

Tools for Sustainability

Financing Strategies for Lifespan Respite Programs and State Respite Coalitions

1 Make Better Use of Existing Resources

Approaches:

- ⚙️ **Redeployment:** Shifting funding from higher cost to lower-cost programs and services.
- ⚙️ **Operating More Efficiently:** Cutting costs that can be reinvested in expanding services.
- ⚙️ **Reinvestment:** Allocating funds that can be “saved” through redeployment, refinancing, or reductions in spending to new or alternative supports and services.
- ⚙️ **Embed Lifespan Respite Activities into Ongoing State Efforts:** State agencies and others continue to face economically challenging times. Rather than relying on new funding, some states are working diligently to embed the activities they developed as a result of the Lifespan Respite projects into ongoing sustainable state efforts.

Examples:

- ⚙️ Many Lifespan Respite grantees collected respite provider lists or registries as part of a needs assessment or environmental scan. Some of the grantees (*NE, NY, TX, VA*) used state or federal grant funds **to develop or enhance online databases of respite providers and programs**. To ensure sustainability, others embedded their respite provider lists and resources into state respite coalition websites (*AL, CO, IL, WI*) or the ARCH National Respite Locator Service (*DC, NC, PA*).
- ⚙️ In recent years more states increased the reach of Lifespan Respite grant funds through the use of **respite vouchers or subsidies** to allow family caregivers to purchase their own planned or emergency respite services (*AL, CO, IL, MD, MT, NC, NE, NV, OK, SC, TN, VA, WA, WI*) and/or developed or expanded less costly respite using **volunteers** (*AL, NE, NV, NY, RI, TN*).
- ⚙️ **Innovative voucher approaches** have been implemented including using a “Universal Respite Voucher” prioritization tool to provide respite to gap populations with greatest need (*Alabama*) – and addressing emergency needs through a statewide emergency respite voucher program where families can either select their own provider or obtain home care services from an agency that the state contracts with (*Maryland*).
- ⚙️ More states are **collaborating with their Aging and Disability Resource Centers (ADRCs) or No Wrong Door (NWD) Systems** to increase access to respite services and providers (*AL, ID, MT, NC, NV, NY, SC, SD, TN, TX*).
 - The *Idaho Lifespan Respite grantee*, working with the ADRC and the Idaho Department of Health and Welfare 211 Careline, created a caregiver landing page on the 211 website that includes an online respite information site with search capability.
 - *Montana* updated its Lifespan Respite Coalition website through coordination with the ADRCs, expanding the statewide resource database to include respite providers. A state map was also added to the website so caregivers and stakeholders can view where the respite vouchers are being used.

- **New York State Office for Aging** expanded access to caregiver services through improved respite listings in the NY Connects Resource Directory across all ages and disabilities. This interagency directory provides consistent and comprehensive information on long-term services and supports (including respite).
- **South Carolina** has built on existing infrastructure to systematically establish a coordinated statewide Lifespan Respite system through the ADRCs, the SC Respite Coalition (SCRC), and Family Connection of SC. Gaps have been filled by providing direct respite services through respite events, faith-based respite programs, and development of a voucher program.
- **South Dakota** is creating a Lifespan Respite website to include how to access state and federal respite programs using the Dakota at Home (ADRC) Resource Directory database.

Maximize Federal and State Revenue

Approaches:

- **Grant Writing:** Applying for discretionary grants from public agencies.
- **Leveraging:** Maximizing federal revenue by taking advantage of programs that provide funding contingent on state, local, and private funding.
- **Refinancing:** Utilizing other sources of funding to pay for activities already provided, thereby freeing up your own funds for a new use.
- **Administrative Claiming:** Using available Medicaid and other funds to cover an array of administrative costs, based on local match funds.

Examples:

- The **Nebraska Lifespan Respite Network** has relied on the Nebraska Health Care Cash Fund and the related Tobacco Settlement Trust Fund to support respite services and respite system infrastructure.
- **Rhode Island** leverages grant funds with the Older Americans Act Title III-E National Family Caregiver Support Program and RI state funds designated for respite services to increase participation in the CareBreaks (CB) program. The CB program helps pay part of the respite care costs for families with low to moderate income who have no access to any other program for subsidized respite care.
- **North Carolina** received support from the NC Division of Medical Assistance (DMA) that manages the state Medicaid Program resulting in DMA's **Money Follows the Person Rebalancing Fund**. Funds were used to support Family Caregiver-to-Caregiver Peer Support grantees across the state.
- The **Respite Care Association of Wisconsin** provides respite resource and referral services and is funded with state funds from the Wisconsin Department of Health Services – Division of Medicaid Services.

