplish this included forming an advisory group by "bringing people from across state agencies that are in a position to effect change." The advisory group then conducts "an inventory where respite is being funded in the state, then pulls decision makers from each of those (programs and agencies)" and brings them onto the advisory board. In addition to providing guidance and direction, the advisory group provides a forum for program-to-program communication and support.

- South Carolina used their broad based Lifespan Respite Advisory Committee with diverse membership to develop a 10-year statewide Respite Plan. http://www.lifespanrespite.memberlodge.org/Resources/Documents/State%20Tools/South%20Carolina/SC_StateRespitePlan_2013.pdf
- To improve state respite services, Texas and Colorado have state level, legislatively mandated Respite Care Task Forces that draw on expertise from the state Lifespan Respite Program and State Respite Coalition. They also bring in partners from across state agencies and the private sector to develop cross agency strategies. CO Respite Task Force: https://sites.google.com/a/state.co.us/cdhs-cai-aas/respite-care-task-force-overview TX Lifespan Respite Advisory Committee: http://www.dads.state.tx.us/taketimetexas/about.html#committee

At the state level, state grantees and partners can help work to embed respite into statewide initiatives, such as Medicaid Managed Care, Medicaid Rebalancing initiatives, Caregiver Task Forces, Long-term Care, or No Wrong Door Systems. http://www.acl.gov/Programs/CIP/OCASD/ADRC/index.aspx#Initiatives

North Carolina and Idaho both successfully embed respite and caregiving support into existing state initiatives.

- The North Carolina Lifespan Respite Project partnered with the state Medicaid agency to use the state's Money Follows the Person Rebalancing Fund to support family caregiver peer support and respite volunteer models. Those eligible were family caregivers who had assumed more caregiving responsibilities for an individual transitioning back to their home/community or individuals at risk of being admitted into a long-term care facility. Source: NC DHHS. Notice of Funding Availability Reporting Form. North Carolina Lifespan Respite Project Family Caregiver-to-Caregiver Peer Support. November 13, 2012 http://www.lifespanrespite.memberlodge.org/RFPS
- Idaho is working to integrate respite and caregiver support in statewide initiatives, including their Statewide Healthcare Innovation Plan and a "No Wrong Door" system, and by making sure that respite is included in the work of a legislatively mandated Caregiver Task Force. http://www.lifespanrespite.memberlodge.org/Resources/Documents/State%20Summits/Idaho/Summit%20Presentation%20P%20Catt-Oliason.pdf

- ✔ **Identify goods and services—including personnel, space, or marketing services, for example—to support planning and collaborative work.**
  When identifying resources, remember the importance of in-kind contributions, and "out-of-the-box" programs such as AmeriCorps, Vista, or graduate intern programs to support planning work.

4. **Use performance measures, and numerical/statistical and qualitative data to document the need for and benefits of respite.**
   - ✔ **Focus on outcomes that inform others of lifespan respite's value.**
     Use performance data to bolster funder confidence in the merit of investing in respite services by showing how, and the extent to which, respite benefits families and society.
   - ✔ **Focus on measures that will improve access to respite services.**
     Accountability for responsible use of public resources applies not just to funders, but also to consumers. Collect data that document consumer needs, available resources, and service gaps, and use these data to design and monitor systems that are more accessible, more responsive, and more accountable to consumers.
   - ✔ **Focus on measures that can guide you in making good planning decisions.**
     Performance measures can—and should—be used to monitor and manage programs, inform budget and allocation decisions, and strategic planning. Choose performance measures that closely link to the goals and objectives in your master plan.

Ensure Capacity

In addition to dedicated funds, the resources needed to support lifespan respite systems can come in many forms. Partnerships with organizations that provide space, dedicate personnel to specific tasks, and provide technological platforms and/or support are a few examples of the ways states leverage resources to create coordinated systems. It is important that partners possess sufficient capacity to meet their commitments. As one grantee put it, "In my experience, it's capacity. If you don't have capacity to do your own work, how can you partner with us to do our (collective) work?" Capacity means having skilled staff, dedicated time for tasks, and adequate staff supervision.

