Lifespan Respite Grantee Lead Agency: **Rhode Island Department of Human Services/Division of Elderly Affairs (DEA)**

**Funding Period:** 2014-2017

**Primary Goal:** Integrate, bring to scale, and achieve long-term sustainability of Lifespan Respite Services in the state.

### Key Performance Measures

This project developed a formal evaluation plan to track outputs, outcomes, and the effectiveness of interventions including:

- Number of nursing students providing respite services;
- Number of families served by the newly trained workforce;
- Number of individuals receiving information and education on the Caregiver Alliance;
- Number of families receiving subsidized respite care; and
g caregiver and nursing student satisfaction.

### Notable Achievements

- University of Rhode Island College of Nursing reports positive experiences by both nursing students and caregivers. Interested students provided respite during winter break, beyond course expectations, to ensure continuity for families between school semesters. Caregivers verbally expressed happiness about and appreciation of respite provided and rated them as professional, knowledgeable and caring. Students verbally expressed enjoyment and self-satisfaction with providing respite. One family’s positive connection with a student led to a paid respite position at the completion of the clinical placement.

### Key Objectives, Activities and Outcomes

#### Objective 1: Implement two new sustainable workforce development initiatives targeting nursing students, one of which will recruit nursing students as volunteers and/or as part of clinical coursework, and a second which will offer respite services as a clinical placement option for course credit.

- The Student Respite Initiative launched spring semester, 2016, during which five nursing students provided respite services to five families. During fall semester, 2016, 11 students provided respite services. During spring semester, 2017, 10 families received respite from 16 students. Each student provided between 10 and 56 hours of respite. Overall, 53 nursing students provided respite services to more than 20 families.

- Rhode Island College of Nursing uses a process to match student nurses with caregivers of children with special needs, with families of adults and families of older adults according to their needs.

#### Objective 2: Improve awareness about respite services, and access to respite services, through the Rhode Island Aging and Disability Resource Center (ADRC).

- Create one or more strategically located webpages and links, and engage partners in outreach activities.

- The Department of Elder Affairs (DEA) and Healthcentric Advisors, a nonprofit healthcare quality improvement organization, worked on a DEA website with a Caregivers section that was finalized and supported by Rhode Island’s 2017 Lifespan Respite Grant.

### Coalition, ADRC and Community Partners

#### State Respite Coalition/Organization Role

- The Caregiver Alliance of Rhode Island (the Alliance), the state’s respite coalition, was an informal group comprised of disparate agencies, organizations and individuals prior to funding of this grant. With funding, and membership of the state and community partners listed below as well as service provider agencies, family caregivers, and disability related organizations, the Alliance became a formal non-profit organization and developed tools to effectively advocate and be a resource for family caregivers and respite providers.
### Key Objectives, Activities and Outcomes

- Healthcentric Advisors provided outreach to the medical communities and to other organizations as directed by DEA, including providing materials at medical and at caregiver events, target emails, newsletters and phone contact.

- Outreach was accomplished by United Way of Rhode Island (UWRI) at 235 events in 35 locations across Rhode Island including clinics, food centers, community action programs, senior centers, church gatherings, festivals and community advocacy groups. During these events 315 caregivers received assistance, and 400 caregiver booklets were distributed.

- The POINT receives an average of 600 calls per month from caregivers requesting services and information on the following topics: Medicare/Medicaid, nursing homes and assisted living facilities; HealthSource and other long term care, transportation, and financial assistance. POINT staff trained on available services totaled 147 from January 2015 through August 2017.

- Formalize and strengthen the Caregiver Alliance of Rhode Island as an advocate for caregivers.

  - By-laws for the Family Caregiver Alliance were completed and approved by UWRI as part of their existing infrastructure, thereby formally incorporating the Alliance as a non-profit under UWRI and allowing the Alliance to continue its activities after the grant cycle ended.

- Continue funding the CareBreaks respite program that was implemented under the previous Lifespan Respite Grant.

  - Healthcentric Advisors and project partners updated outreach materials and respite applications to simplify and clarify the process for key community stakeholders, and to create a less burdensome process for caregivers.

  - During the funding period, Catholic Social Services served 190 families through their Carebreaks respite program.

### Coalition, ADRC and Community Partners

#### Aging and Disability Resource Center (ADRC) Role

- The Rhode Island ADRC has been a partner in the Lifespan Respite project since the project’s inception.

- The POINT, a key operating partner within the Rhode Island ADRC system, worked to raise awareness and promote access to direct care services for family caregivers.

#### State and Community Partners

- Caregiver Alliance of Rhode Island (the Alliance)

- United Way of Rhode Island (UWRI)

- University of Rhode Island College of Nursing

- Catholic Charities of the Diocese of Providence

- CEDARR Family Centers

- DEA’s respite program, CareBreaks

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For more information, contact ARCH at (703) 256-2084 or jkagan@archrespite.org
Lifespan Respite Care Program

Lifespan Respite Grantee Lead Agency:  Rhode Island Department of Human Services/Division of Elderly Affairs (DEA)

Funding Period:  2017-2020

Primary Goal:  Integrate, bring to scale, and achieve long-term sustainability of Lifespan respite services in the State.

