

**State Lifespan Respite Grant Activities Aligned with
National Strategy Goals and Outcomes
Working Document**



National Strategy to Support Family Caregiver Goals and Outcomes	Activities States are Already Doing	Ideas for Other Strategies
Goal 1: Increase awareness of and outreach to family caregivers		
<p>Outcome 1.1: Americans are educated about and understand the experience of family caregiving.</p>	<ul style="list-style-type: none"> ● Public awareness initiatives: <ul style="list-style-type: none"> ○ Nevada (Respite Refuels Caregivers) ○ Montana (It's OK to need it, it's OK to want it, and it's OK to get it) ○ North Dakota (Taking Care of You) ● Outreach to underserved populations and professionals: <ul style="list-style-type: none"> ○ North Dakota Lifespan Respite program developed PSAs to push out Native Elder Caregiver Curriculum through Tribal radio stations (watch 1st presentation in 2022 Bring, Brag and Borrow video). ○ Tennessee Respite Coalition Outreach to diverse groups (watch 2nd presentation in 2022 Bring, Brag and Borrow video). ○ South Carolina Respite Coalition's A Physician's Perspective on Using Respite to prevent Caregiver Stress ○ Washington: partnership with TBI community to provide support groups and respite 	

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<p>Outcome 1.2: Caregiver self-identification and knowledge of services is enhanced.</p>	<ul style="list-style-type: none"> ● Multiple states (MS, MT, NC, NV, NY, RI, TX): Efforts to increase respite awareness, referrals and access through state No Wrong Door systems See webinar examples. ● Idaho: Idaho Caregiver Alliance partners with Medicaid to implement the Idaho Family Caregiver Navigator 	
<p>Outcome 1.3: Outreach to family caregivers is improved.</p>	<ul style="list-style-type: none"> ● Montana: Database of respite referral sources and efforts to increase referral ● Idaho Caregiver Alliance hosts an annual caregiver conference attracting 250-300 caregivers, providing information, training, and opportunities for networking ● Multiple states: Ongoing public outreach efforts through coalition/state website, social media, coalition building, e-newsletters and in some cases, radio and TV spots 	
<p>Outcome 1.4: Family caregiving - and caregivers - are embedded in federal, state, territorial, tribal, and local planning.</p>	<ul style="list-style-type: none"> ● South Carolina: State legislature designation of ongoing funding for respite care ● Colorado: State level appointed Respite Care Task Force ● Rhode Island: State Plan for Family Caregivers ● South Carolina: Respite Plan - Take Another Break, SC! ● Massachusetts: Development of enhancements to the MassOptions website and MassOptions and ADRC specialists' respite referral process to 	

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	<p>improve access to respite services</p> <ul style="list-style-type: none"> ● Master/Multisector Plans for Aging address needs of family caregivers <ul style="list-style-type: none"> ○ Idaho: Plan for a Multi-generational Plan for Aging is in the early outreach and planning states in Idaho. ○ New York: The New York State Caregiving and Respite Coalition serves on the Stakeholder Advisory Committee for the NY Master Plan for Aging, and the lifespan respite grantee serves on the Master Plan for Aging Council. 	
<p>Outcome 1.5: Public-private partnerships at all levels help drive family caregiver recognition and support.</p>	<ul style="list-style-type: none"> ● Colorado: Caregiver Friendly Workplace Toolkit ● Nebraska, New York, and Wisconsin: Employer Engagement Initiatives use employer surveys to identify caregiver needs. See video of Panel <i>Supporting Working Caregivers through Employer Engagement</i> at the 2022 National Lifespan Respite Conference ● Oklahoma: Looking to integrate technology (e.g., Facebook Live events) with employer engagement efforts to broaden reach across state ● South Carolina: Development of informational referral cards, videos, and posters for health care community 	
Goal 2: Advance partnerships and engagement with family caregivers		
<p>Outcome 2.1: Family caregivers are recognized as essential partners in the care teams of the person(s) to whom they are providing support.</p>	<ul style="list-style-type: none"> ● New York: Some AAAs have created packets for caregivers for hospital discharge planners to help get them connected to caregiver support program. 	<p>This goal is primarily within the context of health care but can be interpreted more broadly.</p>

