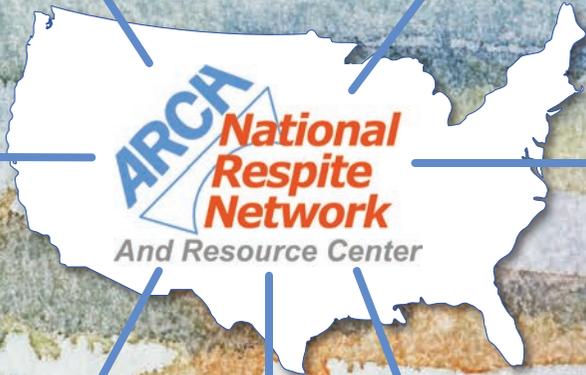


# ARCH State Respite Coalitions A Compendium of Fact Sheets

2017 Update





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## Introduction and Acknowledgements

State Respite Coalitions in a number of states have been affiliated with the ARCH National Respite Network since the early 1990s. In the late 1990s, several of these coalitions were instrumental in helping to enact state Lifespan Respite legislation that spurred other states to similar action. These early programs laid the foundation for best practices in today's federally funded Lifespan Respite Program. Other state respite coalitions have developed since 2009 to support Lifespan Respite Program implementation in the states.

State Respite Coalitions are mandated partners in the implementation of Lifespan Respite Care Program grants administered by the Administration for Community Living, U.S. Department of Health and Human Services. In this capacity, the coalitions take on various roles and assume responsibilities based on a Memorandum of Understanding with the state lead agency. State Respite Coalitions may help to sustain Lifespan Respite grant activities once federal funds have been expended. A few also exist in states that have never received a Lifespan Respite grant and serve as the central contact point for respite information and services.

Each state coalition is unique in structure, design, membership and in the activities they undertake. Most are focused solely on respite for family caregivers of all ages, but a few are broader in scope and promote additional caregiver supports. Nearly all are statewide and diverse, have an advocacy and oversight focus to promote respite at the state and federal levels, and engage in activities for networking, education, and enhancing public awareness about respite. However, some also engage in research, service delivery, volunteer respite, voucher administration, respite provider training and recruitment, and/or continue to have direct involvement with their State's Lifespan Respite grant program, if they have one.

The effort to compile state respite coalition fact sheets began in 2008. Original fact sheets were first updated and additional fact sheets were added in 2011 and 2014. This latest update contains information supplied by the coalitions. Each fact sheet contains the following information for each state respite coalition:

- **Start-Up Process and Coalition History**
- **Structure**
- **Staff**
- **Funding**
- **Membership**
- **Meetings and Communication**
- **Major Activities**
- **Available Documents/Resources**
  - Bylaws
  - Surveys
  - Strategic Plans
  - Brochures
  - Reports
  - Websites
- **State Contact Information**

It is our hope that these fact sheets will be used widely by state respite coalitions to educate prospective members, family caregivers, funders, the public, and policy makers about the resources they have within their own states (each fact sheet has been formatted to stand alone as



a separate document that can be downloaded from the ARCH website at <https://archrespite.org/state-respite-coalitions>).

The compendium is also used widely by ARCH to share information among state respite coalitions and with prospective new state respite coalitions as well as to disseminate state coalition information widely to the public, national, state and local agencies, programs and organizations, and federal and state policymakers and administrators. These fact sheets can be used to educate Lifespan Respite grantees and partners. For information on State Lifespan Respite programs, see <https://www.archrespite.org/lifespan-programs>.

Fact sheets are included from the following states: **Alabama, Arizona, Arkansas, California, Colorado, Delaware, District of Columbia, Florida, Idaho, Illinois, Iowa, Kansas, Maryland, Massachusetts, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New York, North Carolina, Rhode Island, South Carolina, Tennessee, Virginia, Washington State, and Wisconsin.** Fact sheets from newly formed or reformed State Respite Coalitions in **Florida, Maryland, and Mississippi** are new to this compilation. Since 2014, a few respite coalitions have disbanded, due to loss of funding, restructuring and/or leadership, including the Hawaii, Louisiana, Ohio, Oklahoma, and Texas respite coalitions. In Oklahoma, while the OK Respite Resource Network has disbanded, a new caregiver coalition is emerging that will support a Respite Committee. Other state respite coalitions including Missouri, New Jersey and Pennsylvania did not provide updated information and as a result are not included in this compilation.

I would like to acknowledge the representatives from each state respite coalition, who took the time to provide, edit and update the information contained in this compendium. Many thanks to Casandra Firman, Senior ARCH Staff, who compiled the fact sheets and to Norma McReynolds, our layout consultant, for the inviting new format.

**Jill Kagan**

ARCH National Respite Network and Resource Center

[www.archrespite.org](http://www.archrespite.org)

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## Alabama Lifespan Respite Coalition

### Start-Up Process and Coalition History

- In 2000, Alabama Council for Developmental Disabilities (DD Council) issued an RFP to develop a single point of contact for caregivers of children with disabilities up to age 19 to receive information and referral about respite services in Alabama.
- United Cerebral Palsy of Huntsville and Tennessee Valley, Inc., (UCP) was awarded a three-year grant from the DD Council. UCP convened a task force of more than 45 caregivers, disability organizations, faith-based staff and state agencies to develop a directory of respite services in Alabama and create a statewide strategic plan. The task force was organized into four committees: funding, advocacy, public awareness and resources.
- Alabama Respite Resource Network (Alabama Respite), a statewide program began in 2000, to accomplish the task outlined in the strategic plan and from that document a project management plan emerged.
- In 2003, after the introduction of the Lifespan Respite Care Act, Alabama Respite changed their mission to include caregivers across the lifespan and made a name change to Alabama Lifespan Respite Resource Network®.
- Alabama Respite staff planned and carried out significant state legislative education, and in 2007, received a small line item through the state Education Budget. Alabama Respite contracts with the Alabama Department of Rehabilitation Services to fund a portion of its operational needs.
- In 2009, House Joint Resolution 170 was passed by the Alabama Legislature establishing Alabama Respite as the state's lead entity to coordinate the Alabama Lifespan Respite Coalition.

(Coalition). HJR170 created the Coalition composed of members appointed by the Governor who shall be culturally, economically, and geographically diverse and representative of the state demographics. The appointed key Coalition stakeholders include state senators and representatives, state agency commissioners, for- and non-profit organizations and consumers.

- In 2012, using the 2009 resolution as a guide, the Alabama Legislature introduced HJR170 as a state statute, which became the Alabama Lifespan Respite Resource Network Act 2012-410.

### Structure

- Alabama Respite staff coordinates the Coalition. The Coalition has three primary workgroups (Public Awareness, Education/Resources and Capacity Building).

### Staff

- The Coalition has no staff.

### Funding

- The Coalition has no funding.

### Membership

- The Coalition is made up of 28 members appointed by the Governor including policy makers, state agency personnel from agencies serving clients with disabilities or chronic illnesses, non- and for-profit organizations and caregivers.

### Meetings and Communication

- The Coalition meets at least twice a year in its entirety; however, the workgroups meet as needed to address respite issues and concerns. Alabama Respite maintains contact with membership on a regular basis.



Updated in 2017 by the Alabama Lifespan Respite Coalition.  
For more information, contact ARCH; (703) 256-2084; [jkagan@archrespite.org](mailto:jkagan@archrespite.org)  
ARCH Website: [www.archrespite.org](http://www.archrespite.org)

## Major Activities

- The Coalition is tasked to:
  - 1 build partnerships and coordinate respite efforts statewide, and prepare Alabama to compete for federal funding as the Lifespan Respite Act is funded;
  - 2 provide public awareness about respite to Alabama citizens;
  - 3 identify, coordinate, and develop community/funding resources for respite services; and
  - 4 build local partnerships and collaborations regarding respite services.

## Documents/Resources Available

- Website: <http://www.alabamarespite.org>
- Alabama Respite's Brochures:
  - Alabama Lifespan Respite Resource Network
  - Give me a Break
  - Information for Our Respite Provider
  - Faith-Based Respite Ministry
  - Guide for Hiring and Keeping Respite Providers

- Alabama Respite's Resource Directory hosted on website
- Logo
- Voucher Respite Funding Documents
- Emergency Respite Funding Guidelines and Documents
- The Alabama Lifespan Respite Resource Network Act (2012-410) establishing the Coalition and naming Alabama Respite as the state's lead entity for respite information and referral services.
- Sharing the Care Tool Kit
- Faith-Based Respite Program Tool Kit

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## Arizona Caregiver Coalition – Lifespan Respite Care Network

### Start-Up Process

#### 2006

- Governor's Advisory Council on Aging forms an informal Caregiving Sub-Committee, which embarks on project to develop a statewide coalition to support informal caregivers.
- Legislation to create an Arizona Lifespan Respite Program introduced to Arizona Legislature by Valley Interfaith Project.

#### 2007

- Legislation establishing Arizona Lifespan Respite Program (LRCP) passed with a \$500K appropriation to include a new full time employee within the Division of Aging and Adult Services. State bill follows the 2006 federally enacted Lifespan Respite Program, including the requirement to develop a statewide organization or coalition to help facilitate development of the program.
- Stakeholders, including representatives from the Governor's Advisory Council on Aging, various Arizona State Agencies, and numerous non-profit agencies, agree to combine efforts to form a statewide caregiver coalition with need/requirement to develop a statewide respite coalition. Respite coalition becomes a task force within the Caregiver Coalition.
- In August, Arizona Division of Aging and Adult Services established an advisory committee of caregivers, respite providers, and representatives of state agencies to assist in the development of the LRCP. University of Arizona's Center on Aging is contracted to conduct a study related to respite care in Arizona to help the committee identify whom the LRCP should serve and what service delivery model should be utilized.

#### 2008

- University of Arizona Study on respite care completed – *Arizona Respite Care Throughout the Lifespan: Characterizing Unmet Needs Final Report*, Jan. 15.
- Caregiver Rally in March attracts hundreds to the Arizona State Capitol to support caregiver issues. The rally is the first public exposure for the new statewide Arizona Caregiver Coalition (ACC) and the Lifespan Respite Care Network (LRCN) that is nested as part of that coalition.
- By April, the LRCP begins delivering services through the Area Agencies on Aging throughout Arizona.
- ACC “officially” launched as part of the Governor's Conference on Aging held May 14–16 in Mesa. The LRCN is established as an integral component of the overall mission of the ACC and will function as one of four action committees within the coalition: C – Collaboration A – Advocacy R – Respite E – Education
- The Arizona LRCN held first official meeting on June 4 at the Caregiver House of the Foundation for Senior Living.
- Developed ACC charter and bylaws to guide the LRCN.

### Structure

- The Arizona LRCN functions as a focused network within the ACC.
- The ACC leadership currently consists of three voluntary co-chairs.

### Staff

- A part-time volunteer coordinator for the LRCN was hired by the ACC in July 2010, using the LRCP grant funds, to help setup and staff the



Updated in 2017 by the Arizona Caregiver Coalition – Lifespan Respite Care Network. For more information, contact ARCH; (703) 256-2084; [jkagan@archrespite.org](mailto:jkagan@archrespite.org); ARCH Website: [www.archrespite.org](http://www.archrespite.org)

resource line, helped with the national conference planning in 2011 and the ongoing support and growth of the ACC. This coordinator now oversees the ACC.

## Funding

- The Division of Aging and Adult Services at the Department of Economic Security graciously hosts the ACC's operations. Current funding of the Respite Rebate Program is through a partnership between Arizona Caregiver Coalition, Arizona Association of Area Agencies on Aging, and the Division of Aging and Adult Services.
- Arizona has a statute authorizing \$500K annually in state funding for the Arizona LRCP, but that funding is currently not available. Advocacy steps have been taken since 2011 to re-establish funding for the state LRCP.
- Future funding for the LRCP is expected to include support from stakeholders and others, and will incorporate grant writing, sponsorships, and possible support from the state-funded LRCP.

## Membership

- Statewide membership of service providers and caregivers from both the child, aging and disability communities, including Area Agencies on Aging, faith-based agencies and organizations, and representatives of state governmental agencies that support caregivers. Membership also includes family caregivers, respite providers, Centers for Independent Living, disease specific associations, and any other individuals, agencies, or organizations interested in developing lifespan respite as a resource to support caregivers.
- Membership is currently free and is broken down into three categories:
  - Individual caregivers and stakeholders
  - Service providers and non-profit agencies
  - Corporate sponsors

## Meetings and Communication

- Meetings are announced and advertised on the websites and via email.
- Member database being developed for communication and organization.
- The ACC website includes: access to resources, respite vouchers, Caregiver Resource Line toll-free number/email requests, caregiver forums, blogs, and downloadable information: [www.azcaregiver.org](http://www.azcaregiver.org)

## Activities

- Recruited and trained Caregiver Advocate volunteers to operate the Arizona Statewide Caregiver Resource Line (CRL).
- Launched August 2012, the Arizona Statewide Caregiver Resource Line.
- Ongoing advocacy action steps to keep the statewide LRCP funded and able to continue to provide direct services accessible by calling the CRL.
- Launched in 2013 statewide on-line registry of respite/direct care workers.
- Launched in 2013 Respite Vouchers, reimbursement payment for family caregivers to take a well-deserved break.

## Documents/Resources Available

- Development of Charter Membership Drive
- Articles of Incorporation, bylaws and establishing new ACC Board and re-establishing of ACC Board Members (under development)
- Establishing the ACC as 501(c)(3)
- PSAs and 3 videos on Respite Care, Caregiver Resource Line/Arizona Caregiver Coalition, Arizona Lifespan Respite Network (under development)
- Arizona LRCP Brochure
- ACC Brochure
- Arizona Respite Registry Brochure (2) Looking for Work/Looking to Hire a Respite Provider/Direct Care Worker

- Caregiver Assessment Tool (CAT) used statewide at Area Agencies on Aging: pre and post assessment for receipt of respite services and implemented in the accessing and determination receipt of Respite Vouchers
- University of AZ report: *Arizona Respite Care Throughout the Lifespan: Characterizing Unmet Needs*, University of Arizona, Jan. 2008.
- Re-branded and re-launched ACC website: [AZCaregiver.org](http://AZCaregiver.org)
- Created a support group database: <http://azcaregiver.org/resources/resource-database/>
- Developed a community calendar: <http://azcaregiver.org/community-calendar/>

## State Contact Information

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## Arkansas Lifespan Respite Coalition

### Start-Up Process

#### 2013

- The Arkansas Lifespan Respite Coalition (ALRC) was established as a response to the statewide Lifespan Respite Summit held in February 2013.
- At the summit, attendees signed up to become charter members of the coalition and the group began monthly meetings the following month at the Department of Human Services.
- One of the initial tasks of the group was to form committees including a workgroup for the development of an MOU between the coalition and the Division of Aging and Adult Services which houses the statewide Aging and Disability Resource Center (ADRC). Other committees included: Grant Development, Communications, Membership, Advocacy/Policy and Training/Education.
- The coalition used the ARCH's "Building a Statewide Respite Coalition: Where Do We Begin?" as a guide to begin building the statewide infrastructure.
- One of the first actions of the group was to develop Goals and Objectives, a Mission and Vision Statement and a list of Values.

#### 2014

- The ALRC worked with a local graphic artist who volunteered her time to help create a logo.
- The ALRC was awarded the 2014 Lifespan Respite Grant Award.
- The first Arkansas Lifespan Respite Awareness Day was held Oct. 29 at the State Capitol with a proclamation signed by Governor Mike Beebe.
- The ALRC created an Advocacy/Policy Committee to promote state legislation that will provide future funding to help sustain the coalition.

