State Lifespan Respite Grantee and Partner ORIENTATION GUIDE

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Respite is...
Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

Lifespan Respite Care Act definition PL 109-442

Getting Started

CONGRATULATIONS on being a new Lifespan Respite Grantee or Partner!

WELCOME to the Lifespan Respite Network.

As you may have already discovered, ARCH has a wealth of information that is available to view or download from the ARCH website, or that you can access through online networking or in-person events.

This orientation packet provides helpful information at your fingertips so you can quickly access the resources you need to make your state Lifespan Respite initiative a success.

Consider this a QUICK START GUIDE that you can easily use to locate essential information and resources, or just to learn more about the Lifespan Respite Care Program and its purpose.

As a new grantee the orientation packet will be helpful if you are wondering:

- How can I learn more about Lifespan Respite? On the ARCH website, start here.
- What are barriers to providing respite to family caregivers?
- What family caregiving resources and tools would be most helpful for my program?
- How can I contact and network with other state grantees and partners and learn about their accomplishments and best practices?
- Where can I find resources to start up or enhance my volunteer respite initiative?
- How can we start a respite provider or volunteer training program?
- What strategies do grantees use to build a strong respite coalition?
- Where can I find useful resources for respite providers in our network?
- How do grantees ensure sustainability for their respite initiatives?
- How do I know if our efforts are working?
- And much more!
Lifespan Respite Quick Links

I need some general information to get started now – just tell me where to go!

- Visit the new ARCH website
- Get help from ARCH on Lifespan Respite implementation at the Lifespan Respite Technical Assistance and Resource Center.
- Search the Resource Library.
- View Presentations and Webinars.
- Explore the ARCH YouTube Channel.

Need more information about respite services and programs?

- Listen to Conversations on Caregiving Podcasts.
- Search for Innovative and Exemplary Respite Services.
- Learn about Respite Voucher Programs or Volunteer Respite.

What Is Lifespan Respite?

Lifespan Respite is defined in the Lifespan Respite Care Act as “coordinated systems of community-based respite for family caregivers of children or adults regardless of special need.”

Respite across the lifespan focuses on the respite needs of all of the nation’s family caregivers such as those caring for older adults, children and adults with disabilities, Veterans, and individuals with chronic illnesses.

Since the Lifespan Respite Care program was first funded in 2009, the Administration for Community Living (ACL) in the U.S. Department of Health and Human Services has funded 38 states and the District of Columbia to establish or enhance Statewide Lifespan Respite systems. These statewide coordinated respite systems:

- Provide planned and emergency respite care;
- Recruit and train respite workers and volunteers; and
- Connect family caregivers to respite information and services.

The Administration for Community Living in the U.S. Department of Health and Human Services administers the Lifespan Respite Care Program. To learn more about the Lifespan Respite Care Program, go to the Administration for Community Living (ACL) Lifespan Respite Care Program webpage.
**Lifespan Respite Program Requirements**

As a state lifespan respite grantee there are requirements that your program must meet. As you plan for, develop, and implement your lifespan respite initiative be sure to:

1. Advance your state’s ability to meet respite needs;
2. Serve all populations and disability groups, especially unserved gap populations;
3. Coordinate with, and on behalf of, existing respite programs and infrastructures;
4. Have a consumer focus; and
5. Demonstrate collaboration with interested individuals, programs, and agencies.

Current and previous Lifespan Respite Programs have learned many lessons as they provide respite services for family caregivers:

- It takes time
- Build on model approaches
- Partnerships are essential
- Flexibility is key
- Measure performance indicators from day one
- Sustainability planning is critical at the outset

**Lifespan Respite and Family Caregivers**

When developing lifespan respite systems and services, it’s important to understand the scope of caregiving in the United States. At least 53 million family caregivers in the U.S. provide care to an adult or child with a disability or chronic condition.

**How does family caregiving look across the lifespan?**

- 54% of family caregivers care for an adult ages 18-75;
- 50% care for an older adult 50-74;
- 14% care for someone ages 18-49; and
- 1 in 5 households cares for a child with special healthcare needs, representing more than 14 million children.