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<p>Outcome 2.2: Where appropriate, identifying services and supports needs for caregivers consistently starts with a review of family caregiver strengths and preferences using evidence-based assessments.</p>	<ul style="list-style-type: none"> ● South Carolina Caregiver Self-Assessment ● Nevada Respite Rx Caregiver Assessment ● Idaho: Use of T-Care in Idaho Family Caregiver Navigator 	
<p>Outcome 2.3: Where appropriate, family caregivers are included and considered in the development of care recipient's plans of care across a range of settings and circumstances.</p>	<ul style="list-style-type: none"> ● Multiple States: Many state respite coalitions engage and encourage family caregivers in coalition activities. 	
<p>Outcome 2.4: When policies are proposed or revised, the potential impact on family caregivers is anticipated and understood.</p>	<ul style="list-style-type: none"> ● Idaho: Idaho Caregiver Alliance hosts an annual Legislative Luncheon for policymakers to hear from caregivers and long-term care providers 	
<p>Outcome 2.5: The education curricula of professionals who will potentially work with family caregivers include specific topics and coursework designed to ensure they have the skills to do so effectively.</p>	<ul style="list-style-type: none"> ● Kansas: Respite Provider Training Initiative ● Multiple States: Ten states participated in a field test of a competency-based respite provider training curriculum. ● South Carolina Respite Coalition: developed a respite training course for the SC Department of Disabilities and Special Needs' (DDSN) Family-Selected Respite Program. ● Wisconsin: Respite Care Association of WI offers a variety of free online training courses for respite workers. 	

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Goal 3: Strengthen services and supports for family caregivers.		
<p>Outcome 3.1: Person- and family-centered, trauma-informed, and culturally appropriate caregiver services and supports are accessible for all family caregivers.</p>	<ul style="list-style-type: none"> ● Washington: Tribal Kinship Navigator Program ● Nevada used the LifeCourse tools for respite in their Respite Rx pilot voucher program to ensure person and family-centered and culturally competent respite care. See Charting the LifeCourse Tools for Respite: Examples from State Lifespan Respite Programs ● Montana, Rhode Island and others use trusted members of diverse and underserved communities to share information about respite services. ● Idaho: Spanish speaking navigators are available through Idaho Family Caregiver Navigator 	
<p>Outcome 3.2: Family caregivers can obtain respite services that meet their unique needs.</p>	<ul style="list-style-type: none"> ● Multiple states: Twenty-one current and former state Lifespan Respite grantees/partners implement self-directed respite voucher, grant or reimbursement programs to help family caregivers pay for respite (AL, AR, AZ, CO, DE, ID, IL, MD, MT, MS, NC, ND, NE, NY, OK, RI, SC, TN, VA, WA, and WI). ● Multiple States: Most state grantees partner with ADRCs/No Wrong Door Systems to provide information and referral to respite care or help connect family caregivers to respite services through State Respite Coalitions, statewide information lines and/or state respite registries. See webinar examples ● New York: Caregiver & Respite Wellness Center 	

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<p>Outcome 3.3: A range of evidence-based, education, counseling, and peer support services are available to family caregivers.</p>	<ul style="list-style-type: none"> ● Alabama: Caregiver Wellness Initiative to increase emergency respite funds and provide no-cost statewide mental health counseling to caregivers ● Idaho: Family Caregiver Navigator ● Colorado: Stress Busting for Family Caregivers training, Coming Up for Air respite weekends ● Montana: Respite Retreats ● New York: Powerful Tools for Caregivers training offered through NYS Caregiving and Respite Coalition 	
<p>Outcome 3.4: Family caregivers and families have safe places to live, nutritious food, and adequate transportation.</p>	<ul style="list-style-type: none"> ● Washington Lifespan Respite grantee partners with a crisis nursery that supports vulnerable families ● Nevada: Nevada initiative to create respite options for families with an individual with a dual diagnosis (IDD/SED) ● Multiple states: Lifespan respite programs throughout the country recognized the need for food, transportation, and technology from the outset of the COVID-19 pandemic, and worked to incorporate these into their service models. 	
<p>Outcome 3.5: Family caregivers have innovative tools and technology to assist them in their roles.</p>	<ul style="list-style-type: none"> ● Multiple states: Distribution of tablets and technology support during COVID-19 pandemic and ongoing ● Multiple states: Partnership with and/or promotion of technology tools for families (e.g., Trualta) ● Alabama: Partnership with State Assistive Technology Program to make technology available to family caregivers through their <i>Helping Those</i> 	

