Lifespan Respite Learning Collaborative

on the National Strategy to Support Family Caregivers

April 20, 2023
## Agenda

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<tr>
<th>Time</th>
<th>Session</th>
<th>Presenter/Panelists</th>
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<tr>
<td>2:00 – 2:05 PM</td>
<td>WELCOME AND OVERVIEW OF AGENDA</td>
<td>Meghan Kluth, ARCH Consultant</td>
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<td>2:05 - 2:10 PM</td>
<td>WHITE HOUSE EXECUTIVE ACTIONS</td>
<td>Jill Kagan, ARCH</td>
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<td>2:10 – 2:20 PM</td>
<td>REVIEW OF RESpite ACTION GUIDE &amp; DISCUSSION</td>
<td>Kimberly Hodges, Policy Associate, Behavioral Health, Aging, and Disability National Academy for State Health Policy</td>
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<td>2:20 - 3:20 PM</td>
<td>APPROACHES TO STATE POLICYMAKING AND DIVERSIFIED FUNDING</td>
<td>Presentations from:</td>
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<td>● Siena Ruggeri, Policy Analyst, Center for Consumer Engagement in Health Innovation, Community Catalyst</td>
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<td>● Lisa Schneider, Executive Director, Respite Care Association of Wisconsin</td>
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<td>● Tracy Cieniewicz, Sustainability Director, Alabama Lifespan Respite</td>
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<td>● Doris Green, Director, New York State Caregiving and Respite Coalition</td>
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<td>3:20-3:30 PM</td>
<td>Q&amp;A and NEXT STEPS</td>
<td>Meghan Kluth, ARCH Consultant</td>
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Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers

More than 50 Executive Actions Across Multiple Agencies

- Increase compensation and improve job quality for family caregivers and care workers
- Make care more accessible and affordable for families
- Expand options for families by building the supply of care.
Links to Executive Order

- Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers

- FACT SHEET: Biden-Harris Administration Announces Executive Actions to Improve Care
Building State-Level Caregiver Leadership

Reflections from the Changing the Care Conversation Project

Siena Ruggeri, Community Engagement Consultant, Community Catalyst
Changing the Care Conversation Project Goals

- Build the coalition and grassroots power of a diverse group of family caregivers to advance state and federal policy solutions that improve support for family caregivers

- Provide training, technical assistance and an online learning community as well as funding so organizations can participate in these activities

- Focus will be on building strategies/skills for moving policy change and on building policy expertise
UNITED FOR HEALTH JUSTICE

Mobilizing Family Caregivers

- Trainings
- Workshops
- Technical Assistance
- Building Community
Hawaiʻi Family Caregiver Coalition

• Special emphasis on recruiting Native Hawaiian caregivers for leadership
• Addressing implementation challenges of the Kupuna Caregivers bill
• Meeting regularly with legislators as a coalition
Utah Family Caregiving Collaborative

• Recruited a 13-member Caregiver Advisory Board
• Promoting a state roadmap for family caregiving to policymakers
• Building strategic partnerships with legislators, administrators, and advocates
SE Michigan Senior Regional Collaborative

• Organizing family caregiving champions that represent the diversity of southeast Michigan

• Highlighting the impact of cultural diversity on the sphere of caregiving

• Increasing access to social supports and community-based resources
1. Always include family caregivers as a stakeholder group

2. Identify family caregivers who are already part of your advocacy

3. Co-create your policy agenda with, not for, family caregivers

4. Provide opportunities for family caregivers to build their advocacy skills

5. Cultivate community

6. Follow the work of local, state, and national caregiver-led advocacy groups
All State Coalition Convening Organizations

Organizations

- Aging Services Council of Central Texas
- Arizona Caregiver Coalition
- Utah Family Caregiving Collaborative
- Hawaii Family Caregiver Coalition
- Illinois Aging Services
- New York State Caregiving and Respite Coalition
- North Carolina Coalition on Aging
- Southeast Michigan Senior Regional Collaborative
- University of Southern California Family Caregiver Support Center
- Wisconsin Aging Advocacy Network
We believe in the power of people to change the health system.
Thank you.
APPROACHES TO STATE POLICYMAKING AND EXPANDING RESPITE FUNDING
Background

• Respite Care Association of Wisconsin (RCAW) is a 501(c)(3) non-profit charitable organization organized in 1987 to support and advocate for quality systems of respite care for Wisconsin families.

• In 1999, Wisconsin adopted state Lifespan Respite Care legislation (SS 46.986), authorizing Wisconsin DHS to issue state lifespan respite care grant funds to RCAW to administer the program.

• At that time, Wisconsin led the nation in recognizing the need to establish funding to support lifespan respite activities.

