

**Lifespan Respite Technical Assistance Center
2020-2025 Project Work Plan Summary (Year 5 Update)**

Goal: Provide technical support to the Lifespan Respite Care Program, its grantees and partners, and the national effort currently underway to ensure the availability of, and access to comprehensive, high quality respite care services and information for family caregivers across the lifespan.

- ✓ = Completed Task/Event
- = Underway or in development

Objectives	Key Tasks	Activity Status
<p>1. Advance a respite research agenda that supports activities and innovations to develop an evidence base for respite care and related services</p>	<p>Respite Research Consortium</p>	<p>Ongoing</p> <ul style="list-style-type: none"> • Link researchers to funders. • Provide quarterly updates on research and funding opportunities. See archived updates. • Link researchers to ARCH-recognized Innovative and Exemplary respite services to study impact of respite models. <p>See Innovative and Exemplary Respite Services Evaluation below.</p>
	<p>Establish and convene a Committee for the Advancement of Respite Research (CARR) charged with examination of how to improve access to and quality of respite services; identification of aspects of respite models that make them exemplary; encouragement of evaluation and replication of promising services; and translation of research findings into practice. Committee will also identify methods for evaluating the impact of alternative respite options to support family caregivers during the pandemic.</p> <p>Review RAISE Family Caregiving and Supporting Grandparents Raising Grandchildren Advisory Councils' recommendations for possible research areas.</p>	<ul style="list-style-type: none"> ✓ Full CARR Committee Meetings were held Oct 23, 2023, March 5, 2024, and June 4, 2024. Agendas and Meeting Notes. ✓ CARR workgroups: <ol style="list-style-type: none"> 1) Cost-Benefits Research 2) Identifying common data elements 3) Conducting culturally and linguistically competent research <p>Workgroup products completed:</p> <ul style="list-style-type: none"> ✓ White Paper: Measuring the Value of Respite Care ✓ The Value of Respite Model – A Multi-level, Life Course Perspective ✓ Environmental Scan - Resources to help expand culturally and linguistically competent respite research

Objectives	Key Tasks	Activity Status
	<p>CARR will review respite recommendations proposed by the Raise Family Caregiving (RFC) and the Supporting Grandparents Raising Grandchildren (SGRG) Advisory Councils and develop additional recommendations for future research to assist in the implementation of the <i>National Strategy to Support Family Caregivers.</i></p>	<ul style="list-style-type: none"> ✓ Alignment of CARR Work Groups to Key Recommendations in the National Strategy to Support Family Caregivers • White Paper on Common Data Elements in Respite Research (in draft) • Ensuring Cultural and Linguistic Competence: Guide for Respite Care Researchers (in draft)
	<p>Convene a Respite Research Summit to assess progress made to date in stimulating new respite research.</p>	<ul style="list-style-type: none"> • Respite Research Summit scheduled for October 28, 29 and 30, 2024. For agendas and speakers, see Summit website • Final report summarizing Summit conclusions and recommendations in year 5.
	<p>Collaborate with Building Respite Evidence and Knowledge (BREAK) Exchange Partnership to build a global data base of model, research-ready respite services, and a cadre of researchers willing to study them. The BREAK Exchange is housed at Marquette University.</p>	<p>Ongoing</p> <ul style="list-style-type: none"> • ARCH serves on the steering committee of the BREAK Exchange. • Link ARCH's Innovative and Exemplary services to the BREAK Exchange annually to encourage researchers to study these models. • Cohosted Webinars. See Webinars below.
	<p>Maintain a current Annotated Bibliography of Respite and Crisis Care Studies</p>	<ul style="list-style-type: none"> ✓ Updated and disseminated Annotated Bibliography, 6th Ed, with 19 new peer-reviewed journal articles through 2022.
	<p>Research and develop Ensuring Cultural and Linguistic Competence: Guide for Respite Care Researchers that provides information to researchers that will enhance their capacity to use culturally and linguistically competent approaches in the conduct of all phases of research including planning, theory development, instrumentation, analysis, interpretation, dissemination, and knowledge translation.</p>	<ul style="list-style-type: none"> • Tawara Goode with the Georgetown University National Center for Cultural Competence held a listening session with CARR members to inform guide development. • Release and disseminate the guide via the CARR at the Respite Research Summit on Oct 30, post on the ARCH and NCCC websites, and in other venues to diverse researchers and stakeholders who should partner in the conduct of research.