#### 2015

- The two-day REST train-the-trainer course was held Aug. 18–19 for training nine nurses with the UAMS Schmieding Caregiver Training Program.
- The one-day REST training was conducted Sept. 24 by the Schmieding nurses at each of the eight Schmieding Caregiver Training sites around the state.
- The 2nd Annual Arkansas Lifespan Respite Awareness Day was held Oct. 29 at the State Capitol with a proclamation signed by Governor Asa Hutchinson.

#### 2016

- A media campaign for the 2016 REST Volunteer Respite Trainings was launched in February with ads appearing in a statewide newspaper.
- REST Volunteer Respite Trainings were held throughout the state.
- The 2016 Arkansas Lifespan Respite Summit was held Oct. 21 with a focus on faith-based and community-based respite programs. The summit also offered an afternoon break-out session with the new four-hour version of the REST volunteer respite training.
- The Summit also included a member of the Arkansas Legislature sharing her caregiver story and reading the 3rd Annual Lifespan Respite Awareness Day Proclamation signed by Governor Asa Hutchinson.

### Structure

- The ALRC is made up of state government agencies, professional organizations, consumers and family members and other community partners with a mailing list of 30 members.
- The ALRC is a statewide organization that does not currently have regional or local chapters.



Updated in 2017 by the Arkansas Lifespan Respite Coalition. For more information, contact ARCH; (703) 256-2084; [jkagan@archrespite.org](mailto:jkagan@archrespite.org); ARCH Website: [www.archrespite.org](http://www.archrespite.org)

- The Program Administrator for the ADRC in the Arkansas Division of Aging and Adult Services acts as a liaison between the ALRC and state government.
- The coalition has the following committees: Outreach, Advocacy, Training and Development & Operations.
- The ALRC does not currently have 501(c)(3) status or have a Board of Directors.
- The ALRC is facilitated by a volunteer Chair and Co-chair.

## Staff

- The ALRC has no paid staff.

## Funding

- The Arkansas Division of Aging and Adult Services (DAAS), in collaboration with the Arkansas Lifespan Respite Coalition, was awarded the 2014 Lifespan Respite Care Grant.

## Membership

- Membership is comprised of family caregivers, representatives from state agencies, providers, advocacy organizations and other interested parties.
- Members are asked to sign a membership form.
- Active members are asked to serve on at least one committee.
- There are no membership fees or other requirements.

## Meetings and Communication

- Meetings are held monthly on the third Thursday of each month at the Arkansas Department of Human Services Central Office Building in Little Rock. Some members may also participate with the option of joining by phone. The meetings

are open to everyone interested in supporting the ALRC goal of providing awareness of current respite services available in Arkansas and building on and expanding those opportunities.

- Committee meetings are held monthly prior to the main meeting. Current committees include Outreach, Advocacy, Training and Development & Operations. The Committee Chair schedules and makes needed arrangements for their specific committee meeting.
- Meeting invitations, announcements, copies of minutes from meetings and other communications are distributed to members by email.

## Major Activities

- The Lifespan Respite Summit held in 2013.
- Arkansas was awarded the 2014 Lifespan Respite Care grant.
- A brochure, display banner stand and various promotional items have been developed for providing outreach and awareness at various conferences, health fairs and other events throughout the state.
- A membership form has been developed for use in member recruitment efforts and is available on the website.
- REST Volunteer Respite Training has been conducted throughout the state.
- Two Arkansas Lifespan Respite Awareness Day events have been held at the Arkansas State Capitol.

## Documents/Resources Available

The following documents and resources are available on the ALRC website or by contacting the coalition directly.

- The Goals and Objectives, Vision and Mission statements, and Values have been established and are located with other information about the ALRC on the Choices in Living Resource Center (ADRC) website at <http://www.choicesinliving.ar.gov/alrc.html>
- Arkansas Lifespan Respite Coalition Brochure
- Membership Letter of Invitation
- Membership Form
- Arkansas Respite Coalition Infographic and Fact Sheet
- ALRC Educational Booklet
- Postcard
- Lifespan Respite Summit Agenda Booklet
- 2015 Respite Awareness Day Program
- The Arkansas Lifespan Respite Awareness Day Proclamation
- Information for Volunteer Provider
- Arkansas Lifespan Respite Banner Stand Display
- ALRC MOU with the Division of Aging and Adult Services

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## California Respite Association

### Start-Up Process

- The Respite Services Association of California [DBA California Respite Association (CRA)] was created by a group of interested respite agency individuals from the Sacramento, California area.
- The organization was incorporated Oct. 5, 1981.

### Structure

- CRA is a 501(c)(3) non-profit based corporation.
- As a membership-based organization, CRA's mission is to support the expansion and enhancement of respite services to individuals, families and caregivers to the elderly, persons with developmental and/or physical disabilities, brain impairment and other disabling conditions.

### Staff

- The bulk of CRA's entire history has been supported via the volunteer efforts of its Board of Directors and Members.
- On occasion, consultants have been hired to assist with specific projects.

### Funding

- As a membership based non-profit association, dues have been the primary source of income. Dues had been set at a fixed annual rate for all respite agencies. To help the association with its future needs for either consultants or paid staff, the dues structure is now a tiered system based on the number of respite families each member agency serves and the number of respite workers it employs.

### Membership

- Voting Members represent a respite agency that provides services in the State of California.

Members in good standing have one vote per member agency.

- Non-Voting Members may consist of individuals who are not associated with a respite agency, but are interested in respite services in California or may include recipients of services in California.
- Agency membership will assist in recruiting family caregiver representation.

### Meetings and Communication

- There are two statewide meetings during each calendar year, one in Northern California and one in Southern California.
- In addition, regional meetings in either Northern or Southern California may occur as deemed necessary by the association leadership.
- Communications include minutes from the above meetings, and forwarded e- mails to membership from regional, state and national respite related entities. CRA's website is [www.calrespitem.org](http://www.calrespitem.org) and includes information about members, news, links to other agencies important to the provision of respite, etc.

### Major Activities

- Work closely with policy makers or funding sources to assure the continuation of quality respite services.
- Letter writing campaigns related to the provision of respite services.
- Surveys important to agency understanding of what affects respite services.
- Advocacy related to respite agency interests.
- Sharing of respite agency best practices.
- Sharing of respite agency contact information for families or workers searching for California respite services.



Updated in 2017 by the California Respite Association. For more information, contact ARCH; (703) 256-2084; [jkagan@archrespitem.org](mailto:jkagan@archrespitem.org). ARCH Website: [www.archrespitem.org](http://www.archrespitem.org)

- The above may be local, regional, statewide or national in scope as long as the impact is on the provision of respite services in the State of California.
- The CRA hosted the 2009 ARCH National Respite Conference in Burbank, CA on Sept 24-25, 2009, and the California Lifespan Respite Summit on Sept. 23, 2009.

## Documents/Resources Available

- Articles of Incorporation and By-Laws
- Website: [www.calrespice.org](http://www.calrespice.org)
- Minutes from CRA Meetings

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## Colorado Respite Coalition

### Start-Up Process

- Colorado began creating a respite coalition in 2000, after a small group of interested parties met to discuss respite needs in Colorado.
- In 2001, the group formed the Colorado Lifespan Respite Coalition and a representative from the ARCH National Respite Network attended a meeting. The coalition had some success, but disbanded a few years later.
- In October 2007, the Emergency Respite Project was launched by a group of interested parents, employees from concerned local and state agencies and representatives from various community partners. The group was later renamed the Colorado Respite Coalition (CRC).
- The two co-founders Janis De Baca and Valerie Saiz, who are parents of persons with developmental disabilities, organized the first CRC meeting and provided support as members.
- The original impetus for the CRC was to create a respite center that would be available 24/7 for emergency and non-emergency respite for children. The goal was based on a successful model of a center-based respite program in Ft. Collins, CO called Respite Care Inc.
- This mission eventually evolved into the current mission, which is to establish more extensive respite options for Colorado families. The CRC strives to provide accessible information, resources and referrals to family caregivers seeking respite care by creating a statewide collaborative network of families, professionals and advocates.
- In 2010, the CRC partnered with the State Unit on Aging, Easter Seals Colorado and the Chronic Care Collaborative to apply for the Federal Lifespan Respite Care Grant. The State Unit on Aging was awarded the grant in 2011.

### Structure

- The CRC represents about 200 professional organizations, and has a mailing list of more than 400 family caregivers, advocates and professionals throughout the state.
- CRC is a statewide organization and has helped form four regional coalitions, including the Denver Metro Respite Coalition, throughout the state. The CRC works to reach the entire state through community partners and participation from various organizations that work with the special needs population.
- The CRC is currently housed at and overseen by Easter Seals Colorado.

### Staff

- The CRC is supported by two staff funded by the federal Lifespan Grant, and housed at Easter Seals Colorado.

### Funding

- In 2014 the Colorado Respite Care Program received a second three-year Lifespan Grant to help support the CRC and its partners. It was also awarded an expansion grant in 2016.
- In 2013, as part of the Lifespan Grant objectives, the CRC and Easter Seals Colorado held three statewide regional summits to increase regional participation in respite efforts. The summits were funded through a grant from the Colorado Trust.
- The CRC receives in-kind donations as part of its sustainability efforts.
- In 2013, the CRC and Easter Seals Colorado successfully advocated for \$150,000 to be placed in the 2014 Colorado State budget. The group received \$250,000 in FY2015 and \$350,000 in FY2016 and FY2017. The funds are distributed through grants to agencies providing respite across the state and lifespan.



Updated in 2017 by the Colorado Respite Coalition. For more information, contact ARCH; (703) 256-2084; jkagan@archrespite.org. ARCH Website: [www.archrespite.org](http://www.archrespite.org)

- House Bill 1226 was passed in 2012 which imposes a surcharge on crimes against at-risk populations. Funds from the surcharge allow the CRC to distribute grants to agencies providing respite across the state and lifespan. A formal grant application process has been established.
- JFK Partners has supported the efforts of the CRC by providing consultation and financial support for the co-facilitators to attend annual respite conferences 2010, 2011 and 2012. JFK Partners continue to support the maintenance and enhancement of the CRC website.

## Membership

- Membership in the CRC is volunteer-based and there are no membership fees.
- There are about 200 member organizations. Members include families, caregivers, state agency representatives, providers, advocates and employees of various organizations that provide services to the special needs populations across the lifespan.

## Meetings and Communication

- Meetings are held quarterly at the offices of a local non-profit foundation. Quarterly meetings are open to everyone interested in supporting and expanding respite opportunities in Colorado. Meetings are accessible in-person or by teleconference.
- Regional coalitions host meetings and events in their respective regions quarterly and maintain specific email list serves directed towards people in their region.

## Major Activities

- The CRC was a strong community partner in the startup of “Discovery Clubs.” The Adventure Center in Alamosa, CO, was the model used to provide respite to families of children with special needs. Community college nursing students provided most of the respite hours. This model was then used by Easter Seals with community partners’ support as they launched the

first “Discovery Clubs” in the Denver metro area in 2006. There are now five such programs in the Denver metro area, with at least one program available each week. Easter Seals provides administrative, programming, and grant writing support as well as training for the nursing students.

- The CRC launched its website in 2012. The website, [www.coloradospitecoalition.org](http://www.coloradospitecoalition.org), includes many resources for families including a Respite Locator. JFK Partners has supported maintenance of the website and in 2012–2013 an intern was assigned to increase the number of respite providers on the Respite Locator. The CRC website underwent a design overhaul in 2014, and continues to be maintained and updated by Easter Seals Colorado.
- During the 2009–2010 legislative session, CRC leaders and families testified and advocated for a Catastrophic Bill to help cover respite costs for families in crisis. This bill was spearheaded by another CRC partner, Family Voices of Colorado, and although it passed three House committees, it was defeated in the Senate.
- In 2015, the CRC advocated for the formation of a statewide Respite Care Task Force, which was developed and held until January 2016. The task force developed recommendations for the legislature on how to better support respite care services across Colorado. The recommendations included a cost-benefit study of respite care, developing an online training inventory and training best practices for Colorado, and an outreach campaign to increase awareness of caregiver needs and policy efforts to better streamline services and regulations. In 2016, the recommendations were funded by House Bill 16-1398. An RFP was released by the Colorado Department of Human Services to conduct the project. Easter Seals Colorado was awarded the contract, and began efforts in 2017.
- In 2016, the CRC co-hosted the National Lifespan Respite Conference in Denver, CO, with the ARCH Respite Network,

Easter Seals Colorado, Colorado Department of Human Services and National MS Society–CO/WY Chapter.

- Lifespan Respite Grant Plan: to improve the coordination and distribution of respite care services for family caregivers of individuals with special needs which includes:
  - bringing agencies, coalitions, respite providers and families together to develop a lifespan infrastructure;
  - identifying existing resources (i.e., funds, providers, training);
  - providing care worker and volunteer training; and
  - improving caregivers’ knowledge about respite.

## Documents/Resources Available

- Mission and Vision Statements
- Website: [www.coloradospitecoalition.org](http://www.coloradospitecoalition.org)
- Brochures, PSA video and one pager documents used for outreach
- Survey results

## State Contact Information

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## Delaware Lifespan Respite Care Network

### Start-Up Process

- In Fall 2003, The Center for Disabilities Studies at the University of Delaware (UD) published a report documenting the work of the Respite Care Task Force, "Respite Care in Delaware: A Critical Need for Change." Building on the momentum of the report, Easter Seals Delaware & Maryland's Eastern Shore called together a group of interested stakeholders to form a coalition to continue discussion and work around the issue of respite care in Delaware.
- The group, known as the DE Caregivers Support Coalition, began meeting formally in January 2004, and developed a team charter, which defined its goal, mission, and objectives.

### Structure

- Until January 2009, the group structure was informal and mostly volunteer. The work of the group from 2004 to 2006 included surveying both caregivers and providers to better define the need, and understand the strengths and needs of the respite care service delivery system. From 2006 to 2008, the group developed a three-year operational plan for a statewide system to address needs defined by the surveys – caregivers' need for easy access to information, concern for affordability of services, and limitations of qualified and quality providers.
- When the coalition received foundation funding in 2009, which allowed part-time staff to be hired, a decision was made not to incorporate as a separate entity, but to allow one of the coalition's members, Easter Seals, to become the lead agency and act as the fiscal agent for the group. The coalition has operated under the principle of using existing community resources through contracting rather than developing new systems and services.

- The Coalition continues to function, serving as an Advisory Committee to the funded project, the Delaware Lifespan Respite Care Network (DLRCN). Subcommittees have been established to address issues raised by the Advisory Committee such as Outreach, Sustainability, and Financial Assistance.
- The DLRCN is part of Easter Seals Community Outreach Program providing resources and supports for caregivers. The Community Outreach Program also encompasses a Caregiver and Assistive Technology Resource Center, and manages the state's Low Interest Loan Program to purchase assistive technology.

### Staff

- Easter Seals has a contract with Delaware's Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), through federal funding from AoA, which pays for a part time Outreach Assistant, and part of the Case Manager's time, as well as some funding for the program director, for a total of 0.7 FTE.

### Funding

- UD's Center for Disabilities Studies received a \$50,000 grant from the Governor's Commission for Community-Based Alternatives for Individuals with Disabilities to work with the Delaware Caregivers Support Coalition to develop a three-year operational plan for a statewide lifespan respite system.
- Another member of the Coalition, Children & Families First, Delaware's Information & Referral agency, received a two-year \$15,000 grant from Delaware's Developmental Disabilities Council to develop a web-based database of respite care services in Delaware. Currently, the database lists agencies that serve children and adults either in home or at another location.



