Caregiver Alliance of Rhode Island

Start-Up Process
• Parent Support Network of Rhode Island formed the Lifespan Respite Coalition as a goal under the statewide family network grant with the Substance Abuse Mental Health Services Administration.
• Rhode Island Congressman Langevin and Rhode Island advocacy groups supported the passage of the Lifespan Respite Care Act.
• Rhode Island Respite Coalition begins to meet monthly and educate state agencies, partners, and caregivers about the Lifespan Respite Act and planning advocacy agenda.
• Rhode Island Respite Coalition becomes a member of the National Respite Coalition.
• Rhode Island Respite Coalition advocates for the passage of appropriations for the Lifespan Respite Act and holds press conference with Congressman Langevin to announce funding appropriations.
• Rhode Island Respite Coalition leadership approached Department of Elderly Affairs to apply for the Lifespan Respite Act funding for the state. Rhode Island received 3-year Lifespan Respite Act grant with the Administration on Aging in 2009.
• Department of Elderly Affairs recognized the Rhode Island Respite Coalition as leaders in the delivery of the Lifespan Respite Grant and worked in close partnership to implement the goals and objectives of the grant.

Structure
• The Rhode Island Respite Coalition has formed into the Caregiver Alliance of Rhode Island. The mission of this Alliance is to ensure caregiver needs of families and friends providing long-term care at home for children and youth with special needs, adults with disabilities, and elders.
• Caregiver Alliance meetings are open and continue to be focused on the priority to raise public awareness of respite, increase access to respite and coordinated service delivery across the lifespan, and expand the availability of volunteer respite programs.

Staff
• The Caregiver Alliance is run by staff of United Way of Rhode Island and volunteers. The Chair of the Caregiver Alliance remains committed to communications, monthly meetings, minutes, and website page updates.

Funding
• The Caregiver Alliance of RI does not have a budget as of July 1, 2017. We are in the process of formalizing the Caregiver Alliance under the auspices of United Way of Rhode Island.

Membership
• The Caregiver Alliance has 80 partners on our mailing list and we average 15 participants per meeting. Membership is open and currently there are no membership fees or eligibility requirements to participate. Members include family caregivers, self-advocates with disabilities, provider agencies, advocacy organizations, and state partners who represent individuals of all ages and disabilities.

Meetings and Communication
• The Caregiver Alliance meets once a month. Meeting announcements and minutes are sent out in advance of meetings.

Major Activities
• Caregiver Recognition event held at State House during National Caregiver month each November. The program has included state speakers and family caregivers sending powerful messages and providing awareness. We honor family, professional, and volunteer caregivers for their work with individuals across the lifespan through the Langevin award, which was created
• Mapped the availability, eligibility, and cost of respite services across ages, disabilities, and special populations and produced a matrix of findings.
• Continues to advocate at state policy meetings in regards to respite care, home and community-based service delivery, and national respite funding to be sustained and increased to meet the respite needs of caregivers.
• Published and disseminated state of respite report in RI with recommendations, *Respite Care in Rhode Island: A Recommendation Report for the Rhode Island Executive Office of Health and Human Services*.

**State Contact Information**

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