Objectives	Key Tasks	Activity Status
<p>2. Target the needs of Lifespan Respite Care Program grantees (past, present and future), and advance the overarching goals of the Lifespan Respite Care Program in program implementation, technical assistance, and resource development by identifying, developing, and disseminating T/TA resources that address the role of respite in supporting families in developing natural support systems.</p>	<p>Individual technical assistance. Respond to telephone, email or mail requests.</p>	<p>Ongoing</p>
	<p>ARCH Quick News Update. Disseminate monthly e-newsletter to respite field on timely news related to best practices, new research findings and reports, data sources, policy issues, family caregiving, disability and aging issues.</p>	<p>Produced monthly Archived newsletters</p>
	<p>Fact Sheets/Issue Briefs. Research and develop fact sheets on topics to be determined from training/TA needs assessment, work plan objectives, TA requests, consumer requests, and RAISE Family Caregiving and Grandparents Raising Grandchildren Advisory Council respite recommendations.</p>	<p>New since September 2023 ✓ Respite for Individuals with Autism</p>
	<p>Identify and promote Natural and Informal Respite Supports</p>	<p>Ongoing Identify and feature model volunteer and faith-based respite services in Learning Collaboratives, webinars, conference presentations, and through Innovative and Exemplary Respite Services recruitment, recognition, and promotion. ✓ ARCH Resources on Volunteer and Faith-based Respite ✓ Volunteer and Faith-based Respite Resources/Tools Data Base</p>

Objectives	Key Tasks	Activity Status
		See <i>Volunteer and Faith based Learning Collaborative and Podcasts</i> below.
	Hold network-wide and national webinars on a variety of topics using outside experts.	<p>Archived webinars</p> <p>New Webinars ARCH co-hosted webinars in 2023/24 with the BREAK Exchange.</p> <ul style="list-style-type: none"> ✓ “It’s like a weight lifted off your shoulder”: A qualitative study of adult carers taking a break, April 12, 2024 ✓ Family Respite Services: A Profile of Respite Support in Windsor, Ontario, Canada, November 16, 2023 <p>Volunteer and Faith-based Learning Collaborative hosted 4 network-wide webinars in the past year.</p>
	Learning Collaboratives	<p>See <i>Learning Collaborative Resources, PPTs, and meeting recordings</i>.</p> <p>1) Implementing the Respite Actions in the National Strategy to Support Family Caregivers Learning Collaborative –</p> <ul style="list-style-type: none"> ✓ Launched in February 2023, met monthly. All meeting recordings. ✓ LC Concluded September 5, 2024. ✓ In October 2023, refocused on Building Leadership Skills among grantees and partners to implement the National Strategy at the State level. Framework for the Lifespan Respite National Strategy Learning Collaborative Focus on Development and Utilization of Leadership Skills ✓ Updated May 2024, State Lifespan Respite Grant Activities Aligned with the National Strategy's Goals and Outcomes