Create More Flexibility in Existing Resources

Approaches:

- **Coordination:** Aligning categorical funding from a number of agencies and funding streams to support community and program-level initiatives, such as interagency fiscal partnerships to support direct services or infrastructure.
- **Pooling:** Combining a portion of funds from several agencies and programs into a single unified funding stream.
- **Decategorization:** Advocating for removing narrow eligibility requirements and rules governing allocations from existing funding streams.

Examples:

- In 2014, **Alabama Lifespan Respite and the State Respite Coalition** partnered to conduct a caregiver support survey in faith-based communities. Based on the needs identified in the survey, Alabama Respite developed a toolkit entitled **Providing Breaks for Family Caregivers: A Toolkit for Volunteers and Faith Communities** to expand respite volunteer options.
- The **Arkansas Division of Aging and Adult Services (DAAS)** provided staff, outreach and marketing, and a State General Revenue cash match to support caregiver/respite worker training.
- **Alabama Lifespan Respite, Tennessee Respite Coalition, and Lifespan Respite Washington** draw on different state agency funds to provide respite services through a coordinated funding stream.

- ⚙️ **Develop Interagency Fiscal Partnerships:** A core component of a coordinated Lifespan Respite system is developing partnerships with other state agencies to support direct services or the system's infrastructure.

4 Build Public-Private Partnerships

Approaches:

- ⚙️ **Leveraging:** Creating partnerships that expand the fiscal base for respite services.
- ⚙️ **Leadership:** Building new, shared public-private leadership for investments in respite services.
- ⚙️ **Technical Assistance:** Creating opportunities for sharing knowledge, skills and technical resources needed to create and sustain systems of support and services.
- ⚙️ **Grassroots/Community Engagement:** Grassroots support and efforts, especially through the use of volunteers, the faith-based community, and other localized resources are showing promise in assisting with long-term sustainability.
- ⚙️ **Foundation Funding:** Public funding options are scarce and unlikely to grow in the near term. Private funding has also been limited in these economically challenging times. But private foundation, including community foundation funds and private donations should not be overlooked. States can look to state respite coalitions or other private sector partners to help pursue such funding opportunities.

- ⚙️ **Lifespan Respite Washington** collaborated with the state Department of Health, Children/Youth with Special Health Care Needs (CYSHCN) program to conduct an outreach pilot program. This expands their ability for caregivers of children to access respite voucher programs through local health departments using Maternal Child Health funds. This partnership has continued for three years as a model for other special populations to access respite vouchers for their constituent populations, e.g., disease/condition groups.

Examples:

- ⚙️ The **Alabama Lifespan Respite's Sharing the Care model** uses diverse community volunteer stakeholders to identify gaps and barriers to respite, provide education and public awareness about the need for and benefits of respite, develop new, or expand existing resources, and advocate at the grassroots level to educate federal, state and local legislators. Alabama Respite has successfully received community foundation grants to sustain these and other LR activities including partnering with home health agencies across the state.
- ⚙️ Using Lifespan Respite grant funds, several states have expanded respite services and options to gap populations (e.g., those with mental health conditions, autism, dementia) through **targeted respite mini-grants** to local service providers and faith-based organizations. Funding mini-grants helps demonstrate need and community buy-in. In turn, this can help leverage other funds (**AL, AR, MA, NC, NY, OK, SC**).
- ⚙️ **Nebraska** sought public/private partnerships by leveraging their local Lifespan Respite Coordinators to **engage businesses** in increasing awareness of employee caregiver issues, the benefits of respite care, and access to resources available through the NE Lifespan Respite Network. One example of how this reached families is that the University of Nebraska Medical Center and Nebraska Medicine both integrated information on respite resources into their employee new hire orientation process.
- ⚙️ In **Pennsylvania's TakeFive initiative**, which was an outgrowth of their Lifespan Respite grant, the PA Department of Public Health funded over 20 community and faith-based volunteer respite initiatives across the state. Key to sustaining many of these efforts was the ongoing technical assistance funded by the state through the University Center on Excellence in Developmental Disabilities at Temple University.
- ⚙️ Grantees **partnered with university students** to provide respite:
 - In 2016, **Rhode Island** launched the **Student Respite Initiative**, a workforce development respite option with Rhode Island College (RIC) and University of Rhode Island (URI) nursing programs that offered **student nurses** clinical experience and course credit while being matched to low to moderate income families who had no access to subsidized respite care. In 2018, they added two more nursing programs to the initiative.
 - One of **Tennessee's Area Agencies on Aging and Disability (AAAD) and Aging and Disability Resource Centers (ADRC)** developed a model for collaboration with **social work students** providing each student with respite provider training and a \$500 stipend as long as they would provide at least 80 hours of respite care.
- ⚙️ **Lifespan Respite Washington** has expanded the reach of their respite care services to support unpaid, unserved family caregivers through several efforts: A grant serving eight tribes in Washington State; matching funds from