- The value of caregiving has been estimated at $600 billion.


**How does family caregiving look in your state?**

Find information about the number of family caregivers and the value of their caregiving in your state.
ARCH Training and Technical Assistance Activities

The ARCH National Respite Network and Resource Center focuses on assisting and promoting the development of quality respite and crisis care programs; helping families locate respite and crisis care services in their community; and serving as a strong voice for respite in all forums.

The ARCH National Respite Network includes:

- The National Respite Locator, a service to help caregivers and professionals locate respite services in their community;
- The National Respite Coalition, the policy division of ARCH, advocates for preserving and promoting respite in policy and programs at the national, state, and local levels; and
- The Lifespan Respite Technical Assistance and Resource Center which is funded by the Administration for Community Living in the U.S. Department of Health and Human Services.

ARCH receives funding from the Administration for Community Living (ACL) to house the Lifespan Respite Technical Assistance and Resource Center (TARC). Through the TARC, ARCH provides training and technical assistance to the Lifespan Respite Network with a focus on performance measurement, sustainability, best practices, and research.

As a state grantee or partner you can benefit from the wide array of ARCH training and technical assistance activities provided. Explore the range of TARC activities including:

- Network-wide webinars
- Respite fact sheets on topics across age and disability categories
- Lifespan Respite grant best practices and key accomplishments
- Innovative and Exemplary Respite Services
- Learning Collaboratives
- Guidebooks and manuals
- Repository for respite training curricula
- Links to specific state resources and tools
- Performance measurement and evaluation guidance
- Sustainability planning
- Promotion of new respite research through the Respite Research Consortium
- Family caregiver resources, including Nine Steps to Respite fact sheets, LifeCourse Tools for Respite, and the National Respite Locator Service
- Assistance with planning State Lifespan Respite Summits to help build or strengthen coalitions and partnerships, prepare for federal Lifespan Respite Grant applications in the future, or enhance and sustain current Lifespan Respite grant activities:
▶ Annual National Lifespan Respite Conference
▶ Annual Lifespan Respite Grantee and Partner Learning Symposium

- Ongoing needs assessment of ARCH and State Lifespan Networks to assess new training and technical assistance needs
- Phone and email consultation
- Explore ARCH resources, training opportunities, and technical assistance that will enhance your state lifespan respite initiatives at the Lifespan Respite Technical Assistance and Resource Center.

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**Lifespan Respite 101**

ARCH provides introductory learning resources (e.g., webinars, presentation slides, guides, fact sheets, infographics, tools) on important lifespan respite topics:

- History of lifespan respite
- Barriers to accessing respite
- Collaborations and partnerships
- Respite care for special populations
- Respite models
- Building statewide respite coalitions

Take time to explore the Lifespan Respite 101 resources. Below are a few highlights to get you started.

- **View the Lifespan 101 Webinar.** This [2010 webinar](#) provides an historic look back at the start of the federal Lifespan Respite Care Program, including a review of Lifespan Respite legislation and best practices in State Lifespan Respite Programs that laid the foundation for the federal effort.

- **View Lifespan Respite: Who, When, Where, and How?** These [PPT slides](#) provide answers to the questions: What is respite? Why is it important? What are the barriers to accessing respite? What is Lifespan Respite and why do we need it?

- **Learn about Building State Respite Coalitions.** Every grantee is required to have a memorandum of understanding with a state respite coalition or statewide respite organization. Access ARCH’s tools for [Coalition Building](#).
Lifespan Respite Grantee and Partner Learning Collaboratives

ARCH is currently facilitating Learning Collaboratives on relevant respite topics that are open to Lifespan Respite Grantees, State Respite Coalition members, and other partners.

- Performance Measurement (resources only)
- Respite Voucher Programs
- Sustainability Planning
- Volunteer and Faith-Based Respite
- Implementing the National Strategy to Support Family Caregivers

Grantees and partners are also welcome to attend the following collaborative facilitated by the BREAK Exchange.