Updated in 2017 by the Delaware Lifespan Respite Care Network. For more information, contact ARCH; (703) 256-2084; jkagan@archrespite.org. ARCH Website: [www.archrespite.org](http://www.archrespite.org)

- In fall 2008, the Coalition approached three local foundations to fund the three-year operational plan to develop a statewide lifespan respite program. All three foundations funded the project for a total of \$500,000. The foundations include Delaware Community Foundation, Longwood Foundation, and Welfare Foundation. The grants provided funding from 2009 through 2011. The funding pays for administration as well as respite vouchers.
- In 2011, DSAAPD received funding from AoA to support the respite program. Since that time, they have received two additional expansion grants for the respite program. The program was funded by a contract with DSAAPD through January, 2015.
- Additionally, a challenge grant of \$200,000 was received from the Longwood Foundation in December 2011 which has helped to maintain the program during gaps in funding. The Coalition has established a Sustainability Subcommittee, which has been addressing sustainability of the DLRCN program if/when DSAAPD funding ends.

## Membership

- Members of the Coalition represent a broad spectrum of stakeholders interested in the issue of respite care. The Coalition includes caregivers and consumers, service providers, and state agencies. The members provide representation that is statewide, and across ages and disabilities. There is no membership fee.

## Meetings and Communication

- The Advisory Committee meets face-to-face on a regular basis, to provide input and guidance for the DLRCN. Meetings are typically held at Easter Seals' Delaware corporate office building in New Castle. Attendees choose to attend either in person or by phone via a toll-free conference call phone line.

- Between meetings, emails are sent to the Advisory Committee, Coalition members, subcommittees, and other interested parties to keep them updated on activities, issues, and general information.

## Major Activities

- The DLRCN has been operational since July, 2009. It provides two major services:
  - ① Information & Referral services through an online searchable database (RespiteOnline) and through telephone consultation via a toll-free number.
  - ② Help with paying for respite care services through grants to families of up to \$500 per year per care recipient.
- In March 2010, with funding from the ARCH National Respite Network (through an agreement with the US Administration on Aging), the Delaware Lifespan Respite Care Summit was held with more than 80 people in attendance. It provided information and discussion toward submission of a grant application to AoA which resulted in receipt of a three-year federal Lifespan Respite Care grant through the state's Division of Services for Aging and Adults with Physical Disabilities. In April 2011 a second summit was held that was more focused on providing resources for caregivers.
- In 2012, a decision was made to combine the Respite Summit with Easter Seals annual Caregiver Conference since the topics and audience were so similar. The conference has grown each year and many caregivers attend annually. Members of the coalition are always involved in the planning of the conference.
- In 2015, the coalition hosted a statewide Lifespan Respite Summit. Summit information is posted on the ARCH website at <https://lifespanrespite.wildapricot.org/StateEvents>.
- In 2016, the DLRCN started Relative Respite, a respite voucher program

designed specifically for grandparents or other relatives 55 and older who are providing the majority of care to a child under the age of 18.

## Documents/Resources Available

- Information about the Coalition and DLRCN can be found at [www.delrespite.org](http://www.delrespite.org). The website contains a history of the Coalition, which includes reports documenting various stages of the Coalition and its work. In addition, the website provides information on the services that are available to caregivers, and access to the online database, RespiteOnline.
- To increase ease of access and provide clearer instructions, the forms and documents needed for voucher submission have been added to the website. Additionally, a "Guide to Respite" was developed to answer caregivers' questions.

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## District of Columbia Lifespan Respite Coalition

### Start-Up Process

- The District of Columbia (DC) Lifespan Respite Coalition (DCLRC) is a city-wide network of private and non-profit providers, caregivers, government agencies, advocacy groups and other stakeholders established by the DCOA/ADRC that identifies, supports, trains and promotes coordination among caregiving and respite resource organizations. DCLRC supports agencies and organizations that help caregivers across the lifespan maintain their own health and well being while providing optimal care.
- The DCLRC started in September 2010 when the DC Office on Aging received the Lifespan Respite Grant from the US Administration on Aging.
- The inaugural meeting was organized by the DC Aging and Disability Resource Center (DC ADRC). The coalition's founding members were representatives from DC agencies that serve aging citizens and citizens with disabilities or fund respite services as well as DC Office on Aging grantees.
- The founding members focused on defining the mission, vision and operations for the coalition and who to invite to join the coalition.
- Four months later, the coalition was opened to membership.

### Structure

- In 2016, DCOA accomplished its goal of transferring leadership of the DCLRC to a non-governmental member that can apply for grants to sustain the program after the federal lifespan respite monies end. The DCLRC leadership is currently provided by Kadamba Tree Foundation, a nonprofit organization which provides education and support programs to family caregivers.

### Staff

- Kadamba Tree Foundation provides staff support of up to 16 hours per week to prepare for coalition meetings and to conduct other coalition building activities.
- Kadamba Tree Foundation also provides additional staff time to coordinate and conduct special caregiver events on behalf of the coalition.

### Funding

- The DCLRC's activities are funded by private donations and in-kind contributions.

### Membership

- Membership in the DCLRC is free to government agency members and family caregivers.
- Membership includes representatives from aging, child and disability services providers, homecare agencies, family caregivers, DC Department of Disability Services, DC Department of Mental Health, Family and Child Services, DC Caregivers Institute, Developmental Disabilities Rights Council, Department of Veterans Affairs and senior and adult care centers. The DCLRC plans to expand membership to faith-based communities/organizations and relevant private stakeholders.

### Meetings and Communication

- The group has agreed to meet quarterly via teleconference. Under Kadamba Tree Foundation's leadership, the coalition will also periodically hold special face-to-face meetings as well as networking and educational opportunities.



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## Major Activities

- Conduct biannual caregiver conferences which promote respite and also feature educational presentations, interactive skill-building workshops and peer support opportunities for area caregivers.
- Production of governance documents including mission, vision and goals statements and operating procedures.
- Created a project brochure and consumer factsheet on how to identify quality respite services.
- Conducted a city-wide survey of 162 respite providers to verify their operations; 62 agencies responded to the survey. A respite care listing was created from this information and entered into the ARCH National Respite Locator Service. Staff continues to identify more respite providers.
- Conducted four focus groups with caregivers to ascertain their needs, wants and experiences with respite care in the

city. Two groups were caregivers of people with disabilities under 60 years of age and two groups were with caregivers of older adults.

- Began an aggressive promotional campaign to inform caregivers that respite care is available. Staff attended community events, conferences, and conducted presentations all over the city as well as placed information in local newsletters.
- Started bi-weekly chat sessions for caregivers about respite care.

## Documents/Resources Available

- DC Respite Care Provider Survey
- Program Brochure
- Consumer Tips for Quality Respite brochure
- Operating Procedures
- Focus Group Reports
- Chat Line  
<http://dcoa.dc.gov/page/caregiver-chat>

## State Contact Information

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## Coalition Leadership's Contact Information

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**F · L · R · A**  
Florida Lifespan Respite Alliance

## Florida Lifespan Respite Alliance

### Start-Up Process and Coalition History

- The Florida Lifespan Respite Alliance (FLRA) was formed in 2015. The catalyst for the FLRA's creation was the recognition of limited information available about respite care in Florida. A group of concerned caregivers and aging and disability professionals met to discuss the need for further community education on respite care. A Lifespan Respite Summit was held to bring stakeholders together from around the state and a leadership team was formed. The FLRA developed to address the lack of visibility of respite care, gaps in service around the state and to promote access to affordable, high quality respite care services.
- Initial activities included:
  - Prior to grant award, a summit was held to bring together stakeholders from around the state. This summit focused on developing a leadership team and partner agencies.
  - Partnerships were developed with the Department of Elder Affairs and Ounce of Prevention Fund of Florida.
  - In December 2015, the FLRA was incorporated and a Board of Directors established.
  - The FLRA contracted a part-time program coordinator to work with the Board and partner agencies.

### Structure

- The FLRA is a non-profit organization with a volunteer Board of Directors.
- The FLRA is a statewide coalition open to caregivers, stakeholders, policy makers, provider agencies and community members.

- The FLRA works in partnership with the Florida Department of Elder Affairs and the Ounce of Prevention Fund of Florida.

### Staff

- One part-time Program Coordinator
- Volunteer Board of Directors

### Funding

- The FLRA is funded by the federal Lifespan Respite Care grant from the Administration for Community Living.
- Activities of the FLRA are supported by the Ounce of Prevention Fund of Florida.

### Membership

- Members include state agency representatives, non-profit organization leaders, respite providers, aging and disability related organizations, representatives from University centers, faith-based community members and family caregivers.
- There is no fee for membership.

### Meetings and Communication

- Conference call meetings are held monthly.
- The FLRA communicates through social media (Facebook) and the FLRA website. The website also includes a blog that is updated monthly with helpful articles. Future posts will include caregiver interviews.
- An email listserv exists for outreach to all members.



Prepared in 2017 by the Florida Lifespan Respite Alliance. For more information, contact ARCH; (703) 256-2084; jkagan@archrespite.org. ARCH Website: [www.archrespite.org](http://www.archrespite.org)

## Major Activities

- Incorporated as a non-profit December 2016.
- Developed a comprehensive website that includes a blog with potential for guest expert posts.
- Created a partnership with all Florida ADRC locations to expand respite resources in the statewide database.
- Presented at the Florida Symposium on Aging with Developmental Disabilities hosted by the University of South Florida – Florida Center for Inclusive Communities.
- Participated as a member of the Florida Developmental Disabilities Council Waitlist Implementation Task Force.
- Invited to present at/participate in two upcoming statewide conferences – June 2017 and August 2017.

- Held the first Florida Lifespan Respite Summit, June 2017.
- Currently partnering with the Agency at the University of Florida to develop a Public Service Announcement for distribution by television, radio and social media.

## Documents Available

- The FLRA website:  
[www.FLlifespanrespite.com](http://www.FLlifespanrespite.com)
- The FLRA Blog to be accessed via the website
- FLRA Facebook page
- Flyers and brochures are in development
- Surveys are in development
- PSA is in development

## State Contact Information

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[www.FLlifespanrespite.com](http://www.FLlifespanrespite.com)

<https://www.facebook.com/FloridaRespite>



## Idaho Caregiver Alliance (Formerly Known as the Idaho Lifespan Respite Coalition)

### Start-Up Process

- The Idaho Caregiver Alliance (ICA) began as the Lifespan Respite Coalition (ILRC). The ICA is led by the Boise State University Center for the Study of Aging (BSU-CSA) in coordination with the Idaho Commission on Aging (ICOA).
- Establishment of the ILRC started in 2002 with the formation of a statewide Respite Advisory Committee hosted by the Idaho Department of Health and Welfare (IDHW). IDHW held seven regional meetings with more than 300 Idahoans attending. The meetings resulted in a Respite Care Needs Assessment Report published in 2002 that established three areas of focus:
  - 1 Identify federal, state and private funding streams to access for respite care.
  - 2 Establish information and referral sources in Idaho (CareLine, Project 211, Child Care Referral services) to use for families to access “one-stop shopping” for information on available and accessible services, information on eligibility criteria and the scope of programs.
  - 3 Develop a registry of respite providers, determining training needs and compiling an inventory of available training.
- The Respite Advisory Committee appointed sub-committees to address the three focus areas, but effort dissolved before objectives could be realized.
- To build on earlier efforts, the Idaho Lifespan Respite Summit was held March 1, 2012 at Boise State University. Primary partners for the Summit were ARCH National Respite Network, BSU-CSA, Justice Alliance for Vulnerable Adults (JAVA) and ICOA. The Summit, funded in part by a grant from the Administration on Aging through the ARCH Lifespan Respite Network, was an opportunity to:
  - Examine the need for respite care services;
  - Work towards strengthening existing respite resources; and
  - Lay ground work for future statewide funding opportunities.
- Summit attendees identified critical needs:
  - Increase services for individuals who fall in the “doughnut hole” of coverage. These caregivers shoulder the responsibilities of care for persons aged 18–59 alone and do not qualify for public assistance programs.
  - Build a respite system that is easier to navigate.
  - Educate caregivers and gatekeepers about access to services. Caregivers do not choose to use respite care, despite need and availability. Often people don’t identify as being a caregiver even though they are actively in that role full time. They view taking care of an aging or disabled parent or a child with a disability as their duty and it should be done without assistance from others.
  - Increase funding for and information about respite care resources.
  - Connect and coordinate respite related organizations and agencies.
- The group decided to form the ILRC and developed the goal of creating and implementing a sustainable respite system of care for Idaho. The ILRC identified the following objectives:
  - 1 Conduct research and create data resource.
    - Need sufficient funding for needs assessment/evaluation;
    - Need to know caregiver’s level of knowledge regarding respite services



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and why people choose not to use available respite care; and

- Need interagency knowledge about other services.

## ② Coordinate services and information sharing.

- Need single entry point for individuals seeking respite services;
- Need education about available resources and limited outreach efforts; and
- The frequent opening and closing of home health agencies makes maintaining databases difficult.

## ③ Increase services.

- Need to find and disseminate resources for middle class families who do not qualify for public assistance (doughnut hole);
  - Need emergency respite options/ crisis registry and rural respite options;
  - Need assistance for caregivers navigating insurance and other forms of payment; and
  - Need caregiver training that includes basic skills and understanding of all levels of care.
- Lead by ICOA and BSU-CSA, the ILRC met April 18, 2012 to develop an Administration on Community Living (ACL) 2012 Lifespan Respite grant proposal. The 2012 proposal was not funded. ICOA and BSU-CSA contacted ILRC members in April and May 2013 to draft another proposal, which was awarded on August 21, 2013.

## Structure

- The ILRC is led by the BSU-CSA. The ICOA is a member of the ILRC and the lead for the ACL Lifespan Respite Project. The ILRC is currently organized into four workgroups:
  - Coalition Development, Marketing, and Sustainability
  - Statewide Needs and Asset Assessment

- Cultivation of Regional Connections
- Development of an Idaho Emergency Respite Network
- The name of the coalition was changed to the Idaho Caregiver Alliance (ICA) in 2015.

## Staff

- Through a contract with the ICOA, BSU-CSA hired a part-time staff person to develop the ICA (formerly known as the ILRC). The contract is funded by ICOA's three-year (2013–2016) ACL Lifespan Respite grant.

## Funding

- Through a contract with the ICOA, BSU-CSA is leading the development of the ICA.

## Membership

- The ICA currently has more than 200 members representing people across the lifespan and more than 50 public and private organizations.

## Meetings and Communication

- The ICA and Lifespan Respite project conducted a kick-off meeting October 31, 2014. Full ICA meetings are held quarterly.
- Subcommittees or workgroups meet monthly or as needed.

## Major Activities

- Statewide Respite Summits held in 2015 in Lewiston and Idaho Falls. More than 100 caregivers across the lifespan participated in each event.
- Implementation of a pilot Lifespan Emergency Caregiver Respite Program in partnership with the Idaho Federation of Families for Children's Mental Health.
- Implementation of Caregiver Taskforce at the request of the Idaho Legislature. An outcome of the Taskforce was the development of a Caregivers in Idaho Report. The report was presented to the 2016 Idaho Legislature.