• From 1997 to 2000, Wisconsin was one of three states that enacted legislation to implement Lifespan Respite Programs, along with Oregon and Nebraska. This legislation established state and local infrastructures for developing, providing, coordinating and improving access for respite services to residents regardless of age or disability.
RCAW formed as a 501(c)(3) non-profit charitable organization

Wisconsin Legislature established funding via state statute to implement a lifespan respite program

Applied for and received first 3-Year Federal Lifespan Respite Grant

Applied for and received second 3-Year Federal Lifespan Respite Grant

Received increase in State GPR Lifespan Respite Program Grant funds – increase request lead by RCAW

Applied for and received third 3-Year Federal Lifespan Respite Grant

Proposed increase in State GPR Lifespan Respite Program Grant funds in Governor’s Budget – Increase request lead by Caregiver Crisis Coalition

Invited by Senator Baldwin to apply for FY2024 Congressionally Directed Spending Request

State and Federal Funding History
### Other Funding Strategies & Sources and RCAW examples

| Partner | Partner with national organization  
|---------|-----------------------------------  
|         | • ARCH National Respite Network  
|         | • National Academy of State Health Policy  
| Partner | Partner with institutions of higher education  
|         | • University of Wisconsin  
|         | • UW Extension  
|         | • University of Marquette  
| Apply   | Apply for grants from local, state, and national foundations  
|         | • Bader Philanthropies  
| Make    | Make friends with your legislators!  
|         | • Senator Baldwin - FY2024 Congressionally Directed Spending Request  

Other Funding Strategies & Sources and RCAW examples

Establish strong relationships with various State Department of Health
- Department of Health/Human Services
- Department of Workforce Development
- Governor’s Office

Be active in state and national coalitions, alliances, taskforces...
- Wisconsin Family and Caregiver Support Alliance
- Governor’s Taskforce on Caregiving
- Caregiver Crisis Coalition
- Survival Coalition
Become a ‘Value Add’ to others

- State Departments
- Counties
- ADRC’s
- Area Aging Agencies
- Others
For Example:

Create programs that address gaps in existing program delivery systems that support family caregivers

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<tr>
<th>AFCSP</th>
<th>NFCSP</th>
<th>CRGP</th>
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<tbody>
<tr>
<td>Alzheimer’s Family &amp; Caregiver Support Program (Jan-Dec)</td>
<td>National Family Caregiver Support Program (Oct-Sept)</td>
<td>RCAA Care Respite Grant Program (July-June)</td>
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<td>Funding Source</td>
<td>State of Wisconsin GPR, State and GWAAR distribute funds to counties</td>
<td>Federal AOA Program, State distributes funds to each Area Agency on Aging (AAA), GWAAR distributes funds to counties in its service area</td>
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<td>Maximum Annual Allocation Per Applicant</td>
<td>$4,000, but agencies may set a lower maximum service level in order to serve more families. Actual service payment is based on care needs.</td>
<td>None in federal policy, but local agencies often set their own limits. Participants are limited to 112 hours of respite per calendar year.</td>
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<td>Eligibility Requirements</td>
<td>Diagnosis of probable irreversible dementia: Alzheimer’s, vascular dementia, Lewy body dementia, Parkinson’s with dementia, Pick’s disease, mixed or undetermined dementia, etc. In-home, or can be used to provide caregiver respite and supplemental services for people living in a CBRF, RCAC or Independent Living arrangement. (Not for room &amp; board) $48,000 max gross income of person &amp; spouse. Not simultaneously enrolled in NFCS or receiving caregiver respite through Family Care. No asset test</td>
<td>1. Has physical limitations or a form of dementia that requires assistance for at least two activities of daily living. 2. Resides in home setting (not facility). 3. Care recipient is age 60 or older – or has Alzheimer’s or other dementia, any age. 4. No income or asset test. 5. Priority is given to low-income individuals and those with a diagnosis of dementia. 6. Available to caregivers of all older adults aged 60+, even if the care recipient is enrolled in Family Care or another LTC program. Caregiver is the program recipient.</td>
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<td>How to Refer</td>
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<td>Anyone may refer: ADRC staff, caseworker, medical staff, family member, friend. The AFCSP Coordinator will assess eligibility, complete paperwork, and work cooperatively with case managers from other programs and dementia care specialists.</td>
<td>Anyone may refer: ADRC staff, caseworker, medical staff, family member, friend. The AFCSP and NFCSP coordinators should meet regularly to determine the appropriate program for enrollment and maximize the number of families served by each program.</td>
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<td>The maximum allocation for each family is determined using DHS eligibility worksheets. Payments are made using invoices and receipts. May pay a service agency directly or reimburse program participants or the primary caregiver: representative for approved expenses.</td>
<td>Services must be approved by the administrative agency in advance in order for goods and services to be purchased using NFCSP funds. Payments to service providers are usually made monthly, but other timeframes are allowed.</td>
<td>Applicants are eligible to apply for a respite grant multiple times a year. Requests are approved based on care recipient needs, geographic location of services provided, length of time respite is needed, and funding availability. Grants are awarded and paid to applicants (usually primary caregiver) so they can pay the respite care provider for services rendered. In circumstances where respite care is provided in a facility-based setting, we can pay the facility directly.</td>
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<td>If all funding is allocated in a given year, a waiting list may be created till funds are available. Once enrolled in AFCSP, a person remains in the program until officially disenrolled by the AFCSP Coordinator (for reasons such as death, facility placement, Family Care, NFCSP, ineligible income, etc.). The AFCSP Coordinator may apply for NFCSP on behalf of clients who have needs that surpass their maximum program allowance under AFCSP. (Assuming there are sufficient NFCSP funds remaining)</td>
<td>Respite care is limited to 112 hours per calendar year. (Jan.-Dec.) Before requesting NFCSP funds for a person with dementia, case managers should check with the AFCSP Coordinator to see if there are funds available through AFCSP, and if so, whether the person is eligible for AFCSP. Best practice is to enroll a person with dementia in AFCSP first rather than NFCSP. If a family is eligible for AFCSP but funds are unavailable, they may enroll in NFCSP but should also be added to the AFCSP waiting list.</td>
<td>• No minimum or maximum limit of hours – must be reasonable. • No minimum or maximum limit on amount – must be reasonable. • Can apply multiple times a year subject to funding availability. • Can process payment within hours in an emergency. Otherwise, typical application is processed in 48 hours.</td>
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Thank you!