- Student Respite Program Collaborative

Learn more about the purpose of the individual Learning Collaboratives, how to participate in a learning collaborative, and where to access recordings of meetings, agendas, and other related resources.

Respite Program Models

Each State Lifespan Respite Grantee collaboratively develops and submits proposals for a wide array of respite programs and services. Below are examples of some key respite models that are currently being provided through the lifespan respite network.

- **Respite Vouchers**: ARCH has a Self-Directed Respite Voucher Guide and a Readiness Assessment Tool for states wanting to start up or expand respite voucher programs.

- **Volunteer and Faith-Based Respite Services**: See ARCH's many Volunteer and Faith-Based Respite Resources, including a Volunteer Manual, respite models, and a searchable database of volunteer and faith-based respite resources.

- **Respite Provider Recruitment and Training**: Learn about the Respite Provider Recruitment, Training and Retention Project, including respite provider core competencies, course descriptions, and training guides and surveys.

  ARCH, in partnership with the Respite Care Association of Wisconsin and the National Academy for State Health Policy, has a new respite provider training curriculum! The Respite Care Provider Training (RCPT) is a competency-based entry level training curriculum designed for programs providing respite care to individuals across the lifespan. A replication toolkit is coming soon.
Networking with State Respite Grantees and Partners

The State Respite Coalitions and Lifespan Respite Grantees provide an invaluable and accessible resource for all grantees. Often, grantees find that they can enhance their lifespan respite efforts when they take time to reach out to states engaged in similar initiatives.

- Find State Respite Coalition and Lifespan Grantee Contacts.
- To jump start making connections with other state grantees, join a Learning Collaborative.
- Read more about Lifespan Respite Grantee Activities and Key Accomplishments, including:
  - Report: In Support of Caregivers: Key Accomplishments of Lifespan Respite Grantees.
  - Webinars: on Best Practices in Lifespan Respite Care Programs.
  - Summaries: Final Reports of FY 2017 and FY 2018 State Lifespan Respite Grantees and summaries of FY 2020-FY 2023 State Lifespan Respite Care Program grant proposals.
- You don’t have to start from scratch! State Lifespan Respite grantees and state respite coalitions frequently share tools, reports, and resources they have developed through their Lifespan Respite grants. Take a look at State Lifespan Respite Tools and Examples.

This web page provides Shared State Tools that have been developed through Lifespan Respite grants across the county. Here are some of the topics covered:

- Coalition Building
- Emergency Respite
- Faith-Based and Volunteer Respite
- Family Caregiver Outreach and Information
- Integrating Respite into State Systems
- Needs Assessments and Surveys
- Public Awareness and Marketing
- Respite Provider Training, Recruitment, and Retention Resources
- Respite Voucher Guidance and Tools
- And much more!

- Take advantage of face-to-face interactions. Attend the annual National Lifespan Respite Conference and the Lifespan Respite Grantee and Partner Learning Symposium.
- If you are planning a State Lifespan Respite Summit, there are helpful planning resources from similar state events that can help you save time and replicate successful summit strategies.
Family Caregiver Resources

If you need resources and information to share with family caregivers, here are some options:

- Fact Sheets for Family Caregivers
- National Respite Locator Service
- How to Choose a Respite Provider
- Planning for Respite: Using the LifeCourse Tools for Respite
- How to Pay for Respite

Learn about all of the helpful caregiver resources on the ARCH website.

Respite Provider Resources

As the state grantee or coalition, you may be supporting and/or providing technical assistance to respite providers and organizations in your networks and coalitions. ARCH has resources for you to share on how to become a respite provider, and resources for existing providers on training, evaluation, respite models and more.

- Resources for Respite Providers and Organizations

Funding and Sustainability

The time to start planning for ongoing funding and sustainability is now. Having ongoing discussions around collaboration, leadership, data collection, and future funding is a high priority to sustain your lifespan respite program.