- Launch of the Powerful Tool for Caregivers (PTC) evidenced-based caregiver training throughout Idaho. Using resources from the ACL Lifespan Respite grant, individuals from across the state received training as PTC class leaders. The PTC curriculum is designed for caregivers across the lifespan.
- Expansion of the Idaho 2-1-1 Careline web-based resource to include a Caregiver Support and Respite access portal.
- Completion of an analysis of impact of dementia behavioral crisis events on first responders and family systems in Idaho. Results were presented to members of the ICA, legislators and the Idaho Alzheimer's Planning Group. In addition, the findings were presented at the 2015 American Public Health Association Annual Conference in Denver, CO.
- Development of an Idaho Family Caregiver Action Plan.
- Passage of a Concurrent Resolution (CR) in the 2017 Idaho House and Senate. The CR recognized the value of family caregivers and supported the Idaho Family Caregiver Action Plan.
- Partnership with Idaho Central Health Collaborative to integrate caregivers in to person-centered medical homes in Ada, Boise, Elmore, and Valley Counties. Project timeline: March–December 2017.

## Documents/Resources Available

- Caregivers in Idaho Report
- Report of Powerful Tool for Caregivers (PTC) Statewide Implementation
- Report of Analysis of Impact of Dementia Behavioral Crisis Events on First Responders and Family Systems in Idaho
- Idaho Family Caregiver Action Plan

## State Contact Information

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For more information go to <https://hs.boisestate.edu/csa/idaho-caregiver-alliance/> or <https://aging.idaho.gov/>

Visit us on Facebook at <https://www.facebook.com/IdahoCommissiononAging>  
or tweet with us <https://twitter.com/commissionaging>





## Illinois Respite Coalition

### Start-Up Process

- In 1998, The Illinois Respite Coalition (IRC) started out as a grassroots organization with parents, respite providers and community leaders. Technical assistance was provided by ARCH.
- In 2001, the Illinois Department of Children and Family Services (DCFS) received federal funding to develop six demonstration grants and funded the IRC.
- In 2013, volunteer board members continued to move the coalition mission and vision forward; Maryville Academy began serving as fiscal agent.

### Structure

- The IRC has a volunteer Board of Directors that serves as leadership for the coalition and meets on a quarterly basis.
- The Board of Directors supervises and supports the Statewide Respite Coordinator.

### Staff

- The Statewide Respite Coordinator is the only paid staff position under the IRC's direction.

### Funding

- State funding through the Department of Children and Family Services
- State funding through the Department of Human Services
- Funding from the Christopher & Dana Reeve Foundation
- Donations

### Major Activities

- The IRC maintains a database of agencies throughout the state of Illinois that provide respite and other services that are of assistance to caregivers and care recipients.
- Services are available to any family caregiver or provider statewide, regardless of age or disability.
- The IRC assists parents and caregivers by providing referrals and connecting them to services in their area.
- Emergency respite funding is available for families who are in crisis and need temporary assistance.
- Trainings on respite and related topics are available upon request.
- The IRC assists the state with identifying gaps in services and builds diverse respite partnerships.
- Distributes literature and information on matters such as child and elder abuse prevention and how to choose a respite worker.
- Provides access to training and caregiving resources online.
- The IRC networks with respite coalitions in other states.
- Outreach is conducted to promote the services provided by the IRC to agencies, support groups, and other organizations.
- The IRC is dedicated to increasing public awareness of the importance of "Lifespan Respite" and advocates support for universal access to quality respite services for residents of the State of Illinois.



Updated in 2017 by the Illinois Respite Coalition. For more information, contact ARCH; (703) 256-2084; jkagan@archrespite.org. ARCH Website: www.archrespite.org

## Documents/Resources Available

- Bylaws
- Brochures (available in English and Spanish)
- Surveys
- Job description of Statewide Respite Coordinator

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## Iowa Lifespan Respite Coalition

### Start-Up Process

- The Iowa Respite Coalition was formed June 1, 1993, by a group of concerned parents and respite providers with the goal of improving the state's respite system. In 1997, an alliance was forged with Iowa Crisis Child Care to form the Iowa Respite and Crisis Care Coalition. The group that originally formed in 1993 had focused on children's respite. Since the 1997 alliance, the Coalition had broadened its focus to include crisis care (for children who do not necessarily have a disability – essentially emergency respite care), and respite for adults, including aging consumers.
- Today, the coalition partners with the Iowa Department on Aging and Capture Marketing on the Lifespan Respite Grant, which provides funds to improve and enhance the current system of respite statewide, including funds for emergency respite care services.
- The coalition continues to advocate for improved access to respite for caregivers of those across the lifespan, including the elimination of waiting lists for Medicaid HCBS waiver services and an incentivized respite workforce.

### Structure

- The coalition is informally member-based, though active individuals and organizations are always encouraged to bring new advocates to the table.
- Members and organizations include Area Agencies on Aging, child welfare agencies, disability advocacy organizations, direct service providers and consumers.

### Staff

- The coalition does not presently maintain staff, though much of its support is provided by Capture Marketing, the contract partner for the Lifespan Respite grant.

### Funding

- The activities of the coalition are currently funded through the Lifespan Respite grant. The coalition has begun an intensive sustainability planning process, an aspect of which will address diversifying funding streams.

### Membership

- While memberships have previously been sold, the coalition, in its present form, has adopted an informal self-declaration process for those individuals and organizations who wish to be involved with its activities.

### Meetings and Communication

- Meetings are held in-person every other month on the third Wednesday of the month at the Iowa Association of Community College Trustees in Des Moines.
- Communication is primarily conducted via email, with primary messages pertaining to upcoming meetings and events. A committee reviews emergency care applications for approval via email.

### Major Activities

- Funding emergency respite services for caregivers in crisis.
- Annually surveying caregivers and providers to gain an accurate portrayal of the respite system, as well as trainings that are offered to its workforce.



Updated in 2017 by the Iowa Lifespan Respite Coalition.  
For more information, contact ARCH; (703) 256-2084; jkagan@archrespite.org. ARCH Website: www.archrespite.org

- Advocacy and information sharing across professional and caregiver networks.
- Building awareness and increasing education on respite to caregivers and non-caregivers alike, especially for underserved populations.

### Previous Major Activities

- Care for Caregiver Conference in 2015 and 2016
- Respite reimbursement for families that are on Medicaid Waiver Waiting Lists or otherwise do not qualify for state funded respite programs

- Online education for providers through a partnership with Essential Learning of San Diego, CA
- Annual state respite conference and training programs
- Hosted the 2008 National Lifespan Respite Conference “Home Grown – Cultivating Caregivers”
- Bi-monthly provider meetings
- Fundraising activities

### Documents/Resources Available

- Application for Emergency Care

### State Contact Information

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## Kansas Lifespan Respite Coalition

### Start-Up Process

- A small group of professionals began conversations about forming a group focused on respite care services in Kansas.
- Statewide summit was held in May 2007 with grant funding. Jill Kagan from the ARCH National Respite Coalition, Senator Byars, a former state senator who championed Nebraska's Lifespan Respite legislation and Rose Ann Percival, founder of the Oklahoma Respite Resource Network, participated in the summit and guided efforts. Result of the summit was formation of the Kansas Lifespan Respite Coalition (KLRC).
- Summit was followed by regular planning meetings to create mission statement, focus, etc.
- Coalition leadership met with various state departments in 2009, which resulted in partnership with the Kansas Department on Aging and the Aging & Disability Resource Center.

### Structure

- Coalition Founder served as Chair during first year.
- New Chair was named for the following year. A steering committee (comprised of Founder, Chair, and active members) was formed to provide direction to coalition.
- Coalition Founder currently serves as Chair.

### Staff

- Currently, the KLRC has no paid staff. However, grant money was received in 2008 and 2010 to pay for an intern to conduct a statewide needs assessment.

### Funding

- The KLRC wrote a grant in 2008 and received about \$12,000 in funding. The grant was used for community engagement and organizational development.
- The KLRC wrote the same grant in 2010 and received about \$11,000 in funding for program development and revenue development.
- The KLRC does not charge dues for membership.

### Membership

- The KLRC currently has about 40 active members with 200 interested stakeholders. For a list of current members, see [http://www.ksrespite.com/links\\_and\\_resources.php](http://www.ksrespite.com/links_and_resources.php).
- The coalition hopes to increase membership by connecting with additional service providers affiliated with the Aging and Disability Resource Center.

### Meetings and Communication

- The KLRC holds periodic statewide meetings. Conference call capabilities have been made available during all meetings to facilitate participation across the state.

### Major Activities

- The KLRC was successful in getting a state Lifespan Respite Care bill drafted and introduced to the Kansas Senate Ways and Means Committee in March 2008. Members of the KLRC testified in support of the bill, but unfortunately the bill did not make it out of Committee during the legislative session.
- The KLRC hosted a strategic planning retreat in Fall 2008 to bring statewide membership together to continue organizational development and focus on initiatives.



Updated in 2017 by the Kansas Lifespan Respite Coalition. For more information, contact ARCH; (703) 256-2084; [jkagan@archrespite.org](mailto:jkagan@archrespite.org). ARCH Website: [www.archrespite.org](http://www.archrespite.org)

- Using grant funding, the KLRC launched a website ([www.ksrespite.com](http://www.ksrespite.com)) and had brochures created to promote statewide involvement and awareness of respite care and of the KLRC.
- The Kansas Department on Aging was awarded a federal lifespan respite grant from the US Administration on Aging in 2010. The KLRC worked collaboratively with the state agency to secure the grant.
- In 2017, the KLRC collaborated with Respite Outreach Care for Kansans Organization, the Arc of Douglas County and Rewarding Work Resources to launch the Kansas Personal Care Directory. The directory helps connect individuals/family caregivers in need of supportive care with

personal care and respite workers and is available at [www.rewardingwork.org/Kansas](http://www.rewardingwork.org/Kansas).

## Documents/Resources Available

- KLRC Mission Statement: The mission of the KLRC is to promote access to and use of respite for all Kansas caregivers, through community awareness, advocacy, education, and collaboration by providing a statewide respite care system.
- Website: [www.ksrespite.com](http://www.ksrespite.com)
- KLRC Membership Application
- KLRC Meeting Minutes
- Statewide Respite Survey

## State Contact Information

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## Maryland

### Respite Care Coalition

# Maryland Respite Care Coalition

## Start-Up Process

- The Maryland Respite Care Coalition (MRCC) first began in 1997:
  - September 28, 1998: Maryland's First Annual Respite Awareness Conference was held; Regional workgroups recommend Respite Coalition; DHR, DDA, MHA, Kennedy Krieger Institute, Governor's Office for Individuals with Disabilities, Prince George's County Foster Parent Association, Arc of Anne Arundel and Montgomery County Commission on Aging members of Planning Committee; Delegate Marilyn Goldwater attended.
  - Strategic planning to establish the coalition took place between December 1998 and June 1999.
  - October 18, 1999, Maryland's Second Annual Respite Awareness Conference.
  - December 1999 Delegate Goldwater begins to research Lifespan Respite legislation in other states and commits to sponsoring legislation.
  - January 2000 MRCC Founding Board meets to establish coalition; Delegate Goldwater sponsored House Bill 632, Maryland Family Caregiver Support Act.
  - May 2000 DDA, DHR, DoA, MHA, Governor's Office for Individuals with Disabilities and the Office for Genetics and Children with Special Health Care Needs meet as a workgroup to support House Bill 632. MRCC provides consultation to Delegate Goldwater.
  - June 2000, MRCC becomes an Incorporated entity in the state of Maryland.
  - The group remained active until 2012, having hosted nine Annual Respite Awareness Day Conferences.
- In 2017, the group is re-established after a period of five years of limited activity.

## Structure

- As of June 2017, the MRCC remains an informal group of respite advocates representing caregivers and human services organizations around the data.
  - In the remainder of 2017 and 2018, the group plans to meet to discuss its structure.
- The Coalition works closely with the Maryland Department of Human Resources, the lead agency for the state Lifespan Respite grant.

## Staff

- MRCC is completely volunteer-based.

## Funding

- No formal funding stream for the MRCC.
- Several human services organizations provide in-kind assistance to the MRCC.

## Membership

- Members include caregivers, respite agencies, non-agency providers, human services organizations, representatives from state and local government and university centers, families and concerned citizens.
- Agencies and individuals donate specific services, funding, or in-kind support and resources to host events.
- At present, no official policies in place around membership requirements.



Updated in 2017 by the Maryland Respite Care Coalition. For more information, contact ARCH; (703) 256-2084; [jkagan@archrespite.org](mailto:jkagan@archrespite.org); ARCH Website: [www.archrespite.org](http://www.archrespite.org)

## Meetings and Communication

- The MRCC meets on a quarterly basis: April, July, October and January.
- Sub-groups of the committee may meet more frequently between quarterly events.
- Regular email communiqués.
- Conference calls.
- Minutes and handouts from meetings are posted on the MRCC’s website.

## Major Activities

- In 2017, collaborating with the state Lifespan Respite program administered by Maryland Department of Human Resources.
- Before 2012, the MRCC achieved a number of notable successes:
  - Hosted 14 annual Respite Awareness Day Conferences.
  - Signing of Senate Bill 567 by Governor, establishing the Maryland Family Caregivers Support Coordinating Council to be housed in the Department

of Human Resources, the Coalition is the only private non-profit organization to be named in the legislation as a member of the Council.

- Partnered with the National Family Caregivers Association, Maryland Caregivers Support Coordinating Council, Montgomery County Department of Health and Human Services, Office of Disability and Aging Services to host a statewide Family Caregivers Town Hall Meeting.
- Sponsored Legislative Breakfast for Maryland’s General Assembly.

## Documents/Resources Available

- Meeting minutes, slide presentations
- Website: [www.marylandrespitecoalition.org](http://www.marylandrespitecoalition.org)

## State Contact Information

*General inquiries about the Maryland Respite Care Coalition, contact:*

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Maryland Family Network

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Department of Human Resources

Social Services Administration

Office of Adult Services



# Massachusetts Lifespan Respite Coalition

## Massachusetts Lifespan Respite Coalition

### Start-Up Process

- The original Massachusetts Respite Coalition was started in 2003. The impetus for the group was a growing recognition of the critical need for respite across caregiving groups.
- In 2009, a planning group was convened to prepare for expected federal funding opportunities and to strategize how to revitalize the Coalition. This planning group applied for and was awarded funding from ARCH to hold the Massachusetts 2010 Lifespan Respite Summit, which took place in March 2010. As a result of the Summit, the Massachusetts Respite Coalition was revived. The new Coalition had its first meeting in Spring 2010.
- Massachusetts was awarded a 3-year Lifespan Respite Care Grant in September 2010.
- Since then Massachusetts has received an Expansion Grant in 2012, a Sustainability and Integration grant in 2013, a 3-year Long Term Sustainability Grant in 2014 and an Expansion Grant in 2016.

### Structure

- The Massachusetts Lifespan Respite Coalition (MLRC) has evolved from a grassroots organization to a more formal entity with 2 part-time staff members
- Currently, there is one statewide group, with plans to expand into regional branches, collaborating with the ADRC regions of Massachusetts.

### Staff

- A part-time coordinator and a part-time consultant are funded through the Lifespan Respite Grant. The Project Director is employed as a Regional Family Support Director by the host agency for the grant (the Massachusetts

Department of Developmental Services) and donates one day per week as part of the state's in-kind match requirement.

### Funding

- Funds that have been donated by various state and private agencies and companies have been specifically directed to Coalition events (CARE Conferences and a National Lifespan Respite Conference) and not used for coalition activities.

### Membership

- The MLRC has grown to more than 600 members.
- Membership is free.
- Members include family caregivers, individuals representing a range of ages, conditions and family circumstances, representatives of all relevant Massachusetts state agencies and many human service organizations.