Objectives	Key Tasks	Activity Status
		<ul style="list-style-type: none"> • Draft Report on Lessons Learned with Recommendations for Respite Actions in the revised National Strategy <p>2) Respite Voucher Learning Collaborative meets quarterly.</p> <ul style="list-style-type: none"> • <u>Scaling Up: Caregiver-Directed Respite Care in New York State</u>, September 14, 2023 • <u>Stretching Your Voucher Dollars to Serve More Caregivers: Cost-Sharing and other Strategies</u>, January 18, 2024 • <u>Reimbursement Strategies for Voucher Programs: Boon or Barrier for Family Caregivers</u>, March 14, 2024 • <u>Ask the Experts! Office Hours and Discussion with Experienced Mentors</u>, June 13, 2024 <p>3) Volunteer and Faith Based Respite Learning Collaborative meets quarterly and features webinars by LC members and outside experts:</p> <ul style="list-style-type: none"> • <u>Youth Volunteers Providing Respite for Children and Young Adults with Disabilities</u>, August 10, 2023 • <u>The National Volunteer Caregiving Network: Celebrating 40 Years of Volunteer Service to the Nation's Caregivers</u>, November 9, 2023 • <u>Creating Dementia-Friendly Congregations to Support African American Families with Fayron Epps</u>, February 29, 2024 • <u>Caregiver to Caregiver (C2C) Respite Network, A community of caregiving rooted in shared experience</u>, July 18, 2024

Objectives	Key Tasks	Activity Status
		<p>4) Performance Measurement Learning Collaborative is no longer meeting formally. Individual TA and coaching are available from ARCH.</p> <p>5) Sustainability Planning Learning Collaborative meets monthly. See Sustainability LC below.</p> <ul style="list-style-type: none"> • A 3-part Webinar Series on Lessons Learned has been proposed for year 5. The purpose of the series is to present: <ul style="list-style-type: none"> ◆ an understandable and usable framework for grantees, especially new grantees, to engage in sustainability planning, ◆ a demystification of sustainability concepts and planning, and ◆ practical help and shared experiences for state grantees, partners, and programs. <p>6) Learning Collaborative on Students as Respite Providers</p> <ul style="list-style-type: none"> ✓ Launched in April 2023 in collaboration with the BREAK Exchange and the Respite Care Association of Wisconsin. Meets monthly to encourage academic institutions, Lifespan Respite grantees, community-based respite providers and others to implement programs that recruit and train students (e.g., nursing, social work) to volunteer/intern as respite providers based on best practice models.

Objectives	Key Tasks	Activity Status
	<p>ARCH National Lifespan Respite Conference with Lifespan Respite track and Grantee/Partner Learning Symposium</p> <p>Hold annually in collaboration with a State Respite Coalition.</p>	<p><u>2023/24</u></p> <ul style="list-style-type: none"> ✓ ARCH hosted the 2024 National Lifespan Respite Conference, RAISE the Bar for Respite, with the New York State Caregiving and Respite Coalition and the New York State Office for the Aging, May 21-23, 2024 in Albany, NY. Presentation Slides. ✓ Lifespan Respite Grantee and Partner Learning Symposium was held in Albany on May 21, 2024. Symposium Agenda and PPTs ✓ Virtual Lifespan Respite Grantee and Partner Bring, Brag and Borrow Session, May 7 and 8, 2024. Recordings and PPT Slides <p><u>2024-2025</u></p> <ul style="list-style-type: none"> • ARCH will host the 2025 National Lifespan Respite Conference, RAISE and Engage, Launch Respite Now! with Alabama Lifespan Respite, April 1-3, 2025 in Huntsville, AL. Conference website. ✓ Call for Presentations is open until Oct. 1, 2024. • Lifespan Respite Grantee and Partner Learning Symposium will be held in Huntsville on April 1, 2025.
	<p>Support development and implementation of Culturally and Linguistically Competent Respite Services by developing a self-assessment checklist for Lifespan Respite grantees, partners, respite providers and others in the Respite Network.</p>	<p>Partnership with the <i>Georgetown National Center for Cultural Competence</i> (Completed)</p> <ul style="list-style-type: none"> ✓ Cultural and Linguistic Competence Assessment for Respite Organizations ✓ GUIDE FOR USING the Cultural and Linguistic Competence Assessment for Respite Organizations ✓ Webinar: An Introduction to the Cultural and Linguistic Competence Assessment for Respite Organizations (CLCARO) and Guide, April 29, 2024