Performance Measures Are Important

Massachusetts formed an evaluation work group to help define: outcomes related to cost-effectiveness and caregiver experience of respite; variables including numbers participating in grant-funded projects, intensity of care recipients' needs, and differences in service models; and data elements including demographics, levels of care, perceived stress, and caregiver satisfaction. http://www.arch.memberlodge.org/Resources/Documents/2014%20National%20Respite%20Conference/Workshop%20PPTs/Kearns_Nazaire.pdf

A recent report from the Nebraska Department of Health and Human Services Lifespan Respite Program analyzes data collected from families receiving Lifespan Respite Care Subsidy funds. In the first phase of a five-year study, data from multiple sources including focus groups and an online survey were collected. Nebraska hired outside researchers to evaluate need, access, caregiver outcomes, system outcomes and cost effectiveness of the system. These data help Nebraska better understand cross-agency collaboration and identify outcomes for caregivers.

One grantee reported using data regularly collected from the state's online navigator system to issue six-month reports on the types of services and number of referrals. These reports guided state and local planning and advocacy.

To learn about ways to measure systems change and consumer outcomes, see: http://archrespite.org/images/docs/2014_Guidebooks/PerformanceMeasurmentGuide_web.pdf

For state examples of performance measurement tools, see: http://www.lifespanrespite.memberlodge.org/SampleTools

To learn more about lifespan respite research, see: *A Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders*. http://archrespite.org/images/docs/2015_Reports/ARCH_Respite_Research_Report_web.pdf

5 **Encourage grassroots support for lifespan respite.**

✔ **Identify key marketing messages and audiences.**
Increase community awareness and build community support for lifespan respite services by providing targeted, accurate information about the need for and benefits of respite.

✔ **Develop marketing tools and an information dissemination plan.**
Based upon identified priorities, and the audiences needing information related to those priorities, develop targeted messaging that: promotes understanding of respite; increases access to respite; and/or advocates for lifespan respite services.

✔ **Build and support local coalitions.**
Local partnerships can strengthen statewide efforts by engaging volunteers at the community level, identifying local resources, and raising public awareness.

Develop Marketing Tools

One grantee emphasized the importance of using the planning process to develop a product, "something that could be used, or should be used, as a marketing piece… when presenting to a potential funder," or when leveraging funds. By keeping funding goals in mind when planning, needs assessments and surveys may be translated in ways that can in turn be used for messaging, public awareness, and advocacy.

In order to raise awareness among service professionals across professional disciplines, and embed a caregiver and respite focus in existing services, the North Carolina Respite Project created and piloted five web-based, on-demand training modules entitled, *Planning and Using Respite: Working with Family Caregivers across the Lifespan*. The intention of this project is to build a "caregiver-savvy" ensemble of professionals. For more information on the project, see: http://www.arch.memberlodge.org/Resources/Documents/2014%20National%20Respite%20Conference/Workshop%20PPTs/Blater-Kendall-Fields_October.pdf

For examples of Marketing and Public Awareness Tools, including brochures, videos, and public service announcements, see: http://www.lifespanrespite.memberlodge.org/Marketing

Build and Support Coalitions

Some statewide coalitions effectively use local coalition and community groups to support their statewide efforts and promote sustainability.