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	<p><i>Who Care</i> program. Webinar presentation.</p> <ul style="list-style-type: none"> ● Oklahoma: Developing a respite app to connect families to services ● Tennessee: Developing app for caregivers to apply for TRC respite vouchers ● Colorado: Planning to do a COVID-19 study on best practice regarding virtual programming ● Washington: Mini-tech grant program to increase equity in access to virtual supports and services 	
<p>Outcome 3.6: Volunteers of all ages and abilities are trained, vetted, and ready to assist family caregivers.</p>	<ul style="list-style-type: none"> ● Rhode Island: CareBreaks Volunteer Students Respite Initiative. Video and Toolkit ● New York: Awards mini-grants to volunteer and faith-based community agencies and requires training of volunteers ● Massachusetts: Piloting a respite program using trained university students that will create an academic respite framework to serve as a tool for other college and universities seeking to replicate the MLRC-UMA model ● South Carolina: Supports Break Room respite using faith and community-based volunteers ● North Carolina: Established a statewide Volunteer Caregiver Respite Consortium ● Colorado: Expanding reach to faith community using their toolkit ● Wisconsin: Developing a toolkit for universities to establish students as respite workers program. 	

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	<p>Webinar presentation</p>	
<p>Outcome 3.7: Family caregivers’ and care recipients’ needs are a key consideration in emergency response efforts.</p>	<ul style="list-style-type: none"> ● Idaho: Family Caregiver Navigator manages risk and prevents crisis through text and personal connection with family caregivers ● Multiple states (AZ, MD, ND, NE, NV, SC, WI): Provide emergency respite vouchers and guidance for providing emergency respite ● New York: Working on emergency preparation program for caregivers ● North Carolina: Working on caregiver and respite resource training presentations for community health, child welfare, and adult protective services workers; and developing outreach materials for caregivers in crisis. Webinar presentation 	
<p>Outcome 3.8: Family caregivers have the skills and tools necessary to prepare for the future needs of the person they support.</p>	<ul style="list-style-type: none"> ● Idaho: Idaho Family Caregiver Navigator telephone and online program 	
<p>Outcome 3.9: An agile, flexible, and well-trained direct care workforce is available to partner with and support family caregivers.</p>	<ul style="list-style-type: none"> ● Arkansas: Caregiver Training Program that provides CEUs for in-home caregivers and registered nurses ● Alabama: Free respite training is available through CareAcademy ● Wisconsin: Development of Respite Care Registry and respite training program ● Multiple states (AR, IL, KS, MT, MA, NV, NM, NY, SC and WI) participated in ARCH/NASHP/RCAW respite recruitment and provider training pilot and will continue to provide and enhance training after 	

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	the field test.	
<p>Outcome 3.10: Kinship families and grandfamilies are recognized, supported, and valued within the child welfare system.</p>	<ul style="list-style-type: none"> • Multiple states: Inclusion of these populations in voucher program eligibility • Idaho: Lifespan respite funds supported Kincare support groups across the state. 	
<p>Goal 4: Ensure financial and workplace security for family caregivers.</p>		
<p>Outcome 4.1: Family caregivers can provide care without negative impacts to their near- and long-term financial health.</p>		
<p>Outcome 4.2: Family caregivers have access to employee-centered flexible workplace policies and practices that support work/life balance and professional performance when personal circumstances change.</p>	<ul style="list-style-type: none"> • Multiple states have or plan to engage with local employers, including: <ul style="list-style-type: none"> ○ Colorado: Caregiver Friendly Workplace Toolkit ○ Nebraska, New York, and Wisconsin: Employer Engagement Initiatives use employer surveyors to identify caregiver needs ○ Oklahoma: Exploring hosting virtual events to engage employers/employees 	
<p>Outcome 4.3: Family caregivers have access to and use of financial education and advance planning tools.</p>		
<p>Outcome 4.4: Long-term services and supports are more affordable, allowing</p>	<ul style="list-style-type: none"> • Arizona: Family Caregiver Reimbursement Program provides reimbursement for eligible home modifications and assistive care technology costs. 	