a crisis nursery that uses no government dollars; annual financial donations from two local foundations; and a partnership with a recent state Traumatic Brain Injury grantee.

- ⚙️ The **Colorado Respite Coalition** received funding from a private foundation to fund respite activities, including collaboration, and a respite toolkit to help families and professionals better understand how to navigate Colorado funding streams for respite services.
- ⚙️ **Alabama Lifespan Respite** secured funding from The Christopher and Dana Reeve Foundation to provide respite reimbursement funding for families caring for someone with paralysis caused by spinal cord and other injuries, diseases or birth conditions.

5 Create New Dedicated Revenue Streams

Approaches:

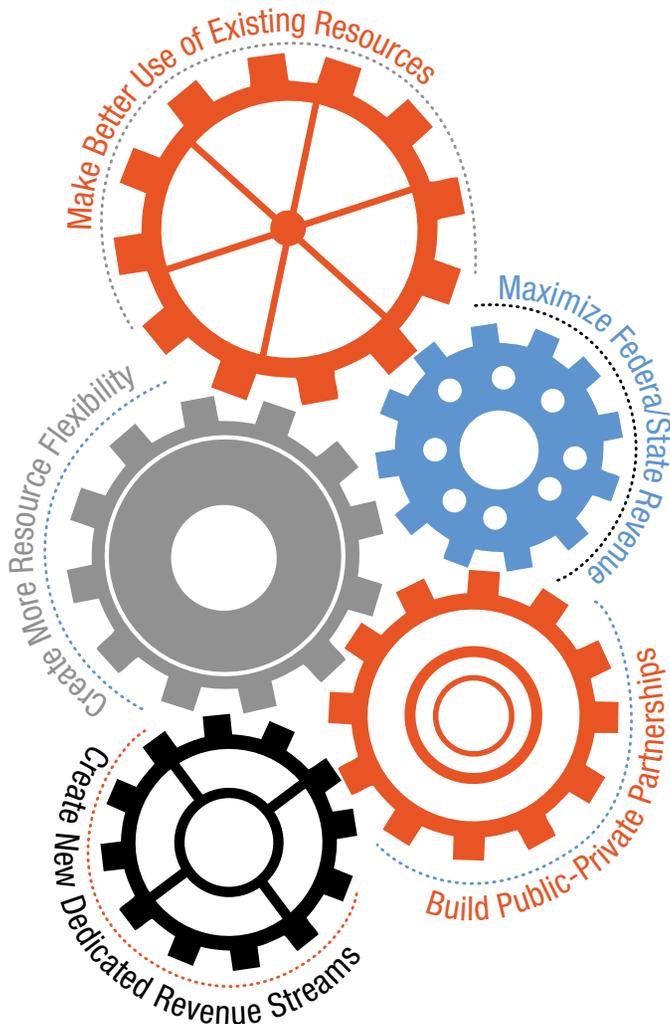
- ⚙️ **Fundraising:** Organizing community fundraising campaigns to generate support.
- ⚙️ **Charging Fees for Service:** Charging fees to service users to help cover the program costs.
- ⚙️ **Generating Unrelated Business Income:** Creating revenue by pursuing an activity not related to the mission of the organization or program.
- ⚙️ **Advocacy/Education:** Committing resources to support a coalition composed of diverse agencies and organizations representing a broad spectrum of the aging, disability, and chronic illness community can help leverage private and state funding, promote public awareness and maintain support, and engage new resources and partners to support respite services and Lifespan Respite systems for the long-term.
- ⚙️ **Special Taxing Districts:** Creating independent units of government with taxing authority dedicated to a specific purpose.
- ⚙️ **Special Tax Levies:** Adding on to existing taxes, with the additional revenues earmarked for specific programs or services.
- ⚙️ **Fees and Narrow-Based Taxes:** Generating revenue from fees or taxes on specific segments of economic activity, usually the use of a service or good.
- ⚙️ **Lotteries and Gaming:** Using lottery and gaming proceeds to support respite programs and initiatives.