- The Alabama Lifespan Respite Network built Sharing the Care (STC) models across the state with Lifespan Respite program funds, state, and private funds to help identify needs unique to a local community. STCs are diverse coalitions of volunteers who work to strengthen and support caregivers by increasing the availability and accessibility of respite resources. Activities may include public awareness, training, technical assistance and resource development. Alabama Lifespan Respite Network published a Sharing the Care (STC) Toolkit to serve as a resource for existing leaders of STC initiatives as well as individuals wishing to start a new STC community initiative. http://www.alabamarespite.org/index.php/get-involved/sharing-the-care
- The Colorado Respite Coalition held respite summits across the state and built regional coalitions to help develop a strategic plan that will ensure resources are more readily available in every region of the large state. http://www.coloradorespitecoalition.org/local-efforts/index.php

6 Use technology to inform, educate and increase access.

✔ Identify information needs for the diversity of Lifespan Respite audiences.
Inventory existing resources for information, education and support according to populations needing respite, and identify information gaps and inadequacies, such as reading levels, difficult to navigate websites, or language and cultural barriers.

✔ Make e-learning opportunities available to professionals and volunteers.
Make training and technical assistance more widely available through on-line and archived modules and videos. Look to other states and organizations for available materials and expertise.

✔ Sustain respite collaborations with the help of technology.
Use technology such as teleconferencing and webinars to promote person-to-person and region-to-region connections in defined, intentional, reliable and useful ways.

Maximize Sustainability with Technology

Several grantees identified technological platforms as important to sustainability. In the following example, a grantee's description makes a clear link between sustainability planning and "coordinated systems of accessible, community-based respite care services."

We have a publication website that we are ready to go live with. This is part of our sustainability plan, to make sure that we had a place on our website—its own button for family caregiver information—that would bring people to the resources that might be available for them in their community, and actually let them search for services.

Nebraska's eLifespan Respite provides a virtual workspace for the state's Respite Coordinators and authorized partners to connect and collaborate in a secure web-based environment. Nebraska's online system is the primary source for statewide respite infrastructure data collection and analysis allowing the state to track, for example, individual, cross-agency and employee caregiver/care recipient referrals for planned and crisis respite. http://www.arch.memberlodge.org/Resources/Documents/2014%20National%20Respite%20Conference/Workshop%20PPTs/Johnson_Sustaining_Respite_Collaborations_wTechnology.pdf

One grantee described a *Family Caregiver Solution Center*, part of her state's online navigator system, designed to help families locate services in their local areas. The system, a public-private enterprise, also includes an online Ask the Expert service through which families can anonymously pose a question that will receive a response from an expert affiliated with the state planning coalition.

In a second example, a grantee describes how to keep Planning and Coalition Partners informed and actively engaged through teleconferencing and interactive technological platforms.

Tomorrow we are going to have eight videoconference sites throughout (our state), and then we'll have three call-ins from (another state that was providing technical assistance to the group), and about 10 people at each site, and 20 here in our conference room.

7 Target and leverage funding.

✔ Look for targeted short-term funding.
Once you have developed a clear plan that includes goals and objectives, and is based upon needs assessment data, you are in a strong position to use your data-based plan to obtain funding that advances your goals and objectives.

✔ Leverage short-term funding to support long-term goals.
Short-term projects for demonstration of new models can provide the data necessary for making decisions going forward. Make sure that short-term projects address planning group priorities and match the goals of your master plan.

One grantee told us, "We don't ever start something regardless of grant funding unless there is a firm expectation that it is going to get sustained and move into infrastructure. Sometimes it doesn't work out that way, but you don't begin it thinking, "I've got these dollars. We'll just try it.'"

To support long term goals, a number of states use data from new and existing databases to help them better understand respite in the contexts of state systems and local communities, and to leverage support for more and better services. The process of needs assessments as part of sustainability planning yields "reliable information," in the words of one grantee, that can be used to leverage planning data into funding for grants and projects.

4 POLICIES

You tend to get bogged down when you work for the state. There's that bureaucratic weight that kind of presses you down. It's really exciting to have something new, that we're in control of and does something positive.
~Grantee

The charge of federal legislation to create "coordinated systems of accessible, community-based respite care services…" means that states must work to strengthen services both within agencies and programs, and across agencies and programs. Every few years when state elections occur and government agency personnel change, programs that are not supported by policy and/or funding may be in jeopardy. State Lifespan Respite Programs and Planning Partnerships in several states have established state and local infrastructure that require accessible and coordinated care—infrastructure that prevents the decline or demise of respite services during times of change.