CONTACT INFO:
LISA SCHNEIDER, EXECUTIVE DIRECTOR, RESPITE CARE ASSOCIATION OF WISCONSIN
EMAIL: LSCHNEIDER@RESPITECAREWI.ORG
PHONE: 608-222-2033
2000: UCP Huntsville established the statewide Alabama Lifespan Respite program and began working with an informal task force of around 45 volunteers from state agencies, non- and for-profit organizations that serve individuals with disabilities. The task force developed an initial strategic plan to identify the respite needs of caregivers in Alabama and the gaps and barriers they face accessing services.

2006: Advocacy and education efforts with the Alabama Legislature resulted in annual state funding for ALR ($100,000).

2009: The Alabama legislature passed resolution HJR170 to establish ALR as “the lead entity for lifespan respite coordination in the state of Alabama” and designated coordinator of the Alabama Respite Coalition.

ALR COALITION

Purpose
Creation of a statewide coalition allows Alabama the opportunity to address issues caregivers face in accessing current respite resources in a productive process, limits duplication of effort when possible, and allows for collaboration on education and training.

Staffing Entity to the Coalition
Alabama Lifespan Respite serves as the staffing entity to the Coalition and is responsible for coordinating at least two regular meetings per year, as well as committee/subcommittee meetings as needed. Additionally, Alabama Lifespan Respite regularly shares caregiver/respite news, resources, legislative outreach, and more with and on behalf of Coalition members.
Composition

The Alabama Lifespan Respite Coalition is composed of members who shall be culturally, economically, and geographically diverse and representative of state demographics and appointed by the Governor or his or her designee.

Duties

The Coalition is tasked to build partnerships and coordinate respite efforts statewide; prepare Alabama to compete for federal funding; provide public awareness about respite to the citizens of Alabama; identify, coordinate and develop community resources; and build local partnerships and collaborations supporting respite services.
ALR COALITION MEMBERS

- Alabama House of Representatives/House Ways & Means Committee (Chair)
- Alabama House of Representatives/Health Committee (Chair)
- Alabama Senate/Judiciary Committee (Chair)
- Alabama Department of Senior Services
- Alabama Department of Medicaid
- Alabama Department of Public Health
- Alabama Department of Child Abuse and Neglect Prevention
- Alabama Department of Rehabilitation Services
- Alabama Department of Human Resources
- Alabama Department of Mental Health
- Alabama Council for Developmental Disabilities
- Governor’s Office on Disability
- AARP Alabama
- Autism Society of Alabama
- UCP Huntsville
- Family Caregivers
- Collaborative Training Partners (VA and Alabama Cares)
- Community Respite Initiatives
- Alabama Hospice, Palliative Care, and Home Health Organizations
- Statewide Advocacy Organization (Alabama Head Injury Foundation)
- Universities
ALR FUNDING

• Alabama Education Trust Fund Budget appropriation for Respite Related Services and Training, administered by the Alabama Department of Rehabilitation Services—$315,000 annually (2023)

ALR contracts with the following state agency partners to provide personal-choice option respite reimbursement services for family caregivers:
• Alabama Department of Mental Health (2007)
• Alabama Department of Rehabilitation Services/Children’s Rehabilitation Services
• Alabama Area Agencies on Aging/Alabama Cares (all 13 programs statewide)