### Meetings and Communication

- Meetings are held monthly on the first Tuesday of each month at the same time to make scheduling for the membership easier. Each meeting has a guest speaker on a relevant topic and the option of conference call attendance. The MLRC is exploring web-based access for improved long-distance participation at monthly meetings.

### Major Activities

- The MLRC conducted an online Family Caregiver Respite Needs Survey in 2011, and conducted Key Informant Interviews and Caregiver Focus Groups to supplement information gained via survey results.
- A Caregiver Awareness Event was held in November 2011 at the Statehouse in Boston.



Updated in 2017 by the Massachusetts Lifespan Respite Coalition. For more information, contact ARCH; (703) 256-2084; [jkagan@archrespite.org](mailto:jkagan@archrespite.org). ARCH Website: [www.archrespite.org](http://www.archrespite.org)

This evolved into the CARE (Connecting and Advocating Respite for Everyone) Conference, a free all day event for family caregivers from across the lifespan, held in November 2012.

- The MLRC website at [www.massrespite.org](http://www.massrespite.org) was launched in January 2013.
- The MLRC along with ARCH, hosted the 15th National Lifespan Respite Conference, The Freedom Trail to Respite, in October 2013 in Boston.
- The MLRC held “A Respite Summit” in November 2013, an overview of the 10 Mini-Grant projects that were funded through the Expansion funds.
- The MLRC held its second CARE conference Making Respite Happen, a day for family caregivers across the lifespan in May 2015.
- The MLRC recognized five exemplary respite programs at the Massachusetts

State House in November 2015 as part of National Family Caregiver Month.

- The MLRC held its second Mini-Grant Respite Summit in April 2016 with the five Mini-Grant recipients presenting on their projects funded through the Expansion Fund. The MLRC held A State Summit: A Working Meeting in June 2017 to explore state respite needs and how state and community partnerships could be strengthened.
- In September 2017, the MLRC will hold its third Mini-Grant summit with the 10 Mini-Grant recipients presenting on their projects funded through the Expansion fund.

## Documents/Resources Available

- Fact sheet
- Brochure
- Website: [www.massrespite.org](http://www.massrespite.org)

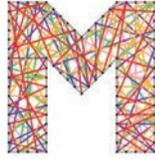
- Family Caregiver Survey
- Link to episodes on Cable Television series on aspects of Family Caregiving
- List of short term residential resources in Massachusetts
- Public Service Announcements

## State Contact Information

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MISSISSIPPI  
FAMILY  
CAREGIVER  
COALITION

## Mississippi Family Caregiver Coalition

### Start-Up Process and History

- The Mississippi Family Caregiver Coalition (MFCC) was created in 2015 as a grassroots organization made up of caregivers, state and private agencies, as well as advocacy groups aimed at identifying and empowering caregivers by educating them about accessing community resources, support networks, and their rights. Caregivers for adults and children make up over 501,000 individuals in Mississippi (AARP Public Policy Institute, 2015).
- Public and private agencies represented:
  - Child Welfare
  - Developmental Disabilities
  - Mental Health
  - Aging
  - Adult Protective Services
  - AARP
  - Alzheimers Association
- Initial Respite Summit held in February 2016 with technical assistance from ARCH.

### Structure

- The Coalition is made up of three co-chairs, a steering committee, and a Respite Committee.

### Staff

- Currently there are no paid staff.
- All are volunteers.

### Funding

- The Mississippi Family Caregiver Coalition assists the Mississippi Access to Care Center, in the Department of Human Services, which is the recipient of the three-year \$250,000 grant from

the Administration on Community Living, to create a Lifespan Respite Network in Mississippi.

- The Respite Committee of the Coalition is completely grassroots and currently receives no funding from state or other resources.

### Membership

- Membership is available to all interested parties and may include:
  - Healthcare Providers (hospitals, skilled nursing facilities, physician practices, home health agencies, dialysis facilities, hospice organizations, palliative care organizations, etc.)
  - Provider Associations
  - Consumer Advocacy Organizations
  - Government Organizations
  - Quality Improvement Organizations
  - Educational Organizations
  - Professionals
  - Consumers
  - Funding Organizations
  - Academics
  - Caregivers
  - Private non-profit organizations
  - Community-based organizations
- No membership fees are currently involved.

### Meetings and Communication

- Meetings are held on a quarterly basis either in person or through media.
- Member groups and individuals are kept abreast of the work of the Coalition through email and dissemination of information from agency leaders.



Prepared in 2017 by the  
Mississippi Family Caregiver  
Coalition. For more information,  
contact ARCH; (703) 256-2084;  
jkagan@archrespite.org. ARCH  
Website: [www.archrespite.org](http://www.archrespite.org)

- Committees meet throughout year.
- Annual One-Day Workshop.

## Major Activities

- Helped enact legislation to establish s state Caregiver Resolution
- Presentations, exhibits and other outreach activities as schedules permit
- Legislative Advocacy
- Information and Referral
- Initiated Respite Companion Training through REST (2017)

## Documents Available

- By-Laws
- Articles of Incorporation
- MFCC Fact Sheet
- Caregiver Blueprint (2014)

## State Contact Information

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## Montana Lifespan Respite Coalition

### Start-Up Process

- A Lifespan Respite Summit was held March 2011 to address respite needs, gaps and current use.
- A group of nonprofit providers, caregivers, government agencies and other stakeholders met to prioritize issues and needs for writing a Lifespan Respite grant.
- Montana's Senior and Long-term Care Division (SLTC) received a Lifespan Respite Grant in August 2011.
- SLTC contracted with Developmental Educational Assistance Program (DEAP), a nonprofit corporation providing a variety of services to special needs populations including a Lifespan Respite services program, to help implement the grant.

### Structure

#### 2011

- A State Workgroup was formed consisting of DEAP and representatives of all the Department of Public Health and Human Services divisions that provide respite and caregivers.
- The Montana Lifespan Respite Coalition (MLRC) was organized and consists of nonprofit providers, caregivers, and other respite providers across the state.

#### 2013

- The State Workgroup merged with the MLRC.
- Four committees were created:
  - Caregiver Education and Training Committee, whose goal is to educate caregivers about the purpose, need for and values of respite.
  - Respite Responders Committee, whose purpose is to educate the people who answer the phones

for the 1-800 and 211 phone numbers about respite needs and available services.

- Website Committee, whose purpose is to develop and maintain a Lifespan Respite website.
- Executive Committee, whose purpose is to maintain a healthy Lifespan Respite Coalition and oversee all grant activities.

#### 2014

- Committees were restructured:
  - Public Awareness committee replaced the Respite Responders and Website committees. This committee's purpose is to work on website improvements and coordinate with other committees for marketing needs.
  - Summit Committee was added to work on the planning of the annual summits.
  - Sustainability Committee was added to focus on the sustainability of the program through other grants and/or support from the state.

### Staff

- Coalition members chair the committees voluntarily. The ADRC Program Director with the DPHHS Senior & Long Term Care Division acts as the Program Manager for the grant and works closely with DEAP's Lifespan Respite Director who acts as the Project Director.

### Funding

- The MLRC has no funding dedicated to it.

### Membership

- The coalition is open to consumers, providers, agency representatives and other interested parties and currently has 103 members.



Updated in 2017 by the Montana Lifespan Respite Coalition. For more information, contact ARCH; (703) 256-2084; [jkagan@archrespite.org](mailto:jkagan@archrespite.org). ARCH Website: [www.archrespite.org](http://www.archrespite.org)

## Meetings and Communication

- Coalition meets every other month, rotating with WebEx meetings and meetings in person.
- Committees meet between MLRC meetings, usually by conference call.
- Communication through email and phone.

## Major Activities

### 2012

- Held caregiver focus groups in four regions of the state.
- March – Aired an Aging Horizons TV show focusing on the Lifespan Respite grant activities as well as highlighting caregiver issues and the importance of having access to respite services.
- June – Distributed a caregiver survey.
- August – Distributed a provider survey.
- October – Completed an Environmental Scan.
- October – Presented at the International Short Break Conference in Canada on Lifespan Respite in rural Montana.

### 2013

- March – Combined the State Workgroup and MLRC into one organization.
- March – Developed a strategic plan.
- June – Began designing the website with a focus on frequently asked questions, caregiver resources and identification of respite providers.
- July – Wrote a sustainability plan and added to the strategic plan.

### 2014

- January – Worked with an MSU Graphics Art student to design the statewide branding and logo.
- January – Distributed provider registry forms to 385 providers to collect respite information for website.
- June – Montana Senior and Long-Term Care Division in partnership with the

MLRC received a 3-year Sustainability State Lifespan Respite grant.

- August – SLTC contracted with DEAP to implement a statewide voucher program.
- September – A Facebook page was created for the MLRC.
- December – PSA about the definition of respite and the need for it aired. PSA added to website.
- December – Respite video titled, “What a Relief, Finding Help for Montana’s Caregivers” completed and distributed for use. Available on the coalition website and on the State DPHHS YouTube site.

### 2015

- January – Partnered in planning with the Governor’s Conference on Aging and the Montana Gerontology Society to add a Lifespan Respite track to the conference agenda and a Lifespan Respite Summit during the last day of the conference.
- March – Finalized an application process and all the necessary paperwork for a respite voucher program.
- May – Held a Lifespan Respite Summit, co-sponsored by ARCH with Jill Kagan as a keynote speaker.
- July – Launched the Lifespan Respite Voucher Program.
- August – A PSA promoting the Lifespan Respite Voucher Program aired statewide through the Montana Broadcasters Association – Radio and Television.
- November – A PSA promoting the Powerful Tools for Caregivers program aired statewide through the Montana Broadcasters Association – Radio and Television.
- December – An Aging Horizons TV show about the Lifespan Respite Coalition and the voucher program was filmed and aired.

### 2016

- February – An Aging Horizons show promoting the Lifespan Respite Summit aired.

- March – Lifespan Respite Summit, titled: Riding the Respite Wave: Sustaining the Momentum.
- May – A Lifespan Respite training module was added to the ADRC Options Counseling program.
- September – Presented on Lifespan Respite at the Governor’s Conference on Aging.
- September – Presented on the Lifespan Respite Voucher Program at the National Lifespan Respite Conference.
- September – Montana Senior and Long-Term Care Division in partnership with the MLRC received a one-year Expansion Grant that added funding for direct respite care through the voucher program.
- September – Spoke at the Governor’s Press Conference along with a caregiver that told her story; Governor announces that he is putting Lifespan Respite in his budget for the next biennium.
- October – Letter of Support signed by the Governor declaring November as “Family Caregivers Month.”
- November – A voucher utilization map by county was added to the coalition website.
- November – The Voucher program PSA begins a 3-month airing.
- December – A caregiver support group plan is finalized.

### 2017

- January – The first monthly Big Sky Caregivers Connect support group was held in Helena at the Covenant United Methodist Church.
- February – Visited the Northern Cheyenne reservation to meet with agencies to promote Lifespan Respite.
- February – Organized email campaigns to legislators to advocate for Lifespan Respite funding in the Governor’s budget.
- February – Work began on adding a caregiver blog to our Facebook page.
- April – The Voucher program PSA began a 3-month airing.

- May – Lifespan Respite Summit, titled: Refuel and Recharge: Coping with Compassion Fatigue. The keynote speaker and caregiver panel were taped and will be available for viewing on the MLRC website.

## Documents/Resources Available

- Website: <http://dphhs.mt.gov/respite>
- Grant Informational Handout
- Guiding Principles for Coalition
- Coalition: What's In It for You?
- Mission and Vision Statement
- Caregiver Survey
- Provider Survey
- Environmental Scan
- Strategic Plan/Sustainability Plan
- Website Provider Registry form with letter
- Lifespan Respite Coalition Brochure
- Powerful Tools Respite Voucher Form
- Lifespan Respite Voucher Brochure
- Lifespan Respite Voucher Forms
- Voucher Application
- Voucher Award Letter
- Respite Voucher Reimbursement Form
- Satisfaction Survey
- Voucher Process Checklist
- Request for Additional Funds Form
- Year 2 Voucher Application
- FAQ Information Sheet
- Database for Tracking Application/ Caregiver/Care Recipients etc.
- Voucher Award Spreadsheet
- Cost Share Sliding Scale Table
- Cost Share Worksheet

- Monthly Voucher Report
- Coalition Membership Spreadsheet
- Publicity Consent Form
- Coalition Committee Descriptor

## State Contact Information

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## Nebraska Caregiver/Respite Coalition

### Start-Up Process

- The Nebraska Respite Coalition was formed in 1998 to advocate for and create state legislation that was championed by Senator Dennis Byars to establish a Statewide Lifespan Respite Network.
- The legislation was passed in November 1999, and in May 2000 the Nebraska Respite Network was funded by the state legislature. The Department of Health and Human Services was charged with administering the program to serve family caregivers across the lifespan and state.
- The Respite Coalition continued to operate as a separate, independent entity from the Department of Health and Human Services and became solely self-supporting in October 1999.
- In 2001, local Respite/Caregiver Coalitions were created across the state.

### Structure

- No formalized structure.
- Since the six Nebraska Respite Network Coordinators perform many of the tasks undertaken by other State Respite Coalitions, the members of the NE Caregiver/Respite Coalition concentrate their efforts on continuing to educate and promote the importance of family caregivers and their need for supportive services, including respite, to the state legislators.
- The National Respite Coalition often works in collaboration with the Nebraska Caregiver Coalition, which was formed in 2004.

### Staff

- All members of the Nebraska Caregiver/Respite Coalition are volunteers.
- The Coalition is led by two co-chairs.

### Funding

- Funding for the Coalition is raised through donations and grants to cover the cost of events.
- The Nebraska Respite Network receives funding through state funds and community grants.

### Membership

- Membership consists of representatives from for-profit, not-for-profit, and governmental organizations serving people with special needs from across the lifespan, as well as family caregivers.

### Meetings and Communication

- Meetings are held the first Tuesday of each month.
- Communication is through emails and teleconferencing. Nebraska is a large rural state with different services and needs. The Nebraska Caregiver/Respite Coalition brings representatives from across the state together to find common ground.

### Major Activities

- In 2001, the coalition successfully advocated for passage of LB 692 to establish stipend funding for families through the Nebraska Lifespan Respite Subsidy Program.
- In 2001, Annual November Caregiver Awareness Activities begin:
  - Coalition members delivered cookies and information about families in need of services to our legislators.
  - Coalition organized Caregiver Celebration luncheon at the Governor's Mansion and proclamation signings by the Governor recognizing November as awareness month for Family Caregivers, Respite, In-home



Updated in 2017 by the  
Nebraska Caregiver/Respite  
Coalition. For more information,  
contact ARCH; (703) 256-2084;  
jkagan@archrespite.org. ARCH  
Website: [www.archrespite.org](http://www.archrespite.org)

Care, Alzheimer's disease, Hospice and Palliative Care.

- In 2004, NE Respite Coalition actively participated in "And Thou Shalt Honor" nationally televised PBS special including excerpts from the Caregiving Town Hall meeting filmed in Kearney, NE.
- In 2006, co-sponsored National Respite Conference in Omaha.
- In 2007, Coalition initiated annual informational luncheons for State Senators at the Capitol to inform legislators and their staff of the importance of family caregivers providing long-term care and their need for services.

- In 2008, NETV Special, "Caring for Your Parents," resulted in training opportunities across the state for family caregivers and professionals.
- Panels of professionals, in collaboration with the Coalition, provide community resources to the participants at the statewide events.