Objectives	Key Tasks	Activity Status
		<ul style="list-style-type: none"> ✓ Resources on Cultural and Linguistic Competence, Equity in Respite Research, Cultural Adaptation, and State Tools from the ARCH Resource Library.
<p>3. Build national capacity at federal, state, and local levels to increase respite capacities in former grantee states, and states yet to receive funding, and to support their efforts to build or strengthen their state respite coalitions.</p>	<p>ARCH-sponsored State Lifespan Respite Summits Plan for and convene Summits in at least two states in years 2, 4 and 5 with priority given to states that have never had a Lifespan Respite grant or to former grantee states that need assistance in rebuilding or strengthening their respite coalitions or for sustainability planning.</p>	<p>None scheduled for year 5.</p>
	<p>Lifespan Respite 101 Toolkit and Resources</p>	<ul style="list-style-type: none"> ✓ Orientation Guide for Lifespan Respite Grantees and Partners
	<p>Network-wide Webinar Series on Addressing the Workforce Crisis by Recruiting and Training Respite Providers (scheduled for years 2-5).</p>	<p>Ongoing activities through Respite Provider Recruitment, Training and Retention Pilot Project in collaboration with NASHP informing this workplan activity.</p> <ul style="list-style-type: none"> ✓ National Respite Care Provider Training (NRCPT) and Replication Toolkit ✓ Presentations on respite provider recruitment, training and evaluation initiative made at <ul style="list-style-type: none"> ◆ <i>ADvancing States HCBS Conferences</i>, August 2022 and 2023 ◆ 2023 International Short Break Conference, Poland, ◆ The Arc National Convention, New Orleans, 2023 ◆ 2022 and 2024 National Lifespan Respite Conferences ◆ NASHP Webinar: National Respite Care Provider Training, Lessons from the States, August 28, 2024 • Evaluation Report • Journal Articles

Objectives	Key Tasks	Activity Status
	<p>ARCH Website Redesign. Consolidate the information, tools, trainings, and resources produced by ARCH and shared by State Lifespan Respite Grantees and Partners, and enhance search capabilities to increase ease and frequency of use by grantees, partners, family caregivers and the general public.</p>	<p>COMPLETED</p> <p>✓ New website went live in February 2023.</p>
	<p>National Respite Locator Service (NRLS). Expand and keep current database and funding/eligibility information and maximize visitation and search engine capabilities. Develop updated or new web platform.</p>	<p>COMPLETED</p> <p>✓ New NRLS launched March 2023</p>
	<p>State respite registry development. Determine state needs and provide resources and assistance.</p>	<ul style="list-style-type: none"> • Ongoing as requested
<p>4. Support long-term capacities and sustainability of lifespan respite programs, activities and/or state respite coalitions.</p>	<p>Facilitate Sustainability Planning Learning Collaborative for Lifespan Respite grantees and partners.</p>	<p>Meets monthly</p> <p>ARCH facilitator prepares discussion guides or tools to generate exchanges, supplement learning and respond to questions.</p> <p>See Sustainability Planning Learning Collaborative for meeting topics, recordings, resources and discussion guides.</p>
	<p>Monitor State progress in Sustainability Planning</p>	<p>Ongoing</p> <ul style="list-style-type: none"> • Post State Sustainability Plans and Documents on Website. Collect and post states' sustainability plans and related planning documents and worksheets on ARCH website. • Promote mentoring. Document peer-to-peer contacts and sustainability planning progress. • Organize and support an all-network 3-part webinar series presenting accomplishments of select Sustainability Learning Collaborative members – in planning