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<thead>
<tr>
<th>Key Performance Measures</th>
<th>Notable Achievements</th>
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<tr>
<td>The grantee’s Evaluation Plan will measure: 1) improvement in access to, and awareness of, respite care programs as measured through enrollment data and number of individuals educated on the existence of and process for accessing respite care programs; 2) the number and types of individuals receiving information and education on the Caregiver Alliance of Rhode Island; 3) caregiver and nursing student satisfaction with the nursing student respite initiatives; 4) the number of nursing students trained to provide respite services and the number of families served by the nursing students; and 5) the growth, success stories, and deliverables of the newly incorporated Caregiver Alliance. Planned products include a nursing student respite training toolkit for replication; the development of a State Plan for Caregiver Support; and respite locator tool to be deployed on United Way of Rhode Island (UWRI) and Department of Elderly Affairs (DEA) websites.</td>
<td>Each partner agency is responsible for collecting and reporting applicable data to the DEA and Healthcentric Advisors, a nonprofit healthcare quality improvement organization, on a quarterly basis. Specifically, each nursing program conducts their own evaluations as part of already established requirements, and shares their data with the group. The Modified Caregiver Strain Index (MCSI) is an example of one evaluation tool used in assessing caregiver outcomes. Healthcentric Advisors will use the data to track the various metrics and will provide DEA and its partner agencies with quarterly reports. Analyses will be performed and conducted in accordance with Healthcentric Advisors’ analytic policies and procedures, to ensure data protection and implement work-check procedures that ensure quality of the analyses.</td>
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Key Objectives, Activities and Outcomes

Objective 1:  Expand the Rhode Island student nursing workforce development initiative among higher education nursing programs in the state.

- DEA previously established a workforce development initiative with Rhode Island College (RIC) and University of Rhode Island (URI) nursing programs that offers student nurses clinical experience and course credit while being matched with low to moderate income families who have no access to subsidized respite care. Building off the successful implementation of targeted training and respite placement programs of nursing students at RIC and URI, DEA is expanding to include nursing programs at New England Institute of Technology (NEIT) and Salve Regina University (SRU). Long-term, the goal for sustainability is that each nursing program can continue this initiative at little to no cost.

State Respite Coalition/Organization Role

- DEA is acting to solidify the Caregiver Alliance of Rhode Island by funding a position to lead, support, represent, and advocate on behalf of the Caregiver Alliance. DEA will task the Caregiver Alliance to help further develop Rhode Island’s framework and respite service system.
### Key Objectives, Activities and Outcomes

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<th>Objective 2: Enhance the framework of the State’s respite program through the newly incorporated Caregiver Alliance.</th>
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<td>The Caregiver Alliance of Rhode Island was incorporated and obtained 501(c)(3) status in 2017 as a subsidiary under United Way of RI (UWRI), the State’s lead ADRC partner and operator of THE POINT. The Caregiver Alliance maintains independence from UWRI, but enjoys the benefits of nonprofit status through association. DEA is taking actions to solidify the Alliance by funding a position to lead, support, represent, and advocate on behalf of the Caregiver Alliance. DEA will task the Caregiver Alliance to take specific actions to help further develop the framework and system of respite service in Rhode Island. By the end of the third year of the grant, the Caregiver Alliance will be a formalized and self-sustaining entity, have produced a State Plan for Caregiver Support, and produced a set of basic competencies to be required of respite care providers.</td>
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<th>Objective 3: Improve awareness about respite services and access to respite services, to include continued funding of the CareBreaks respite program that was implemented under a previous Lifespan Respite grant.</th>
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| Grant funds help 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 through the CareBreaks respite program, established during the previous grant period. CareBreaks is the primary recipient of Title IIIIE National Family Caregiver funds and RI state funds designated for respite services. In addition to the framework of service currently implemented by CareBreaks, DEA is working with Catholic Social Services (CSS) of RI to expand its partnership of referrals to more CEDARR Family Centers and enhance focus on group respite activities as an approach to manage increased costs and a shortage of homecare workers in Rhode Island. 

DEA also will work with UWRI to look at the feasibility of developing a volunteer peer-to-peer program for new parents of children with special health needs to be partnered with families who have experience in the process already. |

### Coalition, ADRC and Community Partners

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<td>The Rhode Island ADRC has been a partner in the Lifespan Respite projects since its inception. THE POINT, operated by UWRI, is a key operating partner within the Rhode Island ADRC system and serves as an accessible walk-in and call-in portal for the ADRC. These statewide call-in and walk-in centers continue to serve as the focal point for family caregivers, and DEA staff continues its work with the ADRC and UWRI to ensure that families have access to comprehensive information on respite care and caregiver support and access to assistance with application preparation and service delivery.</td>
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