### Documents/Resources Available

- Original bylaws
- 2010 strategic plan

### State Contact Information

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## Nevada Lifespan Respite Coalition

### Start-Up Process

- The mission of the Nevada Lifespan Respite Care Coalition is to support caregivers in our community by promoting awareness and access to, as well as coordination and advocacy for, respite services in Nevada throughout the lifespan. Organizers felt the purpose of the Coalition should embody the philosophy of serving the needs of the underserved population.
- A Corporate Charter for the organization was established on November 13, 2007. Annual and regular meetings of the board and members have been held since then.
- Start-up funds and support for meetings and activities of the Coalition came from individual members and their organizations.

### Structure

- The Coalition is an incorporated nonprofit in Nevada. An application for an IRS 501(c) (3) determination is in development, but has been placed on hold until the organization has a stronger need for tax-exempt status.
- The organization is led by a Board of Directors, with membership from state agencies, nonprofits, service providers, and professional and family caregivers interested in respite issues.
- A committee on Advocacy has been formed to monitor legislative activity. Committees for Education/Training & Outreach, Interfaith Outreach, Town Hall Meetings, Advocacy, New Models of Care, and Fundraising Opportunities were formed.
- The Coalition is a statewide organization, serving urban, rural, and frontier areas in Nevada.

### Staff

- There are no paid staff members of the organization; all officers, directors, and general members serve in a volunteer capacity.
- Paid staff under the ACL-funded Lifespan Respite Care Program grant awarded to the Nevada Aging and Disability Services Division assist the State Respite Coalition in accomplishing shared goals. The Lifespan Respite Care Program Coordinator employed by the state's Lifespan Respite Program, works closely with Coalition members as key partners in grant activities.

### Funding

- Members of the Coalition have donated time and resources to incorporate and support meetings and other activities.
- The Nevada Lifespan Respite Care Coalition receives no funding from the state Lifespan Respite Program grant, but the grant was designed to help further some of the Coalition's goals.

### Membership

- Membership is open to all who are interested. Currently there are 45 individuals listed on the organizational roster.
- Membership has been weighted heavily in aging services so recruitment efforts are targeted toward representatives of respite services for children and adults with disabilities.
- Family caregivers are also welcome as Coalition members, but current membership primarily represents public and private agencies.
- The organization does not currently collect membership fees.



Updated in 2017 by the Nevada Lifespan Respite Coalition.  
For more information, contact ARCH; (703) 256-2084; jkagan@archrespite.org. ARCH Website: www.archrespite.org

## Meetings and Communication

- The Nevada Lifespan Respite Care Coalition holds 9-11 meetings during the year. These meetings are held by videoconference to link members in Las Vegas, Reno, and Elko.
- Agendas and minutes of meetings are distributed primarily through email communication. Copies are available at all meeting sites.
- Newsletters, notices and other announcements from the membership are also disseminated through the Coalition, to increase awareness and participation in respite-related activities around the state.

## Major Activities

- Projects of the Coalition include a 2008 survey and a 2009 Town Hall Meeting and participant survey, to gather information on Nevada respite services and the needs of caregivers in Nevada.\*
- In 2009, the Nevada Lifespan Respite Care Coalition was a key partner in the application for the Administration on Aging Lifespan Respite Program grant, administered by the Nevada Aging and Disability Services Division.\*
- In July 2010, the Lifespan Respite Care Coordinator was hired to work on grant activities. Coalition members have made themselves and their resources available to assist the coordinator in reaching grant objectives.\*

- In June 2012, the Lifespan Respite Care Coalition coordinated the Nevada Lifespan Respite Summit. The Summit was an opportunity to discuss respite supports and services in Nevada and discuss what collective goals the Nevada Respite Coalition would like to accomplish. This statewide gathering included representatives from families engaged in caregiving, stakeholder groups (respite providers, human resources, social services, developmental disabilities, public health, mental health, maternal and child health, and aging services) and others who were interested in the future of respite and respite services in Nevada. National speakers from the Administration on Aging (AoA) and ARCH attended and presented. Goals were developed and implementation is an ongoing process.\*

## Documents/Resources Available

- The Coalition does not yet have a website or brochure, but a Facebook page has been established at <http://www.facebook.com/pages/Nevada-Lifespan-Respite-Care-Coalition/128046090602195>. Bylaws for the Coalition are available upon request.
- A survey was conducted in 2008 to gather information about respite services in Nevada. A PowerPoint presentation of the results was created. The survey instrument and results are available upon request.\*
- A Town Hall Meeting was held in April 2009. A summary of the meeting and

the ideas generated were compiled into a report that is available upon request. A survey of attendees was also conducted to assess the impact on caregivers and respite utilization by families. Professional respite providers were surveyed to assess respite benefits and barriers to their clients. The survey results are included in the Town Hall Meeting summary.\*

## State Contact Information

- Key contacts for the Nevada Lifespan Respite Care Coalition are:
  - **Cory Lutz**, President, 2320 Paseo Del Prado, B204, Las Vegas, NV 89102
  - **Korine Viehweg**, Vice President, PO Box 2072, Sparks, NV 89432
  - **Courtney Knapp**, Treasurer, 605 S. 21st., Reno, NV 89431
  - **Jamillah Ali-Rahman**, Recording & Corresponding Secretary, 2400 N. Tenaya Way, Las Vegas, NV 89128
- Key Contacts for the Nevada Lifespan Respite Care Program grant are:
  - **Jeff Duncan**, Chief Supportive Services, Aging & Disability Services Division, 1860 E. Sahara Ave., Las Vegas, NV 89104, 702-486-3558, [jsduncan@adsd.nv.gov](mailto:jsduncan@adsd.nv.gov)
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\* Joint venture or coordination between the Nevada Lifespan Respite coalition and Nevada Aging and Disability Services Division



# New Hampshire Lifespan Respite Coalition

## Start-Up Process

### 2009

- The New Hampshire Department of Health and Human Services chosen to be a Lifespan Respite Grantee, through its Title V – Children with Special Health Care Needs program. There was no statewide respite coalition at that time.

### 2011

- Stakeholders interested in respite met in January 2011 and a core membership for the NH Lifespan Respite Care Coalition (LRC) meets monthly.
- Coalition Chairpersons attended the Statewide Lifespan Respite Summit. Meeting sites were located around the State linked by videoconferencing. The purpose of the Summit was to further the development of the Coalition as a working alliance between stakeholders, caregivers and supporters of respite.

### 2014–2015

- VISTA volunteer assisted in coordinating the Coalition’s outreach program. The VISTA volunteer was funded by Catholic Charities and housed at an Area Agency on Aging.
- The core membership has focused on the Vision and Mission of NH LRC Coalition to guide their meetings and activities.

## Structure

- The group appointed co-chairs from its membership in September 2013. There is no formal structure in the NHLRC Coalition currently.
- The New Hampshire Lifespan Respite Care Coalition is committed to the Vision that, all caregivers in New Hampshire will be able to

access high quality, affordable, and culturally appropriate respite that will be delivered according to the caregivers’ and families’ needs, timelines and special circumstances.

- The NH LRC Coalition is focused on its mission “to recruit and train qualified respite care providers which New Hampshire caregivers can easily access to meet their needs and the needs of those they care for, thereby enhancing the quality of life for individuals of all ages.”

## Staff

- The NH LRC continues to seek funding for a full-time Coordinator for the program.

## Funding

- Currently there is no funding available for Coalition activities other than the Respite Care Training through a contract with Relias.

## Membership

- Recruitment for and participation in the coalition includes stakeholders and partners with an interest or focus on respite.

## Meetings and Communication

- The LRC meets monthly. The meetings incorporate the ability for participants to join by conference call. Space for the meetings has been generously donated by a Coalition member agency.
- Communication includes updates at monthly meetings, email, for meeting notes and resource documents, and telephone conference calls.



Updated in 2017 by the New Hampshire Lifespan Respite Coalition. For more information, contact ARCH; (703) 256-2084; jkagan@archrespite.org. ARCH Website: www.archrespite.org

## Major Activities

- The Vision and Mission have been completed for NH Respite using guidance from the workbook from ARCH National Resource Center *Building a Statewide Respite Coalition: Where Do We Begin?*
- The Coalition Workgroup completed a Statewide Needs Assessment with Maternal Child Health (MCH) in 2011.
- Workgroup identified activities for the Lifespan Respite Coalition in NH:
  - Identify agency/organization's services and resources of who they serve and criteria
  - Define/Assess NH needs for respite care – including crisis or emergency care
  - Find gaps in respite care
  - Describe caregivers and respite
  - Develop video for first time caregivers and providers
  - Prepare conference presentations
  - Research grant funding to develop and sustain NH LRC Coalition Strategic Plan and its Mission/Vision

- Develop guidelines for Lifespan Respite Care Coalition
- Maintain and update Social Media
- Relias (web-based college level courses that are currently utilized by all the State Area Agencies for their Personal Care Attendants) used as a no-cost option for Respite Care training.
- Partnered with an Area Agency to develop NH Provider Link website through Rewarding Work.

## Documents/Resources Available

- Caregiver Needs Assessment
  - 2011 Summary Report of a Needs Assessment Survey that was sent to nearly 100 different organizations and their liaisons. These organizations consisted of government agencies, non-profits, Adult Day Care centers, and more and resulted in responses from 407 caregivers within NH.
- Website – [www.nhrespitecoalition.wordpress.com](http://www.nhrespitecoalition.wordpress.com)
- Website – [www.NHProviderLink.org](http://www.NHProviderLink.org)

- Facebook Page – <https://www.facebook.com/nhrespitecoalition>
- Promotional Materials for Caregivers and Providers
- Coalition Member Survey

## State Contact Information

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## New York State Caregiving & Respite Coalition

### Start-Up Process

- In 2008, educational presentations were made about the Lifespan Respite Care Act to the NYS Family Caregiver Council, the New York State Office for the Aging (NYSOFA) sponsored “Aging Concerns United” Conference, and in Syracuse to the New York State Rural Health Association board meeting. At these meetings, 37 attendees signed up for more information and were sent membership information.
- In June 2008, preparations began in earnest to launch a task force. The Statewide Caregivers Consortium of New York (SCCNY), headed by Renee Benson (who had been the NY contact for the National Respite Coalition for several years), took steps to establish a separate unit of the SCCNY, which was called the NY Lifespan Respite Task Force. On August 5th, Task Force member Beth Finkel, AARP New York, co-presented at a press conference with Senator Hillary Clinton about the Task Force work to date on the Lifespan Respite Initiative.
- Also in January of 2008, the consortium agreed to establish a Statewide Lifespan Task Force as an additional primary function of the organization. By the spring, the Statewide Lifespan Respite Task Force had a supporting membership of 23 agencies representing organizations from every disability service area and caring for clients of all ages. The consortium held a Statewide Respite Summit in May of 2009.
- The objectives of the Task Force were to assist:
  - New York State in becoming eligible for and applying for grants under the Lifespan Respite Care Act of 2006
  - The New York State agency that was designated to apply for such grants in developing its lifespan-respite program

### Structure

- One year after its inception, the SCCNY members realized that the rate of growth of the task force and the consortium was beginning to exceed the capacity of its members and that a separate agency with its own staff was needed. The NYS Office for the Aging brought the Consortium together with the NYS Coalition for the Aging (NYSCA) to discuss a collaboration to create a Statewide Caregiving and Respite Coalition.
- The membership of both SCCNY and NYSCA voted to consolidate the SCCNY program and its Statewide Lifespan Task Force with the NYSCA organization. This was done with the provision that NYSCA would adopt the full mission and bylaws of SCCNY and that it would offer positions on its board to SCCNY members. The Consortium’s name was changed to include the word “Respite” to properly include that function, resulting in the nomenclature “Statewide Caregiving & Respite Coalition of NY (SCRCNY).”
- With the new grant funding structure, the coalition was reorganized under Lifespan of Greater Rochester and named New York State Caregiving and Respite Coalition (NYSCRC).

### Funding

- NYS Office for the Aging
- Finger Lakes Geriatric Education Center

### Staff

- NYSCRC is staffed by personnel from the New York State Office of the Aging (NYSOFA) and Lifespan of Greater Rochester.
- Areas around the State have also received supplemental funding for respite projects. In Rochester, NY, Lifespan of Greater Rochester was awarded a grant to provide respite to people with early stage dementia.



Updated in 2017 by the New York State Caregiving & Respite Coalition. For more information, contact ARCH; (703) 256-2084; [jkagan@archrespite.org](mailto:jkagan@archrespite.org). ARCH Website: [www.archrespite.org](http://www.archrespite.org)

## Membership

- NYSCRC currently has over 700 members.

## Meetings and Communication

- Monthly e-news and advocacy alerts
- Annual State Conference geared toward professionals
- Caregiver Listening Tour

## Major Activities

- **Annual Conference** – NYSCRC sponsors an annual conference:
  - In 2016, the conference had 128 participants and focused on assisting organizations and faith communities to develop and sustain volunteer respite programs in their communities.
  - The 2017 Conference is titled “Understanding and Effectively Engaging Caregivers.” A pre-conference session will feature a “Caregiver Simulation” event.
- **Monthly Newsletters** – Every month, the NYSCRC electronically sends a newsletter to almost 700+members. Periodically, we highlight the work of local coalitions throughout the State. Newsletters are available on our website at [www.nyscrc.org](http://www.nyscrc.org).

- **Mini Grant Awards** – In 2016, NYSCRC awarded nine \$5,000 mini grants to organizations for the purpose of developing or expanding volunteer respite programs.
- **Education and Training** – NYSCRC is dedicated to supporting respite education and training of respite providers by providing REST (Respite Education and Support Tools) throughout NYS.
- **Caregiver Simulation Initiative** – In 2017, NYSCRC initiated a “caregiver simulation” event to expose the wider community to the challenges of caregiving.
- **Caregiver Listening Sessions** – In the summer of 2013, NYSCRC participated in caregiver listening sessions throughout the State in conjunction with AARP – NY and the Council of Senior Centers and Services of NYC. As a result of the listening tour, a joint report was created – *Caregivers in Crisis: Why NYS Must Act*. The report, the culmination of 12 listening sessions around the state with more than 900 caregivers and service providers, highlights the needs and makes specific policy recommendations.

## Documents/Resources Available

- Monthly Newsletter
- Multiple resources available at [nyscrc.org](http://nyscrc.org)
- REST Information
- Report: *Caregivers in Crisis: Why NY Must Act* – <http://states.aarp.org/wp-content/uploads/2013/11/Caregivers-in-Crisis-FINAL.pdf>

## State Contact Information

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# North Carolina Respice Care Coalition

## Start-Up Process

- The NCRCC began in 1996 as a follow up to that year's National Respice Conference hosted by ARCH. A grass roots group of providers and family members took the knowledge and excitement about respice programs and coalitions and returned to NC with a dedicated purpose.

## Structure

- Between 2006 and 2012, the NCRCC was housed at a statewide nonprofit agency that functioned as its fiscal agent. In 2012, The NCRCC reorganized under the direction of a volunteer Board of Directors, with officers from each of its three regions.
- The Coalition was approved by the IRS as an independent 501(c)(3) not-for-profit corporation in spring 2014.
- Mission: To promote and support a statewide quality intergenerational respice care system
- Vision: Throughout North Carolina there is an established sustainable network that meets the respice needs of families, caregivers, and individuals across the lifespan.
- Value Statement: Respice care enhances the quality of life for the caregiver, their loved one and their community through timely, temporary care. Providing the balance to maintain a health approach to caregiving supports families across the lifespan. The NCRCC unites providers, caregivers and communities in growing quality lifespan respice care in North Carolina.

## Staff

- Currently, the NCRCC has no paid staff.

## Funding

- The NCRCC is all-volunteer and depends on grants and monies from previous fundraisers (silent auction, etc).