In 2000, Oklahoma state agencies, private agencies and foundations voluntarily came together to implement a statewide lifespan respite program *without* legislation. By pooling existing resources, Oklahoma made respite vouchers available to families. And an existing statewide resource and referral system with toll-free numbers and website, made respite services and training accessible to families. http://soonersuccess.ouhsc.edu/ServicesPrograms/Respite.aspx

1 Encourage organizations to incorporate guidelines and policies.

- ✔ **Establish a Policy Advisory Board as part of your Planning Partnership.**
  Gather partners with commitment and decision-making authority—those "high enough on the food chain"—as one grantee puts it. Reach out to persons with first-hand knowledge of respite, and with legislative influence, to serve on State Respite Coalition Policy Task Force or Study Groups. Task the board with finding ways to embed respite into, and ways to coordinate with, existing programs and resources.
- ✔ **Seek state agency representation on Policy Advisory Boards.**
  Make sure to include high-needs or under-represented populations such as Veterans and military families, faith-based groups, or children at risk for abuse and neglect.

One State Lifespan Respite Coalition recognized that their group lacked representation by faith-based groups. They asked their state Governor to appoint the person from his cabinet who headed the state's faith-based initiative, thereby forging a connection with an important group, and with a legislative office.

❷ Develop government policies that support lifespan respite.

✔ Take inventory of assets and needs and identify priorities.

Initiate a formal process to assess existing and projected fiscal and in-kind resources, and existing and projected needs. Based on your assessment, identify current and potential gaps in services and systems, and identify priorities.

✔ Form a Translation Task Force and issue policy papers and briefs.

Task the group with translating needs assessment and survey data into papers or briefs that can be used to influence policy and fund priorities.

Support Lifespan Respite with New State Policies

A number of State Lifespan Respite Programs, Coalitions, and Planning Partners have successfully created sustainable infrastructures to support state lifespan respite. A sustainable infrastructure—*the statewide coordinated system of accessible community-based respite* mandated by federal law—is comprised of state respite websites, 1-800 numbers, respite registries, and real and virtual centrally located information about respite for all ages or disability conditions. In 2006, Arizona passed state legislation that supports their Lifespan Respite system infrastructure. In 2009, Texas Legislature initiated Take Time Texas to increase the availability of respite services for family members caring for a person of any age with any chronic health condition or disability. Nebraska relies on Tobacco Master Settlement Funds to support both respite services, and lifespan respite system infrastructure. In this state, a key legislator—who possessed both personal experience and professional knowledge of respite and "saw first-hand the need for caregiving"—was instrumental in shepherding legislation.

WHO are the people in your coalition?

- ✓ Do 50% of the members have the qualities in the blue columns?
- ✓ Does at least one member have political clout (direct or indirect)?
- ✓ Do members from key organizations have decision making power?

	Your coalition should *include or have strong connections with* people in the following systems. Make sure each box on the left can be checked.	Personal experience with respite	Professional knowledge of respite	Political clout and connections	Decision making power
☐	Faith communities	☐	☐	☐	☐
☐	Private sector non-profit organizations	☐	☐	☐	☐
☐	Private sector businesses and employers	☐	☐	☐	☐
☐	Volunteer organizations and clubs	☐	☐	☐	☐
☐	Health care sector	☐	☐	☐	☐
☐	Children's, aging, and disability groups	☐	☐	☐	☐
☐	Education community	☐	☐	☐	☐
☐	Charitable foundations	☐	☐	☐	☐
☐	Philanthropic individuals	☐	☐	☐	☐
☐	Legislators and other policy makers	☐	☐	☐	☐
☐	Veterans and military families	☐	☐	☐	☐

ARCH National Respite Network And Resource Center

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