Ongoing collaboration between state respite grantees, respite coalitions, and other community partners is critical to ensure lifespan respite programs and initiatives have a solid footing for future funding.

- Sustainability Tools, resources, webinars, and funding guides are provided to assist Lifespan Respite grantees and their partners in sustaining their Lifespan Respite grant and State Respite Coalition activities. The resources should be useful to others in the respite network as well.

- Explore the matrix, Tools for Sustainability: Financing Strategies for Lifespan Respite Programs and State Respite Coalitions. It provides a summary of approaches and concrete state and local examples that can be used by lifespan respite grantees or programs and state respite coalitions to assist with financial sustainability.

- Join the Sustainability Planning Learning Collaborative.
Performance Measurement

ARCH has many tools to help you collect data to demonstrate how well your Lifespan Respite Grantee and Coalition activities are working. Engaging in meaningful performance measurement can help you improve service quality, enhance meaningful collaboration, and provide the story you need to share with funders and policymakers.

- Use the guide, Measuring Systems Change and Consumer Outcomes, and search the database for measurement tools, reports, and resources shared by other grantees and partners or nationally-recognized and validated tools.

Innovative and Exemplary Respite Services

The purpose of the Innovative and Exemplary Respite Services recognition is to establish a registry of programs and services to help advance a collective understanding of what respite best practices mean. Respite service providers can apply to be recognized as an Innovative and Exemplary Respite Service.

- Find more information and apply.
- Search for Innovative and Exemplary Respite Services by ages served, disability or condition, program type and level of recognition.

Respite Research

There are multiple respite research resources that can guide you in conducting program evaluation or performance measurement, or just to learn more about respite research.

- Learn more about these research initiatives:
  - Respite Research Consortium
  - Committee for Advancement of Respite Research
  - Respite Research Summit
  - BREAK Exchange
  - Respite Research Bibliography
Policy

Are there policy considerations I should be aware of as I develop or expand respite services in my state?

- To better understand how policy and respite initiatives are connected, read The Role of Respite in the National Strategy to Support Family Caregivers.
- Visit the National Respite Coalition for policy updates, legislative alerts, Lifespan Respite Care Act legislative history, advocacy tips, and talking points.

ARCH Staff Contacts

For more information about the ARCH team, go to the ARCH staff listing.

- To contact the ARCH team, you can call 703-256-2084 or email info@archrespite.org and you will be directed to the right person.
URL Links

References to Internet websites (URLs) were accurate at the time the orientation guide was written. If you find any broken links, please notify ARCH.

1. https://archrespite.org
2. https://archrespite.org/ta-center-for-respite/
3. https://archrespite.org
5. https://archrespite.org/resource-library/
7. https://www.youtube.com/@archnationalrespitenetwork1243
14. https://www.childhealthdata.org/browse/survey/results?q=9314&r=1
17. https://archrespite.org/caregiver-resources/find-a-respite-provider/
29. https://archrespite.org/provider-resources/provider-training-resources/#TrainingAccordion-1
32. https://archrespite.org/ta-center-for-respite/grantee-activities-and-key-accomplishment
41. https://archrespite.org/caregiver-resources/fact-sheets-for-family-caregivers/
42. https://archrespite.org/caregiver-resources/respitelocator/
43. https://archrespite.org/caregiver-resources/how-to-choose-a-respite-provider/
44. https://archrespite.org/caregiver-resources/planning-for-respite/#tools
45. https://archrespite.org/caregiver-resources/how-to-pay-for-respite/
46. https://archrespite.org/caregiver-resources/
47. https://archrespite.org/provider-resources/
51. https://archrespite.org/ta-center-for-respite/performance-measurement/
56. https://archrespite.org/research
57. https://archrespite.org/research/respite-research-consortium/
58. https://archrespite.org/research/respite-research-consortium/#CARR
59. https://archrespite.org/research/respite-research-summit/
60. https://www.breakexchange.org
63. https://archrespite.org/policy/
64. https://archrespite.org/about/arch-team/