## Membership

- The NCRCC launched a membership drive in May 2014, and there are now more than 400 members throughout the state.

## Meetings and Communication

- Meetings are normally conducted via webinars and/or telephone conference calls.
- NCRCC communicates with its "members" via an email listserv.
- The website of NCRCC is [www.northcarolinarespicecarecoalition.org](http://www.northcarolinarespicecarecoalition.org).

## Major Activities

- The NCRCC accumulated a database listing of more than 300 respice providers throughout the state. That database is now subsumed and uploaded onto the ARCH respice locator.
- The NCRCC co-hosted a statewide Lifespan Respice Summit in 2015, along with ARCH, AARP of NC and the state lifespan respice grantee, NC DAAS.
- The NCRCC held a series of strategic planning sessions. As a result, the Board conducted a survey of its members as well as the members of the statewide Lifespan Respice Advisory Team to help ascertain member priorities and their preferred methods of receiving training and information.
- NCRCC has administered two statewide respice voucher campaigns, funded by a Lifespan Respice Grant from NC DAAS and served nearly 200 families. The statewide community of service



Updated in 2017 by the North Carolina Respice Care Coalition. For more information, contact ARCH; (703) 256-2084; [jkagan@archrespice.org](mailto:jkagan@archrespice.org). ARCH Website: [www.archrespice.org](http://www.archrespice.org)

providers served as referring agencies, and NCRCC Board members reviewed the applications. The youngest care recipients were two-year-old twins with developmental disabilities. The oldest recipient was 110 years old (7 recipients were 100 or older). To be eligible, families had to be either:

- on a waiting list for respite services;
  - not eligible for any other respite funding source but unable to pay privately for respite; or
  - had exhausted all other sources of respite funding.
- Developed a Lifespan Respite Volunteer Training Manual in collaboration with NC Lifespan Respite Care Project.
  - Hosted several one-day respite conferences and respite awareness days
  - Assisted State Health Department with incorporation of respite as a benefit under the state's Children's Health Insurance Program.
  - Collaborated with agencies across services, ages and focus.
- Activities related to passage and reauthorization of the Lifespan Respite Care Act.
  - Participated in national respite conferences and networking/consulting with other states on lifespan respite issues.
  - August 2005 – First North Carolina Lifespan Respite Summit.
  - March 2007 – Assisted state Agency on Aging with statewide Videoconference on Lifespan Respite Care Act.
  - May 2007 – NCRCC Restart and Refocus – Workday with ARCH NRC assistance.
  - September 2008 – One Day Respite Conference: “Good for Me; Good for You,” Victory Junction Gang Camp in Randleman, NC.
  - November 2008 – Mini Lifespan Respite Summit in collaboration with ARCH NRC honoring Rep. David Price (D-NC).
  - October 2010 One Day Respite Conference: “Growing Respite with Limited Funding,” Victory Junction Gang Camp in Randleman, NC.

## Documents Available

- NCRCC Respite Voucher Application Package
- Bylaws
- Mission and Vision
- Event Planning Meeting Minutes
- State Conference Flyers
- Voucher information
- Lifespan Respite: An Information Guide for Developing, Recruiting, Training, and Retaining Volunteers, available for download at [http://northcarolinarespitecarecoalition.org/wp-content/uploads/2013/12/Lifespan\\_Respite\\_A\\_Volunteer\\_Information\\_Guide.pdf](http://northcarolinarespitecarecoalition.org/wp-content/uploads/2013/12/Lifespan_Respite_A_Volunteer_Information_Guide.pdf)

## State Contact Information

To contact the coalition, visit the website at [http://northcarolinarespitecarecoalition.org/?page\\_id=46](http://northcarolinarespitecarecoalition.org/?page_id=46).

# 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



Updated in 2017 by the Caregiver Alliance of Rhode Island. For more information, contact ARCH; (703) 256-2084; [jkagan@archrespite.org](mailto:jkagan@archrespite.org). ARCH Website: [www.archrespite.org](http://www.archrespite.org)

in honor of the Congressman for his dedication to respite care. Coalition will continue to award the Langevin award to an outstanding caregiving champion each year.

- Outreach and Public Awareness of the Caregiver Alliance and Lifespan Respite Act to increase Alliance membership and commitment to respite care in Rhode Island.
- Partnership with the Division (formerly known as the Department) of Elderly Affairs in applying for, receiving, and implementing the RI Lifespan Respite Grant.

- 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*.

## Documents and Resources

- *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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## South Carolina Respite Coalition

### Start-Up Process

- The SC Respite Coalition (SCRC) grew out of two small respite projects, both run by parents of children with special needs. One was funded by the SC Developmental Disabilities Council and the other by U.S. Administration on Developmental Disabilities. Sharing a State Advisory Committee, these projects conducted a respite needs assessment/environmental scan and invited 40 key stakeholders to address the identified needs. In 1999, these stakeholders, including family caregivers, state agencies, respite providers, non-profit organizations and University researchers, founded the SCRC.
- The SCRC was launched with in-kind support from the two original organizations, Family Connection of SC, a parent-to-parent network organization, and the Center for Disability Resources, a University Center of Excellence in Developmental Disabilities.
- The SCRC developed as a program of Family Connection until 2000 when a grant from the SC Developmental Disabilities Council enabled it to incorporate as an independent 501(c)(3) entity.

### Structure

- The SC Respite Coalition is the ONLY statewide organization focused solely on respite for ALL age groups in South Carolina, including families caring for someone with mental illness, midlife illness, aging and disabilities.
- The SCRC serves the entire state, though most activity has been in Columbia, the state capital, and surrounding counties.
- The SCRC is operated by a volunteer Board of Directors comprised of up to 14 members with a majority being current or former family caregivers. By-laws have a provision for a non-

voting advisory committee to ideally represent more constituencies than the Board can encompass.

### Staff

- In 2000, the SCRC began with a part-time Director who oversaw incorporation. A full-time Executive Director was employed in 2001 and has remained in the position. With reduced funding, the Executive Director was employed part-time (and sometimes volunteered) for several years, but in 2011 returned full time.
- A part-time Program Coordinator was employed in 2010 to work on the Lifespan Respite Project. This position oversees the Family Caregiver Respite Voucher Program funded by both state and federal dollars. Three Program Assistants work full-time to assist family caregivers across the state in accessing respite services.

### Funding

- The SCRC began with a 3-year grant from the SC Developmental Disabilities Council and in-kind support from Family Connection of SC.
- It has continued to operate with state and private foundation grants from the NORD Foundation, Christopher Reeve Paralysis Foundation, Alzheimer's Resources Coordination Council, the Carolinas Center for Medical Excellence; in-kind support from the University and state agencies; donations through annual campaigns and events and volunteer support.
- The most recent funding (2009–2017) for the SCRC is through the Lt. Governor's Office on Aging (LGOA) which was fortunate to receive 4 federal Lifespan Respite grants. The SCRC is a partner in the development of the Lifespan



Updated in 2017 by the South Carolina Respite Coalition.  
 For more information, contact  
 ARCH; (703) 256-2084;  
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 Website: www.archrespite.org

Respite network, along with Family Connection of S.C., Inc.

- SCRC also receives funding from the state budget thru the LGOA to give to family caregivers in the form of vouchers.
- SCRC contracts with the SC Department of Disabilities and Special Needs (SCDDSN) to provide on-line training and document background screenings for respite providers in the Family Selected Respite Waiver program.

## Membership

- The Respite Coalition currently does not have formal membership or dues, although people from all walks of life are involved with, or receive information via, the SCRC as part of the Board of Directors, sub-committees, annual conference, email alerts and website.
- A majority of the Board are current or former caregivers. The State Committee on Respite (SCOR) has representation from major state agencies, respite providers, University Centers, disability and aging consumer groups for children and adults, non-profits, faith community members, and family caregivers.

## Meetings and Communication

- Monthly Board meetings through physical and conference calling methods and conference planning meetings.
- Periodic newsletters disseminated through the mail and email networks.
- Email alerts, recently through Constant Contact.
- Monthly partners meeting and Quarterly meeting of the State Committee on Respite for the Lifespan Respite project.

## Major Activities

- Outreach to faith communities continues with education about respite and opportunities for coaching and assisting family caregivers to accept offers of help, ask for respite, arrange and fund it.

- Fosters new respite models and efforts through small grants to faith communities across the state.
- Had role in influencing the Lt. Governor to request and obtain \$3 million for respite in 2013–2014 for family caregivers of elders and also older caregivers of adult “children” with disabilities.
- Issue \$500 vouchers directly to family caregivers to arrange for respite. Focus is on families ineligible for Family Caregiver Support Funding: younger parents of individuals with disabilities, midlife families and those in hospice or on the community-based long-term care Medicaid waiver program. A key element of the voucher program is teaching family caregivers about respite, linking them to other resources and coaching them to find providers and create their own “circles of support.”
- Respite Summit held June 18, 2014.
- Held five annual Respite Solutions for the Faith Community conferences attended by approximately 125 people each year. Regional faith community conferences will be planned with help of regional advisory councils.
- Advocacy, increasing awareness about the needs for respite and increasing respite options for family caregivers. Cross training between the Family to Family Health Information Network and ADRCs is a specialized focus.
- Updating and expanding information, focused strictly on respite, available through our website: [www.scredspitecoalition.org](http://www.scredspitecoalition.org)
- Collaborating with other agencies, organizations and family caregivers to establish a coordinated lifespan respite system in SC.
- Developing regional advisory councils.

## Documents/Resources Available

- Mission statement: The mission of the SC Respite Coalition is to expand quality respite opportunities in SC throughout the lifespan for families who have a member with special needs. The Coalition’s goals are to:
  - Educate the general public & specific groups about need for respite care.
  - Develop strategies to provide and improve respite services for families.
  - Provide support for families and providers through coordinated information resources.
- “What you Need to Know About Me” A Notebook for Family Caregivers.
- “Family Caregivers in Your Faith Community Need a Break!” brochure.
- “Take a Break” brochure.
- Coalition brochure and by-laws.
- Respite Resources for S.C. – updated regularly.
- State respite plan “TAKE A BREAK SC! – Sustaining South Carolina’s Family Caregivers through respite” was released in May 2013 by the Lt. Governor and will be updated/revised in 2018.
- How to start a respite co-operative – linked to partner organization, Family Connection of S.C., Inc.
- How to establish a respite benevolence fund at your faith community.
- Most SCRC products available on the website at: [www.scredspitecoalition.org](http://www.scredspitecoalition.org), which also provides links to other resources in SC and across the country.

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## Tennessee Respite Coalition

### Start-Up Process

- In the early 1990s, the Tennessee Department of Mental Health and Substance Abuse took the lead in the startup of the Tennessee Respite Coalition (TRC). The state agency invited all interested parties, including community agencies, family caregivers, other state agencies and service providers to become involved.
- Initial funding for the coalition included in-kind contributions of office space and supplies from the state department coupled with a federal coalition-building grant from the Bureau of Maternal and Child Health.
- Motivating factors in coalition startup:
  - Legislative Awareness Days
  - Gaining funding for a respite resource hub
  - Federal Lifespan Respite Bill
  - Networking opportunities
  - Hosting National Conference in collaboration with ARCH

### Structure

- The TRC was statewide from its inception.
- Before funding, a small group focused on awareness and grant writing (to fund future efforts).
- Once funded and staffed with a full-time coordinator, the TRC began establishing regional groups. Seven regional groups across the state were formed with volunteers serving as chairs. The coordinator traveled to the regions to motivate and organize the groups.
- Newsletters and other communications were distributed to keep the group cohesive.
- By 2003, the regional coalition groups were established and the group had grown to more than 1,000 members. When the coalition building funding was exhausted, the TRC became a 501(c)(3) nonprofit agency in November 2003.

- A board of directors votes on fiscal, operational, and programmatic decisions. The board meets on a bi-monthly basis for business meetings and has a board retreat in June each year. The board has standing committees that meet on a regular basis: Finance, PR/Marketing, Program, and Fundraising.

### Staff

- Originally, a full-time staff person was hired to coordinate the regional groups. The coordinator was a contracted worker for the State of TN Dept. of Mental Health and Retardation, the founding state agency.
- Once the TRC became an independent nonprofit entity, the coordinator became the executive director. Staffing levels and locations have fluctuated over the years depending on levels of funding. Currently, the TRC has 3 staff, including the Executive Director, Program Coordinator for the Respite Helpline and Voucher Program, and Volunteer and Senior Companions Coordinator.

### Funding

- Funding was initially supplied by the State of TN through a grant from the Federal Bureau of Maternal and Child Health. The funds were granted for three years and were allowed to carry over into the fourth year.
- Once the initial grant funding was exhausted, the TRC became a nonprofit organization so that it could solicit funding through grants and private donations. Many foundations require the 501(c)(3) status for funding consideration. Another advantage to this move was being tax exempt and able to offer private donors tax deductions.
- Current funding includes state grants, Corporation for National and Community Service, private foundation grants, private donations through annual campaigns and memorials, and funds collected through events.



Updated in 2017 by the Tennessee Respite Coalition. For more information, contact ARCH; (703) 256-2084; jkagan@archrespite.org. ARCH Website: www.archrespite.org

- Fundraising events have included: Jazzin for Respite, The Art of Time, Beer & Cheese Tasting, Chips and Salsa, Founders Celebration, Riders for Respite and Writers for Respite.
- The TRC receives many in-kind donations of office supplies, silent auction items, caregiver gifts, etc.

## Membership

- The TRC is a loose network of more than 200 community partners that provide information and assistance to caregiving families. Members include diverse representation from medical professionals, social workers, legislators, caregivers, service providers, and teachers. The TRC covers the lifespan and is a cross-disability organization.
- The TRC does not require dues and is not considered to be a “Member” organization because of its 501(c)(3) status.
- Membership is based on interest level. A person or organization must be interested and invested in respite to become a member.
- Members were and are recruited by other members. During the coalition-building period, regional contests helped boost membership.

## Meetings and Communication

- In the past, regional coalition meetings were held throughout the state on a regular basis. Since becoming a 501(c)(3), the TRC groups have meetings when they have activities or need planning time.
- At the inception of the TRC, statewide meetings were held quarterly. Lunch was supplied, regions made reports, national updates were provided, and the TRC director offered ideas to keep the regional groups excited about respite.
- Meeting notices were sent by email, snail mail and fax. Currently, meeting notices go out by email and are coordinated on the local level.

- Marketing materials are available for members to spread the word about respite.
- During coalition building, newsletters were monthly. Now they range from monthly to quarterly.
- The website has been through several incarnations with several volunteers, and currently is operating effectively. In October 2016, a Community Hack event created an online application form for caregivers to use to apply for TRC services.

## Major Activities

- The TRC, in partnership with ARCH National Respite Network and Resource Center, hosted the National Lifespan Respite Conferences in 2004 and 2014 in Nashville.
- In 2010, the TRC received grant funding from the Tennessee Disability Coalition to customize Salesforce to track and report respite services. The database is still used today.
- The TRC was named the partner organization for the Senior Companion Program in Davidson County in 2011. This program, sponsored by the Corporation for National and Community Service, has allowed the TRC to expand the number of caregivers receiving respite.
- The TRC continues to partner with the Tennessee Commission on Aging and Disability in activities funded by Lifespan Respite Care Act funding. Tennessee was granted funds in 2009–2013 and 2014–2017. The most current grant has allowed the TRC and TCAD to complete a statewide assessment of respite needs and is working on a state plan for respite.
- The TRC hosts National Family Caregiver Month activities each November in various areas of the state. Some of the activities include: family caregiver pampering days, legislative activities, banquets, media coverage, family caregiver gifts, etc.
- In 2017, the TRC received a grant to start using Music and Memory as a tool in the Senior Companions Program. Volunteers

create custom playlists for care recipients and use them on iPods while providing respite.