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<p>family caregivers to reduce their out-of-pocket costs.</p>	<ul style="list-style-type: none"> • Idaho: The Idaho Caregiver Association successfully advocated for legislation to improve access of Certified Family Home providers to tax/income changes that would help them maintain their home for caring for adults with disabilities and older adults. • Multiple states: Twenty-one current and former state Lifespan Respite grantees/partners implement self-directed respite voucher, grant or reimbursement programs to help family caregivers pay for respite (AL, AR, AZ, CO, DE, ID, IL, MD, MT, MS, NC, ND, NE, NY, OK, RI, SC, TN, VA, WA, and WI). 	
<p>Goal 5: Expand data, research, and evidence-based practices to support family caregivers.</p>		
<p>Outcome 5.1: A national infrastructure will exist to support the collection of population-based data, using standardized wording of the definition of family caregiving, and standardized wording of questions that address the core characteristics of the family caregiving experience.</p>		

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<p>Outcome 5.2: Family caregiver research facilitates the development and delivery of programs and services that support and enhance the health and well-being of the family caregiver and the person receiving support.</p>	<ul style="list-style-type: none"> • A current focus of the ARCH Committee for Advancement of Respite Research (CARR) is identifying common data elements that measure benefits to family caregivers that may be shared across programs and systems. • ACL’s Office of Supportive Caregiver Services, within AoA, will institute new performance reporting for the Lifespan Respite Care Program grantees beginning in 2024. This new reporting framework will provide ACL and the field of respite care with critical information on the numbers of family caregivers served by the program as well as advancements being made by grantees in the development of state Lifespan Respite. 	<ul style="list-style-type: none"> • Collaborate with local and national researchers interested in caregiving and respite care
<p>Outcome 5.3: Promising and evidence-informed practices are promoted, translated and disseminated to support family caregivers in the delivery of health care and social services.</p>	<ul style="list-style-type: none"> • ARCH recently introduced a competitive mini-grant evaluation project with four recognized Innovative & Exemplary programs to document fidelity to intervention model, to measure caregiver outcomes, and to identify promising interventions for replication. 	

Questions for Group:

- Are there activities you currently do or plan to do soon that align with the National Strategy that should be added to this document?
- Do you have examples of activities you are undertaking that may not align with any of the strategy’s identified outcomes but might help advance the overall strategy?

Sources:

ARCH National Respite Network and Resource Center

- 1) In Support of Caregivers: Key Accomplishments of Lifespan Respite Program Grantees.
<https://archrespite.org/ta-center-for-respite/grantee-activities-and-key-accomplishment/>
- 2) Lifespan Respite Grantee and Partner Learning Symposiums, Bring, Brag and Borrow Presentations, 2022, 2021 and 2019
<https://archrespite.org/ta-center-for-respite/lifespan-respite-grantee-partner-learning-symposiums/>
- 3) Lifespan Respite Grantee Proposal Summaries
<https://archrespite.org/ta-center-for-respite/grantee-activities-and-key-accomplishment/#GranteeSummaries>
- 4) Lifespan Respite Learning Collaborative Presentations
<https://archrespite.org/ta-center-for-respite/learning-collaboratives/>
- 5) Select Lifespan Respite Best Practices – Webinars
<https://archrespite.org/ta-center-for-respite/grantee-activities-and-key-accomplishment/select-best-practices-in-lifespan-respite-webinars/>
- 6) State Lifespan Respite Tools & Examples by Category
<https://archrespite.org/ta-center-for-respite/state-lifespan-respite-tools-examples-by-category/>
- 7) State Summaries of Lifespan Respite Grant Activities and Outcomes: Final Reports, FY 2017 – FY 2020/21
<https://archrespite.org/library/state-summaries-of-lifespan-respite-grant-activities-and-outcomes-final-reports-fy-2017-fy-2020-21/>

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