Examples:

- ⚙️ The **Tennessee Respite Coalition** makes effective use of frequent fundraising campaigns and events to increase community engagement and support the respite services they provide.
- ⚙️ The **Montana Lifespan Respite Program** uses cost-sharing in its respite voucher program, which stretches the funds so that more caregivers can be served.
- ⚙️ Coalitions in **Alabama, Colorado, Idaho, Nebraska, South Carolina, and Wisconsin** successfully advocate for state budget line items or other forms of legislative action to support respite services.
 - The **Colorado Respite Care Program**, with the help of Easterseals Colorado and in partnership with the Colorado Respite Coalition, successfully advocated for \$350,000 State General Funds for State Fiscal Years (SFY) 2016 and 2017, an increase from \$250,000 in 2015 and \$150,000 in 2014. The funds were designated for Lifespan Respite supports, with the majority distributed as community grants and family respite vouchers.
 - The **Idaho Caregiver Alliance (ICA)** and the **Idaho Commission on Aging (ICOA)** gathered survey and assessment data over a three-year period to publish the *Idaho Lifespan Caregiver Action Plan*, which gained unanimous support from the 2017 Idaho Legislature, and includes objectives to enhance the state's Lifespan Respite system and funding strategies.
 - The all-volunteer **Nebraska Respite Coalition** focuses almost exclusively on advocacy and public awareness. They host events for state legislators to ensure that state funds for the Lifespan Respite Program are maintained and partner with the NE Lifespan Respite Network to provide family caregiver education events to support family caregivers who in turn help with advocacy efforts. The NE Special Needs Ministry Network is sponsored by the Coalition to provide resources, trainings and networking for faith-based organizations to encourage family caregiver support, including respite activities.
 - **South Carolina** has built state level respite care funding by maintaining funding for respite vouchers for individuals caring for someone with Alzheimer's or dementia, and successfully advocating in 2015 for \$1 million for respite vouchers as a recurring line item in the Department of Aging budget. By state FY 17-18, with advocacy from respite champions and coalitions across the state, the total state appropriation was further increased to \$2.4 million in recurring respite funds.

- ⚙️ **Income Tax Check-Offs:** Allowing taxpayers to designate a portion of their tax liability or to donate a part of their refunds to specific services or programs.

- ⚙️ Funding for the *New Jersey Statewide Respite Care Program*, which has been in existence since 1988 for family caregivers caring for individuals age 18 or older and have disabilities, comes from **casino revenues**.
- ⚙️ Some states, counties and cities (*OH, San Francisco, CA*) are using **special tax levies** to earmark funds for specific human services needs, including caregiver supports and respite.
 - In 2016, *San Francisco* passed legislation for The Dignity Fund to guarantee funding to enhance support services to help older adults and adults with disabilities age with dignity in their own homes and communities. The Department for Aging and Adult Services (DAAS) administers the fund.
 - In *Ohio*, more than 80% of the state's 88 counties have tax levies that benefit senior services. These levies support a wide array of services for older adults including respite and adult day care.



Need More Information?

If you have questions about your financial sustainability efforts or want to know more about how the ARCH Lifespan Respite Training and TA Center can provide targeted technical assistance in this area, please contact ARCH or visit archrespite.org. For additional resources on financial sustainability for respite services visit lifespansrespite.wildapricot.org/Sustainability_Tools.

This matrix was adapted from an earlier version prepared by *The Finance Project* in collaboration with ARCH.

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