- Lifespan Respite Summit: 2006
- Family directed respite: TRC provides more than 300 family caregivers with respite vouchers for an array of direct services depending on the needs of the care recipient. This empowers caregivers to be in control of where, when and how their respite happens.
- Volunteer Respite: Senior Companions Program in Davidson County matching volunteers over the age of 55 with seniors in need of a companion with caregivers in need of respite.
- Helpline: A toll free number for families and professionals that provides guidance, information and assistance. Last fiscal year, the TRC answered 849 calls to the helpline.

## Documents/Resources Available

- Nonprofit Bylaws and Articles of Incorporation
- Surveys of Caregivers (outcomes and assess needs)
- Surveys of Professionals (assess needs)
- Nonprofit Committee Descriptions
- Program and Organizational Policies
- Marketing Materials and Plan
- Newsletters
- Facebook: [www.facebook.com/tnrespite](http://www.facebook.com/tnrespite)
- Twitter: @tnrespite
- Instagram: @tnrespite
- Video: Portraits in Caregiving
- Website: [www.tnrespite.org](http://www.tnrespite.org)

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## Virginia Caregiver Coalition

**“...dedicated to improving the caregiving experience through education, advocacy and resource accessibility so that caregivers are valued and supported.”**

### Start-Up Process

- The Virginia Caregiver Coalition (VCC) was formed in 2004 with an informal group of 21 professionals and 1 family caregiver (founding members) who attended a coalition building training sponsored by AARP. The Coalition was focused on the caregivers of older adults.
- Currently, there are more than 130 active and consulting members in the statewide coalition. The Coalition has a diverse representation of professional and family caregivers of individuals of all ages, disabilities, and chronic conditions.

### Structure

- The VCC is housed at the Virginia Department for Aging and Rehabilitative Services (DARS), Richmond, Virginia. DARS serves as the VCC's fiscal agent.
- The VCC is governed by an Executive Board. The Executive Board is composed of the VCC's Officers: Chairman, Vice Chairman, and Secretary (Executive Committee). Other members of the Executive Board include: a representative from the Virginia Department for Aging and Rehabilitative Services, a representative from the Founding Members of the Coalition, a representative from the State ADRC Advisory Council, the Immediate Past Chairman of the Coalition, Standing Committee Co-Chairmen and the Coalition's Publicity Chairman.
- The Standing Committees include: Education and Programming, Membership, and Advocacy.

### Staff

- There are no paid staff positions at the VCC; however, there is extensive support from the

DARS Program Coordinator who is responsible for the administration of the National Family Caregiver Support Program and the Lifespan Respite Care Grant.

### Funding

- The VCC received limited funding from the DARS program coordinator's participation in a National Alliance for Caregiving project. The VCC also received a small stipend from the DARS 2025 program.
- In 2014 DARS received the Janet Sainer RAPP Award which included a small monetary gift that was given to the VCC.
- DARS provides administrative, meeting, and videoconferencing support for the VCC.

### Membership

- VCC membership includes volunteers from a variety of governmental agencies, non-profit and for-profit organizations, and family caregivers.
- There is no membership fee to join the VCC, but members are required to complete a formal membership form indicating their willingness to serve as an active or consulting member of the VCC, and their interest in participating in a Standing Committee.

### Meetings and Communication

- Full member meetings are held bi-monthly and are announced through flyers via email networks, and the DARS Facebook Page.
- Members may participate in meetings at the DARS – Aging Conference Room, or at a variety of video conference sites throughout the Commonwealth. Participation by teleconference is also available.



Updated in 2017 by the Virginia Caregiver Coalition. For more information, contact ARCH; (703) 256-2084; jkagan@archrespite.org. ARCH Website: www.archrespite.org

- An educational component and a VCC business section are part of each meeting. Meetings are open to the public.
- The Executive Committee meets in the months that there is not a general VCC Meeting. Standing committees also meet bi-monthly.

### Major Activities

- Partnership with DARS in implementing the Virginia Lifespan Respite Care Program and Lifespan Respite Care Voucher Program.
- Various trainings held during the VCC's eleven year history.

- Presentation about the Coalition at the 2009 NCOA/ASA National Conference.
- Annual November recognition of National Family Caregiver's Month.

### Documents/Resources Available

- Electronic or Hard Copy
  - By-Laws, Policies & Guidelines
  - Meeting Flyers
  - Caregiver Resource Manual – Electronic Copy DARS-Division for the Aging Website

- A Practical Guide to Respite for Your Family – by Partnership for People with Disabilities, Virginia Commonwealth University

### State Contact Information

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## Lifespan Respite Washington

### Start-Up Process

- Lifespan Respite Washington (LRW) began as the Respite and Crisis Care Coalition of Washington (RCCCWA) in 2003 through a two-day statewide conference funded by the state.
- Funding continued with a planning grant from the Paul G. Allen Family Foundation to The Arc of King County, [www.arcofkingcounty.org](http://www.arcofkingcounty.org), to fund a part-time staff person.
- After the Paul Allen Grant ended, The Arc of King County continued to offer part-time staff support until Washington State was awarded a Lifespan Respite Demonstration Grant, (its first of four Lifespan Respite grants) in 2010 through the Administration on Aging.
- The RCCCWA was renamed “Lifespan Respite Washington” in 2012, with the goals of continued statewide coalition development, mapping respite across the state, and connecting unserved, unpaid family caregivers to creative respite options. A website, [www.lifespanrespitewa.org](http://www.lifespanrespitewa.org), was developed in 2013.
- LRW was awarded a second federal grant in 2013 by the Administration for Community Living (ACL), Administration on Aging for Building Integrated and Sustainable Lifespan Respite Care Programs.
- The Arc of King County agreed to have LRW transfer to a statewide entity that represents the respite needs of caregivers who provide care to individuals across the lifespan with a wide spectrum of special needs.
- A pilot project to develop a respite voucher program began in 2014 through Easter Seals Washington, which used contracted respite provider agencies rather than individual providers. Easter Seals agreed to assist in design, implementation, and startup modeling for just over a year.
- A third grant for the years 2014–2017, was received from ACL, Building Long-Term Sustainability in State Lifespan Respite Programs.
- In 2015, Senior Services of Snohomish County (SSSC) was awarded a contract to continue the new and improved respite voucher program starting in 2016 and to focus on sustainability of the voucher program.
- SSSC began working in 2016 in a special pilot project with the Department of Health, Children with Special Health Care Needs to link respite to families with children through their Local Health Jurisdictions.
- In 2016, LRW began working on a new one-year grant, Lifespan Respite Care Program – Competing Program Expansion Supplements, funded through ACL focused on a Tribal Respite Grant, as companion one-year funding to a state legislatively funded Tribal Kinship Navigator project. This innovative opportunity provides technical assistance and some funding to eight Tribes in Washington State working on the development of respite project that fit with their unique cultural wisdom and experiences.
- In 2017, LRW was awarded its fifth Lifespan Respite Grant, a three-year Lifespan Respite Care Integration and Sustainability Grant. This funding will facilitate focusing on specialized populations, including caregivers of persons living with a Traumatic Brain Injury or Developmental Disabilities, along with American Indian/Alaskan Native communities.



Updated in 2017 by Lifespan Respite Washington. For more information, contact ARCH; (703) 256-2084; [jkagan@archrespite.org](mailto:jkagan@archrespite.org). ARCH Website: [www.archrespite.org](http://www.archrespite.org)

## Structure

- Senior Services of Snohomish County (SSSC), [www.sssc.org](http://www.sssc.org), now known as Homage Senior Services, is a 501(c)(3) (nonprofit) organization acting as the fiscal agent for the coalition and its voucher program.
- LRW is a statewide coalition that connects with about 500 individual caregivers and organizations affiliated with or interested in caregiver support.

## Staff

- The SSSC Chief Executive Officer provides oversight for the Coalition and its projects. The Lifespan Respite Project Coordinator attends to coalition development, respite resource needs, facilitation of quarterly meetings, and current contract requirements, including the major activities described below.
- In 2017, a Lifespan Respite Program Assistant was hired to assist with voucher disbursement and other special projects.
- Professionals from various interested social service agencies, government representatives, or caregivers themselves, are invited to attend Coalition and planning meetings. They provide information and assistance to develop strategic planning that furthers LRW mission.

## Funding

- From September 2014 through August 2017, LRW received federal funding for its Lifespan Respite Project from the Administration for Community Living, channeled through Washington State's Department of Social & Health Services (DSHS), Aging and Long-Term Support Administration (AL TSA). The federal grant provides respite, coalition-building, community awareness, and staff support.
- In-kind and direct grantee support is devoted to the Lifespan Respite Project by the following organizations:

- Senior Services of Snohomish County, [www.sssc.org](http://www.sssc.org)
- IlluminAge Communication Partners, [www.illuminage.com](http://www.illuminage.com)
- Washington State, Department of Social & Health Services, Aging and Long-Term Support Administration, <http://www.altsa.dshs.wa.gov>
- Vanessa Behan Crisis Nursery, [www.vanessabehan.org](http://www.vanessabehan.org)

## Membership

- Lifespan Respite Washington has about 500 Coalition affiliates, including family caregivers and a broad cross-representation of various geographical and cultural groups. Both public and private agencies are involved. The core group consists of about 30 members, including:
  - Adoption Advocacy organizations
  - Autism Society of Washington and other groups affiliated with autism spectrum disorders
  - Bureau of Indian Affairs and other Tribal affiliates
  - Caregivers, unpaid family
  - Catholic Community Services of Western Washington, Volunteer Chore Services
  - Chapters of The Arc of Washington, Easter Seals Washington, and other advocacy organizations for persons who have developmental disabilities
  - Churches and other faith-based organizations
  - Community Care, Elder & Adult Day Health and other respite service providers
  - Crisis Clinic/King County – Caregiver Program
  - Disease specific organizations such as National Multiple Sclerosis Society – Greater Northwest Chapter, ALS Association, Alzheimer's Association, Traumatic Brain Injury, and other disease/condition advocates

- Family Caregiver Support Programs administered by various Area Agencies on Aging
- King County Kinship Collaboration and other kinship groups
- Kinship Caregiver Programs and Services
- Parent Trust for Washington Children
- Pierce County Aging and Long Term Care-Aging and Disability Resource Center
- Recreational and scouting groups
- Senior Information and Assistance/Aging and Disability Resource Center providers
- Vanessa Behan Crisis Nursery and other crisis nurseries in the state
- Veterans Administration and other military support programs (such as the Exceptional Families Programs)
- Washington State Child Care Aware (referral network)
- Washington State, Aging and Long-Term Services Administration, Department of Social and Health Services (DSHS), State Unit on Aging
- Washington State, Department of Early Learning
- Washington State, Department of Health
- Washington State, Department of Veterans Affairs
- Washington State, Developmental Disability Administration
- Washington State, DSHS, Children's Administration, Foster and Kinship Care
- Washington State, DSHS, Economic Services Administration/Policy
- There are currently no membership fees or dues. In-kind support has been offered by various members for website maintenance, meeting space, in-kind/pro bono respite services and expertise in various policy and practice areas.

## Meetings and Communication

- Meetings occur on a semi-annual basis, usually via conference phone call. Attempts to utilize video conferencing portals across the state have been problematic but are not to be ruled out as technology improves.

## Major Activities

- Developed and implemented Lifespan Respite statewide needs survey via internet, then conducted seven focus groups across the state based on the survey results.
- Developed a model countywide lifespan respite directory for King County to be used as a model for other counties.
- Developed a statewide lifespan respite approach (use of Girl Scouts groups, rural daycares, Volunteer Chore Services) in relation to the 2010 Lifespan Respite Grant application.

- Assisted the state in successfully applying for the FY 2010–2013 Lifespan Respite Grant from the Administration on Aging, US Dept. of Health and Human Services.
- Assisted the state in successfully applying for the FY 2013–2014 Lifespan Respite Grant, as above.
- Assisted the state in successfully applying for the FY 2014–2017 Lifespan Respite Grant.
- Assisted the state in successfully applying for a specialized grant for FY 2016 Tribal Respite Grant.
- Developed a statewide respite voucher system, implemented in 2014, which is ongoing.
- Developed a pilot project with the Department of Health, Children with Special Health Care Needs.

## Documents/Resources Available

- Statewide survey
- King County resource directory
- Website: [www.lifespanrespitewa.org](http://www.lifespanrespitewa.org)
- PowerPoints on Lifespan Respite Washington
- In the upcoming grant period, the following products will be worked on:
  - Sustainability plan
  - Community awareness plan
  - Respite Voucher System Manual
  - Respite Summit Plan

## State Contact Information

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# Respite Care Association of Wisconsin

## Start-Up Process

- Respite Care Association of Wisconsin was established in 1987 to:
  - Organize respite care agencies and others interested in respite care for the purpose of sharing ideas and expertise and to provide support for each other.
  - Work closely with the appropriate government agencies and private agencies or groups to insure the continuation and replication of quality respite services.
  - Promote and support the concept of quality in the delivery of respite care.
  - To initiate, sponsor and promote educational programs and research.
  - Provide consultation and disseminate information.
- In 1999, Wisconsin adopted state Lifespan Respite Care legislation. The state contracted with RCAW to administer the program.
- In 2008, Wisconsin Children's Trust Fund contracted with RCAW to administer statewide programming utilizing respite care as a strategy to prevent the initial occurrence of child abuse and neglect.
- The State of Wisconsin was awarded Federal Lifespan Respite grant funds from 2010-2015. The Wisconsin Department of Health Services, the grantee of record, contracted with RCAW to administer the program in partnership. In 2017, the State and RCAW are collaborating again to build upon the Lifespan Respite work from the prior years and respond to the changing respite care needs resulting from State and Federal legislation.
- In 2017, Lisa Schneider was hired as the Executive Director.

## Structure

- A 10-person board of directors oversees the program, which is staffed by a part time Executive Director and a full-time Operations Manager.
- RCAW contracts with 5 regional non-profit partners to implement the Wisconsin Lifespan Respite program.

## Staff

- Staffing consists of a half-time Executive Director (possibly full time if federal funds are received in 2017) and a full-time Operations Manager.

## Funding

- RCAW is funded by state general purpose revenue through the Wisconsin Department of Health Services for the WI Lifespan Respite program, and hopefully by Federal revenue through the Administration for Community Living via the Federal Lifespan Respite Program.

## Membership

- RCAW is not a membership organization, but partners with numerous agencies and individuals on a project basis.

## Meetings and Communication

- The board of directors meets quarterly. An advisory group for the Federal Lifespan Respite project meets twice yearly. A Project Management Team meets monthly to manage the federal project.



Updated in 2017 by the Respite Care Association of Wisconsin. For more information, contact ARCH; (703) 256-2084; jkagan@archrespite.org. ARCH Website: www.archrespite.org

## Major Activities

- RCAW provides grant administration and oversight for 5 regional Lifespan Respite projects and 5 regional Child Abuse Prevention projects, information and referral for the general public, technical assistance for respite care programs statewide, training of respite care providers, and advocacy for increased access to respite care in Wisconsin.
- The federal project involves training of respite care providers, creation of a web-based matching service for families and providers, and marketing of RCAW programs and services.

## Documents/Resources Available

- Bylaws, project workplans, brochure, website at [www.respitecarewi.org](http://www.respitecarewi.org), policies, and newsletters.

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