Objectives	Key Tasks	Activity Status
	<p>Update Respite funding/financing strategy documents.</p>	<ul style="list-style-type: none"> • Financing Strategies Matrix for Lifespan Respite Programs and State Respite Coalitions (<i>update in draft</i>) • Medicaid Waivers that Pay for Respite (<i>updated 2019</i>) • Federal Funding and Support Opportunities for Respite (<i>updated Feb 2021</i>)
<p>5. Identify, disseminate, and promote implementation of Lifespan Respite Best Practices</p>	<p>Grow Innovative and Exemplary Respite Services Registry Annually disseminate applications nationally and review applicants through a selection committee. At least 10 new Respite Services will be recognized as Innovative and/or Exemplary and will be added to the registry (annually in years 1-5).</p>	<ul style="list-style-type: none"> ✓ Four respite services were recognized by ARCH as Innovative and Exemplary in 2024. Press Release. ✓ Seven respite services recognized by ARCH as Innovative and Exemplary in 2020 were reviewed and renewed in 2023 for an additional three years of recognition. Press Release. • Respite services recognized as Innovative and Exemplary in 2021 now under review for renewal. Services recognized as Innovative only or Rising Stars may request redesignation to a higher status with appropriate documentation • National Call for Applications for 2025 Innovative and Exemplary Respite Services now open until October 8, 2024. ✓ Information Session held on Sept 4, 2024. Watch recording.
	<p>Promote Innovative and Exemplary Respite Services</p>	<ul style="list-style-type: none"> ✓ Three podcasts released in 2022: <i>Conversations on Caregiving – Exploring Respite Care Innovations</i> that featured select Innovative and Exemplary Respite volunteer respite services. <ul style="list-style-type: none"> ◆ Podcast 1: <i>Not free, but freely given</i> ◆ Podcast 2: <i>Respite is a contact sport, not a spectator sport</i> ◆ Podcast 3: <i>Flooding the airways with kindness</i> ✓ 2024 respite services selected by ARCH as Innovative and Exemplary

Objectives	Key Tasks	Activity Status
		<p>were recognized at the 2024 National Lifespan Respite Conference during the pending ceremony and featured in a breakout session presentation. PPT Presentation.</p> <p>✓ Online searchable data base of all Innovative and Exemplary Respite Services completed. New recognized services added annually. Services reviewed every 3 years to retain status as Innovative and Exemplary.</p> <p>Evaluation and Link to CARR</p> <p>✓ Four Evaluation Minigrants were awarded in April, 2023 to Innovative and Exemplary Respite Services</p> <p>✓ Learning Community of evaluation grantees meet monthly for ongoing technical assistance from ARCH.</p> <ul style="list-style-type: none"> • Grantees drafting their final data briefs. • Panel of Evaluation Grantees will present their preliminary findings at the virtual Respite Research Summit in year 5 to promote model testing, evaluation, and service replication.
	<p>Develop report on Lessons Learned in Innovative and Exemplary Respite Services</p>	<p>To be developed in year 5.</p>
	<p>Grow Lifespan Respite Grant Activities Database Summarize grantees' final reports to ACL, supplement with grantee interviews, and update state facts sheets of grantee objectives, activities, outcomes and partnerships in years 2 and 5.</p>	<p>✓ Six new state summaries of FY 2020 Lifespan Respite grantee final reports (AL, ID, NY, RI, TN and WI) were posted on the ARCH website and added to a new compendium, State Summaries of Lifespan Respite Grant Activities and Outcomes Final Reports FY 2020 Grantees</p> <p>✓ Seven one-page summaries of FY 2023 grant proposals have been prepared and posted on the ARCH website. An additional 9 FY 21 and 22 grantee summaries were updated with new activities funded by FY 23 supplemental funds.</p>

Objectives	Key Tasks	Activity Status
	Develop report on <i>Lifespan Respite Care Program Best Practices and Lessons Learned</i>	To be developed in year 5

Updated September 2024

This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,647,597 with 75 percentage funded by ACL/HHS and \$549,200 amount and 25 percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.